Care Quality Commission

A different ending

Addressing inequalities in end of life care

Overview report

The Care Quality Commission is the independent regulator of health and adult social care in England.

Our purpose

We make sure health and social care services provide people with safe, effective, compassionate, high-quality care and we encourage care services to improve.

Our role

We **register** care providers.

We **monitor, inspect and rate** services.

We **take action to protect people** who use services.

We **speak with our independent voice**, publishing regional and national views of the major quality issues in health and social care.

Our values

Excellence – being a high-performing organisation

Caring – treating everyone with dignity and respect

Integrity – doing the right thing

Teamwork – learning from each other to be the best we can

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How to use this report

This report is one of a suite of documents reporting on our end of life care thematic review, and is designed to be read in conjunction with the other documents. The suite of documents includes:

A different ending: addressing inequalities in end of life care
Overview report

This report provides the background to the review, an overview of the key findings and recommendations for providers, commissioners and local health and care system leaders, as well as information on what CQC will do going forward.

A different ending: addressing inequalities in end of life care
People's experience briefings

These documents provide more detail on people's experiences of end of life care. There are 10 briefings in the series:

- people with conditions other than cancer
- older people
- people with dementia
- people from Black and minority ethnic (BME) groups

- lesbian, gay, bisexual or transgender people
- people with a learning disability
- people with a mental health condition
- people who are homeless
- people who are in secure or detained settings
- Gypsies and Travellers.

A different ending: addressing inequalities in end of life care
Good practice case studies

This document brings together examples of good practice in end of life care that we found through our review, including our visits to local areas, which others can learn from.

Visit **www.cqc.org.uk/differentending** to read the other documents in the suite of products.

Foreword

David Behan
Chief Executive,
Care Quality
Commission

Dying is a universal part of life's journey, and every individual will experience it in a different way. The importance of good care in the last years, months, days and hours of life cannot be overestimated – both for the person who is dying and for those who are important to them.

In the majority of cases, health and care staff who provide care in the last days and hours of life in all settings, from hospices and care homes to hospital wards or at home, are committed and compassionate. We know that end of life care can be good – not only in hospices but also in hospital, where most people die.

However, it is clear that the quality of care for some people at the end of their life is still not good enough. People with a diagnosis other than cancer, older people, people with dementia, people from equality groups and people who may be vulnerable because of their circumstances do not always experience good care in the last phase of their life. Action is needed to make sure everyone receives good quality, personalised end

of life care regardless of diagnosis, age, ethnic background, sexual orientation, gender identity, disability or social circumstances.

As an organisation, we recognise the importance of end of life care as an integral part of the good health and social care that everyone should receive throughout their life. We inspect and rate end of life care services in hospitals, community health services and hospices, and assess quality of end of life care as part of our approach in other settings, including care homes and GP practices.

We are committed to encouraging the improvements in quality needed to make sure that everyone receives the good, personalised care they should be able to expect at the end of their life. This report demonstrates what can be done when commissioners and services understand the needs of everyone in their community and ensure that end of life care is personalised and responsive to people's individual needs. This will be central to our definition of good and outstanding end of life care as we develop our regulatory approach across sectors.

We must ensure that no-one is left behind in achieving the vision of high-quality, personalised end of life care for all. In doing this, health and care commissioners, providers, and staff must be proactive in understanding the needs of everyone at the end of life. This must specifically include the groups that this report focuses on:

people with a diagnosis other than cancer, older people, people with dementia, people from Black and minority ethnic communities, lesbian, gay, bisexual and transgender people, people with a learning disability or a mental health condition, Gypsies and Travellers, people who are homeless and those who are in secure and detained settings. We are all individuals who need care that reflects an understanding of our wishes and aspirations, and enables us to live as well as possible right until the end of our life.

Claire Henry
Chief Executive,
The National Council
for Palliative Care

It is said that we are all equals in death, but this report makes clear that dying does not make equals of us all. It shines a light on the continuing inequalities in end of life care faced by some groups in our society, including Black and minority ethnic groups and people who are vulnerable because of their circumstances. It highlights that end of life care needs to improve for many people. This includes those with a diagnosis other than cancer and also older people. This latter group forms the majority of those who die, but their concerns are often overlooked in a system that is not always designed around their needs. This variation in access to services and quality of care is not acceptable.

The National Council for Palliative Care and the Dying Matters Coalition believe that everyone approaching the end of life has the right to the highest quality care and support, wherever they live, whatever their condition and regardless of race, gender, sexuality or any other aspect of their lives. We work with decision-makers, commissioners, providers and people with personal experience to ensure that end of life care is seen as a core priority. We are committed to working with the Care Quality Commission, as well as our other partner organisations, to ensuring that the findings and recommendations of this report are acted on and lead to change.

Summary

Following the recommendation of *More care, less pathway*, the independent review of the Liverpool Care Pathway, we carried out this review to look more closely at 'how dying patients are treated across various settings'. As people's care in the preceding months has a significant impact on care in the last days, we looked at end of life care from identification through to death and bereavement. In particular, we focused on end of life care for people who may be less likely to receive good care, whether because of diagnosis, age, ethnic background, sexual orientation, gender identity, disability or social circumstances.

We asked people from the following groups to tell us about their experience of end of life care, and the barriers that may prevent them from experiencing good, personalised care at the end of life:

- people with conditions other than cancer
- older people
- people with dementia
- people from Black and minority ethnic (BME) groups
- lesbian, gay, bisexual and transgender people
- people with a learning disability
- people with a mental health condition
- people who are homeless
- people who are in secure or detained setting
- Gypsies and Travellers.

We visited local areas to talk to commissioners, providers and staff about how they address the needs of different groups. From these visits, we have identified examples of good practice that we encourage others to learn from. We also asked a sample of clinical commissioning groups to complete a survey about their commissioning of end of life care. Full details of how we carried out our review are available in appendix A.

What we found

The report shows that where commissioners and services are taking an equality-led approach that responds to people's individual needs, people receive better care. Although some commissioners and providers of end of life care are doing this well, many are not. People from the groups included in the review told us about mixed experiences of end of life care, and highlighted barriers that sometimes prevented them from experiencing good, personalised end of life care.

Some people experience continuing inequalities in the last phase of life

Overall, the quality of end of life care is variable. Our report highlights that people from the groups included in our review are facing continuing inequalities in end of life care. People with diagnoses other than cancer and older

people, who form the majority of those who die, are sometimes overlooked in a system that is designed around the needs of others. People told us that they felt they were not always able to access the right care at the right time, particularly if they had conditions other than cancer.

Good end of life care supports people and those important to them to have a good quality of life, with pain and other symptoms well-managed up to and including the last days and hours of life. Dignity and choice are central to this, as what is important to each individual in the last phase of their life will be different. Identifying people who may be in the last phase of life and having conversations about wishes and choices are important in supporting good, personalised end of life care.

Some people are not being identified early enough, while poor communication is preventing others from receiving good end of life care. The needs of people from different equality groups and people who may be vulnerable because of their circumstances are not always considered. This means that people may not receive end of life care that responds to their needs and preferences.

> "[My husband] was a quiet man who didn't argue and accepted what was going on because he had no choice. It wasn't his choice, it was everybody else's choice really."

It is clear that identifying the end of life phase can be difficult, particularly for people who have conditions other than cancer, including frailty or dementia. Talking about end of life care is challenging for everyone, including health and care staff, but people told us how important good communication is in getting care in the last phase of life right. There needs to be a shift in focus away from only identifying people who are clearly in the last year of life, and towards having conversations about wishes and preferences for care in the last phase of life at an earlier stage, although prognosis may be less clear.

Commissioners and providers should make sure that health and care staff have good communication skills and the support they need to meet people's individual communication needs. Talking about end of life care as part of wider care and treatment in the last phase of life is fundamental in planning and making choices about care.

> "The approach taken by the nursing home was open, inclusive and very professional. They understood the needs of my mother physically and emotionally and also completely supported the family. It was such a relief and reassurance."

Lack of awareness of people's individual needs is a barrier to good care

Each of the groups we looked at, and the individuals within them, have their own unique needs and considerations. These must be understood for people to receive personalised care that reflects their wishes and choices in the last phase of their life. We found some examples of good end of life care where the needs of the individual had been listened to and reflected in their care planning. Some commissioners and providers of end of life care are engaging with different groups and delivering services that meet their needs as a result.

> "The hospice embodied all that was good around end of life care and respected our same-sex relationship."

However, in many cases a lack of understanding of people's needs is still preventing people from receiving good end of life care. The needs of people from some groups, including people with a mental health condition, people with a learning disability, people who are homeless, and Gypsies and Travellers, are not always considered by services and commissioners. People from these groups are often also excluded from wider health services, which is a significant barrier to receiving good care at the end of life. A member of the Gypsy and Traveller community told us,

> "It was hard for me seeing my nephew where he was and trying to deal with these nurses that had no understanding whatsoever, even though I explained on many occasions what was happening and this is how we are. I would

just like for them to be more understanding of our culture and the way we are."

The experiences of the people we spoke to in our review highlight how important it is for commissioners and providers of end of life care, in all health and care settings, to listen and respond to people in their local communities in order to understand and meet their individual needs. This should include people from different equality groups and people who may be vulnerable because of their circumstances, whose needs are often overlooked.

Commissioners and providers do not always consider the needs of everyone in their community

There is variation in the quality of end of life care services, and in the extent to which they are meeting the needs of people from the groups included in the review. Some health and care services provide outstanding, responsive, personalised care that meets people's individual needs. However, while over 90% of hospices we have inspected are rated by CQC as good or outstanding, 42% of end of life care services in acute hospitals are inadequate or require improvement.

Local approaches to organising and delivering end of life care to different groups are variable, and the end of life care needs of people from some groups are not always considered and understood. Under the Equality Act 2010, commissioners and providers have a legal duty to consider the needs of individuals in their day-to-day work. We found that not all commissioners and providers are fulfilling this duty in relation to the delivery of end of life care.

