No painful compromise

A guide for commissioners and providers to improve pain management for dying people at home
Acknowledgements
This report was written by Stephen McCauley at Hospice UK. With special thanks to Dr Sarah Russell at Hospice UK and Jocelyn Hinds, formerly at the National Council for Palliative Care.

For more information
Please contact the Policy and Advocacy team at policy@hospiceuk.org or on 020 7520 8200, or visit the Hospice UK website: www.hospiceuk.org

About Hospice UK
Hospice UK is the national charity for hospice care. We believe that everyone, no matter who they are, where they are or why they are ill, should receive the best possible care at the end of their life.
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Executive summary

People’s first priority at the end of life is to be free from pain and discomfort. But for too many people choosing to die at home means that their symptoms, particularly pain, will not be as well managed when compared to other care settings. In England, research has shown that pain management at home has been consistently rated as poor in comparison to hospice inpatient units, care homes and hospitals, indicating that previous solutions have not addressed the core problem, and that more work is needed to address this inequality.

This study looks at how pain management for dying people being cared for at home might be improved. We explore in detail the experiences of professional healthcare staff, from community nurse specialists and specialist palliative care clinicians to GPs and pharmacists, to understand what factors contribute to good pain management.

Improving pain management at home for people at the end of life requires healthcare services to identify and address the factors that enable or impede good outcomes. We find that pain management at home for people at the end of life is affected by factors linked to both strategic and clinical considerations.

Key findings

Strategic considerations

There are a number of related factors which impact on pain management at home that are strategic considerations for healthcare services.

Increased service demand, service models that cannot meet demand and staff shortages, particularly in community and district nursing, are impacting on the system’s capacity to meet the pain management needs of people being cared for and dying at home. Through an online survey of healthcare professionals with particular experience in pain management in end of life care we found:

- Only one in two respondents think that staffing levels are sufficient to meet the pain management needs of dying people at home.
- While seven in 10 healthcare professionals can access seven-day extended-hour pharmacy services which dispense pain medication for a person at the end of life, many find it a difficult process.
- More than six in 10 rate the effectiveness of their electronic patient record system in sharing information as ‘requires improvement' or ‘inadequate'.

Clinical considerations

The education and training of both clinicians and carers affects the effective delivery of pain management for dying people at home.

A lack of education and training for staff and a lack of information and support for family carers impacts on the pain management outcomes of people at the end of life being cared for at home.
Through our online survey we found:

- Almost one in three respondents rate the availability of end of life care training in their geographic area as ‘requires improvement’ or ‘inadequate’.

- Only one in four had received training on coordination systems that facilitate the sharing of patient information, and two in five had received training on shared decision-making that enables people to actively participate in the decisions about their care.

- One in four healthcare professionals responding to the survey report that they were unaware of access to 24/7 telephone end of life care advice for people at the end of life, their families and carers.

**Improving pain management for dying people at home**

The factors that support or impede effective pain management at home, identified in this report, underpin existing policy and NICE guidelines, and align with the Ambitions Framework for Palliative and End of Life Care and policy set out in the government’s national commitment to improving end of life care.

This report provides a guide for commissioners and providers to improve pain management for people at the end of life being cared for at home, showing how existing policy and guidelines can be used to drive better outcomes.

**Key actions for commissioners and providers**

There are a number of actions contained in this report that commissioners and service providers can take to improve pain management for dying people at home. The key actions to take forward as a minimum come under the themes: caseload and staffing; education and training; and access to advice and support:

- Ensure that workforce planning delivers sufficient staff numbers with manageable caseloads to support people at the end of life being cared for at home.

- Ensure that staff who care for dying people at home have the knowledge, skills and support they need to provide quality care and support.

- Ensure that systems are in place to allow everyone in need to access appropriate end of life care advice and support on a 24/7 basis.
Introduction

We know that pain management for people at the end of life who die at home is rated by their relatives to be less effective than for people who die in other care settings. Many people want to be able to stay at home at the end of their lives, and research shows that one of the things people fear most at the end of their life is being in pain. This may mean that people who wish to die at home have to accept a compromise: if they wish to be at home their pain management may be less effective. This trade-off needs to end.

This report looks at what influences pain management for dying people at home. Identifying and acting on the factors that support or impede effective pain management for people at the end of life being cared for at home has the potential to improve how services deliver care and drive better outcomes for dying people, their families and carers.

