

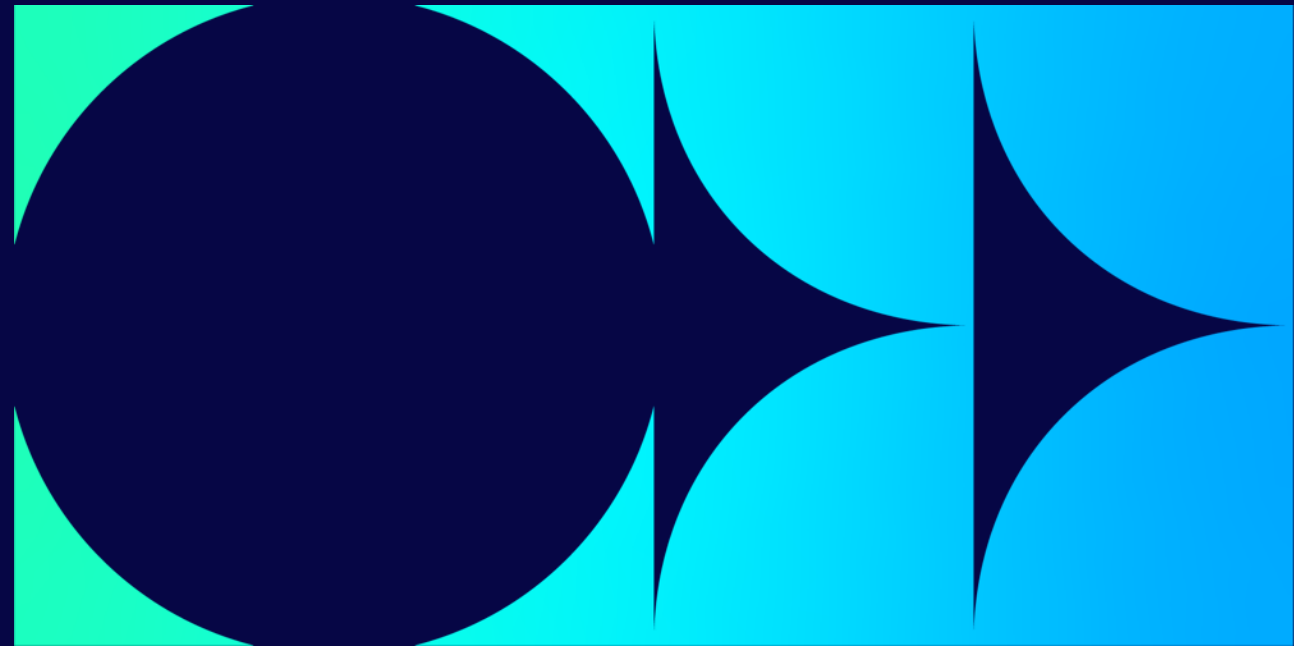
What is community?

Understanding notions of community in relation to English palliative and end of life care and the Ambitions framework

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Ambitions for Palliative and End of Life Care

A national framework for local action

Six ambitions to bring that vision about

- 01 Each person is seen as an individual
- 02 Each person gets fair access to care
- 03 Maximising comfort and wellbeing
- 04 Care is coordinated
- 05 All staff are prepared to care
- 06 Each community is prepared to help