A strategic, equality-led approach at local level that prioritises and delivers personalised care in the last phase of life is essential to ensure good care for everyone. Some commissioners, services and health and care staff are already doing this well, and others can learn from them. We found good examples of services supporting improvement in quality of end of life care for

specific groups. Hospices can play a key role through engaging local communities, delivering care based on individual need, and supporting others to do the same.

Recommendations

Achieving good quality, personalised care at the end of life for everyone is the responsibility of the health and care system and the wider community. CQC supports the vision outlined in the *Ambitions for Palliative and End of Life Care* and we want to see the six ambitions achieved. We are committed to working as a member of the National Palliative and End of Life Care Partnership and playing our part in encouraging the improvements needed.

In order to ensure that each person gets fair access to care we have identified specific actions, which we believe need to be addressed as a priority. These are summarised as follows. Full details are available on page 31.

CQC encourages:

1. **Leaders of local health and care systems** to work together to develop a plan for delivering good quality, equitable end of life care for everyone in their community.

2. **Commissioners and providers** to fulfil their duties under the NHS Constitution, the Health and Social Care Act 2012 and the Equality Act 2010 to reduce inequalities, eliminate discrimination and advance equality when developing, arranging or delivering end of life care.

3. **Commissioners and providers** to ensure that staff who care for people who may be approaching the end of life, including care home staff, have the knowledge, skills and support they need.

4. **Hospices** to champion an equality-led approach, engage communities, deliver equitable end of life care, and support others to do the same.

5. **GPs** to ensure that everyone with a life-limiting progressive condition has the opportunity to have early and ongoing conversations about end of life care, and is given a named care coordinator.

What CQC will do:

1. Reflect the importance of good quality, personalised end of life care for everyone in **the development of our future regulatory approach**, and encourage improvement in the quality of end of life care for the groups considered in this review.

2. In **services that receive a rating for end of life care**, including hospitals, community health services, and hospices, we will reflect the importance of end of life care meeting the needs of people from different groups, and strengthen our assessment of whether end of life care services are meeting the needs of these groups.

3. In **services that provide end of life care but do not currently receive a specific rating**, including adult social care services and GPs, we will include an assessment of the quality of end of life care and whether it is meeting the needs of different groups. In GP assessments, we will assess whether the service is ensuring early conversations and coordinated end of life care for people from different groups.

4. In **services that provide health or social care to people who are vulnerable because of their circumstances**, we will consider how the service identifies and communicates with people and, if relevant, delivers end of life care.

5. We will **use our independent voice** to share our findings and insight about the quality of end of life care to encourage improvement at local and national level.

Background

Good, personalised end of life care that reflects the wishes and choices of the individual is fundamental to providing good health and social care services. This is what we should all be able to expect.

> "It was one of the most wonderful experiences of my life, because my dad died in his own bed, in his own home, with people he loved and who loved him around him. He died with a smile on his face."

Getting end of life care right for people with conditions other than cancer and older people is imperative – the majority of people die of conditions other than cancer, and are aged over 75 when they die. Of approximately 500,000 deaths in England and Wales in 2014, only 29% were caused by cancer.[1] In addition, the age at which people die is rising as people are living longer; two thirds of people who die are now aged 75 or over.[2] Dementia and Alzheimer's disease are the leading cause of death for women, and over 50,000 people died of dementia and Alzheimer's disease in 2014.[3]

In 2008, the End of Life Care Strategy outlined what good end of life care looks like. Since then, good end of life care has been consistently described in national standards and guidance, including from the National Institute for Health and Care Excellence (NICE), the Leadership Alliance for the Care of Dying People and the National Palliative and End of Life Care Partnership.[4,5,6,7]

National Voices and the National Council for Palliative Care use the following description of person-centred, coordinated end of life care:

> "I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s)."[8]

The national End of Life Care Strategy also set out clear guidance about what is needed to deliver good end of life care to everyone, from identifying that a person may be approaching the end of their life to care after death. Progress has been made in delivering elements of the strategy since its publication in 2008 with, for example, the proportion of people dying in hospital decreasing from 57% in 2004 to 47% in 2014.[9] However, the strategy's vision of high-quality care for all "irrespective of age, gender, ethnicity, religious belief, disability, sexual orientation, diagnosis or socioeconomic deprivation" has not yet been achieved.

Good but variable quality of care

We know that end of life care in the UK can be good. In 2015, the UK was ranked the best in the world in the Quality of Death Index.[10] This reflects the national policies on end of life care, the integration of palliative care within NHS services, community engagement, and the strong hospice sector. Over 90% of the hospices

we have inspected have been rated as good or outstanding.

However, we also know that the quality of care that people at the end of life receive can vary. Carers have said that seven out of 10 people with a terminal illness in the UK do not get the care and support they need, and there is significant evidence that certain groups of people have poorer access to and experiences of care at the end of life.[11] An analysis of some of the key findings of the National Survey of Bereaved People (VOICES) highlights how quality of care for people from different groups can vary; for example people from BME backgrounds were less likely to rate overall care as outstanding or excellent.[12]

The Health Select Committee's 2015 Inquiry into End of Life Care also found that the quality of care varied across services.[13] The Committee highlighted the important role of specialist palliative care, and recommended that people with a non-cancer diagnosis, older people and people with dementia should have equal access to palliative care.

More Care, Less Pathway, the review of the Liverpool Care Pathway (LCP), documented multiple failings in care for people in the last days and hours of life, and highlighted that "care of the dying elderly is of the greatest concern".[14] As a result, the LCP was withdrawn in 2014, and *One chance to get it right* introduced the 'Five Priorities for Care of the Dying Person'.[15] The Five Priorities make the dying person themselves the focus of care in the last days and hours of life, and emphasise communication and involving those important to the person, and an individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support. This sets the standard of care for people who are in the last days and hours of life, and we expect the health and care system to take collective responsibility for ensuring that everyone who dies receives this basic standard of care.

Ambitions for improving end of life care

In 2015 the National Palliative and End of Life Care Partnership, of which CQC is a member, published the *Ambitions for Palliative and End of Life Care*.[16] This identifies inequality in care across a range of groups, and sets out the action needed to make end of life care in England even better, including, as one of the six ambitions, that "each person gets fair access to care". The ambitions also emphasise the nature of dying as a social rather than a medical phenomenon, and situate death, dying and bereavement in the context of communities, which can support people and their families at the end of life.

Alongside this, the 2015 independent review *Choice in end of life care* sets out in detail the steps that need to be taken, both at national and at local level, to deliver high-quality, personalised end of life care for all, through a 'national choice offer', by 2020.[17] We support the recommendations of this review, and agree that everyone who is approaching the end of their life should be able to have conversations about what is important to them, regardless of where they live, their individual circumstances or their clinical condition.

We recognise that delivering the Ambitions and the national choice offer comes in the context of the challenges faced by the health and care system in delivering high-quality care to an aging population with complex needs, while making efficiency savings. However, it is clear that, in order to realise the vision of the *NHS Five Year Forward View*[18], the health and care system needs to deliver good quality, personalised care that enables people to make choices for everyone at the end of life.

About our review

As the regulator of health and social care in England, we assess the quality of end of life care as part of our approach in all settings where it is delivered, including care homes and GP services. In our inspections, we look beyond care in just the final days of life, and consider end of life care to include people who are likely to die in the next 12 months. We also look at whether services are delivering the Five Priorities for Care of the Dying Person.

In this review we looked at end of life care for people who may be less likely to receive good care, whether because of their diagnosis, age, ethnic background, sexual orientation, gender identity, disability or social circumstances. We sought to understand better the experiences of people from different groups, and the factors that may prevent them from experiencing good quality, joined up end of life care. We have also identified examples of good practice in local areas that others can learn from.

During the review, we looked at four aspects of care that we identified as particularly important to good end of life care for the groups in the review:

1. **Identification** of people likely to be in the last 12 months of life, and **communication** with people and those important to them.

2. **Coordination** of care, particularly for people with complex needs or vulnerabilities.

3. Timely and equitable **access** to good care, including 24/7 support.

4. **Care in the last days** and hours of life that delivers the five priorities for care of the dying person.

Full details of how we carried out our review are available in appendix A.

CQC recognises the importance of end of life care as an integral part of the good health and care that everyone should receive throughout their life. We take a human rights approach to regulating health and social care services, and are committed to encouraging the improvements

in quality needed to make sure that everyone receives the good care they should be able to expect. We will take this commitment forward through a strong focus on quality of end of life care for everyone in our regulatory approach, as well as working with our partners in the health and care system through the National Partnership for Palliative and End of Life Care.

WHAT DO WE MEAN BY END OF LIFE CARE?

Throughout the review we have used the General Medical Council's definition of end of life care:[19]

"Patients are 'approaching the end of life' when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with:

(a) advanced, progressive, incurable conditions;

(b) general frailty and co-existing conditions that mean they are expected to die within 12 months;

(c) existing conditions if they are at risk of dying from a sudden acute crisis in their condition;

(d) life-threatening acute conditions caused by sudden catastrophic events."

The variable experience of people during the last phase of life

KEY FINDINGS

- Each of the groups we looked at, and individuals within them, have unique needs and considerations. Lack of understanding about these is a significant barrier to people receiving good, personalised care.

- Difficulty in identifying the last 12 months of life for people who have conditions other than cancer, including frailty and dementia, means that conversations about end of life care do not always happen early enough. Talking about end of life care as part of wider care and treatment enables people to plan and make choices about their care.

- It can be challenging for health and care staff to communicate well about end of life care, particularly when the person's prognosis is uncertain. Commissioners and providers should make sure that health and care staff have good communication skills and the right support to meet people's individual communication needs.

- Access to the right end of life care services, such as hospices, is difficult for people from some groups. Everyone should be able to access the right care at the right time in response to their individual needs and preferences.

- The end of life care needs of some people, including people with a mental health condition, people with a learning disability, people who are homeless, and Gypsies and Travellers, are particularly overlooked. This may be because they are often excluded from wider health services. Improving access to services for socially excluded groups, including access to end of life care services, needs to be a priority.

