



National Prescribing Service Limited

**Understanding the issues and
exploring the strategies to achieve
quality use of medicines in
palliative care and end of life**

A consultation report

2009

NPS is an independent, non-profit organisation for Quality Use of Medicines, funded by the Australian Government Department of Health and Ageing.

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Your submission should include:

- A completed consultation submission form (as above)
- Comment/feedback on sections and questions in the Consultation Report that are of interest to you
- If applicable, any other relevant information, comments or suggestions you may wish to provide to NPS.

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Deadline for submissions: **Wednesday 20 May 2009**

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Background

This report has been prepared by National Prescribing Service (NPS) in collaboration with Palliative Care Australia (PCA). It describes the key factors and issues affecting the achievement of quality use of medicines (QUM) in palliative care in Australia and makes recommendations for developing strategies to improve QUM in palliative care.

Consultation with key stakeholders has been sought in both the identification of the key QUM issues and also the proposed actions required. This report aims to summarise the “state of the nation” with respect to QUM in palliative care and guide the direction of future activities to improve this.

In this report, the key factors and issues influencing the QUM in palliative care are based on the elements of the definition of QUM¹. These are:

1. the judicious choice of management options
2. the appropriate choice of medicines, where a medicine is considered necessary
3. safe and effective use

The recommendations for action and further work have been framed using the building blocks necessary to achieve QUM as outlined in the National Strategy for Quality Use of Medicines. These are:

1. policy development and implementation
2. facilitation and co-ordination of QUM activities
3. provision of objective information and assurance of ethical promotion of medicines
4. education and training
5. provision of services and appropriate interventions
6. strategic research, evaluation and routine data collection

Terminology

Palliative care services, predominately established to provide care to cancer patients who were dying, now find that they need to respond to the needs of patients with different diagnoses. Service delivery models have needed to be developed or modified to accommodate this increasing demand for care and new ways of describing the patients, their needs and the care provided have been introduced. This new language has included terms such as ‘end of life’, ‘palliative approach’ and ‘primary palliative care provider’. The introduction of some of these terms has had some unintended consequences. There are now a variety of ways that the same type and level of care or need can be described. Palliative Care Australia (PCA) has developed a Glossary² to encourage the consistent use of terminology and improve clarity in communication about palliative and end of life care. Over time consistent use of language will help to reduce confusion and ensure clear and unambiguous communication between levels of service providers and between services, patients and the wider community. Throughout this consultation document the terms palliative care and end of life have been used interchangeably, reflecting the current language used by the stakeholders involved. It is recognised that this is an important issue for discussion and consolidation through future work.

Current work in QUM and palliative care

It is recognised that there are many stakeholders at the national, state, local and professional level, that are active and interested in medicine use in palliative care. It is also acknowledged that there have been considerable resources invested over the past 8 years in particular, to improve palliative care services in Australia.

¹ Commonwealth Department of Health and Ageing, 2002. *National Strategy for Quality Use of Medicines*

² Palliative Care Australia, 2008. *Palliative Care- Glossary of Terms- Edition 1 2008*.
<http://www.palliativecare.org.au/Portals/46/resources/PCA%20Glossary%20Final%20July%2008%20LR.PDF>

The National Palliative Care Program

Funded by the Department of Health and Ageing (DoHA), the National Palliative Care Program has been instrumental in significantly influencing the landscape for improving QUM. Three of the four broad priority areas identified in the program have direct relevance to QUM:

- 1. Increased access to medicines in the community** through the work of the Palliative Care Medicines Working Group (PCMWG), particularly the development of the palliative care section of the Pharmaceutical Benefit Scheme (PBS) and the ongoing work of the Palliative Care Clinical Studies Collaborative (PaCCSC) which manages multi-site clinical drug trials in order to gather the scientific evidence required to register palliative care medicines on the Australian Register of Therapeutic Goods and to list them on the PBS.
- 2. Research and quality improvement for palliative care services** including the development of the CareSearch Palliative Care Knowledge Network providing evidence-based information and practical resources that will serve the needs of clinicians, other health care professionals providing palliative care, researchers and the National Health and Medical Research Council (NHMRC) Palliative Care Research Program. The NHMRC program comprises of priority-driven research grants, small development grants and a range of scholarships and fellowships to attract new researchers and provide a career path for existing researchers. The Palliative Care Australia National Standards Assessment Program (NSAP) provides a systematic quality improvement program targeted initially at specialist palliative care services but eventually incorporating all providers of care at the end of life. Data and information to support quality improvement are now being routinely collected by specialist palliative care services through the Palliative Care Outcomes Collaboration (PCOC).
- 3. Education, training and support for the workforce** through the development of programs such as the Program of Experience in Palliative Care Approach (PEPA), a sustainable hands-on work placement training program for health professionals in a specialist palliative care service of their choice and the Palliative Care Curriculum for Undergraduates (PCC4U) which aims to promote the inclusion of all health care training in the role of palliative care and its principles and practice in the care of dying people. PCC4U also supports the inclusion of palliative care education as an integral part of all medical, nursing, allied health undergraduate training, and ongoing professional development. The Guidelines for a Palliative Approach in Residential Aged Care (APRAC), and the Guidelines for a Palliative Approach in the Community (ComPAC) both outline the medication management of common symptoms and refer to relevant information resources.

The transfer of the National Palliative Care Program into the Ageing and Aged Care Division of DoHA is important and relevant. Population projections for increased incidence of chronic diseases and the associated expectations regarding the need for care at the end of life indicated an urgent need to broaden the focus of palliative care beyond its historical association with malignant disease to incorporate a broader vision of quality of care for all at the end of life. This will necessitate a rethinking of the relationship between specialist palliative care and primary care services and each of their roles in ensuring that all patients receive the right care, at the right time, in the right place. However it needs to be acknowledged that palliative care is also required in conditions not related to age such as HIV/AIDS, neurodegenerative disorders and conditions affecting children.

Palliative Care Australia (PCA)

PCA is the national peak body established by the collective membership of eight state and territory palliative care organisations, plus the Australia and New Zealand Society of Palliative Medicine (ANZSPM). The membership of these organisations includes palliative care service providers, clinicians, academics, consumers and members of the general community. PCA works to support the principles of quality care at the end of life, raise awareness of palliative care (as a speciality), improve understanding and promote need for better access.

PCA has authored a number of policy documents that influence the framework within which improvements in QUM at the end of life will occur. The documents include:

Standards for Providing Quality Palliative Care for All Australians – key governing documents that influence both primary and specialist palliative care service providers in the way they plan and deliver palliative care.

The standards set out the relationship between primary care providers and specialist palliative care services. They also articulate the level of expectations for all services involved in the provision of care to people with a life-limiting illness.

Service Provision Guide: A planning guide – provides guidance on palliative care service delivery with the aim that all Australians should have equitable access to quality care at the end of life, regardless of where they live, their age, diagnosis or social or cultural background. The guide outlines the minimum professional staffing needs required to ensure specialist palliative care is provided to all who need it.

The Guide to Palliative Care Service Development: A population-based approach – provides the context within which the Standards and the Service Provision Guide can be interpreted and applied. This policy document articulates a needs-based approach to palliative care and implications for service development.

National Palliative Care Core Continuing Professional Education Framework – defines the framework around which continuing education should be developed.

Interim Position Statements on Primary Care, and Residential Aged Care and End-of-Life – outline the expectations that the provision of care at the end of life is within the normal scope of practice in these areas and should be a core competency for staff working in these areas.

Workforce Mapping Report – identifies skill mix and capacity issues in the healthcare workforce.

PCA has recently been involved with a number of medication related issues including the co-ordination of a national review regarding alternative subcutaneous infusion devices following the withdrawal of the Graseby syringe driver, provided submissions regarding the PBS “Cost Recovery” proposal in the 2008 Federal Budget to charge for submissions to Pharmaceutical Benefits Advisory Committee.

The Joint Therapeutics Committee is a forum for clinicians to advise PCA and support significant policy work to improve access to medicines. This committee links with the federal government’s advisory panel: the Palliative Care Medicines Working Group (PCMWG).

National Prescribing Service (NPS)

With the key role of facilitation and implementation of strategies to improve QUM, NPS has worked in many therapeutic areas over the past 10 years. While there have been no palliative care specific interventions thus far, NPS has long recognised QUM in palliative care as an important area and has conducted some initial work to better identify the information needs of general practitioners (GP) and pharmacists, and seek feedback from selected stakeholders regarding the key issues influencing QUM in palliative care.

NPS has been a member of PCMWG from the beginning (2004) to ensure that QUM principles were embedded in the changes to the palliative care section of the PBS.

Work currently undertaken by the NPS around QUM includes:

- independent, balanced, evidence-based publications such as Australian Prescriber, NPS News, Prescribing Practice Review (PPR) and Rational Assessment of Drugs and Research
- telephone services such as the Therapeutic Advice and Information Service (TAIS)
- educational and quality assurance programs whereby health professionals are given opportunities to participate in educational activities and use quality assurance tools to reflect on their own practice and explore and apply best practice activities e.g. educational visits, clinical audits, small group discussions and case studies
- supporting communications in the nursing sector including work with new emerging prescribers with a focus on nurse practitioners
- prescribing curriculum in partnership with medical, pharmacy and nursing schools, postgraduate training organisations and colleges for undergraduate and postgraduate students
- the NPS Research and Development program focusing on enhancing our understanding of strategies that support QUM. It aims to identify barriers to change, gaps in current evidence, and define innovative methods of delivering NPS services. The program also promotes QUM research capacity both within and outside the organisation

Palliative Care Medicines Working Group (PCMWG)

The PCMWG meets twice a year and provides advice and guidance to the Department of Health and Ageing on improving access to palliative care medicines in the community. Membership of the PCMWG is multidisciplinary and includes representatives from a broad range of stakeholders who support the delivery of high quality palliative care across all settings. This includes representatives from industry, regulatory bodies, professional groups as well as clinicians. Through the Palliative Care Medicines Working Group (PCMWG) increased access to palliative care medicines in the community under the Pharmaceutical Benefits Scheme (PBS) has been achieved with the implementation and ongoing development of the palliative care section under the PBS.

