NIHR Dissemination Centre

THEMED REVIEW

Better Endings

Right care, right place, right time

NHS
National Institute for Health Research

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An independent review of NIHR research on end of life care services

"This NIHR themed review is very welcome. It complements policy, and helps those planning and shaping services to understand the extent to which evidence exists, so that better decisions can be made. It also highlights areas where evidence is weak or does not exist. High quality evidence and information is one of the key foundations for achieving our ambition in delivering the best possible care for those at end of life."

Professor Bee Wee, National Clinical Director for End of Life Care
NHS England

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WHAT IS THIS REVIEW?

Helping people to die with dignity, compassion and comfort is an important goal of any health service. But it is difficult to do. Recent accounts have provided rich insights into some of the challenges for healthcare professionals trying to meet the needs of people at the end of life (*McCartney 2014, Gawande 2014*). Our organisations are not always set up in a way to deliver the right care, at the right time, to all dying people and their families where they want to be.

This review brings together recent evidence which might help those delivering, planning or using end of life services. The review focuses on studies funded by the National Institute for Health Research (NIHR), which was set up in 2006 as the research arm of the NHS to provide a health research system focused on the needs of patients and the public. The NIHR has funded a number of programmes, projects, work streams and researchers working in palliative and end of life care over recent years. These different studies from different programmes have not been brought together in this way before. It is not a comprehensive review of all evidence in this field, but offers insights from a range of NIHR funded work published since 2010 in the context of recent evidence on the organisation and quality of end of life care services. Details of the eighteen completed and twelve ongoing NIHR funded studies are given in the appendices.

The review also highlights examples of service innovations around end of life care in different parts of the country which are being evaluated through NIHR projects. We also identify some areas which are still uncertain where more research is needed to inform future decisions.

The focus of this themed review is largely on the quality and organisation of care. It does not address the effectiveness of treatments and procedures, which is covered by new draft clinical guidelines from NICE on the care of dying adults (drawing on evidence including NIHR funded work, such as a review of medical hydration (*Good 2014*)). Other relevant NICE work includes published quality standards and future service delivery guidelines. This themed review sits alongside comprehensive policy guidance from NHS England, Public Health England and elsewhere on improving care at end of life. In particular, it supports the Ambitions for Palliative and End of Life Care, a national framework for local action published in September 2015 by a coalition of key bodies (www.endoflifecareambitions.org.uk). Similar national frameworks have been launched in Wales (NHS Wales Health Board 2013) and Northern Ireland (DHSSPS 2010) with a strategic review currently underway in Scotland. At the same time, the Care Quality Commission is carrying out a themed inspection programme focused on inequalities in end of life care which will report in spring 2016. Our review complements these various initiatives. It focuses on recently published research from NIHR which should add to what we know about making end of life services better.

Full reports and protocols of many of the NIHR funded studies on end of life care mentioned in this review are available in the NIHR Journals Library.

Evidence at a glance

RIGHT CARE

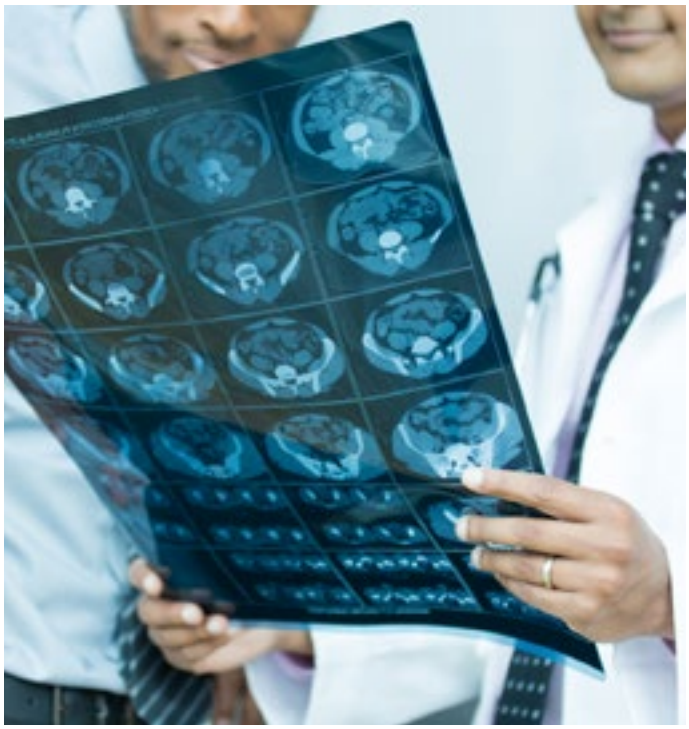
- More people are dying, at older ages and with complex long-term conditions. General staff in the community and in hospital provide most of the every-day care for people in the last years, months and weeks of life. They need time, training and support to do this well. Much care is provided by general practitioners and community nurses, but most people also have two or more unplanned hospital admissions in their last twelve months. Research shows that as many as one third of inpatients may have palliative care needs, but hospitals do not always provide managed end of life care.

- Patients receiving care from specialist palliative care teams tend to do better than those without. But not everyone has the same chance of accessing these services and spend varies greatly across the country. Services are not always matched to need and integration between general and specialist services varies greatly. Evidence is not very clear on the most cost-effective models of specialist palliative care. Ongoing NIHR research will address the important question of which patients are likely to benefit most to help make fairer decisions about allocating resources.

- More support and tailored services are needed to support those with dementia and the very old at the end of life. Most people with dementia now die in care homes. Research highlights the uncertain trajectories at end of life and the need for close working over time between care home staff and those in primary care and specialist palliative services.

RIGHT PLACE

- Research on large numbers of recorded deaths over time show that more people with cancer are now able to die in their place of choice. However, this is not true for people with conditions other than cancer. There are persistent inequalities in who is likely to die where. Hospital deaths are more likely for the very old or deprived and hospice deaths more likely for those with cancer. Current end of life care services are not always able to support people dying where they want, usually home, hospice or palliative care unit. Research shows that patient preferences do change though and place of death may not be the most important aspect of care for many. Issues such as managing pain and other symptoms and the quality of care are key for patients and their family, whatever the setting.



- Better coordination of services is needed, as research indicates variation in out of hours cover (such as 24/7 district nursing services) which can lead to unwanted hospital admissions. Research shows that coordination of care is better for those with cancer than those without. Fewer than one in five primary care organisations had systems between providers to share information about those approaching the end of life. Evaluations of new developments, from hospice at home services to rapid response teams to joined-up information systems, should provide useful learning for the service.

RIGHT TIME

- Uncertainties remain about when best to refer people for specialist palliative care and the cost-benefits of early referral. This is the subject of current research, as well as evaluation of brief palliative care interventions.

- Research suggests that staff and patients find it difficult to discuss arrangements and plan ahead for end of life, particularly for long-term life-limiting conditions where it is hard to predict when people will die or the progress of disease. There is also variation in how hospitals manage decisions about invasive care and when to stop treatments. New research should help to identify good practice in implementing these complex policies.

What does this mean for me?

This evidence raises questions you and your organisation may want to consider to identify areas for improvement.

RIGHT CARE?

- How do we identify patients who need palliative care in the community and in hospital?
- What kind of staff training do we provide?
- Who currently uses our specialist palliative care services – for instance, what proportion have a diagnosis other than cancer? What actions are we taking to reduce inequalities in access to these services?
- What services do we have for people with dementia and carers at the end of life? What kind of ongoing support for care homes?

RIGHT PLACE?

- What proportion of our population die in hospital? How does this compare with stated preferences, national trends and benchmarking?
- What plans do we have to coordinate and integrate services 24/7 including community nursing, pharmacy, hospital, general practice, hospice, care homes, voluntary and social care? Are we evaluating any of these new approaches?
- What arrangements do we have to share information about what individual patients and carers want across these agencies? Is there a designated lead for end of life care in these partner organisations?

RIGHT TIME?

- Looking back, how many patients who died that we look after were identified as having palliative care needs at the right time?
- What are we doing to support staff in discussing with patients and families plans for their next phase of care?
- How can we ensure that the expressed wishes of patients and families about when they want to stop invasive treatments or not be resuscitated are known and acted on by our local hospitals, ambulances and others?

Why do end of life care services matter?

Improving the quality of end of life care is a priority for the NHS. The demand for services is changing. We know from mortality trends and forecasts that we face a 15% increase in the annual number of deaths between now and 2035 (*Choice in End of Life Care 2015*). We also know that most people will be older and will die from chronic disease. Various concerns have been raised about the way services are provided for those in the last year of life. These include reports of variation in access and quality of care; inequalities in access to specialist palliative care; fragmentation of provision across setting and sectors, including out of hours care; lack of involvement of patients and carers in decisions at the end of life; skills and training gaps for general staff caring for the dying; and mismatch between individual preferences and place of death.

This is a pressing problem for the service and a concern for patients and the public. Commissioners are seeking solutions to improve quality and reduce costs, including minimising avoidable hospital admissions and integrating services. Getting it right has a huge impact for individuals and their families. It also matters in terms of good use of resources. A recent population-based study in Canada estimated that 10% of all healthcare budget was spent on end of life care (*Tanuseputro 2015*). In this country, recent analysis suggested average costs of more than £4500 in the last three months of life, most costs through emergency admissions (*Georghiou 2014*).

Policy initiatives include a national end of life strategy from the Department of Health in 2008 (Department of Health 2008) and recent actions to implement this policy (NHS England 2014). As part of this strategy, the National End of Life Care Intelligence Network was set up in May 2012 and provides useful resources for local organisations, including a round-up of latest service, survey and research information (www.endoflifecare-intelligence.org.uk).

