Submission to AIHW Consultation on the National Palliative Care and End-of-Life Care Information Priorities

(Submitted via online survey)

People with a life-limiting illness

Please comment on the priorities in this section (People with a life-limiting illness) for advancing Australia's national palliative care and end-of-life care information needs over the next 10 years.

The priorities in this section are: Patient-reported experience measures (PREMS); Patient-reported outcome measures (PROMS); Identifying and supporting people without carers; Conversations people are having and how they are planning for their future care.

The Society of Hospital Pharmacists of Australia is the national professional organisation for more than 5,000 pharmacists, pharmacists in training, pharmacy technicians and associates working across Australia's health system. SHPA convenes a Palliative Care specialty practice group for palliative care pharmacists who work in a variety of hospital and other settings providing palliative care. SHPA also produced the *Standards of Practice for Clinical Pharmacy Service*[1] and the *Standards of Practice for the Provision of Palliative Care Pharmacy Services*[2] which outline the entitlement of palliative care patients to levels of pharmacy care aligned with other key patient groups.

There is a lack of information gathered from patients and/or carers on their experiences of access to timely, affordable and quality medications and reviews by pharmacists. SHPA strongly believes that the importance of high-quality medication access, cost and safety should be included as part of the information priorities and requirements for people with a life-limiting illness. Without explicit information about patient-reported experiences with medicines throughout their journey, PREMS and PROMS will be limited. This reduces the capacity of health services to appropriately understand the needs of patients for medicine management ensuring safe and effective medicine use for people with a life-limiting illness.

Palliative care pharmacists are crucial to ensuring the safe and quality care of palliative care patients across all care settings, especially with respect to management of their medicines. Patients with a life-limiting illness may be transitioning from hospitals to residential aged care facilities or community palliative care services, and vice versa, and at times may be cared for by a combination of public and private healthcare providers without sufficient communication to ensure continuity of care. These transition points are known to be a high risk for adverse medication events, including missed doses of medications and disrupted supply when patients are transferred to another setting. This population group have complex health needs and medication regimens, so missed doses and incorrect medicines place them at risk of serious complications, lack of symptom relief and re-hospitalisation. It is therefore, vital that sufficient information is gathered to better understand the challenges experienced by people suffering from life-limiting illness and/or their carers, in accessing their prescribed medications and managing their complex medication regimens frequently changed by multiple prescribers across a variety of health settings with minimal coordination.

[1] SHPA Committee of Specialty Practice in Clinical Pharmacy. (2013). SHPA Standards of Practice for Clinical Pharmacy Services. *Journal of Pharmacy Practice and Research, 43*(No. 2 Supplement), S1-69.

[2] SHPA Committee of Specialty Practice in Palliative Care. (2006). SHPA Standards of Practice for the Provision of Palliative Care Pharmacy Services. *Journal of Pharmacy Practice and Research, 36*(4): 306-8.

Families and carers

Please comment on the priorities in this section (Families and carers) for advancing Australia's national palliative care and end-of-life care information needs over the next 10 years.

The priorities in this section are: Identifying who is providing care to Australians at their end of life; Identifying the needs of carers; and Finding opportunities to understand carer experience.

SHPA recommends this section should specifically discuss and identify sufficient support for gathering of information from carers who are responsible for medicines, as a priority. Carers are often responsible for the administration of medications to patients with a life-limiting illness. This can be a major responsibility due to the large and frequently changing regimen of complex and high-risk medicines often prescribed, which can be harmful and unsafe if taken or administered incorrectly.

SHPA member feedback indicates that carers are more educated and confident about managing the patient's medicines after a comprehensive counselling session with palliative care pharmacists. These counselling sessions cover what the patient's medication regimen is, the dosage and frequency of each medicine, whether they are regular or as-required medicines, the side effects of each medicine, and medical referral points for each medicine. The rate of access of carers palliative care pharmacy counselling would be useful in ensuring appropriate care to support end-of-life needs.

During provision of care there is a lot a responsibility and challenges faced by carers especially when considering complex and frequently changing medication regimens and the fragmentation of care, leading carers to be the single coordinators for their loved ones. It is important that gaps in health literacy and opportunities to understand the challenges faced and provide the necessary support are identified in order to best support carers and help them with the responsibilities of complex medication regimens during a stressful period.

Workforce

Please comment on the priorities in this section (Workforce) for advancing Australia's national palliative care and end-of-life care information needs over the next 10 years.

The priorities in this section are: Complexity and capacity of the workforce supporting end-of-life care; Capacity across the workforce to deliver high-quality and person-centred care; and Planning for future workforce requirements.

Information about the provision of palliative pharmacy care in both hospital and community settings in Australia is inadequate for future workforce planning. Anecdotal information highlights a fundamental lack of high-quality pharmacy care for many patients, however without quantitative reporting this is difficult to substantiate. National information relating to pharmacy support provided by hospitals, residential aged care facilities as well as community/retail pharmacies would be essential to ascertain the requirements and priorities for end-of-life care over the next ten years.

