Statement of Jennifer Joy Tieman

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Address: [redacted]
Occupation: Professor
Date: 22 May 2019

1. This statement made by me accurately sets out the evidence that I am prepared to give to the Royal Commission into Aged Care Quality and Safety. This statement is true and correct to the best of my knowledge and belief.

2. Where direct speech is referred to in this statement, it is provided in words or words to the effect of those, which to the best of my recollection, were used at the time.

3. The views I express in this statement are my own based on my education, training and experience. They are not intended to represent any views of my employer.

Professional background

4. I am currently a Matthew Flinders Fellow and Professor in the College of Nursing and Health Sciences at Flinders University as well as being Director of the Research Centre in Palliative Care, Death and Dying at the same University. I have been at this University since 2004 as CareSearch Director and became a Matthew Flinders Fellow and full Professor in 2017. I have assumed the Centre Director role in 2019 when the Research Centre was launched. I am an experienced academic and researcher and have a BSc (Hons), MBA and PhD. I am a Fellow of the Australasian College of Health Informatics.

5. Prior to working at Flinders University, I worked at the Repatriation General Hospital as a Project Officer in palliative care, at Clarence Park Community Centre as the Centre Director and at the South Australian Museum as the Deputy Director.

6. Flinders University is a globally focused, locally engaged academic institution with a reputation for excellence in teaching, learning and research. Its purpose is to provide educational facilities and courses of study for those eligible to enrol and to contribute to the creation and dissemination of knowledge and the promotion of scholarship. Flinders University was established in 1966. Its main campus is located at Bedford Park, with additional Adelaide locations at Victoria Square and Tonsley. It is a member of the International Network of Universities and Innovative Research Universities Australia. There are over 26,000 students at Flinders. Flinders is known for its palliative care postgraduate education and research program.

7. I hold an appointment at Flinders University as a Matthew Flinders Fellow. These Fellow appointments are designed to contribute to the academic and research success of the
University in areas of strategic significance. My role relates to palliative care. I am responsible for the direction and leadership of several grant funded national projects in palliative care and in aged care. I also supervise research higher degree students.

8. I have taken on the role of the Director of a new research centre undertaking research in palliative care and also in consumer and community issues around death and dying.

9. I report to the Vice President and Executive Dean of the College of Nursing and Health Sciences at Flinders University.

In relation to palliative care

a) Please explain the importance of palliative care in the aged care system

10. Australia’s population is ageing with both the number and the proportion of Australians over 65 years projected to continue growing. Most deaths in Australia occur among older people with 66% of deaths being among people aged 75 years or over.

11. Several Australian Institute of Health and Welfare (AIHW) reports have looked at the use of aged care before death. The 2018 AIHW review of the nearly 245,000 deaths of older Australians in the period July 2012 to June 2014 showed that four in 5 of the people in the study cohort had used an aged care program sometime before their death. Another AIHW study of aged care use before death showed that in all groups aged over 65, there was increased take-up of care in the last 6 months of life. The older a person was when they died, the more likely they were to have been accessing a care program at the time of death. Given the increasing number of older people and the related use of aged care services prior to death, aged care services are inevitably involved in providing care for older Australians at the end of their life.

12. The implications of ageing and dying for the health system, the aged care industry and for the individuals, communities and society are being considered nationally and internationally. In 2014, the World Health Assembly passed a resolution calling for member states to strengthen palliative care as a component of comprehensive care across the life course. This resolution highlighted the importance of palliative care being available across the whole of the health system including primary and community care.

The National Palliative Care Strategy recognises that people die in a range of care settings, including in the home, hospitals, residential aged care facilities and hospices.
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13. We must always remember that death and dying is not just a medical or health event, it is a human experience. Hence, care needs to be person centred. Palliative Care Australia’s definition of palliative care is aligned with that of the World Health Organization and is included below:

   Palliative care is person and family-centred care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary treatment goal is to optimise the quality of life.

14. Palliative care can be provided by a range of different health providers and in different settings including the home and residential aged care with support from specialist palliative care if needed. There is evidence that palliative care is effective but there is variability in the availability and the strength of evidence for palliative care as an intervention in different settings.

15. There is some fluidity in the terms that are used to describe the care provided before death. The Palliative Care Australia Service Development Guidelines have moved to distinguish palliative care and specialist palliative care. ‘Specialist palliative care’ is seen as the care provided by a specialist palliative care team comprising a multidisciplinary team, with specialist skills, competencies and training. The term ‘palliative care’ relates to the core competencies and skills expected of all health professionals involved in caring for people living with a life-limiting illness. The Australian Commission has introduced end-of-life care as a term in its national consensus statement. The Consensus Statement describes suggested practices for the provision of end-of-life care in settings where acute care is provided. It is worth noting that previously the term “palliative approach” was used relatively commonly in residential aged care. It is important that there is a common understanding of what is being meant when discussing palliative care and palliative care service provision as reviews have shown differences in definitions, descriptions, components and outcome measures in study reports. Most reviews tend to relate to specialist palliative care services, that is, services delivered by staff working primarily in palliative care and with training in this speciality although one US review highlighted studies of non-specialist interventions, specialist provider intervention, and hybrid non-specialist/specialist-provider interventions.

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4 Palliative Care Australia What is palliative care? Available from https://palliativecare.org.au/what-is-palliative-care
11 Luckett et al 2014 Elements of effective palliative care models: a rapid review BMC Health Services Research 14:136
some extent replicates Palliative Care Australia’s service model in covering community-based palliative care, hospital-based palliative care, and consultative palliative care.\(^\text{14}\)

So, palliative care is very important to aged care as both residential aged care and home care packages are associated with older people at the end of life and dying. Palliative care is an important form of care that addresses needs associated with life-limiting illnesses that lead to death. However, there also needs to be clarity about what is meant when the term palliative care is used.

b) What are the elements of appropriate palliative care in aged care services? In your answer please consider whether or not appropriate palliative care includes adapting the care to the individual needs and identity of the person receiving care. If it does include such adaptations, please give at least one example of how palliative care can be adapted for the individual needs of the person receiving care.

Palliative care identifies and treats symptoms which can be physical, emotional, spiritual or social. The National Palliative Care Strategy explicitly notes that palliative care is person-centred care.\(^\text{15}\) Palliative care recognises the person in their context and that care is provided in a manner that is sensitive and culturally appropriate to the preferences and needs of the person, their family and carers. There are many examples where the ability to understand what is important to the person at the end of life can affect the care that is provided. These can be simple elements such as configuring supports to enable the person to maintain mobility in the home with appropriate equipment or more complex adaptations such as facilitating “going back to country”.

One story from an Aboriginal Manager of an aged care facility, noted “It’s important for our elders to be cared for here their cultural needs are addressed..... We make sure they can get out into the garden, that family can visit whenever they like, and that the stories can be told.”\(^\text{16}\)

Another example reported in a conference presentation by Larissa McIntyre showed how the care needs to be adapted to the situation of the individual person.