Local decision-makers are also tracking key indicators on experience of end of life care in the NHS Outcomes Framework. Following adverse publicity around the Liverpool Care Pathway for the Dying, an independent review led to the withdrawal of this pathway and recommendations for improving the recognition and treatment of patients at end of life in 2013 (Department of Health 2013). Response from a coalition of national bodies ('One Chance to Get It Right') in 2014 underlined a commitment to support professionals to recognise, assess, communicate and provide individualised care and support for people at the end of life (Leadership Alliance for the Care of Dying People 2014). More recently, 25 national organisations signed up to a high-level framework in September 2015 setting out six key ambitions to improve palliative and end of life care in England (National Palliative and End of Life Care Partnership 2015).

People at the end of life need to get the right care, in the right place, at the right time. This is the focus of much recent evidence. We have organised key findings from the most relevant recent NIHR funded research into the following sections:

- Right care
  - Caring by general staff
  - Accessing specialist palliative care
  - Dementia and the very old
- Right place
  - Choosing where you live and die
  - Joining up the care
- Right time
  - Getting care in time
  - Making the right decisions

> ***It is important we don't forget carers. They provide much of the day to day care for those at the end of their lives and can speak up for patient wishes and interests. We know that all too often carers are the only common thread when there are a whole range of different staff dipping in and out. Providing good end of life care isn't just the job of the professionals – it's a shared journey with patients and carers.***
>
> Joanna Eley, service user and carer

Right Care

CARING BY GENERAL STAFF

Most people approaching the end of life will be cared for by non-specialist staff in community or hospital settings. In the community, general practitioners and community nurses like district nurses play an important part in looking after dying people. A current general practice-based research project is developing a tool-kit to target appropriate community support for those dying at home (**NIHR ongoing study two**). Around a fifth of people now die in care homes and nurses and carers in these settings are also pivotal in good end of life care.

General staff need time to look after people and their families at the end of life. This is difficult to do well and training can help. Having prepared and competent staff is one of the key ambitions for better care set out in recent strategy (National Palliative and End of Life Care Partnership 2015). However, a recent national audit of hospital services (Royal College of Physicians/Marie Curie 2014) showed that fewer than one in three hospitals had mandatory training for nurses in care of dying people and only one in five for doctors. NIHR has funded some work in this area, including research to strengthen current medical education by better understanding of student attitudes to death and dying and how they change over time (for instance, *Barclay 2014*). The role of family carers is also crucial and current research is reviewing what kind of support they need.

"Palliative Care embodies the best aspects of primary care. Care for patients in the community, delivered by a team who understand the patient's wishes and needs in a compassionate and professional way, enabling those who wish to be cared for and to die at home to have those wishes met. To offer anticipatory care that avoids the unexpected crisis that can often result in an unwanted, unplanned admission."

Dr Rob Bailey, GP

More people die in hospital than anywhere else. The quality of care for dying people in hospital has been consistently rated lower than in hospices, at home or in care homes in successive national surveys of bereaved people (ONS 2014 and earlier). An interesting study funded by NIHR looked in detail at the pattern of care in two large hospitals (**NIHR published study one**). They found that a third of all hospital inpatients had palliative care needs. But these patients often did not experience a managed transition to a palliative care approach. Hospital staff had difficulty in recognising people approaching end of life. They also found it difficult to discuss the prognosis with the patient and involve them in decisions about their care in the last few days or weeks.

Other NIHR funded research looking at ways to support general clinical staff caring for dying people has focused on intensive care settings. A study

VOLUNTEER-LED SUPPORT OF FAMILY CAREGIVERS

This study is developing and evaluating a model of volunteer support for people caring for family or friends at the end of life. The research uses a participatory approach to work alongside carers and members of the voluntary and charitable sectors.

Lead investigator Chris Bailey says: "We know how important the unpaid care provided by family members is for those at the end of life. This can be difficult and challenging. We know from research that carers do not always approach health staff and others for help. We also know that social isolation makes things harder and can have serious adverse effects on carers' health. These aspects of well-being may be better supported from within people's own communities, an approach that is often referred to as 'compassionate communities'. So in this project we will build on previous research indicating benefits of similar support such as befriending or home visitation for those caring for people with dementia. We will use this to develop a model of community-based volunteer-led support in partnership with caregivers, care recipients and volunteers themselves. We will use qualitative research to find out what support is needed and then evaluate the model to ensure that it actually meets the needs of caregivers and their relatives and friends, and delivers the predicted benefits."

For more details: NIHR ONGOING STUDY ONE

has developed and tested a tool to improve care and communication between staff, families and patients at the end of life with promising results (**NIHR published study two**). Another ongoing NIHR study using mainly qualitative methods focuses on the experience and challenges of staff caring for the dying in intensive care and nursing home settings (**NIHR ongoing study three**).

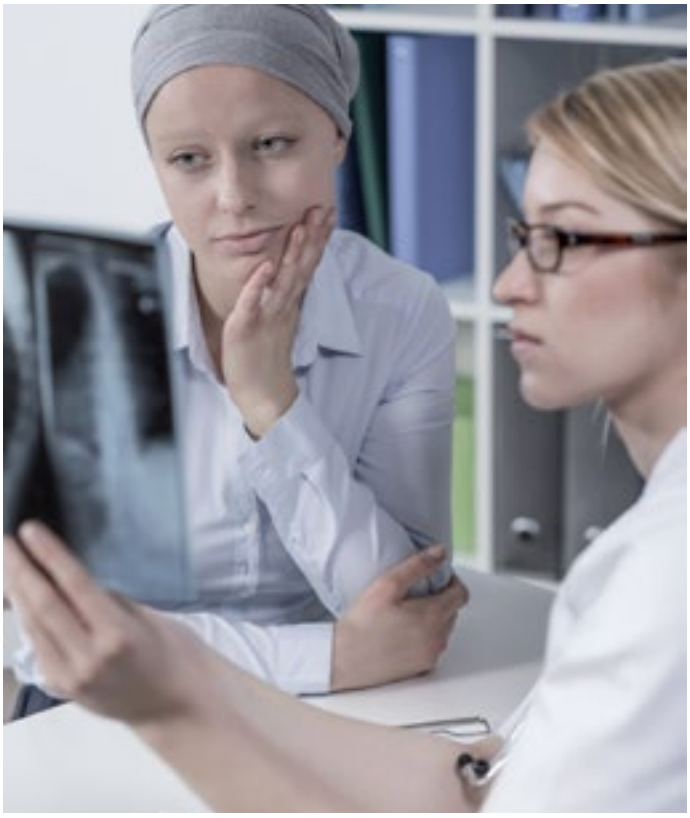
"Patients who are at or nearing the end of their lives deserve the best quality, personalised, and compassionate care possible and well-resourced general practice is at the heart of delivering this.

"We also need to improve coordination at interfaces such as between general practice and hospital services and seriously consider how we transfer the baton of trust between the two so that our patients and their carers have as streamlined and comfortable an experience as possible. The future of end of life care commissioning must revolve around our patients and general practice must be central to any service re-design."

Dr Catherine Millington-Sanders, End of Life Care lead for the Royal College of GPs and Marie Curie

ACCESSING SPECIALIST PALLIATIVE CARE

Good care is needed for people to live as well as possible until the end. This can be provided by general practitioners, community nurses, hospital doctors and nurses and others. There are also dedicated specialists, such as palliative care doctors and nurse specialists who can look after people with complex or intense needs, but can also work alongside the patient's own general practitioner or district nurse providing day to day care. Recent research suggests that around three quarters of people may need palliative care at some point during the end of life (*Murtagh 2014*). This kind of care



can make a difference – evidence (mainly from cancer studies) suggests that specialist palliative care teams, whether working in hospital, hospices or the community tend to deliver better outcomes for patients (*Garcia-Perez 2009, Higginson 2010*). This is measured by reduced burden of symptoms, managing pain and improved quality of life as defined by patients. Another recent review suggested the risk of attending hospital emergency departments in the last month of life was halved for those receiving palliative care (*Henson 2015*). Evidence on costs is not always reliable, given differences in services and variable research quality, but a recent international review suggested a pattern of reduced costs of palliative care (*Smith 2014*).

But people have different chances of getting care from specialist palliative teams. You are more likely to access these specialised services if you have cancer. And older people, those with disabilities, those who are homeless and other particular groups of people are less likely to be referred (*Dixon 2015*). There are also differences depending on where you live, with one study showing thirty-fold variation in spend on

"It's great when you see the system working together. As palliative care specialists, our involvement ranges from attendance at GP practice meetings, to home visits, outpatient appointments, inpatient hospice beds, day therapy, hospital wards and specialty multidisciplinary meetings. Locally our hospice at home service, which provides nursing care overnight, has made an enormous difference to our ability to enable people to stay at home until the end."

Dr Tabitha Thomas, Consultant in Palliative Medicine

HOSPICE AT HOME IN CAMBRIDGESHIRE

Hospice at homes are an important development to support people dying at home with the specialist skills and approach of hospices. One such scheme in Cambridgeshire is being evaluated jointly by the NIHR and a local hospice.

Chief researcher Jackie Buck says: "We used different methods to understand the experience and impact of the hospice at home service. This involved detailed case-note review of 315 patients referred to the service over a year. From these records, we were able to track interactions, care and contact with different professionals from referral to death. We also carried out qualitative interviews with carers, key workers, bereaved lay carers and a wide range of staff involved in the care of a sample of patients. We found that the service was called on for practical nursing care, psychological support for patients and families, coordination of care provision and advice for other professionals. In our study, three quarters of patients cared for by the service had cancer and the great majority (91%) died at home. The service expanded in geographical coverage and team size during the study, but was still unable to meet one third of requests for care. Bereaved carer interviews revealed many view themselves as 'copers', who often resisted initial offers of help until a crisis was reached, at which point the responsiveness of the service was highly valued, alongside the professionalism and emotional support of staff. This evaluation is only of a single service, but emerging findings suggest a demand for this kind of service."

