



Realising the Ambitions: Insights from how People Understand, Interpret and Implement the Ambitions Framework for Palliative and End of Life Care

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1. Executive Summary & Key Recommendations

The Ambitions for Palliative and End of Life Care: a national framework for local action (2021-2026) provides guidance on how to improve palliative and end of life care. It is incorporated into the statutory guidance for Integrated Care Boards (ICB) and has informed service developments since 2015. This project used a multi-stage design to learn from case studies, focus groups and workshops. It focused on how people understand, interpret, and implement the Framework – how they make sense of it to inform action.

We found three ways as to how people operationalise the Framework in their work. Some adopt it at a **strategic level**, some use it to **address action around specific Ambitions**, and some use it to **complement other work** being done. Focusing on the foundations, rather than only the Ambition statements, was easier for people to identify actionable plans. People valued learning what works and how, including challenges faced, through the research events. Leadership and resources were deemed by participants as key to drive implementation. Leadership is not restricted to those in official positions of power, although is expected of ICBs and at national level.

For readers short of time, we suggest jumping to Section 5.4 and Section 7 for key findings and recommendations. For readers looking to work towards realising the Ambitions, we recommend Section 4 for case studies and Section 5.3 provides a Grab and Go Guide to facilitate further action. For readers interested in the study design and application of theory to study findings, we recommend reading Sections 3, 5.1, 5.2, and 6.

Headline recommendations:

- Focus on the foundations to drive action. The Grab and Go Guide (Small Steps, Big Vision) from this project provides prompts for this.
- Foster collaboration and partnership working, investing in relationship building and understanding others' perspectives to enable a system wide approach.
- Expand opportunities for sharing learning about the Framework and examples of practice.
- Acknowledge how interactions of the Ambitions impacts action. The in-depth examination of community provides an example of this.
- Raise awareness and knowledge of the Framework beyond palliative care services.

Ambitions research

For more information on how people have understood, interpreted and implemented the Ambitions for Palliative and End of Life Care: a national framework for local action, visit the link below or scan the QR code for reports from the project, workshop slides, and where possible, data.



Visit open.ac.uk/projects

2. Introduction

[The Ambitions for Palliative and End of Life Care: a national framework for local action](#) relaunched in 2021 for another five years. It now has over 30 partners across a variety of sectors. The Framework provides a vision around six identified Ambitions underpinned by eight foundations. As a framework rather than mandated policy, it provides guidance on how to improve palliative and end of life care locally. The Framework is incorporated into the [Palliative and End of Life Care Statutory Guidance for Integrated Care Boards](#) (ICBs) to meet statutory duties under the Health and Care Act (2022).

People often see the problem as palliative and end of life care is not being consistently delivered effectively to all people who need it. The Framework was originally released in 2015 to help address this. To date, however, there has been minimal research to examine how the Framework has been utilised. Published literature focusing on the Framework falls broadly into three types. Firstly, editorials promoting the Framework.^[1] Secondly, examples of how people used the Framework for service improvements and to develop practice guidance.^[2-4] Lastly, there is a small body of literature that critically examines the impact of the Framework.^[5,6] This questions both ability for implementation and impacts of localism in widening inequalities.

Given this, in 2021-2022 we ran a mapping exercise. This captured examples of use and outlines where, when, and how the Framework is being used.^[7] This project builds on that mapping exercise. This project examines how people understand, interpret, and implement the Framework. Core to this was gathering data on how people who are in a position to use the Framework understand it and have changed services to reflect the Framework.

The project questions were:

- ▶ How do people understand the Ambitions Framework?
- ▶ What lessons can be learned from in-depth case studies of how people have interpreted and operationalised the Ambitions Framework?
- ▶ What key insights, including identification of gaps, can be shared across contexts to further the implementation of the Ambitions Framework?
- ▶ What challenges and opportunities are there for transferring learning from select case studies?

This report describes how we conducted the research as well as the main findings and learnings. This includes case studies, in-depth consideration of community (linked to Ambition 6), and a Grab and Go Guide (Small Steps, Big Vision) that we generated as an outcome of the research.



3. Methods

This was a multi-method qualitative study with several stages. We used qualitative methods that engage participants in a reflexive dialogue. This helps people articulate and make sense of their actions. It can identify ways of learning from case studies and discussions. It also highlights potential gaps in how people engage with the Framework. People were able to take part in one or more of the stages (providing individual consent for each engagement). All data collection was online.

There were four iterative stages, with cumulative data analysis feeding into subsequent stages. The project design and analysis was regularly refined through discussion with the project's advisory group. This group included members of the public, service providers in NHS and third sector organisations, and academics.

