



National Prescribing Service Limited

## Achieving quality use of medicines in the community for palliative and end of life care

A consultation report produced by  
National Prescribing Service Limited  
and Palliative Care Australia

September 2009



**Palliative  
Care  
Australia**

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

PCA is the peak national organisation representing the interests and aspirations of all who share the ideal of quality care at the end of life

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Australian General Practice Network	
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Australian Nursing Federation	Royal College of Nursing Australia
CareSearch	Society of Hospital Pharmacists of Australia
Joint Therapeutics Committee of Palliative Care Australia	The Pharmacy Guild of Australia
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# Executive summary

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The National Prescribing Service Limited (NPS) has prepared this report in collaboration with Palliative Care Australia (PCA). The goals of the consultation were to describe the current landscape of activity related to quality use of medicines (QUM) in palliative and end-of-life care, identify the key factors and issues affecting the achievement of QUM in palliative care in the community in Australia and document suggested opportunities to improve QUM at end of life.

The scope of the work was primarily on palliative care provided in the community, and those health professionals involved in delivering and influencing that, particularly through primary care. Although many of the QUM issues identified also have relevance for palliative care delivered in specialists units in hospitals and hospice settings, this was not the primary purpose of this work. The scope also did not include direct consultation with patients or carers.

The consultation occurred in two phases. Initially, a needs assessment was conducted in 2008 to identify the information requirements of general practitioners (GPs) and pharmacists around medicines used in palliative care. This was enhanced with a series of extensive interviews seeking feedback from 25 selected stakeholders and individuals regarding the key issues influencing QUM in palliative care. Using these findings a consultation document was prepared which described the issues and listed the suggested options for improvement.

In the second phase, during May 2009, the consultation document was released for wider comment. We sought responses from peak health organisations, members and key stakeholders. The document was made available via the NPS website, distributed to trade media and targeted feedback was sought from identified individuals and organisations. There were over 70 responses received. This final report is a collation of all the feedback and suggestions.

The report summarises the current situation with respect to QUM in palliative and end-of-life care and aims to guide the direction of future activities to improve this. It is an important first step in documenting the issues and opportunities around QUM in palliative care, and stakeholders should be encouraged to further expand this work, develop and progress relevant initiatives and strategies within their sectors and engage others to improve QUM in palliative care and end of life care.

## Key issues influencing QUM in palliative care and at end of life

The key factors and issues influencing QUM in palliative care identified throughout this consultation have been described using the elements of the definition of QUM.\* Many of the issues identified in this report are related to systems in healthcare delivery, some are cultural, and others are linked to the knowledge, skills and behaviour of health professionals and consumers. The key issues are below.

### The judicious choice of management options

- Limited evidence for medicines, especially for off-label and off-licence.
- Specialist prescribing practices are influential and can be difficult to influence.
- Consumers and health professionals have knowledge gaps and fear around the use of opioids.
- Lack of guidance for withdrawing medications at the end of life.
- Need better engagement of GPs and other key health professionals involved providing palliative care.
- Need better awareness and use of specialist referral services.
- Use of complementary medicines (CMs) in palliative care is not well understood, reported or documented.

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

## The appropriate choice of medicines, where a medicine is considered necessary

- Knowledge gaps in using a palliative approach particularly for patients with more complex needs.
- Remuneration structures may not adequately reflect the time required for and complexity of effective care.
- Communication between multiple providers and prescribers across multiple settings is difficult.
- Knowledge gaps in the use of some medicines impact QUM and management of patients' symptoms.
- Access to up-to-date, concise and accurate information in a timely manner is essential.
- Knowledge gaps around the use of some medicines used in symptom management in palliative care.
- Awareness and use of the Palliative Care schedule of the PBS is low and should increase.
- Access to non-PBS medicines is often complicated and time consuming for prescribers and expensive for patients.
- Equity of access issues can compromise QUM and patient care.

## Safe and effective use

- Lack of guidance around the safe disposal of medications, particularly opioids.
- Significant waste and excess costs associated with the supply of PBS pharmaceuticals in palliative care.
- Lack of protocols to guide consumers and carers in the safe administration of potent medications in the home.
- Polypharmacy including prescribed and self administered medicines is common and increases the risk of adverse events.
- No system to measure or monitor medication related adverse events in the community other than for adverse drug reactions via the Therapeutic Goods Administration.

## Stakeholder suggestions for opportunities and further work to improve QUM in palliative care and at end of life.

A series of suggestions for change, identified by respondents is described in this report, outlining the opportunities for action and further work to improve QUM in palliative care and at end of life. They have been framed using the building blocks necessary to achieve QUM as defined in the National Strategy for Quality Use of Medicines. The opportunities are described at a high level only, with the view that they may be taken up by interested parties and further developed into strategies to improve QUM in palliative care.

## Priority areas

The following priority areas were highlighted by stakeholders and respondents throughout the consultation as important for QUM.

### *Lack of understanding of end of life care and palliative care.*

Suggestions included improving awareness and access of quality information and tools to assist prescribing, encouraging models of care that better engaged the GPs and other members of the multidisciplinary team with specialist services, enhancement of referral pathways across the continuum of care, supporting undergraduate and post graduate training in medicine use in palliative care, and raising the awareness of the relevance of QUM at the end of life across all the health professions.

### *Lack of evidence base for off-label and off-licence use*

Suggestions include raising awareness and actively promoting existing quality resources such as CareSearch and Therapeutic Guidelines, benchmarking clinical practices, encouraging practice based research, promote emerging evidence and changes in symptom management as they evolve.

### *Deprescribing - withdrawal of medicines*

There was strong support for the need to develop guidance for prescribers in this area, and recognition of the role of pharmacists and nurses and the competencies required.

### *Opioids*

Opportunities exist to work more closely with the pharmaceutical industry to ensure ethical promotion in end of life use, and to develop strategies to improve awareness and use of materials and tools to better manage pain at end of life.

### *Residential Aged Care Facilities (RACF)*

Further work is required in the education and training of RACF staff in the use of medicines at end of life, greater potential to use Advance Care Directives to articulate choices regarding medicine use at end of life, the development of a set of resources to assist staff and professionals better manage care at the end of life to ensure residents achieve their preferred place of death.

### *Consumer support*

Suggestions included development of an resource kit for the home, promotion of the consumer information on CareSearch, updating and improving existing patient information materials, encourage consumer groups to more openly discuss end of life issues and medicines, and promote existing services such as medicines disposal e.g. Return Unwanted Medicines.

### *The complex “system”*

Several suggestions have been made to improve aspects of the healthcare system, and most will require considerable further discussion.

## Conclusion

This report brings together for the first time a shared understanding across a range of stakeholders of the issues related to quality use of medicines in palliative care and end of life. It is a collation of many views and experiences of health professionals and key stakeholders working in the area. It has promoted discussion, generated ideas, raised awareness of areas for improvement and, it is hoped, will inspire interested parties to progress some of these suggestions for change and improvement.

The judicious choice of management options, the appropriate choice of medicines (where a medicine is considered necessary) and the safe and effective use of medicines are as relevant and important at the end of life as any other time, and possibly more so. Ensuring the quality use of medicines at the end of life should be a priority for all those working in the area, and an expectation of patients and carers.

# Introduction

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The National Prescribing Service Limited (NPS) has prepared this report in collaboration with Palliative Care Australia (PCA). The goals of the consultation were to describe the current landscape of activity related to quality use of medicines (QUM) in palliative and end-of-life care, identify the key factors and issues affecting the achievement of QUM in palliative care in the community in Australia and document suggested opportunities to improve QUM at the end of life.

The scope of this work was primarily on palliative care provided in the community, and those health professionals involved in delivering and influencing it particularly through primary care. Although many of the QUM issues identified also have relevance for palliative care delivered in specialists units in hospitals and hospice settings, this was not the primary purpose of this work. The scope also did not include direct consultation with patients or carers.

## About this report

This report presents a collation of the opinions and experiences of health professionals and key stakeholders working in the area based on information gathered from interviews and a consultation process. It aims to summarise the current situation with respect to QUM in palliative care, document issues and opportunities around QUM in palliative care, and guide the direction of future activities to improve this. Stakeholders should be encouraged to further expand this work, develop and progress relevant initiatives and strategies within their sectors and engage others to improve QUM in palliative and end-of-life care.

This report describes the key factors and issues influencing the QUM in palliative care using the elements of the definition of QUM\*:

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

The opportunities 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.

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

# Background

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## QUM landscape of palliative and end-of-life care

There are many stakeholders at the national, state, local and professional level that are active and interested in medicine use in palliative care. And there have been considerable resources invested over the past eight years to improve palliative care services in Australia.

## 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. There are four broad priority areas identified in the program, and three of these have direct relevance to QUM:

- **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 PBS and the ongoing work of the Palliative Care Clinical Studies Collaborative (PaCCSC). PaCCSC manages multi-site clinical drug trials in order to gather the scientific evidence required for commonly encountered symptoms. If the studies are positive, PaCCSC supplies evidence that is sufficiently robust to inform registration applications to the Australian Register of Therapeutic Goods (ARTG) and to seek subsidy on the PBS.

- **Research and quality improvement for palliative care services** including the development of the CareSearch: Palliative Care Knowledge Network (an online resource of palliative care information) providing evidence-based information and practical resources for clinicians and other health professionals providing palliative care, and those involved in research.

The National Health and Medical Research Council (NHMRC) Palliative Care Research Program comprises 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 PCA 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 at the point of care through the Palliative Care Outcomes Collaboration (PCOC). These data are used to work with services to improve the quality of outcomes a service achieves for its clients.

- **Education, training and support for the workforce** through the development of programs such as the Program of Experience in Palliative Care Approach (PEPA) and the Palliative Care Curriculum for Undergraduates (PCC4U). PEPA is a sustainable hands-on work-placement training program for health professionals in a specialist palliative care service of their choice. PCC4U aims to promote the inclusion of all healthcare 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, and allied health undergraduate training, and ongoing professional development.

The Guidelines for a Palliative Approach in Residential Aged Care (APRAC) outlines the medication management of common symptoms and refers to relevant information resources such as *Therapeutic Guidelines: Palliative Care*.

The transfer of the National Palliative Care Program into the Ageing and Aged Care Division of DoHA in 2009 is important and relevant. Projections of an 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 require 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 some 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 individual 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 and end-of-life care as a speciality, improve understanding and promote need for better access.

PCA has published 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 and end-of-life 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 providing care to people with a life-limiting illness.

*Service Provision Guide: A planning guide* — provides guidance on palliative and end-of-life 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 and end-of-life 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 also been involved with a number of medication-related issues including co-ordinating a national review of alternative subcutaneous infusion devices following the withdrawal of the Graseby syringe driver, and providing submissions regarding the PBS 'Cost Recovery' proposal in the 2008 Federal Budget to charge for submissions to Pharmaceutical Benefits Advisory Committee.

PCA's Joint Therapeutics Committee (JTC) brings together a wide range of stakeholders and channels information and expertise to the Government's formal consultative mechanism, the Palliative Care Medicines Working Group. The JTC plays a key role in identifying inequities and barriers, and advising on strategies to improve access to, and the quality use of, medicines.

