

# Dying well at home

## Commissioning quality end-of-life care

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*We had several district nurses who came in. And then the hospice nurse came out, like, a couple of weeks before [he died] and she was the one who kind of said, 'oh, we probably need to get a hospital bed in and we need to do x, y and z'. But he declined too quickly so actually none of those things were in place. We didn't really have any other contact and it was very much, like, because – we didn't know anything about it and we didn't know what we were looking for, we were the ones advocating for him because nobody else was there to see it. So it was like, is he in pain? Is he distressed?... A lot of it was like, just calling up the nurses and being, like, 'he's moving around a lot', or 'he seems like he's uncomfortable', and they'd come out and sedate him essentially. That was, like, pretty much what happened throughout.*

*We persuaded them [my parents] to come and live here because, obviously, their conditions were not going to get better. The GP, as I said, was very good, came out to see them the first few days after we registered, had an hour and a half conversation with them – they hadn't even had an hour and a half in total in the last 10 years with their previous GP! So we were bowled over by that.*

*Compassion – with a lot of health care professionals, I think that's one of the things that was lacking. And when we had to sign the DNR [do not attempt resuscitation order] that was the same, we obviously knew he couldn't be resuscitated, we wouldn't try – but, just – the conversation around having that was a difficult conversation – because it was with us rather than with him, because it was left until so late that he couldn't be the person that was signing off on it. So, yeah, I think a lot of it is around communication, and communication between health care professionals around a person's care if they all have a part to play in it. But also communication with the family and having these conversations prior to end of life, so as soon as someone goes into palliative... to have that in place, so that we didn't feel that we were just making it up at the end.*

*(Focus group participants)*



# About this project

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# Key messages

- The trend of increasing numbers of people dying at home, rather than in a hospital or hospice, is well established and set to continue. The Covid-19 pandemic gave a preview of the higher levels of demand for community services that can be expected. Integrated care systems (ICSs) need to make sure that end-of-life care reflects the change that has already started, and must be ready for a continuation of this trend.
- NHS commissioners have the essential role of understanding local need for end-of-life care and ensuring that high-quality services are in place to meet that need. Their unique position, which can give them sight across all relevant services, is key for assuring the quality of care now, as well as planning for future need, and bringing together all the providers to deliver those plans.
- When we interviewed commissioners of end-of-life care for adults for this report, many of them were not realising the full value of their role because they were not making good use of the data about need and the analytical resources that are available to them. Understanding the local population's needs for end-of-life care, and how those needs are changing, are essential foundations for delivering high-quality care.
- Commissioners were aware that there were likely to be inequalities and unmet need in their local area, but without better use of information they could not gauge the extent of these gaps or develop plans to address them. It is essential that they go further and take action to reduce inequalities and address unmet need in end-of-life care.
- Generalist services such as GPs, district nurses or homecare providers often provide the bulk of end-of-life care for people who die at home. Commissioners need to focus on and plan for these providers' critical role in enabling a good death at home, as well as the role played by specialist services. Yet the commissioners we spoke to often had little or no data about generalist services in their area.



- Commissioners also lacked information about individuals' and carers' experiences of end-of-life care. Quality monitoring should cover three areas: processes (such as whether an advance care plan is in place); the outcomes of treatment and care; and how people experience care. Of these, most commissioners only routinely monitored processes for people who die at home. In our view, regular information on people's experiences of end-of-life care is the first priority for improving this.
- Commissioners are starting to take on different roles to address these challenges – bringing together the range of services involved, facilitating joined-up approaches across those services, engaging communities and developing partnerships with shared understanding and commitment. These are exciting developments that give insights into what the commissioning of end-of-life care might look like once integrated care boards (ICBs) are fully developed.
- In developing new approaches, it is essential that social care is fully engaged and valued as a key partner, not just a stakeholder. Since the pandemic, the role of care homes in end-of-life care has become better understood, but we found that NHS areas did not consistently engage them, and homecare and local authorities' wider roles were often engaged even less.
- Our research took place at an inflection point for commissioning end-of-life care. The creation of ICBs, together with a new emphasis in legislation and guidance on commissioning end-of-life care, requires commissioners to review these services and plan how to manage them as one coherent system. Some are going further, distancing themselves from historical concepts of the commissioner and exploring new ways to approach their roles in planning, assuring and improving health services for their local community. This is an unprecedented opportunity for change and improvement. Our recommendations are intended to help ensure that the potential of this moment is fully realised.



# Introduction

More than half of all deaths in England currently occur in hospitals or hospices, but the proportion of people dying at home<sup>1</sup> has been increasing for at least two decades. This trend is projected to continue, with deaths at home and in care homes overtaking the number of deaths in hospitals and hospices by the 2030s, and accounting for more than three-quarters of all deaths by 2040 (Bone *et al* 2018). This is welcome as it indicates that outcomes are increasingly reflecting individuals' preferences, although hospitals and hospices will of course continue to be the most appropriate place of death in many cases ([Henry and Choice in End of Life Care Programme Board 2015](#)). It also makes clear the need to plan for continuing, significant increases in demand for community-based services that support people at the end of life.

The Covid-19 pandemic gave us a preview of what this increased demand could look like. Deaths at home and in care homes surged in 2020, with 41,000 more deaths than expected in private homes in England and Wales and 25,000 more than expected in care homes – reaching the levels that modelling had predicted would not be seen until 2040 (Higginson *et al* 2021). Only about 7 per cent of deaths in private homes were due to Covid; the increase was seen across different causes of death, broadly in line with previous patterns but at higher levels. For people aged 85 and over, the increases were particularly marked and, for the first time, care homes overtook hospitals as the main place of death ([Office for National Statistics 2021a](#)). The pandemic also exacerbated and exposed inequalities in end-of-life care, just as it did for other health inequalities ([Sleeman \*et al\* 2021](#)).

Yet very little is known about whether all those people who died at home had a good death. The quotes included at the start of this report are from family members whose loved ones died at home during the pandemic. They show how challenging and isolating that experience can be, and the positive impact that thoughtful, supportive care can have. At a national level, there is inadequate data to let us

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<sup>1</sup> In general usage, we take the phrase 'at home' to mean a person's usual place of residence, which will include care homes as well as private homes. However, when presenting statistics, we distinguish between private homes and care homes because the data treats these two categories separately.





know whether people who die at home can access the treatment and care that they need, or whether their care is well co-ordinated and reflects what they wanted. There is no national data to let us know whether we have enough staff in the right place and with the right skills to meet current or future levels of demand, and there is no longer any national data about individuals' and carers' experiences of end-of-life care.

This report explores the roles of NHS commissioners in managing the current situation and planning ahead, as they are responsible for assessing and responding to increasing need at a local level, and for monitoring and assuring the quality of end-of-life care that they commission.

## Our research

Our research sought to answer three questions.

1. What do we know about the quality of end-of-life care for people who die at home, and any inequalities experienced by particular groups in the population, before and during the pandemic?
2. What are NHS and social care commissioners in England doing to measure and assure the quality of end-of-life care for people who die at home, including any inequalities experienced by particular groups in the population?
3. What are the implications of our findings for national bodies and local systems?

To answer these questions, we interviewed NHS commissioners responsible for end-of-life care based in integrated care boards (ICBs) in 10 areas of England, and social care commissioners based in local authorities in a further 5 areas. These areas were randomly selected, with stratification to ensure variation in their location across England and in their level of deprivation. The interviews with commissioners were complemented by interviews with stakeholders and experts in end-of-life care, as well as a review of relevant literature. We also held a focus group and workshop with recently bereaved carers and family members, to capture the perspectives of people with first-hand experience of end-of-life care at home. The focus group helped inform interviews with commissioners, and the workshop informed our analysis of findings. When we were analysing our findings, we convened a workshop



of experts and stakeholders (including commissioners) to advise us. For more detailed information about our methods, please refer to the appendix.

Throughout this report, we refer to ‘commissioning’ and ‘commissioners’, although it should be noted – as we will make clear – that the understanding of what these terms mean, and potentially the vocabulary used to name them, are changing.