For more information www.clahrc-eoe.nihr.ac.uk/category/dementia-frailty-and-end-of-life/

palliative care between different areas (Department of Health 2011). Given resource constraints, we do not know enough about who would benefit most from this specialist input. To address this issue, the NIHR is funding an important five year research programme to develop better ways of identifying needs for specialised palliative care (**NIHR ongoing study four**). This includes research to measure complexity and the outcomes that matter to individuals. This should allow for fairer allocation of specialised services to patients.

Whether or not you receive specialist care also seems to affect where you end up dying. A large Cochrane review (*Gomes 2013*) of 23 studies and more than 37,000 participants showed that access to home palliative care more than doubled patients' odds of dying at home. There was also a reduction in symptoms, particularly for people with cancer. However, the authors found little reliable information on cost-effectiveness.

For those planning services in this country, there are still questions around the most cost-effective models of palliative care, including skill-mix and scope of service. For instance, one NIHR-funded review on improving end of life care for patients with lung cancer (**NIHR published study three**) considered nurse follow-up programmes as part of the review. It concluded that follow-up by specialist nurses rather than doctors appeared safe and effective, with higher levels of patient satisfaction. However, the evidence on cost-effectiveness was not clear, as interventions were not always similar and the true costs of complex nursing interventions (including time spent with patients and in supporting and training staff) was not always available. There is not currently good evidence for commissioners in designing the most cost-effective forms of specialist care inputs across a system.

DEMENTIA AND THE VERY OLD

More people are now dying with dementia. England has had one of the highest rates of hospital death for people with dementia in Europe. However, a recent publication as part of a large NIHR funded study of place of death (**NIHR published study four**) has shown a decrease in the proportion of people with dementia dying in hospital, with an increase in the proportion of recorded deaths of people with dementia in care homes (*Sleeman 2014*). It is still rare for people with dementia to die at home or in hospices. A helpful review (*Goodman 2010*) of mainly descriptive research suggested that people with dementia are likely to receive poorer quality of care than people without dementia at end of life. It noted that there are few dementia-specific, structured service interventions for people at the end of life. The NIHR funded a programme of research (**NIHR published study five**) on the whole dementia pathway, including end of life care. Mixed methods research showed that trajectories for people with dementia were often unclear to care home staff, families and visiting health professionals. This made decision-making difficult. Patterns of care and capacity in care homes and in-reach health services varied greatly. Service improvement approaches were tested, including some promising co-design initiatives between care home and NHS staff (*Amador 2014*). Building on this research, a further ambitious programme (**NIHR ongoing study six**) will develop and evaluate an evidence-based integrated service for people with dementia at the end of life.

Over a fifth of deaths now happen in care homes. An NIHR funded study was able to assess the experience of end of life care in this setting by tracking a large cohort of residents who were dying in care homes (**NIHR published study six**). Mixed-methods research including assessment of patient records, routine data, interviews and observation gave insights into the last months of life for individuals and their families and the complex interactions between care home staff and a range of NHS and other agencies. This research highlighted the need for a variety of responses to different patient trajectories, from steady deterioration to unexpected health crises. Uncertainty was a major theme, especially in three key areas: what treatment is the 'right' treatment, who should do what and when, and in which setting end of life care should be delivered and by whom (*Goodman 2015*). The point about more unpredictable disease journeys was also made in another NIHR published review of evidence on conditions other than cancer. This concluded that patients with conditions like chronic heart failure and COPD had less predictable patterns of illness in the final months of life (**NIHR published study seven**).

The trend towards greater number of deaths in care homes is likely to continue, so increasing effort is needed to ensure good care and the particular support needed for homes with different levels of nursing and other support.

There are also an increasing number of people now living to a very old age. Indeed, the number of deaths of those aged over 100 have increased by more than half in the last ten years (*Evans 2014*). The needs of the very old and those experiencing frailty for a number of years before death require careful management. A population cohort study part-funded by NIHR looked at the experience of the very old (over 85 year olds) at end of life (*Perrels 2013*). The findings confirmed the need for enhanced services and training for end of life care for frail older people in hospitals and care homes, where most very old people currently die. More community-based services would be needed if more very old people were to be supported to die at home. The authors also made the general point that, as populations get older, improved dementia care is a key element of good end of life care in all settings.

SHORT TERM PALLIATIVE CARE SUPPORT FOR OLDER PEOPLE IN SUSSEX

This study aims to work with an NHS community trust to create and test a service re-configuration of short-term integrated palliative and supportive care. This is focused on frail older people with non-malignant conditions living at home or in a care home.

Chief researcher, Catherine Evans says:"We want to see if new forms of care that reconfigure existing resources can make a difference in supporting people in the community at the end of life. Having assessed preferences of patients and families for care, we are developing and testing a model of short-term integrated palliative and supportive care. The service is delivered through integrated professional working between specialist palliative care teams and generalist community nurses and general practitioners. Specialist palliative care is provided for a short period of up to three visits to provide an 'extra layer of support' for the frail elderly with advanced non-malignant conditions at points of unstable/deteriorating symptoms and concerns. We will see how well the new service compares with usual care in improving the older people's well-being, reducing carers' burden and any differences in the services used and costs."

For more information on this NIHR funded evaluation: NIHR ONGOING STUDY FIVE

Right Place

CHOOSING WHERE YOU LIVE AND DIE

Different people will have different preferences about where they want to be cared for in the last months of life and where they want to die. Some people may feel more confident being cared for in a hospital environment, while others may find it important to be in their own home. Around two thirds of people say they would prefer to die at home (*Gomes 2011*) but currently less than a quarter of people achieve this (Public Health England 2015).

The NIHR funded an extensive study of more than 13 million deaths over 27 years, which published in 2014 (**NIHR published study four**). From analysis of death certificate data, researchers found that hospital deaths were more likely for certain kinds of people, such as the very old or those living in deprived or metropolitan areas. Hospices have played an increasing role over time but nearly always for people with cancer. Research also shows that people living in more affluent areas have become increasingly more likely to die in a hospice than people living in deprived areas over the past 20 years (*Sleeman 2015*). Further research is now underway to explore how service factors influence where people die (**NIHR ongoing study seven**).

There are some ambiguities around expressed preferences on place of death. A national survey of more than 21,000 bereaved relatives (ONS 2014) found that seven out of 10 (73%) respondents felt hospital was the right place for the patient to die. However, only 3% of all respondents stated that patients wanted to die in hospital. Individual preferences are likely to be informed by experiences of existing services, good and bad. An NIHR funded literature review around patient preferences (*Hoare 2015*) suggests that existing studies around patient preferences for where they die include large amounts of missing data. Some people's wishes can change over time and place of death is not the most important factor for many. Another issue is that population surveys of patient preferences tend to feature mainly healthy individuals, who do not always reflect the concerns and values of those near to the end of life and their families.

Many local strategies to improve end of life care state the aim of reducing unplanned hospital admissions. Estimates differ but best data suggest that people have at least two (Public Health England 2012) – on some counts, between three to four (*Lyons 2011*) – hospital admissions in the last year of life. Average hospital stays are around thirty days. Keeping people out of hospital is seen as key to improving quality of care and reducing costs.

IDENTIFYING FAMILY CARERS' NEEDS AND PREVENTING AVOIDABLE HOSPITAL ADMISSIONS IN LIVERPOOL

This NIHR-funded study developed and evaluated an alert system for family carers to assess potential crisis points in caring for people at end of life and prevent avoidable hospital admissions.

Chief researcher, Barbara Jack says: "The last year of a patient's life can be extremely stressful for family carers and people are often reluctant to ask for help. We carried out some small-scale research to find out why an increasing number of cancer patients, who had elected to die at home, were being admitted to hospital in the last days of life. We found that, in many cases, carer breakdown played a pivotal role in end of life hospital admission. We identified a need for a quick, easy review to act as an alert to the needs of carers and prompt for assessment by healthcare staff. We were influenced by the concept of the modified early warning systems regularly used in healthcare to detect early signs that patients require a higher level of medical care. We developed a tool for use in daily practice in the home, by non-specialist staff, to identify carers who are at risk and in need of a formal needs assessment. The tool is available freely, for not-for-profit use, on the project website (www.edgehill.ac.uk/carers) along with other resources."

For more information on this NIHR funded project: NIHR PUBLISHED STUDY EIGHT

An NIHR study is exploring further the notion of 'inappropriate' hospital admissions at the end of life. This involves interviews with community and hospital staff involved in the admissions of patients with advanced dementia, lung disease or cancer who died within three days of entering hospital and with their bereaved next of kin six months later (*Morris 2013*). Emerging findings from this ongoing study underline the complexity of patient trajectories and the importance of the ambulance service in end of life admissions (*Hoare, Barclay and Kelly 2015*). Another NIHR study notes the importance of supporting informal carers to reduce avoidable hospital admissions and has developed resources to target those in greatest need (**NIHR published study eight**).

JOINING UP THE CARE

Care of the dying spans a number of services. Within the NHS, these include general practice, community pharmacy, community nursing and therapy, a range of hospital staff, ambulance and out of hours services. There are also specialist palliative care teams who may work in hospitals, community or hospices with expert doctors, nurses and therapists. Social care plays an important part with input from social workers and care staff in a range of settings. Many people at end of life are looked after in care homes by a range of nursing and non-nursing staff. There is a huge contribution from the voluntary and charitable sector, including support for hospices, day centres and home-based services.

