The Role of the Pharmacist in the Provision of Palliative Care

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# Acronyms

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<thead>
<tr>
<th>Acronym</th>
<th>Explanation</th>
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<tbody>
<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>HMR</td>
<td>Home medicines review</td>
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<tr>
<td>IT</td>
<td>Information technology</td>
</tr>
<tr>
<td>M</td>
<td>Mean</td>
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<tr>
<td>MMR</td>
<td>Medication Management Review</td>
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<tr>
<td>PCMMR</td>
<td>Palliative Care Medication Management Review</td>
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<tr>
<td>PPCP</td>
<td>Pharmacy Palliative Care Portal</td>
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<tr>
<td>p/M</td>
<td>per million</td>
</tr>
<tr>
<td>RE-AIM model</td>
<td>Reach; Efficacy; Adoption; Implementation; Maintenance</td>
</tr>
<tr>
<td>RMMR</td>
<td>Resident medication management review</td>
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<tr>
<td>SD</td>
<td>Standard deviation</td>
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<td>UK</td>
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1. Background and Rationale

1.1 Background
The demography of Australia is changing, the population is growing and the proportion of people in older age groups is increasing. As a result of greater longevity a larger proportion of Australians will eventually develop life limiting illness and will need care as they reach the end stages of a chronic illness. Franks et al. examining usage in the United Kingdom calculated that the following palliative care services should be provided:

- Pain control for 2800 people per million (p/M) population dying from cancer each year and 3400 p/M for people dying of non-cancer terminal illness
- Palliative home nursing for 700-1800 p/M people with cancer and 350-1400 p/M people with non-cancer terminal illness; and 400-700 cancer p/M and 200-700 non-cancer p/M people requiring in-patient terminal care.

Lynn describes three trajectories of dying:

- Slow decline with a rapid terminal phase (most cancer fits this trajectory);
- Slow decline with periodic relapses and remissions (for example organ failure); and
- Generalised poor functioning and slow decline to death (for example dementia).

These statistics raise the question of how Australia will respond to the challenge of caring for people in these circumstances. Most people, when asked, indicate that they would prefer to die at home. Home represents familiarity, the presence of loved ones, and a sense of connection with ongoing life. In the last 50 years in Australia and many parts of the Western world however, the number of people who die at home has actually decreased. At the present time only 16% of people die at home. Around 20% of people die in hospices and 10% in nursing homes. The rest die in hospitals. Community pharmacists are among the health professionals most likely to come into regular contact with people in need of palliative care, and will have ongoing communication with their carers, doctors and therapists while they are receiving palliative care in the community.

1.2 Palliative Care: As a Multidisciplinary Model of Medicine
Effective palliative care mandates inter-professional collaboration. The extent to which allied health professionals are able to work collaboratively will determine the extent to which community based teams can provide timely support that responds to changes in the patient’s physical condition and his/her changing management goals. The practice of collaborative health care can be challenging as each team member may have different “framework of understanding”. For example, a social worker may take a patient-centred approach where a physician may adopt a task-oriented approach. Such differences can make the already complex task of sharing information amongst team members more difficult and can ultimately detract from the quality of care.

In order to improve the quality of care for palliative patients, palliative care education must move into a realm where theories and practice form a practical framework of care.

Pain and symptom management are also central issues in palliative care; frequently nurses consult with distressed patients and family members about pain management. When they do they act simultaneously to relieve pain and counsel distressed people. The multi-faceted nature of palliative care requires professionals working with terminal patients to have a greater capacity for empathy, the ability to address psychosocial needs, a sophisticated knowledge of medical ethics, and excellence in communication skills. Although many of these skills are addressed in medical and pharmaceutical training, research indicates that many health care professionals are poorly prepared for the complexities of palliative care.
Exemplary health systems assimilate the input of physicians, pharmacists, nurses and psychosocial carers in a holistic framework and foster increased confidence in delivering excellent palliative care. Medical students who have had exposure to palliative care during their training report increased confidence and demonstrate greater competence when treating palliative care patients. Currently, many medical students take part in some palliative training, however this is not yet the case for all health professionals. In the future, pharmacists could play a greater role in caring for palliative care patients, and should be trained appropriately.

1.3 Community Pharmacists and Palliative Care in the Home

1.3.1 Medication Supply

The primary role for community pharmacists in palliative care is the safe and efficient provision of medications and to act as a source of advice for patients and their carers. With appropriate arrangements pharmacists can also deliver a service to the patients’ home, and enable those in the terminal phase to remain at home for as long as it is practical. For this service to be more widely available the palliative care approach needs to be taught to a wider group of community pharmacists. Systems need to be developed so that community pharmacies have the mechanisms to work in close consultation with the palliative care team caring for the patient and family.

Community pharmacists delivering ‘in home’ care to patients are required to ensure they have access to supplies of the necessary drugs for each patient. Delays in obtaining palliative care medications can lead to avoidable deterioration in the patient’s condition and make remaining at home more difficult. Likewise, as people approach the end of life, a drug’s route of administration may need to be changed to accommodate changes in the patient’s physical condition. Community pharmacists have expressed problems in having access to the full range of the necessary palliative care medicines or the specialist equipment required to deliver some drugs by the appropriate route.

1.3.2 Pain Management

There is some evidence that pain management is not always optimal. The necessary skills required by those managing patients’ pain, including assessment, counselling, dose conversion and the development of treatment plans, are sometimes below accepted standards. Preconceived ideas about a range of issues can often lead to a failure to alleviate pain. These issues include unhelpful attitudes to the meaning and treatment of pain and fears associated with opioids, such as addiction, overdose, respiratory depression and regulatory scrutiny. Research has shown that palliative care training must address these issues, as well as offering tailored and case-based technical information. There is a need for on-going education bolstered by routine assessment and documentation procedures, together with the establishment and adoption of practice standards.

1.3.3 Medical Management Reviews

The community pharmacist’s primary role in conducting a medication management review (MMR) is to promote the quality use of medicine, and in doing so ensure the best possible patient outcomes. This involves the assessment of the appropriateness of an individual patient’s drug therapy, identification of drug related problems and the development of strategies to address these. At the end of life many patients experience multiple symptoms and palliative care is characterised by the need for multiple medications. Polypharmacy and associated iatrogenesis are common. Research has shown that as the number of drugs prescribed for an individual increases, the probability of an adverse drug interactions increases proportionally. Palliative care specialists maintain that the majority of these adverse reactions can be prevented through rigorous medication management reviews in the community. However, in Australia these reviews are uncommon and drugs are often added to existing pharmacological treatments without rationalizing the existing regimen.
In comparison to other fields of health care, prescribing practices in palliative care lack standardisation and a robust evidence base. As a result, treatments vary considerably among physicians and the steady flow of new palliative care drugs and approaches makes keeping abreast of these developments a difficult task. The community pharmacist is therefore well placed, both technically and geographically, to provide MMRs and to fill an important gap in community palliative care. An associated adjunct to MMRs is the education of patients and/or their carers about their drug treatments.

1.3.4 Psychosocial Care

Due to their community location pharmacists often build strong relationships with their clients. Community pharmacists have regular contact with patients and/or their carers and are often aware of their patient’s illness trajectory. As such, it is easy to envisage an extension of their role to support palliative care patients and carers to identifying issues that affect treatment adherence and development of interventions to address these. To assist with this enhanced role, community pharmacists, and those pharmacists who conduct home medication reviews (HMRs), may benefit from general training on psychosocial issues associated with the care of the dying so as to be sensitive to circumstances in which a patient may need to be referred to another service (e.g. counselling).

1.4 The Benefits of Community Pharmacist Involvement

1.4.1 Cost Benefits

Few studies have examined the cost benefits of pharmacist involvement in palliative care, yet a number of studies have shown that generally, community pharmacists’ interventions can result in moderate to high cost savings. An Australian study extrapolated that community pharmacists who proactively assessed their clients’ drug regimes at point of purchase could save Australian health care approximately $15 million dollars annually, primarily through interventions such as correcting doses, the provision of prescribing information and interventions to circumvent drug interactions.

1.4.2 Patient Benefits

The benefits of community pharmacist involvement in general patient care such as asthma, hypertension, pain and medication management, among a host of others, are well documented. Clinical and community pharmacist involvement in palliative care has also shown to be beneficial to patient outcomes. Expert evaluations of interventions made by community pharmacists in community palliative care concluded that 81% of interventions were beneficial to clients. These benefits were achieved predominantly through medication reviews and included benefits such as slowing physical deterioration, improving symptom control, increasing adherence to drug regimes and providing additional support so that people may remain at home when approaching end of life.

1.5 The challenge of involving pharmacists in palliative care

Although there is support for the benefits of palliative care education and community pharmacists’ involvement in palliative care there are still financial, attitudinal and competence issues to be addressed. These have not been systematically explored to date but include the frequently reported limited knowledge of various health professionals, the lack of longitudinal data and the lack of reliable and valid outcome measures. These issues are not unexpected. In comparison to other specialist areas, palliative care is a new field and consequently its methods are still developing. The development of a standardised framework with associated teaching methods and evaluative techniques is vital to improve palliative care education, and ultimately palliative care practice.
Pharmacists should approach palliative care with a view to empowering patients, giving their clients as much control as possible when dealing with the possible side-effects of medications. A problem solving approach to drug-therapy enables pharmacists to accomplish this shift in paradigm for both the patient and the pharmacist. Patient education in the pharmacological process is essential, as patients decide when and if they will take their medications as prescribed. There are a number of reasons for patient non-compliance with medication regimens therefore it is essential pharmacists respond with tailored advice for each individual circumstance. Patients are more likely to share information about their ability to comply with medication regimes if they develop a working relationship with their pharmacist.

Pharmacists have expertise in helping to manage drug related problems, as medication management is a specific focus of pharmacy training. A key feature of innovation in palliative care involves a partnership between pharmacists and physicians to support patients. In a multidisciplinary model of palliative care, pharmacists would be one of several professionals supporting patients; community pharmacists would be able to recognise when additional patient care is necessary and have the resources to respond appropriately.

1.6 This project
This project was divided into several distinct phases and sought to answer a range of research questions. These are listed below in Section 2. However, the broad aim of this project was to increase involvement of community pharmacists in palliative care. Two key approaches underpinned the methodology adopted, the UK's Medical Research Council’s guidance on the development and evaluation of complex interventions, and the RE-AIM model for evaluating the population health impact of health care interventions.

Complex interventions are those that include several components, in this case education of the pharmacists, multidisciplinary group practices, processes for engaging and rewarding involvement in palliative care and patient confidence in the care offered. The evaluation of complex interventions is challenging because of problems of developing, identifying, documenting, and reproducing the intervention. A phased approach to the development and evaluation of complex interventions is recommended to help researchers define clearly where they are in the research process. Evaluation of complex interventions requires use of qualitative and quantitative evidence as planned in the evaluation of this study.

The RE-AIM model considers the key to achieving intended results from an intervention is to take a well rounded approach to program planning. This project used “thought questions”, which served as a checklist for key aspects that should be considered and facilitated reviewing the issues raised and their pertinence to the interventions. This enabled relevant changes to be made before launching the intervention.

1.7. Ethics approval
The project was approved by the following Human Research Ethics committees:
- Curtin University of Technology - approval number: RD46-08
- St John of God Health Care - approval number 386
- Silver Chain Nursing Association Inc. - approval number EC App059
- WACHS (WA Country Health Service – Area Office (South West Branch) - approval number 2009:18
- The Bethanie Group Inc. - approval received (no approval number provided)
- Hollywood Private Hospital - approval number HPH268
2. Objectives and Research Questions

**Objective 1**
To identify the palliative care needs of community-based palliative care patients and their carers and families at different stages of their illness.

*Research Question 1*
What are the needs of palliative care patients (and their carers and families) at different stages of their illness, in relation to community pharmacy support and services generally and to Medication Management Reviews specifically?

*How was this objective met?*
This objective was met through focus groups, which examined the needs of palliative care patients (and their carers and families) at different stages of their illness in relation to community pharmacy support and services generally, and their specific needs in relation to Medication Management Reviews.

**Objective 2**
To develop an educational package for community pharmacists in order to provide enhanced care to palliative care patients.

*Research Question 2a*
What are the educational needs of community pharmacists in palliative care?

*Research Question 2b*
What materials should be incorporated into an educational package to facilitate community pharmacist involvement in palliative care?

*How was this objective met?*
This objective was met in three ways. Firstly, a comprehensive scoping and profiling exercise was conducted in order to identify what materials already existed that could be built upon or modified. This part included an initial review and evaluation of the literature, and a review of education programmes that currently exist in Australia and internationally.

Secondly, focus groups were conducted with carers, community pharmacists, hospital pharmacists, Palliative care doctors and GPs, palliative care nurses and other health care professionals in order to explore what education community pharmacists need to enable them to have an enhanced role in the provision of palliative care.

Thirdly, a cross sectional survey was conducted to examine community pharmacists' knowledge of and attitudes towards palliative care and the reasons for those attitudes. The survey measured pharmacists' attitudes towards providing services and supports for palliative care patients, their beliefs about providing services and supports for palliative care patients, their emotions about providing services and supports for palliative care patients, and their knowledge and understanding of palliative care. The survey was distributed to 1002 pharmacies across Australia. Beliefs about and knowledge of palliative care independently predicted community pharmacists’ attitude to palliative care and demonstrated that (1) palliative care education is needed and (2) palliative care education will lead to a more positive attitude and willingness to take on an enhanced role in this domain.

The final topics for inclusion were: common symptoms in palliative care (e.g. pain, fatigue, constipation); medications commonly used in palliative care; communication with patients; and information about the philosophy and practice of palliative care.
Objective 3
To identify what barriers might prevent community pharmacy involvement in palliative care and what supports are needed to facilitate involvement.

Research Question 3
What are the barriers and facilitators to community pharmacist involvement in palliative care?

How was this objective met?
Focus groups were conducted with key stakeholders to explore barriers and facilitators to the community pharmacist’s involvement in palliative care.

A cross sectional survey was conducted to determine community pharmacists’ attitudes to the provision of palliative care supports and services, to explore pharmacists’ beliefs, emotions, knowledge and understanding of palliative care.

Objective 4
To identify specific needs in relation to medication management services and to develop medication management reviews tailored to the needs of palliative care patients (PCMMR).

Research Question 4a
How can pharmacists be involved in the PCMMR process?

Research Question 4b
How confident are pharmacists in delivering MMR services for palliative care patients?

Research Question 4c
How does the PCMMR service impact on the care of palliative care patients?

How was this objective met?
The key (practical) aim of this stage was to develop medication management review processes and protocols for pharmacists to assist palliative care patients. The resulting model for palliative care medication management reviews (PCMMR) was based on the existing protocols and processes for home medicines reviews (and nursing home medication management reviews), and addressed the specific needs palliative care patients and their family and carers. The PCMMR training addressed: pain and symptom management; the psychosocial, nutritional, dietary and hydration needs of palliative care patients; and medication side effects and interactions, and reflected services provided by clinical pharmacists in hospital and hospice settings. As such they were designed to enable better continuity of care. This objective was addressed via a comprehensive scoping and profiling exercise. This included an initial review and evaluation of the literature, and a review of medication reviews for palliative care that currently exist in Australia and internationally. Focus groups were conducted to explore what education community pharmacists need to enable them to have an enhanced role in the provision of MMRs for palliative care patients and what a PCMMR should include. Palliative care doctors and GPs, home hospice nurses and health care professionals were asked to give their views on how the community pharmacist would work in the palliative care interdisciplinary team. GPs were asked about referral patterns and documentation needs.

The next stage involved a 3 month trial of PCMMRs for community-based palliative care patients. Training was provided to 20 accredited pharmacists in WA, with 13 accredited pharmacists completing at least one PCMMR. We received 48 referrals and 40 reviews were completed. A palliative care brief primer (a 2-day education programme) was developed for pharmacists who are currently accredited to undertake MMRs. The content was focused on pain management; medication side-effects and interactions; psychosocial and spiritual needs and issues; nutrition, hydration and dietary needs. The
medication reviews generally seemed to be a positive experience for patients and for the vast majority left patients feeling more informed and better able to manage their medications.
3. Focus Groups

3.1 Objective
A series of focus groups and interviews were conducted with a range of stakeholder groups in order to: (1) gather an overview of the current and potential role for community pharmacists in palliative care, (2) examine how best to strengthen the role of community pharmacists in palliative care, and (3) gather useful information to feed into the development of the project’s two major deliverables—the palliative care education package, and the model for Palliative Care Medication Management Reviews for Palliative Care patients (PCMMR). The stakeholders included pharmacists, Palliative care doctors and GPs, nurses and the family members and carers of palliative care patients. To ensure that the education module design would meet pharmacists’ needs, the different groups were asked what they thought pharmacists needed to know in order to become more involved in palliative care. To examine whether and how the PCMMR model would work in practice, we asked the groups to provide feedback about our proposed methodology.

3.2 Methodology

3.2.1 Design
An in-depth qualitative design was used. Focus groups were the main source of information, and these were supplemented by individual face-to-face or telephone interviews (when people were not able to attend a focus group meeting for a range of reasons including distance, and caring or professional responsibilities).

3.2.2 Participants
One hundred and twenty two people participated in either a focus group or an interview. The interviews and focus groups were undertaken with those professionals involved in providing services to palliative care patients: pharmacists – accredited and community pharmacists; nurses in community palliative care, hospital, hospice and nursing home settings as well as working with aged patients and children and adolescents; GPs; and carers and family members of patients living with a life limiting illness. Table 3.2.2.1 provides a breakdown of the number of participants by occupation/stakeholder group.

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<tr>
<td>Nurses</td>
<td>44</td>
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<tr>
<td>GPs</td>
<td>10</td>
</tr>
<tr>
<td>Family Members/Carers</td>
<td>24</td>
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<tr>
<td><strong>TOTAL</strong></td>
<td><strong>122</strong></td>
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</tbody>
</table>

A total of 19 individual interviews and 17 focus groups were undertaken. The participants were drawn from both metropolitan and regional areas across Australia (Western Australia, New South Wales, Queensland and Victoria), thus providing a cross section of views that may be reflective of particular practices in various parts of the country. Table 3.2.2.2 provides a breakdown of the number of focus groups and interviews by location.
Table 3.2.2. Focus Groups and Interviews by Location

<table>
<thead>
<tr>
<th>Location</th>
<th>Interviews</th>
<th>Focus Groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>WA Metropolitan (Perth)</td>
<td>12</td>
<td>9</td>
</tr>
<tr>
<td>WA Regional (Albany, Bunbury, Mandurah)</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>VIC Metropolitan (Melbourne)</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>NSW Metropolitan (Parramatta)</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>NSW Regional (Wollongong, Newcastle)</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>QLD Metropolitan (Brisbane)</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>QLD Regional (Mackay)</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>19</strong></td>
<td><strong>17</strong></td>
</tr>
</tbody>
</table>

3.2.3. Materials

The interview schedules for each of the participant groups were developed using an iterative process. A subgroup of members from the project team formed the Focus Group Subgroup; all members of this subgroup had experience in conducting interviews and focus groups. The subgroup developed the key questions, which were then shared with the rest of the project team. After extensive feedback, the questions were revised and updated. The final set of questions provided a schedule of the key issues to be addressed in each focus group (or interview), but was flexible enough to accommodate the natural flow of conversation and the inevitable pre-empting of questions by participants (please see Appendix A for a copies of the focus group information and consent forms and question schedules).

A core team of three highly experienced interviewers from the Focus Group Subgroup conducted the interviews and focus group sessions. Three other subgroup members played a supporting role.

3.3 Results

3.3.1 Analysis Framework

The Focus Group Subgroup developed an analysis framework that was centred on the key research questions, but provided flexibility to accommodate additional and emerging themes. The focus groups and interviews were recorded and transcribed verbatim. To ensure rigour and reliability in our analysis, the Focus Group Subgroup analysed the data as a team and any initial disagreement as to the appropriate coding of excerpts of text was discussed in team meetings until consensus was achieved. The computer based qualitative data analysis program NVivo8® was utilised to store data and to facilitate the analysis of the transcripts. NVivo 8® was used extensively by the Focus Group Subgroup to query the data and provide insights into how each stakeholder group responded to questions in the focus groups/interviews.

3.3.2 General Overview

Presented below is a general overview of the findings regarding community pharmacist involvement in palliative care, discussing both the current and the potential future situation, and the findings that relate to the project’s key deliverables.
3.3.3 Perceptions of Palliative Care

Pharmacists

In general there was a lack of understanding about palliative care by non-palliative care pharmacists. Indeed, respondents in focus group discussions reported that this lack of understanding and knowledge could lead to their colleagues feeling out of their depth.

Some pharmacists suggested that the focus of palliative care is only on patients who experience extreme pain, some suggested that the focus is on patients who are in the terminal stage of life and very close to death, and others perceived the focus to be on patients with cancer. Although most pharmacists were aware that palliative care relies on a team approach, some were unsure about exactly who made up the team.

Nurses

Nurses were less positive and reported significant variability in pharmacists’ understanding of palliative care and especially their understanding of the urgency of the patient’s needs. Some nurses speculated that the variability was largely due to the pharmacists’ underlying attitudes and possible lack of experience in palliative care. There were particular concerns around what nurses considered the large number of inexperienced pharmacists and their ambivalence towards them being involved in palliative care. Nurses also noted that the concept of palliative care was not well understood even by health professionals who regularly worked with palliative patients, and they questioned whether community pharmacists would engage with palliative care.

Carers/Family Members

Despite a patchy understanding of palliative care, reports from carers suggested that many non-palliative care pharmacists grasped and demonstrated some of the key principles of palliative care. For example, pharmacists seemed to understand intuitively the central role of the patient and the carer. They were very aware of the holistic management of, and the need to support patients and their families and to offer them respect at all stages of the patient’s illness. Pharmacists may see this role as part of their usual service, rather than a role that is specific to palliative care. Thus, carers reported being very happy with the support they received from their pharmacist both during the patient’s illness and after death. This was particularly salient if the pharmacist had a long term relationship with the patient or carer and/or family.

Palliative care doctors and GPs

Like nurses, the palliative care doctors and GPs speculated that without experience in palliative care, pharmacists would not be able to fully understand the patient’s and carer’s needs.

3.3.4 Community Pharmacists’ Role in Palliative Care

Pharmacists

Pharmacists clearly articulated a detailed and multifaceted role for themselves in the palliative care team. Pharmacists emphasised their ability to provide in-depth information and advice about symptom management, medications and different kinds of medications, their interactions, side effects, advice on medications that may no longer be needed, counselling the family on the use of medications, (including the practicalities of timing and administration); and maintaining a reasonable stock of medication for patients. Pharmacists also considered they could follow up patients after hospital discharge to ensure patients/carers had sufficient information about medications and were able to manage their medications at home. They also saw their role as potentially providing extra information about medications to Palliative care doctors and GPs and this was apparent in focus group discussions and interviews across Australia. For example:
…in the nursing homes, it’s the GP that are, are running it and a lot of them don’t really have the, the greatest knowledge of palliative care….so I think we could actually give them some advice on certain medications that we use, if we knew what we we’re talking about. (Community Pharmacist Wollongong)

However, they did not see their role as being limited to medications and associated issues. They perceived an important role in supporting patients and their carers by actively listening and offering, and by maintaining an ongoing relationship with the carer. They also considered that there was scope for their involvement in dealing with bereavement and loss in circumstances where they had an established relationship with the carer and his/her family. This focus on interpersonal support was especially important and was seen as a natural extension of their professional role where a longstanding relationship existed. This point was raised in a number of ways, but exemplified by a community pharmacist who suggested that if a community pharmacist has had a professional relationship over an extended period of time, he/she would not, in the patient’s ‘terminal moment’, be wanting to divest him/herself of the care. In this respect this community pharmacist considered that it is almost beholden upon pharmacists as professionals to have whatever expertise is required for dealing with patients who are approaching death.

Note that, although pharmacists did see an opportunity to provide interpersonal support, they also suggested that many pharmacists would need to develop better communication skills to fulfil this role (see further discussion in Section 3.3.5 below).

Pharmacists also suggested that they could play a role in sourcing items such as household aids. Finally, pharmacists felt that they were under-utilised as an accessible repository of community information, and given the appropriate support and recognition, they would be able to provide patients and families with useful information to address a much broader range of issues (for example where to go for financial advice or support services).

Although many pharmacists advocated a broader role in palliative care, some suggested that the best way for pharmacists to be involved in palliative care would be for some pharmacists to become specialised palliative care pharmacies. However, other pharmacists disagreed, and maintained that involvement in palliative care should be the job of all community pharmacists and, as professionals, pharmacists should be sufficiently skilled to provide support to an aging client base irrespective of their needs.

Or if, if there is a, for example, a system just like with Diabetes Australia wide which you know funds, supports certain pharmacies and for Diabetes supplies. And then you have other pharmacies for example that when a customer goes there for a, for a request, they usually say, “Oh go to that one, because that’s a Diabetes Australia Pharmacy. So if, if there’s like just a few pharmacies like that, say, you know, just specially for keeping, you know, palliative, more palliative care products and they’re registered for that, or even maybe subsidised more for that, then other pharmacies would, would know and say, if, if they have a customer with a request like that, they would be able to at least say, “Look, you know, we don’t keep it but this pharmacy, they is more specialised for these products and you can go there.” (Community Pharmacist, Perth)

In summary, pharmacists see their role as important but currently focussed on medications. In general pharmacists suggested that as one of the most accessible health care professionals in the community they are central to a patient’s care, and as such their role could be extended significantly.

Nurses

Nurses were extremely positive about community pharmacists becoming more involved in palliative care, and saw several potential roles they might fill. They saw pharmacists as possible allies in communicating with Palliative care doctors and GPs, speculating that Palliative care doctors and GPs would be more likely to listen to pharmacists’ advice about medications than they would be to act on nurses’ advice. For example:
I think often some doctors don’t know what to do. If you’ve got some information [from the pharmacist] you can give them some suggestions –the pharmacist’s got specialised knowledge and sometimes the GP, because they’re doing everything else, don’t have that specialised knowledge so they [pharmacists] can support you [nurses] [to offer alternatives to the GP] (Nurse – Perth)

They also considered that the accessibility of community pharmacists ideally placed them to address patient concerns regarding medication, given the difficulties often experienced by carers accessing Palliative care doctors and GPs at short notice. Although nurses were very enthusiastic about pharmacists’ involvement, they were aware that pharmacists need to have correct and appropriate information about palliative care medications, and need to be able to convey the information correctly and appropriately. Nurses recognised the potential for pharmacists to influence patients’ medication compliance and were concerned that pharmacists currently lacked knowledge about palliative care medications and dosages, and, as a result, might confuse patients and put them off their medications. Nurses also recognised that given the appropriate training, pharmacists could be a valuable resource and support for patients and their carers. Nurses suggested that they would like to see more active involvement of the pharmacists in palliative care team meetings, and also saw the potential for pharmacists to update nurses and rest of the team about medications.

Carers/Family Members

Carers’ views about the pharmacists’ role in palliative care were—for the most part—extremely positive. However, when carers or patients did have a bad experience with a pharmacist, it seemed to have a huge impact on the family, and often they would change pharmacies as a result. Aside from these few instances, carers’ views were very similar to pharmacists’ views. Carers discussed the importance of having an ongoing interpersonal relationship with the pharmacist. Carers also saw the pharmacist as very knowledgeable, reputable and as a valuable resource to provide advice about medications and side effects and to source household aids. This reputation appeared to be further enhanced through a longstanding relationship. They also saw the pharmacist as a ‘sounding board’ for information on medications and, equipped with this information, they could then go back to their GP. As one carer put it “sort things out, like a three way” (Carer).