### What is end-of-life care and who commissions it?

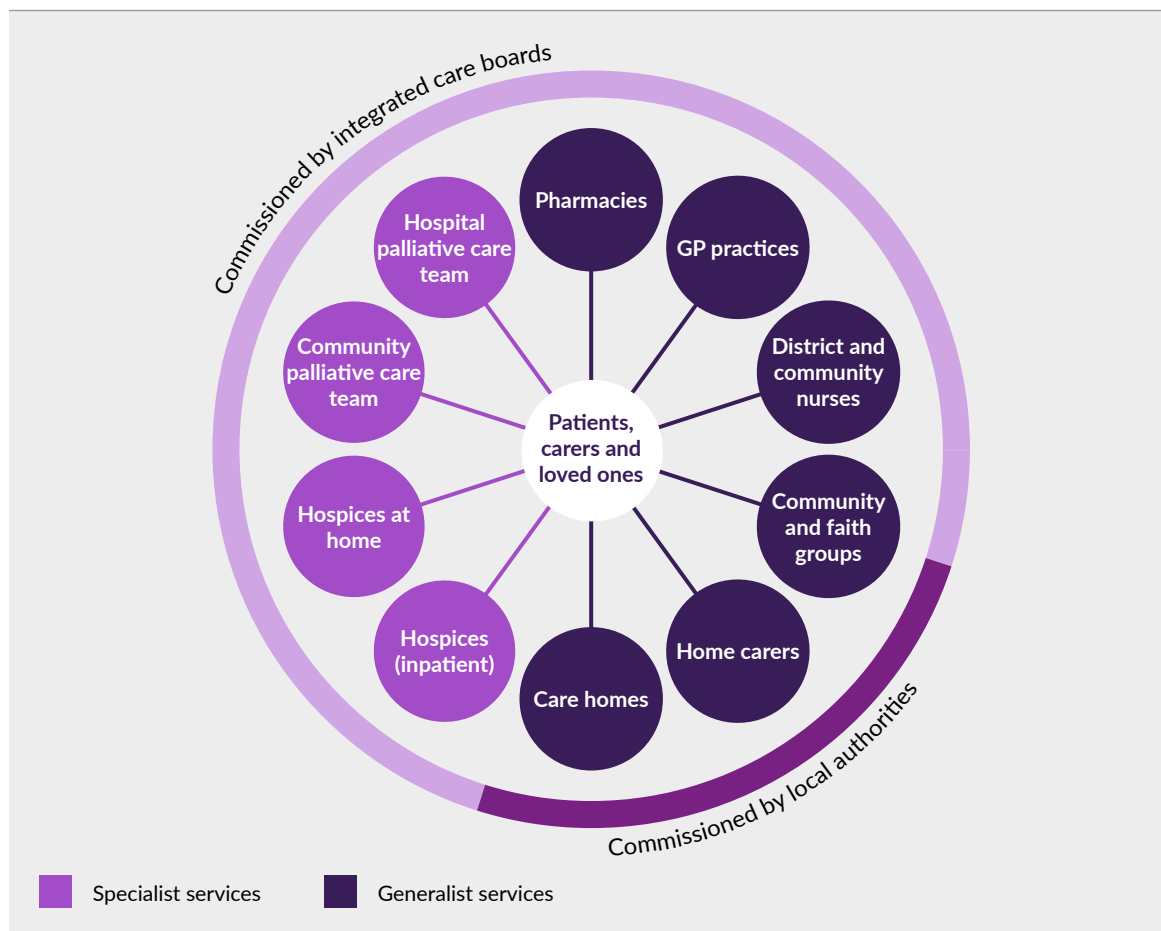
The definition used in England is that a person is ‘approaching the end of life’ when they are expected to die within the next 12 months. Accordingly, end-of-life care encompasses not only the last few hours, days or weeks of life, but also treatment and care when underlying conditions are expected to lead to death over the coming year. It places a strong emphasis on ensuring holistic, person-centred care as well as clinical treatment, and encompasses support for carers as well as the person who is dying ([National Palliative and End of Life Care Partnership 2021](#)).

Figure 1 on page 8 illustrates that end-of-life care involves a complex mix of services, organisations, professionals, and both NHS and local authority commissioners. It is not exhaustive; in practice, the mix and types of service provided by these and other organisations will be or should be personalised to the individual.

Within hospitals, a specialist palliative care team will work across the range of clinical teams and wards to support patients at the end of life. Where they are available, hospices may also provide inpatient palliative care.

In the community, specialist palliative care may be provided by community NHS teams and/or teams provided by hospices. These teams work with a range of ‘generalist’ health services such as GPs, pharmacists and district nurses. However, given limits on capacity, in many cases the generalist health services will also provide end-of-life care to individuals without the involvement of palliative care specialists. Although many areas have a 24-hour advice service, generalists will often be the only health care professionals available to provide treatment out of hours.

**Figure 1** Main organisations involved in commissioning and providing end-of-life care



In most cases, a greater proportion of hospice services are provided for outpatients (either in people’s homes or as clinics and activities at the hospice) than for inpatients. Most hospices are independent, voluntary sector organisations, with a proportion of NHS funding, which varies but is usually less than the charitable funding they receive. The availability of hospices varies considerably, and some areas of the country have none nearby.

Social care – whether in people’s own homes, in care homes or in other settings such as supported housing – is an integral part of end-of-life care at home. As well as a key aspect of the holistic, person-centred quality of end-of-life care, social care can be particularly important in enabling people who wish to die at home to avoid the need for hospital admission.



Family members and unpaid carers play a crucial role in end-of-life care, and the sustainability of end-of-life care at home is dependent on the availability and ability of family members and carers to provide support (Gomes and Higginson 2006). End-of-life care includes support for carers, as well as for the person approaching the end of life. Community and faith organisations can also play an essential role, including in reflecting different communities' needs, and cultural beliefs and practices around death.

Each NHS 'place' – usually the area previously covered by a clinical commissioning group (CCG) – has a lead commissioner for end-of-life care, across the various services involved. These commissioners often also have a range of other responsibilities, so that end-of-life care is just one part of a wider portfolio. For generalist services, end-of-life care will usually be one part of a wider contract for which another commissioner has the lead responsibility – for example, the GP contract – and it is not usually specified in detail in these cases.

For people who are eligible, social care is commissioned by local authorities. It is also arranged directly by many people who pay for it themselves; local authorities monitor overall services that they commission (including where they have a mix of publicly and privately funded users) but do not have routine oversight of wholly privately funded services. In a few cases, where a person has ongoing and complex health care needs that cannot be separated from their social care needs, the NHS may commission social care. The extent to which social care includes end-of-life care will depend on the needs of the individual receiving care.

NHS England has a national strategic clinical network in place for palliative and end-of-life care, to support and promote good practice in commissioning. In some places, social care and NHS commissioners are employed jointly to work across both sectors; there is some evidence that joint funding, together with a joint strategy, can lead to care that is better co-ordinated and thereby result in better identification of patients, savings from reduced hospital admissions, and better feedback from patients and carers (Barker 2021). And in some places, local authority and NHS commissioning of end-of-life care may be co-ordinated at a strategic level (for example, a strategy overseen by the local health and wellbeing board) and/or at an operational level (for example, governance boards or partnership forums that regularly bring together commissioners and providers).



## End-of-life care for children and young people

This research focused on end-of-life care for adults in the context of the trend of increasing numbers of deaths at home. Children and young people are out of scope because their end-of-life care is different in nature to that of adults; it is usually commissioned separately, and the trends in patterns of deaths are different. Children's services are, however, an important part of the overall end-of-life care landscape.

End-of-life care for adults normally starts when they are identified as being in the last 12 months of life, but for children it starts when a life-limiting or life-threatening condition is first diagnosed and continues until death. For congenital and genetic conditions (the biggest diagnostic group of life-limiting and life-threatening illnesses among children), end-of-life care often begins at birth and may continue for 20 years or more ([Together for Short Lives 2017](#)).

Trends in end-of-life care for children are changing, but not in the same ways as for adults.

- The trend of increasing numbers of deaths at home – which was a key reason for undertaking this research – does not apply to children; the proportions of child deaths at home or in hospital are fairly consistent ([Gao et al 2016](#)).
- The numbers of children living with life-limiting and life-threatening illnesses have increased markedly and are projected to continue doing so. Some of this may be due to increases in incidence or to better diagnosis, but better survival rates (for example, following complex surgery or very premature birth) appear to be the main reason ([Fraser et al 2021](#)).

*Some of these children would have been working with professionals for maybe 10 or 15 years with a palliative care diagnosis as they approach end-of-life care. And then those families want those people that they've got to know, that are familiar to the child, familiar to the family, and I think a lot of them will say it's people they can trust at the end of life and that's what's most important to them.*

(NHS commissioner for children's services)

Children's end-of-life care is usually commissioned separately to adult services and involves a different range of providers, including children's hospices, schools,

*continued on next page*



### End-of-life care for children and young people *continued*

disability services and voluntary organisations. The number of children and young people needing end-of-life care is so small, and their needs are so complex, that services are generally commissioned on a bespoke, individual basis. Apart from children's hospices, there is not usually a 'standing' end-of-life service for children in the way that there is for adults.

*When we've got a family in a hospital, if they want to be cared for at home, then we will do everything and move everything to try and commission something in the home to meet that need. And that might mean changing around some of our usual services, it might mean bringing in extra staff. We can be really creative.*

(NHS commissioner for children's services)

Currently, the provision of specialist end-of-life care for children is variable around the country and may not reflect need. The prevalence of life-limiting and life-threatening illness is highest among certain ethnic minority groups and appears to be increasing fastest in areas of greatest deprivation (Fraser *et al* 2021).

### What do we know about quality in end-of-life care at home?

The UK has long been considered an international leader in end-of-life care ([The Economist Intelligence Unit 2015](#); Finkelstein *et al* 2022). However, international comparisons are inevitably broad brush and can mask the variations in quality that various reports have found during the past decade ([House of Commons Health Committee 2015](#); [Parliamentary and Health Service Ombudsman 2015](#); [Care Quality Commission 2017](#)). Furthermore, the variability of access to end-of-life care – notably out-of-hours care, 24-hour advice lines and pharmacies throughout the night, and reliance on accident and emergency (A&E) attendances in the last three months of life – strongly suggests there is significant unmet need for end-of-life care at home, which would not be visible in national data ([Pask \*et al\* 2022](#)).

There is high-level data available about the number of deaths that occur and the diseases people die from, as well as the number of hospital admissions in the last three months of life ([Raleigh 2022](#)). However, there is very little detailed data that is routinely available about the services people received before they died, the quality



of those services, whether care provided was in line with need, how decisions were taken about place of death, and the experiences of individuals and carers. We know that the contributory factors to poor quality of care include: poor communication between services and individuals and families; staff lacking knowledge or skills; and social care and community health services being spread too thinly (Barker *et al* 2021). There is no clear evidence that one service model for end-of-life care at home is more cost-effective or results in higher quality care than another (Durand *et al* 2016), but in general, there is a wealth of evidence that district nurses are perceived by individuals and colleagues as central to high-quality care (see, for example, Coldrick and Crimmons 2019).