Palliative Care Clinical Studies Collaborative (PaCCSC)

PaCCSC is a collaborative research group that consists of 10 sites around Australia. Between the sites, a number of Phase III and Phase IV clinical studies are underway or in the advanced stages of preparation.

The Phase III randomised controlled trials include the following medications and indications:

- Ketamine-uncontrolled complex cancer pain
- Risperidone-delirium
- Megesterol acetate-anorexia
- Octreotide-bowel obstruction
- Ketorolac-literature review

The Phase IV studies will focus on the symptoms being examined within the Phase III studies. They will describe current treatment practices, medication use and incidence of adverse drug reactions. Both the Phase III and Phase IV studies will build the evidence base for current practice within palliative care in Australia.

Other relevant organisations

Professional organisations representing healthcare professionals working in primary health care and palliative care are influential and important in developing and implementing strategies to improve QUM. ANZSPM and Palliative Care Nurses Association (PCNA) are the peak professional organisations representing medical specialists and nurses working in palliative care and provide opportunities for continuing professional development. The Society of Hospital Pharmacists of Australia (SHPA) has developed *Standards of Practice for the Provision of Palliative Care Pharmacy Services* in hospital settings. These outline the pharmacy services required to support a successful clinical pharmacy service including relevant resources required, staffing structure and levels, and training and education.

The Pharmacy Guild of Australia (Guild) has funded a research project as part of the Fourth Community Pharmacy Agreement Research and Development Program which aims to strengthen the role that community pharmacists can play in the provision of care to patients with terminal conditions. This study aims to raise awareness of community pharmacists and their team about the clinical and social needs of people living with a terminal condition and their families and carers. It will promote and strengthen the collaboration between community pharmacists and specialist palliative care service providers regarding patient care.

Organisations such as Cancer Australia and Carers Australia will be important stakeholders in activities to improve QUM in palliative care. Cancer Australia provides national leadership in cancer control by strengthening consumer participation, building cancer research capacity, enhancing the education of cancer health professionals, improving access to cancer services and improving cancer data.

Carers Australia and the network of carers associations in each state and territory promote the recognition of carers to governments, businesses and the wider public. Their services, including counselling, advice, advocacy, education and training, aim to improve the lives of carers.

State based initiatives

State-based guidelines have been developed outlining how medications should be managed within various healthcare settings, for example the *Guidelines for the handling of medication in community-based palliative care services in Queensland*, developed by the Brisbane South Palliative Care Collaborative. These documents need to reflect differences in state-based legislation with respect to how some aspects of medication must be handled particularly Schedule 8 medications.

Palliative Care Queensland (PCQ) has developed a new DVD education resource, *Understanding Palliative Care*. Two versions will be produced: a Queensland specific version, and a generic version that can be used outside Queensland to promote palliative care.

In Western Australia, the Palliative Care Network has received Federal funding through the National Palliative Care Program Palliative Care for 'People Living at Home'. This will fund project work to develop and implement medication protocols that are specific to palliative care across Western Australia. The aim is to standardise availability of palliative care medications across the State, establish links between regional community pharmacies and palliative care teams with additional support available from metropolitan specialists, and develop and implement strategies for medication management by terminally ill people and their family living in the community.

The Cancer Institute NSW facilitates the ongoing operation of the Palliative Care NSW Oncology Group to undertake the following activities:

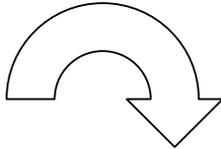
- Provide advise on standard treatments, treatment pathways and protocols for site specific cancers, specifically symptomatology or palliative care issues . It promotes best practice in Palliative Care by assisting to collate Evidence Based Practice and to promote quality improvement activities. It also advises the Cancer Institute NSW on strategic and policy directions with regard to Palliative Care.
- Encourage an increased participation in clinical trials and other research.
- Develop the data requirements for palliative care in addition to the minimum data set.
- Develop educational programs and support the academic palliative care unit
- Develop educational programs to encourage some specialisation and exchange of knowledge relating to palliative care.
- Support the Palliative Care discipline groups, especially in social work, physiotherapy, occupational therapy, pharmacy, dietetics, bereavement, chaplaincy and nursing.

Associated activities

A number of initiatives have been introduced via Community Pharmacies to assist those consumers taking multiple medications and to assist at-risk patients with the management of their medicines. These tools and programs are of particular relevance and value to palliative care patients who often have complex medication regimens.

Home Medicines Review (HMR) is a consumer-focused, structured and collaborative health care service provided in the community setting to optimise consumer understanding and quality use of medicines. It involves the consumer, their general practitioner, their pharmacy, and other relevant members of the health care team. Residential Medication Management Reviews (RMR) aim to provide a structured and collaborative review of a resident's medications to optimise the benefits from medicine use and enhance quality of life. Comprehensive information about the resident and

their medicine use is collated and assessed in order to identify and meet medication-related needs and to identify, prevent and resolve medication-related problems. Dose Administration Aids (DAAs) and Patient Medication Profiling (PMP) are two programs currently funded under the Fourth Community Pharmacy Agreement. Dose Administration Aids (DAA) are recognised as an important tool to assist at-risk patients with the management of their medicines. Patient Medication Profiles (PMPs) are being recognised as an important tool to assist at-risk patients to better understand and manage their medicines. PMPs have not yet been widely implemented as a stand-alone service in community pharmacy, but their intrinsic value has been recognised for some time with the use of discharge summaries from hospital and the availability of general medicine lists from organisations such as the National Prescribing Service (NPS).



Your feedback/comments?

Is there other relevant work, state-based activities or key organisations of which you are aware?

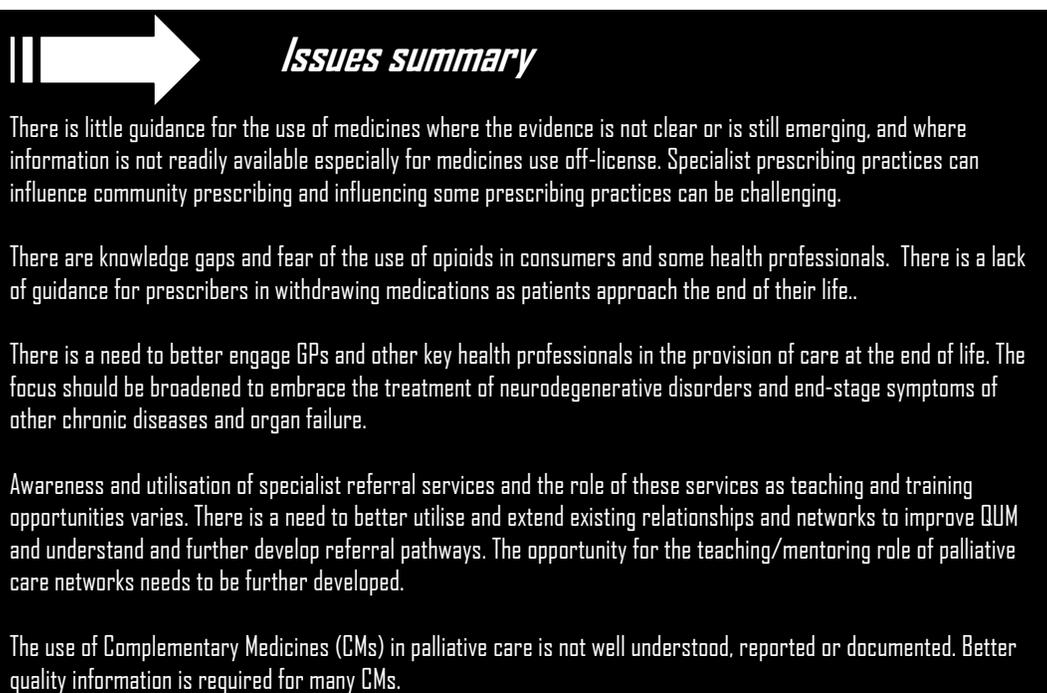
Australian Pharmaceutical Advisory Council 2005 Guiding principles to achieve continuity in medication management. Available from website: <http://www.health.gov.au/internet/main/publishing.nsf/Content/nmp-guiding> - provides a useful framework for people moving between health care professionals and health care settings and establishing a continuum for the safe and effective use of their medications throughout this continuum (and so particularly relevant to people engaged in palliative care.

Factors and issues influencing QUM in palliative care

This section outlines the factors and issues identified through the NPS consultation and discussion with other stakeholders as important in influencing QUM in palliative care. They have been themed using the core definition of QUM:

1. the judicious choice of management options
2. the appropriate choice of medicines, where a medicine is considered necessary
3. safe and effective use of medicines

For each issue relevant work in progress is identified.



Issues summary

There is little guidance for the use of medicines where the evidence is not clear or is still emerging, and where information is not readily available especially for medicines use off-license. Specialist prescribing practices can influence community prescribing and influencing some prescribing practices can be challenging.

There are knowledge gaps and fear of the use of opioids in consumers and some health professionals. There is a lack of guidance for prescribers in withdrawing medications as patients approach the end of their life..

There is a need to better engage GPs and other key health professionals in the provision of care at the end of life. The focus should be broadened to embrace the treatment of neurodegenerative disorders and end-stage symptoms of other chronic diseases and organ failure.