## National Prescribing Service Limited (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 initial work to better identify the information needs of GPs and pharmacists, and seek feedback from selected stakeholders on the key issues influencing QUM in palliative care. NPS works with consumers and health professionals to support appropriate self-management and provide accurate and balanced information to support the best use of medicines.

NPS has been a member of PCMWG since its inception (2004) and has worked with the committee to ensure QUM principles are 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*, *NPS Prescribing Practice Review* and *NPS RADAR (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 and emerging prescribers with a focus on nurse practitioners
- developing prescribing curricula 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 improving our understanding of strategies that support QUM.

## Palliative Care Medicines Working Group (PCMWG)

PCMWG meets twice a year and provides advice and guidance to the DoHA 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 and professional groups, as well as clinicians. Through PCMWG, increased access to palliative care medicines in the community under the PBS has been achieved with the implementation and ongoing development of the palliative care section of 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
- megestrol acetate – anorexia
- octreotide – bowel obstruction
- ketorolac – refractory pain (literature review).

The Phase IV studies will focus on the patterns of current care for symptoms being examined within the Phase III studies across a range of specialist practices. 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 and around the world. PaCCSC has recently received additional funding from DoHA to conduct a clinical research study on opioids in dyspnoea.

## Other professional and consumer organisations

Professional organisations representing health professionals working in primary health care and palliative care are influential and important in developing and implementing strategies to improve QUM. The Australia and New Zealand Society of Palliative Medicine (ANZSPM) and Palliative Care Nurses Association (PCNA) are the peak professional organisations representing medical specialists and nurses working in palliative care, and they 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 divisions of general practice network also plays a key role in supporting general practice to deliver end-of-life care, including implementing the Rural Palliative Care Project supported by DoHA. From 2008 to 2010 this project will resource 36 rural and remote divisions of general practice or, in some areas, consortia of divisions to provide sustainable models of rural palliative care service delivery to address the local needs of rural and remote communities throughout Australia. The program supports access to quality, co-ordinated palliative care for rural Australians by enhancing and ensuring linkages, orientation and co-ordination among primary and tertiary service providers and by identifying and working to address gaps in service provision. The program addresses key elements of quality care for patients with palliative needs, and this includes QUM.

The Pharmacy Guild of Australia (PGA) 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 providing 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 in 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 clinical practice 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. The PCMWG has given in-principle support to the need to develop national guidelines along these lines. This would need to reflect differences in state-based legislation with respect to how some aspects of medication, particularly opioids, must be handled as Schedule 8 medications. Palliative Care Queensland has developed a DVD education resource, *Understanding Palliative Care*.

The Cancer and Palliative Care Network in Western Australia has received Federal funding through the National Palliative Care Program for a 'People Living at Home' project titled the *Palliative Care Community Medications Project*. This project will develop and implement medication protocols 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.

In Tasmania, the Palliative Care Service is developing a number of papers relating to the management of symptoms and has also developed the Tasmanian Palliative Care Formulary.

In Victoria the Department of Human Services has funded a project to 'develop the role of a pharmacist in community palliative care multidisciplinary teams to improve outcomes for people at home and their carers pilot project'.

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

- provide advice on standard treatments, treatment pathways and protocols for site-specific cancers, specifically symptomatology or palliative care issues
- promote best practice in palliative care by assisting the collation of evidence-based practice and promotion of quality improvement activities
- advise on strategic and policy directions in palliative care
- encourage an increased participation in clinical trials and other research
- develop the data requirements for palliative care
- 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.

## Other medication services for palliative care patients

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 Reviews (HMRs) are consumer-focused, structured and collaborative healthcare service provided in the community setting to optimise consumer understanding and QUM. HMRs involve the consumer, their general practitioner, their pharmacy and other relevant members of the healthcare team. An equivalent service exists for consumers who are in residential aged care facilities; Residential Medication Management Reviews (RMMRs) aim to provide a structured and collaborative review of a resident's medications to optimise the benefits from medicine use and to 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.

The Dose Administration Aids Program and the Patient Medication Profile program, funded under the Fourth Community Pharmacy Agreement are recognised as an important tool to assist at-risk patients with the management of their medicines. The Patient Medication Profile programs are being implemented as a stand alone service in community pharmacies.

## Recommendations from the National Health and Hospitals Reform Commission (NHHRC) – *A Healthier Future For All Australians*

The recently released final report of the National Health and Hospitals Reform Commission (NHHRC) – *A Healthier Future For All Australians*\* has made specific recommendations for caring for people at the end of life. A number of these will have relevance for QUM and palliative care. In summary, these are:

- Building capacity and competence of primary care services to provide generalist palliative care support for dying patients. This will require greater educational support and improved collaboration and networking with specialist palliative care service providers.
- Strengthening access to specialist palliative care services for all relevant patients across a range of settings, with a special emphasis on residential aged care facilities.
- Additional investment in specialist palliative care services to support more availability to people at home in the community.
- Advance care planning be funded and implemented nationally, commencing with aged care services. This will require a national approach to education and training of health professionals.

## Contextual issues

### The multidisciplinary team

The model of delivery of palliative care to individuals is varied. In this report we are addressing the care provided by specialist health professionals, generalist medical, nursing and allied health services who contribute to the care of individuals at the end of life in the community and how they related to one another.

Palliative care is an area of practice that has adopted the 'multidisciplinary team' approach from the outset. In many services and settings we were told this is being achieved and working well.

This consultation describes medicines use in palliative care and at the end of life, and the focus has tended towards the perspectives of those health professionals who prescribe; however, it is also intended to address those who administer and dispense medicines. It is also recognised that medicines are in fact a small part of the spectrum of care required by such patients, and that there are many other critical aspects of practice.

Nursing care, both formal and informal, is vital particularly at the end of life but also throughout the course of palliative care. Nurses are the health professionals who spend the most significant amount of time with the patient and their carers, and who are in the unique position to talk to, listen and assess the patients on a regular basis. Their role in improving the QUM in palliative care through regular assessment and observation of symptom management is integral to quality care delivery. Recent changes regarding Pharmaceutical Benefit Scheme (PBS) access for nurse practitioners will provide additional opportunities to influence QUM and patient care. Nurses in all care settings — residential aged care facilities (RACF), community, hospital and specialist palliative care services — have a significant role and responsibility in ensuring QUM.

Pharmacists are also in a position to be more influential. Community pharmacists are often not included in communications between care providers, and are at present an under-used resource. The role of consultant pharmacists conducting formal medication reviews (HMRs, RMMRs) has great potential in palliative care. Hospital pharmacists working with palliative care services have a significant role, particularly in communicating care plans and liaising with health professionals about medicines after discharge. It is also recognised that greater interaction between community and hospital pharmacists would be beneficial.

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\* Commonwealth of Australia. *A Healthier Future For All Australians – Final Report of the National Health and Hospitals Reform Commission*. June 2009.

There are other potential members of the 'team' that have a role in improving QUM in palliative care; for example, diabetes educators, and qualified complementary medicine practitioners.

## Terminology in palliative and end-of-life care

Specialist palliative care services, originally established to provide care to cancer patients who were dying, now find that they need to respond to the needs of patients with different morbidities. Service delivery models need 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 and there are now a variety of ways that the same type and level of care or need can be described.

PCA has developed a glossary\* 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 service providers and among 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.

Consultation feedback has highlighted quite differing interpretations and views on the use of terminology of 'palliative care' and 'end of life'. Some regard 'end of life' as last days or hours and others see it as encompassing a continuum of care from stable, unstable, deteriorating and terminal, each with different needs. Some see this as an important distinction to be made, while others regard this as an issue of semantics. Ultimately however, consumers are the important focus and more work is warranted seeking their views.

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\* Palliative Care Australia. *Palliative and End of Life – Glossary of Terms*, Edition 1. 2008.

# Methods

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## Aims

This project focused on palliative and end of life care in the community setting and aimed:

- to understand the issues that prevent or limit the QUM in palliative and end of life care,
- to explore the strategies to achieve QUM in palliative and end of life care,
- to describe the current landscape of activity that support the QUM in palliative care services in Australia,
- to document suggested opportunities to improve QUM at the end of life.

## Process

A number of strategies were used to collect information to achieve the aims of the project.

**1. Interviews with 22 GPs and community pharmacists.** In 2008, NPS conducted a series of telephone interviews to identify the information requirements of GPs and pharmacists around medicines used in palliative care (the interview guides can be found in Appendix 3).

**2. Mapping of palliative care activities in the community.** NPS undertook a process of mapping the sector with PCA to identify the key stakeholders in the delivery of palliative care in the community and what the QUM issues are for patients at end of life.

**3. Interviews with 25 selected keys stakeholders.** In 2009, extensive interviews were conducted with individuals and representatives of organisations involved in providing and supporting palliative care and end of life services. These interviews provided information on the key issues influencing QUM in palliative care (see Appendix 3 for the interview guide).

**4. Development of a consultation document.** A draft consultation document was developed which synthesised the information from the first three strategies using a form of thematic analysis. The major themes were agreed by two members of the project team and validated by PCA Joint Therapeutics Committee. The document articulated the issues, summarised the implications, and used a process of solution development to match suggested interventions. Potential options for action were identified and provided to the stakeholders for comment.

**5. Consultation process.** During May 2009, the consultation document was released for wider comment. We sought responses from peak health organisations and key stakeholders. The document was made available through the NPS website, distributed to trade media and targeted feedback was sought from identified individuals and organisations. Over 70 responses were received. Respondents are acknowledged at the beginning of this report.

**6. Final document.** Comments and suggestions received through the second round of broader consultation have been incorporated in this report where relevant. Feedback related to specific suggestions has been summarised after each suggestion. Where there was strong support or an expressions-of-interest specific suggestion this is noted in italics after the suggestion.

Many of the issues identified in this report are related to systems of healthcare delivery, some issues are cultural, still others are linked to the knowledge, skills and behaviour of health professionals and consumers. The potential opportunities are described at a high level only, with the view that they will be taken up by interested parties and further developed into strategies to improve QUM in palliative care. Many of the suggestions to improve QUM in this area are large and complex while others are simple, some are technical and some may have been considered elsewhere.

# Factors and issues influencing QUM in palliative and end-of-life care

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This section outlines the factors and issues influencing QUM identified through the consultation. They have been themed using the core definition of QUM:

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

For each issue relevant work in progress is identified.

## 1. Judicious choice of management options

### 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 which is off-licence or off-label.
- 🗨️ Specialist prescribing practices can influence prescribing in the community, and influencing some prescribing practices can be challenging.
- 🗨️ There are knowledge gaps and fear of the use of opioids by consumers and some health professionals.
- 🗨️ There is a lack of guidance for prescribers in withdrawing medicines as patients approach the end of their life.
- 🗨️ There is a need to better engage GPs and other key health professionals in providing care at the end of life.
- 🗨️ The focus of end-of-life care should be broadened to embrace the treatment of neurodegenerative disorders and symptoms of progressive end-stage disease.
- 🗨️ There must be increased awareness and use of specialist referral services. The role of these services as teaching and training opportunities varies. There is a need to better use and extend existing relationships and networks to improve QUM and understand and further develop referral pathways. The opportunity for the teaching/mentoring role in 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 on efficacy and safety is required for many CMs.