Palliative care pharmacists are an integral part of an interdisciplinary team and optimise the outcome of symptom management through evidence-based, patient-centred medication therapy. Palliative care pharmacists educate patients, carers and fellow health professionals on the use of medications, maintain patient medication stock, follow up on patents after discharge and transitions of care, provide prescribing advice to general practitioners and create guidelines for medication use in palliative care settings. SHPA's *Standards of Practice for the Provision of Palliative Care Pharmacy Services*[1] further describe activities consistent with good practice for the provision of pharmacy services to a palliative care unit, service, specialist clinic or hospice. They also encompass services provided to palliative care patients in general wards or being cared for on an outpatient basis or at home.

The priorities for workforce capacity must enable discussion about the importance of access to clinical pharmacy services for palliative care. Current pharmacy services provided to palliative care patients in Australia are mainly provided on a part-time basis and involve clinical, administrative, educational and medication supply functions.[2] The pharmacist responsible for the overall service to a palliative care unit is referred to as a palliative care pharmacist. SHPA believes that palliative care pharmacists should be embedded across all settings where palliative care is provided including: hospital, hospice, ambulatory, residential aged care, within the community and for both rural and remote settings. This section's priorities should reflect the importance of palliative care pharmacists and raise greater awareness of the key role they have in providing safe and effective medication services for patients in palliative care.

SHPA has more than 750 pharmacists engaged in our Palliative Care Specialty Practice stream working in hospitals and health service facilities nationally. This number, whilst significant, is insufficient for the medicine management needs of this important patient cohort. Hospital pharmacists play a crucial role in supporting palliative care patients across Australia each day, and frequently inform SHPA of the workforce shortages in this space. They have highlighted the need to prioritise medication management in palliative care, by improving the pharmacy workforce capacity and increasing access to clinical pharmacy services for this patient population to ensure high quality care is provided at a level that meets community expectation. The SHPA *Standards of Practice for Clinical Pharmacy Service*[3] recommends 1 FTE clinical pharmacist:25 beds (or 30 longer stay admission) based on clinical pharmacy services delivered during normal business hours. SHPA recommends that Australia's National Palliative Care and End-of-Life Care Information Priorities support achievement of these ratios to ensure safe and effective medication management for Australians in this population group.

[1] SHPA Committee of Specialty Practice in Palliative Care. (2006). SHPA Standards of Practice for the Provision of Palliative Care Pharmacy Services. *Journal of Pharmacy Practice and Research*, *36*(4): 306-8.

[2] Gilbar P, Stefaniuk K. The role of the pharmacist in palliative care: results of a survey conducted in Australia and Canada. J Palliat Care 2002; 18: 287-92.

[3] SHPA Committee of Specialty Practice in Clinical Pharmacy. (2013). SHPA Standards of Practice for Clinical Pharmacy Services. *Journal of Pharmacy Practice and Research*, *43*(No. 2 Supplement), S1-69.

Service and system planning and design

Please comment on the priorities in this section (Service and system planning and design) for advancing Australia's national palliative care and end-of-life care information needs over the next 10 years.

The priorities in this section are: Unmet need for palliative care and end-of-life care to support system and service planning; Vulnerable populations; and People's preferences and actual place of care and death.

Healthcare organisations require substantial information and data to support the development of services and systems that promote best practice. There is currently insufficient data to highlight the unmet needs of medication management and access to affordable and quality medications for palliative care and end-of-life care that is required to inform system changes.

As discussed in our response to Question 17, SHPA believes that palliative care pharmacists should be embedded across all settings where palliative care is provided including: hospital, hospice, ambulatory, residential aged care, within the community and for both rural and remote settings. This section's priorities should reflect the importance of palliative care pharmacists and raise greater awareness of the key role they have in providing safe and effective medication services for patients in palliative care. The Australian Commission on Safety and Quality in Health Care's *National Consensus Statement: essential elements for safe and high-quality end-of-life care*[1], discuss the importance of systems that support best practice, such as the development of consistent processes for accessing palliative medications and hence improving the timelines of treatment for distressing symptoms. The statement recommends that systems to ensure appropriate access to medications for palliative care patients, should align with NSQHS Standard 4 (Medication safety). As noted previously our workforce report substantial unmet need for medication management as part of end-of-life care.

The role of a palliative care pharmacist includes the facilitation of safe and smooth access to a patient's medication when transitioning from hospital to community settings. Medications commonly used to support patients in palliative care are not always available from community pharmacies which necessitates considerable effort by caregivers to obtain. Particularly over weekends or holidays obtaining timely supply from community pharmacies without pre-warning may not be possible resulting in missed doses, unnecessary discomfort and considerable stress, especially when the patient's medicine needs are rapidly changing and escalating. Ringing around from one community pharmacy to another in hope of finding a pharmacy that stocks their loved one's medications, can be a stressful activity for carers and may lead to patients missing doses, resulting in adverse events. Palliative care pharmacists can facilitate better access to medications for patients during key transitions, by liaising with their local community pharmacy and requesting they source a patient's medications prior to their discharge from hospital.