Awareness and utilisation of specialist referral services and the role of these services as teaching and training opportunities varies. There is a need to better utilise and extend existing relationships and networks to improve QUM and understand and further develop referral pathways. The opportunity for the teaching/mentoring role of palliative care networks needs to be further developed.

The use of Complementary Medicines (CMs) in palliative care is not well understood, reported or documented. Better quality information is required for many CMs.

1. Judicious selection of management options

Defined as: Consideration of the place of medicines in treating illness and maintaining health, recognising that for the management of many disorders non-drug therapies may be the best option.

a. Practising with a grey evidence base:

There is a lack of an evidence base for some aspects of medicine use in palliative care making it more challenging to promulgate clear guidelines and direction for non-palliative care prescribers, particularly GPs. Community and palliative care nurses often rely on their relationships with GPs to support their role in the team as a prescribing resource and strong feedback from them has indicated the need for clear guidelines.

Medicines used in palliative care have been used for off-licence indications or routes of administration by palliative care specialists for many years. The increased demand for palliative care patients to be cared for in the community will continue to make the initiation of appropriate medicines and ongoing management of these patients increasingly the responsibility of general practice. Support to general practice from specialist services will also be in greater demand. For many aspects of palliative care there is good and emerging evidence and the challenge is pulling this together in a

comprehensive way, making it available through a credible source in a timely and accessible manner, and then updating it as new evidence emerges.

Most health professionals interviewed by NPS recognised that there were inter-hospital prescribing differences, driven by both the prescribing preferences of the specialists and hospital formulary policies. It was noted that while in some areas of treatment, variations in prescribing can be a matter of preference or “variations on a theme”, in other areas there are quite different prescribing practices. Several comments indicated that, in the absence of hard evidence many palliative care medical specialists prescribe by experience and may be reluctant to change even when presented with emerging evidence.

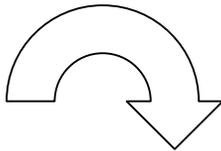
Related work:

PaCCSC work will build the evidence base for a number of medications over time, but there are many more drugs currently in use for which the evidence is unlikely to be formally gathered.

Therapeutic Guidelines – Palliative Care is acknowledged as the most appropriate first line resource for practitioners prescribing for patients at the end of life, including consensus advice where the evidence is still unclear or emerging. Although most of the health professionals consulted in the NPS consultation said they had access to and/or used the Therapeutic Guidelines, most still identified a need for further support for off-licence drug use.

CareSearch has compiled a comprehensive list of information resources for practitioners and literature search templates, although awareness and utilisation among non-palliative care providers appears to be low.

Hospital specific guidelines and protocols often include medicines for off-licensed indications and are used in house and within local palliative care networks.



Your comments/feedback?

Palliative care and end of life care are not necessarily the same thing - the document should therefore highlight the differences and subsequently the different medicines regimes over the continuum of care.

The document appears to medicalise palliative care whereas in reality nurses play a significant role as the caregivers in this area. Nurses specialising in this field have a credible body of knowledge which should be respected in the development of a 'best evidence at the time' base for practice.

b. Key knowledge gaps – opioids

Opioids remain the important mainstay in the management of pain in palliative care yet feedback suggests that there are significant knowledge gaps in their use across all the professional groups. This includes knowing when and how to initiate opioids, dose conversion between opioids, dose escalation, management of breakthrough pain, and understanding the pharmacokinetics of new dosage formulations such as lozenges and patches. Opioid-phobia is an issue for both consumers and health professionals that can significantly impact the achievement of adequate pain management.

The promotion of a number of new products and new formulations over the past few years has made this even more challenging. Most specialist prescribers interviewed by NPS believed that all prescribers should have a good understanding of the pharmacology and pharmacokinetics of opioids and the various formulations in order to adequately manage pain. While there is a wealth of information resources about opioids and pain management available, this remains an area of practice that is often poorly managed and is a key area of concern that requires attention.

Related work:

NPS Therapeutics Program: Analgesic choices in persistent pain.

Therapeutic Guidelines – Analgesia and Palliative Care (3rd edition currently in development).

PCA brochure on opioids for consumers.

Locally developed materials e.g. at Neringah Hospital, Sydney NSW.

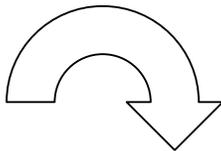
The Royal Australian College of General Practitioners (RACGP) and the Australian College of Remote and Rural Medicine (ACRRM) have developed online education for GPs on opioid medicines in palliative care.

Royal Australasian College of Physicians (RACP) Prescription Opioid Policy: Improving management of chronic non-malignant pain and prevention of problems associated with prescription opioid use, Sydney 2008.

ANZSPM will be holding a series of educational forums for medical practitioners in cities around Australia in April/May 2009. The forums will include a presentation on "Confusion and consciousness at the end of life" and case based discussions on pain and symptom management.

ANZSPM runs a conference every two years to which many palliative care practitioners attend. It is a major source of CPD for palliative medicine specialists in Australia. At these conferences there are also sessions for GPs.

Overseas resources e.g. EAPC opioid prescribing guidelines.



Your comments/feedback?

Nurses practising in palliative care have a significant knowledge base around the medicines regimes required for effective management of pain, especially use of opioids. The ANF takes the position that appropriately qualified nurses and nurse practitioners working in the field of palliative care should be able to prescribe such medicines.

c. Deprescribing

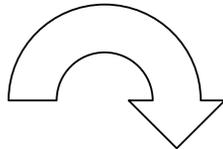
There are issues for primary care and specialist prescribers in withdrawing medications in patients at end of life. There is limited information and guidance on ceasing regular preventive medications such as aspirin and statins, as well as the review of medications used to treat conditions that change as patients progress, for example, hypoglycaemics and antihypertensives.

This is a complex area that requires sensitive communication with consumers. Polypharmacy is a real risk for patients that can significantly affect quality of life and QUM through tablet burden, the risk of side effects and adverse drug reactions or interactions.

Related work:

ANZSPM Clinical Indicator Working Group is working with RACP and the Australian Council on Healthcare Standards (ACHS) to develop evidence based clinical indicators for end of life care.

ACOVE-3 Clinical Indicator work for older persons with poor prognosis and advanced dementia(J Am Geriatr Soc 55:S457-S463,2007)



Your comments/feedback?

The monitoring and review of medicines for people undergoing palliative care, with a view to deprescribing, should be able to be undertaken by any of the range of health professionals involved in the care of a person. Nurses involved in this care are well acquainted with the issues around polypharmacy and the interaction of medicines including those which have the potential for adverse reactions (this is, of course, an issue of general importance and not just confined to end of life care).

d. Understanding the palliative approach

Through the NPS stakeholder consultation, health professionals working in palliative care suggested that there is a need to improve the understanding of all health professionals involved in the provision of care to people at the end of life, in particular GPs who may have had limited experience or interest in this aspect of care. They felt that there is a need for a better understanding of the principles of palliative care, what they try to achieve and a better knowledge of the prescribing principles for medicines used at the end of life. This is sometimes referred to as a palliative approach. It has been suggested that there is a perception among some prescribers that QUM may not be as relevant for patients at the end of life because the patient is terminally ill. The imminent prospect of death can influence the choice of treatment of a particular symptom – or in fact whether to treat it at all.

It has also been suggested that by broadening the understanding of the palliative approach to the care of patients with multiple chronic disease or end-stage organ failure, the principles may have greater application and relevance in general practice. Most GPs only have a few palliative patients at any one time, but have many more patients with chronic and complex diseases. There are many myths, beliefs and attitudes around aspects of care at the end of life that need to change in order to ensure greater achievement of QUM.

Issues of terminology, such as the use of 'palliative care' as opposed to 'end of life' may influence the attitudes of those working in this area. There is anecdotal evidence to suggest that the palliative care 'label' may influence health care providers attitudes, but probably more work in this area is warranted.

Related work:

Guidelines for a palliative approach in residential aged care (APRAC).

Guidelines for a palliative approach for aged care in the community setting (CompPAC) – in development.

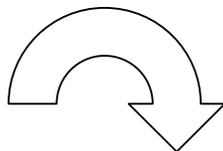
Program of Experience in a Palliative Approach (PEPA).

Engaging GPs Support for the implementation of APRAC guidelines.

RACGP and ACCRM also host an online module on *Palliative care in aged care homes* which was developed as part of the above project.

Price Waterhouse Coopers consultation & review of the implementation of APRAC guidelines.

Gold Standards Framework: Prognostics Indicator Guidance, developed by the Royal College of General Practitioners (www.goldstandardsframework.nhs.uk/gp_contract.php)



Your comments/feedback?

As is noted, a general practitioner may have minimal exposure to palliative care practices. Nurses working in this field have extensive knowledge of all care involved and in particular, the medicines regimes.

e. Complementary medicines

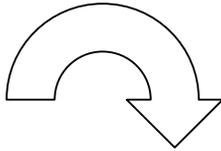
Palliative care is an area where the use of complementary medicines (CM) as an alternative or adjuvant to conventional medicines is potentially high. Raising the awareness of this with both consumers and prescribers is important – the consumer’s awareness of the importance to tell prescribers what they are taking, and the prescriber’s awareness to actively seek this information. There are significant evidence gaps for many CMs and implications for interactions with existing regimens. The quality of information available for many CMs is an issue.

Related work:

NPS research re Complementary Medicines:

Complementary Medicines: Information Use and Needs of Australian Consumers

Complementary Medicines: Information Use and Needs of Australian Health Professionals.



Your comments/feedback?