Individuals often experience fragmented and poorly coordinated services from this complex tapestry of services across many sectors. A third of respondents in a large national survey of bereaved people reported that hospitals did not work well with general practitioners and other community services (ONS 2014). Another recent national audit showed that only one in five hospitals had seven-day face to face palliative care services (Royal College of Physicians/ Marie Curie 2014). An earlier NIHR qualitative study of people with advanced progressive disease suggested poor coordination across services, particularly for those with disease other than cancer (*Mason 2013*) (**NIHR published study nine)**.

The NIHR is funding a five-year research programme looking at one aspect of this – coordinated pain management services across settings (**NIHR ongoing study eight**). This work, due to be published in 2017, will evaluate different aspects of service delivery and should provide practical support for those planning pain management services. On the same theme, a further study is developing and testing resources for patients in managing their pain medicine (**NIHR ongoing study nine**).

EAST KENT RAPID RESPONSE COMMUNITY END OF LIFE SERVICE

This service was to provide additional support round the clock for patients and their families dying at home.

Chief researcher, Claire Butler, said: We know that current services often fail to meet the needs of patients and families. We are evaluating a new service, in addition to established hospice community services, staffed by health care assistants trained at the hospice in East Kent. These health care assistants are available day and night at four hours notice to support patients in the last days of life or when they experience a crisis. Our evaluation will test whether this new service will enable more patients to die at home, if that is their wish, and to assess the impact on carer quality of life. We will also assess the costs of this new service compared with usual care."

For more information on this NIHR funded evaluation: NIHR PUBLISHED STUDY TWELVE

One NIHR funded study indicated variation between and within localities in the provision of out of hours care, such as 24/7 community nursing, for patients at end of life. A survey showed that fewer than one in five primary care organisations had systems between providers to share information about those approaching the end of life. There were also problems in notifying general practice out of hours services and ambulance staff of the status and wishes of terminally ill patients (**NIHR published study ten**).

Many studies in this area are descriptive, but one project tested and evaluated a service intervention to deliver a 24/7 rapid response and crisis service for people at the end of life (**NIHR published study eleven**). This concluded that the addition of a rapid response hospice at home service did not have a significant impact on helping patients to die where they wanted in an area already well served by community palliative care. However, the study also noted how difficult it was to identify an accurate and stable indication of patient preference for place of death.

Out of hours services also featured in another NIHR study published in 2014 as a reason for unwelcome transitions by patients near the end of life (**NIHR published study twelve**). This largely qualitative study found that patients and carers experienced a disjointed system in which organisational processes appeared to be prioritised over individual needs.

The family carer was often the only point of coordination between multiple agencies, but was not always involved in decisions during hospital stays. An important NIHR trial tested an intervention to assess and address the support family carers need at home (**NIHR published study thirteen**). Results suggested modest improvements in carer outcomes and people dying in their place of choice under the intervention.

Information sharing is key to coordinated care. Recent policy guidance has set out pointers for good practice in integrating services and shared electronic records. But it is often hard to achieve. Learning from evaluations helps services to refine and adapt programmes with greater chance of successful implementation.

"Previously it used to be very unplanned and at times distressing: you could have the patient's husband driving round pharmacies on a Sunday night to get hold of the drugs needed. We now advocate GPs prescribe medication 'just in case' it is needed, which can tide us over until the next working day, and has been a great help in keeping patients at home."

Katy Harrison, Community Nurse and End of Life Care Facilitator

DATA SHARING AT END OF LIFE IN CAMBRIDGESHIRE AND PETERBOROUGH

Researchers Mila Petrova and Stephen Barclay are evaluating an innovative scheme to improve exchange of information for people at end of life in Cambridgeshire and Peterborough.

They say: "The vision is that general practitioners (GPs), community nurses and specialist palliative care staff will enter key clinical information about patients and their care preferences into a structured end of life care template within the routine clinical record. Staff in out of hours services, 111 centres, ambulance services, accident and emergency departments and inpatient wards can access a summary or the full GP record, with patient consent. The summary takes two forms: a clinical dashboard for palliative care reviews in GP practices and a business intelligence dashboard for commissioners. The aim is to ensure that care is better coordinated, more effective and more consistent with patient wishes.

"Our research explores the challenges and drivers of the project implementation, its impact on patient care, and patient and professional views on data sharing. We are finding that patients and lay carers strongly support data sharing and it is well used by local GPs and practice managers. Challenges include getting different information systems to interact, changing well-established patterns of work, and managing information governance. There are also difficulties of access in key settings, including limited access to mobile devices for community nurses and problems for the ambulance service, given relentless response time pressures. The research will inform future improvements to this service initiative and the broader debate on patient data sharing."

For more details of this NIHR evaluation: www.clahrc-eoe.nihr.ac.uk

Right Time

GETTING CARE IN TIME

Given scarce resources, those planning and commissioning services need to make informed decisions about what kind of services are best offered at what time to people with advanced disease. This can be difficult to know at a patient level – for instance, research on people with dementia dying in care homes indicated a range of uncertainties which might affect getting the right care in time, from not knowing whether someone was actively dying to who was responsible for making decisions (*Goodman 2015*). At the level of health and care systems, there are also uncertainties about when best to refer patients to specialised palliative care services. There are promising findings (*Higginson 2014*) from a completed NIHR trial showing the effectiveness of early referral to integrated palliative care and respiratory services for those with breathlessness, a distressing symptom for those with advanced disease (**NIHR published study fourteen**). An interesting feature of this and a related NIHR study assessing a breathlessness service is the multidisciplinary nature of the service, where specialist palliative care clinicians work alongside physiotherapists, occupational therapists and others (**NIHR published study fifteen**).

On the question of timing of care, NIHR is also funding a substantive clinical trial comparing early referral to specialised palliative care for people with certain kinds of advanced lung cancer to usual care (**NIHR ongoing study ten**). Another trial funded by NIHR will assess whether it is cost-effective to provide brief palliative care interventions for people with advanced neurological conditions (**NIHR ongoing study eleven**). These kinds of experimental studies take a few years but should provide the NHS with more robust evidence on what works and how to make best use of resources.

"To achieve the right care, in the right place, at the right time, it is crucial to integrate palliative care with active medical management upstream. We need to understand patient wishes at the outset, and revisit these as their illness progresses, as patient preferences are known to change. If referral is made to specialist palliative care only in the last few days or weeks when active treatment is discontinued and death is imminent, we miss an opportunity to work together to ensure the life a person has left is the best quality it can be."

Dr Emma Murphy, Advanced Nurse Practitioner

MAKING THE RIGHT DECISIONS

A key part of good care of dying is patients and carers being able to make informed decisions about their care. This is a key principle in NICE quality standards (NICE 2011). In fact, in a large national survey being informed and choosing who makes decisions ranked as highly as place of death in priorities for bereaved carers (*Gomes 2011*). Policies are in place for advance care planning for people approaching the end of life, with health professionals discussing options with patients and families. A recent qualitative study funded by the NIHR indicated this did not always happen (**NIHR published study sixteen**). The study showed how difficult it was for many clinical staff to initiate conversations with patients and their families and that these were not always welcomed. Although small-

"Social care is an important component of end of life care, working closely with health professionals, hospices, care homes and others. Social workers are skilled in ensuring that individual and family wishes are heard at the end of life. They can also play an advocacy role in ensuring that the most disadvantaged have fair access to resources and services."

Linda McEnhill, Head of Supportive Care, Hospice

scale and exploratory, this study also indicated that place of death was not always a priority for carers, consistent with other research. Patient wishes about their future care can be provisional and shift over time. Another NIHR study looking at advance care planning for people with dementia noted the challenges of timing, given decline in capacity and difficulty in holding conversations about death and dying (**NIHR published study seventeen**).

It is also important that patients and carers are involved in decisions about invasive treatment at the end of life. One ongoing NIHR study looks at practice around Do Not Attempt Resuscitation (DNAR) orders (**NIHR ongoing study twelve**). This is important as procedures including chest compressions, electric shocks, injection of drugs and artificial ventilation may not be appropriate for people who are very frail or have advanced disease. This requires sensitive and complex communication between staff, patients and staff, and carers, continuing at different points of handover. Preliminary findings from the study show variation in how hospitals interpret national guidance (*Freeman 2015*). Staff are often unclear about what to do and how to do it. The team has also reviewed evidence to identify promising processes which could be adopted, such as standardised forms and structured changes to decision-making on admission (*Field 2014*). The study will conclude with expert consensus-building around emerging evidence on good practice.

TOOL FOR TREATMENT DECISIONS IN WESSEX

Working with patients and families, clinical staff in Southampton, Salisbury and Hampshire Hospitals are developing and testing a tool to help make better decisions about their care if their condition worsens.

Chief researcher, Alison Richardson, says: "For patients, families and healthcare professionals deciding on the best thing to do can be hard. We are developing a tool, called a treatment escalation plan. This helps the senior medical clinician looking after the patient to discuss with the patient and family what care would be appropriate if they become more ill and allows it to be clearly recorded. They are about judging what could be done and on occasion what should not be done, for example whether to start a new course of antibiotics, put someone on a ventilator or perform dialysis. It also usually includes an indication of whether someone should be transferred to intensive care. We are developing this tool with clinical staff, patients and carers and are evaluating this for use in hospitals and other settings. We want to see if it will help to improve communication and decision-making at these difficult times."