## Practising with a grey evidence base

The evidence base is lacking for some aspects of medicine use in palliative care making it more challenging to promulgate clear clinical practice guidelines and direction for non-specialist palliative care prescribers, particularly GPs. Community and palliative care nurses often rely on their relationships with GPs both to support their role in the team and as a prescribing resource, and strong feedback from the nurses consulted as part of this work has indicated the need for clear guidelines.

For many years palliative care specialists, together with specialists in other disciplines, have been using medicines in palliative care for off-licence indications or routes of administration. A large body of anecdotal evidence may exist to support much of this. However, in some cases the lack of evidence has permitted some medicines use that would not have had consensus support.

There is a lack of formal data about the stability and compatibility of some drugs commonly mixed in syringe drivers for palliative care patients.

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. This will result in a greater need for support for general practice from specialist services.

For many aspects of palliative care there is good and emerging evidence. The challenges are to pull this together in comprehensive way, make it available through a credible source in a timely and accessible manner, and update it as new evidence emerges.

There are inter-hospital variations in prescribing practices, driven by both the prescribing preferences of the specialists and hospital formulary policies. In the treatment of some symptoms, variations in prescribing can be a matter of preference or 'variations on a theme' but in some cases there are significantly different prescribing practices. In the absence of hard clinical evidence many palliative care medical specialists prescribe by experience which could be challenged when presented with emerging evidence. It was also recognised that promotion by the pharmaceutical industry was influential for many new and emerging therapies and formulations.

### *Related work*

- PaCCSC trials will build the evidence base for effectiveness and/or safety for a number of medications over time, but there are many more drugs currently in use for which the evidence will need to be generated.
- *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 said they had access to and/or used the *Therapeutic Guidelines*, most still identified a need for further information for off-licence drug use.
- CareSearch contains a comprehensive list of information resources for practitioners, and literature searches for the most up-to-date data, although awareness and use among non-palliative care providers at this stage appears to be low.
- Hospital-specific guidelines and protocols often include medicines for off-licence indications and are used in-house and within local palliative care networks with significant content variations between services/hospitals.

## Key knowledge gaps – opioids

Opioids remain an important option in the management of pain in palliative care, yet feedback suggests that there are significant knowledge gaps in their use across professional groups. This includes knowing when and how to initiate opioids, dose conversion between opioids (while there are various calculators available, each varies and there is no consensus), dose escalation, management of breakthrough pain, understanding the pharmacokinetics of new dosage formulations such as lozenges and patches, and confusion between controlled- and immediate-release formulations. 'Opioid-phobia' is an issue for both consumers and health professionals that can significantly affect the achievement of adequate pain management.

Some patients need special consideration regarding the use of opioids, such as those with swallowing difficulties and those with cognitive impairment. Another issue is the management of 'acute on chronic' pain — a patient with pain well controlled on opioids who receives an additional physical insult; for example, a pathological fracture or an operation. This additional pain is often managed sub-optimally as 'the person is already on opioids'.

The promotion by pharmaceutical companies of new opioid products and new formulations has made prescribing even more challenging. Information from industry is generally product-focused, rather than providing education about where these options may fit in pain management from a broader perspective. Most specialist prescribers interviewed by NPS believed that all prescribers should have a good understanding of the pharmacology and pharmacokinetics of the opioids they use and the various formulations available in order to adequately manage pain. They felt that prescribers should know and use one or two opioids well. 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.

Feedback suggests that a 'silo effect' may be a contributing factor to the knowledge gaps. That is, pain management is often seen as the prerogative of experts rather than the responsibility of all health professionals. However, all health professionals have a duty to monitor symptom management, regularly assess the patient's response to medication and consider adjustment as required.

### *Related work*

- NPS Therapeutic Program: Analgesic choices in persistent pain.
- *Therapeutic Guidelines: Analgesics* (version 5), 2007, and *Therapeutic Guidelines: Palliative Care* (version 3 currently in development).
- PCA. *Facts about morphine and other opioid medicines in palliative care*. 2006 (May). Brochure for consumers.
- PCA. *EoL – Towards quality care at the end of life*. Preventable pain 1(1)Winter 2009.
- Locally developed materials — most Palliative Care Services have developed their own brochures and materials.
- Opioid conversion tools, e.g. eviQ Online and CI-SCaT hosted by Cancer Institute NSW.
- Materials developed by various state Cancer Councils and state Palliative Care organisations.
- 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 Australian College of Physicians (RACP) Prescription Opioid Policy: Improving management of chronic non-malignant pain and prevention of problems associated with prescription opioid use, Sydney 2009.
- ANZSPM has held a series of educational forums for medical practitioners in cities around Australia. These forums included a presentation on 'Confusion and consciousness at the end of life' and case-based discussions on pain and symptom management. It is anticipated that these will be held periodically.
- Overseas resources, e.g. European Association for Palliative Care (EAPC) opioid prescribing guidelines.

## ‘Deprescribing’ — withdrawal of medicines

There are issues for both primary care and also specialist prescribers in withdrawing medicines in patients at the end of life. There is limited information and guidance on appropriate cessation of regular preventive medications such as aspirin or statins. This is also true for the review of medications used to treat conditions that change as patients progress, for example, hypoglycaemics and antihypertensives. Many prescribers commented that patients are often told that they must be on certain drugs ‘for the rest of their lives’ and it is difficult to convince them otherwise without appearing to ‘give-up’.

Guidance is also needed about the review and reassessment of drugs for symptom control (e.g. corticosteroids) and when and how these should be ceased. This is a complex issue and requires a balance between controlling symptoms to achieve comfort and quality of life, as well as considering where the individual is on the end-of-life trajectory. Some therapies prevent the onset of certain symptoms which can affect a person’s quality of life (e.g. diuretics or erythropoietin agonists in end-stage renal failure for fluid retention and fatigue). The decision to cease these should ideally be done in consultation with other prescribers and the patient to avoid precipitating new symptoms and worsening quality of life.

Withdrawal of routine medications is a complex area that requires sensitive communication with consumers. Careful discussions are needed to explain the difference between prolonging life and achieving comfort and quality of life, and prescribers need training on how to have this sometimes difficult conversation. 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.

There is an important role for health professionals such as pharmacists and nurses to review medications regularly and discuss this with prescribers.

### *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.
- Currow DC, To THM, Abernethy AP. Prescribing at times of clinical transition in chronic or progressive diseases. *Int J Gerontology* 2009;3(1):1–8.
- Currow DC, Stevenson JP, Abernethy AP, et al. Prescribing in palliative care as death approaches. *J Am Geriatr Soc* 2007;55(4):590–5.
- Wenger NS, Solomon DH, Amin A, et al. Application of assessing care of vulnerable elders - 3 quality indicators to patients with advanced dementia and poor prognosis (ACOVE-3). *J Am Geriatr Soc* 2007;55:s457–63.

## Understanding the palliative approach

Health professionals working in palliative care identified the need to improve the understanding of all health professionals involved in providing care to people at the end of life, in particular GPs who may have had limited experience or specialised interest in this aspect of care. There is a need for a better understanding of the principles of palliative care, what palliative care is trying 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 was 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.

Most GPs only have a few patients in palliative care at any one time, and many more patients with chronic and complex progressive diseases. By broadening the understanding of the palliative approach to the care of patients with multiple chronic diseases or end-stage organ failure, the principles may have greater application and relevance in general practice. From those involved in this consultation it is clear 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.

### *Related work*

- CareSearch website – new section for GPs highlighting the palliative approach.
- Program of Experience in Palliative Care Approach (PEPA).
- The Palliative Care Curriculum for Undergraduates (PCC4U).
- Australian Government. *Guidelines for a palliative approach in residential aged care*. 2006.
- Engaging GPs Support for the implementation of APRAC guidelines.
- Guidelines for a palliative approach for aged care in the community setting (ComPAC) – in development.
- RACGP and ACRRM host an online module on Palliative care in aged care homes which was developed as part of the Engaging GPs project.
- ACRRM materials – *Drs Bag for the Dying, Roadmap for the Dying*.
- Australian Medical Council: *Good Medical Practice Code of Conduct* refers to end-of-life care.
- Gold Standards Framework: *Prognostics Indicator Guidance*, developed by the Royal College of General Practitioners (UK).

## Complementary medicines

Palliative care is an area where the use of complementary medicines (CMs) as an alternative or adjuvant to conventional medicines is potentially high. Raising the awareness of this with both consumers and prescribers is important — both consumer awareness of the importance of telling the prescriber what they are taking, and awareness among prescribers and other health professionals awareness to actively seek this information.

Many consumers do not understand that CMs are classified as medicines. Engaging suitably qualified, registered CMs practitioners and accessing reputable information sources is important. There are probably risks and benefits with many CMs used in palliative care but there are significant evidence gaps for many CMs and potential implications for interactions with existing regimens. The quality of information available for many CMs is an issue. There is not a strong evidence base for most CMs, but good and emerging evidence for others.

Patients generally choose to take CMs to achieve comfort, sustain hope and manage symptoms. Health professionals need to be respectful of patient choices and encourage an open and honest dialogue about all treatments. Patients in palliative care can, however, be a vulnerable target for unscrupulous operators.

Notwithstanding obvious legal issues, alternative medicines may also include illicit substances such as marijuana.

### *Related work*

- NPS research on complementary medicines:  
Williamson M, Tudball J, Toms M, Garden F, and Grunseit A. *Information Use and Needs of Complementary Medicines Users*. National Prescribing Service Limited: Sydney, December 2008.  
Brown J, Morgan T, Adams J, Grunseit A, Toms M, Roufogalis B, Kotsirilos V, Pirotta M., Williamson M. *Complementary Medicines Information Use and Needs of Health Professionals: General Practitioners and Pharmacists*. National Prescribing Service Limited: Sydney, December 2008.

- The integration of complementary medicines in community pharmacy practice – Fourth Community Pharmacy Agreement Research and Development Project.
- The Australian Pharmaceutical Formulary and Handbook (21st edition) – information is tailored to assist health professionals provide evidence-based information for the safe, effective and appropriate use of complementary medicines.
- National Institute of Complementary Medicines (NICM).

## Referral patterns and use of networks and relationships

In an area as complex as providing 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. Ideally GPs should learn by practical experience, and it has been suggested that some existing referral processes may remove this opportunity.

Prescribers sometimes do not use referral networks as frequently or as effectively as they could, 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. Palliative care services should also be encouraged to refer to other health professionals (e.g. to diabetes educators, and other allied health professionals).

GPs and community nurses are supported to provide end of life care to specific patients by outreach services including palliative care physicians and palliative care nurses. Specialist palliative care nurses are a key source of information and education on palliative care medicines, particularly in rural areas. They are also influential in supporting prescribing practices in the management of symptoms and medication management.

Identifying local GPs/GP champions with a special interest in palliative care could be a valuable resource from a local training and implementation perspective. Providing these GPs with additional support/resources could facilitate the delivery of good palliative care services to particular areas.