The important issue here will be for the health professional prescriber not to appear to be judgemental in discussing complementary medicines with the person who is using this form of therapy.

f. Referral patterns/ use of networks and relationships

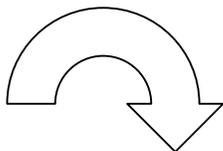
In an area as complex as the provision of care at the end of life, there is a balance between under and over referral to specialist services. Knowledge and experience is in part, a function of how many patients a GP has treated. It was suggested that GPs should learn practically to gain experience and that some current referral processes may remove this opportunity. In some cases these networks are not used as frequently or effectively as they could be by prescribers and there needs to be a better understanding of when and how to access these services for advice and support. The role of these networks as teaching and mentoring opportunities varies between services. The relationships and networks developed, particularly in rural and regional areas, can be very strong and productive and may provide a valuable framework for activities to improve QUM in palliative care.

Through palliative care networks and outreach services, palliative care specialists supported by palliative care nurses, usually working with community nurses, provide practical support to GPs for specific patients. Nurses are a key source of information and education regarding palliative care medicines, particularly in rural areas. They are influential in supporting prescribing practices in the management of symptoms and medication management.

There is an opportunity to utilise and extend the existing relationships and networks (for example, NPS, Australian General Practice Network [AGPN] and palliative care networks) to improve QUM. Referral pathways need to be better defined and the opportunity for the teaching/mentoring role of palliative care networks to be further developed.

Related work:

Rhee J, Zwar N, Vagholkar S, Dennis S, Broadbent A, Mitchell G. Attitudes and barriers to involvement in palliative care by Australian urban general practitioners. *Palliat Med* 2008;11:980-985.
PCA Service Directory.
WA Palliative Care Network.



Your comments/feedback?

Nurses are indeed a key, and excellent, source of information and education regarding palliative care medicines, and as nurse practitioners may also be prescribers of medicines to those requiring nurses services . The emphasis of this section needs to be amended to include these prescribers.

2. Appropriate choice of medicines, where a medicine is considered necessary

Defined as: When medicines are required, selecting the best option from the range available taking into account the individual, the clinical condition, risks, benefits, dosage, length of treatment, co-morbidities, other therapies and monitoring considerations. Appropriate selection also requires a consideration of costs, both human and economic. These costs should be considered for the individual, the community and the health system as a whole.



Issues summary

There are knowledge gaps in using a palliative approach particularly for complex patients. Remuneration structure may not adequately reflect the time and complexity in managing some palliative patients and the demands for home visits and after hours care are not met by the current workforce.

Communication between multiple providers and prescribers across multiple settings is complex. The diversity of workforce knowledge, skills and attitudes can influence the achievement of QUM.

There are perceived knowledge gaps in the use of some palliative medicines that can impact the QUM and adequate management of patients' symptoms, particularly opioids and pain management.

Access to up-to-date, concise and accurate information in a timely manner is important. Access and utilisation of Therapeutic Guidelines – Palliative Care and CareSearch does not appear to be high among primary care prescribers.

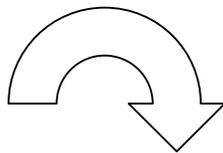
Awareness and utilisation of the Palliative Care schedule of the PBS is low. Access to non-PBS medicines is often complicated and time consuming for prescribers and expensive for patients. There are equity of access issues that compromise QUM and patient care.

a. Prescribing for complex patients using a palliative approach.

There is some concern that not all patients receive the same level of rigorous assessment of symptoms at the end of life as non-palliative patients and that treatment of the underlying cause of the symptoms is not always considered as relevant. The management of some palliative patients can become complex and by necessity often time consuming. Managing a range of symptoms where the endpoint is not cure is challenging. The complexity, or fear of complexity, could make primary care prescribers wary of this area of practice. Comments from specialists indicated that inexperienced prescribers tend to either over prescribe or under prescribe – both suboptimal for the patient. Some specialists interviewed observed that rigorous patient assessment, a careful stepwise approach to treatment and regular review should be adequate to manage most palliative patients in the community but they commented that this does not happen frequently enough.

Related work:

Nil identified



Your comments/feedback?

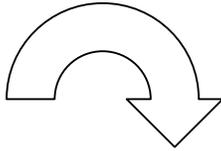
In the absence of the majority of palliative care nurses being able to prescribe in this, their field of expertise, it is essential that medical practitioners who are not familiar with medicines regimes in palliative care practice respect the professional views of these nurses in decision making on appropriate medicines to be prescribed. NPS can assist in facilitating this collaboration.

b. Time consuming nature of palliative care.

There is often additional paperwork required in palliative care, for example, to access some medications. The current remuneration structure does not accommodate the complexity and time required to manage some palliative patients. Complex patients may require many consultations or interventions, and effective communication with patients and their carers or other providers requires time and skill. After hours consultation and home visits are often integral to providing quality care at the end of life and the current remuneration system does not provide sufficient incentives for GPs to provide these services. Due to personal circumstances and commitments many prescribers are not in a position to provide these services.

Related work:

Rhee J, Zwar N, Vagholkar S, Dennis S, Broadbent A, Mitchell G. Attitudes and barriers to involvement in palliative care by Australian urban general practitioners. *Palliat Med* 2008;11:980-985.



Your comments/feedback?

This very real issue would be better dealt with by allowing appropriately qualified experienced palliative care nurses to prescribe medicines as part of their practice (as per pg 21).

c. Multiple providers and prescribers across multiple sites (communication)

Achieving QUM in palliative care is challenged by the fact there are multiple providers and prescribers (for example, GPs, palliative care specialists, oncologists, nurse practitioners) across multiple settings and patients often move between these settings. Communication of progress, plans and action with respect to symptom and medication management is essential to ensure each of the health professionals understands what is happening. Communication between settings is essential as patients often move between home and hospital, hospice or Residential Aged Care Facilities (RACF). Feedback suggests that communication and documentation varies and could be improved.

Related work:

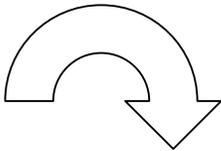
National E-Health Transition Authority (NeHTA).

Australian Pharmaceutical Advisory Council's (APAC) Guiding principles to achieve continuity in medication management.

Area Health Services' local projects.

Patient held record initiatives e.g. The Red Book, Yellow Envelope.

MediLists.



Your comments/feedback?

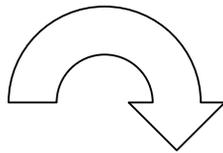
This is an area where electronic messaging facilities would be ideal. There is a need for NPS to assist in expediting the introduction of e-health technology to improve the continuity of care for people moving between facilities - this being a particular feature of people engaging in palliative care.

d. Diversity of workforce knowledge skills and attitudes

The specialist palliative care workforce is varied, so ensuring the right messages are reaching the target audience is important. As with many areas of health, there is a high proportion of part-time staff. As choices for consumers improve, and as Advanced Care Directives become better understood there will be an increased demand for end of life care to be provided in the community and workforce knowledge and skills will be an issue. Each care setting has unique issues that can affect QUM including the ability to access appropriate medicines, availability of health professionals to provide care, and access to health professionals who have the appropriate knowledge, skills, attitudes and access to appropriate resources. There are also differences in the levels of knowledge and information required by the various providers in each setting, in the current level of education and training available, and the awareness and utilisation of these. As previously mentioned, despite the availability of a number of quality information resources and recently developed guidelines, utilisation and implementation is low.

Related work:

PCA Workforce Mapping Report.



Your comments/feedback?

Nurses have consistently demonstrated a preparedness to keep themselves abreast of professional practice issues. The issues raised in this section are a further incentive for equipping appropriately qualified nurses (as well as nurse practitioners) with the ability to prescribe to increase the number of health professionals able to prescribe and give greater flexibility to a qualified competent workforce able to deliver quality use of medicines.

e. Knowledge gaps regarding palliative medicines/ information resources

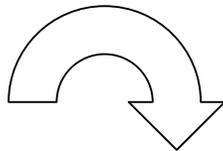
The NPS consultation suggested that there are perceived knowledge gaps within the specialist profession, particularly around the pharmacology and pharmacokinetics of newer drugs and the suggestion that there was a tendency to become “novices of many drugs and experts of few”. It was noted that palliative care is an area where evidence is emerging for many treatment approaches, drugs are being used in very different ways and a thorough understanding of how these drugs work is essential, particularly for specialists.

Primary care prescribers should understand their level of knowledge regarding medicines used at the end of life, and know where to find information, when to seek advice and who to turn to when they need help and support. Most palliative care specialists interviewed in the NPS consultation felt that prescribers should have a basic knowledge of the pharmacology and pharmacokinetics of the commonly used groups of drugs such as opioids, anti-emetics and benzodiazepines, in order to understand which drug to choose under which circumstances. They felt that this level of understanding was lacking and this can lead to inappropriate treatment choices and inadequate symptom management. GPs indicated they wanted easy to access, simple, stepwise treatment options for symptoms i.e. 1st, 2nd and 3rd line treatment options and advice about what works and what doesn't.

It would appear that in general, there is a large amount of information available about most medicines used in palliative care and at the end of life. It seems that the issue is accessing the right information in a timely manner and ensuring the information is current and concise. Ensuring the latest information and guidance is available for areas where the evidence is sparse or still emerging is an issue. Accessibility is an issue especially in rural areas. Feedback from the NPS consultation suggests that utilisation of Therapeutic Guidelines – Palliative Care is low despite high awareness and respect for the publication, and most non-specialist health professionals are unaware of CareSearch.

Related work:

CareSearch Knowledge Network Project – list of resources and PubMed search templates.



Your comments/feedback?

Nurses working in palliative care are knowledgeable about the medicines regimes specific to that care. This resource should be used more and acknowledged by GPs who may have limited exposure to people undergoing palliative care.

f. Access issues affecting QUM in palliative care

Despite changes to improve access to some medications via the palliative care section of the PBS, access to some important medicines remains an issue and this can affect QUM and patient care. While it is recognised that in time, the PaCCSC trials will help provide evidence for or against the use of a number of important medicines, access to many non-PBS medicines remains an important issue particularly for specialist prescribers. Some medicines such as gabapentin used for neuropathic pain or cyclizine and levomepromazine used for nausea may never become widely available in Australia.

