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Primary Health Reform Steering Group
Department of Health
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Dear Primary Health Reform Steering Group

Re: Discussion Paper to inform the development of the Primary Health Reform Steering Group recommendations on the Australian Government's Primary Health Care 10 Year Plan

Thank you for the opportunity to make a submission on the draft recommendations from the Primary Health Reform Steering Group. Palliative Care Australia (PCA) is pleased to offer input into the future direction of primary health care reform and the Primary Health Care 10 Year Plan.

Palliative Care Australia (PCA) is the national peak body for palliative care. PCA represents those who work towards high quality palliative care for all Australians who need it. Working closely with consumers, our Member Organisations and the palliative care workforce, we aim to improve access to, and promote palliative care. We believe quality palliative care occurs when strong networks exist between specialist palliative care providers, primary care providers and support care providers and the community.

PCA supports the broad intention of the recommendations outlined in this Discussion Paper. PCA considers that if these recommendations are enacted there will be significant improvements in the care delivered to patients through primary health care settings. This includes palliative care for people who are living with a life-limiting illness and/or are near the end of life. Palliative care can improve their quality of life and the quality of life of their carers and loved ones.

PCA makes the following observations in relation to the Discussion Paper.

People living longer and with more chronic illness

The Discussion Paper quite correctly notes (page 1) that without attention, the primary health care system will have limited ability to respond to challenges including the growing number of Australians with chronic illness, mental health needs and frailty, workforce development, resourcing, regional service integration and futuristic models of care. Palliative care providers are at the forefront of seeing (and responding to the implications of) the increased numbers of people living with often multiple chronic illnesses (and often living for longer). The ability and incentive for primary care providers to facilitate inter-disciplinary case management for these patients is also currently limited.

Palliative care provided by primary health care providers

While some palliative care is provided by Specialist Palliative Care Teams, particularly for complex cases, it is primary health care generalists and non-palliative care specialists that are delivering generalist palliative care as they support patients to manage the physical, emotional, spiritual or social aspects of these conditions. Primary health care providers are particularly involved in rural, regional and remote Australia where access to specialist palliative care services can be limited.

It is important to note that palliative care can be provided at any age where people are living with a life-limiting illness. In this respect, **Action 7.3 Tailor supports across the life cycle** would benefit from a specific mention of palliative care.

Quality palliative care is provided by professionals caring for people with a life-limiting illness who:

- Maintain the dignity of the person, their family and carers;
- Empower the person, their family and carers to use their strengths to manage challenges;
- Act with compassion and kindness towards the person, their family and carers;
- Consider equity in the accessibility of services and in the allocation of resources;
- Demonstrate respect for the person, their family and carers;
- Provide culturally appropriate and culturally safe care;
- Are inclusive and respectful of Aboriginal and Torres Strait Islander people;
- Are responsive to the specific needs of vulnerable populations;
- Advocate on behalf of the expressed wishes of the person, their family, carers and communities;
- Are committed to the pursuit of excellence in the provision of holistic, evidence-based care and support; and
- Are accountable to the person, their family, carers and the community¹

PCA is aware that the above list encapsulates the work that professional primary health care providers conduct on a daily basis with their patients who are living with a life-limiting illness and/or nearing the end of life. Palliative care provision in primary health care also aligns with the National Preventative Health Strategy which states: health is a state of physical, mental and social wellbeing, and for Aboriginal and Torres Strait Islander peoples and other communities, this also includes cultural wellbeing” (p4).

Palliative care has the benefit of directly supporting the person living with a life-limiting illness or approaching the end of their life and it also supports the family and loved ones of the person. This acts as a preventative health measure, which can have long term implications for family functioning, mental health, and productivity and engagement in workplaces and education settings.

Carers and loved ones of people receiving palliative care often benefit from grief and bereavement support. PCA has two relevant Position Papers that are relevant:

[PCA and ACGB Policy Statement Grief and Bereavement](#) and [Palliative Care and COVID-19: Grief, Bereavement and Mental Health](#). Grief and bereavement support can be provided in a number of ways including informal support from family and friends up to intense grief and bereavement therapy. In many cases, people talk to their General Practitioner (GP) and in this respect it would be helpful if grief and bereavement support services were included under **Action 7.6 Map local wellness services**.