Everyone we spoke to during our review had a unique experience of end of life care. Overall, people's experience was often mixed. Some people described a good experience of care in the last days of life despite a lack of good care in the preceding months. Others told us how services and staff overcame barriers to provide care that was personalised and well-coordinated to meet their needs.

> "My mother was eventually discharged back to her care home, met at the door by the excellent district nurse who coordinated her care with the care staff, and my father could be with her – we couldn't have asked for more."

We identified some common barriers to good care that people in our review had experienced. These are outlined below to demonstrate the impact on people from different groups. They highlight the importance of an individual approach. Where we found good practice, there was invariably a focus on personalised care based on an understanding of people's individual needs and choices.

This section highlights the main barriers to good care that people from different groups told us about, and the impact this had on their experiences. Our detailed findings on the experience of people from each of the groups included in the review are available in the accompanying briefings.

Identifying the end of life phase can be difficult

Identifying that a person may be approaching the last phase of life is not always straightforward, and is particularly challenging for people who have conditions other than cancer. This is partly because it is more difficult to predict how some conditions will develop. When people are not identified as approaching the end of life at an early stage, this can prevent them from receiving the right care during the last phase of their life, and can place an additional burden on carers.

> "Actually, one of my problems in this situation was I felt very confused as to when end of life care did kick in… Nobody in the home was willing to have a conversation with me about it."

Identifying when people who are old and frail are approaching the end of life is also challenging. This is highlighted by examples where people told us they thought healthcare professionals were reluctant to move from continuing to treat their family member's condition to providing palliative care. Families may interpret this reluctance as the health professional not understanding the person's wishes. In some cases, people told us that their loved one only received the right care when they were moved from hospital to a care home or nursing home in the last weeks or days of life.

> "My mother, who died of old age at 86… wished to die at home in her sheltered accommodation. She was admitted to hospital two to three weeks before she died and, expressly against her repeated wishes, she was given intravenous fluids and fed. While my mother knew she was approaching end of life (and welcomed it…), the hospital consultants did not recognise that… The week before she died we were finally able to persuade the hospital to put her on the end of life register and we moved her to a palliative care bed in a local nursing home where she finally received the morphine she needed two to three days before she died."

Some of the groups we considered in the review, including people with a learning disability or a mental health condition, people who are homeless, prisoners, and Gypsies and Travellers, have poor access to physical healthcare, which means they are often not identified as approaching the end of life until a late stage. One person, whose brother had serious mental health problems, said:

> "If they'd done something earlier, they could have caught his cancer at a much earlier stage. He could have come to live with me, and I could have looked after him, given him the stability and family life he never had."

Health professionals told us that they sometimes find it difficult to identify when people who have conditions other than cancer, including frailty and dementia, are likely to be in the last 12 months of life. People with dementia need the opportunity to talk about their end of life care wishes and preferences before the last year of life as they will progressively lose the capacity to make decisions. However, health professionals do not always recognise dementia as a life limiting condition, and as a result this opportunity may be lost. Families and carers of people with dementia told us that they were unsure about when the end of life phase began; for some people, the end of life phase can start much earlier than the last year of life. One person told us:

> "I guess I would've known when she first had her diagnosis of dementia that it was a journey towards her death, so that would probably have been maybe 15 years ago."

Fear of getting it wrong was one reason GPs gave for not always identifying people with a diagnosis other than cancer at an early stage. For doctors, judging how long a person may have left to live is one of the key challenges in delivering good end of life care.[20]

One hospice nurse told us:

> "It's incredibly difficult to identify last year of life without cancer. When we opened the respite unit, the two first patients had advanced [chronic obstructive pulmonary disease]. [If I had been] asked at the time I would have expected both to be in the last year of life, but both lived for three years. There are indications that people are at the end but it's incredibly difficult to know when they're in the last year…"

A number of tools have been developed to help recognise people who are likely to be in the last 12 months of life.[21,22] However, given the difficulty in identifying when a person is entering the last year of life, and the need to talk about end of life care earlier for some people, the importance of having a definitive prognosis may be overstated.

Conversations about wishes and choices for the last phase of life need not be limited to the last 12 months of life. We need a cultural change to break down the barriers and stigma about talking about death and end of life care, as advocated by the Dying Matters Coalition, to enable people to have conversations about their wishes for care at the end of life much earlier. Advance care planning, which enables people to make decisions about their future care, can be done at any stage, including when a person is well, and can be revisited and updated as the person's wishes change.

There is a need for a shift in focus away from identifying only people who clearly have less than 12 months to live, towards having conversations about a person's wishes and preferences for care during the last phase of their life at an earlier stage. Some people told us that advance care planning at an early stage had helped their family member to get the right care at the end of their life.

> "[I] had the frankest conversation I've ever had with a medical practitioner. She said that she had looked at his advance directive of wishes, and she said 'he really is very ill', and I said, 'I know that'. For the first time ever, I felt that she listened to me. She didn't say what she was going to do or what she wasn't going to do, but she didn't need to, we understood each other."

People who have a life-limiting progressive illness should have the opportunity for early and ongoing conversations about end of life care in the last phase of life as part of wider treatment and care planning. This gives people the opportunity to plan and make choices about their care. GPs have particular responsibility for initiating these conversations as part of their central role in delivery and coordination of care for people who are in the last phase of life.

Communication about end of life care is not always good enough

People we spoke to about their experience of end of life care told us that it can be difficult. Talking about end of life care is difficult for all of us, and there are cultural barriers that can

prevent people from being open about the last phase of life.

> "It is hard to have the conversations we all need to have with family, friends, colleagues and in the media, but this has to happen as professionals alone are not going to solve the problem."

We found little commissioned support from the voluntary and community sector for people to discuss and consider care in the last phase of life. Although there are local groups that support people to manage long-term conditions and maintain independence, they played a limited role in supporting people to have conversations about end of life care. This reflects a wider reluctance in our culture to talk about care in the last phase of life, and means that there is a lack of support for people and their families when they are approaching the end of life. We found some organisations addressing this challenge, for example through the Dying Matters Coalition.[23]

Health and care staff have a key role in giving people the opportunity to talk about their wishes and choices for end of life care. However, people said that they felt that there was a lack of openness, honesty and sensitivity from health professionals in communication about end of life, and they often felt they were not well-informed. As well as having a negative emotional impact on them as family members, this meant that the person receiving end of life care was not always able to make choices about their care.

Involving people in decisions about their care is a requirement of the NHS Constitution, which states:

> "You have the right to be involved in planning and making decisions about your health and care with your care provider or providers, including your end of life care, and to be given information and support to enable you to do this."[24]

We found that this was not always happening, particularly for older people and people with dementia. People told us that health and care staff sometimes ignored the input of family members and the person themselves, and

showed a lack of compassion in the way they spoke to older people and their loved ones.

> "At the end the doctor visiting the home would not accept that my mother did not wish to be kept alive. She had made this clear to the staff at the home."

Conversations with patients where the prognosis is more uncertain are particularly difficult. People felt that healthcare professionals were sometimes reluctant to talk about end of life care to people with conditions other than cancer. GPs told us that they found conversations about end of life care difficult to start. Our review of 70 people's case notes found that although end of life had been discussed with 83% of the sample, the proportion for people with non-cancer conditions was lower (20 out of 27, 74%) than people with cancer (11 out of 12, 92%).

This could mean that advance care planning is delayed or conversations about end of life care do not happen at all. One person told us:

> "After he came out [of hospital] in April, and went back to the home, it was only then that I saw on his notes that he was receiving palliative care... nobody actually talked to me about end of life care, I was just left to work that out for myself."

The way in which people want to talk about their condition and their wishes and preferences for end of life care will vary and is likely to change over time. Communication needs to be sensitive to this. Although some people we spoke to felt they had not had the opportunity to talk about end of life care, others felt that communication had been too heavy-handed.

> "The nurse was awful, all she wanted to know was where my dad wanted to die. My dad wasn't interested in dying. He was trying to live."

Others told us that good communication had led to the right care for their family member.

> "All professionals especially the district nurses were very supportive and we felt they listened and responded to our concerns. My mum had a good death. She died at home with care she felt comfortable with."

Sometimes an individual approach to communication is lacking, even where people are likely to have specific communication needs. In our case note review, 76% of the overall sample showed that health and care professionals had considered the individual's communication needs. However, this dropped to only five out of 11 (45%) for people with dementia.

Some of the GPs we spoke to said that this was because the person lacked the mental capacity to make decisions. While people with dementia may lack the capacity to make some decisions, they should be supported to communicate and express their wishes and preferences about their care where possible through communication that meets their needs. We found that health professionals' understanding of the Mental Capacity Act 2005 is patchy, and varied in relation to assessment and decision making. Only four out of 11 (36%) people with dementia in our case note review had evidence of a mental capacity assessment in their records. One person told us that:

> "Mine and my wife's wishes were ignored despite the Mental Capacity Act."

Some people from Black and minority ethnic (BME) communities experience language barriers, which further complicates communication about end of life care. Sometimes family members are used as interpreters. This can cause difficulties because people may not feel able to communicate their true feelings and wishes through a family member. It also places additional stress on family members. One person caring for her mother in law told us,

> "[I] had to be there all the time to explain to the staff and the managers. It was so hectic for me and my family."

Communication was also identified as a significant barrier to good care for people with a learning disability. People told us that health and care staff sometimes make assumptions about an individual, for example that they may not be able to 'cope' with discussions about end of life, and staff do not always have the skills or tools they need to communicate effectively. In contrast, good communication can lead to the person's

wishes and choices for the last phase of their life being met.

> "Last year we supported a gentleman [with a learning disability] age 18 to get married just three days before he passed away; he died a happily married gentleman in a local children's hospice, with his bride, myself and hospice staff at his side."

For people from some of the groups in the review, a one-to-one relationship with a health or care professional is key to effective communication and builds trust. This is particularly important for people who may have had negative experiences with health and care services previously, such as people who are homeless or Gypsies and Travellers.