Ms. L made a decision to withdraw from haemodialysis knowing full well the consequences and made the decision to die at the (Residential Aged Care) facility... Throughout this Ms. L was supported by her very good friend, who was able to attend each day with the support of the social workers at the local hospital... Specific post-death requirements and support were discussed with Ms. L to ensure cultural obligations were fulfilled... Ms. L died three days after

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\(^{15}\) PCA 2018 Palliative Care Service Development Guidelines Available from www.palliativecare.org.au


making this decision ... Ms. L died in a manner which enabled her to complete her 'story'.17

20. Palliative care needs may change over time highlighting the importance of ongoing assessment and the ability to plan for and change care as needed. The End of Life Directions in Aged Care Project16 has identified a series of elements to describe palliative care: advance care planning; recognising end of life; assessing palliative care needs; providing palliative care; working together; responding to deterioration; managing dying; and bereavement. Depending on the needs and circumstances of the individual, the elements of care may be adjusted. For example, the choice of assessment tools may alter between residents or clients depending on the ability of the individual to verbalise.

21. Fundamental to all capacity to provide palliative care is recognition that an older person is not just older but approaching the end of their life. Timely identification of palliative care needs is necessary to ensure that appropriate care is provided. Tools such as the Surprise Question and/or the Supportive and Palliative Care Indicator Tool (SPICT), may assist in the early identification of palliative care needs for residents and those on home care packages who are at risk of dying.19

22. There is limited data that comprehensively describes the movement between residential aged care and home care setting to hospital or hospice specifically for palliative care. AIHW provides a range of reports that provide some insights.

23. In 2015–16, 73,900 palliative care-related hospitalisations were reported from public acute and private hospitals in Australia. 52.2% of these hospitalisations were for people aged 75 and over. Almost all (94.7%) palliative care-related hospitalisations involved an overnight hospital stay, compared with 40.1% for all hospitalisations. The average length of stay was 10.3 days or almost 4 times as long as for all hospitalisations. More than half of all palliative care-related hospitalisations ended with the patient’s death (52.5%), compared with less than one in a hundred (0.7%) for all hospitalisations. Cancer was the principal diagnosis.20

24. Another data report looked at the movement between residential aged care and hospital but not limited to palliative care hospitalisations. This AIHW 2013 report found that most of the nearly 1.1 million hospitalisations for people aged 65 and over were for people who had come from their home in the community. Around 9% of hospitalisations were

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19 Liyanage T, Mitchell G & Senior H Identifying palliative care needs in residential care Australian Journal of Primary Health, 2016; 24, 524-526
from people living in residential aged care. The movement out of hospital for the whole cohort was as follows: 83% went back to their home in the community, 8% returned to their home in residential aged care and 5% died during admission. The remaining 4% were newly admitted to residential aged care or moved to transition care. Data on a 2014/15 cohort showed that almost 5,600 deaths were recorded for recipients of Home Care packages, which are one form of community-based aged care. The July-December 2018 Palliative Care Outcomes Collaboration report showed that of 23,333 patients who received palliative care in this period just over half were male with an average age of 73.3 years. Females receiving palliative care were on average 73 years. Three percent of referrals were from residential aged care.

25. The relationship between aged care use and hospitalisation around the time of death is explored in the AIHW's report on pathways in aged care during 2012-2014. This report shows that hospitalisation was common in the lead up to death for the almost 108,000 people who had last used residential aged care, and 10,200 people who last used aged care packages at death. For both of these groups, more than two-thirds (69% and 70%, respectively) had taken hospital leave some time before their death. A longitudinal study of more than 12,000 older women showed that hospital use in the last year of life is complex and differs according to the cause of death. They suggested an inability to recognise and effectively manage end of life care or lack of access to appropriate palliative care in community settings as potential issues in care planning and provision.

26. Where hospital transfers from residential aged care occur, aged care nurses seem to have a significant role in the decision. A 2014 JBI systematic review found that multiple factors appear to influence the nurse's decision to transfer to the emergency department rather than to continue care on site. These included limited flexibility in staffing capacity, poor access to multidisciplinary support, difficulties in discussing a resident's deterioration with other decision makers, and fear of working outside of their scope of practice. A recent study in an Adelaide confirmed that residential aged care nurses appeared to be responsible for most decisions about hospital transfer and that suboptimal access to physician input was influencing these decisions. The same study...
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reported that the mean hospital stay to death was 5.2 days from transfer to death for the 109 residents who died in hospital. 27

27. All the data indicates that not only is there a relationship between ageing, aged care and dying but that there is an impact from older aged deaths on hospitalisations. The data also highlights the importance of finding models, strategies and approaches that can support palliative care provision in a proactive way to ensure that the person receives care in the appropriate place without unnecessary hospitalisations and in accordance with their wishes and preferences. It also suggests that a system wide approach to management of end of life for older Australians is needed particularly given the increasing importance of home care within aged care.

d) Where an approved aged care provider provides palliative care services, which members of staff of that approved provider should be involved in that care?

28. Palliative care employs a multidisciplinary approach and the team would normally involve nursing and care staff, primary care staff particularly GPs, and allied health professionals as required. Each would have different responsibilities according to needs of the person and the scope for practice of the individual care practitioner. Possible team members could include: Aboriginal health workers; Careworkers; Chaplains/pastoral care workers; Dietician; Nurses (RN and EN); General practitioners; Allied Health (Occupational Therapist; Pharmacist; Physiotherapist; Speech Pathologist).

29. As palliative care particularly recognises the role of the family and family carers, aged care staff who interact with the family and family carers may also need to be considered. This could include lifestyle co-ordinators and counsellors.

d) i) Are people who are not staff members of approved aged care providers often involved in the provision of palliative care within aged care services?

30. Others can be involved depending on the needs of the individual or the approaches to palliative care used within a service. Some facilities or services may use specialist palliative care teams as well as primary care providers including both General Practitioners and General Practice Nurses. There are also individuals or services that can play a specific role in palliative care particularly for those living at home who may be in receipt of a home care package.

31. Pharmacists have a critical role to play in terms of the timely availability of medications particularly in the terminal phase. In the community, they may also have a role in terms of an ongoing relationship with the person and their family carer 28.

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32. Community nursing may also be involved depending on the palliative care needs of the individual person (and the home care package arrangements).

33. Paramedics/Ambulance Services are often an under-recognised participant in palliative care as are those providing Domiciliary Equipment Services.

e) What is the relationship between palliative care and person-centred care in the aged care system?

34. Palliative care looks at the whole person and addresses their specific and individual needs. In the past, people were expected to fit in with the routines and practices that health and social services felt were most appropriate. In contrast, person centred care is respectful of, and responsive to, the individual person’s preferences, needs, and values. This has a natural articulation with palliative care. As noted above, the National Palliative Care Strategy explicitly notes that palliative care is person-centred care. Palliative care recognises the person in their context and that care is provided in a manner that is sensitive and culturally appropriate to the preferences and needs of the person, their family and carers.29

35. The Aged Care Quality Standards describe the right of the consumer to dignity and respect and to make choices about the care and services they wish. Similar principles can be found in the National Palliative Care Standards which highlight the importance of assessment that focuses on the individual as a whole.

36. The ability to provide meaningful person centred care and/or palliative care depends on the capabilities of the workforce to be able to address a holistic approach to assessment and engagement and a culture that supports a human rights approach to care provision.

f) Are there obstacles to people accessing palliative care within the current aged care system? If yes, what are they?

37. Palliative Care Australia’s service guidelines indicate that all people living with a life-limiting illness should, at a minimum, have access to Level 1 palliative care provided by other health professionals with clear processes for referral to specialist palliative care services. Level 1 needs would be straightforward and predictable and the majority of care would be provided by health professionals other than specialist palliative.30 For aged care residents or clients with more complex needs, access to specialist palliative care would be envisaged.