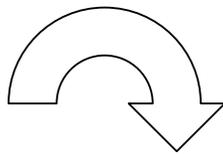
Equity of access issues exist between hospitals in many states where individual hospital drug committees determine the availability of certain medicines for inpatients and outpatients. Non-PBS listed drugs, usually those used for off-license indications, for example, gabapentin and midazolam must be fully funded by patients if ongoing supply is not provided by a public hospital outpatient clinic. In hardship cases, particularly in rural areas, this means these drugs are often not used or less effective drugs are substituted. In some circumstances lack of access to non-PBS drugs in the community can result in hospitalisation in order to access certain medications.

Special Access Scheme (SAS) drugs, for example, cyclizine, levomepromazine and non-PBS drugs commenced in hospital, are only subsidised via outpatient clinics of some public hospitals – often making access difficult for rural patients returning home. SAS paperwork is time consuming and complicated if prescribers are not doing it regularly. Many GPs are unaware of the SAS/SIOD scheme or that some non-PBS drugs can be provided from hospitals. Access to less commonly prescribed drugs (usually end-stage) or SB drugs in adequate quantities via community pharmacies can sometimes be an issue, especially after hours or on weekends. This can, for the most part, be managed by pre-emptive prescribing and good communication, but sometimes can be problematic. The co-ordination of this is time consuming and usually dependant upon the nurses involved.

With the exception of specialist palliative care health professionals, it would appear that there is a low awareness of the PBS Palliative Care Schedule and generally low utilisation. The paperwork associated with the PBS Authority system can be significant for specialist prescribers.

Related work:

PCMWG
PaCCSC



Your comments/feedback?

3. Safe and effective use

Defined as: Ensuring best possible outcomes of therapy by monitoring outcomes, minimising misuse, overuse and underuse, as well as improving the ability of all individuals to take appropriate actions to solve medication-related problems, for example, adverse effects and managing multiple medications.



Issues summary

There is a lack of guidance around the safe disposal of medications, particularly opioids.
There is significant wastage and excess costs associated with the supply of PBS pharmaceuticals in palliative care.

There is a lack of protocols to guide consumers and carers in the safe administration of potent medications in the home. There is inadequate written information about medicines for non-licensed indications in palliative care.

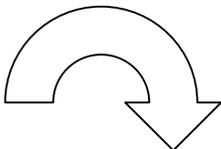
Polypharmacy from both prescribed and self administered medicines and products increases the risk of adverse events in patients. There is no system to measure or monitor medication related adverse events in the community or palliative care setting.

a. Disposal of unused medicines, especially opioids, and equipment

Feedback suggests there is a lack of guidance for consumers and carers around the safe disposal of medicines, particularly opioids, after the death of a patient or when treatment regimes change. The Return of Unwanted Medicines (RUM) program does not currently adequately address this.

Related work:

- RUM program.
- RACP Prescription Opioid Policy.



Your comments/feedback?

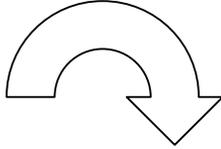
This comment relates to the whole of Section 3.
Nurses are the health professional most seen by an individual and his/her family in a palliative care continuum. Nurses are well able to inform families about issues such as, disposal of unopened medicines, use of syringe drivers/pumps, how to interpret Consumer Medicines Information, review of medicines including complementary medicines, adverse medicines events, and monitoring for effectiveness of medicines.

b. Wastage of pharmaceuticals (and costs to consumers)

The current PBS system does not enable flexible supply of medicines to accommodate strength or formulation changes, dose escalation or reductions. Symptom management in complex patients often involves the trial of a number of medications in differing strengths and quantities some of which may not prove to be effective. Often large quantities of unopened medications remain after a patient dies.

Related work:

Current consultation via the Fourth Community Pharmacy Agreement – Review of Existing Supply Arrangements of PBS Medicines in Residential Aged Care Facilities and Private Hospitals.



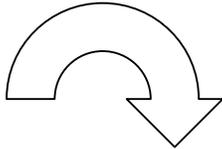
Your comments/feedback?

c. Lack of protocols for consumers or carers for medicines administered at home

Feedback suggests that there is little guidance or formally documented protocols to assist patients or carers to administer often potent medicines at home. There is often little training in the use or maintenance of syringe drivers or pumps. Documentation and communication around the administration of breakthrough doses, dose escalation, and anticipatory medication supply appears to vary. Consumers and carers are often in a stressed and emotional state making communication challenging. These issues have real safety implications for those involved.

Related work:

Locally developed guidelines within palliative care services.
APAC Guiding Principles for Medication Management in the Community.

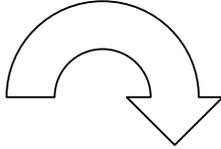


Your comments/feedback?

d. Inadequate written information for many medicines used in palliative care

The Consumer Medicines Information (CMI) leaflets for many medicines used in palliative care do not include indications for off-licence use. Patients depend on verbal communication from their health professionals. In the absence of the correct and timely information, it is possible that consumers could be inappropriately alarmed or confused, thus impacting on QUM.

Related work:
Nil identified



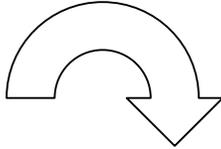
Your comments/feedback?

e. Polypharmacy is a real risk for palliative patients

Multiple medications, often prescribed by more than one prescriber for the treatment of multiple symptoms, together with medications for other chronic diseases significantly increases the risk of an adverse event occurring. The addition of non-prescribed medications such as CMs and medicines purchased over the counter further complicates the situation. Regular review of medications and excellent communication skills are essential.

Related work:

Home Medicines Review (HMR) and Residential Medication Management Review (RMMR).
The Role of the Community Pharmacist in Palliative Care Project (Curtin University)



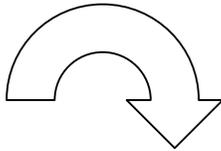
Your comments/feedback?

f. Adverse event monitoring

There is little information about adverse medication events occurring in the community or in the palliative care setting. There is no formal adverse event monitoring system to determine the incidence or to develop strategies to minimise risks. We are not aware of formal linkages with Coronial Offices to identify systems where medication misadventure has been implicated in the death of a palliative patient.

Related work:

Adverse Drug Reactions Advisory Committee (ADRAC).
Australian Commission of Safety and Quality in Health Care.
Adverse Medicine Events (AME) line.



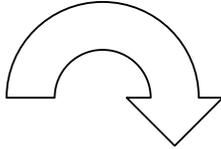
Your comments/feedback?

g. Monitoring effectiveness/outcomes

Monitoring effectiveness and outcomes in many areas of health care is challenging, but palliative care has its own unique issues. In terms of QUM there has been limited work.

Related work:

Palliative Care Outcomes Collaboration (PCOC) – data collection re symptom assessment scores but no specific information re medicines use.
Palliative Care Needs Assessment Framework.



Your comments/feedback?

4. Other factors and issues that influence QUM in palliative care

Issues summary

Many prescribers “don’t know what they don’t know” about palliative care medicines and are a primary target for programs to improve knowledge and provide support.

There is a need for an educative framework around the medicines used in palliative care practice for all the health professional groups, including palliative care specialists, across multiple settings with consistent, streamlined, targeted messages.

There is limited information available describing the QUM issues for consumers and carers in palliative care.

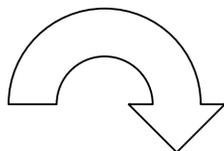
a. Targeting the prescribers who “don’t know what they don’t know”

Feedback from the NPS consultation suggested that the group of prescribers of most concern is those who “don’t know what they don’t know”. Specialists indicated that there was a small core of GPs with a special interest in palliative care who seek education and training and attend Continuing Professional Development (CPD). They felt however, that the majority of GPs had pressures to keep up to date in so many more mainstream areas of medicine, that CPD in palliative care would always be a low priority. It is therefore difficult to reach, communicate and update most GPs on aspects of end of life care when it is not their primary patient casemix.

Related work:

Rhee J, Zwar N, Vagholkar S, Dennis S, Broadbent A, Mitchell G. Attitudes and barriers to involvement in palliative care by Australian urban general practitioners. *Palliat Med* 2008;11:980-985.

ANZSPM will be holding a series of educational forums for medical practitioners in cities around Australia in April/May 2009. The forums will include a presentation on “Confusion and consciousness at the end of life” and case based discussions on pain and symptom management.



Your comments/feedback?

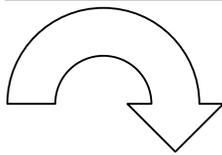
Again, the target of the paper seems to be medical practitioners with scant reference to the fact that nurse practitioners and nurses expert in palliative care are frequently the most significant health professionals involved in the care of people accessing palliative care services. This needs to be reflected in the document to give a comprehensive picture of health professionals involved. The knowledge and advice of these nurses needs to be respected by their health professional colleagues within the palliative care team.

b. Education, information and knowledge

Feedback suggests there is likely to be a balance of needs between education, information and knowledge required by the various health professionals and stakeholders in developing strategies to improve the QUM in palliative care. In this context knowledge refers to an understanding of death and dying, the system and the palliative approach, first principles of pharmacology and pharmacokinetics and the ability to apply this knowledge in the clinical setting. Information refers to the factual information and resources required to make a specific clinical decision. There is a need for an educative framework around the medicines used at the end of life for all the health professional groups, including palliative care specialists, across multiple settings with consistent, streamlined, targeted messages.

Related work:

National Palliative Care Core Continuing Professional Education Framework.
PCC4U.



Your comments/feedback?