For more details of this NIHR evaluation: www.clahrc-wessex.nihr.ac.uk/theme/project/10

Further Research

The NIHR is funding many new programmes and projects on end of life care, featured in the appendices. Other studies will be funded shortly, including an NIHR call launched earlier in 2015 for new assessments of interventions in the last thirty days of life, such as anticipatory prescribing for symptom relief. Several of the local NIHR Collaborations for Leadership in Applied Health Research and Care (CLAHRCs) have identified end of life as a priority for applied research, with active partnership between health and care organisations and academic teams. These include a range of activity on complexity at end of life in CLAHRC Wessex (with a focus on practical tools, such as implementing treatment escalation plans); research to improve outcomes and reduce inequalities in place of death in CLAHRC South London; and work on stopping cancer treatments, data sharing and admissions towards the end of life in CLAHRC East of England; and work on end of life in CLAHRC Greater Manchester.

For future research across the different programmes and organisations, the NIHR will build on uncertainties identified by patients, carers and clinical staff through the Palliative and end of life care Priority Setting Partnership with the James Lind Alliance. Their top ten priorities for future research on palliative and end of care were published in January 2015 and are reproduced in the appendices (www.palliativecarepsp.org.uk). In order to understand better coverage and gaps in current evidence on care for dying people, NIHR has also funded an initiative to map relevant reviews and other research to the five Priorities for Care of the Dying Person (papas.cochrane.org/palliative-care-database).

Experienced researchers with a range of skills are needed to take forward new research in this area. Over the last ten years, NIHR has funded a number of research posts, fellowships and training programmes in palliative care research to increase capacity in this important area . This includes, for instance, current fellowships to improve staff-patient communication, enhanced pathways for people with COPD at end of life and integrated models of palliative care for children and young people (www.nihr.ac.uk/about/about-the-trainees-coordinating-centre.htm).

NIHR has also funded methodological research and resources for investigators doing research in this difficult area. This provides guidance in areas from ethical issues to missing data to mixed methods in evaluation of complex end of life services (**NIHR published study eighteen**). Funding research training and posts and developing methods are a good way to strengthen the future evidence base.

Conclusions

Improving end of life care is a priority at national and local level. Research to date has given us a clearer idea of the problems facing the service. These include persistent inequalities and variations in care, with poorly coordinated services and limited access to specialist palliative care for those with conditions other than cancer. Other research has challenged current notions, suggesting place of death is not always a priority for patients and families and noting the changing and ambivalent nature of expressed choice. More people are now dying from longer term, life-limiting disease with uncertain trajectories which can make planning ahead difficult.

There are some areas where there is good evidence to act. For instance, we know that more people could benefit from specialist palliative care. New research will help to target this better at those who need it most, but we don't know enough about what model of specialist care is best. Given the increasing demand for services, as more people die with more complex needs, we also need to focus on improving care across all settings in the most cost-effective way. There are a number of promising interventions and models of care, many of which are being evaluated. These include new forms of care from integrated 24/7 models to brief palliative interventions to hospice at home services. Our priority now is to test and assess solutions for today's complex health and care systems. This will provide better information for those making difficult decisions when planning, delivering and using end of life care services.

The NIHR has funded many world-class programmes and projects on end of life care. This report features eighteen published studies and twelve ongoing projects. Together, they represent an investment of over £14 million of public money. To decide which research gets funded, we use panels of clinicians, managers, patients and researchers. They consider whether each project is addressing an important service problem with a sound study design. Only the best and most relevant research gets funded. In addition, NIHR has funded fellowships and posts in palliative care research and funded methodological research. Together, this targeting of research at priority problems and developing capacity and tools for best research provides a solid foundation for improving future decisions around organisation and quality of end of life care.

> ***This themed review offers health and social care professionals better understanding of the evidence base on organisation and quality of care. This is helpful in planning and delivering the right services and understanding what is important for those at the end of life and the people who matter to them.***
>
> Veronica Snow, National End of Life Care Programme Lead, Wales

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Appendices

NIHR STUDIES FEATURED IN THIS DIGEST

These studies were funded by the NIHR through a number of programmes – Health Services & Delivery Research, Health Technology Assessment, Programme Grants for Applied Research, Research for Patient Benefit and through local Collaborations for Leadership in Applied Health Research and Care. These range from five-year grants of up to £2 million to smaller project grants and reviews of published research. To find out more about these programmes and other funded work, visit www.nihr.ac.uk.

PUBLISHED

Full reports are available for many of these reports from the NIHR Journals Library (www.journalslibrary.nihr.ac.uk/collections/end-of-life-care). For other research, a key publication is given, with full citation in the References section of this report.

NIHR PUBLISHED STUDY ONE: TRANSITIONS TO END OF LIFE CARE IN HOSPITALS

Published 2013 Ingleton C

This was a mixed-methods study of how the transition to palliative care was managed and experienced in two hospitals. The research used a range of approaches, from an inpatient survey of patients and staff, to interviews and focus groups. The team also reviewed patient case-notes to estimate the proportion of patients who need not have been in hospital.

The survey of over 500 patients found that more than a third had palliative care needs – a substantial proportion of all inpatients. The authors also found that there was poor agreement between medical and nursing staff on how best to identify patients in the last year of life. The findings indicated assumptions among healthcare professionals, for instance that specialist palliative care support was for people with cancer. The study estimated that just over 7% of hospital admissions for people in this sample with palliative care needs were potentially avoidable. Overall, the study found limited evidence that a managed transition to a palliative care approach was initiated within hospital settings.

Source: Transitions to palliative care for older people in acute hospitals: a mixed-methods study, www.journalslibrary.nihr.ac.uk/hsdr/volume-1/issue-11#abstract

NIHR PUBLISHED STUDY TWO: IMPROVING CARE FOR DYING PATIENTS IN INTENSIVE CARE

Published 2013 Higginson

This study used a range of methods as the first stage to develop and evaluate ways of improving care for those at the end of life in intensive care units. This was a complex intervention to modify and change different aspects of the care pathway. The first stage included careful observation, focus groups, case-note review and other approaches to understand how care is delivered and areas for improvement.

The research findings helped to identify components of an improved care package. This included an amended withdrawal document; a psychosocial assessment; education and awareness-raising among staff and increased psychosocial support. Other particular outputs from this study included a tool to improve communication and information exchange between staff and families of dying patients. This was done by individualised assessment on admission, collecting information on family, social issues and patient preferences for treatment. This was evaluated and seemed beneficial in terms of staff and family satisfaction and family perception of symptom control.

Source: Implementation of an end of life care pathway in intensive therapy units based in an inner London teaching hospital: does it make a difference? www.biomedcentral.com/1741-7015/11/213 Higginson (2013)

NIHR PUBLISHED STUDY THREE: NON-INVASIVE TREATMENTS AT END OF LIFE (LUNG CANCER)

Published 2011 Rueda J-R

This Cochrane systematic review considered available evidence from clinical trials on non-invasive interventions for patients with lung cancer at the end of life. Fifteen trials were included, with over fifteen hundred patients. This included six new studies which had been published since the earlier review of this topic. The interventions were variable, from psychosocial and educational programmes, structured nursing care, exercise and initiatives to manage breathlessness. These had been grouped into six main categories for this review.

The authors concluded that programmes to manage breathlessness and nurse follow-up showed beneficial results (and nurse follow-up was as effective as doctor follow-up). Other interventions from counselling to education and psychosocial programmes showed some effect, but the evidence was not conclusive. There was less benefit from nutrition and exercise programmes. The interventions studied were diverse, which makes

general conclusions difficult. The authors also noted risk of bias, with few studies reporting proper means of allocating patients and blinding.

Source: Non-invasive interventions for improving well-being and quality of life in patients with lung cancer onlinelibrary.wiley.com/doi/10.1002/14651858.CD004282.pub3/abstract

NIHR PUBLISHED STUDY FOUR: PLACE OF DEATH

Published 2014 Gao W

This study was the largest population-based analysis of place of death in England. The team reviewed over 13 million deaths registered between 1984 and 2010 and were able to use this large dataset to analyse trends and explore reasons for variation. To do this, the study carried out a series of sophisticated analyses and used regression modelling to understand the importance of different factors at an individual and area level and how these might predict place of death.

There were a number of important findings from this study. These are summarised in the main report and in a series of publications on particular aspects of the study. Analysis showed that just under two-thirds had died in hospitals. The second and the third most common place of death varied according to the cause of death. Hospices played an increasing role over time but almost exclusively for people with cancer. There were marked inequalities in the pattern of where people die. People aged over 75 years old, those who were divorced, single or widowed and people living in more deprived areas were more likely to die in hospital.

Source: Geographical and temporal Understanding In place of Death in England (1984 – 2010): analysis of trends and associated factors to improve end-of-life Care (GUIDE_Care) www.journalslibrary.nihr.ac.uk/hsdr/volume-2/issue-42

NIHR PUBLISHED STUDY FIVE: DEMENTIA CARE FROM DIAGNOSIS TO END OF LIFE

Published 2015 Iliffe S

This programme of research considered aspects of improving dementia care at different stages in the disease journey. One component was to develop and test modes of improving palliative care for those with dementia. A prospective study was carried out of over two hundred residents with dementia at end of life in six care homes. Different research methods were used, including interviews and case-note reviews. Other routine data on medication and service use (such as hospital admissions) were collected. Findings from the first phase were tested further and approaches such as appreciative inquiry used to identify modes of good practice.