Methodology

This report is a mixed methods approach based on research undertaken with healthcare professionals across England. First, a literature review informed a series of 14 semi-structured interviews. These in turn informed the development of an online survey that 370 self-selected healthcare professionals with particular experience in pain management in end of life care completed.

A more detailed explanation of the methodology, including interview and survey questions, is available in the appendices.
Strategic considerations

Evidence shows that dying people’s pain is reported to be consistently not as well-managed at home compared to other care settings such as hospice inpatient units, care homes and hospitals.²

We sought to explore aspects of the health and care system which have particular relevance for pain management for people approaching the end of life at home.

Caseload and staffing

Healthcare services need to have sufficient staff numbers who are available to provide the quality care and support for dying people being cared for at home.

We asked a series of questions regarding caseload and staffing levels, including: whether respondents’ caseload or practice list numbers had increased in the past 12 months; how ‘manageable’ their caseload is; and whether they thought that staffing levels in their area are able to meet the pain management needs of dying people.

The findings show that staff shortages and increased caseloads are seen as a barrier to effective pain management at home. Indeed, survey respondents identified caseload and staffing as the biggest barrier to effective pain management:

- One in two (51 per cent) think that staffing levels are sufficient to meet the pain management needs of dying people at home.
- Two in three (66 per cent) report that their caseload has increased over the past 12 months.
- One in five (20 per cent) describe their caseload as ‘not manageable’.

Figure 1. Staffing levels sufficient to meet needs

Figure 2. Caseload increased in past 12 months
Our findings indicate that increased service demand, service models that do not meet demand as the need for end of life care outpaces service provision, and staff shortages, particularly in community and district nursing, are impacting on the system’s capacity to meet the pain management needs of people being cared for at home.

As one GP put it:

“We need more district nurses to support our system, they are an endangered species!”

The finding on staff shortages is supported by a recent King’s Fund report on how financial pressures in the NHS are affecting patient care. The report found that dying people are sometimes left for hours without adequate pain relief as a consequence of nursing shortages in the community.

Many survey respondents, and interview subjects, also reported challenges affecting patient care in rural locations due to the distances staff had to travel to reach people’s homes.

The availability of healthcare professionals to attend to the needs of dying people at home is a significant factor in effective pain management. Our research shows that a shortage of staff and increased caseloads are a barrier to meeting those needs.

With increased service demand demonstrated by high caseloads and staff shortages, it is clear that current models are struggling to meet need. In a later section in the report, under ‘Access to advice and support’, we set out how families and carers have an important role in effective symptom management, and that when they have the right support this could make a difference in meeting pain management needs.

The NICE quality standard for end of life care states that services need to have a workforce in place that is sufficient in number and skill-set to provide quality care and support.

**ACTION – Commissioners and providers**

Ensure that workforce planning delivers sufficient staff numbers with manageable caseloads to support people at the end of life being cared for at home.

Explore new models of care and support: for example, staff acting as mentors and trainers to support the administration of pain relief by families and carers.

**Prescribing and dispensing**

We know that pain can be relieved with expert palliative care and that attending to pain and symptom management is the primary obligation of clinicians when a person is approaching the end of life. Supporting healthcare professionals, services and systems can help meet the pain management needs of dying people at home.

The survey included a number of questions on prescribing and dispensing, including whether there are shared or local guidelines for general symptom assessment and prescribing at the end of life, and for anticipatory or ‘Just in Case’ prescribing; how confident people are to prescribe or advise on opioid choices or doses; and whether there is 24/7 access to telephone advice on pain management for healthcare professionals from specialist palliative care services or professionals.
The survey findings report that there are established guidelines for assessment and prescribing, and 24/7 advice is in place for most healthcare professionals:

- Over nine in 10 (91 per cent) say there are guidelines for general symptom assessment and prescribing, and for anticipatory or ‘Just in Case’ prescribing.
- Eight in 10 (80 per cent) report availability of 24/7 telephone end of life care advice for healthcare professionals.
- Eight in 10 (80 per cent) are confident or very confident in prescribing or advising on opioid choices or doses.
- Seven in 10 (69 per cent) can access seven-day extended-hour pharmacy services which dispense pain medication for a person at the end of life, but many (42 per cent) find it a difficult process.

While guidelines and documentation for assessment and prescribing seem to be in place, the findings also show that a large number of healthcare professionals find the process of accessing pain medication from extended pharmacy services to be a difficult process.

This was an issue raised in the interviews and also by many survey respondents in answer to an open-ended question in the survey. There are reported problems with accessing medication within and especially outside of normal working hours, and out-of-hours service considerations in general linked to staffing shortages.