➤ Case studies: 17 in-depth interviews identified from previous mapping work and targeted invites to services to increase the diversity of the case studies. Interviews focused on how people operationalised the Framework, impacts this generated, and challenges faced. Several participants offered documents (e.g. local strategy) to further illustrate their examples. Participants consented to anonymised data about case studies being shared publicly; hence contact and specific location details are not included in the case studies reported here.

➤ Focus group discussions: four sessions, each organised by role – service managers, service providers (i.e. frontline staff), commissioners, and members of the public. Participant numbers ranged from 2-8 (21 in total). Discussions focused on how people understand and have responded to the Framework.

➤ Workshops: Four themed workshops based on themes from the case studies and focus groups. Themes included: 1) sharing learning, 2) strategy, self-assessment, and measuring progress, 3) partnership working, and 4) community. Workshops shared examples of practice, discussed challenges and barriers to realising the Ambitions related to the theme, and invited further discussion around understanding, interpreting, and operationalising the Framework. Each workshop had between 6-14 participants (40 in total).

➤ Evidence Cafés: Two sessions aimed at sharing evidence from the research and collecting further data on examples of practice and feedback on project output. The object discussed was a Grab and Go Guide – Small Steps, Big Vision (see Section 5.3). Guide developed based on data collection from Stages 1-3 and informed by the Framework. Evidence Cafés are an established method of knowledge exchange with embedded data collection.^[8]

Participants were asked to discuss the Grab and Go Guide, focusing on: use, content, format, and general feedback; this was conducted in facilitated break-out rooms. Sessions were two hours long, with between 6-15 participants per Evidence Café.

Analysis focused on how people understood, interpreted, and implemented the Framework. This is a three-stage theoretical model. We used this model because implementation requires many steps that involve making sense of the guidance. Additionally, people and organisations may be at different stages of implementation or operationalisation. The Framework is not official policy; thus 'implement' may be perceived to be an inaccurate description since Ambition Partners refer to it as 'realise the guidance'. Yet, participants view the Framework on similar terms to other policy documents and used terminology referencing implementation. Since this project is about how people use the Framework, we are guided by their use of language and how they perceive and interact with the document.

The project team is based at The Open University. We were not involved in the development or relaunch of the Framework. The project ran from April 2022 to March 2023; data collection was between May 2022 and January 2023. The project received ethical approval from the Human Research Ethics Committee at The Open University (HREC/4304/Borgstrom). Materials from the project (e.g. workshop slides) are publicly available online from the [Ambitions Framework ORDO repository](#). These have been made available to enable re-use with attribution, for example, in local training or discussions.

More information

Find out more about this project from OU.



Visit open.ac.uk/projects

4. Case studies

We analysed a wide range of case studies collected from all project stages. They represent a range of settings, with most being NHS or hospice led. Where there was considerable similarity between two or more case studies, we created a composite rather than list each individually. The case studies are provided as examples and have not been evaluated by the research team; we are therefore not referring to them as ‘best practice’ and cannot ascertain their impact. Here they are mapped against the eight foundations and the six ambitions these contribute to (listed as A1-6).

1. Personalised care planning

Typically, this involved advance care planning; however, it could relate to a wider range of decision-making and planning. Case studies mentioned the role of education, communication skills, and infrastructure to support personalised care planning.

- ▶ **Education programme** providing training across a whole locality on advance care planning (ACP). This is provided by Mental Capacity Act team who provide support to staff to understand their duty of care within the principles of the Act. Full day training on the principle of the Mental Capacity Act and Deprivation of Liberty safeguards (DoLs) including ACP and how to implement (A1, A5)
- ▶ **Adaptations to ACP documents** for people with learning disabilities and culturally sensitive language translations (A1)
- ▶ Use of the [Universal Principles for Advance Care Planning](#) (A1)
- ▶ Looking to use **codes in data systems** to recognise a wider range of personalised care planning to avoid ‘tick box’ approach to whether someone has a particular document or not (A1, A4, A5)

2. Shared records

This focused on who had access to what information and when, especially about end of life care plans. We had examples of both treatment escalation plans and ReSPECT; ReSPECT incorporates treatment escalation plans. In many case studies, work is ongoing to ensure access to this information across local IT systems and care systems. Non-professionals mentioned the importance of patient/client and carer access to records. Many of these examples also related to personalised care planning.