Health and care staff who care for people who are approaching the end of life need to have access to the right knowledge, skills and support to communicate well with them and those who are important to them. People's communication needs are individual and unique, and may change over time, and staff need to be equipped to take a tailored communication approach which responds to this.

People are struggling to access the services they need

Good end of life care is not limited to specialist palliative care services such as hospices; it can equally be delivered in hospitals, care homes and at home, by GPs, district nurses and care workers. One person told us about the excellent care her father received at home at the end of his life:

> "The care team that he had in were fantastic. I had absolutely no complaints about the care team that he had. The district nurses, the GP, they were wonderful, I couldn't have asked for more and I couldn't have asked for better."

People who are approaching the end of life need to be able to access the right care, which responds to their individual needs and preferences, at the right time. Good quality care out of hospital has to be available to everyone so that people can choose to be cared for at

home or in a care home at the end of their life. People whose symptoms cannot be managed by their usual care team should be able to access specialist services on the basis of need rather than their diagnosis.

Although cancer was the cause of only 29% of deaths in England and Wales in 2014[25], just 7.7% of all deaths in hospice inpatient units between 2008 and 2012 were from conditions other than cancer.[26] Our review found that people from some groups are not always able to access specialist palliative care services when needed, and that generalist care is not always good enough. We found some hospices were proactive in meeting the needs of people with conditions other than cancer, older people, people with dementia and other groups, while others were not.

People told us that they felt that appropriate end of life care was not always available to people with conditions other than cancer, and that the care they received was not as good.

> "[People with] cancer... seem to have better end of life care... better discussions, support, choices, information; other conditions such as [chronic obstructive pulmonary disease (COPD)] seem left out in the cold even though they have clear prognosis of terminal illness and palliative care."

People also said that people with dementia did not have access to the same services as those with other conditions.

> "Dementia is a terminal illness and sufferers should be given the same help as someone with terminal cancer. I had to battle for everything my mum received and it was exhausting."

They told us that staff did not always have the right skills to care for people with dementia, even in dementia specific care homes. Several people highlighted concerns about staff, including a lack of training, staff not supporting people to eat and drink, and a lack of understanding. This supports the findings of our review of dementia care, *Cracks in the Pathway*, which found that staff do not always have enough support or training to care for people with dementia.[27]

People told us that being cared for in the right environment, by staff who have the right skills, is crucial.

> "We need more social care services willing and able to care for people at the end of their lives – we were very fortunate to find an amazing care home for my father for the last two weeks of his life. I think that people with dementia who are approaching the end of their life often experience poor care due to lack of understanding and training about dementia and end of life. Hospices often aren't an option for people with dementia, and if a suitable care home or care-at-home package can't be arranged, they may well languish in hospital."

Where appropriate services are not available, people may end up dying in hospital when they would have chosen to be cared for somewhere else. The burden can also fall on the person's family and friends to fill the gap. Some carers told us they felt overwhelmed by caring for their loved one 24 hours a day, but felt there was no alternative.

> "End of life care was not discussed, because it wasn't cancer. I have cared for people with end stages of COPD and renal failure – neither got any end of life care and their lives and mine as carer were adversely affected, even though it was known they would shortly die. Only cancer sufferers appear to be included in end of life care."

Lack of knowledge and awareness about end of life care services and the support available can be a barrier for people from some groups. For example, at one focus group for people from a BME community, people said they did not know anything about end of life care before a family member started receiving it, and were not confident or familiar enough with the services to know what to ask for.

Some people from a BME background told us that they felt hospices were not accessible to them. One focus group participant told us that,

> "Not a lot of people go to the hospice – people think you go there just to die, but they offer a lot of other support."

An organisational lack of familiarity with people's cultural preferences can be a barrier for people from BME groups, Gypsy and Traveller communities and others. The attitude of health and care staff and services also has a significant impact on the experience of people from some groups, including lesbian, gay, bisexual and transgender (LGBT) people and Gypsies and Travellers. People sometimes felt that staff made assumptions about their preferences so they were less able to make choices, and that there was a lack of understanding of what was important to them, including their relationships. We found a limited understanding and awareness of the factors that may prevent people from some groups from receiving good quality, personalised end of life care, including LGBT people.

Some of the groups of people we considered in the review are often excluded from wider health services and receive poor physical healthcare, including people with a learning disability or a mental health condition, people who are homeless, and Gypsies and Travellers. This has an impact on end of life care as the barriers that prevent them from accessing health and care services also have an impact at the end of life. There are very few suitable services for people from some groups, including homeless people and people who are in prison, although some hospices are proactive in meeting these needs.

> "My elderly friend was admitted from a care home to hospital for physical problems and was subsequently transferred to the elderly mental health facility as the care home would not have her back. They did their best but could not cope with her physical needs. She was eventually transferred back to the acute hospital where she died slowly."

End of life care for people who are in prison is dependent on local arrangements. Although there is some good care, including prisons with a palliative care unit and links with hospices and specialist palliative care teams, efforts to obtain temporary or compassionate release to allow prisoners to die with dignity in the community are not always good enough.

We found that commissioners and services in most areas had done very little to reach out to some parts of their community, including LGBT people, the Gypsy and Traveller community and homeless people. There was very limited awareness of the end of life care needs of people with a severe and enduring mental health condition. Healthcare for socially excluded groups needs to improve, with a focus on improving end of life care as part of this.

End of life care is not well-coordinated around the person

Coordinating care around the person is essential to good end of life care. People told us that end of life care is often not well-coordinated, and that having a number of different people involved in different aspects of care was confusing. They said they often had to repeat information multiple times and that care provided by different staff and services was not consistent.

Uncoordinated care has a significant impact on carers, who may have to step in and attempt to coordinate health and care staff and services themselves. People told us about the impact of poor coordination, including a loss of focus on the person and their wishes. One person told us:

> "A lot of my work was informing services as to what was going on with another service."

Lack of coordination of care is not a concern unique to the groups we considered in the review. However, for people from some groups coordination is even more important because they have complex needs or multiple services are involved in their care. We found good practice where people had a named care coordinator and they reported more positive experiences of care.

Lack of knowledge about the needs of different groups

People from different groups sometimes felt that health and care staff and services did not understand their needs as they approached the end of life, and in the last days of life. This was supported by our fieldwork findings that commissioners and providers had sometimes not taken any action to assess the needs of their community.

The needs of people who are homeless are often overlooked by commissioners, services and health and care staff, which means that there may be no services at all that meet people's needs. Lack of awareness of the number of homeless people locally, and even lack of acknowledgement of the existence of some groups, is part of the problem.

People from some groups told us about a lack of cultural understanding. For example, people from the Gypsy and Traveller community said that staff did not understand that the family of a member of their community all need to visit to pay their respects to the person while they are still alive. This means that members of the Gypsy and Traveller communities have large numbers of visitors in the last days of their life.

"It was hard for me seeing my nephew where he was and trying to deal with these nurses that had no understanding whatsoever, even though I explained on many occasions what was happening and this is how we are. I would just like for them to be more understanding of our culture and the way we are."

LGBT people felt that their partners were often not involved in their care in the same way that a heterosexual partner would be. This suggests a limited understanding of who may be important to an individual, which doesn't reflect the reality of diverse families as well as important relationships outside of a family structure.

The lack of understanding experienced by people from different groups highlights the need for early and ongoing communication with people and those who are important to them to understand their preferences and choices in relation to end of life care.

The role of the health and care system in ensuring good end of life care for all

KEY FINDINGS

- The quality of end of life care varies, and the needs of different groups across sectors are not always met. Hospices have higher CQC quality ratings for their end of life care services, but 42% of end of life care services in acute hospitals are inadequate or require improvement. However, we also found examples of outstanding, responsive and personalised end of life care in all settings.

- Local areas where we saw good practice had a collaborative leadership approach, with a shared focus on addressing inequalities and meeting people's individual needs. Local Sustainability and Transformation Plans provide an opportunity to prioritise end of life care for everyone.

- The end of life care needs of different groups, particularly equality groups and people whose circumstances may make them vulnerable, are not always considered and understood by commissioners and providers. Commissioners and providers need to take an equality-led approach to organising and providing services, including an assessment of the end of life care needs of their local population, to deliver services that meet the needs of each group.

- Services and initiatives to support improvement in the quality of personalised end of life care for specific groups, including new models of care, provide examples of good practice for others to learn from. Staff training and support is important in ensuring that staff are able to deliver personalised care to everyone.

- Electronic Palliative Care Coordination Systems are not yet working effectively at local level, and it is unclear if they are supporting coordinated end of life care for people from different groups. Having an appropriate care coordinator, who ensures care is coordinated around the person, means people are more likely to experience good, personalised end of life care.

- Some hospices are taking a lead locally and working with others to improve the quality of end of life care for everyone. Where this is happening, hospices have taken an equality-led approach that engages local communities, delivers care based on individual need, and supports other local health and care services to do the same.

Local area approaches to end of life care vary across the country. In some areas, commissioners and providers are taking a personalised approach, which meets the end of life care needs of people from different groups well. However, we found that the end of life care needs of some groups are often being overlooked.

We recognise that resources are a factor, particularly in relation to adult social care where there is a lack of availability of services. However, in spite of these challenges we found some good examples of services meeting people's individual needs. Areas where end of life care services reflected the needs of the local community were characterised by strong local leadership and a strategic approach to delivering end of life care. This was usually based on a local strategy that was developed collaboratively by local stakeholders and responded to the needs of the local population.

This section presents the findings from our inspections of end of life care services in hospitals, community health services, and hospices, alongside the findings from our fieldwork in 17 local areas. We identify important aspects of an equality-led approach to end of life care for different groups at local level, and highlight examples of good practice, which are documented in more detail in our good practice publication.

Providers of end of life care services

All health and care services have a part to play in making sure that everyone gets good care at the end of their life. As the regulator of health and social care, we assess the quality of end of life care in services where it is delivered. For hospitals, community health services and hospices, we provide a specific rating for end of life care.