38. There are indications that there is not equitable access to palliative care nor specialist palliative care across the aged care industry nor across the country and the community.

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30 PCA 2018 Palliative Care Service Development Guidelines Available from www.palliativecare.org.au
The 2017 Productivity Commission Report into Human Services highlighted a range of the around palliative care and residential aged care.

*All aspects of end of life care should be core business for residential aged care facilities. However, under current arrangements, many people miss out on the clinical care they need at the end of life. Intensive nursing and other end of life care services are only funded in the last week or days of life, and are not available to those with pre-existing high health care needs.*

A lack of coordination between state and federal services, lack of community palliative care resources and the lack of sequenced and integrated advance care planning approach that encouraged community conversations and support for document completion was also noted. More broadly, the international literature suggests that low socioeconomic groups experience barriers to access in palliative care services. An Australian study confirmed significant differences in the uptake of, and proximity to specialist palliative care services in Australia with a more nuanced statement of the impact of socioeconomic status particularly around proximity to specialist palliative care services.

There are potential structural and societal considerations in palliative care access across residential and homecare services. Discussions of palliative care do not always specify whether access to specialist palliative care services is being discussed or provision of localised palliative care for identified needs. Within this context, there are some specific considerations around obstacles. The first relates to the initial recognition of a transition to end of life. This requires a systematic monitoring of physical and behavioural changes that could indicate a changing status with regard to approaching end of life. Recognition of end of life is not yet normalised practice. A skilled, knowledgeable and capable aged care workforce that can respond to identified palliative care needs and that is able to plan and manage anticipated and unexpected issues is needed but still emerging. Palliative care provision also relies on the availability of health practitioners who are available to, and capable, of providing care. A recent review of GP knowledge and attitudes notes that while a core cohort of GPs are knowledgeable about palliative care and care needs at the end of life, a substantial proportion are not. Indeed, many GPs saw palliative care quite narrowly in terms of non-curative care and pain and comfort relief rather than providing holistic care built around needs and preferences of the individual. Finally, access to specialist palliative care service/teams can be a challenge. It requires that there is sufficient availability of palliative care teams to meet increasing demand due to population ageing as well as increasing demand from a more

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32 Lewis et al 2011 Dying in the Margins: Understanding Palliative Care and Socioeconomic Deprivation in the Developed World Journal of Pain and Symptom Management 42(1): 105-110

33 Currow et al Referral patterns and proximity to palliative care inpatient services by level of socio-economic disadvantage. A national study using spatial analysis BMC Health Services Research 201212:424

active aged care system interacting with specialist palliative care services. It would also require established frameworks for engagement between facilities and specialist palliative care at the operational and the jurisdictional levels.

41. There would also need to be specific attention paid to potential barriers to access for populations group who may be unfamiliar with, or reluctant to receive, palliative care. This may include multicultural and/or non-English speaking groups and Aboriginal and Torres Strait islanders. The Aged Care Diversity Framework reminds us that older people display the same diversity of characteristics and life experiences as the broader population. This means that palliative care for older Australians needs to be similarly responsive to this diversity in terms of access and care planning\textsuperscript{35}. A lack of comprehensive implementation of advance care planning with specific population groups, as well as more generally within the community, means that there are still uncertainties in the system about the completion, capture, portability and application of advance care planning documents in care planning and in care delivery in the last months of life and in the terminal phase\textsuperscript{36}.

42. For individuals there can be practical considerations in accessing palliative care because of the complexity of the systems and awareness that palliative care is an option. Some of this complexity arises from the different frameworks for funding and accountability and some is a lack of community awareness and knowledge. This means understanding what is possible, what is available and what are the processes (and paperwork required) is challenging. More generally, building an understanding and awareness of the contribution of palliative care to aged care and older people is important to reduce barriers to its use.

f) i) How can these obstacles be overcome?

43. A comprehensive and system oriented approach is needed to create awareness, develop knowledge and skills, manage processes, and monitor and evaluate activity. First there needs to be greater emphasis and promotion of death and dying as part of life as this frames the environment in which individuals, families and systems are operating. It underpins the role and contribution of aged care in providing palliative care to older Australians in receipt of aged care. Normalising dying also supports the value of advance care planning as a normal part of life planning.

44. A capable workforce is fundamental to meeting the demand and the person centred care described above. Aged care is already in a major reform process\textsuperscript{37}. There have been a number of recent reviews that have highlighted ways to build workforce capacity


\textsuperscript{37} Australian Government Department of Health Aged Care reform Available at https://agedcare.health.gov.au/aged-care-reform
including the recent A Matter of Care report. In any workforce reform agenda for aged care, palliative care must be included. Consideration should also be given to mandatory training for careworkers. Education is obviously a critical element going forward. There are already a range of palliative care aged care resources funded by the Department of Health that are available to support palliative care awareness, knowledge and practice which could be used in building workforce capability in this area. Making the range of education already available more accessible to the aged care and primary care sectors could be valuable. Aged care workforce capability also needs to recognise the role of general practice and again there are currently funded resources that have already been developed to build knowledge.

45. Assessment and monitoring against the new Aged Care Quality Standards starts from July 2019. At the moment there are limited palliative care resources and examples included in this guidance. The Aged Care Quality and Safety Commission could expand the range of resources to include the major palliative care resources that have already been developed and to develop case studies that provide insight into proactive palliative care recognition, assessment and care provision. Examples that show how palliative care integrates with the new standards would also provide a focus for aged care palliative care activity. Again, pathways or cases that demonstrate how specialist palliative care, primary care and aged care can interact across the sectors in providing palliative care in the home and residential aged care would be valuable.

46. The need for integration highlights the need for system solutions. There needs to be clarity around how the state funded palliative care services interface with those in receipt of aged care services. This may be particularly important in the home care setting where different services may be involved in wrapping care around an older Australian coming to the end of their life. The introduction of the second edition of National Safety and Quality Health Service (hospital accreditation) Standards, may alter practices within hospitals as they address the new end of life standards. In particular hospitals will need to have processes to identify patients who are at the end of life that are consistent with the National Consensus Statement, have processes to provide clinicians with access to specialist palliative care advice, and ensure advance care planning documentation is included in the patient record. This is a useful and potentially powerful mechanism to look at aligning care practices and processes across the sectors and the system.

47. There are also possibilities around how technology and digital options could increase communication and coordination between providers and also provide prompts and reminders for care. Computer and mobile based applications and health informatics tools have been used in health domains for over three decades, however, they are more lightly recognised and applied within both palliative care and aged care. Given an increasing commitment to homecare packages in aged care and community based palliative care services, digital solutions could be important. They could also assist in

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38 A Matter of Care Australia’s Aged Care Workforce Strategy, Aged Care Workforce Strategy Taskforce, June 2018
addressing the Aged Care Standards and enabling continuous quality improvement around end of life in aged care.

48. Funding analysis is obviously critical and need to address not only funding for aged care services supporting palliative care activity but also considerations of how primary care activity is resourced. The relative costs of care in the different sectors adds to the complexity of analysis of different models and approaches to palliative care provision within a person centred care framework. Funding for advance care planning as an activity also needs to be considered given its potential importance in this sector.