The study reported variability in the way end of life services were provided and uncertainty about roles and responsibilities. For instance, GP input to the care homes varied considerably, from visits on request for specific indications to fixed GP sessions at a home. There were frequent calls on GP out of hour services, calls depending on experience and confidence of the care home staff in dealing with crises. Contact with community nurses was frequent. Three out of six of the care homes received no visit from a specialist palliative care team. The typical trajectory to death for people with dementia was one of progressive functional decline over a prolonged period. Qualitative research underlined the uncertainty for staff and difficulties in accurate prognosis for people with dementia. This made planned pathways of care at end of life difficult. However, this study was able to develop a framework addressing levels of uncertainty which could be used to consider future interventions to improve end of life care for people with dementia in care homes.

Source: Changing practice in dementia care in the community: developing and testing evidence-based interventions, from timely diagnosis to end of life (EVIDEM) www.journalslibrary.nihr.ac.uk/pgfar/volume-3/issue-3#abstract

NIHR PUBLISHED STUDY SIX: EXPERIENCE OF END OF LIFE IN CARE HOMES

Published 2011 Goodman C

This prospective two-year study used mixed methods to examine the views, expectations and experience of residents, families and staff in care homes around end of life care. The research was set in six care homes and 121 residents were consented for a prospective study. This used mixed methods including interviews with residents at different timepoints, their family carers and a range of care home and other (general practitioner, community nurse) staff, focus groups and case-note review. Other health records, including hospital admission data, were tracked for individual end of life journeys and observation methods used.

This study showed the different and uncertain trajectories at end of life for care home residents. Part of the study included tracking patient deaths and developing a typology of deaths, from steady deterioration to unexpected crises and events. Rich findings from this study helped to describe the different kinds of responses needed and identify opportunities for planning tools and coordination points for care homes with out of hours and other staff.

Source: The experience and expectations of older people resident in care homes, their carers and professionals of end of life care and symptom relief needs: a prospective study (EPOCH study) Goodman (2015) www.biomedcentral.com/1472-684X/14/42

NIHR PUBLISHED STUDY SEVEN – REVIEW OF END OF LIFE CARE FOR CONDITIONS OTHER THAN CANCER

Published 2013 Murtagh F

This complex systematic review considered evidence on place of death, preferences and transitions of care for conditions other than cancer. The evidence on end of life care for particular conditions is dispersed and lessons not always shared. The authors identified 290 relevant papers, featuring both quantitative and qualitative research. They graded the strength of evidence for the quantitative study and combined all findings in a narrative synthesis.

The authors found some important differences in preferences and care for those at end of life with conditions other than cancer. This included lower rates of preference for home death overall in non-cancer patients. There were also marked differences in the trajectory of disease, for instance those with chronic heart failure or COPD having less predictable patterns of illness. This made planning end of life services more challenging. The authors noted the heterogeneity of evidence, which made it difficult to extract general lessons, and the fact that most evidence came from the US with a different healthcare system and context.

Source: Understanding place of death for patients with non malignant conditions: a systematic literature review www.nets.nihr.ac.uk/projects/hsdr/081813257

NIHR PUBLISHED STUDY EIGHT: IDENTIFYING RISKS TO CARERS

Published 2015 Jack B

The early identification of carer needs and appropriate intervention can help avoid crisis situations for the carer and avoidable hospital admissions. The aim of the study was to explore what professionals and carers of patients with cancer and advanced progressive illness, in their last year of life, find burdensome and to develop an alert system for use by non-specialist staff. The tool would help to identify those carers requiring formal assessment and extra support for referral to healthcare staff. The research consisted of a mixed-method, multi-phased, consensus study. To develop the tool, 245 people (117 carers and 128 professionals) participated in the study across a range of health and social care settings in the north west of England.

A number of key domains were identified and prioritised by consensus for inclusion in the tool. The eight domains covered both support needed by the carer to provide care and the support needed for the carer's own health and well-being. The resultant tool is an evidence-based alert thermometer consisting of ten questions, guidance on the possible actions for each alert and space for an action plan to be jointly agreed by the assessor and carer. Preliminary piloting of the tool has shown it to be valued, fit for purpose and suitable for use by a range of staff.

Source: Development of Carers Alert Themometer (CAT). Knighting (2015) www.biomedcentral.com/1472-684X/14/22 and project website www.edgehill.ac.uk/carers/

NIHR PUBLISHED STUDY NINE: COORDINATING CARE IN LAST YEAR OF LIFE

Published 2013 Murray

This multiple method, multi-site study considered how care was coordinated for people with advanced progressive disease. The authors carried out ethnographic research in three general localities – a hospital acute admission unit, respiratory outpatient clinic and a large general practice. This involved interviews and observation with 56 patients, 25 carers and 17 clinical staff. Consensus methods were then used to explore how coordination of health care services could be improved. Additional sub-group analyses were conducted to focus specifically on issues around multimorbidity, respiratory diseases and the impact of personhood on care.

The findings suggested poor coordination of care, although patients with cancer had more joined-up services. This was largely because most people, except those with cancer, who could have been identified for palliative care were not identified for it. Identifying people with advanced multimorbidity and an understanding of palliative care as marking a "transition" to death and dying caused particular problems. Lack of care coordination was evident during emergency admissions and discharges. Patients, families, and professionals identified multiple problems relating to lack of information and problems in communication at care transitions. Family carers or specialist nurses, where present, usually acted as the main care coordinators. The prime aim of patients and family carers was the preservation of dignity and autonomy, often minimising interactions with the NHS.

Source: Coordination of care for people at risk of dying in the next 12 months: a multi-site prospective study and consensus seeking exercise www.nets.nihr.ac.uk/projects/hsdr/081813258

NIHR PUBLISHED STUDY TEN: OUT OF HOURS ARRANGEMENTS FOR END OF LIFE CARE

Published 2013 Addington-Hall

This study looked at variations in England and Scotland in out of hours arrangements for caring for people at the end of life. The research included detailed interviews with those planning and shaping services at regional and local levels. There was also a telephone survey with a large number of primary care organisations – half of all primary care organisations in England and Scotland were sampled and information was obtained from 42% of these. An expert panel of general practitioners, nurse leaders and commissioners considered the findings and identified areas for improvement.

This study highlighted the complexity of providing out of hours care for those at the end of life, as part of a system including 'inhouse' general and specialist palliative care, as well as out of hours GP, urgent care, nursing and social care. The study also found marked variations in access and provision to out of hours services. At the time of the survey, less than one in five primary care organisations had systems to share electronic records of people at the end of life across different providers. Less than half of ambulance providers were able to access information on end of life patients. There was varying provision of key services, such as 24/7 district nursing services.

Source: Variations in out of hours end of life care provision across primary care organisations in England and Scotland www.nets.nihr.ac.uk/projects/hsdr/081813259

NIHR PUBLISHED STUDY ELEVEN: EVALUATING 24/7 RAPID RESPONSE SERVICE

Published 2015 Butler C

This study assessed the impact of one rapid response hospice at home service (intervention) on people dying in their preferred place, and carer quality of life, compared to usual care (control). This was done through a quasi-experimental mixed methods design in a community served by one hospice in three contiguous sites. The study collected data from 953 hospice patient records and 64 respondents to a carers survey.

The study found no significant difference between control and intervention groups in proportions achieving preferred place of death. People living at home alone were less likely to die where they wanted. Carers in the intervention group reported worse mental health component summary scores than those in the control group; there were no differences in other carer outcomes. The addition of a rapid response hospice at home service did not have a significant impact on helping patients to die where they wanted in an area already well served by community palliative care. The authors noted that recording preferences, and changes over time, is difficult and presented challenges for this study.

Source: Evaluation of Pilgrims Hospices Rapid Response Community End of Life Service in East Kent pmj.sagepub.com/content/29/9/817 reference Holdsworth (2015)

NIHR PUBLISHED STUDY TWELVE: UNDERSTANDING TRANSITIONS FOR PATIENTS AT END OF LIFE

Published 2014 Hanratty B

This study used largely qualitative methods to explore the experience of people in their last year of life, focusing on transitions between different care settings. Research included indepth interviews with thirty older adults diagnosed with heart failure, lung cancer and stroke in their last year of life and more than 100 carers of those who had recently died. These were used to develop case scenarios discussed with 43 providers and commissioners of care. The study also had a quantitative component, with analysis of linked hospital and mortality data in last year of life for those with heart failure or lung cancer.

There were rich findings from the qualitative data. This included insights into the disjointed system experienced by many, with reliance on carers and family members to fill the gap between services. General practitioners were seen as central figures in end of life transition. Out of hours GP services and care homes were seen as generating many (some avoidable) transitions at the end of life. The authors suggested that, compared with studies in other countries, the organisation of services and the way they were delivered were a greater cause of concern to patients and carers than other aspects, such as symptom control. Quantitative analysis was limited by data quality and completeness, but indicative findings included, for example, deprivation associated with more frequent admissions in the last few months of life for those with heart failure.

Source: Transitions at the end of life for older adults – patient, carer and professional perspectives: a mixed-methods study www.journalslibrary.nihr.ac.uk/hsdr/volume-2/issue-17

NIHR PUBLISHED STUDY THIRTEEN: TRIAL OF CARER SUPPORT INTERVENTION

Published 2015 Grande

Services do not always provide the right support for those caring for patients at the end of life. This study trialled a 14 item evidence-based, validated tool developed with carers, to identify and prioritise the kind of support they needed in discussion with healthcare staff. A stepped wedge trial was carried out of the intervention at six home palliative care sites. Outcome data was collected from a survey returned by 681 bereaved carers.