We also review end of life care as part of our inspections of other types of services, including care homes and GPs, but we do not always look at it consistently so it is difficult to compare the quality of end of life care across services in these sectors. We do not routinely assess the quality of end of life care in health and care services for people whose circumstances may make them vulnerable, for example people with a learning disability or prisoners. This is something that we will review as we develop our future regulatory approach.

As part of this review, we looked at the findings from our inspections in acute hospitals, community health services and hospices. We found that the quality of end of life care for people in hospices is high when compared with other services **(FIGURE 1, page 22)**. However, our review has also found that people from some groups are not always able to access this care, and there is variation in how proactive hospices are in meeting the needs of different groups. For example, access to inpatient hospice care varies for people with dementia; one hospice told us told us that they "only accept dementia patients who are 'able to cooperate'."

In our approach to regulating hospices, we are clear that good, responsive care includes personalised care that meets the specific needs of people with dementia at the end of their lives. There is more that some hospices can do to proactively meet the needs of people from different groups, and we will reflect this in our future regulatory approach.

End of life care services in hospitals and community health services are rated less well than care in hospices. Fifty-eight per cent of hospitals and 69% of community health services are rated good or outstanding for end of life care **(FIGURE 1, page 22)**. People we spoke to during the review told us that poor end of life care in hospital was a particular concern for older people, people with dementia and people with conditions other than cancer.

As part of our key question 'are services responsive?' we ask whether services take account of the needs of different people, including people whose circumstances may make them vulnerable, and we look at how the service is meeting people's individual needs. We found a slightly higher proportion of good or outstanding services for this key question compared to the overall rating, although a similar pattern in ratings across the sectors **(FIGURE 2, page 22)**.

FRIMLEY PARK HOSPITAL, SURREY: OUTSTANDING CARE AT THE END OF LIFE

In September 2014, we rated Frimley Park Hospital as outstanding for having responsive end of life care services. When we inspected, we found a trust-wide commitment to providing caring and compassionate support that was tailored to people's individual needs. The trust had systems in place to identify people who were approaching the end of life early, including people with conditions other than cancer, and to involve specialist palliative care staff in conversations. Over half of the people seen by the specialist palliative care team had conditions other than cancer.

The trust ensured that people's social, cultural, religious and language needs were met. It did this, for example, by providing family rooms that accommodate same sex partners or large Traveller families, and trained interpreters from the local Nepali community. The end of life care needs of people with dementia are specifically considered in the Dementia Strategy, and people with dementia and their families are supported by the dementia lead nurse and link nurses. Consideration of equality and diversity is embedded in practice. The demographics of the local population informed the development of services and the quality of care was monitored for different groups.

End of life care services that we have rated outstanding for the responsive key question, including Frimley Park Hospital and Salford Royal NHS Foundation Trust, show that personalised end of life care that meets people's individual needs can be delivered in an acute hospital and community setting.

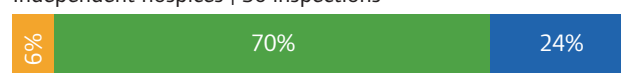### FIGURE 1: OVERALL END OF LIFE CARE INSPECTION RATINGS, BY SECTOR

Acute hospitals | 161 inspections

| 4% | 37% | 52% | 6% |

Community services | 49 inspections

| 31% | 67% | 2% |

Independent hospices | 50 inspections

| 6% | 70% | 24% |

Based on ratings published up to 25/04/2016

- ■ Inadequate
- ■ Requires improvement
- ■ Good
- ■ Outstanding

Note: Figures may not add up to 100% due to rounding

Source: CQC. Data is up to 25 April 2016

FIGURE 2: END OF LIFE CARE INSPECTION RATINGS FOR THE RESPONSIVE KEY QUESTION, BY SECTOR

Acute hospitals | 161 inspections

| 2% | 30% | 60% | 8% |

Community services | 49 inspections

| 18% | 76% | 6% |

Independent hospices | 50 inspections

| 2% | 70% | 28% |

Based on ratings published up to 25/04/2016

- ■ Inadequate
- ■ Requires improvement
- ■ Good
- ■ Outstanding

Note: Figures may not add up to 100% due to rounding

Source: CQC. Data is up to 25 April 2016

Local leadership to address inequalities in end of life care

The *NHS Five Year Forward View* sets out the vision for the future of the NHS based around new models of care, with the 'triple aim' of improved health and wellbeing, transformed quality of care delivery, and sustainable finances.[28] In order to deliver this vision at local level, local health and care systems are developing Sustainability and Transformation Plans (STPs).[29] CQC is supporting local areas to develop STPs by providing a dashboard of ratings of services in the local area, including end of life care services. We encourage local health and care leaders to use this opportunity to give consideration to end of life care in their STPs and to develop a strategic plan to deliver good quality, equitable end of life care for everyone in their community as part of this process.

The *Ambitions for Palliative and End of Life Care* provides a framework for this. It calls on clinical commissioning groups (CCGs), local authorities, and Health and Wellbeing Boards to work together with local health and care leaders to improve end of life care. We found this collaborative leadership approach working well in a number of local areas.

Hospices have a key role as local leaders in addressing inequalities in end of life care. During our fieldwork we heard about many examples of good practice in hospice care that are meeting the diverse needs of people from different groups at the end of life. This goes beyond the direct provision of care to engaging with, understanding and developing communities, and providing training and support to health and care staff in local health and care services.

Based on our findings about what works well at local level, we have identified five key aspects of an equality-led approach to end of life care that meet the needs of different groups. These are:

- an end of life care strategy that addresses the needs of different groups.
- equality-led commissioning of end of life care.
- an improvement approach to end of life care for specific groups.

- coordination of care and information sharing.
- community development.

An end of life care strategy that addresses the needs of different groups

The local areas in our fieldwork that showed good practice in end of life care had a clear strategy in place. End of life care was prioritised at local level and commissioners and providers worked together.

NEEDS ASSESSMENT AND PRIORITISATION IN NORTH WEST SURREY

North West Surrey Clinical Commissioning Group (CCG) has prioritised the needs of its local population in developing its end of life care services. As well as conducting a needs assessment to inform its strategic commissioning plan, the CCG is updating the Joint Strategic Needs Assessment to focus on the needs of different equality groups.

In particular, the CCG has focused on the end of life care needs of older people and people with dementia. It is supporting professionals to identify people earlier so that there is a proactive and planned approach to care. The needs of other groups including people with a learning disability, people who are homeless, and Gypsies and Travellers, have also been identified.

The CCG has commissioned the Coordinated, Safe, Integrated (CoSI) team to improve care in the last six to eight weeks of life for people with chronic progressive illness. The team helps people to choose their preferred place of care, and helps to prevent inappropriate admission to hospital. The service supports over 90% of people to die in their preferred setting, and recently won the Kent, Surrey & Sussex Academic Health Science Network award for End of Life Care.

However, this is not always the case. In November 2014, we sent an information request to 44 CCGs and had a good response rate, with 40 responses. Only 61% of the CCGs that responded to our information request said that they had an end of life care strategy that had been developed with local services **(FIGURE 3)**.

People with a diagnosis other than cancer, people with dementia and older people were considered in over half of end of life care strategies. BME groups and other groups of people who may have specific needs were considered less often **(FIGURE 4)**.

Although many of the CCGs we visited had strategies and plans in place to improve access to end of life services, these were often in various stages of development and not all initiatives were fully embedded. We did not always find that the strategy resulted in good care for people from the groups included in the review. While there was clear ambition to improve access for all, a lack of effective monitoring meant that CCGs could not demonstrate the impact on outcomes for people who use services.

FIGURE 3: PROPORTION OF CCGS WITH AN END OF LIFE CARE STRATEGY, BASED ON 38 RESPONSES

No 39%

Yes 61%
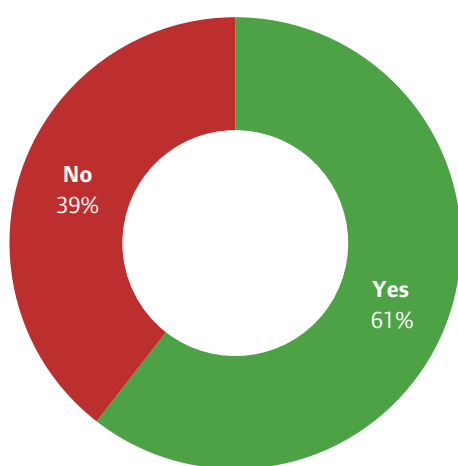
Source: CQC survey of CCGs, November 2014

FIGURE 4: NUMBER OF CCGS CONSIDERING DIFFERENT GROUPS IN THEIR END OF LIFE CARE STRATEGY, BASED ON 38 RESPONSES

Number of CCGs

Priority group	Non-cancer diagnosis	Older people	Dementia	BAME groups	Other with specific needs
Rarely, never or no EOLC strategy	39%	42%	41%	54%	57%
Yes, to some extent	11%	13%	22%	22%	23%
Yes, mostly or always	50%	45%	38%	24%	20%

- Yes, mostly or always
- Yes, to some extent
- Rarely, never or no EOLC strategy
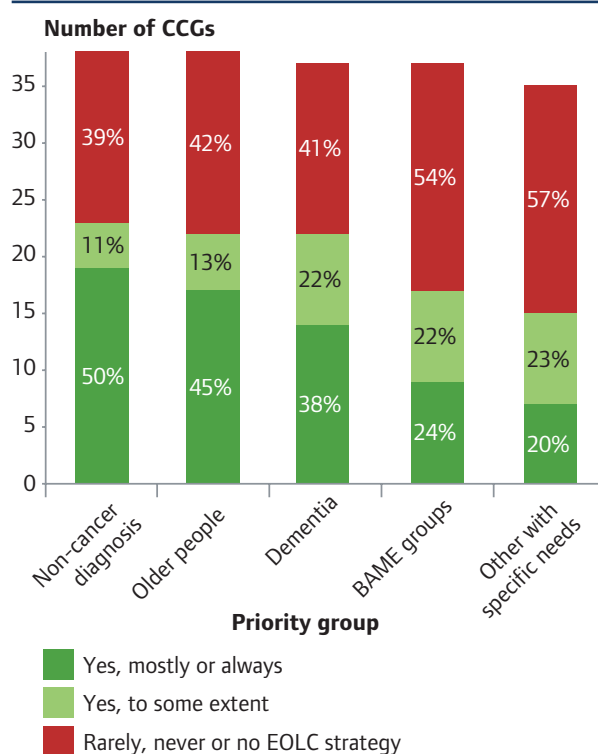
Source: CQC survey of CCGs, November 2014

Equality-led commissioning of end of life care

Under the Equality Act 2010, public bodies – including commissioners and providers of health and social care – have a legal duty to consider the needs of a range of equality groups when carrying out their day-to-day work.[30] There are a number of tools for building an equalities approach into the commissioning and development of services. These include using the local Joint Strategic Needs Assessment to understand the local population's needs, undertaking equality impact assessment, monitoring individual outcomes by equality group, and the NHS Equality Delivery System (EDS2), which NHS commissioners and providers are required to use.