49. There also needs to be consideration as to how to support and inform family, family carers, and surrogate decision makers for older Australians if their roles in end of life are to be properly recognised and integrated. Again, there are resources that have been, or are being, developed through the National Palliative Care Program that could contribute in this area such as Advance Care Planning Australia, Caring@Home, CarerHelp, CareSearch, and Palliative Care Australia. There is a need to maximise the value of these resources by building awareness of them within the aged care sector for use with residents and clients.

f) ii) Are these obstacles different in rural regional or remote areas compared to urban areas? If yes, how do the obstacles differ and why does this occur?

50. There are particular considerations that must be addressed in providing palliative care for aged care clients and residents in rural and remote areas primarily to do with geography, availability of multidisciplinary team supports and the capacity to provide equipment medications and other care infrastructure.

51. The Royal Australian College of General Practitioners has argued that in the country areas, a GP-led model of palliative care where the GP coordinates and enables care for rural palliative care patients, is usual. They have also highlighted a set of gaps relating to a funding base for travelling to care and the need for an MBS item for palliative care multidisciplinary case conferences including for bereavement.

52. For some rural areas a lack of GPs and local hospital access are important concerns. Teams may configure differently due to a decrease in the number of GPs in many rural areas which may mean less medical input and less choice when being cared for at home. Accessing after hours care can also be problematic. Distances to travel in conjunction with a lack of transport can also be real issues particularly for older...
Australians. A number of these concerns were confirmed in the AIHW report on a Survey of Health Care. They found that people in Outer regional and Remote/Very remote areas were the least likely to have a usual GP and were more likely to not see a GP or specialist because of travel and proximity. An Australian study of linked population and healthcare data with geographic information showed that proximity was a major barrier to accessing specialist palliative care services.57

There are also possible issues with regard to medication availability that would need to be considered and responses to an emergency or exacerbation of symptoms. Carer availability and capability would also need to be discussed particularly with regard to management in the terminal phase. However, it should be noted that rural communities do often offer social support with many older people being part of integrated social networks.

The role of telehealth and digital options is still underexplored in palliative care and aged care and could contribute to reducing barriers to palliative access and support in rural areas.

g) Please explain the importance of advance care planning in the context of the aged care system

Advance care planning is an important component of person-centred healthcare. It is a process that helps to articulate, document and communicate a person’s wishes on the type of care they want at the end of life. This can be critical in aged care where for many, death may be a foreseeable event. It is also particularly important in aged care because of the high levels of people living with dementia and other forms of cognitive impairment. Advance care planning provides a mechanism for them to have their wishes respected when they can no longer express them. If advance care planning is left until the end-of-life it may be too late for those with dementia to be able to fully participate. There is an increasing interest in advance care planning as illustrated by the substantial increase systematic reviews published on this topic in the last five years.59

h) What is the relationship between advance care planning and palliative care?

48 AIHW Survey of Health Care: selected findings for rural and remote Australians Available at https://www.aihw.gov.au/reports/rural-remote-australians/survey-health-care-selected-findings-rural-remote/contents#summary
56. Advance care planning is an important avenue for a person to articulate their preferences and wishes for care at the end of their life. Completed documents have a legal status preserving the person's instructions after their capacity to communicate has been impaired.

57. Advance care planning documentation can guide and support palliative care decision making and can also inform care choices made by clinicians in the terminal phase. At the end of life, people wish to be treated with dignity, have relief from pain and, as much as possible, have some control over what happens to them. Palliative care focuses on identifying what is important to the person and understanding their wishes which aligns with the purpose of advance care planning.

58. Research studies suggest that advance care planning can help a person's wishes and preferences be considered by others when they are not able to communicate or to make decisions. People with an advance care directive are also more likely to experience fewer unwanted medical interventions, less likely to be moved from their home or community care to a hospital, and less likely to die in a hospital. There is a need for parallel and interconnected work on all elements having influence on advance care planning implementation including legislation, policy, social and cultural beliefs of people and of organisations and health systems, funding, and availability of a skilled workforce to fully realise its benefit. This view has been supported by recent Australian research.

59. A person with decision-making capacity has the right to decide what is or is not done to their bodies. They can consent to medical treatment, or refuse it. This includes advance care planning, or preferences for care at the end of life. A individual can make specific decisions about future treatment (either wanting a specific treatment or more usually refusing a treatment); express general wishes about future care as well as care preferences relating to their personal values (e.g., cultural or religious requirements); or appoint a substitute decision maker who would act for them, effectively by "walking in the person's shoes" when making decisions.

60. All adults are presumed to have capacity to consent to or refuse treatment, unless it can be shown that they do not. Capacity relates to the ability to comprehend and retain the information needed to make the decision, including the consequences of the decision; and to be able to use and weigh that information as part of the decision-making.
process. Generally, capacity is assessed by a person’s doctor. In some cases it may be decided by a medical practitioner with expertise in capacity assessment. It should be noted that decision making capacity is not diagnosis specific and that decision making capacity can fluctuate or be affected by environmental circumstances (e.g., too noisy, being very anxious).

h) ii) What can be done to improve the ability of people with cognitive impairments or reduced decision-making capacity to make choices about their palliative care?

Addressing advance care planning early in the illness trajectory can maximize the chances that people can participate meaningfully. Alzheimers’ Australia (now Dementia Australia) highlights it is important for a person with dementia to discuss their views and wishes with family and friends, and to finalise relevant documents while they are still legally capable of doing so. If advance care planning is left until dying it may be too late for those with dementia to be able to fully participate and therefore to have care enacted as they may have wished. Approaches for people with dementia that may be helpful include spreading advance care planning over an extended period of time and including a wider range of issues; timely prognosis and information about potential prognosis; appointment of one or more substitute decision makers; involving the person with dementia in discussions and decision-making as much as possible; and ensuring that wishes and documentation are continued if a change in location occurs. Anticipatory guidance and ascertaining values as well as identifying substitute decision-makers can provide a framework that enables decision-making that can include and/or act as the person in palliative care decisions.

Supported decision-making describe the process of assisting a person with cognitive disability to build their capacity to make decisions for themselves. It has grown from a belief that the human rights of people with cognitive disabilities are systematically undermined because it is commonly thought that they are not capable of expressing their wishes or that they lack the capacity to make decisions. A review of a series of Australian pilots suggests that there are benefits associated with approach. This represent a new approach that could assist some people living with dementia who may have been presumed to not have capacity to be involved in future planning.

54 Field S & Cartwright C Dementia and your legal rights: A practical guide to help people diagnosed with dementia, their families and carers, to better understand the legal issues they may be faced with, their legal rights and the actions they can take to protect their rights. Alzheimers’ Australia
55 Field S & Cartwright C Dementia and your legal rights: A practical guide to help people diagnosed with dementia, their families and carers, to better understand the legal issues they may be faced with, their legal rights and the actions they can take to protect their rights. Alzheimers’ Australia
63. There are also a number of tools and resources that can be valuable for those with
cognitive issues and/or dementia. Dementia Australia has a web resource called Start to
Talk\textsuperscript{58}. The included resources are also available in multiple community languages.
Palliative Care Australia has developed resources to support people living with dementia
discuss their end-of-life wishes and is currently trialling them in four residential aged
care facilities\textsuperscript{59}. Planning Dementia Care through Case Conferencing provides
resources that GPs can use to have conversations involving the person with dementia
and their family\textsuperscript{60}. Where individuals agree, making advance care planning documents
available through electronic means may also increase the likelihood of use at the point
of need.