What is the role of professional organisations in developing an educative framework?
With funding support, professional organisations can develop education programs, which can be provided electronically to give greatest dissemination of the programs to health professionals in all geographic areas.

c. Patient and carer expectations and perceptions re QUM in palliative care

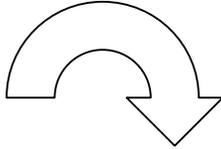
Related work:

PCMWG Communications Sub-group.

A/Prof G. Mitchell current research: Can the needs of caregivers of patients with advanced cancer be met using a General Practitioner Caregiver Toolkit?

Prof Afaf Girgis current research: Evaluation of the Palliative Care Needs Assessment intervention.

Prof. M. O'Connor current research: "What happens after dark". Improving 'after hours' palliative care planning in urban and rural Victoria.



Your comments/feedback?

Nurses, as the most trusted of health professionals and those providing most of the care to those requiring palliative care, are well placed to provide education and support to patients and carers. In reality, this is happening . NPS should acknowledge and support the role of nurses in this area.

What are the opportunities to improve QUM in palliative care?

This section outlines proposed options to address the issues and factors influencing QUM in palliative care and identifies the action required and areas where further work is needed. It has been framed using QUM building blocks:

1. policy development and implementation
2. facilitation and co-ordination of QUM activities
3. provision of objective information and assurance of ethical promotion of medicines
4. education and training
5. provision of services and appropriate interventions
6. strategic research, evaluation and routine data collection

1. Policy development and implementation

(e.g. National Health Policy, National Medicines Policy, National Medicines Disposal Policy, IT policy in health, Federal/State/Territory policies/strategies on QUM and policies/strategies at institutional/organisational/professional level.)

As previously discussed, there has been significant development in policy and implementation via the National Palliative Care Program. A number of the following options come from direct feedback through the NPS stakeholder consultation.

Option 1a: Recommendations for PCMWG to consider regarding palliative care medicines and the PBS.

PBS-online: practical issues including better search capacity, cross-referencing between general and palliative care sections, increasing the general awareness of the section, promotion of WIFM for prescribers and their patients, the need for a hard copy Yellow Book particularly for rural and outreach practitioners, and GP home visits.

PBS Authority status: consider Specialist Authority/Authorised Prescriber status where suitably accredited (mechanism TBC) palliative care specialists may not need to go through all the paperwork for current Authority medicines. Consider a competency-based GP Authority Status where “competent and appropriately qualified GPs” (mechanism TBC) could prescribe ongoing maintenance prescriptions originally authorised by a specialist – similar to some drugs covered by the S100 scheme being managed by a GP but overseen/reviewed periodically by a specialist. This may provide incentives for GPs to consider palliative care training/education and could involve ongoing monitoring via NPS audits or Drug Utilisation Sub-Committee (DUSC) data.

PBS quantities: consider more flexible supply arrangements such as part dispensing of Authority quantities of some palliative care drugs where drug doses are changing as symptoms fluctuate, or where death is imminent, . (i.e. week by week supply, but without financial penalty to either patient or dispensing pharmacist) to avoid significant wastage/costs/safety risks to consumers and carers.

Option 1b: Investigate options for incentives for GPs to provide palliative care services.

These incentives may not necessarily be financial but, for example, could be administrative in the form of less paperwork with streamlined authority applications for GPs who have undertaken formal postgraduate or approved educational activities. Consideration could be given for Practice Incentive Payments for palliative care patient load.

Option 1c: Explore opportunities to link QUM with Advanced Care Directives (working with DoHA).

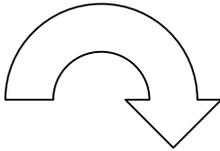
To ensure the choices and medication management plan are understood and where relevant, included as part of the Advanced Care Directive.

Options 1d: Recommend PCMWG discuss with pharmaceutical industry/ Therapeutic Goods Administration end-of-life use in product applications.

Approach regulators to determine if observational data collected from multiple sites can be considered to register/list products for palliative indications. Consider industry incentives such as patent extensions and other incentives to conduct trials in palliative care.

Option 1e: Alternate/interim funding options for non-PBS medications.

PCMWG to consider options for access to high cost non-PBS medications, for example, Compassionate Access Scheme, co-funding/cost sharing models with industry. As above, benchmarking/surveillance mechanisms could be put in place to monitor their use and outcomes.



Your comments/feedback?

Refer to comment at end of Section 6 of Options

2. Facilitation and co-ordination of QUM activities

(e.g. national mechanism for facilitation, co-ordination and promotion of QUM, endorsement of QUM by all partners, processes of funding and evaluation of QUM, mechanisms for dialogue and collaboration amongst partners, and mechanisms to foster and facilitate research into QUM.)

While there are a number of key initiatives in place working towards improving medicines used at the end of life, there is a need for a national approach to facilitate and co-ordinate QUM activities in the area. Key partners include NPS and professional organisations. Existing quality information resources include Australian Medicines Handbook (AMH), Therapeutic Guidelines and CareSearch Palliative Care Knowledge Network.

Option 2a: Enhance QUM focus within CareSearch

Recommend that CareSearch:

- maintain a routine and ongoing national stock-take of available resources to support QUM in palliative care
- consider hosting an Australian version of www.palliativedrugs.com with real time, chat, local issues and information share.

Option 2b: Develop/enhance NPS programs to include a palliative care focus.

Following is a summary from the NPS consultation of the suggestions for how NPS could improve QUM in palliative care: Develop an NPS Palliative Care program/stream including NPS News, PPR and Audit facilitator visits with the following components:

- Demystify palliative care – reinforce to GPs that end of life care is part of their role and responsibility and describe the support networks available. Raise the profile of specialist palliative care
- Promote principles of rigorous assessment of symptoms and causes as the first step to QUM
- Symptom management (pain, nausea, dyspnoea, fatigue, constipation, insomnia, delirium, depression, anxiety) based on consensus where evidence is lacking and updated as evidence emerges over time. Promote a broader symptom approach to include chronic diseases e.g. for dyspnoea treatment principles will have applicability to management of other disease states such as Heart failure (HF) or Chronic Obstructive Pulmonary Disease (COPD). Promote best evidence for pharmacological and non-pharmacological interventions and discussion of options for which there is little or no evidence. The Gold Standards Framework could be used to include organ failure and frailty/dementia.
- Keep the information short, succinct and stepwise for generalists with options to upgrade for those with a special interest in palliative care.

Integrate palliative care education/focus horizontally into other NPS programs. Link palliative care education to other disease states/symptom management where relevant e.g. management of dyspnoea in palliative care and relevance to COPD and heart failure.

Develop a communication piece (column/ article/ regular section) in one of the NPS communication vehicles regarding myths, attitudes and beliefs (could be broader than just palliative care) e.g. opioid-phobia, “life long drug therapy” and issues of ceasing medications at the end-of-life, polypharmacy etc.

Dismiss myths and misconceptions around opioids and improve understanding of pain management at the end of life for prescribers, consumers and carers. Issues include: choice of drug, opioid conversion, formulation differences, the role of patches, side-effects, opioid phobia and updates on new drugs to balance pharmaceutical promotion – especially patches, gabapentin etc.

Utilise existing networks and relationships. Consider using palliative care services/units and palliative care RNs to reinforce NPS information and educational materials to GPs particularly in rural/remote areas.

Develop NPS website with resources for palliative care featuring evidence updates, new drugs, educational material, useful links, existing resources, promotion of CareSearch, Therapeutic Guidelines, AMH, PCA resources, state-based contact details for local resources and support networks, and perhaps a moderated “bulletin board”.

NPS sponsored events such as workshops and education forums including education by specialists (medical, nursing, pharmacy) and consider a multidisciplinary audience via Divisions of General Practice – promoting local networks, resources, links etc particularly for regional/rural areas.

NPS to increase awareness of programs and courses available to health professionals to address information needs and knowledge gaps.

NPS to consider practical promotion of CareSearch search strategy and key features.

Option 2c: Enhance palliative care focus within AMH.

Recommend that AMH consider cross-referencing to resources such as Therapeutic Guidelines and CareSearch for medicines used at the end of life where the evidence is still emerging. Where appropriate include consensus advice and flag medicines listed in the PBS palliative care section.

Option 2d: Increase awareness and utilisation of CareSearch.

Recommend that all palliative care agencies and organisations actively promote CareSearch. NPS promote CareSearch through its educational activities.

Option 2e: Develop and adopt a modified working definition of QUM for palliative care

The definition needs to recognise the inevitable evolution of evidence regarding the use of some medicines, the reality that for some medicines strong evidence may never be available and that consensus may be appropriate, but that the key principles of QUM should be acknowledged and practiced whilst being cognisant of the end-of-life considerations. The notion of experimentation or compromise should not be acceptable.

Option 2f: NPS and state-based Therapeutic Assessment Groups to co-ordinate the development of local/state/national benchmarks for drug use in palliative care using specific clinical indicators.

Develop drug use evaluation (DUE) activities to compare/benchmark targeted prescribing practices at the end of life between palliative care services/units/hospices/primary care services. Consider the methodology used in the National Standards Assessment Program (NSAP).

Plan strategic research and data collection where data is not available from existing data or reports.

Option 2g: Extension of 24 hour support telephone lines.

Recommend the extension of the state-based help lines (currently available in WA and QLD) for prescribers and health practitioners to access support and information after hours.

Option 2h: Develop guidance around deprescribing.

Recommend that NPS develop guidance and define principles and practice points around how and when to withdraw medications at the end of life. Consider work such as ACOVE-3 quality indicators for patients with poor prognosis and advanced dementia.

Option 2i: Develop clear referral pathways with symptom/medication triggers to ensure appropriate referral.

Develop an assessment driven algorithm to assist appropriate referral. Develop strategies, risk factors, treatment objectives and expected outcomes around pain management and therefore determine at what trigger points referral to specialist services is required.