In our local area fieldwork we found some CCGs using needs assessment to inform their commissioning of end of life care. However, only a minority of CCGs were using tools such as equality impact assessment to ensure an equality-led approach to commissioning end of life care services for their local population, for example Central Manchester CCG and Havering CCG.

In response to our information request, only 67% of the CCGs we asked said that they had undertaken any assessment of local end of life care needs **(FIGURE 5)**.

Seven CCGs mentioned that they had commissioned services for one or more of the groups in our review as a result, including four that had commissioned services for older people or people with dementia, and one that had commissioned a service for BME groups.

In November 2015, we sent the CCGs a second information request, to which 30 CCGs responded. In total, 24% said they had undertaken an equality impact assessment for the end of life care services they had

commissioned to consider the impact for groups with a protected characteristic **(FIGURE 6, page 26)**.

FIGURE 5: PROPORTION OF CCGS THAT HAVE UNDERTAKEN A NEEDS ASSESSMENT, BASED ON 40 RESPONSES

No 33%

Yes 67%
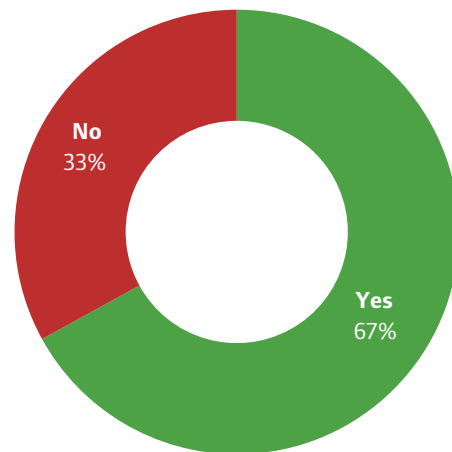
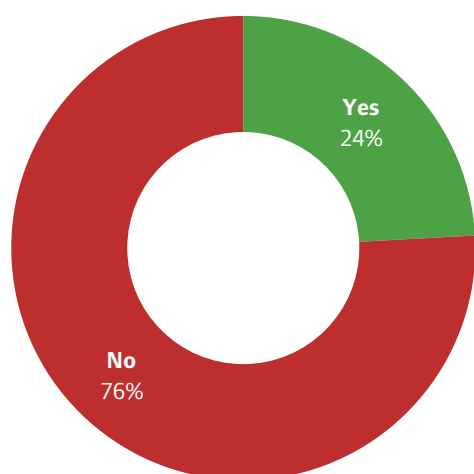Source: CQC survey of CCGs, November 2014

AN EQUALITY-LED APPROACH IN CENTRAL MANCHESTER

Central Manchester Clinical Commissioning Group (CCG) has made equality a central part of its end of life care approach. As well as embedding equality analysis into its decision-making processes, the CCG looks at the impact on people from socially excluded groups, such as people who are homeless, Gypsies and Travellers and migrant workers, as well as those with protected equality characteristics.

As part of its approach, the CCG works closely with MACC, Manchester's voluntary and community sector support organisation, to gain feedback from people and advocates. As a result of this engagement, a care home project was commissioned to ensure frail, older people with non-cancer diagnoses have access to the right services. The project has delivered training to staff in care homes, to enable them to be more confident in discussing preferred place of death and advance care planning, and to deal with a crisis more effectively.

The CCG has also commissioned the Manchester Pathway (MPath) service to reduce A&E attendances for homeless people and reduce re-admissions. MPath provides 'hospital in-reach', with staff from the service visiting the acute hospital to assess homeless patients and ensure they are discharged with a package of care, housing, and engagement with primary care services. The project has helped with identification of end of life in a number of people.

FIGURE 6: PROPORTION OF CCGS THAT HAVE UNDERTAKEN AN EQUALITY IMPACT ASSESSMENT, BASED ON 29 RESPONSES

Source: CQC survey of CCGs, November 2015

Although 67% of CCGs told us they had undertaken an assessment of the end of life care needs of their local population, during our local area visits we found limited evidence that CCGs were commissioning end of life care based on the needs of local groups. People frequently told us that they felt they were not able to access the right services because of their condition or characteristics such as age, ethnic background or sexuality. Some groups felt marginalised as services did not seem to understand their cultural needs, while for others, such as people who are homeless, there were sometimes no services at all to meet their needs.

Barriers that prevent access to care are often not recognised at a local level. CCGs told us that there was a wide range of services and support for people at the end of life, and that diagnosis, age, and ethnic or cultural background did not prevent people from accessing end of life care services. However, treating everyone with the same approach does not necessarily mean that they will receive good care or have equal access to services. Some CCGs had very limited understanding of the end of life care needs of different groups, had not undertaken any needs assessment and were not taking any action to address barriers to good care as a result. This meant that people from different groups in the local area were sometimes not able to access the care they needed.

In contrast, some CCGs had taken an approach based on needs assessment in collaboration with local partners, including the Health and Wellbeing Board and the local authority, using the Joint Strategic Needs Assessment or their own needs assessment to understand local population needs. This was the basis for commissioning services that met the end of life care needs of different groups and addressed the barriers to good care that people experience. In these local areas, we found examples of good practice for many of the groups included in the review, as outlined in the following section.

"We identified the specific needs of the Nepali population, and introduced education to the community on end of life care services, in joint work with the acute provider and Macmillan".

An improvement approach to end of life care for specific groups

Where local leaders are taking a strategic approach to prioritise and improve the quality of end of life care for different groups, we often found good, personalised care that met people's needs and enabled them to make choices. Services and initiatives to support improvement in the quality of personalised end of life care were often in place. In some areas, commissioners and services have taken a bespoke approach to improving care for people from some groups, for example improving end of life care for homeless people as part of improved healthcare, as demonstrated by Inclusion Healthcare Social Enterprise in Leicester.

End of life care for frail older people and people with dementia, including people who are living in care homes, has been identified as a priority for improvement in several areas. We found good examples of GP links with care homes, with GPs carrying out weekly visits and regular reviews of people's health needs as the basis for personalised care planning which included end of life care plans.

Improved end of life care should also be included as part of proactive care for older people, as seen in some of the enhanced health in care home vanguard sites, which are leading the development of new models of care nationally.[31] We saw a number of examples of this care model working well in our local area fieldwork, such as the Care Homes Initiative Programme in South Sefton.

INCLUSION HEALTHCARE: IMPROVING END OF LIFE CARE FOR HOMELESS PEOPLE

Inclusion Healthcare provides primary medical services for homeless people in Leicester. It was rated outstanding following its CQC inspection in November 2014. Our inspectors found strong leadership at its heart and a positive culture that ensures patient safety is paramount.

The practice was committed to reducing health inequalities and improving the health and wellbeing of vulnerable population groups, including homeless people, Travellers, and people with a learning disability. It had an identified lead for end of life care who worked with the local hospice.

Each patient had an 'emergency health care plan' (EHCP). This informs healthcare professionals of the patient's wishes and any treatment they should receive. Patients were involved in developing the EHCP with the clinician and any relatives or carers where appropriate.

The practice also contributed to funeral costs and memorials for patients who were homeless. They have created a memory wall at a local day centre and a project for homeless people.

You can hear more about the experiences of the staff and patients at Inclusion Healthcare in our online video: **www.cqc.org.uk/soc-outstanding**

IMPROVING QUALITY OF CARE IN SOUTH SEFTON, LIVERPOOL

South Sefton Clinical Commissioning Group (CCG) identified care for older and vulnerable people, including end of life care, as a priority. Frail older people make up a large proportion of the deaths in the local area, with around 1,200 people living in care homes across South Sefton. However, in many cases people were frequently being transferred to hospital, sometimes unnecessarily, or were not being identified as approaching end of life until their very final days.

The Care Home Innovations Programme (CHIP) aims to improve the quality of care that people receive and to reduce unnecessary interventions, with the ultimate goal to increase the number of people dying in their preferred place of care. CHIP also encourages advance care planning through the support of a community multidisciplinary team (MDT).

CHIP provides a multifaceted approach, including a focus on quality improvement, locally based care home community matrons, community geriatrician, and training for healthcare staff in care of the dying through the Six Steps programme. A telemedicine service provides MDT support for the care homes 24/7 and is available for emergency and less urgent clinical matters.

Feedback from care homes is that staff have increased confidence in caring for people at the end of life. There is good support from other services including out of hours; there are fewer transfers to hospital and quicker access to services when needed.

Making sure that staff are appropriately trained in end of life care is another key area for improvement for commissioners and providers. While 76% of the 30 CCGs who responded to our 2015 survey had commissioned training on end of life care for some of the groups in our review, including older people, training in different settings varied both within and between local areas. In particular, during our fieldwork we found that training for healthcare assistants and care assistants in care homes and the community was not good enough, and high staff turnover had an adverse impact. We found good practice where training and support was provided by specialist palliative care teams, specialist nurses or local hospices, for example using the Six Steps Programme for care home staff.[32]

SIX STEPS TO GOOD CARE IN OLDHAM

The Six Steps programme had been rolled out in Oldham and Central Manchester CCG areas. The programme aims to develop the skills of care home staff in the provision of end of life care to prevent unnecessary hospital admissions; it includes care in the last days of life.