Carers valued the accessibility of the community pharmacist, with a number suggesting that it was often easier to talk to the pharmacist than to their GP if they had questions or needed advice and they often consulted them as a ‘first point of call’ (Carer). The carers saw Palliative care doctors and GPs as very busy and focussed specifically on medical/symptom issues, whereas a number saw pharmacists as having a much broader role. (The lack of a longstanding relationship tempered the potential scope that carers saw in the role of the community pharmacist). Carers seemed to have a general perception that pharmacists would go out of their way to help, whereas GPs would not. In sum, carers were very positive, and saw pharmacists as having a broad and multifaceted role led by—but not limited to—medications.

Palliative care doctors and GPs

Overall, Palliative care doctors and GPs had a very limited view of pharmacists’ role in palliative care, restricted to dispensing medications and ensuring the appropriate medications are in stock. The following quotes exemplify GPs:

*Of course medication [is an appropriate role], or probably medication review or just check that all medication given is working altogether. I think they [community pharmacists] could probably give advice about the way medication is prescribed as well as the form (GP Mackay)*

*I think in many cases, they [community pharmacists] can alert people to what potential side effects the medications can give (GP Perth)*
The most important role is, is to be aware of the sorts of drugs that we’re [GP] using and the reasons for its use and to educate the patients who go looking to have their prescriptions filled about how the drugs are used and, and why they’re used (GP Mackay)

Although GPs suggested a role that was very limited in scope, they saw it as a very specific and detailed role.

GPs suggested that pharmacists could be a resource for doctors to consult about medications and there was the perception that, in this specific area, GPs do not make sufficient use of the pharmacist’s expertise. However, only some GPs said they would ask for advice, as a pharmacist would have a different focus as he/she would not be privy to information on the patient’s condition – just the drugs being prescribed. Generally, GPs did not support the idea of pharmacists providing advice or information directly to the patient. They did, however, feel that the GP could approach the pharmacist on behalf of the patient.

The pharmacists’ lack of exposure to palliative care patients was also seen to limit their potential role. GPs did not think it was necessary or desirable for pharmacists to provide interpersonal support for the patient or carer, and felt that this kind of support role belongs to the GP. For example:

\[I\ don't\ see\ a\ pharmacist\ role\ as\ a\ psychosocial\ role\ (GP\ Perth)\]

Regional GPs, on the whole appeared more open to an extended role for community pharmacists, including a role in providing psychosocial support. This view is suggestive of these GPs having existing longstanding relationships with community pharmacists in their area; that GPs recognise the relationships community pharmacists have with their customers; and that the community pharmacist can relieve some work pressure on what is described as a very hectic GP work schedule. For example:

\[when\ you…have\ a\ pharmacist\ that\ you\ can\ share\ the\ job\ with,\ you\ think,\ “You\ beauty.”\ And\ delegate\ as\ much\ as\ you\ can\ and\ you’re\ going\ to\ be\ a\ bit\ more\ of\ a\ team\ person\ when\ you’re\ out\ in\ the\ bush\ because\ you\ just\ have\ to\ be\ (GP\ Mackay)\]

3.3.5 Needs and Supports for Pharmacists to become more involved in Palliative Care

Pharmacists

The needs and supports that pharmacists considered they required to become more involved in palliative care were consistent across Australia and consistent between regional and metropolitan areas. Pharmacists placed surprising emphasis on the need to develop better communication skills – or, as one community pharmacist described it, “some kind of people skill” (Accredited Pharmacist, Melbourne). Pharmacists emphasised learning how to communicate when dealing with difficult questions, upsetting situations (such as when the carer brings back unused medications following the patient’s death) and implementing appropriate boundaries. For example:

\[We\ [community\ pharmacists]\ don’t\ have\ that\ much,\ much\ knowledge\ in\ psychological\ help\ in\ what\ they\ go\ through\ and\ how\ they\ like,\ talk\ to\ them\ [patients/carers]\ and\ just\ not,\ not\ understand\ one\ hundred\ percent.\ It’s\ important,\ but\ we\ don’t\ know\ how\ to\ support\ them\ –\ how\ to\ communicate”\ (Community\ Pharmacist\ Parramatta)\]
I think that it, it’s easy, like I say, if someone brings in a script over the counter, for example…. Oxycodone, it’s easy to dispense that, mention some side effects, but put that in the whole concept of palliative care, that, that prescription is part of, you know, this family has come in, they’ve got emotional concerns, they’ve got, you know, there’s a whole lot of other issues other, other than just handing that box over the counter. So I think pharmacists maybe sometimes find it hard to, to maybe confront that situation of the worried family member or even if the person who’s dying, has come in to pick up their own medication. So I think maybe they need some social skills and maybe… things to say to them which, which will somehow encourage or help them or strengthen them without sounding over patronising and saying, “Oh you know, they’ll be okay.” (Community Pharmacist Wollongong)

Pharmacists would also like to know more about palliative care medications, dosages, interactions and conversions. For example:

I don’t think the majority of community pharmacists would have a, a too great a knowledge of the way drugs are used in palliative care, to be honest. I remember that my only real experience of palliative care hospital was at uni and I remember that things were used quite, quite differently than what they are otherwise, and I think that without looking it up in a book … I wouldn’t know any of that off my head. So there needs to be a fair bit of education I would imagine. (Community Pharmacist Wollongong)

They also felt it would be extremely valuable to have a list of the essential medications to stock for palliative care patients, and information about where to source the medications quickly. Pharmacists also wanted information about where they could find palliative care help and advice in an emergency (for example an emergency helpline for after-hours advice).

**Nurses**

Nurses suggested that pharmacists need a better knowledge and understanding of the principles, goals and values of palliative care, the specific pain, symptom, and side-effect management needs that palliative care patients have (importantly, including children and adolescent palliative care patients), especially the immediacy of those needs, and how to source medications quickly. For example:

It’s the urgency and it’s the palliative care, care that they don’t comprehend when people, people have fairly severe symptoms on top of the fact that they have a terminal illness. So there’s a lot of emotion attached around stuff. If they’re not able to access medication, it’s stressful. And so we want everything yesterday (Nurse Perth)

Some pharmacists they’ll take the script and they’ll say, “I’ll get them in this afternoon’s delivery.” The next chemist you’ll do the same thing and they’ll say, “Oh we’ll get it tomorrow afternoon.” You know there’s only, there’s a big warehouse that they all get their drugs from, this is what they say, so I can’t see the difference in, they don’t understand the urgency (Nurse Perth)

Nurses also highlighted that pharmacists should know about the different uses and dosage of medications when they are used in palliative care versus when they are used for their usual purpose. Typical of discussions are exemplified as follows:
Haloperidol gets prescribed. One of my clients rang up in an absolute rage because the pharmacist has said, “There’s nothing wrong with your brain, what have they put you on that for?” And we’ve given it for, you know, as an anti-nausea agent (Nurse Perth)

A solid understanding of drug equivalence (indications, adverse effects, interactions and dosages) for substitution, drug combinations for use in syringe drivers and pumps, and how to use syringe drivers and pumps were also seen as essential. Finally, nurses suggested that pharmacists should have appropriate skills and knowledge to be able to empathise with the patients’/carers’ situation (for example, understand that the situation may result in distress) and appropriate knowledge of where to refer people for psychosocial support.

**Carers/Family Members**

Carers had great respect for their community pharmacists, in particular those that had longstanding relationships. They were extremely positive about the support and service they received. On the whole, they felt they got what they needed from their pharmacist and did not articulate any specific needs (or barriers). Some carers, however, did think that it would be beneficial for community pharmacists to understand the types of diseases and illnesses that patients receiving palliative care experience and what medications are prescribed. Additionally, those that had relationships with their community pharmacist did consider that some skills in listening would be advantageous. For example:

* I think all they need really is to be a good listener... and to have social skills. because it all comes back to that...It’s the relationship that you build up between you and your, your, your chemist....we go to chemists who have got some connection with us (Carer)

**GPs**

GPs saw pharmacists’ role as very limited and focussed on medications. As a result GPs did not see the potential for change and did not recognise any needs (or barriers) other than knowing more about the use and dosages of palliative care medications. The following quote typifies responses in this regard:

* I think that they, need to be educated more on the actual what drugs because you know, it’s a completely different kind of pain and different kind of medication and they need to understand, they need to grasp what pain, what pain medications are, the, the ones that need to be used for, you know, palliative care. And once they grasp the actual, the pain, the different type of pains and different type of medication and different class of patient medication (GP Perth)

For those GPs who could see an extended role in palliative care for community pharmacists, information on care of people dying was considered valuable as was information on some of the more common symptoms for patients in palliative care. For example:

* all kind of things happening in palliative care and the specific problems in palliative care...like, well, they get short of breath, pain they will know probably quite a lot about but there are a lot more things like the nausea, like, hallucinations, psychotic symptoms, dry mouth for instance, and things like that. I'm not sure whether they [community pharmacists] are really into that (GP Mackay)*
3.3.6 Barriers to Pharmacists Involvement in Palliative Care

Pharmacists

A major issue for community pharmacists is being able to recognise when a patient is receiving palliative care; pharmacists said they often simply guess based on the prescription presented. Many pharmacists reported that trying to get more information about a patient from the GP was difficult. Some pharmacists did not feel as though they were part of the palliative care team—in part because they were not physically present on the team—and felt that other health care professionals did not really recognise or understand the pharmacist’s role in the team.

Pharmacists were concerned about stocking palliative care medications for a variety of reasons. Some were worried about stocking restricted medications in case they became a target for burglary. Others were loath to stock medications with a short shelf life or medications that came in large batches, believing that they would never sell the whole amount and would have to carry the cost of the remainder. Similarly, pharmacists said if they stocked everything that palliative care patients might need, there would be little room left in the pharmacy for anything else. Additionally community pharmacists were concerned that they had no way of knowing whether a patient would require a particular medication, and hence they are not able to plan to either have the stock in the pharmacy, or to be able to access appropriate stocks quickly. Currently, they felt their only way of knowing such information is through “a reasonably emotional family member so you don’t like to pry because you know it’s going to upset them to talk about it” (Community Pharmacist Perth).

Similarly, to provide a complete service to palliative care patients, pharmacists felt they would need to be familiar with, and stock, aids and devices specific to palliative care including catheters and specialised dressings.

Pharmacists saw another barrier in the amount of time that potentially would be taken up by involvement in palliative care. It was a possibility that more time would be required to meet the needs of palliative care patients and their carers relative to other patients and they would also require time to acquire new knowledge:

You must be willing to, you know, invest your time to pick up a new thing and some people might not be willing to invest more time (Community Pharmacist Parramatta)

An added barrier for community pharmacists was weighing up the investment required against the potential intermittent nature of servicing palliative care patients and what that might mean for retention of knowledge. For example, a community pharmacist explained it:

From a team point of view…we tend to get palliative care patients intermittently. So you might go two or three months, nobody you really know and then there could be two or three, together for a time…it’s just every so often….And that is a barrier in terms of the sort of remembering, or being cued in (Community Pharmacist Perth)

Despite the ease with which pharmacists noted these barriers, many were willing to work around the barriers to be more involved in providing care for palliative care patients.

Nurses

According to nurses, the major barrier preventing pharmacists from being involved in palliative care was their ability to stock or obtain necessary medications in a timely manner. Nurses recognised pharmacists’ concerns about becoming targets for burglary by stocking larger quantities of restricted drugs.
Nurses also suggested that the level of support given by pharmacists to palliative care patients was highly dependent on the pharmacist’s attitude towards palliative care, and speculated that differences between pharmacists were often to do with the amount of knowledge and experience they had in palliative care and in life generally. For example:

> There are pharmacists who have the attitude that they will get it in [required medication] in the afternoon or courier it, is different perhaps than the attitude of somebody who hangs onto it for a day and a half …but that comes from their….life experiences as well (Nurse Perth)

Nurses saw the lack of privacy in the pharmacy setting as a potential barrier for patients although carers did not see this as a barrier. Indeed where the issue of privacy was discussed, carers appeared to be content with being spoken to “at the end of the counter or he’d [pharmacist] come around to you and go more-or-less down into the shop” (carer).

**GPs**

Generally, GPs did not mention barriers preventing community pharmacists from being involved in palliative care as they largely conceived the pharmacists’ role as focussed around medications and—notwithstanding their needs and supports to undertake this role specifically in palliative care—they considered that this role was squarely in the pharmacists’ professional ambit. However, there was some discussion around time as a possible barrier for the community pharmacist. This was discussed primarily in terms of the time required to be involved in the palliative care team (and how that would impact on the pharmacy) and whether the financial reward for being involved would be adequate.

The lack of articulation of barriers was consistent across the country.

### 3.3.7 Communication Issues in the Palliative Care Team

**Pharmacists**

Pharmacists highlight the key communication as being with the patient or carer. Some pharmacists—especially more recent graduates—suggested they would communicate directly with the nurse. Others felt that the GP was the key professional with whom to communicate, although a number of pharmacists reported little success in engaging the GP.

Pharmacists felt they could enhance their role (and the patient’s care) by providing information that was beyond the knowledge of the other health professionals.

Pharmacists suggested that information could be shared in the palliative care team by email, fax or through a web system, with different levels of access for the different health professionals. They recognised that there might be important privacy considerations in this proposal.

**Nurses**

Nurses saw their potential relationship with the pharmacist as valuable and felt they would like to have more access to pharmacists. This was often described in terms of a three way relationship between the pharmacist, GP and nursing staff. Many nurses said they often took a patient’s script to the pharmacy to pick up medications, and through this and other avenues had developed a very good relationship with the local pharmacist. For example:

> When I work in an area for a long time I go around and I talk to the pharmacist and I say, “Look, this is my number. If there’s ever a problem with any people’s scripts, I’ll always make sure that you get the prescription”. And that’s worked well in some of the areas. I know the pharmacist, and they know who you are, and that’s good (Nurse Albany)
Nurses saw pharmacists as playing a role in caring for the patient, but did not seem to recognise the pharmacist as part of the palliative care team. However, they did support the idea of the pharmacist being part of the team when it was suggested to them. Nurses felt that Palliative care doctors and GPs might be initially resistant to pharmacist involvement in the palliative care team but this reluctance would decrease over time. Nurses saw pharmacists as having stronger medication management skills than many GPs, and the ability to easily understand the subtle nuances of different drugs and deal with bothersome side effects in a timely manner (for example mouth ulcers or thrush).

Like pharmacists, nurses were also happy to communicate via fax, email or a web-based system, but given the very sensitive nature of some of the content, emphasised that it was not necessary to share all information and discussed the importance of different levels of access depending on the professional’s role.

**Carers/Family Members**

Carers saw the pharmacist as central to the patient’s care, but not necessarily as part of their palliative care team. They also saw that there should be good communication between the pharmacist and their GP, and considered patient care would be improved if that were the case. Where this did occur, carers commented on the high level of patient care received. Also, carers saw themselves as central to patients’ care and therefore expected to be involved in any discussions. Thus communication between the pharmacist and the carer/family/patient was considered essential.

Carers were happy for the pharmacist to see the patient’s medical notes, with one carer suggesting that it would be necessary and another suggesting that it should be mandatory. Suggestions for information sharing included through “a common data base where they [health professionals involved in care] can all log into and see exactly what’s happening.” (Carer)

**GPs**

In keeping with the nurses’ suggestions, GPs were reluctant for pharmacists to become involved as part of the palliative care team. GPs felt that their own interpersonal support role would be infringed or duplicated if pharmacists also provided interpersonal support.

GPs would prefer to communicate via fax or email, and generally were not supportive of a web based system.

There was reluctance among GPs for information sharing, due to issues of confidentiality and due to the limited role that GPs saw for community pharmacists in palliative care. Some however, did see that in future, there may be a case for the sharing of medication profiles with community pharmacists depending on the role that the latter play in palliative care.

The views of GPs were consistent across the country.

**3.3.8. Deliverables**

**3.3.8.1 Medication Management Review for Palliative Care Model**

A model for the proposed PCMMR was presented at focus groups and interviews for participants to comment upon. A copy of the proposed model is attached as Appendix B.

**Pharmacists**

Pharmacists generally felt that the model was a good idea. Many of the concerns raised by pharmacists were informed by experiences they have had with Medication Management Reviews (MMRs) in general, rather than being specific to the proposed model. For example, some pharmacists suggested that the reimbursement was not commensurate with the time required to conduct an MMR. They also suggested
that the outcomes would be highly dependent on the motivation of individual GPs and pharmacists, and noted the potential for delays and time-lags throughout the different steps of the model.

There was also concern about the number of steps in the process. There was much discussion about whom (if anyone) could be omitted from the model and ostensibly, the ‘who’ was dependent upon the care provided in each location. For example, NSW participants suggested omitting the Hospice GP as they tended to have less contact with the patient than the patient’s GP or nurse. Accredited pharmacists felt that the patient’s GP is more accessible and, as such, if a step were to be removed from the model, then it would be preferable for it not to be the GP. Unlike NSW, in Queensland the Palliative Care GP had more contact with patients and thus pharmacists there saw the palliative care GP as an important step in the model.

Palliative care pharmacists thought that due to the inevitable medication changes that happen day-to-day in palliative care, the timelines involved in the PCMMR model might be problematic, especially considering the number of steps in the model.

Accredited pharmacists were very positive and willing to take on the palliative care aspect of the MMR and a number volunteered to be involved in the trial.

Some community pharmacists suggested that the PCMMR should not be a speciality, but should be the job of all community pharmacists.

Nurses

Nurses felt the model was an excellent idea. Given that there were a number of steps, they suggested that the best way for it to work would be for palliative care home hospice nurses to manage and coordinate the process so that the nurses could work around any blocking by Palliative care doctors and GPs not authorising referrals and delays at each step. Nurses also considered that hospice GPs were incredibly busy and this too was a potential stumbling block for the review, or a potential point of delay in the process. The nurses thought that patients would benefit enormously and that nurses would learn from the process too.

Carers/Family Members

Carers thought that the model was a great idea, and were pleased about the opportunity to have dedicated time with the pharmacist to discuss medications and side effects, to ask questions and gain a better understanding. They saw the PCMMR as a holistic review where they would be able to ask questions and gain a better understanding of the whole regime rather than just focussing on specific medications. Carers compared this prospect to the current situation with the GP, who they saw as very busy and focussed on symptoms rather than medications. Carers reported that the pharmacist is usually the first person they approach about medication problems, and saw a great potential for this role. However, carers were not concerned about how the model would actually work in practice—they would be happy just to get the PCMMR.

Of concern to some carers, however, was the convoluted nature of the model and what they saw as the potential for information to go missing. Of particular concern, however was the fact that there was no ‘carer or patient’ voice in the model and thus, patients could be seen as being mere passive recipients of care rather than being central to the entire process as described in the philosophy of palliative care. It was also noted that those carers who held power of attorney should be involved to advocate on behalf of the patient.

GPs

GPs felt that the model was acceptable in principle, but reported that MMRs are not part of regular practice so not many patients would get to the model in the first place. GPs reported that they only refer patients for MMRs in very complex cases. In less complex cases GPs feel that they are quite capable of managing the patient’s medications themselves without the need for an MMR. GPs, like pharmacists, saw the general MMR model as problematic due to the administration and form filling involved, and due to the report often being technical and long. GPs also highlighted the often unclear role between the
hospice GP and the patient’s GP, and how that might impact on the model; as well as also highlighting the lesser role that GPs often plays when their patient enters palliative care.

3.3.8.2 Education Modules

Pharmacists

There was consistency across the board about what pharmacists thought they needed to learn in order to facilitate their involvement in palliative care. The key issues of symptom management, palliative care medications and communication skills came up time and time again. Pharmacists were very clear that they prefer experiential learning: learning by doing rather than learning by reading lots of text.

Nurses

Nurses felt it was essential to teach pharmacists about the principles, goals and values of palliative care, and what working in palliative care involves. Additionally, they suggested that pharmacists should have a good understanding of the special needs of palliative care patients and the immediacy of those needs.

Carers/Family Members

The carers did not clearly articulate what should be included in the education package, but did indicate that they considered communication skills to be the key.

GPs

GPs suggested that pharmacists should be given education around specific information to do with medications used in palliative care such as dosages, interactions, side effects, administration, and titrations. They also suggested including information on the role of non-prescription medications.

3.4 Limitations

Most of the focus groups were homogenous and involved 8 – 12 participants, which is ideal. However, some of the groups organized by others or that were conducted at the beginning of a team meeting were more heterogeneous and one involved a large number of participants.

It was difficult to organize focus groups for GPs. However, we managed to find a suitable time and venue for one group and we conducted interviews with the other GPs.

Some of the focus groups were facilitated by one person (due to costs and needing to conduct many groups in a short period of time) and this was not ideal. However, our team is experienced and we overcame these difficulties easily.

3.5 Discussion

Feedback was generally very positive from all stakeholder groups, although pharmacists indicated that there would be a number of community pharmacists who would not be interested in or who would be ambivalent about involvement in palliative care.

The pharmacists we spoke to were very keen to be involved and could articulate a clearly defined, multifaceted role for themselves in palliative care. Pharmacists emphasised their ability to: provide in-depth information and advice about symptom management and medications, including their interactions and side effects; advice on medications that may no longer be needed, counselling for the family on the use of medications; and give support for patients and carers. Nurses and carers/family members were also very supportive of enhancing the role of the community pharmacist in palliative care. GPs were
more reserved in their support and, in general, preferred that the support and information was provided to them and they would then pass on any information to the patients and family members/carers.

Several barriers to community pharmacists becoming more involved in palliative care were identified. These included the need for education. Nurses, in particular, felt that the community pharmacists needed to know much more about the goals and philosophy of palliative care and the needs of palliative care patients and their carers/families. The nurses highlighted that a quick response was often needed and that the community pharmacists need to know about the particular uses of medications in palliative care. Nurses also highlighted that a negative attitude was a major barrier to the involvement of the community pharmacist in palliative care and they stated that they were selective about which community pharmacists they worked with or approached for support depending on the community pharmacist’s attitude and willingness to help. Community pharmacists mentioned reimbursement and drug storage issues and also emphasized the need for education. There emerged a need to develop a list of essential palliative care medications for pharmacists to stock and a list of how and where to find palliative care medications quickly.

There was consistency in the responses regarding what educational content was required with palliative care philosophy, medications, symptom management and communication emerging frequently. Experiential learning was preferred by community pharmacists.

The PCMMR model was received positively. However, there was consensus that it had too many steps and the process had to be streamlined as the patient would usually need to be seen in a short period of time. There was less agreement about who to ‘leave’ out of the model.

3.6 Conclusions

There was general support for enhancing the role of the community pharmacist in palliative care, albeit with some reservations. There was also agreement about the necessity of education in key aspects of palliative care. Alongside education of community pharmacists, there is a need to promote the potential role of community pharmacists in the palliative care team; especially to Palliative care doctors and GPs, and to educate other health care professionals about how community pharmacists can contribute to the palliative care team. There is also a need to develop a process for health care professionals to share relevant information about their patients.
4. Community Pharmacists’ Attitudes about Palliative Care: Nationwide Survey

4.1 Objectives

The focus groups suggested that some community pharmacists may be reluctant to be involved in palliative care. Additionally, participants in some focus groups suggested that there was a direct link between a pharmacist’s attitude towards palliative care and the level of support that pharmacist would give to palliative care patients. In this survey, the primary objectives were to examine community pharmacists’ attitudes towards palliative care and the reasons for those attitudes. Specifically, the survey measured pharmacists’ attitudes towards providing services and supports for palliative care patients, their beliefs about providing services and supports for palliative care, their emotions about providing services and supports for palliative care patients, and their knowledge and understanding of palliative care.

The survey provided a means to identify any misconceptions or reluctance that pharmacists might have to being involved in palliative care, and a means to identify which information is important for a given attitude and what predicts a given attitude.

4.2 Methodology

4.2.1 Survey Construction

In order to develop a valid survey instrument grounded in theory, we constructed the survey using Eagly, Mladinic and Otto’s attitude survey template, which is based on Zanna and Rempell’s tripartite model of attitudes. The key idea of the model is that people’s attitudes are comprised of three distinct types of information: their knowledge and experience, their emotions, and their beliefs.

Eagly et al.’s survey template has been used and published extensively, including in the palliative care arena. For instance, Cohen, O’Connor and Blackmore adapted Eagly et al.’s template to investigate nurses’ attitudes towards providing palliative care in nursing homes. They found that beliefs and emotions both independently predicted registered nurses’ attitudes, but knowledge did not. In other words, there was no evidence that providing these nurses with more information (and thus knowledge) about palliative care would affect their attitudes towards it; the results suggested that in order to improve nurses’ negative attitudes, any education would need to target the nurses’ beliefs and feelings about palliative care.

We adapted the survey template to make it appropriate for measuring community pharmacists’ attitudes towards providing palliative care. We gathered feedback from the stakeholder advisory panel, the Expert Advisory Group and from pilot testing with several community pharmacists, and then refined the survey to make it more acceptable to the target audience.

The survey is made up of five key parts (see Appendix C). First, the pharmacists were asked to rate their “attitude about providing services and supports for palliative care patients” using a 7-point scale ranging from -3 (“negative”) through to 3 (“positive”). In the Section 2, pharmacists are asked to report their beliefs about providing services and supports for palliative care patients. The pharmacist could report up to six beliefs in his or her own words. The pharmacist then rated how positive or negative each belief was using a 7-point scale ranging from -3 (“negative”) through to 3 (“positive”). In the Section 3 pharmacists could report up to six emotions they had about providing services and supports for palliative care patients, rating how positive or negative each emotion was in the same way. In Section 4, the pharmacist was asked to provide some personal information including their gender, location, how long they have been qualified and their experience in palliative care. Finally in Section 5, the pharmacist was presented with 20 knowledge statements about palliative care. For each statement the pharmacist was asked to indicate whether it was true or false or whether he or she was unsure of the answer. For example, one statement read, “Dexamethasone 16mg/day is a reasonable dose for treating decreased appetite and mood.” Half of the statements were true and half were false.
There were two key differences between the final survey used and Eagly et al.’s original template. First, the crucial attitude statement was changed from being a measure of a general attitude (e.g. towards palliative care) to be a measure about pharmacists’ attitudes towards personally providing services and supports for palliative care patients. Second, the number of available spaces was reduced for pharmacists to report their beliefs and emotions from ten for each, to six for each.

To develop the statements for the knowledge section of the survey, experts from the research team suggested short true and false statements relevant to pharmacists’ knowledge of palliative care. These were compiled and a list containing 19 true and 24 false statements was sent to the research team to rate in according to how appropriate each was for measuring pharmacists’ knowledge of palliative care. The survey research subgroup then selected the final 20 statements using these ratings and their own judgements to ensure the final set of statements (1) covered the different areas of knowledge and (2) were not repetitive.

4.2.2 Survey distribution

The website for the yellow pages online (www.yellowpages.com.au) was used to obtain a random sample of pharmacies stratified by state. Pharmacies were identified by searching for “pharmacy” and the relevant state (e.g. “NSW”). A random number between 1 and 9 was generated (using www.random.org) to choose the starting point for each list. We recorded the first address and then every 7th address in an MS Excel® file. Surveys were posted to the 1002 pharmacies identified using this procedure (Approximately 1/7 of the pharmacies listed in the yellow pages across Australia).