Palliative care makes economic sense and takes pressure off other parts of the health system

In 2020, PCA released a report [Investing to Save: The Economics of Increased Investment in Palliative Care](#) which was undertaken by KPMG to investigate the economic impacts of investment in palliative care. KPMG investigated three key settings in which palliative care is provided:

¹ ASPEX Consulting Report for Palliative Care Australia (PCA), *Generalist Supplement (to the National Palliative Care Standards, 5th edn)*, July 2021, available on request.

- Hospitals
- Residential aged care
- Integrated home-based palliative care

Integrated home-based palliative care services support individuals, families and caregivers outside institutional settings of care. Home-based palliative care supports patients who wish to be cared for at home as long as their needs can be met, and where possible, to die in the place of their choice. Primary health care providers, including General Practitioners (GPs), Aboriginal Health Practitioners, and community or remote area nurses, all play an important role in this setting in identifying palliative care needs, facilitating discussions around treatment goals and developing care management plans.

Examples of this care include but are not limited to:

- Symptom assessment and management;
- Case conferencing, care management planning and coordination;
- Access to after-hours care;
- Knowledge and skill sharing for all those involved in patients' care;
- Spiritual and psychosocial support for patients, carers and families;
- Personal care, food and transport services.

In addition to providing the care that many people with a life-limiting illness prefer, home-based care with its emphasis on care provided by primary health care providers also has an economic benefit. The KPMG report noted that investment can:

- 1. Reduce presentations to the Emergency Department** Individuals receiving integrated home base palliative care services visited the Emergency Department by between two and 13 percent less in the last year of life.
- 2. Lead to less time spent in hospital** Studies of the integrated home-based palliative care recipients have reported fewer average total bed days of between 4.5 and 7.5 in the last year of life; rates of hospitalisation were also seen to fall by between one and 66 per cent.

In return on investment terms, KPMG found that:

- Integrated home-based palliative care services support individuals, families and caregivers outside institutional settings of care. In the last year of life, integrated home-based palliative care services are expected to save between \$4,544 and \$6,109 (2019 Australian dollars) per person from reduced emergency department and hospitalisation costs. KPMG estimate that a **\$1.00 investment in integrated home-based palliative care services can return between \$0.53 and \$1.56** – or cost neutral on average (2019 Australian dollars).

PCA notes these findings from the KPMG report to emphasise that investing in General Practice and Primary Health Care is important because it supports person-centred care, and it also has the benefit of reducing health expenditure at the acute end of the health spectrum.

Support primary health care in Residential Aged Care

Palliative Care is core business in aged care. Many residents in residential aged care are living with life-limiting illness (including dementia) and/or they may be nearing the end of their life and in needs of a palliative care response to their care and support needs. The capacity of primary health care providers to be able to visit and treat residents in aged care facilities is recognised widely in the palliative care sector as integral to quality care for aged care residents. While there have been some measures to support providers to utilise the Medicare Benefits Schedule (MBS) in care provision there is scope for further work. The MBS needs to be funded to support GPs and other appropriate primary health care providers to undertake longer consultations for palliative care patients, undertake advance care planning discussions and attend residential aged care facilities (including time for travel, planning and follow-up work).

Further, more work should be prioritised to ensure the interoperability between General Practice software systems and government software systems including My Care Aged Care and My Health Record. This will improve communication, clinical information and patient care for residents in aged care facilities. This relates to **Action Item 2.1.7 Digital Platform**.