Option 2j: Develop local palliative care registers

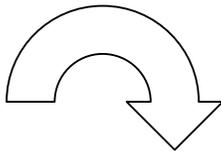
Local palliative care registers would allow for priority flow of patients and information across all settings dictated by patient needs.

Option 2k: Mentoring role of specialist networks and services.

Encourage specialist palliative care services to have a proactive teaching and mentoring role with GPs and nurses, working directly with them and their patients in a true shared care model to develop skills, expertise and confidence to practise in the community.

Identify successful models, refine and describe models of service that enable true shared care arrangements, identify resource requirements, standards of service, training and competencies of staff and funding requirements etc.

Promote awareness and utilisation of Medicare Benefits Scheme (MBS) items that support this i.e. General Practitioners Management Plan (GPMP) and Team Care Arrangements (TCA).



Your comments/feedback?

Refer to comment at end of Section 6 of Options

3. Provision of objective information and assurance of ethical promotion of medicine.

(e.g. national formulary, national therapeutic guidelines, national therapeutic bulletins, ethical promotion, medicines information for consumers, including CMI and objective information integrated with IT developments.)

It is generally accepted that there is adequate information available for most prescribing situations in palliative care. The challenge is knowing when and how to access the relevant information in a timely manner and when and how to refer for additional support. In addition, for those prescribers without a specialist interest or practical experience in palliative care, the issue is identifying what they don't know. It is important that new evidence is communicated and translated into practice change.

Option 3a: NPS to work with palliative care specialists to develop an NPS package/program to engage/communicate with palliative care specialists about emerging evidence, drug updates, trends etc.

Work with ANZSPM to develop and implement strategies to ensure that specialist prescribers have access to the best available evidence and QUM resources.

Option 3b: Develop an “End-of-Life Resource Kit” to support prescribers and health care providers in cases of crisis/ after hours.

Similar to the After Hours Kit developed by North West Melbourne Division of General Practice, this could include a list of resources such as symptom assessment tools, practice points, anticipatory prescribing guidelines, checklists, contact lists etc.

Option 3c: Develop material for existing publications to support quality use of medicines at the end of life

Update publications such as the Queensland Health's Chronic Disease Guidelines used in rural and remote health clinics, CARPA (Central Australian Rural Practitioners Association) Guidelines and the RACGP's Silver Book which do not specifically address end-of-life prescribing and issues related to medicines used at the end of life.

Option 3d: Work with pharmaceutical industry to ensure ethical promotion of opioids and medicines in end-of-life use.

NPS to work with the pharmaceutical industry to develop palliative care versions of relevant CMIs.

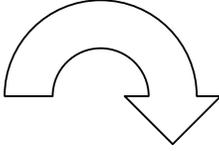
Recommend that PCMWG work with the industry to develop relevant educational material and programs for representatives and ensure end-of-life issues are better understood.

Option 3e: Recommend to PCMWG to discuss the availability of the ‘Yellow Book’ for prescribers and health professionals where access to online versions is limited or unavailable.

Feedback suggests that this is a limiting practical step in the provision of care for rural and remote practitioners, providers of home visits and after hours care.

Option 3f: Increase awareness of CM issues with consumers and health professionals.

Raise the awareness of the risks and safety of CMs at the end of life, i.e. the importance of discussion and documentation to ensure that all possible precautions can be considered via NPS, CareSearch etc.



Your comments/feedback?

Refer to comment at end of Section 6 of Options

4. Education and training

(e.g. community education, community programs, education resources/education kits, school curriculum, teachers and childcare workers, QUM curricula for health professionals – undergraduate and post graduate – and QUM principles and resources linked to accreditation processes.)

It is acknowledged that there are significant education and training opportunities available across the country. Increasing the awareness of these and encouraging utilisation is the important step. Most health professional groups are catered for, although there are still some gaps. There needs to be much greater awareness of the needs of patients and families at the end of life and the palliative approach among all health professionals but particularly GPs and specialists in other disciplines.

Activities need to be developed for both consumers and health professionals. These activities should be planned and co-ordinated at the national level to ensure consistency of messages. CME and Continuing Professional Development (CPD) need a different approach to identify and reach those health professionals who are not actively working in palliative care and those who “don’t know what they don’t know”.

Option 4a: Recommend that CareSearch maintain a routine and ongoing national stock-take of available education and training to support QUM and a national mapping of Australian courses and resources available in this area.

This could be referred to the National Palliative Care Core Continuing Professional Education Framework (PCA).

Option 4b: Broaden the palliative approach to incorporate end of life care for patients with chronic diseases.

Demystify palliative care by encouraging a broader approach and application of palliative principles to chronic disease management. Knowledge and experience gained in symptom control and medicines used in the end of life would have applicability in managing patients with other chronic and complex diseases. For example, the assessment and management of a patient with dyspnoea at the end of life has applicability to the treatment of breathlessness in patients with heart failure. Organisations such as National Heart Foundation (NHF) and other chronic disease groups should be encouraged to address end-of-life issues in their guidelines and resources.

Option 4c: Work with consumer health organisations and PCA to horizontally theme end-of-life messages with other messages.

Consumer based chronic disease organisations, as well as groups such as Carers Australia, Consumers Health Forum (CHF), and Council on The Ageing (COTA) should be encouraged to consider issues relating to end-of-life and medicines use. For example, greater discussion of early signs and symptoms of the condition and what to tell the doctor, management strategies including self-care, expected outcomes of different treatments and where to find quality information about treatment options, promotion of consumer information e.g. CareSearch, Cancer Australia, Carers Australia and PCA.

Option 4d: Develop a community education resource kit around medicines commonly used at the end of life in the home for consumers and carers.

Target consumers and carers – including information about self-care: explain the role of anticipatory prescribing and supply, what to expect, safety issues re storage and disposal of medications and equipment, administration guidelines re pumps/subcutaneous infusions etc, information resources, where to seek help or advice regarding medications etc.

Option 4e: Define the competencies required for health professionals to deliver high quality end of life care.

This is relevant for GPs, nurses (hospital, community and RACF) and pharmacists (community and hospital)

Work with the relevant professional organisations and training/educational bodies to develop these for palliative care e.g. work with ANZSPM and General Practice Education and Training/RACGP/RACP/ACRRM to define competencies for prescribers in the assessment and management of palliative care patients and treatment of common symptoms.

Option 4f: Identify gaps in education and knowledge and provide support for accredited pharmacists.

Work with SHPA and Australian Association of Consultant Pharmacy to ensure up skilling and support for accredited pharmacists.

Option 4g: Better co-ordination of resources and implementation of training for all RACF workers in the provision of high quality care at the end of life.

Work with PCA and relevant RACF groups on Encouraging Best Practice in Residential Aged Care projects. Link education and training of staff in medication management to quality accreditation of facilities and to national standards assessment.

Option 4h: Curriculum for undergraduate and postgraduate training of healthcare workers.

Undergraduate and postgraduate training should address principles of team care and maintaining functionality of teams, and acknowledgement of the consumers' experiences, knowledge, expertise and skills in managing their care at the end of life.

Undergraduate training for medical, nursing and pharmacy should include core components of pharmacology and pharmacokinetics of medicines commonly used at the end of life and should promote the palliative approach.

Postgraduate training courses in palliative care should include advanced pharmacology, pharmacokinetics and pharmacodynamics of medicines used in palliative care and should promote the palliative approach.

Discuss recommendations with PCC4U.

Option 4i: Consider alternative approaches to CPD in palliative care.

Feedback to RACGP/ACRRM concerns regarding the lack of incentives to diversify general practitioner CPD learning e.g. current face-to-face CPD activities around palliative care appear to only attract those who already have a special interest in palliative care. Shift the focus from 'additional' palliative care knowledge to integrated end of life care as a core component of the GPs role.

Consider a broader collaborative approach for pharmacy CPD, bringing together the community and hospital pharmacists (e.g. via Pharmaceutical Society of Australia and SHPA together with NPS) to focus on end of life care and the palliative approach and help to break down perceived professional barriers.

Facilitate multidisciplinary CPD events particularly in rural areas, via Divisions of General Practice raising awareness of specialist resources and local networks (medical, nursing and pharmacy resources).

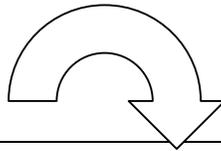
Develop a CPD program for rural and remote health care workers (medical, nursing and support staff). Work with ACRRM and other relevant organisations.

Option 4j: Identify gaps in education and training for postgraduate groups not formally covered by specialist organisations, for example, community nurses providing end of life care.

Identify gaps in education for community nurses not formally trained or working in a palliative care services. Work with PCNA and other relevant nursing groups such as Blue Cross and Silver Chain, to determine needs and competencies.

Option 4k: Encourage recognition and reward within the healthcare system for postgraduate work undertaken in palliative care.

As palliative care is a comparatively new discipline, there is limited recognition of postgraduate qualifications within the health system and a lack of career structure within many professions, therefore providing little incentive for health professionals to pursue such formal postgraduate training. Implement credentialing for palliative care specialists.



Your comments/feedback?

Refer to comment at end of Section 6 of Options

5. Provision of services and appropriate interventions.

(e.g. mechanism for consumer led initiatives, mechanism for health professional led initiatives, Adverse Drug Reaction services, education and feedback, medication error reduction programs, medication management aids, national continuum of care standards, medication review services, medication disposal services, drug utilisation feedback, QUM campaigns, national media liaison strategy, guidelines for monitoring drug use, independent medicines information services for health professionals and consumers, self-audit activities.)