The surveys were addressed to “The Community Pharmacist” and the package sent included a cover letter, an information sheet, the survey itself, a complimentary tea bag, and a reply paid envelope (copies of these documents appear in Appendix D). The survey was anonymous. We offered a $30 gift voucher for returning a completed survey. To receive the voucher, the pharmacist filled in an address slip at the bottom of the cover letter and posted it back with the completed survey.

We conducted two follow-up telephone reminders using the numbers provided in the yellow pages. Pharmacists were also offered the option of returning the survey by fax or email if that suited them better. A number of pharmacists mentioned that they had misplaced the original survey but would be happy to complete it if we re-sent it. In these cases a new copy of the survey was provided either by post, fax or email depending on the pharmacist’s preference.

4.2.3 Data Analysis

All data was analysed using SPSS v 17.0®.

4.3 Results

4.3.1 Participants

In total 250 completed surveys were returned. An additional 34 were returned by Australia Post because the pharmacy was no longer at the address given in the yellow pages, producing a final response rate of 26%. Given that pharmacists’ response rates are typically very low (for example Nation et al. reported a 10.3% response rate for their survey of pharmacists) this is deemed to be acceptable.

Of the 250 completed responses, there were 114 females and 135 males, with one unknown. The pharmacists ranged in age from 20 to 72 years, \( M = 37 \text{ years, } SD = 11.8 \). The respondents had been qualified as pharmacists for between 0 and 50 years \( M = 13.8 \text{ years, } SD = 12.4 \), and working in community pharmacies for between 0 and 54 years \( M = 14 \text{ years, } SD = 11.3 \). The community pharmacies where the respondents worked employed between zero and 12 other pharmacists \( M = 2, SD = 1.9 \). Table 4.3.1.1 provides a breakdown of the locations of the community pharmacies that the pharmacists worked in by State or Territory.
Table 4.3.1.1. Locations of community pharmacists by State or Territory.

<table>
<thead>
<tr>
<th>State</th>
<th>Metropolitan</th>
<th>Regional</th>
<th>Rural or Remote</th>
<th>Not reported</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>New South Wales</td>
<td>49</td>
<td>23</td>
<td>9</td>
<td>1</td>
<td>82</td>
</tr>
<tr>
<td>Northern Territory</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Queensland</td>
<td>26</td>
<td>17</td>
<td>11</td>
<td>0</td>
<td>54</td>
</tr>
<tr>
<td>South Australia</td>
<td>14</td>
<td>3</td>
<td>7</td>
<td>1</td>
<td>25</td>
</tr>
<tr>
<td>Tasmania</td>
<td>0</td>
<td>3</td>
<td>2</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Victoria</td>
<td>38</td>
<td>9</td>
<td>1</td>
<td>0</td>
<td>48</td>
</tr>
<tr>
<td>Western Australia</td>
<td>27</td>
<td>3</td>
<td>3</td>
<td>0</td>
<td>33</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>155</strong></td>
<td><strong>58</strong></td>
<td><strong>34</strong></td>
<td><strong>2</strong></td>
<td><strong>249</strong></td>
</tr>
</tbody>
</table>

Only 29 pharmacists reported having any training in palliative care, yet 121 pharmacists reported that they were currently providing services and supports for palliative care patients. Additionally, 92 pharmacists reported having personal experience in palliative care (for example, caring for a relative). A substantial proportion of the sample reported that they had not seen any palliative care patients in the previous 12 months (n = 48, 19%). Conversely, four pharmacists reported seeing 100 palliative care patients in the previous 12 months, and one pharmacist reported seeing 500. Excluding these five pharmacists from the analysis, on average pharmacists reported seeing 6.7 palliative care patients over the previous 12 months (SD = 9.7).

4.3.2 Pharmacists’ attitudes towards providing services and supports for palliative care patients

Most pharmacists reported having a positive attitude about providing services and supports for palliative care patients. Of the 232 responses to this question, all but 11 pharmacists rated their attitude on the positive side of the scale (95%). The remaining 11 all rated their attitudes as neutral (5%). Not surprisingly, pharmacists’ average attitude rating was positive (M = 2.3, SD = 0.82). In short, we found no evidence that pharmacists were reluctant to be involved in the provision of palliative care.

4.3.3 Pharmacists’ beliefs about providing services and supports for palliative care patients

Pharmacists listed between zero and six beliefs about providing services and supports for palliative care patients, (M = 4.7, SD = 1.4). Concerns that pharmacists would not fill the empty sections of the survey were unfounded with 103 pharmacists (41%) completely filling this section and reporting six beliefs each. In total, the pharmacists reported 1159 beliefs. Despite their positive overall view of providing services and supports for palliative care patients, pharmacists rated some their beliefs on all parts of the scale, with ratings ranging from -3 through to 3. We collapsed the more and less positive ratings, and the more and less negative ratings to calculate the proportion of positive and negative ratings overall. As Figure 4.3.3.1 shows, pharmacists rated 21% of their beliefs as negative (n = 246), 4% of the beliefs as neutral
(n = 45) and 75% of their beliefs as positive (n = 868), suggesting that while pharmacists were aware of negative aspects of palliative care, the positives outweighed the negatives.

![Figure 4.3.3.1 Percentage of Beliefs rated as Positive, Neutral and Negative](image)

We next looked at what topics and issues the pharmacists’ beliefs focused on; each response was coded into a category. Table 4.3.3.1 provides examples of responses coded in to each of the categories. As shown in Figure 4.3.3.2, common topics of interest were about the support or benefits for the patient and their carers, needing palliative care education and support, and information about how the pharmacists could play a role.
Table 4.3.3.1. Pharmacists’ beliefs about providing services and supports for palliative care patients

<table>
<thead>
<tr>
<th>Category</th>
<th>Example Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beneficial for community</td>
<td>I believe… <em>that it is a community need</em></td>
</tr>
<tr>
<td>Support and benefits for patients and carers</td>
<td>I believe… <em>improves patient and family understanding and acceptance</em></td>
</tr>
<tr>
<td>Need for palliative care education and support</td>
<td>I believe… <em>I would need more training to provide services for palliative care</em></td>
</tr>
<tr>
<td>Emotional impact</td>
<td>I believe… <em>it takes lots of emotional energy</em></td>
</tr>
<tr>
<td>Enables patient to stay at home</td>
<td>I believe… <em>the patient should be able to choose home or hospital for their last days</em></td>
</tr>
<tr>
<td>Communication/Palliative care team</td>
<td>I believe… <em>pharmacist can play a role in the Palliative care team</em></td>
</tr>
<tr>
<td>Pain management</td>
<td>I believe… <em>in optimal pain relief minimising side effects such as constipation and drowsiness</em></td>
</tr>
<tr>
<td>Non-pain symptoms and quality of life</td>
<td>I believe… <em>providing medication advice allows patients to maintain control for as long as possible</em></td>
</tr>
<tr>
<td>Pharmacist’s role</td>
<td>I believe… <em>that accurate information about PC drugs (e.g., opiates) should be offered by pharmacists</em></td>
</tr>
<tr>
<td>Work load/increased costs</td>
<td>I believe… <em>it may not generate enough profit for the time and resources required</em></td>
</tr>
</tbody>
</table>

Figure 4.3.3.2. Percentage of Beliefs in each Category

- 27% Work load/increased costs
- 18% Pharmacist’s role
- 11% Non-pain symptoms and quality of life
- 9% Pain management
- 7% Communication in palliative care team
- 7% Enables patient to stay at home
- 5% Emotional impact
- 4% Need for palliative care education and support
- 3% Support/benefits for patients and carers
- 2% Beneficial for community
- 9% Other

I believe... that accurate information about PC drugs (e.g., opiates) should be offered by pharmacists.
4.3.4 Pharmacists’ emotions about providing services and supports for palliative care patients

Pharmacists also listed between zero and six emotions they experienced in relation to providing services and supports for palliative care patients ($M = 3.9$, $SD = 1.6$), with 59 pharmacists (24%) completely filling the section and reporting six emotions. In total the pharmacists reported 955 emotions. These were again collapsed across the more and less negative ratings, and the more and less positive ratings to calculate the overall number of emotions that were rated as positive and negative. As shown on Figure 4.3.4.1, pharmacists rated 38% of their reported emotions as negative ($n = 360$), 5% of their emotions as neutral ($n = 43$), and 58% of their emotions as positive ($n = 552$). The higher proportions of negative ratings for pharmacists’ emotions (compared with their beliefs) fits with the idea that working in palliative care can be a confronting experience on a personal level.

![Figure 4.3.4.1. Percentage of Emotions rated as Positive, Neutral and Negative](image)

Next we looked at what emotions the pharmacists experienced in relation to providing services and supports for palliative care patients. Table 4.3.4.1 provides examples of responses coded in to each of the categories. As shown in Figure 4.3.4.2, the most common response was that the pharmacists felt necessary and valued. It was also common to report feeling sad and feeling uncomfortable.
Table 4.3.4.1. Pharmacists’ feelings about providing services and supports for palliative care patients

<table>
<thead>
<tr>
<th>Category</th>
<th>Example Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Angry/annoyed</td>
<td>I feel… angry as nothing more can be done</td>
</tr>
<tr>
<td>Empathy</td>
<td>I feel… compassionate for those suffering</td>
</tr>
<tr>
<td>Emotional</td>
<td>I feel… emotional</td>
</tr>
<tr>
<td>Fortunate</td>
<td>I feel… grateful for health</td>
</tr>
<tr>
<td>Happy/good</td>
<td>I feel… good to be able to help patient and family</td>
</tr>
<tr>
<td>Necessary/valued</td>
<td>I feel… that I am an integral part of the patient's health care</td>
</tr>
<tr>
<td>Redundant/ineffective</td>
<td>I feel… inadequate to provide the required level of care</td>
</tr>
<tr>
<td>Responsible</td>
<td>I feel… responsible for medication use</td>
</tr>
<tr>
<td>Sad</td>
<td>I feel… sad, as the patients time is coming to an end</td>
</tr>
<tr>
<td>Satisfied</td>
<td>I feel… satisfaction</td>
</tr>
<tr>
<td>Uncomfortable</td>
<td>I feel… uncomfortable how will my interaction make the patient feel patronized</td>
</tr>
<tr>
<td></td>
<td>uncomfortable angry</td>
</tr>
<tr>
<td>Unsure</td>
<td>I feel… a little uncertain</td>
</tr>
</tbody>
</table>

Figure 4.3.4.2. Percentage of Emotions in each Category
4.3.5 Pharmacists’ knowledge about palliative care

The overall score of each pharmacist’s performance on the 20 true and false statements was calculated as a measure of their knowledge and understanding of palliative care. The pharmacists’ scores left significant room for improvement, with scores ranging from 2 to 16 questions correct (10% - 80%), with an average score of 9.5 questions correct out of 20 ($SD = 2.9$). These 20 facts were selected because they were seen as essential for community pharmacists working with palliative care patients to know; the pharmacists’ below average performance highlights the need for palliative care education targeted towards pharmacists.

There was some evidence that the pharmacists were aware of their limited palliative care knowledge. More specifically, the pharmacists were asked to respond “unsure” for any statement that they did not know the answer to. Overall, the pharmacists gave between 0 and 14 “unsure” responses ($M = 4.7$, $SD = 2.9$). Thus, on average, pharmacists were unsure about the truthfulness of 24% of the statements, suggesting that they recognised the gap in their knowledge of palliative care.

Table 4.3.5.1 provides a detailed breakdown of the pharmacists’ responses to each of the true and false statements. The correct responses are shaded in grey.

<table>
<thead>
<tr>
<th>True Statements</th>
<th>True</th>
<th>False</th>
<th>Unsure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Laxatives should be prescribed whenever opioids are to be used</td>
<td>201</td>
<td>41</td>
<td>6</td>
</tr>
<tr>
<td>The evidence about the safety and efficacy of combining drugs for subcutaneous infusions is very limited</td>
<td>45</td>
<td>46</td>
<td>156</td>
</tr>
<tr>
<td>Haloperidol is good for treating nausea and vomiting</td>
<td>124</td>
<td>56</td>
<td>63</td>
</tr>
<tr>
<td>Chemotherapy is used as a non-curative treatment in palliative care</td>
<td>88</td>
<td>87</td>
<td>70</td>
</tr>
<tr>
<td>Most palliative care patients experience shortness of breath during their illness</td>
<td>101</td>
<td>39</td>
<td>107</td>
</tr>
<tr>
<td>The major focus of palliative care is maximising the patient’s quality of life and addressing the needs of both the patient and their carers/family members</td>
<td>241</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Medications are often used for non-standard indications and at non-standard dosages in palliative care</td>
<td>203</td>
<td>11</td>
<td>29</td>
</tr>
<tr>
<td>Sleep reversal is common in palliative care patients</td>
<td>72</td>
<td>5</td>
<td>165</td>
</tr>
<tr>
<td>Many palliative care patients experience oral thrush at some stage of their illness</td>
<td>164</td>
<td>9</td>
<td>72</td>
</tr>
</tbody>
</table>

(Table continued on next page)
There are three important results displayed in the table. Firstly, the results illustrate that pharmacists have a good understanding about some aspects of palliative care. For example, 209 pharmacists (84%) correctly rejected the suggestion that medication needs took priority over spiritual needs, and 203 pharmacists (81%) recognised that medications may be used for different indications and at different dosages in palliative care. Secondly, the responses highlight a number of areas where pharmacists lack knowledge about palliative care. For example 156 pharmacists (63%) reported being unsure about the evidence for combining drugs in syringe drivers, 165 (66%) were unsure whether sleep reversal is a common experience for palliative care patients and 95 pharmacists (38%) were not sure whether withholding opioids until the patient was in severe pain was a good idea. Finally, the results identified some common misconceptions about palliative care. For instance, the majority of the sample (n = 226, 90%) erroneously thought that all palliative care patients would experience depression, and 171 pharmacists (68%) thought that the major focus of palliative care is managing pain at the end of life.

Taken together these findings illustrate that there are significant gaps in pharmacists’ knowledge and understanding of palliative care, and support the need for palliative care education targeted towards pharmacists.

### 4.3.6 Predicting pharmacists’ attitudes to providing services and supports for palliative care patients

We next analysed the data to see if pharmacists’ overall attitudes about providing services and supports for palliative care patients could be predicted by their beliefs, their emotions or their knowledge. To that end, we conducted a standard (simultaneous) multiple regression, regressing pharmacists’ overall
attitude on the three predictors: mean belief rating, mean emotion rating and knowledge test score (percentage correct).

We first evaluated whether the data met the assumptions required to conduct the regression. There were 224 completed surveys that could be used in this analysis, giving adequate power to detect medium effects or greater (the remaining 26 surveys were missing data in one or more of the sections required). No outliers were found in the variables, and there was no evidence of multicollinearity or singularity between the predictor variables. The relationship between the residuals and the criterion variable was sufficiently normal, linear, and homoscedastic, and no outlying residuals were found. In short, the data met the necessary assumptions to conduct the regression.

The regression showed that pharmacists’ overall attitudes were predicted by both their beliefs about providing services and supports for palliative care patients, and by their knowledge about palliative care (see Table 4.3.6.1). More specifically, the more positive pharmacists rated their beliefs, the more positive their overall attitude, and similarly, the higher the pharmacists’ score on the knowledge test, the more positive their overall attitude. These results suggest that improving pharmacists’ knowledge and understanding of palliative care might improve their overall attitudes towards providing services and supports for palliative care patients. Palliative care education should, therefore, focus on fostering positive beliefs about palliative care as a way to improve pharmacists’ attitudes.

<table>
<thead>
<tr>
<th>Predictor</th>
<th>b</th>
<th>SE b</th>
<th>β</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Belief (Mean rating)</td>
<td>.118</td>
<td>.050</td>
<td>.164</td>
<td>2.35</td>
<td>.020</td>
</tr>
<tr>
<td>Emotion (Mean Rating)</td>
<td>.056</td>
<td>.045</td>
<td>.086</td>
<td>1.23</td>
<td>.218</td>
</tr>
<tr>
<td>Knowledge (Proportion correct out of 20)</td>
<td>.986</td>
<td>.375</td>
<td>.171</td>
<td>2.63</td>
<td>.009</td>
</tr>
</tbody>
</table>

Notes: $b$ = unstandardised regression coefficient; $SE b$ = standard error of $b$; $\beta$ = standardised regression coefficient; $t$ = t-test statistic; $p$ = significance of t-test statistic.

Although pharmacists’ ratings of their emotions did not predict their overall attitudes towards providing services and supports for palliative care patients, there was a significant correlation between pharmacists’ ratings of their beliefs and ratings of their emotions, ($r = 0.36, p <0.001$). The direction of this relationship is not clear, but it may be that fostering more positive beliefs about palliative care also improves pharmacists’ ratings’ of their emotions, thus removing a potential barrier preventing pharmacists’ from providing services and supports for palliative care patients.

### 4.4 Limitations

One limitation is the low response rate for the survey (26%). Although this rate is typical of other surveys in community pharmacy, it does limit the generalisability of the results. More specifically, it may illustrate that the sample who returned completed surveys had a respondent bias. Given that no pharmacist reported having a negative overall attitude—and given that in the focus groups it was a common theme that some pharmacists were ambivalent about palliative care and reluctant to be involved—it seems likely that the sample was biased. In the covering letter of the survey, it was requested that pharmacists return the survey even if they had no interest in palliative care so we could get a range of attitudes. However, it may be that only pharmacists with an interest in palliative care responded.
There are a number of other reasons why the response rate may have been low. Firstly, the surveys were sent to community pharmacies rather than individual pharmacists. It is well established that response rates are much better when surveys are personalised. Secondly, not having the pharmacists’ names made the ‘follow-up phone calls’ very difficult as the researcher often spoke to someone different each time they called. Finally, the survey were posted out at the end of the year (a very busy time for community pharmacies), which potentially may have decreased the opportunity for the pharmacist to complete the survey.

**4.5 Discussion**

We surveyed community pharmacists to determine their overall attitude to palliative care. We also looked at their beliefs and emotions and their knowledge of key aspects of palliative care. The majority of pharmacists reported having a positive attitude about providing services and supports for palliative care patients. This was surprising given that some pharmacists in the focus groups indicated that there would be some pharmacists who would not be interested. This could have been due to social desirability bias i.e. that people wanted to be seen in a positive light or it could have been responder bias i.e. that only people who were interested in palliative care responded.

1159 beliefs were reported: with the majority of pharmacists rating their beliefs positively (75%). This suggests that that while pharmacists were aware of negative aspects of palliative care, the positives outweighed the negatives.

Pharmacists reported 955 emotions: 38% of emotions were negative (n = 360), 5% of their emotions neutral (n = 43), and 58% of their emotions were reported as positive (n = 552). The higher proportions of negative ratings for pharmacists’ emotions (compared with their beliefs) fits with the idea that working in palliative care can be a confronting experience on a personal level and that, coupled with a lack of understanding of what palliative care is, palliative care is associated with death and dying and having to broach topics many community pharmacists are not comfortable with.

The regression analysis showed that pharmacists’ overall attitudes were predicted by both their beliefs about providing services and supports for palliative care patients, and by their knowledge about palliative care. More specifically, the more positively pharmacists rated their beliefs, the more positive their overall attitude was, and similarly, the higher the pharmacists’ score on the knowledge test, the better their overall attitude towards palliative care. We argue that improving pharmacists’ knowledge and understanding of palliative care is likely to improve their overall attitudes towards providing services and supports for palliative care patients. These conclusions are consistent with Joranson and Gilson’s research on the influence of pharmacists’ knowledge of and attitudes to opioid pain medication. They concluded “the incorrect knowledge and inappropriate attitudes of some pharmacists could contribute to a failure to dispense valid prescriptions for opioid analgesics to patients in pain.” Further we suggest that palliative care education should focus on fostering positive beliefs about palliative care as a way to improve pharmacists’ attitudes.

**4.6 Conclusions**

These results support the broad initiative of enhancing the role of the community pharmacist in the provision of palliative care. Beliefs and knowledge predict and therefore underpin a positive attitude towards palliative care and the provision of services and supports for palliative care patients. As such, we looked at ways to challenge and modify beliefs and increase knowledge in the education package developed as part of this project.

The focus groups suggested strongly that pharmacists’ attitudes are extremely important in their involvement in the delivery of palliative care in the community – as such we need to work with this in any education modules and in professional development and training.
We found that community pharmacists’ attitudes are underpinned by beliefs and by knowledge. This is not the same in all areas. For example, attitudes towards the environment are underpinned by beliefs and emotions. As such challenging myths and increasing knowledge are essential.

Emotions were a lot more negative than beliefs. Even though emotions did not underpin attitudes – we need to support community pharmacists to have less fear and anxiety about palliative care. As part of the education tool we need to build in how to communicate appropriately with palliative care patients and families and how to elicit and respond to emotional cues. We also need to incorporate how community pharmacists' can 'protect' boundaries and maintain wellbeing. This will support patients and families, and also the community pharmacists.
5. Development of the Pharmacy Palliative Care Portal

5.1 Objectives
The Pharmacy Palliative Care Portal (online palliative care education package; PPCP) was developed with two primary objectives. Firstly, the portal would operate as a learning tool for pharmacists to improve their knowledge and practice when working with palliative care patients and their families. As such, the portal consists of four sections that address the various facets of holistic palliative care. There is an emphasis on medication use for patients with palliative care needs. Additionally, the Simulated Learning Space presents several authentic problem based simulations providing pharmacists with the opportunity to apply their knowledge and compare their assessment of a situation to that of an expert panel.

The second primary objective was to create a comprehensive resource that would operate as a ‘just-in-time’ information reference point to assist pharmacists with the immediate management of a patient or carer issue in the pharmacy. As an information reference point, the Pharmacy Palliative Care Portal has an intuitive global and topic level search tool that enables pharmacists to locate the information required quickly. The high level of detail provided for each section ensures a successful search result.

The goal has been to provide information relevant to pharmacists providing services and supports for palliative care patients without repeating more general information that is available elsewhere (for example, information available in the Australian Medicines Handbook).

5.2 Methodology

5.2.1 Design and Development of Content
Topics and issues for the education package were selected through a rigorous process which included (1) a comprehensive review of the literature and existing palliative care education materials, (2) speaking with pharmacists, nurses, GPs, carers and other interested parties about community pharmacist involvement in palliative care, about what should and should not be included in an education package and about how the package should work, (3) through an iterative consultation process with the experts on our project team, and (4) via feedback from the Expert Advisory Group.

The final result is an education package with four key sections each covering a range of salient topics and subtopics (see Appendix D for a full list of topics and subtopics). The four sections are:

Philosophy and Practice
This section covers the basic principles and practice of palliative care, patient characteristics and common diseases, and details of various support services.

Medication
This section addresses general issues encountered with the use of medications in palliative care, including administration techniques. It includes detailed information (for example, palliative care indications, dosage and access) about palliative care medicines listed in the WHO list of essential medications in palliative care; the PBS Palliative Care Schedule; the Therapeutic Guidelines for Palliative Care; the results from surveys in Australia and Germany about the essential medicines in palliative care, and the Department of Health WA Cancer and Palliative Care Network list of essential medications for pharmacists to stock. (Please note, all medicines from these sources were included with the exception of acetylsalicylic acid, dipyprone, sodium picosulphate, diphenhydramine and trazodone which are not available in Australia and nitrous oxide, methoxyflurane, and substance-P neurokinin-1 receptor antagonist which are not used in the community).
**Symptom Management**

This section addresses the basic principles of symptom control and provides details about the common symptoms experienced by patients with palliative care needs. For each symptom there is information regarding possible causes, criteria to assist the pharmacist to appropriately assess and treatment options.

**Interpersonal Skills**

This section covers effective communication strategies for working with palliative care patients and their families, information about how to cope with challenging interpersonal situations (a common request from pharmacists in the focus groups) and strategies for responding appropriately to emotional cues.

The sections are hyperlinked where appropriate to ensure seamless movement to further information about a topic.

After developing the topic outline, the executive team worked closely with the educational design team to create a detailed list of learning objectives for each part of the package. The team developed the objectives using Bloom’s taxonomy (of learning objectives). The final learning objectives provide a standard to test against to ensure the package meets its objectives as a learning tool and as well as a reference point. For a full list of learning objectives see Appendix E.

The executive team enlisted a group of expert writers to create the content for the package. Each writer was provided with templates of specific topic subheadings for the relevant sections. The majority of the medication and symptom management sections were written by a palliative care pharmacist, the interpersonal skills section was co-written by two psychologists, and the general information by a palliative care nurse and palliative care pharmacist. The process of writing included utilisation of evidence based information where available and their clinical expertise to further enhance the practicality and usability of the information. After each section draft was written, it underwent a rigorous review process, with feedback sought from between 3 and 7 expert reviewers for every section. The reviewers for each section comprised of a multidisciplinary team (membership varied but included: doctors, pharmacists, nurses, psychiatrist, psychologists, counsellors) with varying expertise in palliative care and education to ensure the content was comprehensive (See Appendix F for the list of contributors). The writers then revised the content in line with the reviewers’ feedback. The project executive team (Moyez Jiwa, Jeff Hughes and Moira O’Connor) gave their final approval on the written content and it was passed on to the instructional design team. They worked through the content to ensure it was appropriate for the internet and that it was written consistently throughout.

Some sections did not gain the executive team’s final approval after the first round of review and revision (e.g. lack of clarity, incomplete content, and style issues) and these sections were sent for a second round of review and revision until they met the team’s requirements.

**5.2.2 Design and Development of the Simulated Learning Space**

It was clear from the focus groups that many community pharmacists favour experiential learning. To include interactive learning in the portal, the Simulated Learning Space was developed. This part of the portal presents 12 simulated scenarios that require the pharmacist to draw on his or her knowledge to manage each situation and recommend a course of action.

Each scenario touches on key issues across the four different PPCP learning sections (demonstrating how the content of the education package is relevant to different situations) and emphasises the holistic approach involved in palliative care. The scenarios provide the pharmacists with an authentic task, encouraging them to test their skills at managing different situations that could arise in the pharmacy (many taken from examples given in the focus groups). The process assists the pharmacist to identify areas where their knowledge of palliative care is lacking. This is an important process since they may otherwise be unable to identify these gaps if they have not had experience of similar situations. For each scenario the pharmacist is provided with suggested linked learning sections of the portal to enhance their knowledge and learn about the different palliative care issues.
For each scenario, the learner watches a short video and the video stops at a point that requires a response from the pharmacist. The pharmacist is asked to identify the main issues and any peripheral issues presented, and to use the available resources to prioritise and formulate a response, and recommend a course of action. The pharmacist has the option of looking at the presenting prescription, the patient’s medication history, asking the patient or carer further questions, asking the doctor further questions and looking up more detailed information in the content of the resource. The question options were designed to include both relevant and irrelevant questions. After devising a plan to address the situation, the pharmacists can “consult the experts”. They can watch a video of an interdisciplinary team discussing the key issues and the best course of action. The pharmacist is then able to compare the experts’ responses to their own and determine which sections of the portal they may wish to refer to for further information.

For screen shots of the education package see Appendix G.

5.2.3 Pilot tests of the Pharmacy Palliative Care Portal

Usability Evaluation Technique

To evaluate a system’s usability, there are a number of different techniques that may be used. Nielsen and Molich suggest that there are four main ways to evaluate a user interface: “(1) formally by some analysis technique, (2) automatically by a computerized procedure, (3) empirically by experiments with test users, and (4) heuristically by simply looking at the interface and passing judgement according to personal opinion”.

