

Inequalities and variations in End of Life Care

CQC's thematic programme

CQC's purpose is to make sure health and social care services provide people with safe, effective, compassionate, high-quality care, and to encourage care services to improve. In addition to registering and regulating health and social care services, CQC encourages improvement through its thematic programme of work.

The purpose of CQC's thematic activity is to expand our understanding of the quality of care beyond our existing regulatory activity, in order to provide an authoritative voice on the quality of care on priority issues that CQC is uniquely placed to assess.

Each thematic project is developed to respond to a particular question about the quality of care. The approach is characterised by flexibility and learning, with methods developed according to the question being addressed, and the involvement of teams across CQC, people with personal experience, and external stakeholders from the start.

The findings and recommendations of our thematic work are published externally to influence others in health and social care to change what they do, and inform our own understanding of what good looks like and our regulatory approach. In order to achieve this, we work in partnership with others across the system to strengthen the impact of our work.

Why focus on inequalities in End of Life Care?

There are many examples of good practice in delivery of end of life care in different settings, but we also know that people's experience of end of life care can be very varied and is often poor. This has been highlighted in recent reports such as the review of the Liverpool Care Pathway. Inequalities in people's experience of end of life¹ care, both between different geographical areas and across different groups of people, are well-documented.

CQC has strengthened its approach to inspection of end of life care services across the health and care sectors under its new approach. We have talked to people with experience of services and other organisations working in end of life care about what we should focus on beyond this to encourage improvement in the quality of care for people at the end of life. They told us that we should look at the experience of people with multiple conditions, dementia and older people, care for people who don't have cancer, variations in different areas and availability of services, as well as people's experience of joined up care. We have developed our approach to respond to this, and will focus on differences across geographical areas and the experience of different groups, including particularly vulnerable groups, and the integration and coordination of services across sectors.

¹ For the purpose of this thematic work, we will use the definition that "People are 'approaching the end of life' when they are likely to die within the next 12 months", as defined by the GMC in [Treatment and care towards the end of life: good practice in decision-making](#), and also used in [NICE QS13](#).

What do we want to find out?

Evidence shows that people from particular groups, including people with the most complex conditions and those who are vulnerable because of their circumstances, experience end of life care which is of poorer quality and does not always meet their needs, and that variations in care, and coordination of care, at local level contribute to this. However we know that there are examples of good practice at local level which we can identify and document to enable others to learn from what works well.

Through this thematic programme, we want to develop our understanding of the barriers which prevent people with the poorest experience of care from receiving good quality, joined up care at the end of life. We will also identify and describe good practice which others can learn from. Working with others in the health and care system, we will identify action which national and local stakeholders, including commissioners, can take to address inequalities, based on our findings.

We will answer two questions:

1. What factors prevent people from different areas and from particular groups, particularly those with non-cancer diagnoses, older people, people with dementia, and people from BAME communities, as well as LGBT people and people with specific vulnerabilities due to mental health needs, learning disabilities or other reasons, from experiencing good quality, joined up care at the end of life?
2. What good practice can others learn from at local level, and what action can national and local stakeholders take in the next five years to address inequalities in experience of end of life care?

How will we do this?

The thematic work on inequalities in End of Life Care is planned in three phases. Each phase will be informed and shaped by what we have learned in the previous phase.

In Phase One, we will explore geographic variations in the quality of end of life care through a data review which will enable us to select Clinical Commissioning Group (CCG) areas to follow up with using a targeted information request. The process of selecting CCGs will initially involve bringing together currently available information to create CCG level profiles displaying comparative information relevant to understanding end of life care in that area.

Once these profiles have been created we will select the CCGs that will be sent an information request, based on their characteristics. We will ask CCGs whether they have identified End of Life Care as a priority, about end of life care systems, services and experiences in their area, and about their role in ensuring that people from all groups receive good end of life care. This work stream will be completed in phase two.

In Phase Two, we will gather qualitative evidence about people's experience of end of life care, following up on issues identified in our area profiles and through the CCG information request.

We will do in-depth fieldwork in 20 CCG areas, in order to assess whether commissioning is having an impact on quality of care for people from particular groups.

We will identify people for pathway tracking from the groups we have prioritised, and develop our understanding of their experience across services through talking to people approaching the end of life and those close to them, looking at records, and talking to staff. We will undertake focus groups at local level to explore issues of inequalities and end of life care, and to identify barriers to good care.

We will focus particularly on the factors which people have told us we should prioritise and which the evidence shows are variable - timely identification of people who are approaching the end of life, and the coordination and integration of care from the perspective of the individual.

In Phase Three, we will bring together our evidence about the experience of people from prioritised groups, with our inspection findings about services, and bespoke area profiles to identify the barriers to people receiving good quality, joined up care. We will consider individual care, services, systems and commissioning. We will identify areas where people in the selected groups experience good quality care at local level and we will describe how this is achieved. We will work with others in the health and care system to identify recommendations for national and local stakeholders, and will develop a strategy to communicate and follow up on our recommendations, together with appropriate stakeholders. In addition to this we will identify learning which we will reflect in our future inspection approach, and we will follow up the thematic work through our inspection programme.

How can this work lead to improvements in quality of End of Life Care?

- Increased understanding and awareness of the individual experiences of people from groups which usually have a less good experience of end of life care;
- Identifying and describing challenges and barriers to good care, and making information on good practice available more widely available;
- Improved understanding of what good care looks like for different groups at local level, what some of the challenges are in meeting diverse needs, and how commissioning can improve care;
- Improved understanding of the quality of end of life care in different settings;
- Working with stakeholders to identify actions which encourage national and local bodies, including commissioners, to learn from good practice and improve quality of care;
- Following up recommendations through our own inspections and with stakeholders as part of the health and care system.

What happens next?

June – August	<ul style="list-style-type: none"> • Analysis of existing data • Review of published literature • Review of other evidence
September – February	<ul style="list-style-type: none"> • Develop information request to CCGs • Information request to CCGs • Analysis of CCG response
March – June	<ul style="list-style-type: none"> • Develop and test fieldwork and involvement methods
July – September	<ul style="list-style-type: none"> • Focus on people’s experiences • Local area fieldwork
October – December	<ul style="list-style-type: none"> • Analysis of findings • Workshops and engagement • Production of report
January	<ul style="list-style-type: none"> • Publication • Follow-up activities

Further information:

Please contact endoflifecarereview@cqc.org.uk.