SHPA would like to caution the use of Pharmaceutical Benefits Scheme data as insight into medication use to inform service and system planning and design. This is due to the PBS data available being skewed as it only captures authority prescriptions and does not reflect the full picture of what is going on with medications dispensed under the PBS for use in palliative care. Much of the prescribing and dispensing of medications in a palliative care setting is outside the Palliative Care Section of PBS and is often non-PBS as it may be prescribed for an off-label indication, or the medicine does not require a prescription (e.g. laxatives). This means that reporting, as included in the annual national report on palliative care, through collecting Palliative Care Section PBS data is not representative of the breadth and spectrum of all medicines prescribing and dispensing in palliative care[2]. This is due to limitations in the data capture - although there is the ability to capture some specialist palliative care prescribing through prescriber numbers, this is only available for consultants and nurse practitioners, and currently the prescribing undertaken by registrars and other junior medical officers is often not captured. Further complicating this are large gaps in reporting and data capture capabilities of medicines prescribed and dispensed to palliative care patients to hospital inpatients and upon discharge, which in many cases are funded by the public hospital – and thus the state government – if the medicine is not a PBS medicine and prescribed for its PBS indication. SHPA believes it is important for all medication use in palliative care, where they are supplied and how they are funded, to be understood by policymakers to accurately inform service and system planning and design and implement streamlined reforms to palliative care medication access and funding. This is highlighted in the Palliative Care Australia and SHPA joint position statement on Sustainable access to prescription opioids for use in palliative care.[3] This position statement recommends that the Australian Government re-form the Palliative Care Medications Working Group to review the Palliative Care Schedule of the Pharmaceutical Benefit Scheme (PBS). This Schedule must meet current, evidence-based practice guidelines and an improved awareness to prescribers.

Given the many pathways to palliative care SHPA also believes it is important to support the education of a broad base of pharmacists to support high quality medication management for community-based and residential aged care patients. In particular, SHPA advocates for greater use of Home Medicine Reviews and implementation of service management to support SHPA's Standard of Practice for Geriatric Medicine in Pharmacy Services.[4]

[1] Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safe and high-quality end-of-life care. Sydney: ACSQHC, 2015.

[2] Health, A. I. o., & Welfare. (2020). Palliative care services in Australia. Retrieved from Canberra: https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia

[3] Palliative Care Australia. (2019). Position Statement: sustainable access to prescription opioids for use in palliative care. Retrieved from: https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2019/05/PalliativeCare-Opioid-Position-Final.pdf

[4] Elliott, R.A., Chan, H.Y., Godbole, G., Hendrix, I., et al. (2020). Standard of Practice in Geriatric Medicine for Pharmacy Services. J Pharm Prac Res.

Service delivery and integration

Please comment on the priorities in this section (Service delivery and integration) for advancing Australia's national palliative care and end-of-life care information needs over the next 10 years.

The priorities in this section are: Data capture on care at home and in the community; Ease of access, coordination and transition between services; and Data sharing for appropriate and coherent care across services and care settings.

The transition of care remains a known high-risk period for patients. Data capture of the patient journey and outcomes across the transition is an essential element of advancing Australia's national palliative care and end-of-life care efforts. The fragmented nature of medicines management leaves patients at an unacceptably high risk of error, adverse event, polypharmacy, suboptimal symptom control and subsequently poorer outcome. In particular, with multiple changes to medications, route of administration, dose forms etc. made during the last few weeks of life, maintaining appropriate supply can be a challenging experience, especially on weekends, creating much anxiety for carers during what is already a difficult time.

In most states and territories of Australia jurisdictionally funded healthcare systems provide limited outreach services frequently handing patients over to General Practitioners, residential aged care services and palliative care services which rely on community pharmacies for medicine supply. At a service level information about provision of palliative care pharmacy services would be invaluable. At a patient level information capture about the incidence of disruptions to medicine supply, access to prescription revisions after hours or on weekends, provision of beneficial deprescribing, access to pharmacy counselling and education on medicine supply and the provision of advice on medicine disposal would all be useful for future policy development. In addition reporting of adverse medication events should be encouraged for all palliative patients.

Performance and public reporting

Please comment on the priorities in this section (Performance and public reporting) for advancing Australia's national palliative care and end-of-life care information needs over the next 10 years.

The priorities in this section are: Improve the quality of existing data; Identify the characteristics of people at the end of life; and Monitor the quality and provision of palliative care in the system overall.

In addition to the points included in the document SHPA believes the following indicators should be gathered by researchers and policymakers to monitor the quality and provision of palliative care services:

- The proportion of palliative care services that have a clinical palliative care pharmacy service
- The ratio of clinical palliative care pharmacists to patients
- The rate of complete and accurate medication lists provided to clinicians at transitions of care
- The rate of medication-related interventions delivered to palliative care patients (this must be supported by development of appropriate and complete clinical coding for these activities)
- The incidence of missed medication doses for palliative care patients
- The incidence of incorrect medicines or doses administered to palliative care patients
- Accurately examining who bears the cost of medications and the proportion in which this cost is borne by each entity

Given the significant role medications play in palliative care and end-of-life care, a greater focus must be placed on gathering information on these indicators to inform an overall system that supports safe and quality use of medications in this patient population.