Heuristic Evaluation is an inspection technique and is one of a selection of inspection techniques suggested by Nielsen. The other techniques are: Heuristic estimation, Cognitive walkthrough, Pluralistic walkthrough, Feature inspection, Consistency inspection, Standards inspection and Formal usability inspection. “Heuristic evaluation is the most informal method and involves having usability specialists judge whether each dialogue element follows established usability principles (the "heuristics")”. Heuristic evaluation does not necessarily require the interaction of a system to be executed; it can be used at almost any stage of the system development lifecycle. As such, a heuristic evaluation is generally easier to set up and conduct than some of the other formal techniques. Hence, a heuristic evaluation was selected as the most appropriate technique for reviewing the PPCP.

Determining the Number of Evaluators

In principle, individual evaluators can perform a heuristic evaluation of a user interface on their own but the experience from researchers indicates that poor results are achieved when relying on single evaluators. Experienced evaluators suggest that single evaluators found only 35 percent of the usability problems in the interfaces. However, because different evaluators tend to find different problems, it is possible to achieve substantially better performance by aggregating the evaluations from several evaluators. It is recommended to deploy about five evaluators, but certainly at least three.

Nielsen and Landauer present such a model based on the following prediction formula for the number of usability problems found in a heuristic evaluation.

Problems Found(\(\hat{N}\)) = \(N(1 - (1 - l)^i)\)

Problems Found(i) indicates the number of different usability problems found by aggregating reports from (i) independent evaluators, (N) indicates the total number of usability problems in the interface and (l) indicates the proportion of all usability problems found by a single evaluator.
Usability Heuristics

The general approach to conducting a heuristic analysis is to identify the heuristics or rules to test against and to walk through the software several times considering the aspects of each heuristic, and noting usability problems and potential solutions. This is considered a simple and rapid technique and is intended to be conducted by a usability expert at several points in the software development lifecycle.

Five evaluators were selected from a convenience sample of potential end users available locally. The evaluators were asked to view the program and complete the survey tool (shown below in Table 5.3.3.1) as adapted from an online resource to test educational modules. For each of the issues mentioned in the survey tool, the testers were asked to rate the usability using the notation shown in Table 5.2.3.1.

Table 5.2.3.1. The severity ratings suggested by Nielsen

<table>
<thead>
<tr>
<th>Score</th>
<th>Notation</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>I don't agree that this is a usability problem at all</td>
</tr>
<tr>
<td>1</td>
<td>Cosmetic problem only: need not be fixed unless extra time is available on project</td>
</tr>
<tr>
<td>2</td>
<td>Minor usability problem: fixing this should be given low priority</td>
</tr>
<tr>
<td>3</td>
<td>Major usability problem: important to fix, so should be given high priority</td>
</tr>
<tr>
<td>4</td>
<td>Usability catastrophe: imperative to fix this before product can be released</td>
</tr>
</tbody>
</table>

5.3 Results

For the evaluation of the PPCP, there were five evaluators available; one a usability expert with limited familiarity of the portal, three who were familiar with the portal, and one who was not an expert in the portal and had no familiarity with usability.

Nielsen explains that a heuristic evaluation consists of four phases: pre-evaluation training session, the actual evaluation, a debriefing session to discuss the outcome of the evaluation and a severity rating phase. For the evaluation of the PPCP, the approach was modified from that suggested by Nielsen and the phases were: (i) pre-evaluation familiarisation with the system, (ii) evaluation and (iii) debrief and design session.

The addition of possible design solutions at the end of the evaluation phase (ii) is not generally included in a heuristic evaluation. In this case, given the usability and user-centred design capability of Evaluator 1 and the time-frame required for this development iteration, this was included to speed up the iteration by adding the design activity into the debrief session (iii).

The evaluation took two hours. The PPCP was displayed on a 20 inch computer screen and the evaluators given a tour of the site. Questions were encouraged and evaluators were given the opportunity to explore the site following the presentation. The scores and evaluators comments were discussed with the usability expert and discussed with the site developer for further comments.
### Table 5.3.3.1. Assessors’ evaluation of Pharmacy Palliative Care Portal (PPCP)

<table>
<thead>
<tr>
<th>Topic</th>
<th>Assessor</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Site Design</strong></td>
<td></td>
</tr>
<tr>
<td>The site has a table of contents, which includes an explanation of why the content was organised in that way.</td>
<td>3 1 0 0 0</td>
</tr>
<tr>
<td>All pages are printable, and printed pages are accurate and complete.</td>
<td>0 1 0 0 0</td>
</tr>
<tr>
<td>Accommodation is made for users who turn off graphic information displays in their browser. Absence of graphics does not dilute the value of the information.</td>
<td>0 1 0 0 0</td>
</tr>
<tr>
<td>Page download times for the least sophisticated hardware/software configuration do not exceed 10 seconds.</td>
<td>2 0 0 2 0</td>
</tr>
<tr>
<td>Page backgrounds are white or pale pastel colours, with contrasting text colours and saturations.</td>
<td>0 0 0 0 0</td>
</tr>
<tr>
<td>Textured and patterned page backgrounds are used only when they do not interfere with the clear, legible, and usable display of information.</td>
<td>0 0 0 0 0</td>
</tr>
<tr>
<td>Screens take advantage of white space to guide the viewer’s eye through the display of information on the page.</td>
<td>0 1 0 0 0</td>
</tr>
<tr>
<td>Terminology is used consistently throughout the site.</td>
<td>0 0 0 0 0</td>
</tr>
<tr>
<td><strong>Navigation</strong></td>
<td></td>
</tr>
<tr>
<td>Site navigation is intuitive and allows for multiple modes of navigation.</td>
<td>0 1 0 0 0</td>
</tr>
<tr>
<td>All hyperlinks work correctly.</td>
<td>2 2 2 4 0</td>
</tr>
<tr>
<td>De facto standard colours are used for unvisited and visited links.</td>
<td>3 4 3 0 2</td>
</tr>
<tr>
<td>Navigation options are clear and consistent.</td>
<td>0 1 0 1 0</td>
</tr>
<tr>
<td>Hyperlinks are attached to a few key words or a meaningful phrase.</td>
<td>0 1 0 0 4</td>
</tr>
<tr>
<td>Links and URLs are unambiguous, clear, and specific, and are as brief as possible.</td>
<td>0 1 0 0 2</td>
</tr>
<tr>
<td>Backward links are provided so that learners can easily return to their starting place.</td>
<td>0 1 0 0 0</td>
</tr>
<tr>
<td><strong>Learning design</strong></td>
<td></td>
</tr>
<tr>
<td>Learning objectives are stated in observable, measurable terms.</td>
<td>3 2 3 3 0</td>
</tr>
<tr>
<td>The learning activities allow for multiple perspectives.</td>
<td>3 1 0 0 1</td>
</tr>
<tr>
<td>The learning activities are engaging and provide the user with the opportunity to articulate their knowledge.</td>
<td>0 1 0 0 1</td>
</tr>
<tr>
<td><strong>Content organization</strong></td>
<td></td>
</tr>
<tr>
<td>“Reference” or “More About” links are used for less important content.</td>
<td>0 1 1 0 0</td>
</tr>
<tr>
<td><strong>Sequencing</strong></td>
<td></td>
</tr>
<tr>
<td>Each page in a sequence clearly shows its place in the sequence.</td>
<td>0 0 0 0 0</td>
</tr>
<tr>
<td>Each page in a sequence allows navigation to other meaningful places in the sequence (e.g. start, end, previous, next).</td>
<td>3 1 0 0 0</td>
</tr>
<tr>
<td>Any hyperlink that takes the learner out of the instructional program is clearly labelled as such.</td>
<td>0 3 0 0 1</td>
</tr>
<tr>
<td>Each hyperlink is labelled clearly and consistently.</td>
<td>0 1 0 0 0</td>
</tr>
</tbody>
</table>
Each hyperlink uses wording that clearly identifies where it leads. 0 1 0 0 0

Graphics

Graphics occupy minimum screen space while retaining meaningfulness. 0 1 0 0 0
Each graphic serves an instructional or informational need. 0 1 0 0 1
Graphics file sizes are minimized. 0 1 0 0 0
Any animation or media serves an instructional or informational purpose that cannot be achieved more simply. 0 1 0 0 0

Text

Text blocks are written in minimalist style: compact, yet useful. 0 1 0 0 1
Fonts are restricted to two (or, at most, three) families per page. Sans serif fonts are recommended for headlines, serif for body text. 0 1 0 0 1
Fonts (style, colour, saturation) are easy to read in both on-screen and printed versions. 0 2 2 3 2
Line length is short enough that readers do not have to turn their heads side-to-side to read complete lines of text, even on very large monitors. 0 4 0 0 0
All text is grammatically correct. 0 0 0 0 0

5.4 Limitations
It was noted that some of the content to be used on the site was submitted late to the designer because of delays in obtaining feedback from the expert content reviewers. Therefore not all the material had been loaded on to the site at the time of the evaluation. The review of the site, submitted here is limited to what was available. Nonetheless, it was deemed that sufficient material was available to conduct the usability testing as defined by the methods deployed.

5.4.1 Evaluation of the educational capacity of the Pharmacy Palliative Care Portal
The portal was not been evaluated directly for educational capacity due to lack of time. However, the extensive review process of the written material included educational experts at every stage of preparation.

Since it is envisaged that the resource will be utilised in several ways, a comprehensive analysis of its various uses will take considerable time. As a comprehensive learning package it is anticipated (and designed in such a way) that pharmacists will work through the content at a pace that is convenient to them, and may take a couple of months to complete. Evaluation is therefore delayed. For the ‘just-in-time’ usage, the assessment of the educational benefits is reliant upon the pharmacist being presented with situations that necessitate usage in this way.

5.5 Discussion
The ratings shown in Table 5.3.3.1 were discussed with the site designer after the evaluation and his comments sought on changes that could be made to the final product from the usability perspective. Any issue that was regarded as being more than a minor usability problem was discussed in detail. Ten issues were discussed as shown in Table 5.5.1.
Table 5.5.1. Portal evaluation findings and designer comments and actions

<table>
<thead>
<tr>
<th>Issue Identified</th>
<th>Comment and action proposed</th>
</tr>
</thead>
<tbody>
<tr>
<td>The site has a table of contents, which includes an explanation of why the content was organised in that way.</td>
<td>The site uses the inbuilt wiki sitemap function. Topic areas are clearly titled and each area has a contents page. Each topic area also has a brief description of the content within that area. A clear users’ guide will be incorporated in the final version.</td>
</tr>
<tr>
<td>All hyperlinks work correctly.</td>
<td>All hyperlinks will be re-evaluated prior to the resource going ‘live’.</td>
</tr>
<tr>
<td>De facto standard colours are used for unvisited and visited links.</td>
<td>This was not considered necessary by the web designer. However this issue will be revisited by further testing before the site is ‘live’.</td>
</tr>
<tr>
<td>Hyperlinks are attached to a few key words or a meaningful phrase.</td>
<td>They are. (This was demonstrated to the assessors)</td>
</tr>
<tr>
<td>Learning objectives are stated in observable, measurable terms.</td>
<td>The simulated learning space is guided by the Authentic Learning theoretical framework. As such, the simulations represent real-world scenarios (complex, ill-defined problems, multiple sources of information) and allow for multiple perspectives. There are no right or wrong responses; however, the user has access to the perspectives of an expert panel by which they can compare their analysis and understanding of the presenting situation.</td>
</tr>
<tr>
<td>The learning activities allow for multiple perspectives.</td>
<td>The simulations require the learner to observe a scenario (presenting client), access additional information (e.g. client’s presenting prescription or medication history, as well as providing an opportunity to asked specific questions of the client and of the client’s GP) then identify the key issues and make action recommendations. The scenarios are designed to be immersive and interactive.</td>
</tr>
<tr>
<td>Each page in a sequence allows navigation to other meaningful places in the sequence (e.g. start, end, previous, next).</td>
<td>The site uses a wiki breadcrumb trail.</td>
</tr>
<tr>
<td>Any hyperlink that takes the learner out of the instructional program is clearly labelled as such.</td>
<td>It is clear.</td>
</tr>
<tr>
<td>Fonts (style, colour, saturation) are easy to read in both on-screen and printed versions.</td>
<td>The web designer will investigate the use of a larger font.</td>
</tr>
<tr>
<td>Line length is short enough that readers do not have to turn their heads side-to-side to read complete lines of text, even on very large monitors.</td>
<td>It is. This was agreed by the assessors.</td>
</tr>
</tbody>
</table>

5.5.1 Use of the Pharmacy Palliative Care Portal

The portal has potential for education of pharmacists in palliative care by various methods:

1. A comprehensive self-directed educational package

Pharmacists can embark on a self-directed learning experience using the information provided by the portal as the basis of their learning. The information is comprehensive, evidence based and practically
orientated to meet the specific needs of a pharmacist wishing to enhance their knowledge of palliative care.

2. A just-in-time resource
Palliative care is a growing area of health care provision and all pharmacists are going to be involved in the care of patients with palliative care needs. For those who do not need comprehensive knowledge, but require practical, timely advice for an individual patient it provides an easy to access resource.

3. Adjunct to formal undergraduate or postgraduate education
The portal can be used as a resource or as an adjunct to formal education. The usage is only limited by the inventiveness of the educator. For example, the educator may direct students to certain sections of the PPCP as pre-reading or preparation prior to lectures or tutorials. They may use the scenarios in a tutorial situation and build on the learning experience initiated by the video with further discussion or role play. They may direct the students to sections to compliment the material they presented.

5.5.2 Use of the Pharmacy Palliative Care Portal within the palliative care education framework
There are various excellent educational programs around Australia designed to educate health professionals in palliative care. These range from formal university based courses, to lectures provided by individual palliative care providers and computer based self directed learning packages. The PPCP is unique in that it addresses in detail the use of medications in palliative care. The portal is both evidence-based and experientially robust. Although designed with primarily the community pharmacist as the focus, this portal could be used across all health professional groups to enhance medication knowledge and use in palliative care.

5.6 Conclusions
The PPCP provides a unique resource and educational package with wide ranging applicability. It was designed with attention to the needs highlighted by pharmacists and other health professionals and written and reviewed extensively to provide a product that is practical and educational. The usability test for the PPCP revealed very few significant faults with the site. The site was deemed to be user friendly and the changes required to the online version were relatively minor.
6. Training Workshop for Palliative Care Medication Management Reviews

6.1 Objective
As a preliminary step to developing a model for pharmacists to conduct Palliative Care Medication Management Reviews (see Part 8, below), a two-day palliative care training workshop was developed for accredited pharmacists. The key objective of the workshop was to provide accredited pharmacists with a comprehensive overview of what palliative care is and how to work in palliative care. More specifically, the goal was that by the end of the workshop participants would have a sound awareness of the clinical and psychosocial needs of palliative care patients and a clear understanding of some of the most common and controversial issues in palliative care. Additionally, they would be familiar with a range of skills and strategies to work effectively in palliative care, and would have had some practice at conducting medication reviews for hypothetical palliative care scenarios.

6.2 Methodology

6.2.1 Participants
An email was sent to accredited pharmacists in Western Australia (via the State HMR facilitator). Altogether 20 pharmacists completed the workshop; 16 were from Perth, one was from Bunbury, one was from Albany and two were from Geraldton. Pharmacists were reimbursed $200 per day for attending the workshop. An additional Perth pharmacist withdrew from the workshop after the first day.

Of the 20 pharmacists who completed the workshop, there were 13 females and 7 males, aged between 25 and 66 years (M = 38.8 years, SD = 12.6). The pharmacists had been qualified for between 3 and 44 years (M = 16.2 years; SD = 13.3), and accredited for between 0 and 12 years (M = 5.4 years, SD = 4.0). On average the pharmacists reported having seen 2.2 palliative care patients over the previous 12 months, but the vast majority had not conducted any medication reviews for palliative care patients during that time. Half of the pharmacists had some personal experience with palliative care (for example, caring for a relative) and seven had completed some professional development in palliative care. None had any undergraduate training in palliative care. The pharmacists were employed in a range of different roles including working in a community pharmacy, working in a hospital pharmacy and conducting HMRs/RMMRs.

6.2.2 Workshop design
The majority of the workshop was designed and facilitated by Penny Tuffin, an expert consultant palliative care pharmacist. Ms Tuffin regularly conducts medication reviews for hospice based palliative care patients and is heavily involved in providing palliative care education. The workshop was designed around the key issues that might arise for accredited pharmacists conducting palliative care medication management reviews. For the complete workshop schedule see Appendix H. Each pharmacist was given a workshop manual that included the schedule, lecture slides, tutorial exercises, case studies, space for notes, relevant resources and documentation for the feasibility pilot study (see Appendix I).

The workshop began with an overview of the project and an introduction to the philosophy and goals of palliative care. It included practical tutorial sessions on converting opioid doses and on conducting practice medication reviews for different palliative care scenarios. The workshop also included sessions on medication administration and the use of complementary and alternate medicines. By popular decision, the scheduled presentation about terminal phase symptoms was omitted in favour of spending more time working on the practice medication reviews (the pharmacists were still given the written material about terminal phase symptoms).

One afternoon was dedicated to communication skills; this part of the workshop was facilitated by Dr Lisa Miller and Dr Derek Eng. After a discussion about communication, the accredited pharmacists
broke into two groups and worked with one of two actors in a communication role play. One actor took the role of a patient and the other the role of a carer, each with the basic scenario that the pharmacist was coming to their home to conduct a medication review. The two scenarios involved different issues and the pharmacists took turns to communicate with the actors and identify and work around the issues presented.

The workshop ended with a detailed explanation of the PCMMR feasibility pilot study and the pharmacists’ role in it.

6.2.3 Workshop evaluation

The success of the workshop was evaluated in two ways. Firstly, we examined pharmacists’ palliative care knowledge on a pre-test and again on a post-test. At the beginning of the workshop, participants were asked to complete a pre-test to examine their understanding of palliative care; the test had two parts. In Part 1 the pharmacists were presented with a series of 20 true and false statements about palliative care (similar to those used in the survey described in Section 5). For example, one statement read “Laxatives should be prescribed whenever opioids are to be used”. The pharmacists were asked to respond by reporting whether each statement was true, false or whether they were unsure. In Part 2 the pharmacists were asked to solve several practical problems (for example, converting opioid doses). At the end of the workshop, participants were asked to complete a similar post-test (see Appendix J for copies of the tests and marking schedules). We compared participants’ responses on the two tests to determine whether their knowledge and understanding of palliative care improved as a result of the workshop.

The success of the workshop was further evaluated by asking the participants to complete workshop evaluations, asking for their views about each part of the workshop (see Appendix K).

6.3 Results

6.3.1 Pre-Test and Post-Test Scores

Each pharmacist’s percentage score was calculated for each part of the test and their scores from pre-test to post-test compared. There was a misleading spelling error in one of the true/false statements in the post-test (“dossing” instead of “dozing” – read by a number of the pharmacists as “dosing”) so this statement was excluded from the analysis.

**Part 1: True and False statements**

As shown on Figure 6.3.1.1, pharmacists were significantly better at identifying the correct answers to the true and false statements on the post-test, suggesting that the workshop training improved pharmacists’ knowledge about palliative care. $M_{pre} = 73.2\%$, $SD = 11.8\%$; $M_{post} = 86.0\%$, $SD = 9.0\%$; $t(19) = 5.313$, $p < 0.001$. Additionally, the pharmacists were significantly less likely to select “unsure” as their answer on the post test, suggesting they also experienced an improvement in confidence $M_{pre} = 18.0\%$, $SD = 11.2\%$; $M_{post} = 7.6\%$, $SD = 6.3\%$; $t(19) = 4.04$, $p = 0.001$. 

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Tables 6.3.1.1 and 6.3.1.2 provide a detailed summary of the pharmacists’ responses to each of the true and false statements in the pre-test and the post-test. As mentioned above, one pharmacist withdrew from the workshop after the first day; as a result 21 pharmacists completed the pre-test but only 20 completed the post-test. Responses shaded in grey are correct.

Table 6.3.1.1. Pre-test responses for true and false statements

<table>
<thead>
<tr>
<th>True Statements</th>
<th>Pre-test</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative care is about treating symptoms and maximising quality of life</td>
<td>21</td>
<td>0</td>
</tr>
<tr>
<td>Palliative care involves a multidisciplinary team</td>
<td>21</td>
<td>0</td>
</tr>
<tr>
<td>Palliative care does not only consider the patient’s needs</td>
<td>17</td>
<td>4</td>
</tr>
<tr>
<td>One important aspect of palliative care is referral to appropriate specialist services</td>
<td>19</td>
<td>1</td>
</tr>
<tr>
<td>Professional boundaries with palliative care patients are less defined</td>
<td>9</td>
<td>3</td>
</tr>
<tr>
<td>Shortness of breath is a common symptom in palliative care patients</td>
<td>12</td>
<td>2</td>
</tr>
<tr>
<td>Laxatives should be prescribed whenever opioids are to be used</td>
<td>21</td>
<td>0</td>
</tr>
<tr>
<td>A patient’s appetite will change as they get closer to death</td>
<td>16</td>
<td>0</td>
</tr>
<tr>
<td>Sleep reversal is common in palliative care patients</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Chemotherapy is used in palliative care</td>
<td>10</td>
<td>7</td>
</tr>
<tr>
<td>The patient’s spiritual needs are an important component of palliative care</td>
<td>21</td>
<td>0</td>
</tr>
</tbody>
</table>
Pre-test

<table>
<thead>
<tr>
<th>False Statements</th>
<th>True</th>
<th>False</th>
<th>Unsure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative care is involved in only the last few days of life</td>
<td>0</td>
<td>21</td>
<td>0</td>
</tr>
<tr>
<td>Relatives should be encouraged not to inform the patient of their diagnosis</td>
<td>1</td>
<td>16</td>
<td>4</td>
</tr>
<tr>
<td>Depression is inevitable in palliative care patients</td>
<td>3</td>
<td>12</td>
<td>6</td>
</tr>
<tr>
<td>It is good practice to reserve opioids until the patient’s pain is severe</td>
<td>0</td>
<td>21</td>
<td>0</td>
</tr>
<tr>
<td>The risk of becoming addicted to morphine is high at doses &gt; 1g/day</td>
<td>2</td>
<td>12</td>
<td>7</td>
</tr>
<tr>
<td>A patient who is close to death and not drinking is at risk of dying of dehydration</td>
<td>8</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td>All patients will require sedatives in the terminal phase of their disease</td>
<td>1</td>
<td>12</td>
<td>8</td>
</tr>
<tr>
<td>You cannot prepare to give bad news</td>
<td>2</td>
<td>16</td>
<td>3</td>
</tr>
<tr>
<td>Admitting a patient to hospice to die is a failure of the community palliative care service</td>
<td>0</td>
<td>20</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 6.3.1.2. Post-test responses for true and false statements

<table>
<thead>
<tr>
<th>True Statements</th>
<th>True</th>
<th>False</th>
<th>Unsure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative care is about supporting patients to live as actively as possible</td>
<td>18</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Palliative care uses a team approach to address the needs of patients</td>
<td>20</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Respite palliative care services are available</td>
<td>19</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Professional boundaries with palliative care patients are less defined</td>
<td>16</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Oral thrush is a common symptom in palliative care patients</td>
<td>11</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>Oral morphine is the medication of choice for shortness of breath</td>
<td>19</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>If the morphine dosage is titrated for pain management, patients won’t become addicted</td>
<td>20</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Prophylactic use of laxatives in encouraged in patients taking opioids</td>
<td>20</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>A patient’s preference for food will change as they get closer to death</td>
<td>11</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Palliative care should be provided, if possible, in place of patient choice</td>
<td>12</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>The patient’s psychosocial needs are an important component of palliative care</td>
<td>20</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>False Statements</th>
<th>True</th>
<th>False</th>
<th>Unsure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative care is involved only in the last few days of life</td>
<td>0</td>
<td>20</td>
<td>0</td>
</tr>
<tr>
<td>Palliative care services do not have adequate resources to support the family and carers</td>
<td>0</td>
<td>19</td>
<td>1</td>
</tr>
<tr>
<td>GPs and generalist community services can adequately treat all palliative care patients’ needs</td>
<td>2</td>
<td>18</td>
<td>0</td>
</tr>
<tr>
<td>Palliative care patients are generally depressed</td>
<td>0</td>
<td>20</td>
<td>0</td>
</tr>
<tr>
<td>Palliative care patients in the terminal phase need parenteral hydration</td>
<td>2</td>
<td>12</td>
<td>6</td>
</tr>
<tr>
<td>All patients will require sedatives in the terminal phase of their disease</td>
<td>3</td>
<td>17</td>
<td>0</td>
</tr>
<tr>
<td>Pharmacists should recommend that palliative care patients avoid complementary and alternative medicines</td>
<td>1</td>
<td>17</td>
<td>2</td>
</tr>
<tr>
<td>You cannot prepare to give bad news</td>
<td>1</td>
<td>18</td>
<td>1</td>
</tr>
</tbody>
</table>
As Figure 6.3.1.2 shows, the pharmacists also experienced a substantial and significant improvement on Part 2 of the post-test, further demonstrating that the workshop training was effective in improving knowledge and understanding of palliative care, $M_{\text{pre}} = 31.7\%$, $SD = 12.9\%$; $M_{\text{post}} = 54.4\%$, $SD = 10.8\%$; $t(19) = 7.23$, $p < 0.001$.

![Figure 6.3.1.2. Correct Responses on Part 2 of the Pre-test and Post-test](image)

Although these scores seem low, it is important to note that most pharmacists did not have the usual resources available during the test that they would in real life. In fact, many of the marks lost were on questions regarding dose ranges, and unless the numbers given were a perfect match to the marking guide, no marks were given. Dose range information accounted for 30% of the marks on Part 2 of the pre-test and 36% of the marks on Part 2 of the post-test. In retrospect, it was not expected that pharmacists would know this information without checking and this information would be easily sourced outside of the workshop setting (for example in the Therapeutic Guidelines for Palliative Care). As such, these questions may have unfairly deflated their scores on Part 2 of the test.

Taken together, the results show that pharmacists’ scores improved significantly from the pre-test to the post-test, demonstrating that the two-day palliative care training workshop achieved its intended goal of improving pharmacists’ knowledge and understanding of palliative care. To assess what the pharmacists thought of the workshop they were asked to complete an evaluation questionnaire at the end of the workshop.

### 6.3.2 Workshop Evaluations

There were five parts to the evaluation form (see Appendix K). Firstly, the pharmacists were asked to rate how much they agreed with each of six statements about the workshop. For example, one statement read, “This workshop has increased my understanding of palliative care”. The pharmacists rated the statements using 5-point Likert scales ranging from 1, “strongly disagree”, to 5, “strongly agree”, where 3 was “neutral”.

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Secondly, the pharmacists were asked to answer 3 open-ended questions, reporting how the workshop compared to their expectations, three things they liked about the workshop and three things they would change. Thirdly, the pharmacists rated the importance of each of the sections of the workshop using 5-point Likert scales which ranged from 1, “not at all important”, to 5, “very important”, where 3 was “neutral”. Fourthly, the pharmacists rated the presentation of each of the different sections of the workshop, using 5-point Likert scales ranging from 1, “not at all clear”, to 5, “very clear”, where 3 was “neutral”. Finally the pharmacists were given space to record any further comments about the workshop.