Survey respondents identified prescribing as both the second main barrier and the most important enabler for effective pain management. While this enabler seems in place in terms of guidelines and advice, it is still seen as a key barrier which could also be due to other factors contained in this report such as issues with information sharing and access to advice and support for families and carers.

NICE recommends that commissioners and service providers make sure that dying people have their physical needs met, including accessing medicines at any time of the day or night.\(^5\)
ACTION – Commissioners and providers

Plan for services and systems to be in place for quick access to medicines to meet the pain management needs of people at the end of life being cared for at home.

Sharing information

Healthcare professionals need to be able to record, share and access up to date information that is focused on a dying person’s needs and wishes. Electronic information sharing systems enable consistent and coordinated care at any time of the day or night for people approaching the end of life at home.

We asked respondents to rate the effectiveness of their organisation’s electronic patient record system in sharing information about people’s pain management needs between healthcare professionals. We also asked a specific question regarding the roll-out of Electronic Palliative Care Coordination Systems (EPaCCS) which NHS England is committed to implementing across England by 2020.7

The findings show that many staff working in end of life care do not consider their electronic patient record systems to be up to the task of sharing information between teams and organisations, and that there is progress to be made in the roll-out of EPaCCS:

- More than six in 10 (62 per cent) rate the effectiveness of their electronic patient record system in sharing information as ‘requires improvement’ or ‘inadequate’.
- Only one in four (27 per cent) respondents currently use EPaCCS.

Figure 5. Effective at sharing information

The communication of patient and family needs, discussion and care was hampered by inconsistent electronic communication systems and ineffective IT. Many survey respondents described the difficulties of working with different electronic systems that are not able to share information with each other.

The communication of patient and family needs, discussion and care was hampered by inconsistent electronic communication systems and ineffective IT. Many survey respondents described the difficulties of working with different electronic systems that are not able to share information with each other.
A hospice community service lead said about their experience of different systems locally:

“It’s quite disjointed as not everyone has the same system and even when you have, sharing data is challenging as it’s not set up to be shared and you can’t access all the notes.”

It was also reported that even if an area had started to implement EPaCCS and share patient records, that the information held is incomplete and not sufficient to support community staff to effectively and confidently manage people’s pain.

Healthcare services and healthcare professionals need to be able to work together to record, share and access information that is focused on a dying person’s needs. The commitment to the roll-out of shared electronic records, as well as the system-wide plans to use data and technology to improve patient outcomes under the Personalised Health and Care 2020 framework, could also help support the sharing of information on people’s choices and preferences in care plans and promote personalised care.

The Ambitions Framework includes the ambition that care is coordinated. A key building block to realise that ambition is the ability to electronically share care records, but the reality for many healthcare professionals is inconsistent electronic communication systems and ineffective IT.

According to the NICE quality standard, dying people being cared for at home should expect the same consistent, coordinated care at any time of day or night as people in other care settings; delivered by healthcare professionals aware of the person’s condition, care plan and preferences.

**ACTION – Commissioners and providers**

Enable electronic information sharing systems to be in place, and support practice and behaviours for using these fully, to ensure that healthcare professionals, across public and third sector services, can provide consistent and coordinated care on a 24/7 basis to people approaching the end of life being cared for at home.
Clinical considerations

The education and training of both clinicians and carers is an important factor in the effective delivery of pain management for dying people at home.

We examined the end of life care education and training available for healthcare professionals, and the information and support available for family carers.

**Education and training**

Having the right knowledge and skills to provide quality care and support for people approaching the end of life is essential for healthcare professionals.

We asked survey respondents to rate the availability of education or training on end of life care in their area. We also interrogated further what specific end of life care education or training was provided.

We found that many staff do not think enough training is available, and that certain topics relevant to providing effective pain management at home were under-represented in the survey sample findings:

- Almost one in three (29 per cent) rate the availability of end of life care training in their area as ‘requires improvement’ or ‘inadequate’.
- Only one in four (24 per cent) had received training on coordination systems that facilitate the sharing of patient information, and two in five (39 per cent) had received training on shared decision-making that enables people to actively participate in the decisions about their care.

**Figure 6. Availability of EoLC training**
Many reported that they were unable to attend education or training, or indeed to provide or lead sessions as trainers, due to service demands and staff shortages.

A district nurse stated that:

“There used to be a really good training programme here but they had to stop doing it last year as they can’t manage both their caseloads and education ... it comes down to [being] short-staffed.”