Telehealth

PCA recently sought feedback about the use of telehealth for palliative care patients. While this was in the context of the provision of palliative care during COVID-19 using temporary MBS items, some of this feedback is relevant for primary health care over the next decade when it can be expected that provision of telehealth consultations will be utilised both during pandemics or other disasters and also as part of mainstream health provision. In summary PCA offers the following about the use of telehealth (**relating to Action Item 2.1.4 (GP MBS Telehealth)**):

- Access to telehealth should focus on ensuring access to methods with video capability (rather than phone only) with experience reporting better acceptance from patients, more opportunity to build rapport and the ability to better utilise visual cues to enhance communication and contribute to clinical assessment.
- Access can be limited at several levels, with inadequate infrastructure within a health facility to use telehealth (in particular video), and/or limited administrative and technical support for setting up and facilitating patients to use it. Older patients often need a family member to support access, but it is noted many have become more technologically savvy throughout the pandemic.
- Equity in ability to access telehealth appointments is influenced by socioeconomic factors, including accessing an appropriate device, reliable internet access, language proficiency and economic poverty.
- While patients will often prefer face to face consultations, some patients continue to choose telehealth appointments due to reasons such as location or frailty.
- Telehealth consultations include an administrative workload including following up with community nursing teams, allied health, pharmacies and pathology, so any permanent MBS items need to reflect the full workload of a telehealth consultation including interdisciplinary case management, not just the time of call/video consultation.

Recommendations for telehealth models for palliative care patients in primary health care include:

- Face to face consultations are most important in palliative care, especially for initial consultations, physical assessments, new/complex symptoms, patients in an unstable phase of care and for the ability to monitor patients and to build strong rapport and trust. It is also important for complex and difficult discussions such as advance care planning discussions, delivering bad news or poor prognosis/advancing disease status and where there is a need for an interpreter. For many patients, human contact plays an important role in the therapeutic connection between patient and clinician. Patients should always be given the option to change appointments to face to face if they feel the need or there is a change in their symptoms.
- Face to face consultations may be essential to meet the needs of vulnerable people including those who are socially isolated or homeless and those who have drug and alcohol issues, psychosocial or psychiatric issues, low health literacy and trust issues
- Telehealth appointments are noted to have particular utility when there is an established relationship and/or for straightforward issues such as monitoring of a specific defined clinical problem (diabetes, pain management) or for re-assessment for ongoing prescriptions for relatively stable problems.

- It is also valuable to be able to offer telehealth appointments to patients and their families when it is difficult for patients to get to a clinic such as when the patient is in the terminal/deteriorating phase and situations such as when a patient has a spinal compression.
- Telehealth models for people with palliative care in rural and remote regions to access specialist consultations provide an important approach to support equitable access to the full complement of interdisciplinary specialist palliative care and should be further developed and evaluated. Telehealth options in rural and remote regions rely on adequate infrastructure and internet bandwidth.

Supporting GPs through increased knowledge and awareness to improve quality use of opioids

The use and management of opioids in the Australian health care system and around the world is a critical area of policy and health systems regulation. PCA recognises that governments and regulators need to take appropriate action to prevent and mitigate against the misuse of opioids and the increasing rates of opioid addiction and dependence in the general population.

PCA however, is concerned that palliative care patients can be at risk of unintended harm and put at greater chance of increased pain and suffering when regulations at the legislative and health system level place restrictions without appropriate exemptions or separate arrangements for palliative care patients.

Prescribing of opioids is necessary for many palliative care patients to address pain and other symptoms such as breathlessness. General Practitioners need to be supported in this aspect of their care provision. PCA considers that the Australian Government's Primary Health Care 10 Year Plan would benefit from reference to appropriate prescribing and stewardship of opioids for palliative care patients within the primary health care setting. Palliative care patients require their GPs and other primary health care prescribers to be able to prescribe appropriate medications for symptom relief. This would be supported by the introduction of national real time monitoring for all opioid prescriptions with software that is enabled to identify palliative care prescriptions at point of care across acute, sub-acute, aged care and primary care sectors. This relates to **Recommendations 15 (Innovation and Technology) and Recommendation 16 (Care Innovation)**.

Thank you for your consideration of this submission. If you require any further information or need to clarify any aspect, please contact Margaret Deearin, National Policy and Strategy Manager on (02) 6232 0700 or email margaret.deearin@palliativecare.org.au

Yours sincerely



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