There is an opportunity to use 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 needs to be further developed.

### *Related work*

- PCA Service Directory.
- Palliative Care Needs Assessment Tool: Progressive Disease - Cancer. This aims to help clinicians efficiently identify issues of concern, particularly in areas that are not routinely well addressed, such as psychosocial issues, and hence decide when and to whom to refer.
- WA Cancer and Palliative Care Network telephone support line for specialist advice.
- Palliative Care Consortia Network in Victoria
- 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;11:980–5.
- Johnson CE, Girgis A, Paul CL, Currow DC. General practitioners' palliative care referral practices and perceptions: results of a national survey. *Palliat Support Care* 2009; (accepted for publication).

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

### Issues summary

- There are knowledge gaps in using a palliative approach particularly for patients with more complex needs.
- Remuneration structures may not adequately reflect the time and complexity in managing some palliative care patients, and 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 knowledge gaps in the use of some palliative medicines that can impact QUM and the adequate management of patients' symptoms.
- Access to up-to-date, concise and accurate information in a timely manner is important.
- Access and use of *Therapeutic Guidelines: Palliative Care* and CareSearch do not appear to be high among primary care prescribers.
- Awareness and use of the Palliative Care section 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.

### Prescribing for complex patients using a palliative approach

Respondents to this consultation expressed some concern that not all palliative care patients receive the level of rigorous assessment of symptoms as patients without a terminal diagnosis and that treatment of the underlying cause of the symptoms is not always considered important. The management of some palliative care 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 some inexperienced prescribers may 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; however, they commented that this does not happen frequently enough. There is a role for all health professionals working with the patient to regularly assess, review response to treatments and escalate concerns or recommendations as required. Symptom assessment also needs to consider the underlying causes of the symptoms and address these appropriately. Additional consideration needs to be given to the route and method of administration as well as the choice of medication. Even in hospitals, symptom management by non-palliative care teams can be less than ideal. Management of symptom control problems may be delayed by delayed referral to specialist palliative care services or by delay in gaining access to drugs when treatment could easily be commenced by that team.

Managing some patient groups, such as those with dementia or neurodegenerative diseases, can be challenging and these patients may benefit from the skills of other specialists such as geriatricians. Additionally, specialist advice regarding nutrition and fluid intake, and counselling regarding withdrawal of interventions at the end of life may also be required.

### *Related work*

None identified.

## Time-consuming nature of palliative care

There is often additional paperwork required in palliative care (e.g. to access some medications). The current remuneration structures do not sufficiently accommodate the complexity and time required to manage some palliative care 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.

Because of personal circumstances and commitments, many prescribers are not in a position to provide after-hours consultation and home visits. There needs to be a good interface between GPs and deputising services to ensure continuity of care, ideally a shared medical history, plan and details of any advance care directives. Electronic health records or smart card technology would be useful.

The current funding models supporting palliative care services (professional services as well as pharmaceutical) are not patient-focused, and do not address adequate co-ordination of care. Access to high quality, co-ordinated care in a timely manner is critical at the end of life. Feedback suggests that the use of relevant Medicare Benefits Schedule (MBS) items by GPs and specialist palliative care services could be improved, with one barrier being the associated paperwork required.

### *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;11:980–5.

## Multiple providers and prescribers across multiple sites (communication)

Achieving QUM in palliative care is a challenge because there are multiple providers and prescribers (e.g. GPs, palliative care specialists, oncologists, nurse practitioners) across multiple settings, and patients often move between these settings. Communicating of progress, plans and action on symptom and medicine management is essential to ensure each health professional understands what is happening. Communication between settings is essential as patients often move between home and hospital, hospice or RACF. Tools such as the Liverpool End of Life Pathway have been used by a number of palliative care services with success.

Feedback from those interviewed indicates that communication and documentation varies between services and facilities and could be improved. Ideally there should be an identified health professional responsible for co-ordinating care including prescribing, and in most cases that is most likely to be the GP. Feedback suggests that patient-held records are not routinely updated or reliable. There is a need for electronic health records to improve communication and care. Case conferencing is available, but use varies and paperwork is considerable.

### *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*).
- NPS MediLists.
- Related work in Queensland includes:
  - Centre for Palliative Care Research and Education
  - Research on Liverpool End of Life Pathway at RBWH, Brisbane including use of medications at EOL (Dr Carol Douglas)
  - Research on Palliative Care Discharge package at RBWH (Dr Carol Douglas)
  - Research on Multidisciplinary Pre-discharge case conferencing (Dr Geoff Mitchell).

## Diversity of workforce knowledge skills and attitudes

The palliative care workforce is varied, so ensuring the right messages are reaching the target audience is important. As choices for consumers improve, and as advance 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. Helping health professionals discuss end-of-life issues and proactive planning with patients and carers is important.

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 use of these. Also, despite the availability of a number of quality information resources and recently developed guidelines, use and implementation is low.

### *Related work*

- PCA Workforce Mapping Report.
- National Survey of Palliative Care Physicians.

## Knowledge gaps regarding palliative medicines/information resources

There are perceived knowledge gaps among general practitioners and other medical specialists, particularly around the pharmacology and pharmacokinetics of newer drugs, as well as the suggestion that there is a tendency to become 'novices of many drugs and experts of few'. 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 considered 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. The level of understanding was sometimes deficient 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.

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. Use of *Therapeutic Guidelines: Palliative Care* is low despite high awareness and respect for the publication, and most non-specialist health professionals are currently unaware of CareSearch.

### *Related work*

- CareSearch Knowledge Network Project – list of resources and PubMed automatically updated searches.
- *Therapeutic Guidelines: Palliative Care* (version 2) 2005. Version 3 is in progress and due for release in 2010.

## Access issues affecting QUM in palliative and end-of-life care

Despite changes to improve access to some medications through 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 .

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-licence indications (e.g. 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 PBS-listed alternatives have to be substituted. In some circumstances, lack of access to non-PBS drugs in the community can result in hospitalisation in order to access certain medications. Some medicines such as cyclizine and levomepromazine used for nausea may never become widely available in Australia.

Special Access Scheme (SAS) drugs (e.g. cyclizine, levomepromazine) and non-PBS drugs commenced in hospital, are only subsidised through outpatient clinics of some public hospitals; this often makes access difficult for rural patients returning home. SAS paperwork is time-consuming if prescribers are not doing it regularly. Many GPs and community pharmacists are unaware of the SAS or Section 100 (S100) scheme, or that some non-PBS drugs can be provided from hospitals. Access to less commonly prescribed drugs (e.g. midazolam) or Schedule 8 (S8) 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 it can be a problem. The co-ordination of this is time-consuming and usually depends on the nurses involved.





With the exception of specialist palliative care health professionals, it appears that there is a low awareness of the PBS Palliative Care section and generally low use. The time-consuming approval process associated with the PBS Authority system can be significant for prescribers with many palliative care patients.

### *Related work*

- Palliative Care Medicines Working Group (PCMWG) and Palliative Care Clinical Studies Collaborative (PaCCSC).
- Seidel R, Sanderson C, Mitchell G, Currow DC. Until the chemist shop opens – palliation from the doctor's bag. *Aust Fam Phys* 2006;35:225–31.
- Fourth Community Pharmacy Agreement *Review of the Existing Supply Arrangements of PBS Medicines in Residential Aged Care Facilities and Private Hospitals*. Proposals have been put forward to help lessen the burden on prescribers around PBS Authority medicines which may be relevant to some extent in the QUM of palliative care medicines.

### 3. Safe and effective use of medicines

#### Issues summary

-  There is a lack of guidance around the safe disposal of medicines, particularly opioids.
-  There is significant waste 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 medicines 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 medicine-related adverse events in the community or palliative care setting other than the mechanisms broadly available in health.

#### 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 regimens change. The Return of Unwanted Medicines (RUM) program does not currently adequately address this. Disposal of opioids is further complicated by different legislative requirements between States.

#### *Related work*

- [Return of Unwanted Medicines program \(RUM\).](#)
- [Royal Australian College of Physicians \(RACP\) Prescription Opioid Policy.](#)

#### Wastage of pharmaceuticals (and costs to consumers)

The current PBS system does not facilitate flexible supply of medicines to accommodate strength or formulation changes, dose escalation or dose reductions. Symptom management in complex patients often involves the trial of a number of medicines of differing strengths and quantities some of which may not prove to be effective. Large quantities of unopened medicines can remain after a patient dies. Dose administration aids such as blister packs are often used to support QUM by patients in residential aged care facilities and in the home. The need to repack these when there is any change to the medicines regimen often results in waste. In circumstances like palliative care, where changes to medicines can be frequent particularly at the end of life, this can result in time delays for the patient, and significant waste and cost.

#### *Related work*

- [Consultation via the Fourth Community Pharmacy Agreement – Review of Existing Supply Arrangements of PBS Medicines in Residential Aged Care Facilities and Private Hospitals.](#)

## 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 complicated, medicines at home. Often, there is minimal information on the use or maintenance of syringe drivers or pumps or regular subcutaneous administering medicines by family members. Documentation and communication around administering doses for breakthrough pain, dose escalation and anticipatory medication supply appears to vary. Consumers and carers may be in a stressed and emotional state making communication challenging. Information provided to patients and carers needs to consider health literacy, capability and social support resources. These issues have safety implications for those involved.

### *Related work*

- Locally developed guidelines within palliative care services.
- Australian Pharmaceutical Advisory Committee (APAC) Guiding Principles for Medication Management in the Community.
- Queensland Health Safe Medication Practice Unit have designed and are implementing a state-wide standardised prescription and monitoring document for continuous subcutaneous infusions of medications in palliative care.

## 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 or off-label use. Patients depend on verbal communication from 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. Patient and family health literacy is an important issue with respect to self-management and administration of complicated medication regimens and also deciding whether to use medicines at all.

### *Related work*

This review did not identify any specific resources however it is likely that some hospitals/services have developed patient information sheets pertinent to palliative care. Where they exist they are likely to be available only locally.

## Polypharmacy is a real risk for palliative patients

Polypharmacy is not unique to palliative care, but these patients are a particularly vulnerable group. Multiple medicines, often prescribed by more than one prescriber for the treatment of multiple symptoms, together with medicines for other chronic diseases can significantly increase the risk of an adverse event occurring. The adding of non-prescribed medications such as CMs and over-the-counter medicines can further complicate the situation. Regular review of medicines by prescribers, pharmacists and nurses and excellent communication skills are essential. Formal medicines reviews such as HMR and RMMR can be useful, but use for palliative care patients is low. For this patient group the rules restricting the frequency of review are limiting, particularly when the medicines regimen can change frequently at the end of life. Ensuring patients understand the importance of informing their health professionals about all the medicines and therapies they use is important. Where positions exist, clinical pharmacists working with palliative care services are a valued asset.

### *Related work*

- Medicines Review Services (HMR and RMMR).
- The Role of the Community Pharmacist in Palliative Care Project (Curtin University) funded under the Fourth Community Pharmacy Agreement Research and Development Program.