64. A more structured approach around advance care planning for all older Australians
would be useful but it may have particular value for those with dementia. Promoting the
availability and purpose of tools and resources for to the community is very important
but health professionals must also be aware of the advance care planning processes
involved in developing documents and skilled in their use at end of life including in
palliative care planning and delivery.

i) Do you consider the skills and availability of the aged care workforce to be a barrier to
people accessing palliative care within the aged care system?

65. Supporting older Australians to be cared for and die in the place of their choice requires
a high-quality and well-prepared health workforce. The aged care industry comprises
both health professionals and care workers. Some of the skills needed are technical and
knowledge based while others relate to an awareness and comfortableness around
death and dying. The 2011 Productivity Commission projected that the number of aged
care workers needed by 2050 to provide the direct hands on care to older Australians in
aged care will quadruple\textsuperscript{61}. At the moment the majority of the workforce in residential
aged care and in home care are Certificate 3 trained. There is no mandatory
requirement for palliative care training at this level.

66. The aged care workforce is increasingly providing care for people who have complex
conditions, co-morbidities, and cognitive impairment and dementia. There are also
expectations that care will be person-centred and ensure the dignity of our population.
End of life and the need to support palliative care provision is increasingly going to be
part of aged care delivery whether in residential aged care or homecare and many
careworkers will be the primary continuous contact for older people. Palliative Care
Australia’s service development guidelines note that there is considerable evidence
documenting gaps in palliative provision by GPs and for people living in residential aged
care. They reported the following factors as contributing to lower provision of palliative

\textsuperscript{58} Dementia Australia Start2Talk Available at https://www.dementia.org.au/planning-ahead
\textsuperscript{59} Palliative Care Australia New resources to support people living with dementia
\textsuperscript{60} Planning dementia care through case conferencing website Available at
\textsuperscript{61} Productivity Commission (2011) Caring for Older Australians Inquiry Final Report
Continued Statement of Jennifer Joy Tieman

Care in residential aged care: lack of knowledge about palliative care among some nurses and other staff, limited implementation of effective advance care planning practices, and gaps in the availability of suitably trained and experienced staff.62

i) i) How can the aged care workforce be improved to facilitate better access to high-quality palliative care services, both in residential aged care facilities and home care?

67. The need for workforce change in terms of nurse composition has been raised in a number of reviews. Palliative care requires access to skilled nursing care that is available to support changing needs. If palliative care is to be managed within facilities and through home care, then nursing support is necessary. This also needs to recognize the increasing complexity of care needs of older Australians who may have a number of co-morbid conditions and the impact of dementia on care and support.

68. At present, the Palliative Care Australia Service Guidelines indicate that there is not a sufficiently robust basis on which to set national workforce ratios for planning the requirements for palliative care nurses that form part of the specialist palliative care workforce. A 2016 report on aged care ratios in residential aged care indicated that staff ratios should equate to around 4 hours a day per resident with a skill mix requirement of RN 30%, EN 20% and careworker 50%.63 As demand for palliative care grows within the older Australian population, inevitably there will be the need for additional nursing staff either in the specialist palliative care workforce or the aged care workforce if they are directly providing palliative care.

69. There is also an urgent need for training of staff in aged care around the role and principles of palliative care. Training needs to reflect the scope of practice and the specific skills around palliative care that each group of practitioners within the aged care workforce will need to contribute to an individual's care and assessment.

70. There is work being undertaken by Queensland University of Technology to develop palliative care workforce capability across the system.64 This will be continued to create a National Palliative Care Workforce Action Plan including evidence based actions to ensure a highly skilled and sustainable workforce.65 In addition there are a number of significant education resources that are already available that can be accessed and promoted to build individual palliative care knowledge and skills for care workers, nurses, allied health and GPs. They include modules or learning resources from the following:

65 PEPA website Palliative Care Education and Training Collaborative Available at https://pepaeducation.com/about-pepa/palliative-care-education-and-training-collaborative/
Advance Care Planning Australia (eLearning for careworkers and health professionals); The Advance Project (eLearning for General Practitioners, General Practice Nurses and General Practice Managers); CareSearch Education (identifying and providing information on palliative care education for careworkers, volunteers and all health professionals); End of Life Essentials (eLearning for staff in acute care settings); Palliative Care Training and Information Online Portal (frontline palliative care eLearning to support care for aged persons in the community); End of Life Law for Clinicians (addresses current gaps in clinicians' knowledge of end of life law); palliAGED Practice Tip Sheets and palliAGED apps (provide on the spot support for care); PCC4U (palliative care education integration in medical, nursing, and allied health undergraduate courses); and PEPA (free placements in palliative care services for practicing health professionals). Queensland University of Technology has also developed an EN Toolkit through PCC4U. This toolkit aims to develop capacity in the enrolled nurse workforce, providing care for people with life-limiting conditions. The suite of eLearning modules and supporting resources have been designed to support learning in EN training packages.

Further structured resources that can facilitate in-house training and support careworker development for practical palliative care activity within their scope of practice would also be valuable. Feedback on the release of the palliAGED Practice Tip Sheets for careworkers and for nurses demonstrates not only an interest in them for self-learning but an interest in using them as teaching and eLearning resources within aged care settings and facilities.

Availability of, and afterhours access to, GPs has been identified in some reviews as an issue that could reduce palliative care capacity in aged care. Nurse Practitioners may represent an option for providing systematic assessment and management of older Australians with palliative care needs as part of a team approach with GPs and aged care services. Link nurses have also been used to connect palliative care services with aged care services but these nurses exist as an informal network and can be vulnerable to staff changes.

Given the coverage of education and training options already existing, promotion of available resources could be an immediate benefit. Articulating the value and benefits associated with increased knowledge in terms of care outcomes could encourage participation increasing individual levels of skills and knowledge. Aged care nurses could be encouraged to undertake palliative care education options as part of their CDP requirements for registration. There is also the need for structured resources that can facilitate in-house training and support careworker development for practical palliative care activity within their scope of practice. This could form an initial step while broader discussions around workforce, funding models and care organisation occur.

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67 PCC4U EN Toolkit Available at http://www.pcc4u.org/en-toolkit/
i) ii) Are there any successful workforce models for delivering palliative care services in aged care? If yes, what are they and what makes them successful?

74. There are a number of palliative care aged care innovations occurring in Australia. The first involves providing proactive specialist palliative care in residential aged care facilities. This appears to be a promising approach that could reduce transfers and hospital stays and deaths. The pilot study involved a nurse practitioner visiting four Canberra facilities each month to conduct a palliative care needs round. During the round staff identified residents who were likely to die within the following six months. Case conferences were attended by these residents, their family and GP, and staff. Goals of care were discussed and documented in advance care plans. It reduced resident transfer to the acute care setting, and achieved a reduction in hospital deaths. This simple intervention was associated with a substantial reduction in the length of hospital stays and a lower incidence of death in the acute care setting. While rates of hospitalisation were unchanged on average, length of admission was reduced by an average of 3.22 days\(^69\). The value of this approach is the systematic assessment of those who may be approaching end of life which enabled specific goals of care for the individual to be developed. It also made use of a specialist provider in a local setting, building capacity and connections.

75. Resthaven in SA has implemented a Palliative Care Nurse Practitioner model and is the first aged care provider in South Australia to employ a dedicated person in this role. The position takes responsibility for embedding palliative care into Resthaven’s clinical structure as well providing clinical care and developing education programs. This initiative was recognised with Excellence in Palliative Care in an Aged Care Setting award at the Palliative Care Australia National Awards.\(^70\) In this approach the dedicated Nurse Practitioner role normalises palliative care as part of aged care activity and embeds expertise within the facility. A second Nurse Practitioner example involves a pilot study of a Nurse Practitioner led coordinated care planning project, targeting people living in a rural area nearing the end of their lives. This approach resulted in prompt initiation of treatment, good follow up, and a care plan where all professionals had named responsibilities\(^71\). This model again enables systematic identification and coordination of care with clear responsibilities of the individual team member.