A survey of bereaved carers in 2020 highlighted significant issues with care received at home during the pandemic. For example, 67 per cent of respondents said they were unable to say goodbye as they would have liked, 23 per cent said they were 'never' involved in decisions about the care of their loved one, and many respondents demonstrated high or severe levels of overall vulnerability in grief (Harrop *et al* 2020). These issues are longstanding, and although they may have been particularly stark during the pandemic they are by no means unique to it, having also been highlighted in an earlier national survey of bereaved carers (ONS 2016). Similarly, various research studies over the years have highlighted that some people are unable to access services (Pask *et al* 2022). These studies repeatedly indicate variability in end-of-life care, including poor-quality services, but we do not have longitudinal data that would show trends or enable analysis below the national level.

The pandemic added pressure to an already stretched system. An online survey of palliative care services conducted between April and July 2020 showed that services were under pressure during the pandemic – particularly homecare services and nursing care provided in people's homes (Sleeman *et al* 2022). There are examples of community-based palliative care services that increased activity and innovated in response – including shifting some services online, and specialist palliative care teams educating and supporting the wider health and care workforce (Marie Curie 2021; Keeble *et al* 2022). Overall, however, there is a lack of evidence about whether all individuals were able to get all the care that they required.



## What national data is available for monitoring the quality of end-of-life care at home?

There is some data available from national NHS bodies to support local quality monitoring, most notably local palliative and end-of-life care profiles and other guidance, analyses and bulletins issued by the National End of Life Care Intelligence Network (NEOLCIN) of the Office for Health Improvement and Disparities. These resources can help areas understand issues such as demographic characteristics and circumstances of death (for example, place and cause) in their area and relative to others. Additionally, the Care Quality Commission (CQC) publishes ratings for the quality of end-of-life care in hospitals and hospices and has carried out national reviews. Where people die in acute, community or mental health hospitals, the National Audit of Care at the End of Life (NACEL) monitors standards related to the quality of the end-of-life care provided.

Between 2011 and 2015, the VOICES (Views of Informal Carers for the Evaluation of Services) national bereavement survey provided information on carers' experiences of the quality of end-of-life care. Since its discontinuation, there is no national data on people's experiences, but some areas have developed their own local approaches, often based on the VOICES model.

There are various validated outcome measures that provide information on the quality of palliative care from the patient's perspective – based on the patient or a proxy such as a clinician responding to a questionnaire. These include the Integrated Palliative care Outcome Scale (IPOS) (Murtagh *et al* 2019), the Palliative Care Phase (Masso *et al* 2015) and the Karnofsky Performance Status (KPS) scale (Abernethy *et al* 2005). They are used in research and also in clinical practice to support quality improvement.

Place of death has often been used as a proxy indicator of the quality of end-of-life care, including in England's 2008 national strategy and elsewhere. However, assumptions that a death at home is 'good' and a death in hospital is 'bad' can be over-simplifications or even misleading. While other types of quality measures are available, they all have limitations: outcome metrics are often too complex for non-specialist settings; bereavement surveys are inherently retrospective and so use carers' experiences as a proxy for individuals' experiences;





and process measures usually only cover one process in one provider at a time. While there is growing awareness that place of death is not a reliable indicator, there is as yet no consensus on what measures should be used nationally (Hoare *et al* 2022).

### What do we know about inequalities in end-of-life care at home?

It is well established that there are inequalities in access to end-of-life care services and quality of care (National Palliative and End of Life Care Partnership 2021). We know that there are significant variations in the types of end-of-life services people access, which in turn suggests there could be significant levels of unmet need. For example, the percentage of people who die in hospital who have had a holistic assessment of their needs varies from 100 per cent in the highest-performing hospitals to 3.8 per cent in the lowest-performing (Public Health England 2018). Based on the literature, the following factors are likely to play a role in inequalities in access to end-of-life care.

- **Availability and extent of family support** can affect whether people are able to die at home (Grande *et al* 2009).
- **Staff capability** to identify individuals at the end of life, and confidence to plan care with them, is a key factor (Bakhai *et al* 2013).
- **Access to services**, as not all areas have hospices located nearby (Chukwusa *et al* 2020), and out-of-hours services are lacking in some areas (Pask *et al* 2022).
- **Disease group**, as support for people with cancer (for example) can be better than for other diseases (Cox *et al* 2017; Wahid *et al* 2018; Wyatt *et al* 2022).
- **Socio-economic status**, with evidence that quality of end-of-life care is worse in the most socially deprived areas of England and people in the most deprived areas are more likely to die in hospital. People from lower socio-economic groups are also less likely to receive specialist palliative care (French *et al* 2021).
- **Rurality**, as people living in rural areas may have less access to palliative and end-of-life care services than others in urban or suburban areas (Chukwusa *et al* 2019).



- **Ethnicity**, as people from ethnic minorities have lower rates of referrals to end-of-life care services and higher levels of dissatisfaction with services (Evans *et al* 2012; Calanzani *et al* 2013).
- **Religious beliefs** are often important to families but may not be understood by service providers (Venkatasalu *et al* 2014; Hospice UK *et al* 2018).
- **Homelessness**, with health care staff often ill-equipped to support and provide adequate care to people who are homeless at the end of life (CQC and Faculty for Homeless and Inclusion Health 2017).
- **People living with dementia or a learning disability** are more likely to experience gaps or poor co-ordination of end-of-life care (Dixon *et al* 2015; Public Health England 2018).
- **LGBTQ+ people** may access palliative and end-of-life care services late or not at all, and their partners can feel isolated or unsupported during bereavement (Marie Curie 2017).

The lack of national data on the quality of end-of-life care provided at home means that we do not know about the current prevalence of all these inequalities across different parts of England and whether they are being affected by the increase in deaths at home. There is also a lack of data on how these inequalities intersect: a person could be affected by any number of these inequalities at the same time, but we do not know how much that happens or what impacts it has.

### What is the focus of national policy on end-of-life care?

The end-of-life care strategy published by the Department of Health in 2008 was a landmark, representing 'the first [strategy] of its kind both nationally and internationally' (Borgstrom 2016), due to its creation of an integrated framework for care that was not focused on particular conditions.

In the ensuing years, national policy for end-of-life care has developed significantly. The timeline in Figure 2 on page 16 highlights some key moments.



**Figure 2 Policy development in end-of-life care – a timeline**



2008	End of Life Care Strategy is published
2009	Dying Matters Coalition is established to raise profile of issues around end-of-life care
2010	White Paper, <i>Equity and excellence: liberating the NHS</i> , sets out choice agenda, including for end-of-life care
2010	National End of Life Care Programme is published, creating a framework for social care in end-of-life care
2011	National Institute for Health and Care Excellence (NICE) publishes Quality Standards for End of Life Care
2012	First publication of the National Survey of Bereaved People (VOICES)
2013	Independent review of the Liverpool Care Pathway <sup>2</sup> recommends that it should be phased out
2013	Care Quality Commission begins publishing quality ratings for end-of-life care services
2014	<i>One chance to get it right</i> strategy is published by the Leadership Alliance
2015	Final publication of VOICES survey
2015	<i>Ambitions for palliative and end of life care</i> published
2018	First round of the National Audit of Care at the End of Life published
2018	End of Life Care programme is established by NHS England
2021	<i>Ambitions for palliative and end of life care 2021–26</i> published
2022	Health and Care Act 2022 places statutory duty on integrated care boards to commission end-of-life care

Source: Updated and adapted from [Barker 2020](#).

<sup>2</sup> A care pathway covering options for palliative care in the last days or hours of life, which had been the subject of critical media attention.



The key current policy document for end-of-life care at home is the *Ambitions for palliative and end of life care: a national framework for local action 2021–2026* (National Palliative and End of Life Care Partnership, first published 2015, updated 2021). It sets out ambitions for six key aspects of high-quality care: personalised care; access to end-of-life care; comfort and wellbeing; care co-ordination; staff capability; and community support. Each of these ambitions is built on a set of common foundations: personalised care planning; shared records and information systems; evidence and information; carers and those important to the dying person; staff education and training; 24/7 access; co-design; and leadership. These ambitions and foundations represent a consensus among the main organisations and specialists involved in providing end-of-life care in England and are a widely accepted articulation of the components needed for high-quality end-of-life care.

Most recently, the Health and Care Act 2022 supported further integration between the range of services that may be involved in end-of-life care at home. It also placed a duty on ICBs specifically to commission end-of-life care (commissioners have a general duty to ensure appropriate services – including end-of-life care – to meet the reasonable needs of the local population; the new legislation singles out and places an explicit focus on the requirement to commission appropriate end-of-life care within this). This has been reinforced through statutory guidance, which sets expectations of the approaches ICBs should take and the priority they should give to commissioning end-of-life care. Further technical guidance will be issued in due course (NHS England 2022).



## 2 Our findings

In this section, we set out our findings from interviews with NHS and local authority commissioners in 15 areas of England.

We describe what commissioners told us about their role and how it is changing. We then review what they told us about how they measure the need for end-of-life care at home, how they monitor its quality, and how they measure and address any inequalities in that care.

Before the interviews, we asked people with lived experience of end-of-life care about what, in their experience, good-quality end-of-life care required and, in light of that, what we should ask commissioners about in interviews. After the interviews, we asked people with lived experience (some of whom were the same ones we had engaged with before) to comment on and help us understand what we had heard. We summarise their main messages at the first of these two stages in the box on page 19, as a prelude to our findings. Later in the report, we summarise their response to what commissioners said in the interviews.