In Oldham, 20 nursing and residential care homes and some dementia care homes had completed the programme. Anecdotally, hospital staff reported fewer admissions and care staff reported feeling more confident in looking after people at the end of life. This meant more people were able to go back home for the last days of life. The programme was being rolled out further because of this positive feedback.

Coordination of care and sharing information

Poor coordination and lack of shared information were barriers to good care for all groups in most of the local areas we visited. People told us that not knowing who was coordinating their care caused problems as they did not know who to contact for advice and support. It was also confusing for health and care staff with things being missed as it was unclear whose responsibility it was.

In some of our local area visits, health and care staff did not know who was responsible for coordinating care, and in others there was a need for clearer care pathways to define roles. However, we also found examples of good care, where a named care coordinator played a central role, helping people to overcome some of the barriers they experienced in accessing personalised care. For example, in Erewash, there is a care coordinator role within GP practices.

COORDINATING CARE IN EREWASH, NEAR NOTTINGHAM

The care coordinator in Erewash highlights the important role a care coordinator plays at the end of life. The care coordinator looks at admissions and discharges from hospital to identify those patients who may be approaching the end of life. Together with the GP, they also manage and lead regular community delivery team meetings, and review admissions and discharges for 'high risk' individuals, including older people and those with conditions other than cancer.

People in the last 12 months of life are entered on GP palliative care registers and have a named GP to support continuity of care. Specific GP practices are responsible for each care home, and there are regular multidisciplinary palliative care meetings to talk about people on the register.

While it is very important that there is a named care coordinator, who the most appropriate coordinator is will vary according to the person's individual needs. However, if there is no lead professional responsible for identifying a care coordinator, this key role may be lost. Our view is that the person's GP should be responsible for making sure that there is an appropriate, named care coordinator in place.

Our local area visits also highlighted that underdevelopment of Electronic Palliative Care Coordination Systems (EPaCCS) was a significant barrier to effective information sharing. This

has an impact on everyone who receives end of life care. Where EPaCCS were in use, there was a sense that the system was not properly embedded yet. Although commissioners often felt that EPaCCS were a key tool, staff who were using the system had difficulties.

We did not find examples in our local area fieldwork where EPaCCS were clearly helping to achieve good outcomes for people in the groups we were considering. Where EPaCCS were in place, it was not clear to what extent people with conditions other than cancer, and people from other groups, were included on the EPaCCS.

When implemented well, as part of a wider system that supports coordinated care and individual choice and decision-making, EPaCCS have the potential to improve individualised care at the end of life for everyone. However, to realise the benefits of this providers and commissioners should ensure that people from all groups are included.

Community development

Community development initiatives can result in services that are more relevant to people's needs, which build on the skills, knowledge and capacity in communities, support coping and resilience, and change attitudes to death and dying. They are part of a wider approach to developing a culture where people are more able to talk about their wishes and choices for the last phase of their life.

Among the voluntary and community groups we spoke with, condition-specific groups were often focused on supporting people to manage and live well with their condition but had little or no knowledge of care as people approached the end of their lives. Many groups recognised the importance of the issue, but rarely encountered end of life care. This makes it even more difficult for those who are going through end of life and bereavement, and contributes to the reluctance of health and care staff to have difficult conversations with people who are likely to be in the last year of life.

Hospices often take a lead on community engagement and development to promote understanding of the role of the hospice in end of life care, as well as to encourage people to talk openly about death and dying more generally. Community engagement is key to changing culture and breaking down some of the barriers that prevent people from talking about death and dying. Examples, such as the work of St Joseph's Hospice with their local community, demonstrate this.

SUPPORTING PEOPLE TO TALK ABOUT END OF LIFE IN HACKNEY

St Joseph's Hospice supports people by working with local spiritual leaders and community organisations. For example, the imam attached to the hospice has liaised with local mosques so that discussions about death and dying have been introduced at prayer sessions and meetings at mosques. There have been broadcasts about end of life care on the local Ramadan radio network.

The hospice has also introduced a neighbourhood befriending scheme. Volunteers have been recruited to represent the different BME communities in the local area, and given training to act as 'compassionate friends' to support neighbours with end of life care needs. These volunteers also speak with members of their community at established meetings, for example, women's groups and carers' groups, to raise awareness of end of life care.

Conclusion and recommendations

Everyone deserves caring and compassionate care that meets their individual needs and responds to their wishes and choices in the last years, months and days of life. In order to address inequity, it is not enough to improve quality of care for the majority. Each of the groups we looked at, and the people within them, has unique needs and considerations, but our review has shown that these are not being recognised or understood. This needs to be addressed for everyone.

In particular, many of the groups we looked at felt marginalised because they did not have the same level of access to services or they felt like they were treated differently to other people receiving end of life care. Commissioners, providers and professionals are required by law to organise and deliver end of life care that meets the diverse needs of individuals effectively, and it is concerning that barriers to accessing services are not being recognised or addressed in some areas. We found that commissioners and providers are not always meeting the requirements of key legislation, including the Equality Act 2010 and Mental Capacity Act 2005.

While we are aware of the challenges faced by health and social care services, our review has shown that equality-led commissioning approaches, new models of care, community

engagement and outstanding services can make good end of life care for everyone a reality. Local authorities also have a key role in achieving equality of care for all through their responsibility for adult social care, public health and housing, as well as their role in Health and Wellbeing Boards. Local leaders have come together in 44 'footprints' to enable local level planning of Sustainability and Transformation Plans. They need to work together through this joint planning process to ensure everyone has equal access to personalised end of life care.

How well health and care staff communicate with people also has a big impact on their experience of end of life care. Conversations about end of life are difficult, but they are important to give people the opportunity to make plans and choices about their care. Commissioners and providers must ensure that training for health and social care staff in providing personalised, compassionate end of life care is available and accessible, so that staff are confident in proactively communicating with people who are at the end of life, and are able to understand and respond to the needs of the individual and those who are important to them.

More widely, there continues to be a reluctance to talk about death and dying. If we are to improve end of life care, we need a cultural

change to break down the barriers and stigma about talking about death and end of life care, as advocated by the Dying Matters Coalition. We have seen this working in practice through community initiatives and groups. Local areas need to continue to take a proactive approach to engaging with their local communities, in particular the groups in our review, and encourage others to learn from them.

As the regulator of health and social care, we are clear that in order to deliver good end of life care, services must meet the individual needs of everyone, including people whose circumstances may make them vulnerable. If we can ensure that people from the groups included in this review receive caring and compassionate care that meets their individual needs and responds to their wishes, then we can reduce the gulf between those who are receiving the outstanding end of life care for which the UK is known, and those who are not.

Our commitment is to fully reflect the importance of this in our regulatory approach across sectors, and to make a reality of end of life care as a litmus test for health and care services. In doing this, we will encourage and support the sharing of learning about good practice in end of life care for everyone, regardless of diagnosis, age, ethnic background, sexual orientation, gender identity, disability or social circumstances.

Recommendations

As a member of the National Palliative and End of Life Care Partnership, CQC encourages all those with influence over care for people who are dying and those who are bereaved to work together to deliver the vision of individual, personalised end of life care as outlined in the **Ambitions for palliative and end of life care**. We are committed to working as a member of the Partnership to play our part in encouraging the improvements needed in the quality of end of life care.

We support the recommendation of the independent review into choice in end of life care that each person who may be in need of end of life care is offered choices in their care focused

on what is important to them. We also support the associated recommendations that specify what is needed to make this a reality. Taken together, these provide a roadmap for taking forward NHS England's **Actions for end of life care**, and delivering the triple aim articulated in the **NHS Five year forward view** in relation to achieving good quality, personalised care at the end of life for everyone.

We expect all providers delivering end of life care in any setting to follow national guidance on the quality of end of life care, including NICE guidance and the **Five priorities for care of the dying person**.

CQC encourages the health and care system to work together to ensure that everyone receives good quality care in the last phase of their life, irrespective of age, gender, ethnicity, religious belief, disability, sexual orientation, gender identity, diagnosis or social circumstances, as required by the Equality Act 2010 and the Health and Social Care Act 2012.

To ensure that each person gets fair access to care, specific action is needed; this is set out below.

CQC encourages:

1. **Leaders of local health and care systems**, including NHS England regional teams, Health and Wellbeing Boards, local authorities and CCGs, to work together with local services and their local community to give due consideration to end of life care in their Sustainability and Transformation Plan, and develop and deliver a strategic plan to deliver good quality, equitable end of life care for everyone in their community as part of the local level planning of health and care services in their area.

2. **Commissioners and providers** of end of life care services to fulfil their respective duties under the NHS Constitution, the Health and Social Care Act 2012 and the Equality Act 2010 to reduce inequalities, eliminate discrimination and advance equality when developing, arranging or delivering end of life care:

- Through assessing and understanding the end of life care needs of their local population.
  - By using available tools such as the NHS Equality Delivery System (EDS2) and impact analysis to identify and agree actions to deliver on these duties.
  - Supported by monitoring of access to end of life care services and outcomes for people from different groups.

3. **Commissioners and providers** to ensure that staff, including care home staff, who care for people who may be approaching the end of life have the knowledge, skills and support they need in identification, communication, cultural awareness, five priorities for care of the dying person, and care for people who have dementia.

4. **Hospices** to use their unique role as local leaders, funders and providers of end of life care to champion an equality-led approach that engages local communities, delivers equitable end of life care based on individual need, and supports other local health and care services in doing the same.

5. **GPs** to ensure that everyone with a life-limiting progressive condition has the opportunity, if they wish, to have:
   - Early and ongoing conversations about end of life care in the last phase of life as part of planning their treatment and care, in a way that responds to their individual communication needs.
   - A named care coordinator who is the lead professional who coordinates services around them; this could be the GP, district nurse, specialist nurse, care coordinator or any other professional most appropriate to the person's needs.