The pharmacists’ responses to each of the evaluation statements are shown in Table 6.3.2.1. The mean responses were all on the positive side of the scale but they do show the need for further refinement.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Mean (SD)</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. This workshop has increased my understanding of palliative care</td>
<td>4.75 (0.91)</td>
<td>1 – 5</td>
</tr>
<tr>
<td>2. I feel more confident in my ability to provide care for palliative patients</td>
<td>4.15 (0.81)</td>
<td>2 – 5</td>
</tr>
<tr>
<td>3. This workshop has improved my ability to solve drug related palliative care problems</td>
<td>4.05 (0.76)</td>
<td>2 – 5</td>
</tr>
<tr>
<td>4. I feel prepared to conduct HMRs for palliative care patients</td>
<td>3.85 (0.81)</td>
<td>2 – 5</td>
</tr>
<tr>
<td>5. I understand my role in the palliative care team</td>
<td>4.05 (0.76)</td>
<td>2 – 5</td>
</tr>
<tr>
<td>6. I feel confident in my ability to communicate with palliative care patients and their carers</td>
<td>3.90 (0.79)</td>
<td>2 – 5</td>
</tr>
</tbody>
</table>

Note: 1 = strongly disagree, 3 = neutral, 5 = strongly agree

The pharmacists’ ratings of the importance and presentation of the different workshop sessions were also analysed. These data are displayed in Table 6.3.2.2. As the table shows, the pharmacists rated all sessions as being important and they gave the highest ratings to the practical sessions. They also rated all sessions as being clear. Taken together these results suggest that the pharmacists were satisfied with the workshop.

<table>
<thead>
<tr>
<th>Workshop sessions</th>
<th>Importance</th>
<th>Presentation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Presentation: Palliative care introduction</td>
<td>4.25 (0.55)</td>
<td>4.70 (0.47)</td>
</tr>
<tr>
<td>Practical: Opioid conversions</td>
<td>4.75 (0.44)</td>
<td>4.65 (0.49)</td>
</tr>
<tr>
<td>Practical: Medication review case studies</td>
<td>4.90 (0.31)</td>
<td>4.70 (0.47)</td>
</tr>
<tr>
<td>Presentation: Communication</td>
<td>4.75 (0.55)</td>
<td>4.70 (0.47)</td>
</tr>
<tr>
<td>Practical: Communication role play</td>
<td>4.70 (0.47)</td>
<td>4.70 (0.47)</td>
</tr>
<tr>
<td>Presentation: Medication administration</td>
<td>4.40 (0.50)</td>
<td>4.60 (0.50)</td>
</tr>
<tr>
<td>Presentation: Complementary and Alternative Medicines</td>
<td>4.10 (0.64)</td>
<td>4.50 (0.61)</td>
</tr>
</tbody>
</table>

Note: For importance ratings scale ranged from 1 – not at all important to 5 – very important; for presentation ratings scale ranged from 1 – not at all clear to 5 – very clear.
The pharmacists were typically very positive about the workshop in the open ended questions. When comparing the workshop with their expectations, all comments were very positive with the exception of one; this pharmacist reported that the workshop was “confronting”. Other comments included, “better than I could have possibly expected”, “excellent, informative”, and “a very good rehash and update”. The pharmacists’ reports of three things they liked about the workshop were also very positive and the most common suggestion for improvement was to extend the length of the workshop (For a full list of comments and suggestions, see Appendix L).

6.4 Limitations
There were two minor problems with the workshop tests. Firstly, there was a misleading spelling error in one of the true/false statements in the post test (“dossing” instead of “dozing” – read by a number of the pharmacists as “dosing”). This statement was excluded from the analysis. Secondly, the pharmacists did not have access to the resources they would typically have on hand during the test (for example the Therapeutic Guidelines for Palliative Care) and as such the substantial proportion of the test questions regarding dose ranges were very difficult to answer correctly. These questions accounted for 30% of the marks on Part 2 of the pre-test and 36% of the marks on Part 2 of the post-test. In retrospect, we would not expect pharmacists to know this information without checking, and this is information that would be easily sourced outside of the workshop setting, so these questions may have unfairly deflated their scores on Part 2 of the test.

6.5 Discussion and Conclusions
Considered as a whole, the pharmacists’ workshop evaluations and improvements in their post-test scores suggest that the workshop was successful at improving pharmacists’ knowledge and understanding of palliative care and in preparing the pharmacists to conduct medication reviews for palliative care patients.
7. Palliative Care Medication Management Review (PCMMR) Feasibility Trial

7.1 Objective
The major objective of the PCMMR feasibility trial was to develop a protocol for accredited pharmacists to conduct medication management reviews tailored specifically to the needs of palliative care patients and to evaluate the feasibility and efficacy of this protocol.

7.2 Methodology
The study consisted of two stages:
- Stage 1: Recruitment and training of the accredited pharmacists (Section 6)
- Stage 2: PCMMR Feasibility Trial

Stage 2: PCMMR Feasibility Trial
Of the 20 pharmacists who completed the two-day palliative care training workshop (see Section 6 above), 18 took part in the pilot study (two pharmacists from Geraldton who were trained were not able to take part because the trial did not run in Geraldton). The trial was conducted in metropolitan Perth and in the Albany and Bunbury regions. The team worked with the clinical nurses at home hospice services in these locations.

Figure 7.2.1 displays the procedure for the trial. The clinical nurses identified eligible patients and completed a palliative care medication management review referral form (see Appendix M). To be eligible for the trial patients had to have been (1) receiving palliative care, (2) using five or more medications and (3) be able to give informed consent to participate.

![Model protocol adopted for palliative care medication management review feasibility trial.](image)

*In locations with no hospice GP, the patient's GP will fill this role.*
The nurse's referral was authorised by the hospice GP (or when there was no hospice GP, by the patient's GP), and forwarded to the project manager. The project manager engaged a suitable accredited pharmacist (based on location and time availability) to conduct the review and passed the referral on. Each of the trained accredited pharmacists could receive up to 10 referrals during the course of the trial. A copy of the referral form was also sent to the patient’s GP (if not the person who had authorised the review) and community pharmacist for reference (as members of the patient’s palliative care team) and to request basic medication records (e.g. prescription history) for the accredited pharmacist to conduct the review.

Initially, the accredited pharmacist accompanied the hospice nurse during one of the nurse’s regular visits to the patient’s home to conduct the review. This was done so that the nurse, a person with established rapport with the patient and their carers, could introduce the pharmacist. However, it became clear that it was very difficult for the nurses to coordinate their home-visits with the pharmacists and it got in the way of the nurse’s need for flexibility. This created degree of reluctance amongst the nurses to refer patients to the trial. Therefore, the protocol was changed so that instead of arranging to join the nurse on a home visit, the pharmacist simply contacted the nurse for any necessary information, and then contacted the patient or carer directly to organize the visit for the review. The pharmacist then visited the patient’s home and conducted the review. The pharmacist gave the patient a copy of the patient evaluation form to gather the patient’s views of the PCMMR (full description below; see Appendix N) and a reply-paid envelope to return the form directly to the researchers. To decrease any social pressure the patients may have felt to give positive responses, the evaluation form was completely anonymous and was not linked to the reviewing pharmacist in any way.

After the review, the accredited pharmacist wrote a report detailing their findings and recommendations, and forwarded the report to the referring GP and the project team. The project team sent copies of the report to the rest of the palliative care team.

Post the review, the pharmacists also kept a diary of their ongoing contact with each patient (See template in Appendix O). This contact could be initiated by the patient or their carers, the nurse, the GP, the community pharmacist, the accredited pharmacist or any other person engaged in the care of the patient. The accredited pharmacist documented reason for each contact and any recommendations made. The follow-up period continued for a minimum of 4 weeks beyond the initial review (maximum 3 months).

At the end of the follow-up period, a sample of the people involved in the feasibility trial (patients, carers, clinical nurses, hospice GPs, GPs, community pharmacists and accredited pharmacists) were contacted and invited to take part in follow-up exit interviews about their experiences of the PCMMR (see Appendix P for schedule of interview questions). Participants were given a $30 Coles-Myer voucher to thank them for their time.

Pharmacists delivering a PCMMR were remunerated at the standard rate for conducting a home medicines review (HMR) for the initial review. At the completion of the follow-up period they were remunerated for the time spent beyond the initial review at a rate equivalent to conducting a second HMR. The referring GPs were remunerated at the standard rate for participating in a HMR.

### 7.3 Results

#### 7.3.1 Referrals

Altogether 48 PCMMR referrals were received; 36 were from Perth, six were from Bunbury and six were from Albany. The patients ranged in age from 8 years to 85 years ($M = 65.7$ years, $SD = 14.5$). According to the referral forms (Appendix M), the patients reviewed were experiencing between 0 and 7 of the common palliative care symptoms listed ($M = 2.3$, $SD = 1.8$) at the time of referral, with the majority (65%) experiencing multiple symptoms. Table 7.3.1.1 displays the number of patients who experienced each of the symptoms included.
Table 7.3.1.1. Number of patients who experienced each of the symptoms listed on the referral form.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Patients Experiencing Symptom</th>
<th>n</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficulty sleeping</td>
<td></td>
<td>8</td>
<td>17%</td>
</tr>
<tr>
<td>Delirium/Confusion</td>
<td></td>
<td>2</td>
<td>4%</td>
</tr>
<tr>
<td>Vomiting</td>
<td></td>
<td>4</td>
<td>8%</td>
</tr>
<tr>
<td>Breathing problems</td>
<td></td>
<td>15</td>
<td>31%</td>
</tr>
<tr>
<td>Fatigue/Lethargy</td>
<td></td>
<td>24</td>
<td>50%</td>
</tr>
<tr>
<td>Bowel problems</td>
<td></td>
<td>13</td>
<td>27%</td>
</tr>
<tr>
<td>Appetite problems</td>
<td></td>
<td>11</td>
<td>23%</td>
</tr>
<tr>
<td>Nausea</td>
<td></td>
<td>6</td>
<td>13%</td>
</tr>
<tr>
<td>Pain</td>
<td></td>
<td>24</td>
<td>50%</td>
</tr>
</tbody>
</table>

7.3.2 Medication reviews

Three patients died before their PCMMR could be scheduled, two patients withdrew from the study prior to their review due to deterioration in their health and a further two withdrew before their review without stating a reason. Another one referral did not provide sufficient information, leaving a total sample of 40 patients who completed the trial.

Pharmacists were contacted based on the match between the patient’s and the pharmacist’s location and availability. Of the 18 eligible accredited pharmacists, only 13 conducted PCMMRs. A further two received referrals but the patients withdrew prior to the review. The remaining three pharmacists did not receive (or accept) any referrals. The 13 pharmacists who did conduct reviews, conducted between one and nine each \(M = 3.1, SD = 2.3\). One pharmacist withdrew from the study after conducting one review due to feeling inadequately prepared. The case reviewed by this pharmacist was later assessed as requiring specialist palliative care input, and outside the expertise of an accredited pharmacist with limited experience in the area.

The trial was designed to ensure rapid delivery of the PCMMR service given the perceived immediate needs of palliative care patients. Unfortunately, this did not eventuate. It took between 2 and 30 days from the time the patient signed the consent form for the referral to be completed, the review conducted and the pharmacist to send their report to the referring doctor \(M = 10.6\) \(SD = 6.0\). A number of reviews were delayed because the patient’s health deteriorated and the review was put off until their health improved again. However, there were also delays due to the time taken for the referral form to be completed and signed off by the doctor, the time taken to find a pharmacist to conduct the review and due to the time taken for the pharmacist to schedule a suitable appointment with the patient.

Typically the medication lists provided on the pharmacists reports were longer than those provided on the referrals, \(M_{\text{referral}} = 10.5\) medications \(SD = 2.8\), \(M_{\text{report}} = 11.4\) medications, \(SD = 3.6\). Although this is a small difference it was statistically significant, \(t(38) = 2.11, p = 0.04\), suggesting that the PCMMR reports consistently included additional medications that the referrer was not aware of. Additionally, many of the PCMMR reports listed medications that were prescribed but no longer being used \(M = 1.7\) medications, \(SD = 1.7\), \(Range = 0 – 7\) and often these redundant medicines had been included on the referral list of current medications. This supports the idea that pharmacists can play an important role in assessing exactly what medications are being used.
7.3.3 Pharmacists’ recommendations

For the 40 patients for whom a PCMMR was completed the pharmacists provided between zero and nine recommendations/issues per patient in their reports to the doctor ($M = 3.6$, $SD = 2.0$). In total, they made 145 recommendations.

These reports were sent to experts on the project team to rate their clinical significance. The raters were A = pharmacist, B = pharmacist, C = GP, D = pharmacist and E = pharmacist and F = GP. For each report, the experts were asked to consider clinical significance of each of the individual recommendations in the report and the overall clinical significance of the report. The rating was based on a 7-point scale ranging from -3, “negative,” to 3, “positive.” They were also asked to provide explanations of their ratings if they felt it was appropriate.

A final rating was calculated for each report and each recommendation by taking the mean of the experts’ ratings for each part. As shown on Figure 7.3.3.1, the majority of the ratings for the overall reports were positive, with only one (of 40) rated as negative and two rated as neutral. The overall mean ratings ranged between -0.50 and 2.50 ($M = 1.25$, $SD = 0.68$). One rater (pharmacist) commented that although the recommendations made were generally good, based on the available information a number of reports omitted potential problems and this brought had brought the reviewer’s the overall ratings of the reports down.

Figure 7.3.3.1 Percentage of Positive, Neutral and Negative Mean Ratings for Pharmacists’ Reports
The mean ratings for the individual recommendations ranged between -1.0 and 2.7, \((M = 1.2, SD = 0.69)\). As Figure 7.3.3.2 shows, the vast majority of the mean ratings were positive; two were negative and six were neutral.

Although the combined ratings of the reports were typically positive, there was a lack of consistency between the individual raters. For instance, one recommendation was rated -2 by one expert and 3 by two others. To generate a rough estimate of how similar the experts' ratings were, we calculated correlations between each of the raters. We found three significant correlations. Firstly, rater E and A gave the most similar ratings \(r = 0.46, p < 0.05\); rater A's ratings were also correlated with rater B's ratings although to a lesser degree, \(r = 0.24, p < 0.05\), and finally rater B's ratings were correlated with rater F's ratings, \(r = 0.41, p < 0.05\). This suggests that the raters' different experience and roles were leading them to evaluate the reports and recommendations in different ways. For example, while some of the experts may have rated the “overall clinical significance” in terms of what recommendations were made and what was missed out, others may have rated in terms of whether the suggestions made would be useful to the doctor, or whether the changes would make a difference for the patient. These differences highlight that there are multiple outcomes from an HMR, and a number of different ways of examining effectiveness. These ideas are discussed more fully in Section 7.3.6 below.

**7.3.4 Pharmacists' interaction records**

There was much less contact following the PCMMR than first anticipated. Only three pharmacists returned diaries with patient interactions recorded in them at the end of the study, with the majority reporting that they didn’t use the diaries. Two pharmacists recorded details of the review in their diaries but because this information was not about follow-up contact, it was not included in the analyses.

During the follow-up period (i.e. after the initial HMR), pharmacists report a total of 17 patient interactions involving 13 different patients. These interactions took between 1 minute and 15 minutes \((M = 6.3 \text{ minutes}, SD = 4.7)\).
Eight interactions were initiated by the accredited pharmacists (47%) and these were typically to check-up on the patient following the review or to provide additional information that was requested during the review. Seven interactions were initiated by the doctor (41%) who discussed the report and recommendations with the pharmacist. Two interactions were initiated by carers who asked questions of the pharmacist. Two of these interactions resulted in a change in medication (in both cases increasing the dose of pain medication for pain that was not well controlled), but otherwise the follow-up contact was mainly focused on sharing or requesting information.

It was envisaged following the initial HMR that the accredited pharmacist would act as a resource for the patients and their carers and other members of the palliative care team. As such this would result in a number of patients would requiring further interaction with the accredited pharmacist during the follow-up period post-review given the frequently changing needs of palliative care patients. To cover the time required to cover these interactions during the follow-up period remuneration for this post-review contact was set at the cost of a follow-up review to ensure adequate remuneration for the pharmacists’ time. In light of the low level of contact during the follow-up period, and the variable time commitment, both of which may be a reflection of novelty of the new service, the appropriate level of remuneration for the follow-up component of the PCMMR still needs to be determined.

7.3.5 Patient evaluations of PCMMR

The forms for patients’ evaluations of the medication reviews had two parts (see Appendix N). First, the patients were presented with seven statements about the medication review. For example, one statement read, “I feel more comfortable about taking my medications”. For each statement the patient rated how much he or she agreed (or disagreed) using a 5-point Likert scale ranging from 1 “strongly disagree”, to 5, “strongly agree”, where 3 was “neutral”. In the second part of the evaluation, patients were asked to provide comments about the review.

Twenty five evaluations were been returned (of 40, 62.5%). Table 7.3.5.1 shows the patients responses to each of the seven statements. In short, the patients were generally very positive about the medication review with the mean responses falling between “agree” and “strongly agree” on the rating scale.

Table 7.3.5.1. Patients’ ratings of evaluation statements

<table>
<thead>
<tr>
<th>Statement</th>
<th>Mean (SD)</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The pharmacist provided me with information about my medications</td>
<td>4.36 (0.86)</td>
<td>1 – 5</td>
</tr>
<tr>
<td>2. I was able to ask the pharmacist questions about my medications.</td>
<td>4.72 (0.46)</td>
<td>4 – 5</td>
</tr>
<tr>
<td>3. The pharmacist helped me to understand my medications better.</td>
<td>4.36 (0.91)</td>
<td>1 – 5</td>
</tr>
<tr>
<td>4. I feel more able to manage my medications.</td>
<td>4.20 (0.87)</td>
<td>1 – 5</td>
</tr>
<tr>
<td>5. I feel more comfortable taking my medications.</td>
<td>4.16 (1.03)</td>
<td>1 – 5</td>
</tr>
<tr>
<td>6. I felt comfortable talking to the pharmacist.</td>
<td>4.80 (0.41)</td>
<td>4 – 5</td>
</tr>
<tr>
<td>7. I would contact the pharmacist again to ask questions about my medication if I needed to.</td>
<td>4.64 (0.49)</td>
<td>4 – 5</td>
</tr>
</tbody>
</table>

The small ranges for statement 2, statement 6 and statement 7 highlight that all patients felt comfortable talking to the pharmacist, able to ask questions of the pharmacist and willing to contact the pharmacist in the future if need be. For the remaining statements, some of the lower responses came with comments from patients emphasizing that they felt they already understood their medications; these ratings may have been more a reflection that some patients were already very well informed rather than a reflection of unsatisfactory input from the pharmacist, as suggested by all the average score being greater than 4.
The final question on the evaluation asked patients whether they had any comments about the review. Of the 25 responses received, 18 provided comments (72%). The comments were coded into one of five pre-determined categories: (1) positive, (2) neutral, (3) negative, (4) providing information, or (5) making a suggestion for improvement. In total, 15 comments (83%) were coded as positive. For example, one comment read “It was very comforting to someone actually sit down with me and go through my meds.” One comment was coded as providing information, as it simply provided a description of the outcome of the review and doctor’s subsequent intervention. One comment was a suggestion, “It would have been helpful to receive a post meeting letter reviewing the meeting and advising of further steps/options”. The final comment was coded as neutral. This comment read, “We don’t have any issues with our medications. We have been on the same ones for 15 months. We know if we have a problem we can contact a pharmacist.”

In summary, the medication reviews generally seemed to be a positive experience for patients and for the majority left patients feeling more informed and better able to manage their medications.

### 7.3.6 Exit interviews

In-depth, semi-structured qualitative interviews were conducted at the end of the PCMMR feasibility trial in order to obtain feedback from the key participants. Interviews were either conducted face to face or by telephone. The key questions were: “How has the process worked for you?”; “How satisfied were you with the process?”; “What benefits do you see?”; and “What problems?”. For patients: “Were your needs met?”; For health professionals: “Were patient needs met?”; “Were there any clinical improvements for the patients?”; and “How effective was your collaboration with other health care professionals?” (See Appendix P for full interview schedule). Participants included: accredited pharmacists, palliative care nurses, referring GPs, patients and carers, the project manager, and the palliative care specialist pharmacist. Table 7.3.6.1 shows the number of interviews for each stakeholder group.

<table>
<thead>
<tr>
<th>Group</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accredited Pharmacists</td>
<td>16</td>
</tr>
<tr>
<td>Palliative Care Nurses</td>
<td>15</td>
</tr>
<tr>
<td>Referring GPs</td>
<td>6</td>
</tr>
<tr>
<td>Patients/Carers</td>
<td>5</td>
</tr>
<tr>
<td>Project manager</td>
<td>1</td>
</tr>
<tr>
<td>Palliative care specialist pharmacist</td>
<td>1</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>43</strong></td>
</tr>
</tbody>
</table>

### 7.3.6.1 Analysis

The exit interview subgroup developed an analysis framework that was centred on the key interview questions, but provided flexibility to accommodate additional and emerging themes. Notes were taken during and after each interview and these were analysed using thematic content analysis. Rigor within the interview and analysis processes was optimized via a number of processes recommended for qualitative researchers including; interviewing multiple participants, having a clear audit trail and conducting each stage of the research in an experienced, interdisciplinary team.55
7.3.6.2 General Overview

We present a general overview of our findings regarding the PCMMR feasibility trial below. Three general themes emerged from the analysis: satisfaction and benefits of the PCMMR feasibility trial; problems with the PCMMR feasibility trial; and collaboration between team members. There is some overlap between these themes but they are presented separately for ease of interpretation.

Theme 1. Satisfaction with and benefits of the PCMMR feasibility trial

Accredited pharmacists

Accredited pharmacists reported that the PCMMR feasibility trial was a success and the majority felt they had made a difference. They felt most positively about their role in the PCMMR service when they had changed or modified medications or found a potential interaction; i.e. when they were impacting on patient care. There were many recommendations for adding, discontinuing or reviewing medications; however, there were also many smaller changes to regimens that would have impacted on quality of life, a major aspect of palliative care. Examples included: Changing a child’s medications from wafers to tablets. The child was not keen on wafers so the parent was dissolving them in water. This change to tablets increased compliance. Advising a patient to take medication at night rather than first thing in the morning as the medication was causing (or exacerbating) tiredness. After two weeks the patient reported feeling ‘as bright as a button’. A carer was sprinkling capsule contents on ice cream as the patient could not swallow; the pharmacist recommended giving liquid medication. One pharmacist reported giving simple advice to a patient about lollies to keep the patient’s mouth moist and improve taste.

The key roles outlined by accredited pharmacists were: providing recommendations to review or change medications; patient or carer education; ensuring that the patient or carer was comfortable with the medication regimen; conducting literature searches about medications, particularly for complementary and alternative medicines (CAMS); and ensuring greater compliance and adherence. The pharmacists reported that they found the role satisfying and they saw a place for PCMMRs. A few pharmacists stated that they preferred the referrals for a PCMMR when the patient was just starting palliative care as they felt they this would be more beneficial, rather than when patients were in the terminal stage.

Most of the accredited pharmacists believed that the patients were extremely well looked after but they could provide an in-depth look at one aspect of treatment. In essence they felt they could value-add to the service.

When feedback was received from GPs or patients it was excellent but often no feedback was given. Some pharmacists followed up with patients, particularly when the pharmacist had done a search for a patient or when they wanted to know about the impact of a suggested change, others left cards and instructions that they could be contacted post-review. Anticipated concerns about the time needed for the deliver the PCMMR service, including follow-up, were unfounded. The average time for the PCMMR was not much more than a usual HMR. Follow-up varied but was usually conducted via telephone rather than through a second medication review.

The pharmacists found the training workshop extremely valuable and most felt prepared for seeing palliative care patients.

Palliative care nurses

The nurses felt the PCMMR feasibility trial was beneficial to both patients and nurses. Most found the process easy and straightforward. The following quote from one nurse reflected what most nurses felt about the PCMMR process: “It’s as easy as ABC, 123. As nurses we’re asked to do lots, but this one was simple. Importantly, you could see an outcome quickly and the outcome for the patient was tangible and clearly evident – medications that matched needs”.

The nurses reported that many recommendations were made that improved clinical outcomes for patients. Even when no changes were recommended they felt it was reassuring to know that nothing was being missed. The nurses reported that patients and carers found the process positive,
especially as the pharmacist had the time to talk to patients and come up with solutions to issues, and could also carry out research for patients, for example on CAMS.

One nurse stated that: “For palliative care patients, their life is about drugs and their side effects: constipation, dry mouth etc. So the patient could ask a third person do I really need this medication? Is there anything I can do?" The fact that the PCMMR was conducted in the patient’s home was also seen as a positive for nurses.

In terms of benefits for the nurses, the idea of “another pair of ears and eyes" emerged strongly. The nurses acknowledged that palliative care is a complex area and that having a specifically trained professional with specific medication knowledge doing a review of medication was reassuring. The nurses also stated that they learned from the process. In short, many of the nurses felt that the pharmacists supported and complimented their role.

The nurses reported that the pharmacists were professional with good communication skills and, importantly, most conducted the PCMMRs in a timely manner. Many wanted to see the service permanently established.

**Referring GPs**

Referring GPs acknowledged that they cannot do everything and, as such, found the PCMMR process beneficial and helpful for them and their patients. One referring GP stated that: “It was very helpful. [The pharmacists] pointed out a couple of things I had not specifically thought of that prompted me or reminded me". Information on side effects, potential interactions and CAMS was found to be helpful (and often of interest) to GPs.

The GPs’ comments mirrored the nurses’ statements that it was helpful to patients and carers to have an experienced professional giving close attention to aspects of the medications. One GP also thought it was helpful to patients to feel ‘heard’ regarding their concerns and issues regarding medications. The GPs thought the timely manner in which the PCMMRs were conducted was very satisfactory.

**Patients and carers**

The process worked well for patients and carers who liked the fact that the nurse made the referral and spoke to them about the process in the first instance. Most patients and carers thought the PCMMR was excellent and considered that the pharmacist had made a difference. One interviewer recorded that: "The review was very beneficial for the patient – his medications were reviewed and changed somewhat and now he follows a new routine and he is travelling along well. He attributes this to the changes in medication made. So he was really positive about the support". Another carer said that they had little idea of what medications the patient (her husband) was on and why. They were, therefore, pleased to get the PCMMR as the pharmacist explained the medication in language they could understand. Some patients and carers were pleased to talk to another health professional, especially one who could give detailed input into their care. The terms; ‘extra support’ and ‘comforting’ were used by patients and carers.

Carers also found the pharmacists friendly and approachable and appreciated that the PCMMRs were done in a timely manner.

**Project manager**

The project manager received feedback from many people involved in the PCMMR feasibility trial with many people indicating that it was a valuable process. Pharmacists indicated that they felt they were making a difference. Patients also gave very positive feedback.

**Palliative care specialist pharmacist**

The palliative care specialist pharmacist reported that some recommendations were good and a few excellent and some reports/letters were of a good standard. The accredited pharmacists also used their general pharmacy skills well in most reviews with an explanation of medications and administration alternatives and many were able to contribute to care of the patients.
Theme 2. Problems

Accredited pharmacists

The accredited pharmacists reported a range of administrative issues such as trying to contact the nurses to get contact details for the patient. This process was usually smooth but when problems arose the pharmacists found it very frustrating and delays were inevitable. There was also some confusion at times about where to send the report.