### **What aspects of quality of care did families and carers emphasise to us?**

We asked a focus group of recently bereaved carers and family members what they thought commissioners should prioritise to assure the quality of end-of-life care.

They asked us to probe how commissioners get the information they need to assess the following, which in their individual experiences had been problematic.

- Is care consistently compassionate?
- Do staff have the right training and skills – caring skills, as well as clinical skills?
- Is there good communication with patients and good involvement in care planning?
- Do people know what to expect, what services are available and how to access them?
- Do services wrap around the individual's needs (which may change at different times) without disconnects at organisational boundaries?
- Are services responsive to the specific needs and wishes of people from different ethnic minorities and religions?

Stepping back and reflecting on their collective experience, the group wanted commissioners to consider the following.

- Is there clarity about what good, continuous care looks like and how to deliver it?
- How are individuals involved in designing and delivering services?
- Who has the overview of all local services and how are they making sure those services work closely together?
- How is the role of carers valued and supported?

We have reflected the answers to these questions in our findings, or noted where commissioners had insufficient data to provide the answers.



## How is end-of-life care at home commissioned in practice?

### Commissioning approaches before the establishment of integrated care boards

The approaches taken by NHS commissioners were going through changes as ICBs became established. They told us that previously, with the former CCGs – not just in relation to end-of-life care – commissioners' relationships with providers had been largely driven by contract monitoring, one provider at a time.

*I would say that pre-pandemic, what we knew was what we were contracted to, what we contracted. And then we made some assumptions that the providers worked well together.*

(NHS commissioner)

However, some commissioners had also worked closely with providers – for example, regularly attending their quality meetings – and a few emphasised promoting personalised care as key to their role more so than contract management.

Commissioners told us that they were spread thinly and also that they sometimes had limited influence over independent hospices. The literature shows that commissioning end-of-life care at home has not been a priority in many areas (McCauley and Caper 2016; Sleeman *et al* 2018). It appeared to us that, in these circumstances, providers – particularly specialist providers – had sometimes taken the lead in planning service development and quality monitoring. For example, in one area, we found that the local hospice had taken on the role of lead commissioner for end-of-life care (covering all of the commissioner's role apart from financial aspects of contracts). Several commissioners told us how, effectively, they let each provider decide what data would be collected and monitored on the quality of end-of-life care.

*So in setting up that contract what we asked [the provider] for was, what do you report already around quality assurance, quality improvement, and quality governance? What's your quality governance structure, how do you manage that already? And if you share that with us, we then won't ask you for a separate return around quality metrics for your organisation.*

(NHS commissioner)



Many commissioners told us that service models for end-of-life care and commissioning arrangements had evolved organically, one element at a time, and with the rationale for some developments lost to organisational memory. Within a single area, there could be multiple different approaches to commissioning, with inconsistent and unaligned information flows. In the case of the wider 'block' contracts for generalist services, there were often no detailed specifications for end-of-life care. As a result, some local arrangements had become extraordinarily complex.

*Up until recently, our palliative care consultants were hosted by our hospice. We have since changed that arrangement, with the support of the hospice, so the palliative care consultants are now employed directly by our community trust. The specialist nurses are employed by our acute trust, and our 24-hour, seven-day-a-week advice line is part of [a local community interest company]... So we have an amalgam of resources at our disposal, which have probably historically grown up organically.*

(NHS commissioner)

### **Developing approaches to end-of-life care within integrated care boards**

With the merger of former CCGs, commissioners were required to manage the complex mix of services and contracts that they inherited as one system. Most were using the opportunity to review their approach to end-of-life care overall. In some cases, this meant developing a single overall model or service specification as the basis for contracts with providers; in others, it meant multiple specifications but alignment of performance and quality metrics; and in a few cases, it was expected to lead to a provider collaborative.

We heard that the way they were reviewing and developing end-of-life care gave commissioners six broad types of new roles. Many of these were accelerated rather than initiated by the establishment of ICBs, and overall, commissioners described them to us as still developing and evolving rather than being fixed or embedded.





## Six new roles for end-of-life care commissioners

**Partners** – a majority of the commissioners we spoke to described their new approach in terms of a partnership relationship with providers, with shared aims and dialogue. This also included reaching out to new partners such as primary care networks to get them engaged too.

*And certainly we've seen over the past six months or so a real transition in the way that we have those conversations with our providers, that means we're having an open dialogue I suppose, [as opposed] to sort of contract management by Excel spreadsheet.*  
(NHS commissioner)

**Convenors** – commissioners told us how they brought the range of providers and professions together to develop an end-to-end approach along the end-of-life pathway.

*Currently what we've got is quite a large network with quite a lot of clinical representation on it and that's where we go to, we have meetings every other month for about an hour and a half and various working groups that are part of that.*  
(NHS commissioner)

**Facilitators** – where new ways of working were needed, we heard commissioners supporting providers to understand the need for change and to manage the change process.

*We've had, for about three years probably in the council something called the quality improvement team, which is a flying squad of hands-on registered managers and nurses, who help struggling care providers. And, in the past six months, we've made that a joint service with the NHS.*  
(Local authority commissioner)

**System stewards** – commissioners described always thinking about all parts of the local end-of-life pathway as a system, making sure they used their unique position to step back from individual providers' perspectives and keep their focus on the whole.

*It's much more about harnessing and facilitating change, and providing support to various elements of the system, not just the providers. I think that it enables much more innovative approaches to working with other sectors, industry, for example, is there an opportunity to work very differently with our local authorities, and also, the third sector.*  
(NHS commissioner)

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## Six new roles for end-of-life care commissioners *continued*

**Champions** – especially as ICBs were getting established, commissioners had a key role in raising the profile of end-of-life care, engaging senior leaders with it and getting agreements for strategies and resources at the right level of the governance arrangements.

*Historically, the end-of-life steering group hasn't had any teeth, because it's not reported to the right place. So what we've done, as we've become an ICB, is landed that quite clearly reporting up to our quality and pathways of care committee.*

(NHS commissioner)

**Challengers** – while we did not hear examples yet, commissioners expected that they would need to challenge some practices and ways of working, and that they would initiate difficult conversations from time to time.

*So for the next 6 to 12 months, I expect the commissioner to fulfil the role of dragging everybody into a place where we can make a provider collaborative work.*

(NHS commissioner)

Two NHS commissioners in our sample – who both sat in jointly funded, joint commissioning teams – described how they wanted their role to develop so that commissioning joined up more across health and social care. The others initially described their role only in terms of health services and some did not mention social care at all until prompted. Despite much learning during the pandemic, we heard that the development of NHS commissioners' engagement with social care was still variable.

*I think that really what everybody realised during the pandemic was just how much care homes first of all were integral to the [end-of-life] care, but also just how much we relied on care homes and how much, or certainly from a health perspective, the lack of support we gave to them. Domiciliary care is still a little bit more at arm's length really in terms of health commissioning. Care homes, I would say up until the pandemic, were very similar.*

(NHS commissioner)



## Approaches taken by local authority commissioners

Local authority commissioners described their role as commissioning personal care and residential care, some of which would be for people approaching the end of life. They consistently talked about personalised care, rather than service models.

*Most of our services, they wouldn't be labelled as end-of-life care. So people obviously will die at home and will die in care homes, but it's part of their [provider's] overall responsibilities about how people are living their lives and having a good death.*

(Local authority commissioner)

They mostly described working closely with their NHS counterparts (and those that did not, expressed an appetite for doing so in future). However, some also characterised their experience of working with the NHS as being more like a consultee or stakeholder, rather than a full partner.

*So, if you've seen [our local end-of-life] strategy, you'll know straightaway that it is very clinical, very health orientated, and it refers to local authorities being a stakeholder within this. So, I personally feel that that's a little bit disappointing and I feel as though we should be a fully fledged partner in this, because as you've already realised, quite often, many of the people who face end of life are in council-commissioned services.*

(Local authority commissioner)

Local authority commissioners noticeably also talked about their role in working with communities. This included awareness-raising and engagement with older people and other communities of concern, to understand their needs and preferences.

*We've also had the public health team working with, for example, the lead for our social care financial assessments team, who manages the Court of Protection. And they've done some of the work around, you know, the work we've done so far around things like lasting power of attorney and also death cafes, those kinds of issues, raising awareness.*

(Local authority commissioner)



Local authority commissioners placed an emphasis on ensuring training around end-of-life care for care workers as part of their role. Some of them also highlighted their ability to involve other council departments.

It was noticeable that all of our sample of local authority commissioners wanted to talk about their experiences of end-of-life care during the pandemic, particularly with care homes, which had clearly affected them all personally – not just in their emotional responses to it, but also in their professional determination to support high-quality end-of-life care at home. They emphasised the expertise available in care homes, and the support that these establishments needed from their local NHS, councils and the third sector. They also emphasised the essential role that homecare had played, and continued to play, even though it often had not developed the same level of visibility to the local NHS as care homes.

*And some of the shocking things we were hearing, about how people were ending their lives in care homes, and some of the shocking scenes I personally saw in care homes, going into them during the pandemic, delivering gloves and aprons and face masks to them. Getting in my car and driving around and seeing the looks on people's faces because they knew that another five people died that morning.*

(Local authority commissioner)

### Interesting practice

Both sets of commissioners described very engaged, hands-on approaches – regularly visiting services and, in some cases, working directly with them to support improvement. We heard multiple examples of interesting practices or plans, such as:

- partnership forums to bring all providers and commissioners together to review data and co-ordinate services
- inclusion of additional detail on end-of-life care in primary care networks' enhanced service contracts
- commissioning a single, county-wide specialist homecare service with embedded training to ensure consistent end-of-life care with good access, even in very rural areas



- homecare workers working flexibly with district nurses during the quieter part of their day, between getting people up in the morning and preparing them for bed in the evening
- involving the public health team to provide advice to care workers – for example, on hydration and infection control.