Education and training is crucial in enabling more skilled assessment and symptom management. As set out in the Ambitions Framework, attending to pain and symptom management is the primary obligation of clinicians when a person is approaching the end of life, and their skills and competence must be up to date.\(^6\)

Also just a quarter of respondents had received training on care coordination systems, which links to the above section on the issue of inconsistent electronic communication systems and ineffective IT impacting on the communication of patient and family needs.

The Ambitions Framework has the ambition that all staff are prepared to care.\(^6\) To realise this ambition, all healthcare professionals need to be trained and supported so they can provide the necessary compassion and skill to the most difficult and delicate time in a person’s life.

The NICE quality standard for end of life care makes clear that healthcare professionals need to have the right knowledge and skills to provide quality care and support for people at the end of life and their families and carers.\(^5\)

**ACTION – Commissioners and providers**

Ensure that staff who care for dying people at home have the knowledge, skills and support they need to provide quality care and support.

Support staff to attend education and training, focusing on key elements, including: assessment and management of pain and other symptoms, medicines optimisation, shared decision-making and use of coordination systems.
Access to advice and support

Families and carers have an important role in caring for a dying person, including in effective symptom management, and need to be able to access advice and support at any time of the day or night.

The survey asked people whether there are 24/7 telephone palliative or end of life care advice lines available for people at the end of life, their families and carers. We also asked if there are any specific courses or education for friends or family carers about looking after someone at the end of life.

The findings show that a quarter of respondents state that families do not have access to 24/7 advice lines, and that just 22 per cent knew of relevant courses for unpaid carers:

- One in four (25 per cent) were unaware of access to 24/7 telephone end of life care advice for people at the end of life, their families and carers.
- Only one in five (22 per cent) know of courses or education for family carers looking after someone at the end of life.

The lack of information and support for family carers is particularly significant, given the importance of their role in caring for a person at the end of life.

We also received multiple reports regarding the lack of support for carers regarding the administration of medication and obtaining repeat prescriptions. The difficulties with the process of accessing pain medication, both within and particularly outside of normal working hours, has already been cited in the prescribing and dispensing section of the report. An illustration of the problem was provided by a commissioner:

“The general frustration in the community setting is the amount of running around that’s needed getting agreements for the prescription that might not be completely accurate and so won’t be dispensed and it has to be all redone.”
With the increased service demand demonstrated by our findings regarding high caseloads and staff shortages, it is clear that a professionally-led care model is struggling to meet need. We heard from survey respondents who are exploring the potential for supporting families and carers to administer pain medications themselves.

Families and carers are crucial in effective symptom management, and when they have the confidence and support, and have access to advice on a 24/7 basis, this could make a difference in meeting pain management needs.

One key foundation of the Ambitions Framework is that good end of life care includes involving, supporting and caring for those important to the dying person. Family carers have an important role in caring for a dying person, and so the lack of available information and support could be having an adverse effect on good pain management.

NICE recommends that dying people and their families and carers should expect appropriate and accessible information and support, including about treatment and care options, medication and what to expect at each stage of the journey towards the end of life. They should also know who they can contact to obtain advice and support.

**ACTION – Commissioners and providers**

Ensure that systems are in place to allow everyone in need to access appropriate end of life care advice and support on a 24/7 basis.

Ensure that training and support on practical issues is available for those caring for people at the end of life who require extra help with daily living or extensive care.
Conclusion

Many people want to spend as much of their last stage of life at home as possible, which is supported by government and NHS England policy. Being in pain is one of the things people fear most at the end of their life, so it is crucial to develop a better understanding of why addressing dying people’s pain at home appears to lag so far behind hospice inpatient units, hospitals and care homes.

Healthcare services will only be able to achieve improvements in pain management for people at home if they have a better understanding of the factors that enable or impede effective outcomes. The findings contained in this report contribute to this understanding, and are underpinned by existing policy and guidelines to help services deliver more effective pain management and drive better outcomes for dying people, their families and carers.

Meeting the pain management needs of people at the end of life being cared for at home will not only lead to better outcomes for people, their families and carers. It will also help to address key structural challenges facing our health and care system, ensuring people’s needs are met quickly and effectively with appropriate community services, rather than having to access inappropriate and expensive acute care.

We should all expect the best possible end of life care no matter where we die. No one should die in unnecessary pain because our healthcare systems are poorly designed or because of the availability and capability of healthcare professionals.