A further frustration was that there was no space on the form for information on diagnosis, no medication list provided and no laboratory results. The pharmacist had to rely on the patient or the nurse for this information and often had to give more than one recommendation as the recommendations could potentially change depending on the diagnosis/history.

Some pharmacists felt that more training (top up training) was needed on specific medications and some were not very confident and relied on the workshop facilitator to give suggestions or reassurance. One pharmacist did not feel he could add anything extra to the existing expertise in the team.

As stated above, the accredited pharmacists preferred to make changes to the medication regimens and felt, at times, that their involvement had minimal impact.

Palliative care nurses

Some of the palliative care nurses reported issues with the PCMMR feasibility trial – mainly related to the time taken to complete the paperwork. Most felt this was an easy task but some indicated that they found this onerous. One nurse stated: “Most nurses were happy to refer, but others point blankly refused because they didn’t want to do any extra paperwork”.

A few nurses mentioned communication problems; mainly that they did not know much about the PCMMR feasibility trial and how it would benefit patients in that the process was not explained fully.

Some nurses also found the information sheet too detailed and would have preferred a very brief summary. The timing of reports was usually prompt but when they were late it caused frustration. A few changes were implemented and this caused some initial confusion.

One nurse was disappointed that the pharmacist could not answer all the questions asked, particularly about what was available on the PBS, and one nurse mentioned that they (the nurses) did all the work for the referral and the GP was paid for his/her signature. One nurse felt that the pharmacist did not understand the balance between side effects and quality of life left for some palliative care patients.

The nurses also highlighted problems with the Palliative care doctors and GPs not wanting to be involved with the PCMMR feasibility trial and not wanting their patients involved.

Referring GPs

The GPs mentioned very few problems with the process. However, some of the GPs chose not to participate in the PCMMR feasibility trial. As such, feedback is from GPs positively disposed towards PCMMRs.

One problem highlighted was the report that was received from the accredited pharmacist. The GP felt it was like a “school report”.Whilst the information was very useful and informative, the feeling was that it could have been presented in a way that would be more “face saving” for the GP.

Patients and carers

Most of the patients and carers did not raise any problems, although some patients and carers stated that they were getting such an excellent service already that they did not need any extra input. However, even these patients and carers said they found the process of talking to another health care professional positive.
Project manager
The project manager indicated that the PCMMR process was very difficult to co-ordinate. This was mainly due to general confusion about where to send information, what information to send and to whom the information had to be sent. This resulted in many referrals following a different process that set out in the model protocol (Figure 7.2.1). This was despite, an information letter being sent to everyone involved in the trial that outlined the protocol. However, people did not read the letter, misinterpreted the letter, or had preconceived ideas about how the PCMMR service should be delivered. The protocol as laid out was rarely followed. A couple of reports were sent back to the wrong GPs and some reports were not forwarded to the project manager. All of these issues were sorted out eventually, but it took a lot of time and effort to chase things up and work out where things had gone. Inevitably this impacted on the timing of PCMMRs.

Palliative care specialist pharmacist
The palliative care specialist pharmacist indicated that the overall standard of the recommendations and reviews was poor. Although general advice given to patients and carers was good, many crucial things, in their opinion, were missed and these were not necessarily complex or related to palliative care. The standard of some of the reports/letters was deemed to be poor and examples were given where the names of medications were spelt wrongly and doses not indicated. The palliative care specialist pharmacist felt this was unacceptable. The accredited pharmacists also did not always indicate on the reports/letters the patient’s diagnosis or past medical history. If the accredited pharmacists were not supplied with this information on referral then it needed to be sourced before making recommendations. The palliative care specialist pharmacist felt that in some reviews the accredited pharmacists did not take into account the patient’s prognosis when making recommendations. There was also a lack of understanding in some instances of the use of medications in patients with palliative care needs and also the importance of addressing symptoms promptly. However, the palliative care specialist pharmacist felt that this would improve with more experience, extra experiential training, mentoring and feedback.
A final issue raised by the palliative care specialist pharmacist was that some referrals were not appropriate; either because they were too complex or because the patient was in the terminal phase.

Theme 3. Collaboration
Accredited pharmacists
Most accredited pharmacists reported that they felt part of the team, particularly when they received feedback from the GP or patient or carer. However, some of the pharmacists felt that they did not make much of a difference. One pharmacist felt that he could not contribute and that other team members had far more experience and expertise.

Palliative care nurses
Despite reporting a few administration and communication problems, the palliative care nurses welcomed the accredited pharmacists into the team and wanted the process to continue. They could see several roles for the pharmacist including education for patients and nurses.

Referring GPs
The GPs we interviewed saw the accredited pharmacist as a useful resource. However, there were differences in how reports were written and how information was presented and this meant that collaboration was not always as positive as it could be.

Project manager
The project manager suggested a review of why GPs were reluctant to refer patients for PCMMRs.
Palliative care specialist pharmacist

The palliative care specialist pharmacist felt that there was a need to ensure reports/letters are written to a high standard and that this improvement could improve collaboration.

7. 4 Limitations

We interviewed people who were very positive and the findings may reflect this. Quite a few GPs did not participate in the PCMMR feasibility trial and some nurses. It would be helpful to know the reasons for non-participation.

Most of the accredited pharmacists conducted a limited number of PCMMRs. As such, their experience was limited and they could only speak about a few examples. The same situation is true of the nurses and GPs – they could only speak about a limited number of examples.

However, the information can be triangulated with findings from rating scales to build a comprehensive picture of how the PCMMR feasibility trial was experienced by stakeholders.

7.5 Discussion

The PCMMR feasibility trial was deemed a success by stakeholders. However, protocols need to be clarified, tightened up and refined so that the process of referral is smooth and people are very clear about every step. A key issue, which is not unique to PCMMR, is the need for a standardized referral which includes all relevant information, most importantly the reason for referral. Despite using a standard referral form, often sections of the form were left blank, leaving the Accredited Pharmacist uncertain as to whether the information was not available or irrelevant for that particular individual. A clear, unambiguous reason for referral is invaluable to the reviewing pharmacist; the use of the criterion “one 5 or more medications” does not provide adequate direction to allow the pharmacist to direct their review to meet the expectations of the referring GP or the patient.

The forms need to include sufficient detail for pharmacists to make informed decisions. There is an urgent need the development of standards for referral for medication management reviews, and the implementation of these standards through incorporation of electronic proforma in patient care software (e.g. Medical Director) used by GP and other healthcare professionals.

When the PCMMR process worked, it worked very well but when it broke down it resulted in frustration and dissatisfaction. Whilst the GPs generally felt that the reviews were conducted in a timely manner, the process of having referrals generated by the nurses authorized by the GP often resulted in delays. This highlights the need to streamline the process, to allow any member of the palliative care team to complete a referral for a medication review. It also highlights the need for a change in the current remuneration practices which sees only general practitioners and pharmacists being paid for participating in the medication management review process. To facilitate the PCMMR process we would suggest that referral for a PCMMR would be remunerated under Medicare, with nurses and general practitioners being able to claim, and that general practitioners should be remunerated for reviewing the pharmacists’ medication management reports as per the current arrangements for Home Medicines Reviews.

In consistency in quality of the reports provided by the accredited pharmacists, raise the need for continuing efforts to improve accredited pharmacists’ report writing skills. As was the case for referrals there is a need for agreed standards on the format and content of such reports. These standards must meet the expectations of the end user, i.e. Palliative care doctors and GPs, but at the same time ensure that the information provided is sufficient to describe the problem/issue identified and explain the recommendation made. A standard format which identifies the problem/issue, the pharmacists findings and recommendations, which is consistent with language used by doctors and other health professionals needs to be adopted. As was the case for patient referrals there is a need for pharmacists to have access to electronic proforma report forms which will compile the agreed standards. To further enhance the impact of the accredited pharmacists
engaging in the PCMMR service there is also a need for training in communicating and working with the team, not just with patients.

If the specialised PCMMR service is to be introduced, there will be a need to provide intensive and ongoing training, with an emphasis on experiential learning, and specialised mentoring for the accredited pharmacists who provide it. The two-day intensive workshop training provide in Stage 1 of the feasibility trial was perceived to be excellent by the accredited pharmacists. However, it was seen as a start with further more training necessary. Inevitably, this will need adequate resourcing. The PPCP will provide an excellent resource for those accredited pharmacists who engage delivering reviews to patients under palliative care, and as such should be made available to all accredited pharmacists as part of their registration package. Incorporation of multiple choice questions (MCQs) related to palliative care could also be included in the suite of MCQs that are required to be completed by pharmacists as part of their initial accreditation assessment or as part of their reaccreditation.

7.6 Conclusion
The PCMMR feasibility trial was successful, positive feedback was received from patients and their carers, nurses, Palliative care doctors and GPs and the participating accredited pharmacists. The pharmacists made numerous recommendations as result of their reviews which were viewed by the patients/carers, nurses and GP as contributing positively to the patient care. This feedback supported the expert panel’s assessment of the clinical significances of the recommendations made. The palliative care nurses at exit interview strongly supporting the continuation of the PCMMR service.

The feasibility trial identified a number of problems with the PCMMR model used, some of which were unique to the delivery of the PCMMR service, but others which are generic to the medication management review models currently in operation in Australia. The first was the referral process, in particular the need to the GP to act as the gatekeeper and the inconsistency of the information provided. These two issues are applicable to both the HMRs and collaborative RMMRs. The first resulting in either the non-authorization or delays in referrals for the PCMMR service, and the second inadequate information being provided for the accredited pharmacist to make an informed assessment of the purpose of the review without first seeking further information. The later, also then resulting in potential delays in the medication review process, and failure of the pharmacists to meet the expectations of the person making the referral. The convoluted process of referral used in the trial could be addressed by allowing nurses to directly refer patients for the PCMMR service (and having provision for them to be remunerated for this referral under Medicare).

The second problem was the need for access to suitably trained accredited pharmacists, who are prepared to engage with patients in palliative care. In the PCMMR trial all the accredited pharmacists used were given advanced training in palliative care (a need identified through the focus groups and pharmacist survey), in light of this direct referral to an appropriately credentialed accredited pharmacist is seen as essential for successful implementation of the PCMMR service. Direct referral creates the opportunity to pharmacists to work within palliative teams where they developed a strong rapport with the other team members, hence gain their acceptance and respect. The failure to allow direct referral for HMRs has been seen as an impediment to its acceptance by Palliative care doctors and GPs, who traditionally refer their patients to other (medical and allied health) specialist whom they have professional relationship with.

The third problem is the availability of adequately trained accredited pharmacists to deliver the PCMMR service. The need for additional training was identified by both pharmacists and other health care professionals, and whilst the two-day intensive training undertaken by the accredited pharmacists participating in the trial provided a foundation, there is a need for ongoing education and support (including mentoring) for pharmacists who wish to practice in this area. The credentialing of specialist palliative care pharmacists should be considered.

The last problem was that of the pharmacists’ ability to identify clinically significant drug related problems and to communicate their findings and recommendations to the GP and other health care providers in the palliative care team. Clinical knowledge in specialist areas must be developed over
time and with experience, and it is accepted that those who engaged in the trial would develop
greater expertise with time. The issue of inconsistency of reports provided following the pharmacists’
reviews is reflected in comments from GP regards HMR and RMMR reposts also. This is an issue
which both has the potential to reduce the effectiveness of the report and the acceptance of the
value of medication management reviews in general. Great emphasis, training and resources need
to be focussed on report writing skills for accredited pharmacists.

In summary the PCMMR model trailed was successful but there are modifications that could be
made. At the individual pharmacist level the education needs to be expanded; at the organisational
level, standards for reports need to be reviewed; and, at the systemic level, processes and protocols
need to be refined and there needs to be a mechanism for encouraging referrals and closer
collaboration between Palliative care doctors and GPs and accredited pharmacists.
8. Discussion

Objective 1

To identify the palliative care needs of community-based palliative care patients and their carers and families at different stages of their illness.

The needs of people towards the end of life have been extensively outlined in the literature. People experience very different trajectories. Some people spend a long time in a relatively stable condition only to deteriorate dramatically in the final days of life. Others remain very ill for a long period of time before finally succumbing without a great deal of change in their condition. Most people die in hospital even though people consistently express the wish to die at home. It was evident from the data that pharmacists are already significantly involved with patients towards the end of life. Two specific issues were highlighted as essential to high quality palliative care: pain management and psychosocial care. The need for these exists notwithstanding the involvement of a specific professional group. Recognized reasons for failure to alleviate pain relate to the prescriber’s knowledge of analgesics and their failure to tailor the regimen to the needs of the patient. This means that pharmacists, with their knowledge about medicines, have a significant role in helping people to die in comfort and dignity. We note that 50% of the patients involved in our feasibility trial reported that they were experiencing pain before the involvement of the pharmacist. Associated with this is the potential for iatrogenesis in a population that often requires multiple drug treatments. In practice we found inconsistencies in the feasibility trial between the list of drugs the patient was prescribed at the time of referral for the PCMMR and the drugs that the patients had at their disposal. This confirms that this group of patients are at risk from adverse drug reactions by virtue of drug interactions and/or patients’ lack of knowledge about their medications.

Pharmacists did not see their role as limited to advising on medications and associated issues. Death and dying are frequently associated with significant psychosocial morbidity for patient, carer and family. Pharmacists also identified as part of their role, supporting patients by listening and providing general advice when needed, and by maintaining an ongoing relationship with carers of the dying person. This was underscored by the fact that people are often familiar with the pharmacist and if been in contact with him or her on many occasions before the final phase of their illness.

The effect of a terminal illness may be exacerbated in circumstances where the professional advisors are not attuned to the need in these circumstances. A prerequisite is an established relationship between all those affected by the illness and experienced professionals with whom they may come into contact. This issue was highlighted in the survey of pharmacists in which only a minority of pharmacists reported having any training in palliative care, yet almost half the respondents claimed that they were currently providing services and support for palliative care patients. Additionally, a substantial proportion of pharmacists reported having personal experience of palliative care (for example, caring for a relative). A significant proportion of the sample reported that they hadn’t cared for any palliative care patients in the previous 12 months. In the focus groups respondents expressed a lack of understanding about palliative care by non-palliative care pharmacists. They reported that this lack of understanding and knowledge could lead to their colleagues feeling out of their depth. Although most pharmacists were aware that palliative care relies on a team approach, some were unsure about exactly what professional groups were contributing or indeed what formal role they might play in the care of patients who had been clearly identified as close to the end of life.

Findings from the focus groups indicated that carers usually had a close relationship with their community pharmacist and went to them for advice about medications and aids. Many carers articulated a 3-way relationship between themselves, their community pharmacist and their GP, indicating that they already regarded the community pharmacist as part of their palliative care team. The exit interviews at the end of the PCMMRs supported these findings and indicated high satisfaction with the reviews completed. The reviews provided education as well as knowledge. The carers and patients said they felt that the pharmacist had time whereas the GP often was rushed and needed to deal with many different aspects of care.
Objective 2

To develop an educational package for community pharmacists in order to provide enhanced care to palliative care patients.

In summary one might say that the primary role of community pharmacists in palliative care is to ensure the safe supply and use of medication and to act as a source of advice for patients. For this activity to be practised more widely the palliative care approach needs to be adopted and therefore taught to a wider group of pharmacists than is currently the case. We also note from the literature that effective palliative care is predicated on inter-professional collaboration. Palliative care requires pharmacists, physicians, nurses, social workers, psychologists, counsellors, occupational therapists, chaplains and, at times, psychiatrists to work together to create a supportive framework of care for patients and their families.

The extent to which allied health professionals are able to work collaboratively will determine the extent to which community based teams can provide timely support that responds to changes in the patient’s physical condition and his/her changing goals. The practice of collaborative health care can be challenging as each team member may have different “framework of understanding”. In the focus groups pharmacists placed great emphasis on the need to develop better communication skills – or as one community pharmacist described it “some kind of people skill”. Pharmacists emphasised refining communication skills when dealing with difficult questions, upsetting situations (such as when the carer displays emotional distress when they return unused medications following the patient’s death) and implementing appropriate boundaries. We noted that very limited or appropriate, tailored information is currently available to train community pharmacists in palliative care. In the focus groups and interviews there was consistency about what pharmacists thought they needed to learn to facilitate their involvement in palliative care. The key issues—symptom management, palliative care medications and communication skills—came up repeatedly. Each of these domains was therefore incorporated in the development of our Pharmacy Palliative Care Portal.

Pharmacists were very clear that they prefer experiential learning: learning by doing rather than learning by reading. Hence the incorporation of case studies with expert panel discussions in the PPCP. In terms of knowledge, the survey of pharmacists offered particular insights. Pharmacists were clearly aware of their limited palliative care knowledge suggesting that they recognised their limited expertise in palliative care, even in the medication management domain, a field in which they could legitimately claim mastery. Therefore a clear outcome of this study was the recognition that more involvement in palliative care will only be possible after formal induction in the philosophy and practice of palliative care, but also after updates on the indications, doses and interactions of drugs used to manage symptoms at the end of life.

The portal has the potential to be used to educate pharmacists in palliative care through a number of ways:

- As a just-in-time resource to assist pharmacists in reviewing patients’ prescriptions, providing advice on symptom management, and to provide drug information and patient education
- As a comprehensive self-directed educational package for continuing professional education
- As a foundation for undergraduate and postgraduate university palliative care curricula, or as an adjunct to formal undergraduate and postgraduate education.

We believe the PPCP will provide an excellent resource for those accredited pharmacists who engage delivering reviews to patients under palliative care. Incorporation of multiple choice questions (MCQs) related to material in the portal could be included in the suite of MCQs that are required to be completed by pharmacists as part of their initial accreditation assessment or as part of their reaccreditation.
Objective 3

To identify what barriers might prevent community pharmacy involvement in palliative care and what supports are needed to facilitate involvement.

A key prerequisite for high quality palliative care is a team approach with effective collaboration between doctors, nurses, pharmacists and those able to provide specialist psychosocial care. Therefore, a significant barrier to the involvement of pharmacists in palliative care relates to their acceptance as a contributor to the patient’s care. The feedback through the focus groups highlighted many of the current barriers to the involvement of the pharmacist. Palliative care doctors and GPs were ambivalent about engaging pharmacists without experience in palliative care, claiming that pharmacists would not be able to fully understand the patient’s and carer’s needs. Many pharmacists in the focus groups reported that trying to get more information about a patient from the GP was difficult. This reluctance to share information may have reflected a determination to preserve confidentiality or an attempt to limit the involvement of a professional who was not perceived as having a significant contribution to make. Some pharmacists did not feel as though they were part of the palliative care team—in part because they were not physically present on the team—but also felt that other health care professionals did not really recognise or understand the pharmacist’s role in end of life care. GPs who were interviewed stated that they did not see the value of MMRs generally and PCMMRs specifically. GPs felt they were the key professionals caring of their patients and, if they needed support in any area related to medications, they would ask the pharmacist directly. Many GPs in the feasibility pilot of PCMMRs did not participate or refer any patients. Communication between Palliative care doctors and GPs and pharmacists needs to be improved and supported.

Nurses were also reported significant variability in pharmacists’ understanding of palliative care and especially their understanding of the urgency of the patient’s needs. Some nurses speculated that the variability was largely due to the pharmacists’ underlying attitudes and experience, or lack thereof, in palliative care. There were particular concerns around the experience of relatively young pharmacists. Nurses also noted that the palliative approach was not well understood even by experienced health care professionals and questioned how community pharmacists would engage given their lack of experience.

On the other hand carers in this study suggested that many non-palliative care pharmacists grasped and embodied some of the key principles of palliative care. For example, pharmacists seemed to intuitively understand the central role of the patient and the carer. They were aware of the need to support patients and their families at all stages of the patient’s illness. A key finding of this study was that pharmacists may underestimate their involvement and importance at the end of life because they perceive the skills they display as integral to their usual service, rather than skills that are specific to serving people in palliative care.

The results of the national pharmacist survey identified some common misconceptions about palliative care. We have already alluded above to the lack of training materials available to up skill practitioners appropriately. The Pharmacy Palliative Care Portal has been specifically designed to increase pharmacists’ understanding of palliative care. The workshop, which was developed to prepare accredited pharmacists to participate in the PCMMR pilot study, was centred on case based problem solution session was also successful in significantly improving pharmacists’ knowledge and skills. However, such workshops are merely a starting point and there is a need for regular updates and mentoring. A key finding of this study is the need for continuing education. The survey also revealed that beliefs and knowledge significantly and independently predict attitudes to the provision of palliative care. This is a positive finding as we can work with these aspects via the PCPCP, up-skilling pharmacists and dispelling myths.

The need for timely medication reviews presents another barrier to the involvement of pharmacists in the care of palliative care patient as evaluated in the feasibility trial. It was hoped that the PCMMR model, with the palliative care nurse as the person identifying patients suitable for review and facilitating the initiation of a referral from the doctor, the referral process would speed up. However, this was not always the case. It took between 2 and 30 days from the time the patient signed the consent form for a referral to be completed, the review to be conducted and the pharmacist to send their report to the referring doctor. This timeline was longer than we had anticipated. Delays arose...
for a number of reasons: delays in the referral form being completed and endorsed by the doctor, delays in finding a pharmacist to conduct the review, and in the pharmacist scheduling a suitable appointment with the patient and, in a number of cases, due to the patient’s health deteriorating. These procedural and pragmatic factors are likely to impact on a wider extension of a scheme dependent on medication management reviews. Therefore one cannot conclude that PCMMRs are necessarily the best or only way to engage pharmacists. Significant human factors impact on the smooth operation of such a scheme. However, this is the only process that allows remuneration for formal in-patient palliative care. This issue could be addressed by remodelling the way services are funded; either when tailoring patient medicine regimens or attending to the patient or carer’s need for advice or information. Hiring the pharmacist as a consultant could also be an option. Funding for any new model would need to be streamlined.

Finally, there were factors that were much more closely associated with the business of pharmacy. Pharmacists were concerned about stocking palliative care medications for a variety of reasons. Some were worried about stocking restricted medications in case they became a target for burglary. Others were loath to stock medications or supplements with a short shelf life or medications that were packaged in large quantities, believing that they would never dispense all the stock and would have to suffer financial losses. Similarly, pharmacists said if they stocked everything that palliative care patients might need, there would be limited scope to stock other items. Additionally community pharmacists were concerned that they had no way of knowing whether patients would require a particular medication, and hence they are not able to plan to either have the stock in the pharmacy, or to be able to access appropriate stocks quickly. Similarly, to provide a complete service to palliative care patients, pharmacists felt they would need to be familiar with and stock aids and devices specific to palliative care including catheters and specialised dressings. Pharmacists were concerned about the opportunity cost of being involved in palliative care. Time was a barrier also because of the need to invest time acquiring new knowledge. Community pharmacist also expressed concerns that a low level of exposure to palliative care patients made it difficult to maintain specific knowledge and skills. Therefore the demand for and materials required to participate in palliative care remained a significant barrier. Many pharmacists suggested that there could be pharmacies that specialised in palliative care. Patients, carers and nurses would be able to utilise the services of these specialised pharmacies and other pharmacists in the community would be aware of where to send people in emergencies.

Objective 4

To identify specific needs in relation to medication management services and to develop medication management reviews tailored to the needs of palliative care patients (PCMMR).

Several key elements are required to engage pharmacists in palliative care through the MMR process. It requires pharmacists to feel confident and supported, to ensure that there is financial remuneration for the time invested and agreement in the local community that allows the pharmacist to make a contribution that could benefit the patient and their carers. As for the other recommendations, in detail these include: training as described in the workshop exercise above; consultation with the local medical practitioners and palliative care providers such that there is an agreement to request a PCMMR; a process whereby the required documentation is not held up by the need for detailed referral notes. Despite these arrangements the recruitment of patients to this pilot had a limited success. We set out to recruit 150 people and despite project champions at each site we got less than a 1/3rd of this number. Some of these limitations were related to the time required to get multiple ethics committee approvals for our research project. However even when the study was in full flow there was failure to record data in the required format and some information could not be included in the final analysis. It is evident from the exit interviews that some medical practitioners refused to order a PCMMR, some nurses were put off by the paperwork and indeed three pharmacists in our cohort of 18 did not receive (or accept) any referrals. It was also evident that some referrals did not provide enough information to proceed with a PCMMR. This may relate to the misgivings about involving pharmacists as discussed above or it may reflect on the need for
documentation and form filling which added to the bureaucracy of a remunerated and auditable process.

It is to be anticipated that some patients will not be referred in time because they die before their PCMMR is due or withdraw due to deterioration in health. It is also possible that a suitable pharmacist may not be available locally. The pharmacists involved in this study were trained and mentored by a specialist palliative care pharmacist. Unfortunately none had access to the PPCP as this was not available until later in the project. Within our trial with 18 pharmacists, only 13 conducted medication reviews. It may also take longer than anticipated to get the PCMMRs done for clinical reasons but also because of the delays in getting the signed and correct documentation to the relevant trained pharmacist.

Notwithstanding, the issues raised above, having the palliative care nurse identify the potential patients for review was an effective triage method. The final endorsement for the request was by a medical practitioner. As some doctors refused to refer patients identified by the nurse for review, having the nurse authorise the review would have increased the number of referrals received. Patients and carers consented to the PCMMR so we question whether it supports patient choice to have the review authorised only by a medical practitioner.

There were a number of issues that impacted on the pharmacist’s confidence in the review process. Administrative issues played a large part in causing frustration on occasion. This ranged from having to contact nurses for details that were omitted from the referral and unexpected delays in the review process. In some cases there was also confusion about where to lodge the pharmacist’s report. The format of the report was unclear and failed to indicate where to log details. As is commonly the case with HMRs, critical information was often missing on the patient referral forms including the patient’s current medications and laboratory test results. These issues are generic to the MMR process and not specifically related to PCMMRs. The pharmacist had to rely on the patient or the nurse for this information and often could not make recommendations without further information about diagnosis or medical history.

Some pharmacists felt that more training (top up training) was needed on specialist medications and some relied on other experts to offer suggestions or reassurance. One pharmacist did not feel they could add to the existing expertise on the palliative team. Some participants also felt that their involvement had minimal impact on patient care. Given that this was a feasibility trial, and that many of the pharmacists involved had little prior experience with palliative care patients, it is not surprising that they questioned their value to the team, however with more experience we would predict that this self-assessment of worth would change.

In general, patients and their carers reported that they benefitted from contact with a pharmacist through the PCMMR process. However it had been thought that patients and/or their carers, and the palliative care nurses and doctors would have engaged with the pharmacists more after their initial PCMMR. In fact the rate of post-review interaction was low, and almost half of the interactions (47%) were initiated by the review pharmacist. It was encouraging that 41% of the interactions were initiated by the general practitioners, pointing to an increase in pharmacist-doctor interaction in the course of the study. Two of the interactions were initiated by carers, who were seeking assistance with the patient control of their patients, which indicates an acceptance of the pharmacists’ expertise in this area. Whilst much of the follow-up interaction was focused on sharing or requesting information, this is to be expected in what was a feasibility of an innovative service. As a rapport develops between pharmacist and patient, and the pharmacist and other health care professionals, we anticipate that that frequency and level of post-review interactions would increase.
9. Conclusions

Our review of the literature clearly demonstrated that community pharmacists are engaged with people under palliative care. Traditionally, community pharmacists ensure the supply and safe use of medication, and the provision of advice to patients and their carers. However, their role often extends to psychosocial support of patients and their families. Still many community pharmacists feel that they are ill prepared to deal with patients under palliative care, citing lack of knowledge and the required communication skills as barriers to the delivery of more advanced care. This perceived lack of knowledge, both of the palliative care process and the medications used in palliative care, was also identified by palliative care nurses when interviewed about the role of the community pharmacist.