## 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 any coronial offices to identify systems where medicine misadventure has been implicated in the death of a palliative patient. It is important to encourage the reporting of adverse events to medicines in this patient group, who are often elderly and have multiple comorbidities, as these are generally the patients in whom the trials have not been conducted and for whom there are significant gaps in post-marketing pharmacovigilance. There does, however, need to be recognition that often high risk medicines are used, and that causation is an issue that needs to be carefully understood to avoid a 'punitive' culture.

### *Related work*

- Adverse Drug Reactions Advisory Committee (ADRAC).
- Australian Commission of Safety and Quality in Health Care.
- Adverse Medicine Events (AME) line.
- PaCCSC: Phase 4 trials in late 2009 will be monitoring adverse events and developing formal mechanisms to attribute medications to adverse outcomes.

## 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. The use of care plans, particularly in the community to document response to treatments is useful, and electronic health records, or equivalent technology, should enable better data collection and communication opportunities in the future. Better information about patients' perspectives on effectiveness and outcomes is required. Feedback suggests that dying patients are often willing to share their experience.

### *Related work*

- Palliative Care Outcomes Collaboration (PCOC) – data collection on symptom assessment scores but no specific information about medicines use.
- Palliative Care Needs Assessment Framework.
- PaCCSC is specifically collecting data at four sites nationally in different palliative care settings – hospital, inpatient palliative care, community, ambulatory care/outpatients.

## 4. Other factors and issues that influence QUM in palliative and end-of-life 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 for all the health professional groups, including palliative care specialists, across multiple settings with consistent, streamlined, targeted messages.
-  There is limited information describing the QUM issues for consumers and carers in palliative care.

### Prescribers who 'don't know what they don't know'

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 events. The majority of GPs have pressures to keep up to date in more mainstream areas of medicine, and CPD in palliative care would always be a low priority. It is thus difficult to reach, communicate and update most GPs on aspects of end-of-life care when it is not their primary patient casemix. This is inevitably the same for other health professionals.

#### *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;11:980–5.
- ANZSPM has held a series of educational forums for medical practitioners in cities around Australia. These forums included a presentation on 'Confusion and consciousness at the end of life' and case-based discussions on pain and symptom management. It is anticipated that these will be held from time to time.

### Education, information and knowledge

There is a need for an educative framework around the medicines used at the end of life for all health professional groups, including specialists, across multiple settings with consistent, streamlined, targeted messages. There is opportunity for professional organisations to work more closely together to avoid duplication of effort in developing a core educational framework and associated delivery of programs. Interdisciplinary education should also be actively encouraged.

#### *Related work*

- National Palliative Care Core Continuing Professional Education Framework.
- The Palliative Care Curriculum for Undergraduates (PCC4U).
- CareSearch for automatically updated information.

## Patient and carer expectations and perceptions of QUM in palliative and end-of-life care

Much more work is required in asking and listening to patients and carers about their expectations and concerns regarding communication, planning and decision making, choices and the quality of care they expect to receive at the end of life.

### *Related work*

- Palliative Care Medicines Working Group (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.
- O'Connor M, Tan H. What happens after dark: improving 'after-hours' palliative care planning in urban and rural Victoria. (Research project conducted through Monash University.)
- Clayton JM, Hancock KM, Butow PH, et al. Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers. *Med J Aust* 2007;186:s77–s108.
- Dunning T, Martin P, Savage S current research funded by the Nurses Board of Victoria: Managing diabetes at end of life.

# Stakeholder suggestions for opportunities to improve QUM in palliative and end-of-life care

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This section outlines suggestions for change identified by respondents throughout the consultation to address the issues and factors influencing QUM in palliative and end-of-life 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

### Access to subsidised palliative care medicines

Suggestions for improvement include:

- PBS online: Practical issues were highlighted including the need for better search capacity on the PBS website and cross-referencing between general and palliative care sections (a future deliverable of PaCCSC). There is a need to increase awareness of the palliative care section for both prescribers and consumers: promotion of WIIFM (What's in it for me?) for prescribers and their patients, the need for alternative sources of information on the contents of the PBS schedule particularly for prescribers in rural and outreach locations, in residential sites and in patients' homes.
- PBS Authority required restriction for palliative care listed items: All prescribers of the larger quantities accessible through palliative care listings are currently required to seek phone approval to prescribe on the PBS. Alternative mechanisms to enable easier access for suitably qualified/accredited people would improve access. This might include considering a Specialist Authority/Authorised Prescriber status established where suitably accredited palliative care specialists are identified; a competency-based GP authority status where 'competent and appropriately qualified GPs' 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. As accreditation for GPs (or other health practitioners) is likely to involve palliative care training/education such a change in access could provide incentives for GPs or other practitioners in this field to consider undertaking this training and would be expected to improve the care of this patient group. Evaluation and monitoring of the PBS listings through NPS audits, Palliative Care Medicines Working Group or Drug Utilisation Sub-Committee (DUSC) reviews will continue to provide information on the progress of changes to PBS listings.
- PBS quantities: 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 waste/costs/safety risks to consumers and carers would be advantageous. There may be certain state/territory legislation issues for opioids that preclude this.

## Investigate options for incentives for GPs to provide palliative care services

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 Service Incentive Payments for palliative care patient load. It would appear that the use of existing MBS items (for example, case conferences, HMR, RMMR, Team Care Arrangements [TCA] and General Practitioners Management Plan [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 use of these services for palliative patients. 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.

*Consultation feedback: There was strong agreement that current remuneration structures do not adequately recognise the complexity of care required to manage palliative care patients. Access to appropriate care and treatments can be delayed, and there is a need for greater patient-focused co-ordinated care particularly at the end of life when time is of the essence.*

## Explore opportunities to link QUM with advance care directives

Many respondents acknowledged that advance care plans could be used as a tool to declare medicine choices at end of life. Education and training of health professionals would be required to ensure the choices and medication management plan are communicated appropriately and understood and, where relevant, included as part of the advance care directive.

*Consultation feedback: This was considered an important strategy. It was emphasised that health professionals need training and education to develop the skills to have these, often difficult, conversations with patients and carers, and information needs to be presented in a format and language that they can understand to make such decisions. It was suggested that a national register to record the advance care directives may be a useful tool as patients move between settings.*

## Consider end-of-life use in pharmaceutical product applications

The pharmaceutical industry should be encouraged to consider 'end-of-life use' in product applications to the Therapeutic Goods Administration. Stakeholders should also work collaboratively with industry to encourage consideration of end-of-life use when conducting trials to increase the evidence base for medicine use in this area, and identify other drugs where evidence should be sought to assist with PBS listing in the future. Consider industry incentives such as patent extensions to conduct trials in palliative and end-of-life care.

*Consultation feedback: It is understood that some discussions in this area are currently in progress. Groups such as PCA are well placed to lead these to discussion, with involvement as appropriate from other bodies such as PCMWG/PaCCSC.*

## 2. Facilitation and co-ordination of QUM activities

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.

## Improve disposal processes of unwanted and out-of-date medicines

There is a need for information (e.g. brochures, information sheets) which describes options and procedures for appropriate disposal of unwanted and out-of-date medicines (particularly opioids). Clear messages regarding disposal of unused medicines need to be developed and communicated through all relevant health professional and consumer organisations. This

should involve pharmacy groups, community nurses, palliative care networks and consumer organisations. Consideration will need to be given to differences in state legislation regarding opioids, but a clear and concise communication strategy will significantly improve awareness and safety of disposal of many medications.

*Consultation feedback: Return Unwanted Medicines (RUM) Project is keen to work with PCA and other relevant organisations to improve disposal of unwanted medicines used in palliative care.*

## Enhance QUM programs to include a palliative care focus

Following is a summary from the consultation of the suggestions for how NPS could improve QUM in palliative and end-of-life care:

- 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 deficient and updated as evidence emerges over time. Promote a broader symptom approach to include chronic diseases (e.g. for dyspnoea treatment, principles may have applicability to management of other disease states such as heart failure 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.
- Keep the information short, succinct and stepwise for generalists, with options to upgrade for those with a special interest in palliative care.
- Integrate a palliative care focus 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 medicines at the end of life, polypharmacy etc.).
- Dispel 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.).
- Use existing networks and relationships. Consider using palliative care services/units and palliative care registered nurses (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 through divisions of general practice — promoting local networks, resources, links (etc.), particularly for regional / rural / semi-urban areas.
- NPS to increase awareness of programs and courses available to health professionals to address information needs and knowledge gaps (e.g. by linking to relevant section on CareSearch website).
- NPS to consider practical promotion of CareSearch search strategy and key features.

*Consultation feedback: There was strong support for NPS to be actively involved in improving QUM in palliative care. For many of the educational activities there was strong support from organisations such as the Pharmaceutical Society of Australia, Australian General Practice Network, CareSearch and the Australia and New Zealand Society of Palliative Medicine to work in partnership with NPS to develop and implement initiatives.*

## Enhance palliative care focus in the AMH

AMH should consider referring to resources such as CareSearch and *Therapeutic Guidelines* for medicines used at the end of life where the evidence is still emerging and consensus-based advice exists. Consider flagging medicines listed in the PBS Palliative Care section.

## Increase awareness and use of CareSearch

All relevant agencies and organisations should actively promote CareSearch, for example NPS will promote CareSearch through its educational activities and website.

## Develop an effective definition of QUM to include palliative and end-of-life care

The key principles of QUM encompass the judicious and appropriate selection of drug or non-drug management options based on the evidence. In applying this to the selection of management options in palliative care one needs to recognise the inevitable evolution of evidence on the use of some medicines. The reality is that for some medicines used for indications which occur only at the end of life, strong evidence may never be available and that use of consensus as a low level of evidence may be appropriate. This paradigm is not dissimilar to that faced in paediatrics, where the evidence base for medicines in paediatric patients is difficult to achieve due to the complex nature of the ethics of undertaking clinical trials in this population. In many ways the other key principles of QUM i.e. safe and effective use, should be strengthened (e.g. monitoring and establishment of agreed therapeutic goals for each medicine) to compensate for this and practised rigorously whilst being cognisant of the end-of-life considerations. The notion of uncontrolled experimentation or compromise should not be acceptable, nor should uninformed, off-licence use or use without consent in palliative patients.

## Develop Benchmarks

Agencies such as state-based Therapeutic Advisory Groups can 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). Consider jointly with Palliative Care Outcomes Collaborative (PCOC).
- Plan strategic research and data collection where data is not available from existing data or reports.

## Extension of 24-hour support telephone lines

The extension of the state-based help lines (currently available in WA and Qld) or a single national line for prescribers and health practitioners would provide support and information after hours.

*Consultation feedback: This suggestion was strongly supported by many respondents throughout the consultation. It was recognised that this would be valuable for residential aged care facilities where access to GPs after hours can be a problem. Resourcing and staffing issues would need to be considered practicably.*

## Develop guidance around deprescribing

Health professionals require guidance around how and when to withdraw medications at the end of life.