This will only happen if healthcare services can identify the factors that enable or impede effective practice, and act on the existing policies and guidelines set out through the expert views of healthcare professionals and policy-makers.
References


Appendix 1: Literature review

A rapid review of the existing literature took place between May and November 2016. Academic literature and policy and strategic documents were searched using databases such as Pub Med, Google Scholar, Cumulative Index to Nursing and Allied Health Literature, Web of Science, Department of Health, Research Gate and Cochrane library.

The literature reviewed covered the period from 2010 to 2016. The search terms included; pain, pain management, opioids, cancer, community, hospice(s), hospital(s), care home(s), nursing home(s), admission(s), just in case, anticipatory prescribing, advance care planning, PRN, syringe drivers, syringe pumps, out of hours, 24 hour(s) care, end of life, last days of life, care of the dying, end of life care, pharmacy, pharmacists, palliative care, hospice care, and coordination.

The review identified several topics of interest for example:


Underpinning these topics of interest are the person-centred themes illustrated by national strategic reports including:

- One Chance to Get it Right: Improving people’s experience of care in the last few days and hours of life (The Leadership Alliance for the Care of Dying People 2014).
- Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020 (National Palliative and End of Life Care Partnership 2015).
- A low priority? How local health and care plans overlook the needs of dying people (Hospice UK, 2016).
- Our Commitment to you for end of life care: The Government Response to the Review of Choice in End of Life Care (Dept. of Health 2016).

The rapid review of the literature informed the next steps of the project, namely the question topics for the interviews (coordination, medication and workforce) with a purposeful sample (care staff, commissioners and strategic staff).
Appendix 2: Interviews – purposeful sample

Interview subjects were identified as staff of services with particular engagement in pain management for people at end of life being cared for at home, across strategic management, commissioning and frontline care. These staff were chosen as interview subjects as our research question centres on how services can improve pain management.

Fourteen face to face interviews with key staff in each of the four locations, including the two pilot areas, were carried out between May and November 2016. A very similar question schedule was used for all of the interviews (Appendix 4).

The first 12 interviews were carried out by interviewers one and two. The last two interviews were carried out by interviewer three. Each individual interview was audio recorded and then transcribed verbatim by the interviewer and then thematically coded and analysed into overarching and subthemes by interviewer three. The themes were then independently reviewed and areas of agreement and disagreement discussed and resolved.

Figure 9: semi-structured interviews, sample

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<tr>
<th>Locality</th>
<th>Number of interviews</th>
<th>Roles of interviewees</th>
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<tr>
<td>A</td>
<td>3</td>
<td>Strategic, Commissioner and Nurse roles</td>
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<tr>
<td>B</td>
<td>3</td>
<td>Strategic and Nurse roles</td>
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<tr>
<td>C</td>
<td>3</td>
<td>Strategic, Commissioner and Nurse roles</td>
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<td>D</td>
<td>3</td>
<td>Commissioner and Nurse roles</td>
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<tr>
<td>Pilot 1</td>
<td>1</td>
<td>Strategic role</td>
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<td>Pilot 2</td>
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<td>Commissioner role</td>
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Appendix 3: Themes from interviews

The interview were transcribed and then thematically coded and analysed. The preliminary findings covered three topics: coordination, medication and workforce. New topics did not arise as a result of the interviews.

In analysing the interviews, each of the interview topics can be broken down into core themes, and then further detail (subthemes) which provided practical insights into the challenges and opportunities of delivering effective pain management in home settings.

The findings from these interviews identify that there appears to be an association of several factors on pain management in the community, under the three key topics of coordination, medication and workforce. These are (as shown in Figure 10): communication, advance care planning, social care, equipment, pharmacy, prescribing, caseload and staffing, district nurses, travel and training (and within these factors several specific issues).