## How do commissioners measure need and quality?

### How commissioners assess end-of-life care needs in their local community

When we asked commissioners how they assessed needs for end-of-life care at home, a few were able to talk us through joint strategic needs assessments (JSNAs), which had projected future trends in demography, epidemiology and mortality. Some commissioners indicated awareness of analyses by the Office for Health Improvement and Disparities, such as local end-of-life profiles and bulletins on particular causes of death such as liver disease. But most found it difficult to answer questions on how they assessed need, and none of the commissioners were able to describe how they were actually using the data to plan services and inform contracts for end-of-life care at home. This is in line with a study in 2018, which found that CCGs had inconsistent and sometimes absent data on population needs and significant variation in levels of spending on end-of-life care (Lancaster *et al* 2018).

Commissioners emphasised their desire for qualitative information about need, based on individuals' and carers' experiences, as well as quantitative data. Most expressed disappointment that this kind of information was lacking locally and national reports were no longer available from the National Survey of Bereaved People. In some cases, local bereavement surveys were planned or being conducted. However, when we probed this, it mostly turned out that individual providers and Healthwatch had instigated these local surveys rather than the commissioners, and that they were one-off rather than regular forms of collecting data.

Furthermore, the commissioners in our sample had gaps in routine activity data on health service use at end of life. For example, generalist providers' contracts often either did not record activity on end-of-life care separately or did not require it to be submitted to commissioners. In other cases, especially hospices, activity could



be recorded in multiple ways, making it hard to put providers' data together and see the whole picture.

Some of the data on need that commissioners told us they wanted was quite basic – such as more accurate data on how many individuals in their area were approaching the end of life. This partly reflects a need to improve data quality and completeness, and partly a need to ensure that clinicians are confident to identify those approaching the end of life and get them on to a register.

*We know that possibly 1 per cent of the population is going to die every year and a percentage of that percentage you could expect, you could predict that they might die within 12 months. So we've got a fair idea about how many people from a practice population should be on an end-of-life care register and we're nowhere near where we should be.*

(NHS commissioner)

Having said that, we also found some interesting and potentially impressive analysis of data about need. Some commissioners were looking to develop dashboards at ICB level to help bring together data from various providers and services; it was anticipated that the dashboards would help build a more population-wide understanding of need and inequalities. One commissioner was developing population health management approaches to identify people likely to need end-of-life care. Another was engaging with different population groups to understand their differing needs and priorities. Another commissioner was analysing activity across primary and secondary care data to understand total health care usage in the last few months of life and how that might be used to identify opportunities for preventive or anticipatory interventions. And yet another was analysing across Electronic Palliative Care Co-ordination System (EPaCCS) data for indicators of need, activity and performance.

Overall, it appeared that existing contracts were often being 'rolled forward' rather than revised on the basis of analysis of needs. It also appeared that there might actually be some more intelligence about activity locally than commissioners were able to see – but if so, it was generated and shared through partnership forums and similar arrangements for co-ordinating individuals' care at an operational level, and was not necessarily recorded and aggregated, so would not be visible to commissioners.



*So as a system, I don't know that we do [have a view of population need], if I'm honest. I think we see some of that through providers, working out what providers need in their quality reporting based, usually, on what they reported the year before. But we see that per organisation, rather than as a system.*

(NHS commissioner)

### How NHS commissioners monitor the quality of end-of-life care at home

Many NHS commissioners told us that they were using data from EPaCCS to monitor quality of end-of-life care. This included measures such as number of hospital admissions (especially in the last three months of life), preferred versus actual place of death, percentage of patients with an advance care plan in place, and use of specialist palliative care services. These were almost exclusively proxy indicators from process measures. They are clearly useful and important metrics but, ideally, quality monitoring should include a mix of process, outcome and experience measures (Hoare *et al* 2022). It is likely that this emphasis on process measures has its roots in previous national guidance and historical assumptions (Dixon *et al* 2019).

As noted earlier, commissioners expressed concern about their general lack of qualitative information on individuals' and carers' experiences. Several told us that they wanted this to be a key part of their quality monitoring.

*Yes, I think we need more data [about patient and carer experience] but I also think that maybe we do need to just do some more outreach with communities as well... Data is really important but actually more community engagement with a diverse range of people is also important.*

(NHS commissioner)

Within specialist palliative care services, we saw indications of both outcome and experience measures in place, as well as process measures. In general, we heard that specialist palliative care data was considered the most robust on quality of care for people who die at home. This was because of a history of work in this area by specialists, including NICE guidance (National Institute for Health and Care Excellence 2019). But not all localities had specialist services, and commissioners generally did not feel able to extend these more sophisticated metrics to generalist care.



*We've talked about IPOS [a validated system of outcome measures] but they don't all have IPOS. And we can't stipulate that as commissioners, we can't demand that they have that.*

(NHS commissioner)

Outside of specialist services, we found variable ability to measure the quality of end-of-life care at home. Even where only process proxy measures were collected, building up a partial picture across different providers could be something of a jigsaw for commissioners.

*So, the hospice can provide data on place of death, because they seem to be able to get it more quickly than we can. And the community provider counts numbers of deaths in place of choice, so we have that as well.*

(NHS commissioner)

*[In] the contracting arrangements within the community trust, for instance, end-of-life care is completely hidden. There is nothing in there that says, we want to understand how many people you care for at home. What are the timeframes between referral and that person dying? We have no idea of that.*

(NHS commissioner)

In some cases, NHS commissioners told us that they had literally no quality measures for generalist end-of-life care at home.

*We do have quality measures in place for hospice care, but what happens to the population that dies at home, are there any quality measures in place? No, there are not. There is none whatsoever.*

(NHS commissioner)

We noted that one ICB had grouped end-of-life care with frailty in its strategy for personalised care and its governance (including quality monitoring) arrangements. This raises a potentially interesting question of whether end-of-life services can learn from quality monitoring in other care services provided at home for people living with frailty or multiple long-term conditions.

We heard frequently from commissioners and stakeholders that there was variability in general practice, in issues such as engaging with end-of-life care as a priority,





identifying patients approaching the end of life, capability and willingness to discuss end of life and advance care planning, use of EPaCCS, use of end-of-life care registers, referral rates to specialist palliative care, and monitoring arrangements within practices for the quality of end-of-life care. Early identification of people approaching end of life is a well-known challenge for general practice (Bakhai *et al* 2013). Only one commissioner in our sample was analysing the variability in primary care to understand its causes and significance. That commissioner was also the only one providing feedback to general practices on whether their practice appeared to differ from that of their peers. More generally, this variability appeared to be accepted as the norm.

*We had some GP practices that were very quick off the mark to adopt electronic advanced care plans, no problem. Others, never go anywhere near it. So, didn't even consider it as part of their work as a practice. They knew it was there, they knew that there was an expectation, but actually, in terms of their list of priorities, it was probably towards the bottom, really.*

(Local authority commissioner)

Across both specialist and generalist end-of-life care, NHS commissioners indicated that the data they had on quality often depended on what the provider offered them. This was particularly the case for smaller specialist (eg, hospices) and generalist providers. Even where commissioners were, in theory, able to require data returns from NHS providers and GPs, we did not collect any examples of them specifying and using outcome or experience measures. Overall, this meant that commissioners could gain a good view of quality within individual providers, but could not gain a view across the whole end-of-life pathway. As with activity data, it is possible that information-sharing through partnership forums and the like may mitigate this problem at an operational level. But if so, the data is not being recorded or aggregated to act as indicators for end-of-life services as a whole.

In one area, gaps in data and fragmented quality monitoring had made fertile ground for assumptions to build up over time – that providers all worked to a shared view of what good care required, that they had a shared understanding of how to work together, and that they all had the necessary capabilities. A CQC rating of 'inadequate' revealed those assumptions to be unfounded. As well as highlighting the importance of formal quality monitoring, this suggests that as commissioners review and develop their approaches to end-of-life care, they should be careful



not to pass too quickly over the fundamentals of ensuring shared understanding of what the change will look like and what it will require.

*We sort of had an assumption that we did things really quite well. And then during that review [following a poor inspection result], some things came out that were really – you couldn't unhear it. Some very simple things, like, 'oh, how are the hospice working with community trusts? Because from what I'm hearing, they do things completely different...' There's a bit of holding mirrors up to yourself, isn't there?*

(NHS commissioner)

### **How local authority commissioners monitor the quality of end-of-life care at home**

Local authority commissioners were consistently able to describe how they monitored and assured the quality of care in social care services, which would include end-of-life care, but did not single it out. They monitored quality in all providers with any publicly funded places. Unlike their NHS counterparts, local authority monitoring systems were only based on data and performance indicators to a small degree – for example, monitoring complaints and incidents, and CQC ratings. They had more of a qualitative focus, mainly based on regular visits to services, which would include talking to service users. Commissioners had well-established arrangements in place for these visits, including full inspections and quality teams who worked with providers where needed.

Local authority commissioners also placed a noticeable emphasis on training as a proxy indicator for quality of care. For example, several of them described how variable different providers' training was for end-of-life care, so they saw it as part of their quality assurance role to share good practice in training from one provider to another and to require (and, in some cases, to directly provide) additional training where they had identified concerns. We also saw some indications, among NHS commissioners, of a similar interest in training as a proxy indicator, particularly for GPs and community nurses.