76. The Palliative Care Home Support Program is a NSW Ministry of Health funded initiative, providing patients with greater choice to die at home by topping-up the education of community care workers and evaluating service quality outcomes. Packages are administered by HammondCare and provide practical, in-home assistance with personal care and domestic support and allow more patients to fulfil their wish to remain at home for as long as possible. More than 400 care workers are now available across NSW providing coverage for 177 towns, plus full coverage across


\(^{70}\) Resthaven 2017 Palliative Care Australia National Award Win! Available at https://www.resthaven.asn.au/palliative-care-award-winner/

\(^{71}\) Mitchell et al 2018 Evaluation of a pilot of nurse practitioner led, GP supported rural palliative care provision BMC Palliative Care 2015 15:93
three metropolitan LHDs. The benefit of this model is its approach to capacity building in the areas where the care is needed.

77. The Nightingale Program is a palliative model of care, provided by specialist nurses, under the auspices of Dementia Australia, Adelaide, South Australia. It provides strategies and advice to support people living with dementia, their families and care providers with a focus on promoting choice and well-being during all stages of diagnosis. The value of this model is that it looks at the specific needs of a person with dementia and provides continuity of support and information across the illness course.

78. A Queensland initiative, Hospital in the Nursing Home (HiNH), aims to avoid (or reduce the length of) the emergency hospital care among RACF residents. HiNH involves a team of two or three ED-based nurses (as the main program staff) coordinating with the RACF staff, general practitioners and other health professionals to plan for the medical and nursing care for individual RACF patients. It appears to increase RACF staff's competency in delivering some relatively unsophisticated acute care within their own facility as an alternative to transfers to acute hospital settings. RACF patients are also discharged earlier back to their facilities as the program enables fast tracking of the residents through the hospital system. Again one of the benefits of this model is that it provides continuity across the system and builds capacity at the local level.

79. Such examples indicate that there is a richness of possible models and programs that could contribute to palliative care provision in aged care. The challenge is how to bring useful models to scale having resolved funding and governance issues and with evaluation to assist with assessing not only efficacy but effectiveness in implementation.

80. Given there appear to be gaps and shortcomings in palliative care services, it would appear that more funding would be valuable. It is clear that aged care and health care are funded under different models and also older people may receive palliative care under different arrangements. Parts of care are enabled through aged care packages and residential aged care entry while other health care needs may continue to be met through primary care provision or hospital admission. Family care provision is also part of the various arrangements underpinning palliative care delivery. This is made more complex by differences in care requirements. New models are often initiated through project grant funding so their integration into existing governance and funding models is unknown. It is also difficult to find data on costs associated with palliative care service delivery.

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\(^{72}\) Dementia Australia 2018 The Nightingale Project Available at https://www.dementia.org.au/support/support-in-your-region/south-australia/nightingale-program

81. However, even given the complexity around funding, the gaps in access and use suggest that there are potentially specific skill gaps and a lack of nursing care available to undertake palliative care clinical assessment and management. The PCA Service Development Guidelines include workforce ratios for medical staff, allied health, and nursing. The nursing workforce level for a designated palliative care bed requires a mix of direct care from CNC, RN and EN level nurses with a predominance of RNs over ENs of equivalent to 6.5 hours per day. A FT nurse would be responsible for 6.7 beds in an acute ward\textsuperscript{44}. The National Skills Staffing Skills Mix Project reported a range of 1 hr 59 minutes per resident per day to 3 hours 14 minutes per resident per day depending on the type of service provider for general resident care. Careworker time outstripped RN's daily time with residents.\textsuperscript{45} While it is not possible to compare the two roles and workloads directly given the differences in setting, client groups, acuity and care needs, it highlights the potential value of additional nursing skills to deliver palliative care within aged care.

82. Outside of staffing positions, funding for careworker participation in education should be considered. Funding to support primary care participation, particularly GP participation, in advance care planning activities, palliative care case conferences and potentially bereavement follow up reviews could also be useful. Funding for other enablers such as home care digital supports, online self-care programs, and programs to enable community awareness of death and dying would also be useful.

k) Is bereavement support important in palliative care? If yes, why?

83. Bereavement, grief and loss are an important part of palliative care practice and principles. Bereavement - the loss of a loved one through death - is a normal, common human experience. Most people experiencing a bereavement will feel loss and suffering but will adapt and reconcile to the loss and change. Others can struggle to adapt, and grief becomes prolonged and persistent and can have implications for functioning. Palliative care services often try to support those who love and care to prepare them for the loss.

84. There is also a recognition that grief and loss can be felt before the death by the person coming to the end of their life and by their family. There can be grief felt about losses associated with function and capabilities. Staff can also suffer from grief and loss.

85. Bereavement may not receive as much attention in the aged care setting because the death of an older people is seen as more expected. However, a lack of carer and community support for persons affected by prolonged grief is a significant unmet need. Given an anticipated increase in the number of deaths, the primary care sector is likely to need to respond to increasing demand for support with end-of-life care and

\textsuperscript{44} Palliative Care Australia Palliative Care Service Development Guidelines Available at http://palliativecare.org.au/wp-content/uploads/dm_uploads/2019/02/PalliativeCare-Service-Delivery-2018_web2.pdf
bereavement-related issues, including prolonged grief. PHNs are well placed to support primary health care providers to address the needs of people at risk of, or experiencing, prolonged grief.\(^\text{78}\)

1) Are you aware of bereavement support being offered by aged care providers, either in the residential or home care setting? If yes, please describe the features of the support offered.

86. Many facilities provide some form of memorialisation within the aged care centre. For example a picture of the deceased resident will be placed in a cabinet or included in a newsletter. Notes and condolences from residents are commonly forwarded the deceased family with an invitation to attend a Memorial Service onsite. These represent practical ways to remember and to value the person who has died. A review of bereavement approaches in aged care confirmed this perception noting that there does not appear to be any particularly structured approach to bereavement support either through pastoral care programs or more broadly within the sector. There is a reliance on chaplaincy and volunteers rather than paid staff for bereavement support.\(^\text{77}\)

87. There is less reported about models that support families and individuals who may be suffering grief and loss prior to bereavement nor about aged care involvement in supporting individuals who may have difficulties adjusting to a bereavement. It should be noted that resident funding ceases shortly after the death of the resident or client hence there is no funding availability to support bereavement through aged care.

88. There is also limited reported information on how aged care supports staff who are experiencing losses as part of their everyday care. The CHSD Report on bereavement in aged care notes that one of the most frequently discussed unmet needs was providing people (residents, carers and staff) with the opportunity to talk about bereavement.\(^\text{78}\)

m) Could you describe the ‘ELDAC’ project, and its relationship to both palliative and person-centred care?

89. End of Life Directions for Aged Care (ELDAC) is a project that seeks to improve the care of older Australians through palliative care connections and advance care planning activities. The ELDAC project is funded by the Australian Government Department of Health. It is being delivered by a consortium that brings together three universities (Queensland University of Technology, Flinders University, and University of

\(^{76}\) Williams K, Thompson C and Morris D (2017) Prolonged grief: Applying the evidence in the primary care setting - Issues Brief for Primary Health Networks. Centre for Health Service Development, Australian Health Services Research Institute, University of Wollongong.