*Consultation feedback: This suggestion was overwhelmingly supported by most respondents. There is clearly a need for greater guidance and tools in this area, with the opportunity for proactive planning and discussions to be linked to advance care directives. There is also the need to develop health professionals' skills in having these difficult conversations. NPS is well positioned to lead this work.*

## Develop clinical pathways to ensure appropriate referral

Develop clear pathways with symptom/medication triggers or an assessment-driven algorithm to assist appropriate referral. Identify risk factors, treatment objectives and expected outcomes around pain management and therefore determine at what trigger points referral to specialist services is required. Consider the timeframes before referral for uncontrolled symptoms.

*Consultation feedback: This suggestion received positive responses. Feedback suggested that this was an opportunity to broaden the referral networks to be more 'two-way' and to include other health professionals. It could also be an opportunity to break down some of the 'territorial' boundaries between professions. There needs to be a willingness to refer to specialist services when the situation develops beyond the level of expertise, an awareness of available referral services, and the availability of timely specialist input. Currently, many palliative care services would have capacity issues if expected to significantly increase their role and community patient casemix.*

## 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. Consider e-health opportunities to enhance palliative and end-of-life care.

*Consultation feedback: This suggestion received a substantial amount of interest from respondents. It was suggested that if set up appropriately, funding options could be linked to these registered patients. A challenge will be to adequately define when a patient is palliative, as many life-limiting diseases can have a long course. Local care co-ordinators in divisions of general practice or GP liaison officers in palliative care services are examples of roles that have been developed that could facilitate such an initiative. Once electronic health records are in place, such a system could have benefits nationally in terms of access and continuity of care. A concern was raised regarding potential negative impact of such a register in terms of a patient's access to high-quality care in all settings.*

## Develop the mentoring role of specialist networks and services

- Specialist palliative care services should have a proactive teaching and mentoring role with GPs, pharmacists, nurses and other health professionals e.g. dieticians working directly with them and their patients in a true shared care model to develop skills, expertise and confidence to practise in the community.
- Successful models can be identified and used to 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.
- Promotion, awareness and use of MBS items that support multidisciplinary care plans and services (i.e. GPMP and TCA) will be required.

*Consultation feedback: This suggestion received considerable support and comment. Several concerns were raised regarding the capacity of specialist palliative care services to undertake such an extended role within current funding models. There was significant support for the shared-care model as well as the mentoring role of palliative care services as the most appropriate for palliative care. It was also recognised that both of these are very resource- and time-intensive, but ultimately would provide the best outcomes in terms of patient care and skill building. The comment was made that education in this setting should be interdisciplinary,*

*interactive and case-based. There was agreement that the opportunity exists to involve local GPs or GP champions with special interest in palliative care in developing and delivering education locally. Other health professionals such as pharmacists and nurses need to be actively engaged in future models to ensure sustainability across the settings.*

### 3. Provision of objective information and assurance of ethical promotion of medicines

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.

#### Develop a national 'End-of-Life Resource Kit'

With the increasing trend to end-of-life care in the home it is important that national guidelines be developed for health professionals to guide them in the quality use of medicines, along the lines of the *Guidelines for the handling of medication in community-based palliative care services* in Queensland. An important component of this would be an 'end-of-life resource kit' to support prescribers and healthcare providers in cases of crisis/after hours similar to the After Hours Kit developed by North West Melbourne Division of General Practice. This should include a list of resources such as symptom assessment tools, end-of-life pathways/roadmaps, practice points, anticipatory prescribing guidelines, checklists, contact lists, etc.

*Consultation feedback: There was extensive support for this suggestion. Notwithstanding legislative differences between states with respect to opioids, it was recognised that a nationally consistent set of information and tools available to health professionals in after-hours situations would be of benefit. It was also recognised that there is current work with respect to PBS reform and guidelines such as APRAC available. It was suggested that this could be a role for PCMWG. It was also suggested that such a kit should include practical ways to assist patients to achieve their preferred place of death.*

#### Develop material for existing publications to support QUM at the end of life

Updates are necessary for publications such as the Queensland Health's *Chronic Disease Guidelines* used in rural and remote health clinics, Central Australian Rural Practitioners Association (CARPA) 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.

*Consultation feedback: This suggestion received strong support from organisations such as PSA to work with NPS to include end-of-life QUM issues into existing publications such as journals and future educational materials for professionals and consumers. It is surmised that this would be a similar opportunity for other health professional organisations.*

#### Ensure ethical promotion of opioids and medicines in end-of-life use

Peak bodies should work with the industry to develop relevant educational material and programs for representatives and ensure end-of-life issues are better understood. They should also be encouraged to work with the pharmaceutical industry to develop appropriate consumer information around medicines used at the end of life.

*Consultation feedback: Promotion of some of the newer formulations of opioids by the pharmaceutical industry was a high concern for many respondents. Pain management is the highest priority area identified by everyone involved in this consultation, and the use of the newer agents and formulations is the greatest concern. There is an urgent need for evidence-based objective information and for industry to understand the appropriate education required for use in palliative care for many of these products.*

## Ensuring access to the PBS schedule in all settings

The availability of an alternative to the 'yellow book' (hard copy PBS schedule) remains an issue for prescribers and health professionals where access to online versions is limited or unavailable.

*Consultation Feedback: Many respondents suggested 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.*

## Increase awareness of complementary medicine (CMs) issues with consumers and health professionals

There is a need to raise the awareness of the risks and safety aspects of CMs at the end of life, i.e. the importance of discussion and documentation to ensure that all possible precautions can be considered.

*Consultation feedback: It was recognised that CMs will be used by palliative care patients for a variety of reasons, and there needs to be a better understanding of this by health professionals involved in their care. It was suggested that as the risks and benefits for some CMs are becoming better understood, the opportunity exists for more collaborative work with, for example, the National Institute for Complementary Medicine (NICM). At the same time, it was also commented that there continues to exist elements of 'quackery' that prey on vulnerable groups such as palliative care patients. CareSearch has developed a section on complementary medicines for consumers.*

## 4. Education and training

It is acknowledged that there are significant education and training opportunities available across the country. Increasing the awareness of these and encouraging use 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. CareSearch maintains a routine national stocktake of available education and training to support QUM and a national mapping of Australian courses and resources available in this area. This valuable resource requires greater promotion to increase awareness. 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. Continuing Medical Education (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'.

## Broaden the palliative approach to incorporate end-of-life care for patients with chronic progressive 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 progressive diseases. For example, the assessment and management of a patient with dyspnoea at the end of life may have 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.

*Consultation feedback: Responses from non-palliative care specialists indicated that there was a growing awareness within their professions of their role in managing their patients through to palliative care. Those interviewed recognised that the option of no treatment or the discussion to withdraw active treatment, such as dialysis, was still one that many specialists were reluctant to have with their patients.*

## 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 care 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, and promotion of consumer information (for example, CareSearch, Cancer Australia, Carers Australia and PCA).

## Develop a community education resource kit

There is a need for national guidelines around medicines use in the community setting. A gap exists for community education resource kit around medicines commonly used at the end of life in the home for consumers and carers. It should target consumers and carers and include: information about self-care

- explain the role of anticipatory prescribing and supply
- safety issues (e.g. with storage)
- disposal of medications and equipment
- administration guidelines re pumps / subcutaneous infusions / regular administration of subcutaneous medications
- information resources and where to seek help or advice regarding medications

*Consultation feedback: There was very strong support for this suggestion.*

## Ensure competencies for health professionals address issues of medicine use in end-of-life care

This is relevant for GPs, nurses (hospital, community and residential aged care facilities) and pharmacists (community and hospital). Work with the relevant professional organisations and training/educational bodies to develop these for palliative care; for example, work with the Chapter of Palliative Medicine within the RACP, ANZSPM and training or accreditation bodies (General Practice Education and Training, RACGP, ACRRM) to define competencies for prescribers in the assessment and management of palliative care patients and treatment of common symptoms. This work should link with PCC4U.

## Ensure systematic training for workers in residential aged care facilities on medicine management at end of life

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 and integration of APRAC guidelines. Link education and training of staff in medication management to quality accreditation of facilities and to national standards assessment.

*Consultation feedback: There were many comments that residential aged care facilities should remain a prime target for support to improve QUM in palliative care. There are many factors that make the provision of palliative care challenging in this setting, but there is high community expectation that it should be excellent. This was identified by many respondents as a high priority area.*

## Encourage uptake of relevant curriculum for healthcare workers

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. It is acknowledged that PCC4U is an important first step.

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.

*Consultation feedback: Several GP respondents indicated that postgraduate training for GPs is very difficult. PEPA is an excellent start, but requires significant commitment. There were a number of suggestions for greater training in palliative care during GP registrar training via a General Practice Education and Training (GPET) module. Comments were also made that PCC4U is very difficult to implement into already overcrowded curricula.*

## Consider alternative approaches to CPD in palliative care

Professional groups such as RACGP and ACRRM should consider the respondents concerns of a lack of incentives to increase uptake in GP learning in palliative care; for example, 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 of the educational content from 'additional' palliative care knowledge to integrated end-of-life care as a core component of the GP's role.

A broader collaborative approach for pharmacy CPD should be considered, bringing together the community and hospital pharmacists (e.g. through PSA and SHPA together with NPS) to focus on end-of-life care and the palliative approach and help to break down perceived professional barriers.

Facilitated multidisciplinary CPD events particularly in rural areas, through divisions of general practice could raise awareness of specialist resources and local networks (medical, nursing and pharmacy resources). CPD program for rural and remote healthcare workers (medical, nursing and support staff) should continue through ACRRM and other relevant organisations.

*Consultation feedback: There was strong support for interdisciplinary education and training, providing opportunities to better integrate the 'team' and to break down some traditional barriers.*

## Identify gaps in education and training for postgraduate groups

Gaps in education and training for postgraduate groups not formally covered by specialist organisations; for example, community nurses providing end-of-life care should be addressed. PCNA could work with other relevant nursing groups such as Blue Cross and Silver Chain, to determine needs and competencies.

## 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 in the health system and a lack of career structure in many allied health professions and general practice. Thus little incentive is provided for health professionals to pursue formal postgraduate training in this area.

## Identify and train general practice 'champions'

Training of general practice champions within regions should be considered to support knowledge transfer and also to enable patient and provider access to GPs with a special interest in palliative care. This is an area that the Divisions Network may also be able to assist with through practice support models, facilitating CPD events and in helping to identify potential GP champions.

*Consultation feedback: There was strong support for the role of local GP champions, and support from the AGPN for this suggestion.*

## 5. Provision of services and appropriate interventions

There are a number of services and interventions currently funded and available to assist in providing complex care (such as required for patients at the end of their life), which appear to be under-used. The reasons for this may be varied, but work should focus on increasing awareness and use 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.

## Increase general awareness and use of relevant MBS items by GPs and palliative care services

It would appear that the use 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.

## Improve IT decision support to enhance prescribing at the end of life

Discuss with prescribing software vendors (e.g. Medical Director) the possibility of linking medicines commonly used at the end of life with online specialist resources or relevant information. Consider the use of 'flags' with additional support/information when opioids are prescribed, highlight links to the palliative section of the PBS, or provide additional clinical decision support tools.

## Implement 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 and multiple providers are also issues. Consider technology-based solutions to address the access to services; for example, video conferencing, electronic medical records, smart cards and standardised documentation. Refer to NeHTA and the Australian Commission on Safety and Quality in Health Care.