*I think there is something about how do we support, develop, train not just specialist workers but the vast group of care workers, generic community nurses, to be able to feel more confident and skilled in this area. Because when it works, it works.*

(Local authority commissioner)



### Quality monitoring across NHS and local authority commissioned services

In our sample of commissioners, we did not find any examples where quality monitoring was brought together across the two sectors (although, as noted earlier, this may happen informally at an operational level). Some commissioners suggested that different data and information systems might make it difficult to do so. Some commissioners also told us about system-wide quality committees that were being formed in ICBs, which suggests that there may be opportunities in the near future for bringing quality monitoring information together.

#### North East Essex: an example of an NHS quality monitoring approach

##### What's happening?

In North East Essex, an Electronic Palliative Care Co-ordination System (EPaCCS) and a data dashboard are being used to monitor, assure and improve end-of-life care.

The EPaCCS is called the My Care Choices Register and was set up in 2013 to capture the palliative care preferences of the local population. Currently, it is used by about half of the people that die in North East Essex each year, and allows providers across the landscape of palliative and end-of-life care to see people's wants and to understand what conversations have been had with individuals and their carers in terms of care planning.

The information that the register collects about people's preferences is then used to feed into a dashboard that is used to monitor quality in end-of-life care. The dashboard was co-produced with patients, who were consulted on what kinds of things they consider to be markers of good-quality care. Ten domains were established (around, for example, patient identification, pain control, and minimising hospital admissions), and data is then collected to inform metrics within each of these domains. As well as information such as clinical outcomes statistics, the spread of data used here includes things like text (SMS) surveys of people at the end of life, who offer their perspective (by offering ratings) on how services are performing in different areas.

The dashboard also allows for analysis of inequalities, as data can be broken down by patient diagnosis, neighbourhood, primary care network, ethnicity and deprivation.

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## North East Essex: an example of an NHS quality monitoring approach

*continued*

### What impact is it having?

The utility of having this quantity of data, beyond simply being able to monitor quality, is that it allows for providers and commissioners in their system – in the words of a member of the local integrated end-of-life working group – to ‘justify business cases’. When you can see which parts of end-of-life care are performing better than others, and when you can see which groups are experiencing poorer outcomes, ‘it gives people the evidence to say, “okay, I’m going to address that”’. This allows resources to be directed in a more targeted way than would otherwise be the case.

### What has enabled this approach?

The journey to embedding these kinds of approaches in North East Essex has been a long one. The development of the EPaCCS and the dashboard did not occur in a vacuum, and both built on prior work that had already been happening locally to help primary care to identify people approaching the end of life. This meant that when it came time to ask GPs and others to do the work of having the conversations needed for the My Care Choices Register, a focus on end of life was already on their agenda.

From a commissioning perspective, it has also been important that the extra time and energy that data collection requires is compensated for. GPs are rewarded for their work, and small amounts of money are made available to cover the administrative costs of adding people to the register.

## How do commissioners identify and act on inequalities?

We asked commissioners about inequality in end-of-life care, and they all commented on its importance. Many of them spoke about their experience of inequalities during the pandemic in order to illustrate the priority this issue should have.

However, all but one of the commissioners had difficulty when trying to explain local inequalities in any detail, as they had no robust data. Most commissioners only described groups with worse health status overall, rather than worse health or worse access to services specifically at the end of life.



People from ethnic minority backgrounds were most commonly cited as a priority that commissioners need to focus on. This was partly due to observations during the pandemic rather than analysis of end-of-life care in normal times. It was also due to observed low numbers of people from ethnic minorities in hospices, although we did not hear any examples of rigorous analysis of usage rates (eg, relative to population size) or the reasons for any differing rates.

*You've got a bus route in [our city] from where I'm sitting, the leafy area, a bus route all the way down into the most deprived area. And your life expectancy drops as you sit on that bus from, I think it's as a man down to 72, something like that. And as a woman, it's 86 down to 76. And if you've got a learning disability, take 20 years off that. So, we're conscious and living with that, and everything that we do from a health and care partnership perspective takes that lens. We're mandated by our leaders to look at health inequalities. I can't give you anything specific on end of life, sadly, but I know that's the approach they'll be taking.*

(Local authority commissioner)

The one commissioner who could describe specific actions to explore and act on inequalities in end-of-life care had embarked on a programme of work to engage with a number of population groups to better understand their needs and preferences, and whether they were currently encountering any barriers to accessing end-of-life care. Other commissioners also highlighted the importance of this qualitative approach, as well as analysing quantitative data, even though they did not have specific activity on it.

None of the commissioners in our sample could tell us about actual work in progress to reduce inequalities in end-of-life care. Overall, they had all identified that the issue was important, and one had even started a structured investigation of the challenges; but none yet had a basis for action. This was the case even in one area that had a very large ethnic minority population and could not explain how its end-of-life care services were tailored to their needs.

*We have a 50 per cent BAME [Black, Asian and minority ethnic] population, yet we have no single service designed for them. We have a standardised service that caters for the entire population irrespective of where you come from or what your faith is, and that's it.*

(NHS commissioner)



## **A response to our findings: what feedback did carers and families give?**

When we presented our findings to a workshop of families and carers, they told us that they resonated with their experiences and helped them to understand both why some things had happened, and what they should have been able to expect.

Their main reflection was that they would like to see more transparency. This was partly about services doing more reporting on the quality of end-of-life care, and partly about being more proactive in letting families know what to expect, the different services available and what they are entitled to.

The families and carers emphasised that commissioners should engage with their local communities so that individuals and carers are directly part of monitoring and feeding back on the quality of end-of-life care. The need for commissioners to engage with communities was a recurrent theme in the discussion; workshop participants felt that engagement should also extend to local communities helping to inform service planning, and that commissioners should consult communities to understand what would work for them in terms of providing information about the quality of local services and letting them know what services are available. Participants were not always aware whether this type of engagement was currently possible, and emphasised that it must be both accessible and meaningful.

Within their overall desire for commissioners to engage communities, participants in the workshop felt it was important that commissioners capture the range of different perspectives, needs and experiences of different groups within the community – for example, different ethnic minorities or faith groups. They felt that commissioners should actively ensure that they are inclusive and take account of the full range of people's experiences.



## 3 Discussion

We developed this research because the growth in the number of people dying at home accelerated during the pandemic (ONS 2021b; Raleigh 2022), highlighting how little we know about the quality of end-of-life care received outside hospital. There are also questions about whether community-based services that are already under strain are equipped to support a growing number of people, often with highly complex needs, to die at home (Marie Curie 2021; Mitchell *et al* 2021).

This context puts the onus on commissioners to understand the changing nature of need in their area, reshape supply in line with need, and ensure that they have a clear overview of quality and inequalities, so that issues are identified and acted on.

This study is one of only a small number that look specifically at the role of NHS commissioners in end-of-life care, and it is the only research we found that explores their role together with that of local authorities as commissioners of essential social care aspects of end-of-life care at home.

In this section, we reflect on our findings about what commissioners are doing locally to understand quality, and identify inequalities and act on them.

### **Commissioners know what good looks like, but not how to measure it**

The commissioners we interviewed had a clear understanding of what good-quality end-of-life care involves, which was in line with the key aspects of quality described during our focus group with bereaved families and carers and in the national Ambitions Framework (National Palliative and End of Life Care Partnership 2021). However, we found that the data that was available to help commissioners understand quality and need was not being used to its full potential and, as a result, there were significant gaps in their understanding of the quality of care being provided to people at home.

Much of the information commissioners had related to hospital activity, place of death, numbers of people on palliative care registers, and the activities of specialist



care teams. However, many of the services people receive during their final months and weeks come from general practice, district nursing and homecare – areas in which little data is collected nationally about activity and outcomes (Charles *et al* 2018; Beech *et al* 2022). Also, local data is limited by end-of-life care being a small part of the service provided, with few (if any) specifics about the end-of-life element of the service within contracts.

The commissioners acknowledged the importance of getting an end-to-end view of quality across the end-of-life care pathway in their local ‘place’, but were also candid about not currently having this. If commissioners are to get an end-to-end view, some key questions need to be addressed: what information is needed to enable the planning and assurance of high-quality services? How can commissioners get this, without creating unreasonable burdens for providers? And once they have collected the information, how will they make sure it drives quality improvement?

### **Searching for an end-to-end view of quality along the pathway – start with individuals’ and carers’ experiences**

The ability to monitor the quality of end-of-life care at home is very limited – both for commissioners locally, and for policy-makers at a national level. The aim should be to build up a picture of the quality of end-of-life care at home across all three domains of processes, outcomes and people’s experiences, and across all services.

Within these three domains, we believe that information on individuals’ and carers’ experiences is a priority. As well as being powerful in its own right, it can also indicate where processes such as care co-ordination or advance care planning are working (or not). It can serve as a ‘tin opener’ to indicate where more monitoring may be needed, rather than adding additional routine data requirements on to providers, and help understand the significance of quantitative data. At present, information on individuals’ and carers’ experiences is largely absent.

Most areas in our research did not have the processes or capacity in place to collect this kind of data. Where they did, they were conducting or planning local surveys as a one-off exercise and were not sure whether it would be repeated. Differing local methodologies also mean that the data they collect cannot be aggregated and will not be comparable. In view of these challenges, and given the overall lack of national data on the quality of end-of-life care, especially for people who die





at home, collecting information on individuals' and carers' experiences must be a priority at national and local level.

