Hampshire and Isle of Wight Integrated Care System: Community engagement

What is this case study about?

This case study shows how an **Integrated Care System (ICS)** engaged with patients, carers and the community to develop a Palliative and End-of-Life Care (PEoLC) Strategy, coproduced by and for the local community. This approach illustrates the delivery of Sue Ryder and sector partners recommendation:

"ICSs should work with the Voluntary, Community and Social Enterprise (VCSE) sector to understand the needs of their communities, and work with PEoLC providers to reduce health inequalities."

Let's talk about death and dying: a community conversation event.

Engagement with patients and communities

Building on Solent NHS Trusts established network of community partners, Hampshire and Isle of Wight (HIOW) ICS carried out 'a community conversation', with members of the public, carers, VCSE organisations and PEoLC providers across Hampshire, Southampton, Portsmouth and the Isle of Wight, to ask 'what matters most to you?' around palliative and end-of-life care.

Engagement with clinical colleagues

A similar event was also held with clinical colleagues asking what 'ending well' means for end-of-life care.

Inequalities in End-of-Life Care

The engagement work highlighted areas of inequality in end-of-life care, in particular: people from ethnic minority groups, people living in poverty, people with non-malignant (non-cancer) diseases, people with additional disabilities including dementia and learning disabilities, and people who are homeless.

"The community conversations have become central to our programme of work."

Faye Prestleton
PEoLC Programme Lead

Developing a Palliative and End-of-Life Care Strategy for the ICS

This engagement work helped the ICS understand what the public, community, VCSE and local clinicians wanted local organisations to prioritise.

Key priorities included:

- **Improving communication** to enable professionals to communicate with each other, and with patients and carers.
- **Support for carers** to be embedded in everything end-of-life.
- **Additional training** to support end-of-life care conversations and understanding of different cultural and religious needs in end-of-life care.
- **Working closely with communities** to challenge stigma around death and dying.

The ICS incorporated national requirements for PEoLC, local PEoLC data alongside clinical feedback and VCSE and community feedback, in order to shape the ICS's End-of-Life Care Strategy.

Accompanying this Strategy is a Delivery Plan, which outlines how the Strategy will be delivered. The Plan includes a commitment to continued engagement with patients, carers, the VCSE and communities.

Sue Ryder

Engaging the community: Top tips from Hampshire and Isle of Wight

- ✓ **Get feedback reports signed off by the community, not just the Board:** To create ownership, Hampshire and Isle of Wight have asked community partners to sign off feedback reports, to ensure that they are fairly representing what the community has said, and how the community wants to proceed.
- ✓ **Ask yourself who you are excluding:** Consider who you not hearing from, map those gaps, and get in touch with VCSE organisations and communities who represent the voices you have not heard. People will want to engage in different ways: you may need to run things in person and online.

> **"What might feel like a relatively simple conversation can turn into 20 actions."**
>
> Joe Croombs
> PEoLC Project Manager

- ✓ **Use the power of stories:** Stories can be an influential tool to engage clinical audiences. Two stories were used from parents who had lost children; one a positive story of end-of-life care and one which showed opportunities for improvement around access and delivery of care. The impact of different care for the families was powerfully illustrated by using two very different stories.
- ✓ **Don't underestimate how long it will take:** This strategy was shaped over almost three years. You have to spend time getting to know your community. As you get more involved in projects, you have less time to spend, but getting to know people is essential. Ask to attend meetings, even if you just wash up or have a cup of tea!
- ✓ **Keep a distribution list:** Solent NHS Trust worked to develop connections and established relationships with community partners, resulting in a distribution list of over 5,000 public and community stakeholders who receive information and work alongside us.

Governance at a glance

- The Integrated Care Board (ICB) is a statutory committee of Health and local authorities in the ICS. The ICB is responsible for the Palliative End-of-Life Care Strategy, which covers all ages and aspects of palliative and end of life care, delivered across Hampshire and Isle of Wight ICS.
- Ongoing community engagement is overseen by the HIOW ICB PEoLC Board, a committee ultimately reporting to the ICB.
- The local independent hospice collaborative, comprising of VCSE hospices, has a place on the HIOW ICB PEoLC Board working alongside other HIOW PEoLC service providers.

For more information about this case study or the recommendations for commissioning and delivering better end-of-life care, contact john.kemp@sueryder.org.

Palliative and End-of-Life Care: best practice case studies

Sue Ryder and sector partners working in PEoLC have developed Key recommendations for commissioning and delivering better end-of-life care within Integrated Care Systems.

This case study from Hampshire and Isle of Wight ICS is one of a series showcasing how ICSs around the country are implementing some of these recommendations:

- ✓ **Well-functioning collaboratives**
- ✓ **Local solutions to workforce challenges**
- ✓ **Measuring population need for PEoLC**
- ✓ **Innovative services and roles**
- ✓ **Using data effectively**