What CQC will do:

1. In **the development of our future regulatory approach** across sectors, we will:
   - Consider our approach to assessing the quality of end of life care for everyone, including people from equality groups and people whose circumstances may make them vulnerable, and how we can encourage improvement in the quality of end of life care for the groups included in this review.
   - Reflect the importance of equity in access to end of life care services as well as good quality, personalised end of life care in our approach, including ratings.
   - Review how we report on our assessment of end of life care for different groups to ensure that our findings are clear and accessible, particularly in services where we do not currently provide a specific rating for end of life care.
   - Consider how we reflect the learning from methods used in this review in future inspection approaches to assess the quality of end of life care for everyone, including people from equality groups and people whose circumstances may make them vulnerable.

2. In **services where we provide a rating for end of life care services**, including hospitals, community health services, and hospices, we will:
   - Strengthen our assessment of whether end of life care services are meeting the needs of everyone, including people from equality groups and people whose circumstances may make them vulnerable, in our inspection of the key question 'Is the service responsive?', and report on this consistently.

3. In **services that provide end of life care but do not currently receive a separate rating for end of life care**, including adult social care services and GPs, we will:
   - Include an assessment of the quality of end of life care and whether it is meeting the needs of everyone, including people from equality groups and people whose circumstances may make them vulnerable, and report on this consistently.

- In GP assessments, include an assessment of whether the service is ensuring early conversations and coordinated end of life care for everyone, including people from equality groups and people whose circumstances may make them vulnerable.

4. In **services that provide health or social care to people who are vulnerable because of their circumstances**, including services for people with a learning disability, people with a mental health condition, people who are homeless, Gypsies and Travellers, and people who are in prison, we will:

- Consider identification, communication and delivery (if relevant) of end of life care as part of our assessment of how the provider is meeting people's mental and physical health care needs.

5. We will **use our independent voice** to:

- Share our findings and insight about the quality of end of life care across health and social care, including for people from equality groups and people whose circumstances may make them vulnerable, to encourage improvement at local and national level.

Acknowledgments

Expert advisory group

Two people with experience of end of life care were members of our expert advisory group, along with representatives of the following organisations:

- Action for Prisoners' and Offenders' Families
- Age UK
- Barnet Healthwatch
- Carers Trust
- Coordinate my Care
- Demos
- Gold Standards Framework
- Hampshire Hospitals NHS Foundation Trust
- Heart of England NHS Foundation Trust
- Hospice UK
- Hull City Council
- King's Fund
- London School of Economics
- Macmillan Cancer Support
- Marie Curie
- Marie Curie Palliative Care Institute Liverpool
- Motor Neurone Disease Association
- National Care Forum
- National Council for Palliative Care
- National End of Life Care Intelligence Network (Public Health England)
- NHS England
- NHS Gloucestershire CCG
- NHS Improving Quality (now part of NHS England)
- Nottingham University Hospitals NHS Trust
- Royal College of General Practitioners
- Social Care Institute for Excellence
- Sue Ryder
- University of Nottingham

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Appendix A: How we carried out the review

SECTION 48: CQC'S SPECIAL REVIEW POWERS

We carried out this review under Section 48 of the Health and Social Care Act 2008. This gives CQC the ability to explore issues that are wider than the regulations that underpin our regular inspection activity. Using these powers, we can do more to understand people's experience of care across settings, through exploring local area commissioning arrangements and how organisations are working together to develop personalised, coordinated care.

The purpose of this thematic work is to use our position in the health and care system to encourage improvement in the quality of joined-up, personalised care. This includes models of integrated care, the quality of care pathways, and the quality of services in a local health and care economy.

Our work on inequalities in end of life care is one of a series of thematic projects that look at health and care provision across a local area, and that focus on how well services are integrated.

Building on previous thematic reviews, we developed our approach for this review with input from people with experience of end of life care, service providers, commissioners and national stakeholders from the voluntary and statutory sector. This appendix provides details on the activities we undertook as part of the review.

Evidence review

We reviewed existing national data on the quality of end of life care for the specific groups included in our review. We looked at both contextual and performance data across clinical commissioning groups (CCGs) to select a sample of 44 CCGs that had a range of geographic and demographic characteristics, and varied in performance. These CCGs were then sent a request for information in November 2014. We sent a second request for information in November 2015.

We also commissioned Demos to undertake a literature review on the quality of end of life care for the groups in our review, with a specific focus on understanding inequalities. This informed the development of our assessment framework for the CCG information request and local area fieldwork, and has informed our national report.

In order to build on the work other organisations have already done to understand people's experience of end of life care, we commissioned the National Council for Palliative Care (NCPC) to put out a call for evidence of people's experiences of care across national voluntary sector organisations working with our target populations. This generated research reports, good practice guidance and other information from which we extracted 178 individual stories and analysed 73 case studies.

Our approach to local area visits

Through our local area visits we aimed to identify the barriers to good care that people experience at local level, as well as good practice. We also looked at how local areas were undertaking commissioning to address inequalities in end of life care, what the experience of individuals were across the pathway of care, and why people from particular groups often experience poor care.

During our visits, we looked at four key lines of enquiry:

1. **Identification and communication**
Are people from the groups we have identified who are likely to be in the last 12 months of life identified at the appropriate time by a health or care professional and given the opportunity and support to have open and honest discussions about their goals, needs and choices?

2. **Coordination of care**
Is care coordinated effectively to ensure that the person is at the centre of their care, including when they have multiple or complex needs or vulnerabilities? How is this achieved? Is transition between services managed well so that people get the right care, in the right place, at the right time?

3. **Access to good care**
Do people and those important to them have timely and equitable access to good quality care in their preferred place of care, from the services they need, including advice, access to specialist palliative care, support for carers, social care, and 24/7 support?

4. **Care in the last days and hours of life**
Does care in the last days and hours of life in all situations deliver the five priorities for care of the dying person? Is this affected by the person's diagnosis, age, ethnic background, where they live or any other factor?

In collecting evidence to answer the key lines of enquiry, we undertook the following activities:

- **Information request to commissioners**
We requested information about end of life care commissioning for the groups included in the review from the sample of 44 CCGs selected through the data review in November 2014, and again to update the data for a subset of the original questions in November 2015. We received 40 responses to our first request and 30 responses to our follow up request. The information request was undertaken through an online survey with telephone follow-up.

- **People's experience of end of life care**
We undertook an online survey on our website to gather people's experiences of end of life care. The survey specifically targeted those with experience of end of life care for people with dementia for six weeks, and was then opened to all groups. We received 65 responses relating to care for people with dementia, and 202 responses relating to care for people from the other groups of interest. The majority of responses to both online surveys described poor experiences of end of life care and identified very similar themes. In addition to this, we reviewed 769 comments received through our Share Your Experience form in 2013/14 relating to end of life care, against the themes in the National Voices/NCPC narrative.

We commissioned NCPC, National Voices, and the Race Equality Foundation, to undertake targeted public engagement work in 17 local areas. Together, the partners interviewed 22 individuals from the groups included in the review in depth about their experience of end of life care in the last year. They also received feedback from five voluntary and community organisations, undertook two focus groups and visited a prison.

We contacted all local Healthwatch groups to request any information about people's experience of end of life care, met with two Gypsy and Traveller voluntary sector organisations, and carried out a focus group with Healthwatch Barnet and the local Gypsy and Traveller community. NCPC approached 266 local groups who supported people in our target populations across the 20 CCG areas, and contacted carers' groups and bereavement groups. We also contacted all local Overview and Scrutiny Committees and NHS Complaints Advocacy Services across the country. We held a workshop with representatives working with national experience across some of the populations we were targeting.

- **Local area fieldwork to explore barriers to good care and identify good practice**

  We identified 17 local areas from our sample of 44 CCGs where we undertook fieldwork. Our fieldwork teams included two CQC inspectors, a specialist adviser, and an Expert by Experience.

  During the local area fieldwork we spoke to 478 staff through focus groups, and 78 people with experience of services. We interviewed 74 GPs and reviewed the case notes of 70 people. The sample of 70 case note reviews covered people from a range of age bands and were predominantly reviews of GP records, care home plans of care and community nursing plans.

Analysis

We undertook quantitative and qualitative analysis of the evidence we collected, depending on the nature of the evidence source. Qualitative analysis of fieldwork evidence was based on the key lines of enquiry and was further developed to reflect the themes of the data. We used a framework for qualitative analysis based on *Every moment counts: a narrative for person-centred coordinated care for people near the end of life*, developed by National Voices, NCPC and NHS England, to analyse people's stories.[i]

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i. National Voices and the National Council for Palliative Care, Every moment counts: a narrative for person–centred coordinated care for people near the end of life, March 2015.

Appendix B: Definitions

Palliative care: the National Council for Palliative Care defines palliative care as:[ii]

> "…the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.

Palliative care aims to:

- Affirm life and regard dying as a normal process
- Provide relief from pain and other distressing symptoms
- Integrate the psychological and spiritual aspects of patient care
- Offer a support system to help patients live as actively as possible until death
- Offer a support system to help the family cope during the patient's illness and in their own bereavement."

Palliative care can be delivered by specialist services, such as palliative care teams and hospices, or generalist services, including GPs, care homes, district nurses, and domiciliary care.

Carers: by this we mean anyone who cares, unpaid, for a friend or family member who cannot cope without their support, as described in the Care Act 2014.

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ii   The National Council for Palliative Care: **Palliative care explained**

![Care Quality Commission logo]

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Please contact us if you would like this report in another language or format.

See our other reports on the thematic review:

GOOD PRACTICE CASE STUDIES

PEOPLE'S EXPERIENCE BRIEFINGS:

- People with conditions other than cancer
- Older people
- People with dementia
- People from Black and minority ethnic (BME) groups
- Lesbian, gay, bisexual or transgender people
- People with a learning disability
- People with a mental health condition
- People who are homeless
- People who are in secure or detained settings
- Gypsies and Travellers