Stakeholders we talked to described the lack of the National Survey of Bereaved People as a major loss and saw a replacement, equivalent national survey programme as a priority. We agree. This would not replace locally developed forms of data collection (a national survey is unlikely to be able to fully reflect the complexity of local pathways and the differences in people's experiences within local areas) but would be a valuable supplement to them, creating a national view to inform policy and potentially allow for comparison between people's experiences in different areas and across different population groups. A national survey might also be able to provide a template both for designing local surveys in a consistent, comparable way and – given the complexity of end-of-life care pathways outside of hospital, and people's very different circumstances – to support local systems in understanding how to make best use of survey results.

### **Making the most of the data that is available**

Improving information on the need for, and quality of, end-of-life care does not necessarily mean creating new ways to collect data. There is potential to make more and better use of data that already exists, including resources such as Office for Health Improvement and Disparities bulletins and analyses. Possible opportunities include greater use of primary care data, analysis of health service use across primary and secondary care, analysis of EPaCCS data and, where feasible, greater standardisation of data and surveys. Ensuring the quality of existing data sources (for example, accuracy of palliative care registers) could also make a big difference.

Local partnership forums appear to share quite significant amounts of data between providers. However, they tend to only share providers' insights (which may be a reasonable place to start, except that they do not usually include all providers, in particular those from social care) and they are focused on co-ordinating individual cases. There may be potential to use them to build up insights from individual cases into what they indicate about quality across the end-of-life pathway as a whole.

There are various validated outcome measures that provide robust information about the quality of palliative care, such as the Integrated Palliative care Outcome Scale (IPOS) (Murtagh *et al* 2019). The necessary direction of travel clearly



demands making more consistent use of these measures, but it is not yet clear how much they are realistically applicable in generalist services.

As well as improving the data that is available, it is essential to ensure that it is used. The commissioners we spoke to saw the way to do this as to identify key governance processes as they were set up in the ICB, which would have 'teeth', and then make the case to embed requirements for data on the need for and quality of end-of-life care within them.

### **Looking beyond specialist services, and beyond the NHS**

We did not see any examples of monitoring care quality across both social care and health data, even though both sectors make essential contributions to a person's overall experience of end-of-life care; both have systems for quality monitoring, and partnership forums seem to already exist in most areas. The trend of increasing integration across health and care services offers major potential for improving care quality in the complex landscape of end-of-life care, so the lack of joined-up approaches that we observed is a concern.

We were impressed by the one geographical area where commissioners had started analysing primary care data, to explore apparent variations in identifying people approaching end of life, and in what happened following their identification (ie, advance care planning and onward referrals). Their approach was of interest for three reasons: they did not just accept variations as an inevitability; they sought to understand them by using data to explore the scale, causes and significance of variations, dispassionately and without assumptions; and, crucially, they gave feedback to GPs to let them know how their practice compared with end-of-life care provided by other GPs, and to involve them in considering whether action was needed. As GPs have such a fundamentally important role in end-of-life care at home, it is critical that commissioners work with GPs and other primary care professionals to maximise the use of their data and develop the primary care aspects of end-of-life care.

Homecare workers are often the staff who spend most time with people who die at home during their final weeks. However, we heard that they were not well engaged in local approaches to end-of-life care, and that the pandemic had not led to greater understanding and valuing of their role in end-of-life care in the way that



it had for care homes. Feeding in information from homecare services is essential if there is to be a whole pathway, end-to-end view of the quality of end-of-life care at home. And focusing on the way these teams work with the health care side of the multidisciplinary team that supports people at the end of life is a key part of developing end-to-end quality improvement plans.

### **Understanding changing population need for end-of-life care**

We have highlighted that developing end-of-life care services needs to start with an understanding of local need, which the commissioners we spoke to mostly could not articulate. There is a need for realism here: the commissioners we spoke to had substantial workloads, and no doubt in many services (not just end-of-life care) not every contract can be underpinned by an in-depth needs assessment each time it is renewed. But the changing pattern of need for end-of-life care – increasingly in the community rather than in hospital – means that in this particular service area, there is a strong case for a greater degree of rigour and depth in needs assessment than we found in our research.

### **Bringing inequalities into focus**

We were struck by commissioners voicing their frustration with the lack of data available to help them identify inequalities in ways that suggested this was beyond their control. One area was, however, making progress, which suggested to us that the lack of progress in others was not just due to practical or technical challenges; it was also a leadership issue. Many of those we spoke to considered inequalities in end-of-life care a priority for investigation and action. It now needs someone to make that happen, if they are to move beyond statements of intent and aspiration.

There are many dimensions of inequalities and the focus for local investigations will determine what data is needed, but existing GP records are often a rich source for this data as they include information on age, ethnicity and level of deprivation. Even where quantitative data such as this can be collected, there will often (if not always) be a need to complement it with qualitative information such as the different perceptions of end-of-life care among people from ethnic minorities, and their wishes for receiving such care. That can only come from engaging with the communities concerned and, as a core principle of service development, enabling them to have influence. The bereaved family members and carers who took part in



our focus groups highlighted the need for commissioners to do more to understand the experiences of different groups within their communities. This in-depth engagement is an essential complement to the data on individuals' and carers' experiences, which we highlighted as a priority earlier.

### **A new role for commissioners**

Our findings show that NHS commissioners are starting to develop new roles of system leadership and using system thinking to drive efforts to improve quality and address inequalities in end-of-life care. Several interviewees spoke about how their role was changing – from a performance manager and procurer, to a facilitator and partner with a more strategic focus on end-to-end improvement. A key aspect of their emerging role is a focus on population health – understanding need and using this understanding to facilitate the development of a set of services and supports for people approaching end of life across health, social care and the wider system of public services and community support.

This is a change that we have previously described as commissioners acting as 'the glue' or 'connector' in a complex system and providing a 'population eye view' that complements and supports the work of providers (Robertson and Ewbank 2020). It requires particular leadership skills to facilitate agreement of priorities for improving end-of-life care quality, to bring together data on those priorities from across the care pathway, and to mobilise providers to work together as integrated partners. This is a very different dynamic to the situations we observed in some places, where each provider had approached care quality unilaterally and commissioners responded to their lead, but it is one that has great potential.

An important part of this role of commissioners includes amplifying areas that get less attention but are an important part of the individual's care package. If the trend of more deaths at home continues as expected, the role of generalist services such as primary care, community nursing and therapies, care homes, homecare and community pharmacy will become even more important, as will the relationships between lead commissioners for end-of-life care and lead commissioners for these wider, generalist services. It is particularly important that this is addressed if the current situation is allowed to continue, in which some areas appear to have significant numbers of people approaching end of life but who are not identified in



an end-of-life care register; this could lead to increasing, unplanned demands on generalist services. Getting the right balance between developing the critical role of these generalist services and investing in the equally critical role of specialist services should be a priority; at present, the NHS focus often appears skewed towards specialist services without fully recognising the need for, and importance of, the generalist services.

### **A long-term view enables strategic issues to be considered**

End-of-life care is a highly personalised service and 'one size fits all' approaches are not appropriate. Nonetheless, the current complexity of end-of-life care in many areas needs to be simplified and standardised. In one area, the end-of-life care commissioner worked with five different hospices, each with different contractual arrangements, different service models and costs, different activity and quality metrics – and each ultimately independent, able to make decisions without regard to the NHS. This complexity, coupled with the inevitable need for the structural change of creating ICBs to bed in, means change will not only require skilful facilitation, but realistically it will also take time. The upside of this is that if commissioners are required to take a long-term view of end-of-life care, and if they develop the more strategic role that they described to us, that may make it more possible to engage with other long-term issues, such as transferring investment to community services, developing data, ensuring that there is a sustainable workforce, and giving more power and influence to communities.

### **A moment of opportunity?**

Our research took place at an inflection point for commissioning end-of-life care at home. Establishing ICBs and a specific focus on commissioning end-of-life care in new legislation together represent a major opportunity to review and improve care quality. But can it be taken?

The health and care system is in crisis: the need to transform end-of-life care is competing for attention and resources against many other priorities. It will need skilled leadership and strong cross-sector relationships, in an area that has not always been a priority. The issues we have discussed here will need resources – which are scarce – and some will take time to have an impact.



Yet better end-of-life care at home can be expected to reduce hospital admissions and lower costs overall (Durand *et al* 2016). That is particularly important as the number of people reaching the end of life (and therefore the costs involved in their care if we do nothing) is projected to increase year on year. We know that there is already significant unmet need and inequality – people who could benefit from end-of-life care but do not or cannot access it, and families left trying to navigate a complex system on top of their grief. If we do nothing, the numbers affected by inequality should be expected to increase; both the cost-effectiveness case and the moral case are therefore strong.

The pandemic gave us advance sight of the levels of need for end-of-life care at home that we can expect within 20 years (Higginson *et al* 2021). Our research suggests that we are not ready to meet that challenge, but we have opportunities to begin to do so. Inaction will only store up problems for the future. Avoiding that fate requires action now by NHS commissioners, ICB leaders and national policy-makers.



## 4 Recommendations

Our research highlights the need for **NHS commissioners** of end-of-life care to take the following actions.

- Focus on getting an **overview of quality** of end-of-life care in their local ‘place’ that looks across health and social care and that includes both specialist and generalist services. This does not have to mean inventing new data and quality frameworks, but using and building on existing ones where possible.
- At the core of that, develop an in-depth understanding of **individuals’ and carers’ experiences and diverse communities’ perspectives** by gathering and analysing qualitative information about their experiences of and wishes for all aspects of end-of-life care and support.
- Ensure quality improvement initiatives are **co-produced** with individuals and carers with experience of end-of-life care.
- **Convene** partners, including the voluntary and community sector (beyond just hospices), to **facilitate** – and also bring **constructive challenge** to – local partnerships.
- Increase their understanding of **population need** to shape local service development plans, particularly considering the likely future trend of more increases in the number of people dying at home.
- Maximise the **use of data that already exists** – through purposeful use of resources from the Office for Health Improvement and Disparities, use of insights shared for care co-ordination, engagement with available primary care and hospital data, and exploration of analytical techniques across datasets, including use of population health management approaches. This may mean ensuring that there is capacity in data analytics – an essential function within the ICB.
- Move local end-of-life services **beyond just recognising the importance of inequalities**, to actively investigating and taking action on them.
- Ensure that **social care providers and commissioners** are genuine partners with the NHS in service development and quality monitoring.