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

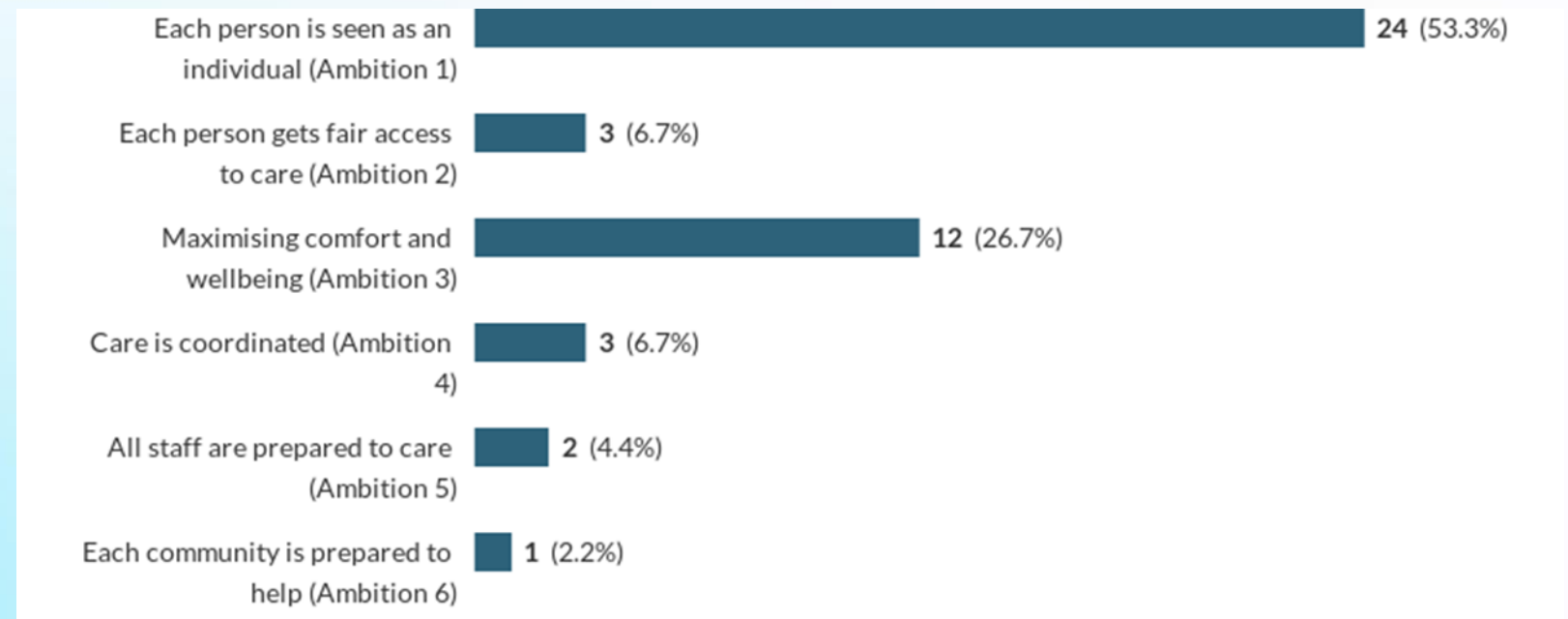


Ambitions for Palliative and End of Life Care

Mapping Survey

Key Findings

- › Ambition 6 least likely to be the focus of service development (yet over 50% still see it as relevant to them)
- › Strategically key to see community referenced in the document



Percentage listed as primary Ambition for each entry in survey (could only select one)

Project methods



Understand, Interpret, and Implement

How do people go from national framework to local action

Marie Curie funded project to examine how people enact the Ambitions

Multi-method research project (April 2022- March 2023) – iterative qualitative data collection & analysis

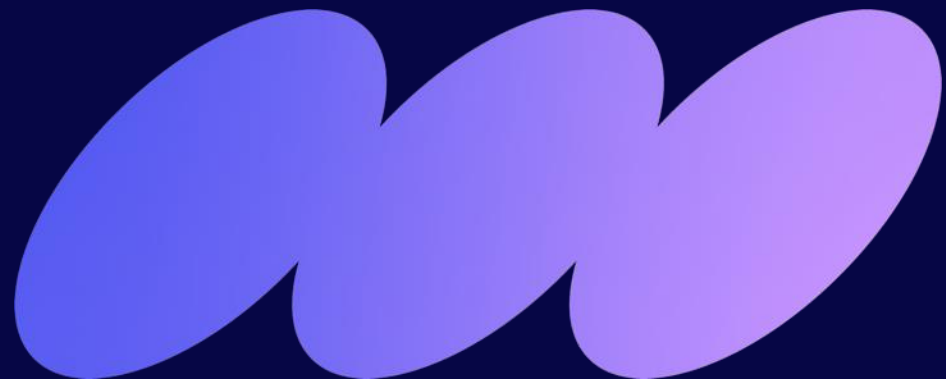
- › Draw on findings from initial mapping survey
- › In-depth case study (17 interviews, document review)
- › Focus groups (4 online sessions: different stakeholder groups)
- › Workshops (4 themed sessions – 1 focused on ‘community’)
- › Evidence Cafes: Grab and Go Guide – Small Steps, Big Vision

Study findings

Importance of community

What is community?

Implications for practice



Importance of Community

In the framework and beyond

'Community' was viewed as something valuable to focus on (and yet...)