There are a number of services and interventions currently funded and available to assist in the provision of complex care such as required for patients at the end of their life, which appear to be underutilised. The reasons for this may be varied, but work should focus on increasing awareness and utilisation of these where they are appropriate and identifying inadequacies or gaps to develop services that better meet the needs of the health professionals providing the care and ultimately the quality of care consumers receive.

Option 5a: Increase general awareness and utilisation of relevant MBS items by GPs and palliative care services.

It would appear that the utilisation of existing MBS items (for example, case conferences, HMR, RMMR, TCA and GPMP) that could support prescribers in the delivery of care and enhance the care of palliative patients is currently low. Administrative barriers may be a factor in this, but work should include raising awareness, developing processes and procedures, and relevant training to streamline the utilisation of these services for palliative patients when appropriate to maximise patient care. The relevance and potential impact of this is significant for rural and regional areas where access to specialist palliative care services is limited or impractical.

Option 5b: Improve IT decision support to enhance prescribing for patients at the end of life in general practice.

Discuss with software vendors the possibility of linking medicines commonly used at the end of life with on-line specialist resources or relevant information, consider “flags” with additional support/information when opioids are prescribed, highlight links to the palliative section of the PBS, potential drop down decision support tools related to referral pathways etc.

Option 5c: Consider IT solutions to improve co-ordination, communication and continuity of care.

In particular the poor co-ordination and continuity of care between specialists and GPs and between hospital staff and community-based health professionals. Multiple sites, multiple providers issue. Consider technology-based solutions to address the access to services, for example, video conferencing, electronic medical records, smart cards and standardise documentation. Refer to NeHTA and the Australian Commission on Safety and Quality in Health Care.

Option 5d: Consider MBS/PBS access for palliative care nurse practitioners or appropriate training for other health professionals (such as pharmacists) where access to medical prescribers is an issue.

For example, for RACFs, or where access to medical staff is difficult, and there is an unmet need for after hours or home visits – protocol prescribing in consultation with a GP or palliative care specialist for a defined number of medications. Some alternative models of prescription and supply of medicines commonly used at the end of life for patients such as those under discussion in the current review of PBS supply arrangements to RACF and Private Hospitals could be further pursued.

Option 5e: QUM in indigenous and CALD groups.

There are concerns about access to services by culturally and linguistically diverse (CALD) groups and socially isolated individuals. There is a need for culturally appropriate and language specific materials for health professionals. Refer to Federation of Ethnic Communities' Councils of Australia and National Aboriginal Community Controlled Health Organisation. There may be potential to extend NPS work with S100 pharmacists and Aboriginal Health Workers to include medicines and issues related to end of life care.

Option 5f: Develop and communicate to health professionals and consumers procedures regarding the safe disposal of unused medicines, particularly opioids.

Develop a clear message regarding disposal of unused medicines (particularly opioids) and communicate this through all the relevant health professional and consumer organisations. Work with PGA, PCA, community nurses, palliative care networks and consumer organisations and other relevant groups, for example, RUM.

Option 5g: Develop a medication event monitoring system for the medication use in the community.

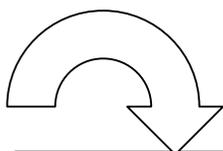
Discuss with Commission on Safety and Quality. Explore the role of AME line and ADRAC.

Option 5h: Develop NPS peer educators module for issues related to medicines commonly used at the end of life.

NPS works in partnership with the COTA organisations to deliver medicines information sessions to seniors groups. Specially trained peer educators run free, interactive medicines information sessions to senior groups using materials developed by NPS. To date the focus has been on “getting to know your medicines”.

Option 5i: Promote NPS Medicines Line for consumers and TAIS for prescribers for queries on medicines commonly used at the end of life.

Capacity and capability/ resource issues would need to be considered.



Your comments/feedback?

Refer to comment at end of Section 6 of Options.



6. Strategic research, evaluation and routine data collection

(e.g. national evaluation, routine reports of achievements, routine reports of outcomes of research and a comprehensive national database.)

There is a paucity of data regarding outcomes related to medication use at the end of life. There are limitations in existing national databases such as PBS and MBS for drug utilisation due to inadequate data linkages.

The PCDC has developed a minimum data set which collects a significant amount of information but does not collect detail regarding medication use or link this to symptom assessment measurements. DUSC does analyse some aspects of medication use related to palliative care.

Option 6a: CareSearch as the national clearing house/database for all funded and local research regarding QUM and palliative care.

CareSearch already has a Research Studies Register. This list details various groups including established research groups, recipients of NHMRC and other major grants and academic units with postgraduate students. This option would require the expansion to include more practice-based research and possibly unfunded local studies within networks or services.

Option 6b: Strategic research when data is not available from existing databases.

Routine collection and analysis of nationally collected administrative data (Medicare Australia, PBS, MBS and DUSC data) where relevant and meaningful.

Extend WA data linkages project (more detail/ref), or using DVA Mates model to improve information about drug use in palliative care.

Option 6c: Benchmark clinical practice in areas where evidence is emerging or unclear.

Recommend that specialist units be supported to formally gather quality practice-based data for medication use for off-license indications (and not those considered via the PaCCSC trials), to enable information gathering, peer review and discussion of medicines use where evidence is emerging or unclear.

Option 6d: Ensure that systems such as morbidity and mortality reviews exist to evaluate death with dignity and ensure reflective self practice and opportunity for improvement.

Ensure that systems are in place for GPs to be involved in morbidity and mortality review (or equivalent) of their patients and post-death peer support as required. This could be part of the extension of the palliative care network teaching and mentoring role.

Option 6e: Encourage a research culture within palliative care around QUM.

Conduct workshops on research technique, critical evaluation workshops and provide mentoring systems. Encourage AGPN, National Medicines Symposium (NMS) and other conferences to include a palliative care medicines / QUM stream and encourage practice-based research presentation and culture. NPS to promote practice-based research through its activities.

Option 6f: Conduct research to better understand the information needs and issues of consumers and carers with respect to medicines commonly used at the end of life, including complementary medicines.

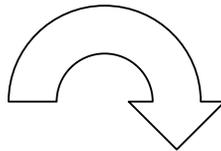
Self-medication practices and CMs and their effectiveness and use together with conventional medicines need to be understood

Option 6g: Outcomes of QUM research in palliative care reported.

Encourage AGPN, NMS and other conferences to include a medicines / QUM stream and encourage practice-based research presentation and culture.

Option 6h: Develop quality indicators to monitor QUM at the end of life across the various health care settings.

While QUM indicators have been developed for Australian hospitals across a number of key therapeutic areas and care settings, medicines use in palliative care has not been specifically addressed. (Ref TAG/CEC work). The opportunity exists to work with relevant groups/conduct research to develop and test a set of indicators to monitor the QUM of medicines use at the end of life across the various settings including acute care/hospital/hospice settings, RACF and primary care e.g. indicator to measure the percentage of patients prescribed an opioid also prescribed an aperient / indicator to monitor the appropriate use of naloxone in RACF and community / indicator to monitor appropriate pain management by measuring breakthrough pain doses/24 hours



Your comments/feedback?

Quality use of medicines (QUM) in prescribing is much more than just the act of writing a prescription. Nurses, whether prescribers themselves or not, play a critical role in QUM, and can greatly influence prescribing habits/practices of medical colleagues. Therefore, while the options outlined above all have merit, the National Prescribing Service (NPS) needs to engage with nurses across a broader front than described in these options. In keeping nurses fully informed, NPS will be able to achieve a wider sphere of influence to other health professionals, including but not limited to general practitioners, and to assist, educate and inform people requiring palliative care or end of life treatment and their families.

Appendix 1: Acronyms and abbreviations

Acronym	Meaning
ACRRM	Australian College of Remote and Rural Medicine
ADRAC	Adverse Drug Reactions Advisory Committee
AGNP	Australian General Practice Network
AMH	Australian Medicines Handbook
AME	Adverse Medicine Events
ANZSPM	Australia and New Zealand Society of Palliative Medicine
APAC	Australian Pharmaceutical Advisory Council
APRAC	Guidelines for a Palliative Approach in Residential Aged Care
CM(s)	Complementary medicine(s)
CME	Continuing Medical Education
CMI	Consumer medicine information
ComPAC	Guidelines for a Palliative Approach in the Community
COPD	Chronic Obstructive Pulmonary Disease
COTA	Council on The Ageing
CPD	Continuing Professional Development
DoHA	Department of Health and Ageing
DUE	Drug Use Evaluation
DUSC	Drug Utilisation Sub-Committee
GP	General practitioner
GPMP	General Practitioners Management Plan
Guild	Pharmacy Guild of Australia
HMR	Home Medicines Review
MBS	Medicare Benefits Scheme
NSAP	National Standards Assessment Program
NeHTA	National E-Health Transition Authority

NHF	National Heart Foundation of Australia
NHMRC	National Health and Medical Research Council
NMS	National Medicines Symposium
NPS	National Prescribing Service Ltd.
PaCCSC	Palliative Care Clinical Studies Collaborative
PBS	Pharmaceutical Benefit Scheme
PCA	Palliative Care Australia
PCC4U	The Palliative Care Curriculum for Undergraduates
PCMWG	Palliative Care Medicines Working Group
PCNA	Palliative Care Nurses Association
PCOC	Palliative Care Outcomes Collaboration
PDP	Professional Development Program
PEPA	Program of Experience in Palliative Care Approach
PPR	Prescribing Practice Review
QUM	Quality use of medicines
RACF	Residential Aged Care Facilities
RACGP	Royal Australian College of General Practitioners
RACP	Royal Australian College of Physicians
RMMR	Residential Medication Management Review
RUM	Return of Unwanted Medicines
SAS	Special Access Scheme
SHPA	Society of Hospital Pharmacists of Australia
TAIS	Therapeutic Advice and Information Service
TCA	Team Care Arrangements
WIIFM	What's in it for me?