<table>
<thead>
<tr>
<th>Interview question topics</th>
<th>Core themes</th>
<th>Subthemes</th>
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<tr>
<td>The role of:</td>
<td>Communication</td>
<td>Systems and workload</td>
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<td>• Different systems, issues &amp; managers</td>
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<td></td>
<td></td>
<td>• Different electronic systems</td>
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<td></td>
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<td>• Impact of (busy) workload on use of systems</td>
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<td></td>
<td></td>
<td>Continuity and collaboration</td>
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<td></td>
<td></td>
<td>• Continuity of nurses</td>
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<td></td>
<td></td>
<td>• Need for collaboration between services</td>
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<td></td>
<td>• Concerns over continuity of care &amp; transfer of, eg advance care planning documents between services</td>
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<td></td>
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<td>• Examples of hospice coordination services</td>
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<td>Structures and documentation</td>
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<td></td>
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<td>• Lack of internal structures in practices</td>
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<td>• Desire for templates</td>
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<td>• Incomplete records</td>
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<td>24/7 care</td>
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<td>• Advice lines (variability)</td>
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<td>• Hospice at Home or coordination services</td>
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<td>• Networks of consultations</td>
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<td>• Overnight cover organisation</td>
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<td><strong>Coordination</strong></td>
<td><strong>Advance care planning</strong></td>
<td><strong>Importance of</strong></td>
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<td></td>
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<td>• Shared records or handing over of information</td>
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<td></td>
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<td>• GPs doing documents &amp; involvement</td>
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<th><strong>Social Care</strong></th>
<th><strong>Consistency</strong></th>
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<td></td>
<td>• Not enough services/capacity particularly in rural areas</td>
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<td>• Skills and training of staff</td>
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<td>• Hard to engage strategically</td>
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<th><strong>Equipment</strong></th>
<th><strong>Consistency</strong></th>
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<tr>
<td></td>
<td>• Systems within care homes</td>
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<td>• Locality/area differences</td>
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<td>• Need for central store</td>
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<td>• Lack of organisation</td>
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<th><strong>Pharmacies</strong></th>
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<td></td>
<td><strong>Supply</strong></td>
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<td>• Some provide key drugs</td>
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<td>• General supply issues</td>
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<th><strong>Systems</strong></th>
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<td></td>
<td>• Slow especially at weekends</td>
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<td>• Dispensing inaccuracies</td>
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<th><strong>Prescribing</strong></th>
<th><strong>Consistency</strong></th>
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<td></td>
<td>• GP lack of information about anticipatory prescribing</td>
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<td></td>
<td>• GP lack of training</td>
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<td></td>
<td>• Just in case varies</td>
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<tr>
<th><strong>Role of nurse prescribers</strong></th>
<th><strong>Consistency</strong></th>
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<tbody>
<tr>
<td></td>
<td>• Inequitable distribution of nurse prescribers</td>
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<td></td>
<td>• Education budget cuts</td>
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<td></td>
<td>• Managing with case load</td>
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<td></td>
<td>• Lack of support/procedures</td>
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<td></td>
<td>• Managing differences in opinion</td>
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<tr>
<th><strong>Workforce</strong></th>
<th><strong>Consistency</strong></th>
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<tr>
<td><strong>Caseload and Staffing</strong></td>
<td><strong>Consistency</strong></td>
</tr>
<tr>
<td></td>
<td>• Number of patients (high/low)</td>
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<tr>
<td></td>
<td>• Short staffed</td>
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<td></td>
<td>• Lower skilled staff</td>
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<tr>
<th><strong>District Nurses</strong></th>
<th><strong>Consistency</strong></th>
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<tr>
<td></td>
<td>• DN Liaison role</td>
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<tr>
<td></td>
<td>• Increasing workload</td>
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<td></td>
<td>• Lack of support</td>
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<td></td>
<td>• Lack of training</td>
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<td></td>
<td>• Deskilled</td>
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<td></td>
<td>• Advance care planning low</td>
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<td></td>
<td>• Hierarchical</td>
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<tr>
<th><strong>Travel</strong></th>
<th><strong>Consistency</strong></th>
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<tbody>
<tr>
<td></td>
<td>• Time to travel</td>
</tr>
<tr>
<td></td>
<td>• Geographical area size</td>
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<tr>
<th><strong>Training</strong></th>
<th><strong>Consistency</strong></th>
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<tbody>
<tr>
<td></td>
<td>• Time to learn</td>
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<td>• Inclusive &amp; responsive programmes</td>
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<td></td>
<td>• Available trainers or programmes</td>
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<td></td>
<td>• Specific role programmes (GPs, Nurses &amp; others)</td>
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<td></td>
<td>• General end of life programmes</td>
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<td></td>
<td>• CNS team educators</td>
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<td>• Budget</td>
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Appendix 4: Example of interview question schedule (care staff)

**Opening questions**

- How long have you been working in palliative care?
- Why did you decide to work in this area?

**[A] Coordination**

(A1) **Tell me about what working with social care providers in your area is like.**

(Probes: how easy is it to get social care organised for someone/do you feel social care levels are adequate/what kind of communication do you have with the social care workers looking after the same people as you)

(A2) **Do you know what EPaCCS are? (If not, define). Are there EPaCCS in place in this area?**

(If yes.) Tell me about the difference EPaCCS have made to coordination between services.

(If no.) Tell me about how you share information between different services.