In the area of medication supply we discovered that patients and their carers were generally happy with the service provided by their community pharmacists, however, palliative nurses expressed concern about the availability of medications and a lack of urgency by community pharmacists to procure medications which not in stock. We also found that community pharmacists identified a number of barriers to stocking medications used in palliative, both logistical and financial. This issue needs to be addressed, and policies and procedures need to be developed and implemented to ensure all palliative care patients have ready access to their medications. Specialist palliative care pharmacies are one way of ensuring best practice in this area.

To address the need for education we developed the Pharmacy Palliative Care Portal, a comprehensive, web-based palliative care resource. The PPCP may be used as an information resource by community pharmacists in their review of prescriptions for palliative care medications, and to assist in providing advice on medication use and symptom control for palliative care patients. It may also be used as an education tool. The PPCP contains four domains: palliative care philosophy, communication skills, symptom control and medication use. It also includes 12 interactive cases, each of which may be used to assist pharmacist develop their problem solving skills in the area of palliative care. The resource should prove invaluable to community pharmacists in the provision of pharmacy services to palliative care patients. We also envisage that the PPCP could become an important component of the palliative care curriculum of undergraduate and postgraduate pharmacy courses across Australia.

It is important to appreciate at this time that the use of the PPCP has not been evaluated in community pharmacists across Australia. Further, a decision as to who will host the portal is yet to be made. The PPCP will require continuous updating, which will require a commitment of further funds. The upkeep of the PPCP will require a team approach; the team will require a project manager, content experts, reviewers and a web designer with Moodle® expertise. As all community pharmacists are likely to become engaged with patients under palliative care in some way, we believe access to the PPCP should be available in all community pharmacies. This could be achieved by providing access to the PPCP free of charge, or mandating that pharmacies have access to the PPCP through the national registering body, and sale of licences to use the portal. To encourage educational institutions to use the portal it is suggested that access to the PPCP should be provided free of charge.

The PCMMR feasibility trial aimed to examine whether the role of the pharmacist could be extended in palliative care through the medication management process. The PCMMR model adopted a collaborative approach in which palliative care nurses were used to identify patients suitable for the service and to facilitate referral by their GP. Whilst, we were unable to recruit the planned 150 patients into the trial, we were able to demonstrate that suitability trained accredited pharmacists could deliver a service which was seen to be beneficial by patients and their carers, the palliative care nurses, Palliative care doctors and GPs. The trial identified a number of areas which need to be addressed to facilitate the widespread roll out of the PCMMR service. These include the need for advanced training for accredited pharmacists wishing to participate in this area of practice, together with ongoing support and mentoring. A revamp of the referral process which would allow both nurses (with suitable remuneration) and Palliative care doctors and GPs to refer patients directly to a suitably credentialed accredited pharmacist are essential to improve the uptake of the medication management reviews. There is need for standards for both patient referrals and pharmacist review reports to ensure effective and efficient transfer of patient information. We suggest investment into
suitable IT solutions to facilitate the implementation of these standards. Uptake of the service will also be dependent on breaking down the barriers which limit GP willingness to refer patients for medication management reviews. This can be achieved on an individual basis through by pharmacist establishing a relationship with the GP and this will be helped by direct referrals. This should be addressed at a professional level through an increased focus on inter-professional education activities.
10. Recommendations

Objective 1
To identify the palliative care needs of community-based palliative care patients and their carers and families at different stages of their illness.

1. Pharmacist education and training in palliative care needs to be increased, both at undergraduate and postgraduate levels. Up-to-date knowledge of the indications, doses, route of administration and other aspects of pharmacology of drugs used in palliative care is required. Pharmacists need to be formally introduced to the palliative care philosophy and practice and they must be prepared to deal emotional needs of the patients and their carers, and confronting situations which arise in palliative care. To achieve this representation needs to be made to a range of education providers, including Schools of Pharmacy, to address these needs.

Objective 2
To develop an educational package for community pharmacists in order to provide enhanced care to palliative care patients.

2. The PPCP needs to be formally evaluated as a resource for pharmacists in a number of practice settings. This evaluation should include the following: an assessment of the usability of the portal, frequency of use of the portal (e.g. number of visits to the website, the bounce rate and pages visited) and its impact on the knowledge of pharmacists who access the resource (e.g. based on changes to self-assessment test scores).

Assuming that the results of the evaluation of the portal are positive then consideration will need to be given to the following:

Hosting and Maintaining of the Portal
- The PPCP will require continuous updating, which will require dedication of further funds. The upkeep of the PPCP will require a team approach; the team will require a project manager, content experts, reviewers and a web designer with Moodle® expertise.

Access to the Portal by Pharmacists, Other Healthcare Professionals and Education Providers
- The range of people who will have access to the portal needs to be determined; these may include community pharmacists, accredited pharmacists, hospital pharmacists, doctors, nurses, and academics.
- At a minimum the PPCP should be available in all community pharmacies. Two possible options to achieve this would be to provide the portal free of charge or mandate that the portal is accessible in all community pharmacies and provide it on annual licence fee.
Objective 3
To identify what barriers might prevent community pharmacy involvement in palliative care and what supports are needed to facilitate involvement.

3. There needs to be systemic support for greater communication between pharmacists Palliative care doctors and GPs. Alongside education for communicating with carers and patients, there should be education for communicating with other health professionals in the palliative care team, particularly Palliative care doctors and GPs. The opportunities for inter-professional education based around case study reviews should be increased in an attempt to enhance communication between Palliative care doctors, GPs and pharmacists.

4. The benefits of the involvement of the community pharmacist and accredited pharmacist on the palliative care team needs to be clearly communicated and marketed to other health professionals. The pharmacist’s potential role needs to be delineated from that of the GP.

5. Education for palliative care should be ongoing and include professional development, top up training and mentoring.

6. Consideration needs to be given to the establishment of specialised palliative care pharmacies. This would help overcome supply and stocking difficulties and also ensure that community pharmacists involved have a positive attitude and a palliative care supply and stock plan. Reimbursement for investment, such as safe storage, needs to be considered as well as remuneration for palliative care services.

Objective 4
To identify specific needs in relation to medication management services and to develop medication management reviews tailored to the needs of palliative care patients (PCMMR).

7. Communication between health care professionals engaged in the medication management review process must be improved. Standards need to be established and implemented in regards to the format and quality of patient referrals and pharmacists’ review reports, to ensure effective and efficient communication. Investment in information technology (IT) solutions to improve both these phases of the medication management review process is strongly recommended.

8. Significant changes are required to the medication management review model to facilitate the widespread roll out of the PCMMR service. These changes should included modifications to the referral process to allow carers, nurses (with suitable remuneration), palliative care doctors and GPs to refer patients directly to a suitably credentialed accredited pharmacist. A remuneration model needs to include payment for both the initial medication management review and follow-up support. As PCMMR service matures and all those involved develop a greater rapport that engagement of the pharmacist post the initial review will increase significantly. Follow-up is essential and the PCMMR service should be remunerated at a rate equivalent to two HMRs. Education should emphasise follow up.

9. Attitudinal barriers which limit GP willingness to refer patients for medication management reviews must be addressed both at a personal level and a professional level. Establishment of good personal relationships between pharmacists, Palliative care doctors and GPs will help foster greater collaboration, and this would be aided by the introduction of direct referrals from Palliative care doctors and GPs to accredited pharmacists. At a professional level inter-professional education activities which engage all healthcare professionals involved in the palliative care team need to be established.
11. References


Appendices

Appendix A

Focus Group Information Sheet, Consent Form and Question Schedule
Focus Group - Participant Information Sheet

Exploring the Role of Community Pharmacists in the Provision of Palliative Care
Researchers: Dr. Moira O'Connor & Dr Georgia Halkett
This study has been reviewed and funded by the Pharmacy Guild of Australia

1. Invitation
You are invited to take part in this research project because you have experience with palliative care. This Participant Information Sheet contains detailed information about the research project. Please read this Participant Information carefully. Once you understand what the project is about and if you agree to take part in it, you will be asked to sign the Consent Form. By signing the Consent Form, you indicate that you understand the information and that you give your consent to take part in the research project. You will be given a copy of the Participant Information and Consent Form to keep as a record.

2. What is the purpose of this study?
Community pharmacists are an important aspect of primary healthcare. They provide advice on symptoms and medication and often give emotional support to the families of their clients. However, the involvement of community pharmacists in palliative care is often minimal which can affect the overall quality of palliative care services. The general aim of this project is to increase and develop community pharmacist’s role in palliative care.

3. Why have I been chosen?
You are invited to participate in this research project because you have experience of palliative care.

4. Do I have to take part?
Taking part in this research project is voluntary. Should you choose to participate then change your mind, you are free to withdraw without prejudice. If you decide to withdraw from this project, please notify a member of the research team before you withdraw by contacting Dr Moira O’Connor on 9266 1763.

5. What do I have to do if I take part?
Should you choose to participate you will be invited to attend a focus group between November of 2008 and March 2009. You will be allocated to focus groups based on your profession. The focus groups will be facilitated by Dr Moira O’Connor or Dr Georgia Halkett from the WA Centre for Cancer and Palliative Care or Dr Colleen Fisher from UWA. The discussion will focus on your views on the role of community pharmacists in palliative care. Focus groups will last no longer than one hour and will be tape recorded and stored on a password protected hard drive for subsequent data analysis.

6. What are the possible benefits of taking part?
We cannot guarantee or promise that you will receive any benefits from this project. However, it is anticipated that as a result of this study that in the future community pharmacists will be more competent, educated, better prepared and more informed about the provision of palliative care and their unique role in this care.
7. What are the possible risks in taking part?
It is not anticipated that these discussions will cause discomfort or distress. Nevertheless, should you feel the need to discuss anything relating to personal issues the focus group facilitators will remind you a variety of applicable service providers.

8. What happens when the research is completed?
Once the study is completed and the results are known, the researchers intend to make the education program available to all interested community pharmacists. If you would like to receive information when the project is finished please contact the researchers responsible for this project (see Section 11 below) and a summary of the key results will be posted to you.

9. Will my taking part in this study be kept confidential?
All information will be placed in a locked filing cabinet or secure password protected hard drive in the Research Offices at the WA Centre for Cancer and Palliative Care in accordance with NHMRC requirements. Your data will be kept for a period of 7 years following publication and then disposed of as confidential waste. Private information will only be disclosed with your permission, except as required by law.

10. Ethical approval
The Curtin University of Technology Human Research Ethics Committee has given ethical approval for the conduct of this project.

11. Contact for further information
If you require further information or if you have any problems concerning this study, you can contact the chief investigator responsible for this study in Western Australia:
Dr. Moira O’Connor (9266 1763) WA Centre for Cancer and Palliative Care.

Thank you for reading this information.
Focus Group - Participant Consent Form

Title: Exploring the Role of Community Pharmacists in the Provision of Palliative Care

I have read and I understand the Information Sheet.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this project according to the conditions in the Participant Information.

I understand I may withdraw my consent at any time without affecting any service provided by Silver Chain now or in the future.

I agree for the focus groups to be tape recorded.

I understand that the researcher has agreed not to reveal my identity and personal details if information about this project is published or presented in any public form.

Consent to participate

Yes

No

Participant’s Name (printed) ________________________________________________

Signature _________________________________  Date _________________

Name of Witness to Participant’s Signature (printed) __________________________

Signature _________________________________  Date _________________

Declaration by researcher: I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Researcher’s Name (printed) _______________________________________________

Signature _________________________________  Date _________________
Focus Group Questions - Community Pharmacists (Palliative Care)

Introduction
We are conducting a project which is funded by the Pharmacy Guild of Australia to examine the role of pharmacists in providing palliative care services. The purpose of today’s session is to find out your views about pharmacist involvement in palliative care. We want to gain a greater understanding of how pharmacists can contribute to palliative care, what pharmacists would need to learn about in order to contribute to palliative care, how best to involve pharmacists in palliative care and the challenges facing pharmacists working in palliative care.

1. What experiences have you had with providing pharmacy to palliative care patients? How were you involved? What did you do?
2. What do you feel is the role of the pharmacist in palliative care?
3. Why did you decide to specialise/work in palliative care?
4. Do you believe there are incentives to work in palliative care?
5. What do you believe are the strengths of community pharmacists in providing palliative care?
6. What do you think are the weaknesses?
7. What improvements do you think need to be made?
8. If community pharmacists are to expand their role in palliative care, what do you believe the potential barriers are? Prompts:
   a. Finance
   b. Time
   c. Communication skills
   d. Knowledge
   e. Training
   f. Availability of information resources
   g. Availability of expert support
   h. Perceptions (pharmacists, patients, carers, other health professionals).
9. What types of issues do palliative care patients/carers approach pharmacists about?
10. Do you feel most community pharmacists would be competent or skilled enough to address these issues?
11. How should pharmacists acquire these skills? Prompts:
    a. Experience
    b. Specialised education and training courses/programs
    c. Mentoring
    d. Help/networks
12. Do you believe that pharmacists providing palliative care services require any specialised training or support? What types? (e.g. mentorship or debriefing)
13. Do you receive or seek out ongoing professional training or support in the area of palliative care?
14. Which health professionals do you communicate with about patients who are receiving palliative care?
15. Have you had to overcome any barriers to be accepted as a member of the palliative care team?
16. How do you perceive your role in the multidisciplinary team?
17. What do you perceive the role is of the Pharmacy Guild or other professional associations in relation to palliative care?
18. What do think should be included in Medication Management Reviews?
19. Can you think of a particular case to discuss?
20. What are the benefits of a medication management review when patients are being managed in the home or aged care facilities?
21. Do you believe patients at home or in aged care facilities would benefit from continued monitoring/access to a designated palliative care pharmacist, or is this service already provided by community pharmacists?
22. Topics needed for PC education?
   (Prompts: medications; symptom control; referrals and resources; talking with patients and families; psychosocial support; drug interactions)
23. We are trialing a model of HMR with palliative care – this is how it looks (show draft model)
24. Any comments on how this will work or how it can be modified?
25. Any potential barriers for the trial?
26. Any other comments?
Focus Groups – Nurses and Health Professionals

Introduction

We are conducting a project which is funded by the Pharmacy Guild of Australia to examine the role of community pharmacists in providing palliative care services. The purpose of today’s session is to find out your views about pharmacist involvement in palliative care.

1. Do you discuss patient/palliative care issues with local community pharmacists?  
   (Prompts: eg)

2. Tell us about the role that you believe community pharmacists could or should play in palliative care. What do you consider to be essential components of this role? (Prompts):
   a. Medications
   b. Aids to daily living (e.g. wheelchair, commodes etc.)
   c. As part of the typical palliative care team of GPs, nurses etc...
   d. Symptom control
   e. Referrals and resources
   f. Psychosocial support
   g. Talking with patients
   h. Medical Management Reviews.

3. What barriers would community pharmacists encounter in undertaking this role?  
   (Prompts):
   a. Other health professionals already involved in care?
   b. Poor communication with other health professionals?
   c. Insufficient knowledge/training?
   d. Language/cultural differences?

4. What would help?

5. One way that pharmacists can contribute to palliative care is to conduct medication management reviews (MMRs). (Prompts: Show diagram and talk them through this and get views)

6. Any comments on how this will work or how it can be modified? (Prompt: Is your role feasible?)

7. Any potential barriers for the trial?

8. Tell us what would make it easier for you to interact with a community pharmacist.

9. In your view, what would be the best way to implement communication between GPs and community pharmacists?
10. What kind of information could GPs share with community pharmacists to improve the care of palliative patients?

11. Topics needed for PC education for community pharmacists?
   (Prompts: medications; symptom control; referrals and resources; talking with patients and families; psychosocial support; drug interactions)

12. Any other comments?
Focus Groups – GPs

Introduction

We are conducting a project which is funded by the Pharmacy Guild of Australia to examine the role of community pharmacists in providing palliative care services. The purpose of today's session is to find out your views about pharmacist involvement in palliative care.

1. Do you discuss patient/palliative care issues with local community pharmacists? (Prompts: egs)

2. Tell us about the role that you believe community pharmacists could or should play in palliative care. What do you consider to be essential components of this role? (Prompts):
   a. Medications
   b. Aids to daily living (e.g. wheelchair, commodes etc.)
   c. As part of the typical palliative care team of GPs, nurses etc…
   d. Symptom control
   e. Referrals and resources
   f. Psychosocial support
   g. Talking with patients
   h. Medical Management Reviews.

3. What barriers would community pharmacists encounter in undertaking this role? (Prompts):
   a. Other health professionals already involved in care?
   b. Poor communication with other health professionals?
   c. Insufficient knowledge/training?
   d. Language/cultural differences?

4. What would help?

5. One way that pharmacists can contribute to palliative care is to conduct medication management reviews (MMRs). (Prompts: Show diagram and talk them through this and get views)

6. Any comments on how this will work or how it can be modified? (Prompt: Is your role and feasible?)

7. Any potential barriers for the trial?

8. Tell us what would make it easier for you to interact with a community pharmacist.

9. In your view, what would be the best way to implement communication between GPs and community pharmacists?
10. What kind of information could GPs share with community pharmacists to improve the care of palliative patients?

11. Topics needed for PC education for community pharmacists?
   (Prompts: medications; symptom control; referrals and resources; talking with patients and families; psychosocial support; drug interactions)

12. Any other comments?
Focus Group Questions – Carers/Patients

Introduction

We are conducting a project which is funded by the Pharmacy Guild of Australia to examine the role of community pharmacists in providing palliative care services. The purpose of today’s discussion is to hear about your experiences with your community pharmacist and to hear your views about how community pharmacists could contribute to palliative care services.

(Introductions)

1. To begin do you have a regular community pharmacist?  
(Prompt: if not why not?)
2. How often do you see the community pharmacist?
3. What can pharmacists offer to palliative care patients and their carers? (Prompts:
   - Ambulatory care?
   - Information on palliative care?
   - Information on how to use medications and side effects?
   - Provision of medications?
   - Provision of household aids (e.g. wheelchair, commodes)
   - Advice on symptom management?
   - Advice on when medical help should be sought?
   - Advice on resources
   - Emotional support?)
4. For what reasons do you consult with your pharmacist? (Prompts:
   - As above and
   - Information on service providers?
   - Dispense prescriptions?
   - Information pamphlets?
   - Information regarding medication?
   - Emotional support?)
5. When consulting your pharmacist do you get the information/support you require?
6. Have you/your family member had a review of medications?
7. Do you think it would be helpful for the pharmacist to reviewing patients’ medications whilst they are receiving palliative care?
8. How does the role of the community pharmacist differ to the GP’s role in working with palliative care patients and families?

9. Who should the community pharmacist communicate with regularly about patients receiving palliative care? (Prompts: 
   - GPs
   - Specialists
   - Home Hospice nurse
   - Carers/Family members)

10. How would you feel about other health professionals sharing medical and personal information with your pharmacist?

11. Do you believe that community pharmacists have the knowledge and skills to become more involved in palliative care?

12. If not – why not?

13. Do you see any problems with your community pharmacist taking a role in your palliative care? (Prompts: 
   - Lack of patient desire to see a pharmacist?
   - Too many other health professionals already involved in care?
   - Lack of acceptance by other health care professionals?
   - Insufficient knowledge/training?
   - Lack of privacy in the pharmacy environment?
   - Lack of remuneration?
   - Inability to visit patients in the home?
   - Time constraints of the pharmacist?)
Focus group questions – pharmacists (Non PC)

We are conducting a project which is funded by the Pharmacy Guild of Australia to examine the role of community pharmacists in providing palliative care services. The purpose of today’s session is to find out your views about pharmacist involvement in palliative care. We want to gain a greater understanding of how pharmacists can contribute to palliative care, what pharmacists would need to learn about in order to contribute to palliative care, how best to involve pharmacists in palliative care and the challenges facing pharmacists working in palliative care.

1. What is your understanding of palliative care?
   Present definition if required (attached)

2. Can you tell us about any palliative care patients and families you have seen?

3. Can you tell us some of the needs and issues facing your palliative care patients?
   (Prompt: if any are identified then ask to elaborate)

4. Do you feel you were able to meet these needs?
   If not: which needs could not be met
   When did it not work?
   What did you do?
   What would have helped?

   If yes: what helped?
   What would you have done differently?

5. How could your relationship with your patients be enhanced?
   (Prompts: communication training; communication with health professionals; more time private area in pharmacy; availability of resources; opportunity to visit patient in home)

6. Do you consider that community pharmacists would want to be involved in the palliative care team/have a role in pc?
   If no: why not?
   If yes: what do you see their role as being?

7. What services would be essential?

8. Do you have a relationship with other health professionals in the pc team?
9. What are some of the barriers to the community pharmacist being involved in the palliative care team?
   (Prompts: remuneration; time pressure; knowledge; training; lack of support from health professionals; fears; perceptions)

10. How do we work around these barriers?
11. What would help/support the cp being part of the palliative care team?
   (Prompts: adequate remuneration; more time; increased staff; improved knowledge of palliative care; specific training programs; availability of resources; support of other health professionals)

12. What are the palliative care educational needs of community pharmacists?
13. Topics needed for pc education?
   (Prompts: medications; symptom control; referrals and resources; talking with patients and families; psychosocial support; drug interactions)

14. How should this education be provided?
   (Prompts: web-based; supplementary materials)

15. We are trialing a model of HMR with palliative care – this is how it looks (show draft model)
16. Any comments on how this will work or how it can be modified?
17. Any potential barriers for the trial?
18. Any other comments?
Appendix B

Diagram of MMR process used in Focus Groups
Referral Pathway

Home Hospice
 Clinical Nurse
Hospice GP

Patient’s GP

Community Pharmacist

Palliative Care Medication Review

Trained Accredited Pharmacist

Patient Management Plan
Appendix C

Survey Cover Letter, Information Sheet and Instrument
Dear Community pharmacist,

We are conducting a project funded by the Pharmacy Guild of Australia to explore pharmacists’ role in palliative care. As part of the project we are conducting a survey to explore community pharmacists’ attitudes to being involved in palliative care.

We are writing to invite you to take part in this survey. Even if you have no interest in palliative care, we would like to get your views as we feel it is important to get a range of attitudes. The survey results will be used to develop education and supports for community pharmacists.

We appreciate how busy you must be so we have attached a tea bag – please take ten minutes to enjoy a cup of tea while you complete the survey.

We have also attached: an information sheet; a copy of the survey; and a reply-paid envelope. We anticipate that the survey should take less than 20 minutes to complete.

The survey is completely anonymous, and you indicate your consent to participate by filling out the survey. Please return the survey (along with the name and address slip at the bottom of this page) in the envelope provided. We will separate your completed survey from your name and address slip immediately, and the information will never be linked. When you return your completed survey, we will also send you a $30 Coles/Myer voucher as a token of our appreciation.

If you would like any more information about the project before you take part, please contact me on 08 9266 1763 or at m.oconnor@curtin.edu.au.

Thank you very much for your time.

Kind regards,

Dr Moira O’Connor

Senior Research Fellow
WA Centre for Cancer and Palliative Care
Curtin University of Technology

Please return this slip with your completed survey so we can send you a $30 grocery voucher as a token of our appreciation. This slip will be separated from your survey immediately and will never be linked.

Name: _____________________________________
Address: ___________________________________
Participan Information Sheet – Survey

Exploring the Role of Community Pharmacists in the Provision of Palliative Care
Researchers: Professor Moyez Jiwa, Dr. Moira O’Connor, Professor Jeff Hughes, & Dr. Lauren French
This study has been reviewed and funded by the Pharmacy Guild of Australia

1. Invitation
You are invited to take part in this research project because you are employed as a community pharmacist. This Participant Information Sheet contains detailed information about the research project. Please read this information carefully. If you agree to take part in the project, you will be able to indicate your consent by completing the attached survey. By filling out the survey, you indicate that you understand the information provided and that you give your consent to take part in the research project. You can keep this Information Sheet as a record.

2. What is the purpose of this study?
The aim of this project is to examine pharmacists’ attitudes, beliefs, feelings and understanding of palliative care.

3. Why have I been chosen?
You have been invited to participate in this research project because you are a community pharmacist.

4. Do I have to take part?
Taking part in this research project is voluntary. Should you choose to participate then change your mind, you are free to withdraw.

5. What do I have to do if I take part?
Should you choose to participate you will complete the attached survey and return it to the researchers along with your name and address slip (in the reply-paid envelope provided). The survey is about your views of being involved in palliative care. We anticipate that the survey should take less than 20 minutes to complete. When we receive your completed survey, we will post a $30 Coles/Myer voucher (to the address you provide) as a token of our appreciation for your time and effort.

6. What are the possible benefits of taking part?
We cannot guarantee or promise that you will receive any direct benefits from this project. However, it is anticipated that in the future—as a result of this study—community pharmacists will have more relevant palliative care education and support available to facilitate their involvement in palliative care, and this may work to improve the quality of care that palliative care patients and their carers receive.
7. What are the possible risks in taking part?

It is not anticipated that this survey will cause any discomfort or distress. Nevertheless, should you feel the need to discuss any issues that arise in the course of the survey, please contact the researchers below (section 11) and they will suggest a variety of services that you may wish to get in touch with.

8. What happens when the research is complete?

The researchers will provide the Pharmacy Guild of Australia with a report of recommendations resulting from the survey, and may write the results into a manuscript for publication. The results will be used to develop palliative care education and support for pharmacists. If you would like to receive information when the project is finished please contact the researchers responsible for this project (see Section 11 below) and a summary of the key results will be posted to you.

9. Will my taking part in this study be kept confidential?

This survey is anonymous and individuals will not be identifiable. Private information will only be disclosed with your permission, except as required by law. We will separate your completed survey from your name and address slip as soon as we receive them and the information will never be linked.

All information will be placed in a locked filing cabinet or secure password protected hard drive in the Research Offices at the WA Centre for Cancer and Palliative Care in accordance with NHMRC requirements. Your data will be kept for a period of 7 years following publication and then disposed of as confidential waste.

10. Ethical approval

This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number RD-50-09). The Committee is comprised of members of the public, academics, lawyers, doctors and pastoral carers. Its main role is to protect participants. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth, 6845 or by telephoning 9266 2784 or by emailing hrec@curtin.edu.au.

11. Contact for further information

If you require further information or if you have any problems concerning this study, you can contact the project manager, Dr Lauren French (08 9266 1765), at the WA Centre for Cancer and Palliative Care.

Thank you for reading this information.
Thank you for taking the time to complete this survey. Your responses will be completely anonymous. Filling out the survey will be taken as your consent to participate.

This survey is about your attitude towards providing services and supports for palliative care patients in your professional capacity as a community pharmacist.

Please complete the five sections of the survey in order without returning to any previous sections.

Section 1

My attitude about providing services and supports for palliative care patients is:

-3 -2 -1 0 1 2 3

Negative Positive
Section 2

We would like you to list up to 6 beliefs that you have about providing services and supports for palliative care patients.

Take a few moments to think about providing services and supports for palliative care patients and what would be involved, and then write down your beliefs. You do not need to fill in every space, only write down as many beliefs as you have.