*Consultation feedback: There was strong support for technology solutions to assist in improving the documentation and communication of care for palliative care patients.*

## Implement MBS/PBS for palliative care nurse practitioners

Consider increased MBS/PBS access for palliative care nurse practitioners or appropriate training for other health professionals where access to medical prescribers is an issue. For example, in residential aged care facilities, or where access to medical staff is difficult, if 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 could be used. 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 residential aged care facilities and private hospitals, could be further pursued. This must be in the context where one health professional co-ordinates the prescribing. Given the management of comorbidities, this is a complex process.

## Address QUM gaps in indigenous and culturally and linguistically diverse 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. There is a need to use what has been successful in previous similar interventions and distribution of information.

## Develop a medication event monitoring system for the medicine use in the community

Without a systematic event-monitoring mechanism many adverse drug incidents go unreported which has implications for the quality of care and patient safety. Discussion needs to occur with the Commission on Safety and Quality and the role of Adverse Medicine Events line and Adverse Drug Reactions Advisory Committee should be considered.

## 6. Strategic research, evaluation and routine data collection

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

The Palliative Care Outcomes Collaboration has developed a minimum data set which collects a significant amount of information; however, it does not collect detail on medicine use or link this to symptom assessment measurements. DUSC analyses some aspects of medicine use related to the palliative care section of the PBS.

## Create a national clearing house/database for research on QUM and palliative care

Consider establishing a national clearing house/database for all funded and local research regarding QUM and end-of-life care to include practice-based research and local studies. Some work is already under way. For example, CareSearch already has a Research Studies Register. This list contains information including established research groups, recipients of NHMRC and other major grants and academic units with postgraduate students.

## Generate 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) can occur where this is relevant and meaningful. There are, however many gaps in the system in order to be able to obtain and interpret meaningful data to relate to QUM in palliative care. Potential suggestions include exploring the Western Australia Data Linkage project, or the DVA Veterans' MATES Program (Veterans' Medicines Advice and Therapeutics Education Services model) to improve information about drug use in palliative care.

*Consultation feedback: There is a need for ongoing support for multi-site collaborative research to gather evidence in palliative care.*

## Benchmark clinical practice in areas where evidence is emerging or unclear

Supporting specialist units to formally gather quality practice-based data for medicine use for off-licence indications and routes of administration (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.

## Establish systems to evaluate death with dignity

Ensure that systems, such as morbidity and mortality reviews, exist to evaluate death with dignity and ensure reflective self-practice and opportunity for improvement. GPs need to be involved in morbidity and mortality review (or equivalent) of their patients in order to discuss any links to untimely death related to prescribing and post-death peer support as required. This could be part of the extension of the palliative care network teaching and mentoring role.

## Encourage a research culture in palliative care around QUM

Academic units should conduct workshops on research technique, critical evaluation and provide mentoring support. Encourage mainstream health conferences, for example the National Medicines Symposium (NMS) to include a palliative care medicines/QUM stream and encourage practice-based research presentation and culture.

*Consultation feedback: It was noted that it is important to address the 'taboo' around research in the area. Interdisciplinary research is important and research training, with a focus on end-of-life care, to better understand ethical issues around vulnerable populations and informed consent is needed. Appropriate research funding and infrastructure is also required.*

## Undertake research to better understand the information needs and issues of consumers and carers

Research is required to better understand the information needs and issues of consumers and carers with respect to medicines commonly used at the end of life, including CMs. Self-medication practices and CMs and their effectiveness and use together with conventional medicines need to be understood.

*Consultation feedback: PaCCSC is conducting some work in this area as part of the Phase IV studies.*

## Develop quality indicators to monitor QUM at the end of life

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. The opportunity exists to work with relevant groups and conduct research to develop and test a set of indicators to monitor the QUM at the end of life across the various settings including acute care / hospital / hospice settings, residential aged care facilities and primary care. For example:

- indicator to measure the percentage of patients prescribed an opioid also prescribed a laxative
- indicator to monitor the appropriate use of naloxone in residential aged care facilities and community
- indicator to monitor appropriate pain management by measuring breakthrough pain doses/24 hours
- multiple medications from the same therapeutic class.

# Conclusion

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## Key themes from the consultation

The responses throughout the consultation were very consistent, with wide support for this work, and general agreement that key issues have been identified. The consultation has provided additional information on work in progress and related work, proffered strong support for many of the suggestions for change or future work, and yielded many expressions of interest from key organisations to work collaboratively to progress areas of interest.

Several important general themes came through strongly throughout the consultation:

- The 'system' is currently overly complex for palliative care patients and their health professionals. The process needs to be simpler, easier to apply and more efficient for both patients and health professionals in, for example, accessing specialist and support services, accessing medications, and escalating care when required. Several suggestions have been proposed to improve aspects of the system.
- Relationships and networks are integral to palliative care. There is a need for fostering and improving local network relationships, mentoring the health professionals working in palliative care or with an interest, to improve their skills and confidence, ensuring that support and backup is available and accessible. A number of the suggestions propose to enhance these.
- The importance of multidisciplinary team care. The palliative care team should be patient-centric and involve health professionals across the continuum of care, from all the settings where palliative care is provided. This is an important point as so many health professionals are involved with patients, most willing and eager to have a greater role. Interdisciplinary education was also an important message.

The following were the gaps most consistently identified throughout the consultation:

- lack of understanding of palliative and end-of-life care
- lack of evidence base for off-licence use
- de-prescribing guidelines
- opioids and dosage forms
- residential aged care facilities
- consumer support
- the complex 'system'.

## Opportunities for interested stakeholders

While this document has described the current landscape and related work, identified the issues outstanding in achieving QUM in palliative and end-of-life care, and highlighted some of the potential future opportunities, there is further work required. The suggestions proposed in this document are only a foundation. They need to be further developed to clearly define the goals, strategies and targets to improve QUM in palliative care, to identify and engage those stakeholders with the highest relevance and capacity to take these forward.

This consultation has provided the opportunity to document the current issues influencing the QUM in palliative care in Australia. Notwithstanding there are many issues to address, much has been achieved and this work has identified that there is a significant amount of high-quality research and important initiatives under way. In and of itself, the process of this consultation has engaged many organisations and individuals with an interest in palliative care and it is hoped that this initial step will encourage them to progress some of suggested opportunities to the next stage.

## In summary

This report brings together for the first time, a shared understanding across a broad range of stakeholders all of the issues related to quality use of medicines in palliative care. It is a collation of many views and experiences of health professionals and key stakeholders working in the area. It has promoted discussion, generated ideas, raised awareness of areas for improvement and it is hoped, will inspire interested parties to progress some of these suggestions for change and improvement.

The judicious choice of management options, the appropriate choice of medicines, where a medicine is considered necessary and the safe and effective use of medicines is as relevant and important at the end of life and possibly more so, than any other time. Ensuring the quality use of medicines at the end of life should be a priority for all those working in the area, and an expectation of patients and carers.

## Appendix 1. Acronyms and abbreviations

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Acronym	Meaning
ACRRM	Australian College of Remote and Rural Medicine
ADRAC	Adverse Drug Reactions Advisory Committee
AGPN	Australian General Practice Network
AME	Adverse Medicine Events
AMH	Australian Medicines Handbook
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)
CMI	Consumer medicine information
CompPAC	Guidelines for a Palliative Approach in the Community
COPD	Chronic obstructive pulmonary disease
COTA	Council on The Ageing
CPD	Continuing professional development
DAA	Dose Administration Aid
DoHA	Department of Health and Ageing
DUE	Drug use evaluation
DUSC	Drug Utilisation Sub-Committee
GP	General Practitioner
GPMP	General Practitioners Management Plan
PGA	Pharmacy Guild of Australia
HMR	Home Medicines Review
MBS	Medicare Benefits Scheme
NeHTA	National E-Health Transition Authority
NHHRC	National Health and Hospitals Reform Commission
NHMRC	National Health and Medical Research Council
NICM	National Institute for Complementary Medicine
NMS	National Medicines Symposium
NPS	National Prescribing Service Ltd.
NSAP	National Standards Assessment Program

## Acronyms and abbreviations

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 Australia
PCOC	Palliative Care Outcomes Collaboration
PEPA	Program of Experience in Palliative Care Approach
PMP	Patient Medication Profile
PPR	Prescribing Practice Review
PSA	Pharmaceutical Society of Australia
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
RN	Registered nurse
RUM	Return of unwanted medicines
SAS	Special Access Scheme
SHPA	Society of Hospital Pharmacists of Australia
TBC	To be confirmed
TCA	Team Care Arrangements

## Appendix 2. Links to related work identified in the consultation

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For the purposes of this report the term 'related work' has referred to programs, projects, organisations as well as publications and literature that were identified during the stakeholder consultation.

### Australia's National Palliative Care Program

General information on the program

<http://www.health.gov.au/internet/main/publishing.nsf/Content/Palliative+Care-1>

Palliative Care Medicines Working Group (PCMWG)

<http://www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-program-prio2>

Palliative Care Clinical Studies Collaborative (PaCCSC)

<http://www.caresearch.com.au/caresearch/WhatIsPalliativeCare/NationalPalliativeCareProgram/PaCCSC/tabid/97/Default.aspx>

CareSearch, palliative care knowledge network

<http://www.caresearch.com.au>

The National Health and Medical Research Council (NHMRC) Palliative Care Research Program

<http://www.nhmrc.gov.au/grants/types/granttype/strategic/palliative.htm>

### Associated palliative care programs/initiatives

National Palliative Care Service Directory

<http://pallcare.gky.com.au/c/pc?a=apps&ap=bd>

The Palliative Care Australia National Standards Assessment Program (NSAP)

<http://www.standards.palliativecare.org.au/>

Palliative Care Outcomes Collaboration (PCOC)

<http://chsd.uow.edu.au/pcoc/>

Program of Experience in Palliative Care Approach (PEPA)

<http://www.pepaeducation.com/>

Palliative Care Curriculum for Undergraduates (PCC4U)

<http://www.pcc4u.org/>

The Australian Palliative Care in Aged Care Project (APRAC)

<http://pallcare.org.au/Portals/46/Aged%20Care/The%20Guidelines%202006.pdf>

The development of guidelines for a palliative approach for aged care in the community (COMPAC)

<http://www.caresearch.com.au/caresearch/WhatIsPalliativeCare/NationalPalliativeCareProgram/ComPAC/tabid/93/Default.aspx>

Palliative Care Needs Assessment Tool – Progressive Disease Cancer

<http://www.newcastle.edu.au/research-centre/cherp/professional-resources/needs-assessment.html>

Society of Hospital Pharmacists, Australia: Standards of Practice for the Provision of Palliative Care Pharmacy Services

<http://www.shpa.org.au/scripts/cgijp.exe/WService=SHPA/ccms.r?PageId=33>

### Palliative Care Australia (PCA) publications

Palliative Care – Glossary of Terms, Edition 1. 2008.

<http://www.palliativecare.org.au/Portals/46/resources/PCA%20Glossary%20Final%20July%2008%20LR.PDF>

EoL – Towards quality care at the end of life. Preventable pain, Winter 2009.

