

How can ICBs improve end-of-life care for people who die at home?

Key findings

Commissioning end-of-life care for people dying at home needs to improve. ICB leaders should ensure that commissioners:

- understand patient, carer and community experiences
- track needs and act on inequalities
- include generalist and social care in quality monitoring
- convene partners to collaborate on improvement.

What's the issue?

- More people are dying at home rather than in hospitals and this trend will continue. This means, alongside specialist palliative care, GPs, district nurses, home care and other generalist services are increasingly important in end-of-life care.
- Many commissioners currently have little or no data to assure the quality of end-of-life care in generalist services and cannot monitor the overall quality of care as people experience it.
- The information commissioners have about local needs is often about demand in individual services and not the whole picture.
- Commissioners are not actively addressing inequalities or unmet need in end-of-life care.

Why now?

- ICBs are reviewing the end-of-life services they inherited from clinical commissioning groups, with a view to developing more integrated care.
- A new statutory duty means commissioning end-of-life care is a national priority.
- Commissioning is changing, with more strategic approaches and greater co-ordination across care pathways.

- Experiences during the Covid-19 pandemic mean staff are motivated to improve the quality of end-of-life care.

What can ICB leads do?

Understand patient, carer and community experiences

ICB leaders are promoting a culture that values and expects feedback, and gives priority to using this feedback to improve quality of care.

In end-of-life care this should include:

- regularly collecting information on **people's overall experiences**, and acting on it to ensure that each service involved is responsive to personalised needs
- understanding and addressing **how people's experiences differ**, for example, in access to services
- **involving patients and carers** in planning and improving services
- seeking out insights for improvement opportunities from all **staff**, including, for example, homecare workers.

Track needs and act on inequalities

Commissioners need to make better use of routine data for local needs assessment, such as health service activity and mortality statistics, as well as using national resources and tools, in order to build a system-wide view of need.

ICB leaders should demand a more robust approach by:

- setting expectations for **better use of available data**, such as analysing service use at the end of life across primary, community, social care and acute providers
- ensuring **analytical capacity and capability** to support this and to drive improvements in data quality.

Better use of information is likely to expose inequalities in end-of-life care between population groups, health conditions, geographies and combinations of these factors.

In response to this, ICB leaders should:

- require commissioners to **co-ordinate the data providers collect** on inequalities (including qualitative experience data), bring it together and use it to agree **shared priorities and actions**
- ensure **accountability** for progress in identifying and reducing inequalities.

Include generalist health and social care in quality monitoring

Overall, holistic quality of care needs to be monitored and assured across health and social care, including generalist services. This is not common practice at the moment.

ICB leaders have a key role in improving this situation, by:

- overseeing a **strategic direction** to:
 - develop the **right balance of priority** (and investment) for end-of-life care in specialist and generalist health services, with data flows to reflect this
 - recognise the important role of **social care** and include this in quality governance reports, quality improvement work and care co-ordination processes.
- facilitating and requiring – for example, through the ICB's organisational structure, governance and information flows – **close working relationships** within the ICB between lead commissioners for end-of-life care and lead commissioners for generalist health services, and externally with directors of adult social services.

Convene partners to collaborate on improvement

Commissioning is changing – some areas no longer even use the term 'commissioning'. Commissioners are increasingly focusing on strategic improvement and working with providers as partners. These roles are evolving.

ICB leaders should support this development and provide strategic oversight, by:

- **supporting commissioners** to develop their new roles, for example, by ensuring space to explore approaches and giving clear backing once they are agreed
- **role-modelling** ways of thinking about health and care services as a system and developing working relationships that result in people experiencing seamless care.

What families and carers told us about end-of-life care

Recently bereaved families and carers said commissioners need to ensure that:

- staff are consistently compassionate – trained in caring skills, as well as clinical skills
- there is good communication, so that patients and carers are fully involved and fully supported
- all the services involved are well co-ordinated and seamless
- people know what to expect, the range of services available for them and how to access them
- services meet the specific needs of people from different ethnic and religious groups.

To achieve this, families and carers said that:

- commissioners need a clear view of what good-quality care looks like and what is involved in delivering it
- patients and carers need to inform that view and be involved in planning services
- commissioners should look across all the services involved to see the whole service that people experience, as well as monitoring individual services
- commissioners should use carers as a key source of feedback and ensure that they, as well as the patient, are supported.

Further reading

Baylis A, Chikwira L, Robertson R, Tiratelli L (2023). *Dying well at home: commissioning quality end-of-life care*. The King's Fund website.

NHS England (2022). *Palliative and end of life care: statutory guidance for integrated care boards (ICBs)*. NHS England website.

Tiratelli L (2022). *Dying matters – which is why we need to deepen our understanding of end-of-life care*. Blog. The King's Fund website.

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