Results showed that carers in the intervention group had slightly better outcomes, were more likely to feel the place of death was right and patients were more likely to die at home than in the control group. However, differences were modest and process measures showed low level of implementation, suggesting that these improvements might partly relate to increased awareness of carer issues rather than a direct impact of the intervention. Further work is underway, including a parallel study in Australia which found a reduction in caregiver strain for those using the tool.

Source: Grande (2015) http://spcare.bmj.com/cgi/content/abstract/bmjspcare-2014-000829

NIHR PUBLISHED STUDY FOURTEEN: EARLY REFERRAL TO INTEGRATED BREATHLESSNESS SERVICE

Published 2014-2015 Moxham J and Higginson I

Breathlessness is a common symptom in advanced disease, which increases at the end of life. It is distressing for patients and can lead to otherwise avoidable hospital admissions. There is uncertainty about its treatment and it affects patients with many conditions, from respiratory and heart failure to cancer and neurological disease. This NIHR study developed a new short term breathlessness support service which was offered at an earlier stage to patients with advanced chronic lung disease, cancer or heart failure. This new model of care was evaluated in a randomised controlled trial with a nested qualitative study and a survey. The service integrated respiratory medicine and palliative care, providing advice, information on self-management and a range of known effective (drug and non-drug) treatments. It comprised two outpatient clinic attendances, and a home visit with physiotherapy and/or occupational therapy.

In the multicentre trial, 105 patients received either the new service or control care (without early referral). Patients who received the new service had significantly improved quality of life, in terms of breathlessness mastery, at six weeks. Mastery assessed patients' feeling of control over their breathlessness and its effects on quality of life and function. It was on average 16% higher for those patients receiving the breathlessness support service. Survival and quality of life was also significantly better for the intervention group and total care costs were the same. By being based in outpatient settings and a single home visit, as a short-term intervention, this breathlessness support service appears scaleable.

For publications, see for example Higginson (2014) (References) www.sciencedirect.com/science/article/pii/S2213260014702267

NIHR PUBLISHED STUDY FIFTEEN: ASSESSING MULTI-DISCIPLINARY HOME-BASED BREATHLESSNESS SERVICE

Published 2014-2015 Booth

This study assessed a new multi-disciplinary complex intervention theoretically underpinned by a palliative care approach, using evidence-based treatments to support patients experiencing breathlessness with advanced disease. This service differed from other breathlessness services by being multidisciplinary, delivered in patients' homes and taking a flexible individualised approach to the number and content of contacts. It was compared with usual care, defined as specialist hospital outpatient appointments, for instance in oncology clinics. This study took the form of two randomised controlled trials, comparing the new service with usual care both for people with cancer and for those with non-malignant disease.

The team has reported on findings for people with cancer. Assessment was done by a small randomised controlled trial, with a total of 54 patients completing the key outcome measurement. The new service reduced patient distress due to breathlessness significantly more than the control group and economic analysis suggested two thirds likelihood of better outcomes at lower cost than standard care. The authors suggested that a key mechanism of impact appeared to relate to improved knowledge, enhancing patients' and carers' understanding and their confidence in living with the symptom. Results from the linked non-cancer study are just completed.

For publications from this study, see for example Farquhar (2014) www.biomedcentral.com/1741-7015/12/194

NIHR PUBLISHED STUDY SIXTEEN: COMMUNICATION ON ADVANCE CARE PLANNING AT END OF LIFE

Published 2015 Pollock K

This qualitative study looked at how patients and health care professionals initiate discussions about Advance Care Planning (ACP) in community settings. It included interviews with 37 professionals (general practitioners, specialist nurses and community nurses) and 21 patient case studies involving serial interviews with patients, family carers and health care professionals with up to six month follow up.

In line with other research, this study found that advance care planning is uncommon, challenging for health professionals and not welcomed by a substantial number of patients. Health professionals found it difficult to initiate discussions and often postponed this until a crisis occurred or death was clearly imminent. Most discussions were around specific documented decisions, such as preferred place of death and cardiopulmonary resuscitation, rather than general beliefs and values in event of future incapacity. The study highlighted the provisional, shifting and provisional wishes of many patients about their future care and highlighted the complexity and challenges of advance care planning in community settings.

Source: Care and communication between health professionals and patients affected by severe or chronic illness in community care settings: a qualitative study of care at the end of life www.journalslibrary.nihr.ac.uk/hsdr/volume-3/issue-31#abstract

NIHR PUBLISHED STUDY SEVENTEEN: ADVANCE CARE PLANNING IN DEMENTIA

Published 2012 Robinson L

This study carried out a systematic review and a range of qualitative research to explore the challenges in advance care planning for people with dementia. Qualitative research included interviews and focus groups with a range of clinical staff in different settings caring for people with dementia. There were

also interviews and focus groups with people with dementia and their carers. The research team held workshops with all participants to test emerging findings.

The review of existing research found little evidence of the effectiveness of advance planning in improving end of life care for those with dementia, although some limited effect in reducing hospital admissions. This review and the qualitative research underlined the importance of timing and the difficulties in having the right conversation at the right time. In particular, research suggested that patients in care homes may no longer have the capacity to make decisions about their care and that earlier discussion would be helpful. Staff emphasised the need to standardise paperwork, lack of clarity about roles and expectations and the need for specialist skills and expertise in this challenging activity.

Source: Robinson (2012) www.ncbi.nlm.nih.gov/pubmed/22156555

NIHR PUBLISHED STUDY EIGHTEEN: BETTER CARE THROUGH BETTER METHODS OF RESEARCH

Published 2013 Higginson and Todd

This study was funded by NIHR and managed through the Medical Research Council as part of its Methodology Research Programme.

Research in palliative and end of life care is difficult to conduct. There are ethical and practical concerns that need careful consideration when conducting research with patients who are so profoundly ill, and those close to them. This collaborative research undertook international evidence-based reviews and consultation to identify the most successful practice. The resulting guide of 36 best practice solutions should help clinicians, policy makers and researchers to develop and evaluate complex interventions in palliative and end of life care. These were published in an overall summative paper (Higginson 2013), with separate aspects considered in depth in other publications. These range from guidance on ethical issues, handling missing data and attrition, selecting outcome measures and studies using mixed methods as well as best practice in social care research. The team is now developing and testing e-learning modules for wider use in the research community.

More information is available at www.kcl.ac.uk/lsm/research/divisions/cicelysaunders/research/studies/morecare.aspx

RESEARCH UNDERWAY

There are a number of substantive studies underway which will complete with full project reports in the next few years. Some projects may have produced publications already on aspects of the work. Some of the key NIHR funded projects are listed here, but not all. For more details, visit www.nihr.ac.uk.

NIHR ONGOING STUDY ONE: VOLUNTEER-LED SUPPORT OF FAMILY CAREGIVERS

Due to publish 2016 Corner

This programme development study is developing and evaluating a model of volunteer support for people caring for family and friends at the end of life. The team will use focus groups, workshops, and interviews to agree what kind of support is needed most and how it can best be delivered on a local level. Researchers will work in partnership with community groups and the voluntary and charitable sector to promote local involvement. The model will be tested to ensure it actually meets the needs of caregivers and their relatives and friends, and delivers the predicted benefits.

Project: Community-based Volunteer-led Support for Family Caregivers Caring for a Relative or Friend with Palliative and/or End-of-Life Care Needs at Home (Co-Care). For more information, contact info@nihr-ccf.org.uk

NIHR ONGOING STUDY TWO: IMPROVING COMMUNITY CARE FOR PEOPLE DYING AT HOME

Due to publish 2016 Barclay

This study recruited 20 practices to carry out research to understand how general practitioners and district nurses can provide better support for those dying at home. The aim is to identify the different care needs of those dying in the community. In each practice, researchers will assess patient records of 20 recently deceased patients to chart patterns of care, care needs, activity and costs of different interactions. Interviews with practice staff and with family carers will also help to gain insights into current provision and barriers to effective care. These findings will help to develop a toolkit for general practitioners and district nurses to tailor the care for their patients at the end of life.

Project: CAPE study. Community cAre Pathways at the End of life: mapping the pathways to improve care. www.nihr.ac.uk/funding/fundingdetails.htm?postid=1778

NIHR ONGOING STUDY THREE: CARE OF DYING IN NURSING HOMES AND INTENSIVE CARE

Due to publish 2016 Ellershaw

This study was a qualitative case at the end of life in nursing homes and intensive care units. The impacts studied included the physical care of the patient; the emotional, social, spiritual and religious needs of the patient; the information/communication needs of carers, and the economic costs of care. The research was carried out in 11 nursing homes and 12 intensive care units in the north-west of England, London and the south-east. Research methods included observation at the bedside of imminently dying people, case-note review, interviews with staff about care in the last days of life in these sites in general and specifically

around the care of those patients whose deaths were observed. The results will provide a unique insight into care processes and delivery, including issues such as the withdrawal of active treatment in intensive care settings and the coordination of care in nursing homes; hydration/nutrition; the management of symptoms; education and training and communication in the last days and hours of life.

Project: The Care of Dying People in Nursing Homes and Intensive Care Units: a qualitative mixed methods study www.nets.nihr.ac.uk/projects/hsdr/081813256

NIHR ONGOING STUDY FOUR – BETTER CARE IN LAST YEAR OF LIFE

Due to publish 2018 Murtagh

This is a five-year programme grant to explore complexity and need for those with advanced progressive conditions in the last year of life. This ambitious programme will use different methods to carry out research with patients, families and a range of clinical staff to understand the complexity and range of palliative care needs of patients in different settings (home/hospital/hospice). This will be combined with information on resource use and clinical information to develop a casemix classification which can be tested as a means to identify and allocate specialist services and other resources more appropriately.