After each belief, rate how positive or negative it is.

Here is an example:

For the issue logging in natural forests you might respond:

1. I believe it destroys the natural forests
   It is likely you would see this belief as negative so you would circle a response on the negative side of the scale:
   
   -3 -2 -1 0 1 2 3
   Negative Positive

2. I believe it decreases the risk of bush fires
   It is likely you would see this belief as positive so you would circle a response on the positive side of the scale:
   
   -3 -2 -1 0 1 2 3
   Negative Positive
Now please list up to 6 beliefs you have about providing services and supports for palliative care patients. Write down each belief and then rate how positive or negative is it.

There are no right or wrong answers: we simply want to know about your beliefs. You do not need to fill in every space—only use as many spaces as you need.

|                               | -3 | -2 | -1 | 0 | 1 | 2 | 3 | Negative | Positive |
|                               |    |    |    |   |   |   |   |          |          |
| 1. I believe                  |    |    |    |   |   |   |   |          |          |
| 2. I believe                  |    |    |    |   |   |   |   |          |          |
| 3. I believe                  |    |    |    |   |   |   |   |          |          |
| 4. I believe                  |    |    |    |   |   |   |   |          |          |
| 5. I believe                  |    |    |    |   |   |   |   |          |          |
| 6. I believe                  |    |    |    |   |   |   |   |          |          |
Section 3

We would like you to list up to 6 emotions or feelings that you experience in relation to providing services and supports for palliative care patients. These emotions may be pleasant or unpleasant.

Take a few moments to think about providing services and supports for palliative care patients and what would be involved, and then write down your feelings. You do not need to fill in every space, only write down as many feelings as you have.

After each feeling, rate how positive or negative it is.

Here is an example:

For the issue *logging in natural forests* you might respond:

1. Makes me feel **Angry**
   
   It is likely you would see this feeling as negative so you would circle a response on the negative side of the scale:
   
   ![Negative Scale]

2. Makes me feel **Safer**
   
   It is likely you would see this feeling as positive so you would circle a response on the positive side of the scale:
   
   ![Positive Scale]
Now please list **up to 6** emotions or feelings you have about providing services and supports for palliative care patients. Write down each emotion and then rate how positive or negative is it.

There are no right or wrong answers: we simply want to know about your emotions. You do not need to fill in every space—only use as many spaces as you need.

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**Section 4**

We would like to know more about you. Please answer the following questions.

1. **Gender**
   - Male
   - Female

2. **Age**
   - ________ Years

3. **State**
   - ACT
   - NSW
   - NT
   - SA
   - QLD
   - TAS
   - VIC
   - WA

4. **When did you become a qualified pharmacist?**
   - ________ (year)

5. **How long have you worked in a community pharmacy practice?**
   - ________ years

6. **How many other pharmacists work in the community pharmacy with you?**
   - ________

7. **Where is the pharmacy situated?**
   - Metropolitan
   - Regional
   - Rural or remote

8. **Have you completed any training in palliative care?**
   - Yes
   - No

9. **Have you had any personal experience in palliative care (such as caring for a relative)?**
   - Yes
   - No

10. **Are you currently providing services and supports for any palliative care patients?**
    - Yes
    - No

11. **Approximately how many palliative care patients/carers have you provided services and supports for over the last 12 months?**
    - ________
We would like to know about your understanding of palliative care. Below are a series of statements. For each statement please indicate whether you think it is true or false or whether you are unsure by ticking the corresponding box. If you do not know the answer, please select “unsure.”

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<tr>
<th>Statement</th>
<th>True</th>
<th>False</th>
<th>Unsure</th>
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<tbody>
<tr>
<td>1. Dexamethasone 16mg/day is a reasonable dose for treating decreased appetite and mood.</td>
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<td>2. Laxatives should be prescribed whenever opioids are to be used.</td>
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<td>3. Oral morphine should not be used by people in respiratory distress.</td>
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<td>4. The evidence about the safety and efficacy of combining drugs for subcutaneous infusions is very limited.</td>
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<td>5. Most palliative care patients experience depression during some stage of their illness.</td>
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<td>6. Haloperidol is good for treating nausea and vomiting.</td>
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<td>7. Chemotherapy is used as a non-curative treatment in palliative care.</td>
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<td>8. The health care professionals on the palliative care team need to meet face-to-face to discuss patients.</td>
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<td>9. The major focus of palliative care is managing pain at the end of life.</td>
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<td>10. Most palliative care patients experience shortness of breath during their illness.</td>
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11. The maximum dose of morphine is 1g/day orally.

- [ ] True
- [ ] False
- [ ] Unsure

12. It is good practice to reserve opioids until the patient’s pain is severe.

- [ ] True
- [ ] False
- [ ] Unsure

13. Palliative care patients’ spiritual needs are secondary to their medication needs.

- [ ] True
- [ ] False
- [ ] Unsure

14. The major focus of palliative care is maximising the patient’s quality of life and addressing the needs of both the patient and their carers/family members.

- [ ] True
- [ ] False
- [ ] Unsure

15. All palliative care patients experience pain at some stage of their illness.

- [ ] True
- [ ] False
- [ ] Unsure

16. The risk of becoming addicted to morphine is high at doses above 1g/day.

- [ ] True
- [ ] False
- [ ] Unsure

17. Medications are often used for non-standard indications and at non-standard dosages in palliative care.

- [ ] True
- [ ] False
- [ ] Unsure

18. Pharmacists should recommend that palliative care patients avoid complementary and alternative medicines.

- [ ] True
- [ ] False
- [ ] Unsure

19. Sleep reversal is common in palliative care patients.

- [ ] True
- [ ] False
- [ ] Unsure

20. Many palliative care patients experience oral thrush at some stage of their illness.

- [ ] True
- [ ] False
- [ ] Unsure

Thank you for taking the time to fill out this survey
Appendix D

List of topics and subtopics for education package
Chapter: 1. Palliative Care: Philosophy and Practice

Topic: 1.1 Basic principles and practice
       (inc. topic objectives)

Page: 1.1.1 Definition & Indicators
       Page Headings: WHO definition of Palliative Care
                      Indicators that a patient is receiving palliative care

1.1.2 Goals and Methods of Care
       Principles of palliative care
       Goals of care
       End of life planning/advance care planning
       The patient centred approach to communication
       The palliative care team: members and roles
       Ways of linking with and working in the palliative care team

1.1.3 Managing Grief and Loss
       Background
       Theoretical explanations of grief
       Prolonged grief disorder
       Key issues
       How you can help

Bibliography
Resources

Content pages (3)

Topic: 1.2 Palliative care patients: characteristics and common diseases
       (inc. topic objectives)

Page: 1.2.1 Cancer
       Page Headings: Background
                      Key issues
                      Specific medication management
                      Practical needs

1.2.2 Cardiovascular disease
       Background
       Key issues
       Specific medication management

1.2.3 HIV
       Background
       Key issues
       Specific medication management

1.2.4 Neurological disease
       Background
       Key issues
       Specific medication management

1.2.5 Renal disease
       Background
       Key issues
       Specific medication management
1.2.8 Terminal Respiratory disease
   Background
   Key issues
   Specific medication management
   Practical needs

1.2.6 Paediatric palliative care patients
   Background
   Key issues
   Specific medication management

1.2.7 Patients with dementia or cognitive impairments
   Background
   Key issues
   Specific medication management
   Practical needs

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            (inc. topic objectives)

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               Reasons for use
               References and resources

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Sub-topic: 2.4.2 Types of CAMs

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Page Headings: General information
               Examples
               References and resources

Page Level: 2.4.2.2 Manual/physical
Page Headings: General information
               Examples
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Page Level: 2.4.2.3 Mind & body/psychosocial
Page Headings: General information
               Examples
               References and resources

Page Level: 2.4.2.4 Pharmacotherapeutic/medicinal/biological
Page Headings: General information
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Page Level: 2.4.2.5 Philosophical systems/alternate medical systems
Page Headings: General information
               Examples
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Topic Level: 3.1 Basic principles of symptom control
(inc. topic objectives)

Page Level: 3.1 Basic principles of symptom control
Page Headings:
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- Communication
- Focus of care
- Monitoring changing needs
- Referral and collaboration
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(inc. topic objectives)

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- Pathophysiology
- Assessment by pharmacist
- Non-pharmacological management
- Pharmacological Management
- Monitoring and adverse effects
- References and resources

3.2.2 Anxiety
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3.2.8 Dyspnoea
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3.2.11 Excessive Respiratory Tract Secretions
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3.2.12 Insomnia
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3.2.15.4 Sore mouth
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3.2.17 Sweating
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4. Communicating With Palliative Care Patients and Their Families
(inc. topic objectives)

Topic Level: 4.1 Communicating effectively
Page Level: 4.1.1 Communicating effectively
Page Headings:
- Why is effective communication important?
- Patient centred approach to communication
- References and resources

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Subtopic: 4.1.5 How to communicate effectively
Page Level: 4.1.5.1 Setting the scene
Page Headings:
- Background
  - What is it?
  - Why is it important?
- Provide a welcoming environment
  - Explanation and examples
- Provide privacy
  - Explanation and examples
- Manage the time
  - Explanation and examples
- References and resources

Page Level: 4.1.5.2 Listening to patients and carers
Page Headings:
- Background
  - What is it?
  - Why is it important?
- Be attentive
  - Explanation and examples
- Acknowledge what people have said and paraphrase
  - Explanation and examples
- Use empathy
  - Explanation and examples
- Attend to non-verbal cues
  - Explanation and examples
- Use silence
  - Explanation and examples
- Don’t interrupt
  - Explanation and examples
- Ask questions for clarity
  - Explanation and examples
- References and resources

Page Level: 4.1.5.3 Giving information to patients and carers
Page Headings: 4.1.5.3.1 Background
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Explanation and examples
4.1.5.3.3 Give important information first
Explanation and examples
4.1.5.3.4 Tailor the information and amount of information to needs
Explanation and examples
4.1.5.3.5 Present information in a number of ways
Explanation and examples
4.1.5.3.6 Check understanding
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4.1.5.3.7 Give specific information and advice
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4.1.5.3.8 Repeat key points
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Page Level: 4.1.5.4 Responding to patients' and carer's emotions
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  Why is it important?
  4.1.5.4.2 Use open ended questions with an emotional/social focus
    Explanation and examples
  4.1.5.4.3 Acknowledge the impact on the patient or carer
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  4.1.5.4.4 Allow time
    Explanation and examples
  4.1.5.4.5 Avoid "jumping in"
    Explanation and examples
  4.1.5.4.6 Use minimal prompts
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  4.1.5.4.7 Elicit any concerns
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  4.1.5.4.8 Normalise and give reassurance
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Page Level: 4.1.5.5 Responding to distress and intense emotions: Distress
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  Why is it important?
  4.1.5.5.2 Allow time for the patient to cry
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  4.1.5.5.3 Use empathy and attend to the person
    Explanation and examples
  4.1.5.5.4 Ask the patient or carer if they wish to talk about their distress
    Explanation and examples
  4.1.5.5.5 Normalise distress
    Explanation and examples
  4.1.5.5.6 Don't "jump in"
    Explanation and examples
  4.1.5.5.7 References and resources
4.1.5.6. Responding to distress and intense emotions: Anger

4.1.5.6.1 Background
   What is it?
   Why is it important?
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4.1.5.6.3 Listen actively
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4.1.5.6.4 Focus on the person not the language
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4.1.5.6.5 Use body language to deflect the anger
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4.1.5.6.6 Avoid being defensive
   Explanation and examples
4.1.5.6.7 Avoid arguments
   Explanation and examples
4.1.5.6.8 Acknowledge the person’s feelings
   Explanation and examples
4.1.5.6.9 Ask for time to respond if needed
   Explanation and examples
4.1.5.6.10 Look at what can be done when the anger subsides
   Explanation and examples
4.1.5.6.11 Offer options for help if appropriate
   Explanation and examples
4.1.5.6.12 Maintain safety of self and others
   Explanation and examples
4.1.5.6.13 References and resources

4.1.5.7 Responding to distress and intense emotions: Anxiety

4.1.5.7.1 Background
   What is it?
   Why is it important?
4.1.5.7.2 Ask scanning questions
   Explanation and examples
4.1.5.7.3 Acknowledge the person’s feelings
   Explanation and examples
4.1.5.7.4 Explore the source of anxiety if appropriate
   Explanation and examples
4.1.5.7.5 Normalise the anxiety
   Explanation and examples
4.1.5.7.6 Suggest short term strategies
   Explanation and examples
4.1.5.7.7 Check that informational needs are met
   Explanation and examples
4.1.5.7.8 Repeat information
   Explanation and examples
4.1.5.7.9 Give written information
   Explanation and examples
4.1.5.7.10 References and resources

4.1.5.8 Responding to distress and intense emotions: Depression

4.1.5.8.1 Background
   What is it?
   Why is it important?
4.1.5.8.2 Ask scanning questions
   Explanation and examples
4.1.5.8.3 Acknowledge the person’s feelings
Page Level: 4.1.5.9 Wrapping up and creating closure
Page Headings: 4.1.5.6.1 Background
   What is it?
   Why is it important?
4.1.5.6.2 Anticipate and flag closure
   Explanation and examples
4.1.5.6.3 Acknowledge the amount of information and repeat key points
   Explanation and examples
4.1.5.6.4 Follow up with written instructions
   Explanation and examples
4.1.5.6.5 Give details of additional supports
   Explanation and examples
4.1.5.6.6 References and resources

Page Level: 4.1.5.10 Self-care: Managing the impact on you
Page Headings: 4.1.5.7.1 Background
   What is it?
   Why is it important?
4.1.5.7.2 Be knowledgeable
   Explanation and examples
4.1.5.7.3 Set limits and prioritise
   Explanation and examples
4.1.5.7.4 Maintain confidentiality
   Explanation and examples
4.1.5.7.5 Acknowledge the impact on you
   Explanation and examples
4.1.5.7.6 Maintain self care and balance
   Explanation and examples
4.1.5.7.7 Manage stress
   Explanation and examples
4.1.5.7.8 Communicate and debrief
   Explanation and examples
4.1.5.7.9 Use reflection
   Explanation and examples
4.1.5.7.10 References and resources

Page Level: 4.1.5.11 Barriers to effective communications
Page Headings: 4.1.5.8.1 Background
   What is it?
   Why is it important?
4.1.5.8.2 Perception that psychological issues are inevitable for patients and carers
   Explanation and examples
4.1.5.8.3 Lack of time
   Explanation and examples
4.1.5.8.4 Lack strategies for communicating effectively
Explanation and examples
4.1.5.8.5 Perception that pharmacist’s role limited to dispensing medication
Explanation and examples
4.1.5.8.6 Reciprocal embarrassment and discomfort
Explanation and examples
4.1.5.8.7 Blocking behaviors
- Dominating the conversation/continual questioning
  Explanation and examples
- Disruptions
  Explanation and examples
- Distancing
  Explanation and examples
- Distractions (part listening)
  Explanation and examples
- Interrupting/jumping in
  Explanation and examples
4.1.5.8.8 Anxiety about palliative care
Explanation and examples
4.1.5.8.9 Difficulty with closure
Explanation and examples
4.1.5.8.10 References and resources

Content Pages (11)

Topic Level: 4.2 Special issues to consider

Page Level: 4.2.1 Communicating with people from different cultures
Page Headings: Introduction and background
                   Key issues
                   References and resources

Page Level: 4.2.2 Communicating with people who have visual, hearing or cognitive impairments
Page Headings: Introduction and background
                   Key issues
                   References and resources

Content pages (2)

Total chapter pages (14)
Appendix E

Learning objectives for the education package
<table>
<thead>
<tr>
<th>Section</th>
<th>Sub-section</th>
<th>Learning Objectives</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Palliative care philosophy and practice</td>
<td>Overarching objectives</td>
<td>Appreciate the complex nature of palliative care with regard to the principles of care, the goals and methods of service delivery, and the role of the palliative care team.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Understand how to approach palliative patients' with different characteristics and diseases.</td>
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<tr>
<td></td>
<td></td>
<td>Accurately source information about emergency, legal, support and referral information.</td>
</tr>
<tr>
<td>1.1 Basic Principles and Practice</td>
<td>Define Palliative Care</td>
<td>Recognise indicators that suggest a patient might be receiving palliative care.</td>
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<tr>
<td></td>
<td>Identify the different members and roles in the palliative care team</td>
<td>Describe the principles and goals of palliative care.</td>
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<tr>
<td>1.2 Palliative care patients: Characteristics and common diseases</td>
<td>Accurately source information about end of life/advance care planning</td>
<td>Identify the different members and roles in the palliative care team.</td>
</tr>
<tr>
<td></td>
<td>Discuss strategies for managing your own and other’s grief and loss</td>
<td>Accurately source information about end of life/advance care planning</td>
</tr>
<tr>
<td></td>
<td>Discuss the key issues to consider when caring for palliative care patients with different characteristics and diseases.</td>
<td>Discuss strategies for managing your own and other’s grief and loss.</td>
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<tr>
<td>1.3 Support and referral</td>
<td>Accurately source information about palliative care service selection and referral</td>
<td>Accurately source information about palliative care service selection and referral.</td>
</tr>
<tr>
<td></td>
<td>List the types of Support services and State services available in palliative care</td>
<td>Accurately source information about palliative care service selection and referral.</td>
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<tr>
<td></td>
<td>Accurately source information about the Support services and State services available in palliative care</td>
<td>Accurately source information about what to do in PC emergencies.</td>
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<td>Accurately source information about what to do in PC emergencies</td>
<td>Accurately source information about what to do in PC emergencies.</td>
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<tr>
<td>2. Medications</td>
<td>Overarching objectives</td>
<td>Identify common issues with medication use in palliative care patients</td>
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<td></td>
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<td>Accurately source information about medications used in palliative care</td>
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<td>Discuss the different uses of medications in palliative care</td>
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<td>Recognise medication combinations/dosages that are consistent with palliative care</td>
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<td>Identify strategies for accessing non-Pharmaceutical Benefits Scheme (PBS) medications</td>
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<tr>
<td></td>
<td>2.1 General issues with medications used in palliative care</td>
<td>List the common medications indicated for end stage management</td>
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<tr>
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<td>Describe the special palliative care patient groups that require dosage adjustment</td>
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<td>Identify situations where you may need to prioritise the patient’s wishes over the treatment regime</td>
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<td>Identify the PC medications that commonly result in clinically significant interactions</td>
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<td>2.2 Medication administration</td>
<td>Describe the situations where it is appropriate to use the different routes of administration</td>
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<td>2.3 Common medications</td>
<td>Identify the advantages and disadvantages of using syringe drivers</td>
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<td>2.4 Complimentary and alternative medications</td>
<td>List the common classes of medications and provide some relevant examples of each class</td>
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<td>Accurately source information about the palliative care indication and appropriate dosage for each medication</td>
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<td>Describe the different types of complementary and alternative medications and provide some examples of each type</td>
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<td>List the common complementary and alternative medications used by palliative care patients</td>
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<td>Accurately source information about the likely adverse effects and interactions of complementary and alternative medications</td>
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<td>Learning Objectives</td>
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<tr>
<td>3. Pain and symptoms</td>
<td>Overarching objectives</td>
<td>Accurately assess palliative care symptoms, provide appropriate management advice, and recognise when appropriate to refer the patient for assessment by a GP or specialist.</td>
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<td>Accurately source information about pathophysiology, management, and monitoring information for the different palliative care symptoms. Recognise and describe symptoms that are suggestive of a patient being considered “palliative”.</td>
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<tr>
<td></td>
<td>3.1 Basic principles of symptom control</td>
<td>Describe the important considerations for symptom control in palliative care patients.</td>
</tr>
<tr>
<td></td>
<td>3.2 Common symptoms</td>
<td>Describe common symptoms experienced by palliative care patients and appropriate pharmacist assessment of each symptom. Accurately source information about the pathophysiology and management of symptoms. Predict a palliative care patient’s likely symptom/s based on prescription of a given medication/s.</td>
</tr>
<tr>
<td>Section</td>
<td>Sub-section</td>
<td>Learning Objectives</td>
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<tr>
<td>4. Communication skills</td>
<td>Overarching objectives</td>
<td>Identify features of “good” and “bad” communication</td>
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<td></td>
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<td>Implement strategies to communicate effectively in complex, difficult and emotional situations</td>
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<td>Appreciate the variety and complexity of issues that may arise when communicating with palliative care patients.</td>
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<td>Understand how to best manage interactions with palliative care patients by creating and maintaining personal and professional boundaries and by creating closure.</td>
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<td></td>
<td>4.1 Communicating Effectively</td>
<td>Discuss the benefits of using a patient-centred approach to communication in palliative care</td>
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<tr>
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<td>Recognise barriers and facilitators to effective communication, and explain how to implement or overcome them</td>
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<td>Describe the goals of effective communication and explain some of the strategies that can be used to achieve each goal</td>
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<td>4.2 Special issues to consider</td>
<td>Identify situations where it would be appropriate to use the different communication strategies and explain why and what would be achieved</td>
</tr>
<tr>
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<td>Discuss how cultural differences could affect communication between you (a pharmacist) and a palliative care patient or family member</td>
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<td>Identify the key issues to consider when communicating with somebody from a different culture.</td>
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<td>Recognise potential communication impairments that are commonly experienced by palliative care patients and explain strategies to communicate effectively in these situations</td>
</tr>
</tbody>
</table>
Appendix F

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CHAPTER 4 Communicating with Palliative Care Patients and their Families

We would like to acknowledge the previous work in this field by

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and

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Special thanks to
Home & Hospitality Pharmacy Services Pty Ltd
St John of God Health Care Medical Centre
100 Murdoch Drive, Murdoch
for providing the location.

This project is funded by the Australian Government Department of Health and Ageing as part of the Fourth Community Pharmacy Agreement Research & Development Program managed by the Pharmacy Guild of Australia.
Appendix G

Screen Shots of Education Packag
This topic will enable you to:

- appreciate the complex nature of palliative care with regard to the principles of care, the goals and methods of service delivery, and the roles of the palliative care team
- understand how to approach different patients with different characteristics and illnesses and the specialty sources for information about emergency, legal, support and referral information.
Medications Used in Palliative Care

This topic will assist you to:
- Identify common issues with medication use in palliative care patients.
- Accurately source information about medications used in palliative care.
- Discuss the different uses of medications in palliative care.
- Recognize medication contraindications that are consistent with palliative care.

General Issues with Medications Used in Palliative Care:
- Access to palliative care medications
- End stage medications
- Off-label use of medications
- Providing information to patients
- Reimbursement issues
- dignity in ensuring the patient's wishes

Medication Administration?
- Opioids
- Benzodiazepines
- Nonopioid analgesics
- Nonsteroidal anti-inflammatory drugs
- Antiemetics
- Anxiolytics
- Antiplatelet agents
- Cardiovascular agents
- Anticoagulants
- Prokinetics
- Anticonvulsants
- Antiepileptics
- Antihistamines

Common Medications:
- Analgesics:
  - Paracetamol
  - Ibuprofen
- Antiemetics:
  - Metoclopramide
- Antidepressants:
  - Escitalopram
- Antipsychotics:
  - Quetiapine
- Antihistamines:
  - Chlorpheniramine
- Antiinfectives:
  - Amoxicillin
- Analgesics:
  - Mecobalamin

Complementary and alternative medicines (CAMs):
- CAMs background
- Types of CAMs
- Medications used in palliative care
This topic will assist you to:

- accurately assess palliative care symptoms, provide appropriate management advice, and recognise when appropriate to refer the patient for assessment by a GP or specialist
- accurately source information about pathophysiology, management, and monitoring information for the different palliative care symptoms
- recognise and describe symptoms that are suggestive of a patient being considered “palliative”

<table>
<thead>
<tr>
<th>Basic principles of symptom control</th>
<th>Common symptoms</th>
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<tbody>
<tr>
<td>Basic principles of symptom control</td>
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<tr>
<td>Anxiety and cachexia?</td>
<td>Delirium and confusion?</td>
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<tr>
<td>Anxiety?</td>
<td>Depression?</td>
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<tr>
<td>Delirium and confusion?</td>
<td>Insomnia?</td>
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<tr>
<td>Depression?</td>
<td>Nausea?</td>
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<td>Insomnia?</td>
<td>Pain?</td>
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<tr>
<td>Nausea?</td>
<td>Sweating?</td>
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<tr>
<td>Pain?</td>
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</table>
Communication skills

This topic will assist you to:

- Identify features of “good” and “bad” communication
- Implement strategies to communicate effectively in complex, difficult, and emotional situations
- Appreciate the variety and complexity of issues that may arise when communicating with palliative care patients
- Understand how to best manage interactions with palliative care patients by creating and maintaining personal and professional boundaries and by creating closure.

<table>
<thead>
<tr>
<th>Communicating effectively?</th>
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<tbody>
<tr>
<td>Why is effective communication important?</td>
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<tr>
<td>Listening is patients and nurses?</td>
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<tr>
<td>Asking informative questions and open-ended questions?</td>
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<tr>
<td>Responding to patient’s verbal and non-verbal communication?</td>
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<tr>
<td>Understanding the importance of body language and non-verbal communication?</td>
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<tr>
<td>Communicating with patients who have different cultures?</td>
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<tr>
<td>Communicating with patients who have visual, hearing or cognitive impairments?</td>
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<table>
<thead>
<tr>
<th>Special issues to consider?</th>
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<tbody>
<tr>
<td>Communicating with patients who are in pain?</td>
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<tr>
<td>Communicating with patients who are in distress?</td>
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<tr>
<td>Communicating with patients who are in grief?</td>
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<td>Communicating with patients who are in fear?</td>
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<td>Communicating with patients who are in anger?</td>
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<td>Communicating with patients who are in confusion?</td>
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Appendix H

Detailed Workshop Schedule
<table>
<thead>
<tr>
<th>Time</th>
<th>Session Description</th>
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</thead>
<tbody>
<tr>
<td>8:30am</td>
<td>Registration and Tea/Coffee</td>
</tr>
<tr>
<td>9:00am</td>
<td>Overview of project: what we are doing and why</td>
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<tr>
<td>9:15am</td>
<td>Palliative Care Introduction</td>
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<td></td>
<td>Test</td>
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<td></td>
<td>• Pre-test of participants’ palliative care knowledge</td>
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<td></td>
<td>Lecture</td>
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<td></td>
<td>• Palliative Care Philosophy and Practice</td>
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<td>• Goals of Care</td>
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<td>10:00am</td>
<td>Opioid Conversions</td>
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<td>Tutorial exercises</td>
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<td>• Converting Opioid dosages</td>
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<td>10:30am</td>
<td>Morning Tea</td>
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<tr>
<td>10:45am</td>
<td>Medication Review Case Studies</td>
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<td>Case Issues</td>
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<td>• Pain</td>
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<td>• Opioid conversions</td>
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<td>• Medication access</td>
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<td>• Neuropathic pain</td>
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<td>• Lethargy and fatigue</td>
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<td>Review</td>
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<td>• Two sets of two similar cases (i.e. four in total)</td>
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<td>• Break into groups of four/five people</td>
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<td>• Groups complete review for one of two similar cases</td>
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<td>• Groups report back to workshop, critique and discuss</td>
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<td></td>
<td>• Repeat for second set of two cases</td>
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<tr>
<td>12:45pm</td>
<td>Lunch</td>
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<td>Finish</td>
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Appendix I

Workshop Materials Book