(A3) **Are there other specialist palliative care services operating in this bit of the community? How do you work with them?**

(A4) **How do you communicate with GPs and district nurses?**

(A5) **Are nurses able to prescribe in this area? How does this work?**

**[B] Medication**

(B1) **Is anticipatory prescribing/Just in Case medication available in this area? How often have you used it?**

(B2) **Have you had any difficulties with accessing medication for people when it’s needed?**

(If yes.) Can you tell me about a time you’ve run into difficulties with pharmacies not being open when you needed? (Or when your patients have had such problems?) Or not having the drugs you needed?
[C] Workforce

(C1) On average, how many patients would you be caring for at any one time? How much time do you spend on travel vs. care?

(C2) Have you received particular training in pain management?
   (If yes.) Can you tell me the sort of things it covered? Can you tell me anything you hoped it would cover but it didn’t?

[D] Holistic care

(D1) Do people at home at the end of life have access to allied health professionals (eg complementary therapists, physiotherapists) to help with pain relief? What is the process for arranging this?

(D2) How easy is it for you to access to pain management equipment such as syringe drivers? Or other equipment such as hospital beds, oxygen, etc.?

Closing questions

• Is there anything else you think we haven’t talked about that you think is relevant to community pain management?
Appendix 5: Online survey

The findings of the literature review and analysis of semi-structured interviews were used to develop an online survey to improve our understanding of the factors that support effective pain management, and to provide quantitative data to underpin the recommendations of the final report.

The survey was aimed at healthcare professionals with particular engagement in pain management for people at the end of life being cared for at home. There were asked a range of questions grouped under the key topics of: pain medication; care coordination; and workforce.

The online survey was open for a month from January to February 2017. We received responses from 370 people, with staff from 20 different types of organisation, in 35 different job roles, completing the survey.
Appendix 6: Online survey analysis – quantitative

The online survey responses were coded and the data for each theme and subtheme was exported into excel to be analysed. The key findings from the survey are shown in the main body of this report.

A small number of questions were not able to be analysed as they were interpreted in different ways by respondents as in hindsight there were poorly worded or phrased. For example, when asked about caseload numbers and those at the end of life, respondents answered in many different ways (eg as practice, team, individual).

The responses were dominated by two types of organisation, with 70 per cent working for either hospices (39 per cent) or NHS Trusts (31 per cent), and very few roles. Community nurse specialists comprised one in four of all responses (89 or 24 per cent), followed by hospice service leads (46 or 12 per cent) and district nurses (42 or 11 per cent).

As few organisation-types and job roles dominate the findings, the survey analysis and key findings are based on an overview of all responses across England.
Appendix 7: Online survey analysis – qualitative

The last survey question gave respondents the opportunity to tell us about anything about supporting effective pain management at home for people at the end of life? 146 out of 370 respondents wrote free text replies to this question.

The replies were coded and analysed using qualitative methodology drawn from the ‘framework analysis’ approach. The replies were copied and pasted in full into a template (an overview of the findings is illustrated in Figure 11).

To each respondent reply initial transcribing coding labels, ideas and thoughts were applied. These were then analysed and developed into coding themes: impact; importance and integrity. These three coding themes distinguished between what participants stated as fact or in their experience (impact) as opposed to their opinion (important) or pride in their service (integrity). The three coding themes were then organised into 12 topic themes and theme categories of strategic or clinical considerations.

Figure 11. Overview of findings of what impacted (experience) or was of importance (opinion) as described by respondents.
Appendix 8: Example of online survey questions

Your details

• Please write the name of your organisation.

• What is your job role? (Drop-down list).

• In which NHS Area Team are you based? (Drop-down list by 25 NHS Area Teams).

• If you do not work for a health or care organisation, are you a person with lived experience? Yes/No.

• If you do not work for a health or care organisation, please write the first part of your postcode.

Opening questions

• What are the main barriers to providing effective pain management at home for people at the end of life? Please rank your top three factors only from the below list (Prescribing/Pharmacies and Dispensing/Equipment/ACP/Sharing information /Access to advice, care and support/Education and Training/Caseload and staffing).

• When everything goes right in managing a dying person’s pain at home, what are the key factors that make that happen? Please rank your top three factors only from the below list (Prescribing/Pharmacies and Dispensing/Equipment/ACP/Sharing information /Access to advice, care and support/Education and Training/Caseload and staffing).

Theme: Pain medication

Prescribing

• In your area are there shared or local guidelines for general symptom assessment and prescribing at the end of life? Yes/No/Don’t know.