Technology Sydney) and five national bodies from aged care, palliative care and primary care (Aged and Community Services Australia (ACSA), Australian Healthcare and Hospitals Association (AHHA), Catholic Health Australia (CHA), Leading Aged Services Australia (LASA) and Palliative Care Australia (PCA).

90. ELDAC focuses on four streams of work to support these directions:

90.1. Capacity building through access to toolkits and to online and phone support:
There is a website at www.eldac.com.au which houses five toolkits and a suite of information and advisory resources. This is complemented by a business hours phone service (ELDAC Helpline) available at 1800 870 155. Toolkits are a collection of information, resources and tools around a particular topic or practice area. They can help users to develop a plan and organise their efforts to follow evidence-based recommendations or practices. Each ELDAC toolkit looks at an important area dealing with palliative care or advance care planning in aged care (homecare, residential aged care, primary care, legal, and working together. They provide a pathway for users to meaningful and practical materials they can use when providing care to older Australians.

90.2. Improved care and service provision through technology solutions:
The technology solutions work stream of ELDAC involves developing embedded technology applications that support aged care and aged care workers. One of the projects currently underway is the development of a prototype for a palliative care digital dashboard utilising information points in data systems to monitor end of life care actions, provide reports, and support continuous quality improvement.

90.3. Better understanding of issues through policy briefings and meetings:
Project staff prepare policy briefs which include synthesised information to inform decision-makers about key policy and planning issues in palliative care and advance care planning in aged care. To date three policy roundtables have been held:

- Roundtable 1: Aged care workforce and skill mix for palliative care, 5 April 2018
- Roundtable 2: Identifying and Funding Palliative Care Needs within Residential Aged Care in Australia, 15 August 2018
- Roundtable 3: Identifying and Funding Palliative Care Needs within Community Aged Care in Australia, 25 October 2018

90.4. Service and sector development through local and regional partnerships:
A team of facilitators are working to create linkages between aged care services and palliative care and primary care services to assist, support and enable health and aged care workers to provide best quality care for older Australians and their families at the end of life. The ELDAC facilitators provide information about where to access resources to support delivery of evidence-based palliative care and advance care planning services for older Australians and their families, assist to build or enhance local and / or regional linkages between aged care, specialist palliative care, primary care and other local service providers and networks, and provide advice on organisational strategies to create / enhance quality palliative care and advance care planning services.

Signature [Signature]
Witness [Witness]
91. All of the streams of work in the ELDAC Project support palliative care knowledge access and use. A specific framework has been developed called the ELDAC Care Model\textsuperscript{79} that provides an easy to understand overview of palliative care and advance care planning processes. Hence this project is directly relevant to palliative care in the aged care context.

92. With respect to person centred care, the content that has been developed for the ELDAC project recognises the importance of identifying and addressing each person's specific and individual care needs as they come to the end of their life. As an example of how person-centred approaches are interwoven with palliative care processes in this project, the content in the assess palliative care needs component of the home care and residential aged care toolkits highlights the importance of assessment across four domains: Physical Wellbeing; Social and Occupational Wellbeing; Psychosocial Wellbeing; and Spiritual Wellbeing.\textsuperscript{80}

m) i) What is your involvement with this project?

93. The ELDAC project is conducted by a national consortium of eight partners including three universities. I represent Flinders University in the consortium. I am directly involved with the delivery of Streams 1 & 2.

m) ii) What are the key objectives of the project?

94. The specific objectives identified in the grant round were to:

- Provide specialist palliative care and advance care planning advisory services to aged care providers and GPs providing health care for recipients of aged care services;
- Improve linkages between aged care services and palliative care services;
- Improve the palliative care skills and advance care planning expertise of aged care services staff and GPs providing health care for recipients of aged care service; and
- Improve the quality of care for aged care recipients, prevent unnecessary hospital admissions, and shorten hospital stays.

m) iii) If any research has been conducted in respect of the project, what are the key findings of that research to that extent they relate to advance care planning, palliative care and/or person-centred care?

\textsuperscript{79} ELDAC Care Model Available from https://www.eldac.com.au/Portals/12/Documents/Factsheet/ELDAC_Care%2020Model.pdf

A comprehensive evaluation framework has been established covering process indicators, activity indicators, and impact measures for palliative care and advance care planning. Measures of person centred care include identifying if the resident/clients advance care and end of life needs were identified and met. This includes co-ordination of care, involvement of families and reduction of unnecessary hospitalisations.

As the project is still underway key findings are not yet available.

It is worth noting that there has been a positive response to the initiative and good engagement from the sector. Since the launch of the ELDAC website in late April 2018, there have been over 28,000 users of the website.

n) Could you describe the 'Palliaged' project?

PalliAGED is a palliative care evidence and practice resource for aged care. Given the pressures on the aged care system and the reform agenda currently in play, there is a continuing need to ensure that current evidence and resources are available to guide care provision for older Australians as they approach the end of their life.

The Palliative Approach in Residential Aged Care (APRAC) Guidelines were the first guidelines in the world that provided evidence based support for health professionals providing palliative care in residential aged care facilities. A companion set of guidelines published in 2011 provided evidence based guidance for a Palliative Approach for Aged Care in the Community Setting (COMPAC). This landmark work acknowledged the importance of aged care as a setting in which palliative care needs would be found and also the impact of an ageing population on demand for palliative care.

While Australia had led the way with aged care palliative care guidelines, guidelines need to be updated to ensure they incorporate new evidence for practice as it emerges and that they address new issues of importance in aged care and palliative care provision. In 2015, the Department of Health undertook a feasibility study to inform a proposed review of the APRAC and COMPAC Guidelines. This study found an ongoing need for a dynamic up-to-date evidence base to drive better practice of palliative care in aged care. The need for accessible and practical tools and support was also clearly expressed in contributions by stakeholders, as was the need to focus on better leverage and implementation of the existing large body of work in this space. CareSearch (Flinders University) was approached to produce a guidance resource in 2016 and in May 2017 palliAGED was launched.

The palliAGED website includes an Evidence Centre and a Practice Centre. This means that aged care staff and health professionals can find the evidence easily and know how to use it in providing care. The palliAGED Project used robust quality processes to ensure the trustworthiness and relevance of the online resource that was developed. Being online means the resource will always be available and able to be accessed when

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CONTINUED STATEMENT OF: Jennifer Joy Tieman

the knowledge is needed. It will also make it easy to update guidance as new evidence emerges.

n) i) What was your involvement with this project?
102. I was the CareSearch Director during the development of the palliAGED resource.

n) ii) What were the key objectives of the project?
103. The purpose of the project was to develop an enhanced knowledge base for palliative care in aged care incorporating the Guidelines for a Palliative Approach in Residential Aged Care (APRAC) and the Guidelines for a Palliative Approach for Aged Care in the Community Setting (COMPAC). This was achieved with the release of the palliAGED website in May 2017.
104. The current objectives are
   - To further consolidate the aged care palliative care resources within palliAGED site including the palliAGED apps and content from the CareSearch RAC Hub, and
   - To grow usage of the palliAGED resource.

n) iii) If any research has been conducted in respect of the project, what are the key findings of that research to that extent they relate to advance care planning, palliative care and/or person-centred care?
105. The objectives and the quality processes embedded within the palliAGED project require that palliAGED website deals directly with palliative care, advance care planning and person-centred care as embedded within the principles of palliative care and advance care planning.
106. PalliAGED is managed with the CareSearch Project. CareSearch has a formal program logic that guides activity and frames evaluation and research activities. As part of the development of palliAGED there was an evaluation exercise undertaken which reviewed the CareSearch program logic for its suitability to incorporate the palliAGED project and a formative evaluation framework developed to support the initial development and release.
107. Data metrics show good usage patterns. In March 2019, the target visit rate of 25,000 per month was exceeded with more than 29,000 visits.
108. Referral analysis indicates that there are 137 institutional referral sites including 7 educational institutions, 12 government and 9 Primary Health Networks suggesting the perceived value and quality of the resources for their constituencies.
109. Over 4,700 people have registered for the monthly palliAGED newsletter which highlights recent palliative care evidence and resources for the sector.