Project: C-CHANGE: Delivering high quality and cost-effective care across the range of complexity for those with advanced conditions in the last year of life www.nihr.ac.uk/funding/fundingdetails.htm?postid=2248

NIHR ONGOING STUDY FIVE – DEVELOPING AND EVALUATING SHORT-TERM PALLIATIVE SUPPORT

Due to publish 2016 Evans

This study focuses on frail older people with non-malignant conditions living at home or in the community. It will evaluate a new short-term palliative care service for this target group. The first part of the study will be used to develop the service, using a postal survey sent to 1200 bereaved relatives or carers of people aged over 75 years to find their preferences for care and personal goals. The research team will then ask older people and carers, professionals providing services and members of voluntary groups about the results of the survey and the best ways to create the new service. The second part of the study will test the feasibility of the service and assess benefits patients and carers. The team will select 52 older people with deteriorating health, and their carers, to receive either the short-term palliative care service or usual care. Impact will be measured by improvement in older people's well-being, reducing carers' burden and any differences in the services used and costs. The results should identify if this new service is likely to benefit patients and carers and how a larger evaluation could be carried out to see if this is the best way to deliver palliative care to frail older people in the community.

Project: OPTCare: Optimising palliative care for older people in community settings: development and evaluation of a new short term integrated service www.kcl.ac.uk/lsm/research/divisions/cicelysaunders/research/studies/OPTCare/index.aspx

NIHR ONGOING STUDY SIX: INTEGRATED DEMENTIA END OF LIFE CARE

Due to publish 2018 Robinson

This five-year programme of research aims to develop, pilot and evaluate an evidence-based integrated care pathway to support good quality end of life care in dementia. The study, which has involved people with dementia and their families in shaping the research, aims to look at the evidence base for key services, from pain management to the organisation of care across agencies. Having developed an evidence-based approach to delivering integrated services, this will be assessed by a pilot trial, economic evaluation and qualitative research to compare with usual care.

Project: Supporting excellence in end of life care in dementia (SEED) (research.ncl.ac.uk/seed/

NIHR ONGOING STUDY SEVEN: SERVICE FACTORS IN PLACE OF DEATH

Due to publish 2018 Gao

This study builds on the team's earlier analysis of trends and variation in place of death. It found large variation which was only partially explained by patient factors. This further work will focus on the role of service factors in explaining where people die. It will use multi-level modelling and spatial mapping techniques to look at service issues in the context of patient factors and population-based need. The findings should help to show the kind of service configurations most likely to lead to people dying in their place of choice.

Project: Geographical understanding of variation in place of death: the role of care services and end of life care improvement (GUIDE_Care Services) www.nets.nihr.ac.uk/projects/hsdr/141922

NIHR ONGOING STUDY EIGHT: BETTER PAIN MANAGEMENT SERVICES FOR PATIENTS WITH ADVANCED CANCER

Due to publish 2017 Bennett

This five year programme of research aims to improve the management of pain from advanced cancer for those at home. This should improve quality of life for patients and families and reduce the impact on the NHS of avoidable admissions. The project will use mixed-methods to develop and test service interventions to improve how patients and their carers access support and advice, communicate their pain, and receive timely and effective painkillers. Service innovations which will be evaluated include new cancer

pain pathways, self-management support, telecare interventions and forms of non-medical prescribing. Evaluation will feature robust economic assessment to provide useful learning for commissioners and service leaders.

Project: IMPACCT – Improving the management of pain from advanced cancer in the community www.nihr.ac.uk/funding/funded-research/funded-research.htm?postid=2205

NIHR ONGOING STUDY NINE: SUPPORTING PATIENTS TO MANAGE THEIR PAIN AT END OF LIFE

Due to publish 2016 Bennett HTA

This study aims to develop and evaluate a support tool to help palliative care patients manage opioids towards the end of life. It was commissioned to address a specific research gap identified in NICE guidance on opioids in palliative care. The goal is to develop a support tool that enables patients approaching end of life and their carers to more confidently manage medications for pain, nausea, constipation and drowsiness at home. This support-tool will be co-designed with patients and carers at each stage of the development process. Acceptability and uptake will be assessed by a mixed-methods observational study involving patients, informal carers and health care staff from four palliative care services.

Project: Self-Management of Analgesia and Related Treatments at the End of life (SMARTE) www.nets.nihr.ac.uk/projects/hta/1218805

NIHR ONGOING STUDY TEN – TRIAL OF EARLY REFERRAL TO SPECIALIST PALLIATIVE CARE

Due to publish 2018 Ahmedzai)

This is a five year trial to see whether early referral to specialist palliative care service makes a difference to the quality of life or survival for people with metastatic non-small lung cancer. These patients have poor prognosis and tend to be older and poorer than many other kinds of people with cancer. Given inequalities in access to specialist care in this country, and evidence from the US suggesting that these particular kinds of patients might benefit from early referral to palliative care teams, this is an important area to study. This research will take the form of a randomised controlled trial in 20 cancer centres across the UK. It will start with a feasibility study and will measure a range of outcomes, including survival, quality of life and various processes of care.

Project: Does early referral of patients with metastic non-small cell lung cancer to uk specialist palliative care services make a difference in their quality of life or survival? SPECIAL (Standard or palliative care in advanced lung cancer) www.nets.nihr.ac.uk/projects/hta/1110806

NIHR ONGOING STUDY ELEVEN – TRIAL OF BRIEF PALLIATIVE CARE INTERVENTIONS

Due to publish 2018 Higginson

Many people live with long-term neurological conditions, such as Parkinson's disease or multiple sclerosis, but not all receive the best care at the end of life. This study assesses the effectiveness and cost-effectiveness of brief interventions by palliative care teams, already tested in a smaller pilot, for such people. This will be tested by a randomised controlled trial of five centres across England delivering multidisciplinary specialist care for brief intervals compared with usual care for around 356 patients. Outcomes will be assessed by a validated measure of symptom control, together with a range of secondary outcomes. The trial will be accompanied by detailed qualitative research with patients, families and a range of clinical staff to understand questions of appropriateness and impact on individuals and organisations.

Project: Evaluation of the clinical and cost-effectiveness of short-term integrated palliative care services to optimise care for people with advanced long-term neurological conditions (OPTCARE NEURO) www.nets.nihr.ac.uk/projects/hsdr/1213047

NIHR ONGOING STUDY TWELVE: EVIDENCE AROUND DO NOT RESUSCITATE DECISIONS

Due to publish – 2016 Perkins

This review looked at current evidence around practice in implementing 'do not attempt cardiopulmonary resuscitation' decisions. This is to prevent inappropriate and invasive processes for restarting heart and breathing for those who are very frail or at end of life, when there may be little benefit and much harm. Getting this right is important to ensure good end of life care. Current guidelines have been issued for healthcare professionals to get informed consent for preventing unhelpful treatment before a cardiac arrest. But this is often difficult to implement. This study carried out a literature review of current evidence on resuscitation decision-making and implementation. The researchers also looked at national coroner reports, complaints and serious incidents around problems in these resuscitation decisions. More indepth work was carried out at hospitals in two regions to study current practice in implementing these decisions and a series of more than 20 focus groups with clinical staff explored barriers and levers for improved processes.

Project: Do not attempt cardiopumonary resusitation (DNACPR) decisions: evidence synthesis

www.nets.nihr.ac.uk/projects/hsdr/12500155

Note that NIHR funds other projects and activities relevant to the end of life not identified here. In particular, much work is underway through the NIHR Collaborations for Leadership in Applied Health Research and Care (CLAHRCs).

PALLIATIVE AND END OF LIFE CARE PRIORITY SETTING PARTNERSHIP WITH THE JAMES LIND ALLIANCE - RESEARCH PRIORITIES IN PALLIATIVE AND END OF LIFE CARE

This exercise overseen by the James Lind Alliance involved over 1400 patients, carers, health and care professionals in identifying areas of research need and prioritising them. This collaboration culminated in a workshop in November 2014 where participants identified the top ten unanswered questions (in order of priority):

1. What are the best ways of providing palliative care outside of working hours to avoid crises and help patients to stay in their place of choice? This includes symptom management, counselling and advice, GP visits and 24-hour support, for patients, carers and families.

2. How can access to palliative care services be improved for everyone regardless of where they are in the UK?

3. What are the benefits of Advance Care Planning and other approaches to listening to and incorporating patients' preferences? Who should implement this and when?

4. What information and training do carers and families need to provide the best care for their loved one who is dying, including training for giving medicines at home?

5. How can it be ensured that staff, including healthcare assistants, are adequately trained to deliver palliative care, no matter where the care is being delivered? Does increasing the number of staff increase the quality of care provided in all settings? To what extent does funding affect these issues?

6. What are the best ways to determine a person's palliative care needs, then initiate and deliver this care for patients with non-cancer diseases (such as chronic obstructive pulmonary disease (COPD), heart failure, motor neurone disease (MND), AIDS, multiple sclerosis, Crohn's disease, Parkinson's disease, dementia, and stroke)?

7. What are the core palliative care services that should be provided no matter what the patients' diagnoses are?

8. What are the benefits, and best ways, of providing care in the patient's home and how can home care be maintained as long as possible? Does good coordination of services affect this?

9. What are the best ways to make sure there is continuity for patients at the end of life, in terms of the staff that they have contact with, and does this improve quality of palliative care? Would having a designated case coordinator improve this process?

10. What are the best ways to assess and treat pain and discomfort in people at the end of life with communication and/or cognitive difficulties, perhaps due to motor neurone disease (MND), dementia, Parkinson's disease, brain tumour (including glioblastoma) or head and neck cancer, for example?

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