• In your area are there shared or local guidelines for anticipatory or Just in Case prescribing? Yes/No/Don’t know.

• In your area do you have formal documentation for anticipatory or Just in Case prescribing? Yes/No/Don’t know.

• Do any of the following community staff roles prescribe in your area: Tick boxes for Hospice CNS/District Nurses/Independent prescribers/SPC nurse prescribers/other (please specify).

• If relevant to your role, how confident are you to prescribe or advise on opioid choices or doses? Very confident/confident/often need advice/leave to others.

• In your area is there 24/7 access to telephone advice on pain management for healthcare professionals from specialist palliative care services and/or professionals? Yes/No/Don’t know.
Pharmacies and dispensing

- In your area can you access a seven-day extended-hour pharmacy service until 10pm which dispenses pain medication for a person at the end of life? Yes – easy process/difficult process/No/Don’t know.

- Is there a pharmacy home delivery service in place in your area? Yes/No/Don’t know.

Equipment

- In your area what medical care equipment is available to support care for people at home at the end of life? Tick boxes for Syringe pump or similar syringes/needles and giving sets/Hospital-type beds/Moving and handling equipment/Pressure relieving aids/Other (please specify).

- How easy is it to order and deliver such equipment within 24 hours? Very easy/easy/difficult/very difficult.

Theme: Care coordination

Advance care planning

- In your role are you involved in discussions or documentation about end of life wishes and decisions (advance care planning)? Very often/often/not often/rarely.

- How would you describe the uptake of advance care planning by patients in your area? Outstanding/Good/Requires Improvement/Inadequate.

- Who is responsible for advance care planning in your area? GPs/District/Community Nurses/Palliative Care/Hospice Nurses/Other (please state).

- Is the advance care planning documentation used in your area standardised? Yes/No/Don’t know.

Sharing information

- In your role do you participate in end of life locality meetings (eg GSF, end of life register or community MDT)? Yes/No.

- Please specify which electronic patient record system(s) are used in your area. Tick boxes for EPaCCS/SystmOne/Emis/My Wishes/iNurse/UNIQUIS/Crosscare/Other (please specify).

- For the electronic patient record system(s) used in your area what type of access do you have – EPaCCS/SystmOne/Emis/My Wishes/iNurse/UNIQUIS/Crosscare/Other (please specify) with: View-only access/read-write access/no access/not applicable.

- How effective are they in sharing information about people’s pain management needs between teams and organisations? Outstanding/Good/Requires improvement/Inadequate.
**Access to advice, care and support**

- In your area are there 24/7 telephone palliative or end of life care advice lines available for people at the end of life, their families and carers? Yes/No/Don’t know.
- Are there hospice at home services available in your area? Yes/No/Don’t know.
- Are there specialist community palliative care services available in your area? Yes/No/Don’t know.
- In your area are there any specific courses or education for unpaid or family carers about looking after someone at the end of life? Yes/No/Don’t know.

**Theme: Workforce**

**Education and training**

- In your role are you provided with specific education or training on end of life care? Yes/No.
- If relevant to your role, do you commission education or training on end of life care? Yes/No.
- Please rate the availability of education or training on end of life care in your area: Outstanding/Good/Requires improvement/Inadequate.
- In your role what education and training in end of life care is provided? Tick boxes:
  
  **Symptom control**
  
  » Pain
  » Respiratory Symptoms
  » Gastrointestinal Symptoms
  » Confusion and Psychological Symptoms
  » Care in last days of life
  » Syringe pumps, Just in Case and Anticipatory Prescribing
  » Palliative care emergencies

  **Communication**
  
  » Empathy, compassion and significant conversations
  » Coordination systems such as EPaCCS

  **Ethical issues**
  
  » Shared Decision Making
  » Mental Capacity Act

  **Other (please specify)**
**Caseload and staffing**

- If relevant to your role, approximately how many patients do you have on your own caseload or practice list?

- Approximately how many of these patients do you consider to be in the last three months of life?

- How ‘manageable’ is your own caseload/practice list number? Very manageable/manageable/not manageable/not at all manageable.

- Has your own caseload/practice list number increased, decreased or stayed the same in the past 12 months? Yes has increased/Has stayed about the same/No has decreased/Don’t know.

- Are staffing levels in your area able to meet the pain management needs of people in the last three months of life? Yes/No/Don’t know.

**Closing question**

- Is there anything else you want to tell us about supporting effective pain management at home for people at the end of life? Free text box.