110. There have been over 5,000 downloads of the palliAGEDgp app. This app for GPs focuses on care practices and terminal prescribing in the palliative care aged care context.

111. The effectiveness of the resources are also demonstrated in the number of downloads and requests for resources. Choosing to download an item indicates an awareness of the resource and an interest/need for the topic. Targeted palliative care resources for careworkers and for aged care nurses (PalliAGED Practice Tip Sheets) were released in March 2019. There was very strong sector interest with the print run of 2,100 copies being exhausted within 4 weeks. There is currently a waitlist of over 222 organisations or individuals waiting for a reprint.

o) Could you describe The Advance Project and CareSearch? Please describe the relationship between these projects

112. The CareSearch Project is funded by the Australian Government Department of Health and managed by Flinders University. Our project is responsible for two major websites, the CareSearch website and the palliAGED website. The CareSearch website consolidates online palliative care knowledge for health professionals, people needing palliative care and their families, and for the general community. The focus of palliAGED is palliative care evidence for aged care. To ensure that what we publish on the websites is trustworthy, we have developed a structured approach to evidence retrieval, appraisal and communication known as the CareSearch Model. The CareSearch Project also works closely with a number of other projects to maximise reach and impact within the aged and health sectors. These collaborations can involve CareSearch undertaking a diverse set of activities to support palliative care initiatives. Activities include partnering in the development of palliative care content and resources, preparation of evidence syntheses, online learning and education module development and management, project website hosting, and online data collection capabilities to support evaluation and research.

113. The Advance Project™ aims to build capacity of general practices and primary care clinicians to provide better care through team-based initiation of advance care planning and palliative care. The project provides a practical, evidence-based toolkit and a training package, specifically designed to support GPs, nurses and practice managers to initiate advance care planning conversations and assess patients’ and carers’ palliative and supportive care needs. The resources and training support person-centred care and early attention and assessment of the needs of older Australians with complex health conditions. The suite of resources and multi-component training program align with the guiding principles from the 2018 National Palliative Care Strategy. They help enable care to be accessible, help ensure that carers are valued and receive the care they need, recognise that death is a part of life, help ensure that care is high quality and evidence-based, and recognises that everyone has a role to play in palliative care.
114. The toolkit includes a suite of resources for GPs, nurses, practice managers, patients and carers. It was informed by literature reviews, comprehensive evaluation in the first phase of the project, input from a national and international advisory group and stakeholder engagement with relevant professional organisations and consumers. The Advance Project Toolkit has been officially recognised as an accepted clinical resource by the Royal Australian College of General Practitioners (RACGP) and endorsed by the Australian Primary Health Care Nurses Association (APNA). The Advance Project is funded by the Australian Government Department of Health with training endorsed by APNA, and accredited by RACGP and the Australian College of Rural and Remote Medicine (ACRRM).

115. One-on-one mentoring is available to support individual primary care clinicians and general practices implement the resources in clinical practice. Four champion primary health networks/alliances across three states of Australia are being supported with grants and train-the-trainer support to deliver face-to-face training and support implementation locally. Data will be collected from a subset of clinical sites to inform ongoing implementation and improvement of the program. The online training and resources are freely available from www.theadvanceproject.com.au. The Advance Project is led by HammondCare, a leading aged care and palliative care provider, in collaboration with various health and university partners including Flinders University.

o) i) What is your involvement with these projects?

116. I am Director and Research Lead of the CareSearch Project and responsible for the CareSearch and palliAGED websites and associated functionalities. I am a project team member of Advance Advisory Committee and Evaluation Committee.

o) ii) What are the key objectives of these projects?

117. The key objectives of the Advance Project are:

- Building ongoing capacity for General Practice Nurses to incorporate the Advance Project assessments in their clinical practice;
- Training General Practitioners, General Practice Nurses and General Practice Managers in the Advance Project model and tailoring the toolkit/training resources to meet their specific needs;
- Enabling the General Practitioners and General Practice Nurses to efficiently and confidently promote awareness of Advance Care Planning (ACP) during routine health assessments and consultations with elderly patients and/or adults with chronic/complex care needs;
- Supporting General Practitioners and General Practice Nurses to identify patients who might be at risk of deteriorating and dying; and in these patients use a structured approach to assess their symptoms, most important
questions, concerns and priorities; and their caregivers' unmet supportive care needs;

- Enabling General Practitioners to work effectively with other clinicians in primary and chronic/complex care settings to efficiently address the patients' and caregivers' identified needs and concerns regarding Palliative Care and ACP; and

- Enabling the General Practitioners and General Practice Nurses to identify patients who would most benefit from referral to specialist palliative care services.

118. CareSearch is a nationally established project (CareSearch) that provides evidence and palliative care information for health professionals and health consumers. The objectives of the project for this period are to:

- Enhance the knowledge and information resources for palliative care in aged care by incorporating pallAGED, Decision Assist resources and the CareSearch RAC Hub to create a substantial resource for the aged care sector;

- Enhance collaborations within three target markets (aged care sector, allied health sector, and patients, carers and families) to facilitate awareness of CareSearch (and pallAGED); and

- Collaborate with other providers under the National Palliative Care to explore linkages and synergies with other funded activities.

119. The first phase of the Advance Project has been formally evaluated. Over 500 nurses in general practices across all states and territories of Australia were upskilled through the Advance Project multicomponent training program. Feedback about the training was overwhelmingly positive, with nurses highly rating the quality and relevance of resources and training to their clinical practice and value for their patients. In addition, there was evidence from the evaluation of strong, significant and sustained improvements in nurses' confidence, comfort, knowledge and attitudes towards initiating conversations about advance care planning and assessing patients' and carers' palliative care needs. Nurses were significantly more likely to have initiated conversations about advance care planning with their patients at the follow up assessment compared to before participating in the training. Nurses also reported positive impacts for their patients and carers following implementation of the resources in their clinical practice and the majority of nurses indicated their intention to continue to implement the tools and skills learnt in the training. The Advance Project demonstrated that nurses in primary care can have an important role in initiating advance care planning and assessing patients' and their carers' palliative and supportive care needs. However, there were also a range of
barriers to implementing the resources in clinical practice including a need for complementary training for GPs and practice managers to enable a team-based approach. The evaluation informed refinement and expansion of the resources and training to support team-based initiation of advance care planning and assessment of palliative care needs assessment in general practice.

Signed: [Signature]
Date: 22/5/2019
Witness: [Signature]
Date: 22/5/2019