**Leaders of integrated care boards** should take the opportunity of their new configuration to do the following.

- **Grasp** the current moment of opportunity to develop end-of-life care commissioning by giving it **priority** – including the issues discussed in our report, and the infrastructure that they may require (such as shared electronic care records) – and **supporting commissioners** to develop end-to-end approaches across the end-of-life care pathway.
- Ensure that governance arrangements and internal structures in the ICB support **close working and relationship-building between end-of-life care commissioners and lead commissioners for generalist services**, and make sure that they follow through on achieving their ambitions for end-of-life care.
- Prioritise getting the relationship right with **local authorities and social care providers**, so that their contribution to end-of-life care as partners is fully valued. This will also enable them to engage local authorities' wider roles relevant to end of life, including the full range of social care services, community engagement, public health and housing.

The **Department of Health and Social Care** and **NHS England** should support local systems by taking the following actions.

- Commission a national programme of regular surveys of **bereaved carers' experiences**. The first step towards this would be to clarify the national survey's purpose, methods and sampling frame and, within that, to explore the potential for: (a) analysing results at subnational levels and across different population groups; and (b) providing a template for designing and administering local surveys in a consistent way and translating their findings into actions.
- **Share learning** across ICBs on issues such as developing service specifications, data development and analysis approaches, workforce strategies and provider collaboratives.
- Produce **additional data resources**, in particular:
  - accessible, easy-to-use tools to help commissioners make **better use of existing data** on population need and primary, community and hospital care





- **more standardised data** for end-of-life care services, where that is feasible
  - guidance or support to help **translate both of the above** into service specifications – for both specialist and generalist services
  - further research and/or guidance to understand how **outcome measures** can realistically be used in generalist services
  - guidance or further research on **analysing across datasets** and **population health management approaches**
  - guidance to promote **local bereavement surveys**, including their regularity and consistency.
- 
- Consider what they can do to encourage progress in **areas where many local areas appeared ‘stuck’**:
    - How can ICBs **move beyond recognising the importance of inequalities**, to measuring and acting on them?
    - What are useful and practicable ways for commissioners at ‘place’ level to engage with **variability in primary care**?



# Appendix: research methods

## Literature review

For this research we conducted a review of available literature related to various aspects of end-of-life care. The research team identified a series of questions to help focus the literature search, and identify already-established answers to the questions and areas of development in end-of-life care. These questions covered issues such as: the quality of end-of-life care for people who die at home; any inequalities experienced by particular groups; the impact of the pandemic on end-of-life care; the role of commissioners and how they go about measuring and assuring quality and reducing inequality; and what kinds of data commissioners use.

Various electronic databases were used, including Google Scholar, The King's Fund databases, PubMed and Social Care Online, using search terms derived from our list of questions. Our search was restricted to the period from 2013 to the present day, and was primarily focused on the UK (with an exception made for any international publications relating to how quality is defined in different places, as well as comparative studies of how England performs on end-of-life care in comparison with other countries).

The search returned 174 publications, which the research team then reviewed by abstract, to select papers to read in full. A total of 100 items were read in full, and key findings and themes that related to the research questions were summarised to contextualise the research.

## Stakeholder interviews

We conducted 12 semi-structured interviews in June and July 2022 with professionals from national and regional organisations responsible for developing policy, planning, and delivering and improving care for people at the end of life. The purpose of these interviews was to further understand the national and regional context in end-of-life care and to help shape our interviews with commissioners.

The stakeholder interviewees were recruited through our existing networks and the networks of our clients for the project – the Department of Health and Social



Care end-of-life care policy and analysis teams. Interviewees were provided with an information sheet and opportunities to ask questions before consenting to be interviewed. An interview topic guide was developed based on our three research questions. The open-ended questions enabled broad discussions at the start of the interviews with prompt questions and in-depth discussions as the interviews progressed.

The interviews were recorded and transcribed. A descriptive approach was used to analyse the transcripts. The research team identified key points highlighted by the interviewees and these were summarised and grouped wherever the same or related points came up.

### **Bereaved families and carers focus group**

Before commencing our interviews with commissioners, we ran a focus group with bereaved family members and unpaid carers of people who had died at home. The purpose of the focus group was to inform our interviews with commissioners by providing us with insights into what carers considered to be particularly important aspects of quality of end-of-life care and, in light of their experience, what questions they would like to see answered by our research. As part of our ethical considerations, part of the inclusion criteria for recruitment was that carers had to have cared for a family member 3–6 months before the focus group took place.

Focus group participants were provided with an information sheet and opportunities to ask questions before consenting to take part. The session was held with five participants, via video call. It was recorded and was run in partnership with colleagues at the University of York.

### **Commissioner interviews**

The key part of the research for this project was interviews with people who commission end-of-life care – both NHS commissioners in the newly formed integrated care boards (ICBs), and social care commissioners in local authorities. Topic guides for these semi-structured interviews were developed taking account of the results of our literature review, stakeholder interviews and focus group with bereaved families and carers. Commissioner interviewees were provided with an information sheet and opportunities to ask questions before consenting to be interviewed.



In our process of recruitment, we wanted to ensure that our interviews represented both a broad geographic spread of England and a range of different levels of deprivation. In order to ensure this, we chose to recruit from areas at the CCG level. The new NHS commissioning structures, ICBs, operate at too large a geographic scale for this, as all ICSs cover a range of both deprived and well-off areas.

We used index of multiple deprivation data ranking CCG areas by deprivation from 2019 (the most recent year for which appropriate data was available). We then segmented the areas into the seven regions used by the NHS (East of England, London, Midlands, North East and Yorkshire, North West, South East, and South West). We randomly selected two areas from each region – one from the most deprived 50 per cent of places in that region, and one from the least deprived. This gave us 14 sites. As our target was to speak to people from 20 sites, we then randomly selected another site from each region apart from the South West, as that was the region containing the fewest CCG areas. This left us with 20 sites. Five of these 20 areas were selected randomly to be areas where we would interview social care commissioners rather than NHS ones.

NHS England facilitated introductions to NHS lead commissioners in the areas selected so that we could invite them to participate, and we approached local authority commissioners directly via the Director of Adult Social Services. Unfortunately, recruitment proved challenging – perhaps because it coincided with a restructuring in the NHS as ICBs were established. Therefore, we repeated this process in full for a second time. After this, we had still failed to reach any NHS commissioners from a number of the seven regions, or to hit our target of social care commissioners. Accordingly, at that stage, we randomly selected further sites within our target regions and approached them directly.

In the end, we conducted interviews in 15 areas. In 10 of those areas we spoke to NHS commissioners, and in 5 of them we spoke to social care commissioners. We spoke with 23 commissioners in total in these interviews. Interviews were conducted between August and October 2022 and were recorded and transcribed.

We also conducted some extra interviews to provide further details on two issues: an example of innovative practice in North East Essex, and the commissioning process for end-of-life care for children. In each instance, we did one further



interview with someone with specialist knowledge of the subject. Those interviews were also recorded and transcribed.

Framework analysis was used to code the interview transcripts with commissioners using MAXQDA 2020 Plus software. The coding framework was created by the research team and tested on two interviews (one NHS, one local authority) before being finalised. Excerpts under each code were analysed thematically and summarised.

### **Bereaved families and carers workshop**

Following the completion of our interviews with commissioners, we held a follow-up workshop with 10 bereaved family members and unpaid carers. This group contained three of those who had attended the focus group, and attendees had a diverse range of backgrounds and experiences. The purpose of the workshop was to present back our initial findings (some of which provided answers to the questions that the focus group had highlighted) and to get their reactions and responses to the findings. The workshop was recorded for note-taking purposes only. Key points raised from the discussions were summarised and helped us triangulate our findings and aid our interpretation.

### **Stakeholder workshop**

Shortly after the workshop with bereaved families and carers, we held a workshop with professionals working in the end-of-life care sector at a national level and in NHS commissioning organisations (from areas other than those involved in the commissioner interviews). The purpose of the workshop was to present the findings from the commissioner interviews, and elicit participants' views and reactions based on their professional experiences and knowledge of the topic at a national level. Participants were drawn from our knowledge of key organisations and individuals – some of whom we had already engaged during our stakeholder interviews – and commissioners were invited via NHS England's strategic clinical network for end-of-life care.

The workshop was not recorded, but the research team took notes of the points made, which were used to triangulate other findings.



## Reporting

The draft research report was reviewed by three members of staff at The King's Fund with relevant experience, and by three external peer reviewers drawn from academia and NHS organisations (not NHS organisations that had been involved in earlier stages of the research). The Department of Health and Social Care also commented on a draft version of the report.



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Based on a literature review and interviews with commissioners and recently bereaved families, the authors looked into how commissioners:

- measure and monitor care quality
- use data to understand population need
- identify and address inequalities
- will need to evolve their roles to become more facilitative and strategic.

The report concludes with recommendations for leaders of integrated care boards, national bodies and NHS commissioners. It signposts ways to have a better understanding of the changing nature of need, reshape supply in line with need and ensure integrated care boards have a clear overview of health inequalities.

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