- › Links to Compassionate Communities and Public Health
- › Limitations in Ambitions framework on how to realise Ambition 6
- › Raises questions about what it means to do this work

"...You know we all know that and trot out how death and dying is a social process, not just the clinical process. And we need to pay more attention to the social bit. But actually the reality and of the culture shift and the funding issues and the different way of managing and holding risk within those kind of projects, that's different...and I think has not been as widely spoken about."

"...working with NHS colleagues...[there's an] emphasis on the importance of bringing clinical leadership to a problem irrespective of whether it is a clinical issue. And I don't think I've ever heard anyone say anything about bringing community leadership to a problem."

What is community?

- › Different ethnic and/or faith groups
- › Marginalised groups
- › Vulnerable groups (e.g. homeless)
- › Local interest groups
- › 'Diverse' or 'intersectional' communities
- › Geographical areas
- › Neighbourhoods
- › Online
- › Sites (schools)
- › General person
- › Lay public

“I always think of it as the layperson, so these are, you know, the general public. This is about taking back, you know, 50 years and small communities working together to provide supportive networks to those in need. And in this instant trust around palliative care.”

Implications for Practice

How different notions of community impact action

The social sciences show how language/concepts/discourse impacts and shapes action. How people think (and talk) about things is entwined with what they do.

“...from a acute NHS Trust point of view, the “each community is prepared to help” within the ambitions is far more difficult for us to see how we can actually facilitate that. You know, that's a much broader community and fantastic as an aspiration, but much more difficult for me to know what the role of the acute trust is within that.”

“The rub was that it was owned in the majority by clinical staff. Rather than looking at it from my perspective, from a holistic sort of community point of view ... I don't think one person in the organization ever talked to me about the ambitions framework unless I was like there's this thing that apparently we're all meant to be [working] towards.”

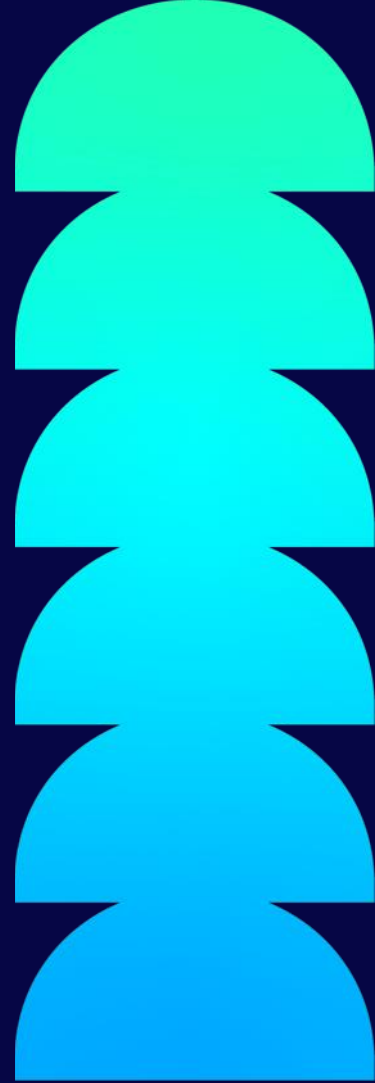
Implications for Practice

How different notions of community impact action

- › Different notions of community at the same time
- › Who is responsible for community engagement – considerations of 'ownership' and expectation that communities provide solution for (health) problems
- › What role does community work have in or alongside service provision
- › Role of partnerships and mindset of collaborating
- › Ability to recognise what is already happening locally
- › Not recognising and valuing the communities people (e.g. staff) are part of
- › Death literacy and awareness raising
- › Building resources or building escalation pathways?

“Ambition 6 was always given lip service by clinicians. It is only since the pandemic and the onset of integrated care system we are given a bigger platform. The biggest challenge has been fitting into the restrictive boxes they place on what is classed as clinically benefit[al] ”

Realising Ambition 6



Where to then?

Different notions of community impact action

- › Encourage open dialogue and reflection
- › Recognise what is already happening (both in communities, but also to them)
- › Importance of valuing range of expertise(s)
- › Hold space for diversity and range of expectations about dying/death/grief
- › Commit resources for 'engagement'
- › Takes time to build trust and shared understandings, ensure consistency
- › Clear signposting of working towards Ambition 6 – value of sharing learning and case studies

Top recommendation from participants:

“Keep it simple and straightforward.”

Thank you

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Project resources and reports: <https://tinyurl.com/ambitionsframework>



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