<http://www.palliativecare.org.au/Default.aspx?tabid=1951>

Brochure for consumers from Palliative Care Australia. Facts about morphine and other opioid medicines in palliative care.

<http://www.palliativecare.org.au/Portals/46/docs/publications/Consumer%20Brochure%20reduced%20res.pdf>

Standards for Providing Quality Palliative Care for all Australians (fourth edition, 2005).

<http://www.palliativecare.org.au/portals/46/resources/StandardsPalliativeCare.pdf>

Service Provision Guide: A planning guide.

<http://www.palliativecare.org.au/Portals/46/resources/PalliativeCareServiceProvision.pdf>

The Guide to Palliative Care Service Development: A population-based approach.

<http://www.palliativecare.org.au/Portals/46/resources/PalliativeCareServiceDevelopment.pdf>

## Related work by National Prescribing Service Limited

NPS Therapeutics Program: Analgesic choices in persistent pain

[http://www.nps.org.au/health\\_professionals/drugs\\_and\\_therapeutic\\_topics/topics/analgesics?queries\\_topic\\_query=Analgesics](http://www.nps.org.au/health_professionals/drugs_and_therapeutic_topics/topics/analgesics?queries_topic_query=Analgesics)

NPS research on Complementary Medicines: Information use and needs of consumers and health professionals

[http://www.nps.org.au/research\\_and\\_evaluation/research/current\\_research/complementary\\_medicines](http://www.nps.org.au/research_and_evaluation/research/current_research/complementary_medicines)

NPS MediLists

[http://www.nps.org.au/consumers/tools\\_and\\_tips/medicines\\_list/brochures/medicines\\_list](http://www.nps.org.au/consumers/tools_and_tips/medicines_list/brochures/medicines_list)

## State-based groups/initiatives

### Victoria

Palliative Care Consortia Network in Victoria

<http://www.health.vic.gov.au/palliativecare/>

Department of Human Services (Victoria) project to 'develop the role of a pharmacist in community palliative care multidisciplinary teams to improve outcomes for people at home and their carers pilot project'

[www.health.vic.gov.au/palliativecare/commpharm-proj.pdf](http://www.health.vic.gov.au/palliativecare/commpharm-proj.pdf)

### Queensland

The Centre for Palliative Care Research and Education (CPCRE)

<http://www.health.qld.gov.au/cpcre/>

Guidelines for the handling of medication in community-based palliative care services in Queensland

<http://www.health.qld.gov.au/cpcre/pdf/medguidepall.pdf>

Palliative Care Queensland (PCQ) has developed a DVD education resource, Understanding Palliative Care.

<http://www.palliativecareqld.org.au/downloads/multimedia/>

### Western Australia

WA Cancer and Palliative Care Network: Palliative Care Community Medications Project

<http://www.healthnetworks.health.wa.gov.au/cancer/palliative/pathways.cfm> Palliative Care

WA Inc also provide general information about palliative care and available services during business hours on 1300 551 704

## New South Wales

The Cancer Institute NSW: Palliative Care NSW Oncology Group

[http://www.cancerinstitute.org.au/cancer\\_inst/nswog/disgroups/pallcare.html](http://www.cancerinstitute.org.au/cancer_inst/nswog/disgroups/pallcare.html)

The Cancer Institute NSW: eviQ Online/CiSCAT

<https://www.treatment.cancerinstitute.org.au/cancerinstitute/cancerinstituteDADAServlet?sid=2347266CIS&ent=1ES100&page=0BENPC&TopTab=Home>

## Related work but not palliative care specific

Adverse Drug Reactions Advisory Committee (ADRAC)

<http://www.tga.gov.au/adr/adrac.htm>

Adverse Medicine Events (AME) line

[http://www.nps.org.au/consumers/ask\\_an\\_expert/contact\\_a\\_pharmacist/adverse\\_medicines\\_events](http://www.nps.org.au/consumers/ask_an_expert/contact_a_pharmacist/adverse_medicines_events)

Australian Commission of Safety and Quality in Health Care

<http://www.safetyandquality.gov.au/>

Australian Medical Council. Good Medical Practice: A Code of Conduct for Doctors in Australia

<http://goodmedicalpractice.org.au/wp-content/downloads/Final%20Code.pdf>

Commonwealth of Australia. A Healthier Future For All Australians – Final Report of the National Health and Hospitals Reform Commission. June 2009

<http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/nhhrc-report>

The National Institute of Complementary Medicine (NICM)

<http://www.nicm.edu.au/>

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

<http://www.archi.net.au/e-library/management/yellow-brick>

<http://www.health.nsw.gov.au/initiatives/myhealthrecord/qna.asp>

Royal Australian College of Physicians (RACP) Prescription Opioid Policy

<http://www.racp.edu.au/page/health-policy-and-advocacy/public-health-and-social-policy>

RUM program

<http://www.returnmed.com.au/>

## Guidelines

Therapeutic Guidelines

<http://www.tg.org.au/>

Australian Pharmaceutical Advisory Council (APAC)

- Guiding Principles for Medication Management in the Community  
<http://www.health.gov.au/internet/main/publishing.nsf/Content/apac-publications-guiding>
- Guiding principles to achieve continuity in medication management:  
<http://www.health.gov.au/internet/main/publishing.nsf/Content/nmp-guiding>

## From the literature

Wenger NS, Solomon DH, Amin A, et al. Application of assessing care of vulnerable elders-3 quality indicators to patients with advanced dementia and poor prognosis (ACOVE-3). *J Am Geriatr Soc* 2007;55:S457–S63.

Currow DC, To THM, Abernethy AP. Prescribing at times of clinical transition in chronic or progressive diseases. *Int J Gerontology* 2009;3(1):1–8

Currow DC, Stevenson JP, Abernethy AP, et al. Prescribing in palliative care as death approaches. *J Am Geriatr Soc* 2007;55(4):590–5.

Rhee J, Zwar N, Vaghokar S, et al. Attitudes and barriers to involvement in palliative care by Australian urban general practitioners. *Palliat Med* 2008;11:980–5.

Johnson CE, Girgis A, Paul CL, Currow DC. General practitioners palliative care referral practices and perceptions: results of a national survey. Palliat Support Care 2009; (accepted for publication).

Seidel R, Sanderson C, Mitchell G, Currow DC. Until the chemist shop opens – palliation from the doctor’s bag. Aust Fam Phys 2006;35:225–31

Clayton JM, Hancock KM, Butow PH, et al. Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers. Med J Aust 2007;186:S77–S108

## Overseas guidelines

European Association for Palliative Care (EAPC) opioid prescribing guidelines

[http://www.epcrc.org/public\\_news\\_detail.php?id=XuVnfGbQTHZEPxs7qQy6](http://www.epcrc.org/public_news_detail.php?id=XuVnfGbQTHZEPxs7qQy6)

Gold Standards Framework: Prognostics Indicator Guidance, developed by the Royal College of General Practitioners

[www.goldstandardsframework.nhs.uk/gp\\_contract.php](http://www.goldstandardsframework.nhs.uk/gp_contract.php)

## Appendix 3. Questions for GPs, pharmacists and stakeholders

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### Questions for key informant GPs

1. How frequently do you care for a patient who requires palliative care?  
Are you confident or comfortable with providing care for these patients? Why/why not?  
When do you refer these patients to specialised services or to a colleague with special interest?
2. What conditions/disease states do you believe/ have you seen that require palliative care?  
Are the issues in drug therapy different for these different conditions? Why/why not?
3. Do you think it is important to have a basic understanding of the drug therapy needed to care for patients requiring palliative care? If yes, what would you define as 'basic understanding' of drug therapy in palliative care?
4. In terms of drug therapy in palliative care, what do you see as your management goals?
5. What do you see as the challenges in drug therapy for palliative care? (or 'What are the things that are complex about drug therapy in palliative care?')  
Which symptoms/areas do you find easy to manage? Why?  
Which symptoms/areas do you find difficult to manage? Why?
6. Besides yourself, who is involved in managing the drug therapy of these patients?  
Does this team approach work? What causes it to work well or go wrong?  
Is it important to have someone who is responsible for co-ordinating the team? Why/why not? Who should be the co-ordinator? Who (if anyone) is currently the co-ordinator?
7. What resources/tools do you currently use to help you manage these patients?  
When there is a problem or uncertainty, how and where do you go for guidance and advice?  
What other resources would you find helpful? What issues/questions/areas would you like addressed/answered?  
What would be the most useful way of delivering this resource
8. What formal training, if any, did you undergo in the area of palliative care? (Please specify)
9. Do you have any other comments in relation to medication management in palliative care?

### Questions for key informant pharmacists

1. How frequently are you involved in assisting with the management of palliative care patients?  
Are you confident or comfortable with assisting with the management of these patients? Why/why not?  
When do you refer these patients to specialised services or to a colleague with special interest?
2. What conditions/disease states do you believe/have seen that require palliative care?  
Are the issues in drug therapy different for these different conditions? Why/why not?
3. Do you think it is important to have a basic understanding of the drug therapy needed to care for patients requiring palliative care? If yes, what would you define as 'basic understanding' of drug therapy in palliative care?
4. What do you see as the pharmacist's role in caring for a palliative care patient?
5. What do you see as the challenges in drug therapy for palliative care? (or 'What are the things that are complex about drug therapy in palliative care?')  
Which symptoms/areas do you find easy to manage? Why?  
Which symptoms/areas do you find difficult to manage? Why?

6. Do you see yourself as part of a bigger team of people who manages the medications for these patients? Or do you think you operate independently? Why?  
Does this approach work (i.e. the one stated above)? What causes it to work well or go wrong?
7. What resources/tools do you currently use to help you manage these patients?  
When there is a problem or uncertainty, how and where do you go for guidance and advice?  
What other resources would you find helpful? What issues/questions/areas would you like addressed/answered?  
What would be the most useful way of delivering this resource?
8. What formal training, if any, did you undergo in the area of palliative care? (Please specify)
9. Do you have any other comments in relation to medication management in palliative care?

## Questions for key stakeholders

National Prescribing Service (NPS) stakeholder consultation on the quality use of medicines (QUM) in palliative care – semi-structured interview questions.

1. What does QUM mean to you?
2. What does palliative care mean to you?
3. What do you see are the issues in achieving QUM in palliative care?
4. Are there barriers in using a QUM approach in palliative care, and if so what are they?
5. What do you see as QUM issues relating to access to palliative care medicines in the community?
6. What information sources do you access in relation to medicines used in palliative care and what type of information do you mostly seek?
7. What are the perceived gaps in knowledge, skills and attitude when prescribing for patients in palliative care?
8. What opportunities are you aware of for education, training and support for prescribers in palliative care?
9. What are the gaps or barriers regarding education, training and support for health professionals who look after patients in palliative care?
10. Are health professionals aware of the palliative care section of the Pharmaceutical Benefit Scheme (PBS) and do they use the schedule?
11. What do you think NPS can do to assist / influence / achieve / improve QUM in palliative care?
12. What other organizations do you see providing QUM support in palliative care to health professionals?
13. Would you like to provide any additional comments or advice to assist NPS with this consultation?