- ▶ **RESPECT forms** (Recommended Summary Plan for Emergency Care and Treatment) to create a summary of personalised recommendations for a person’s clinical care in a future emergency in which they do not have capacity to make or express choices (A1, A3)
- ▶ **Treatment escalation plans** record information discussed between individuals and healthcare professionals. The Plan creates a personalised recommendation for clinical care in emergency situations, where individuals are not able to make decisions or express their wishes themselves (A1, A3,)

- ▶ **Enhanced Summary Care Record** including Summary Care Data in primary care. Roll out with training across GP practices (A1, A3, A4)
- ▶ **Palliative Care Register** across primary care, care homes acute care enable access to timely information and providing reliable and regular performance data to clinicians and policy makers identifying areas for continued improvement (A1, A4)
- ▶ **Increasing use of electronic records** and sharing these across primary and acute care, as well as investing in systems that can link with hospices and social care (A4, A5)
- ▶ Use of the [Palliative and End of Life Care Information Standard](#) (A1, A4)

More information

Find out more about this project from OU.



Visit open.ac.uk/projects

3. Evidence and Information

Examples included the use of both local and national data. People also use audit and research evidence to inform service development. Participants discussed the need to regularly collect data, interpret a wide range of information, and use it to take data-driven or evidence-driven action. The skills to do this varied across settings and people welcomed training on using evidence.

- ▶ **National Audit of Care at End of Life (NACEL)** is a national comparative audit of the quality and outcomes of care experienced by the dying person and those important to them during the last admission leading to death in acute hospitals, community hospitals and mental health inpatient providers in England, Wales and Northern Ireland. People reported that this is helpful to make comparisons and benchmark against other organisations with similar demographics (A2, A4, A5)
- ▶ **Self-assessment** against the Ambitions Framework. This is an excel based assessment tool that can be used by individual organisations and/or the whole system to assess their progress in actions relating to the implementation of the Ambitions (A1-6)
- ▶ **Mortality data** and other related data is – available from a variety of national sources including the Office for National Statistics (ONS), Public Health and the National End of Life Care Intelligence Network. People used this to make comparisons and benchmark against other organisations with similar demographics (A2)
- ▶ **Medical Examiner System** to provide independent scrutiny of deaths, and to give bereaved people a voice.

It also provides enhanced timely feedback to clinicians on the palliative care that has been provided (A2, A5)

- ▶ **Integrated Palliative care Outcome Scale (IPOS)** is designed to measure those symptoms and concerns most often reported by people with advanced illness, physical and psychological symptoms, social and spiritual aspects, communication, information and practical needs (A1, A3)
- ▶ **RAPID score cards** used by commissioners and clinicians to use local data to assess services, identify gaps/issues and develop improvement plans (A2)

4. Involving, supporting, and caring for those important to the dying person

Case studies initially tended to focus on bereavement; participants nevertheless advocated for more carer support which was attentive to social and cultural diversity.

- ▶ **Befriending service** provided by volunteers for older people who live alone, have no family living locally or feel socially isolated and lack social contact (A1, A6)
- ▶ **Bereavement support** carers centre provides support to carers for up to two years offers one to one support a listening ear, support to combat isolation, peer to peer support groups and social activities (A1, A3)
- ▶ **Bereavement Help Points (BHP)** provide drop-ins for anyone who has experienced a bereavement, irrespective of how recently or the type of bereavement. An opportunity to meet with others who have been bereaved in an informal, volunteer, community-led setting (A6)

- ▶ **Compassionate neighbours** are fully trained local people who provide their time, companionship and support to people living in their community. Where possible, people are matched together according to their hobbies, interests and geography in the hope to grow genuine friendships. Good Neighbours provide a similar set-up focused on volunteer support (A6)
- ▶ **National Audit of Care at End of Life (NACEL)** data relating to carers experience used to review and further develop relating to the needs of carers including bereavement (A1, A3)
- ▶ **Medical Examiner System** the aim is to provide independent scrutiny of deaths, and to give bereaved people a voice (A1)

5. Education and training

Training, especially staff training, was a primary focus for many case studies. Some developed systems to keep records of training and/or reviewing the impact of training on changes in the quality of care or staff confidence. The Framework can be used to structure training and illustrate palliative care values.

- ▶ **End of life care facilitator** providing education and training to a range of staff in acute and community services across an area covering all aspects of palliative care (A5)
- ▶ **National e-learning programme End of Life Care for All (e-ELCA)** provides free access to over 120 online modules (A5)
- ▶ **Palliative Care educator and members of the Specialist Palliative Care Service** deliver training programmes for all nursing staff and separate bespoke education for medical and other staff groups (A5)

- ▶ **Coroner education and training** that is coroner-led and aimed at health and social care professionals. Focuses on legislation, verification of death and cremation (A5)

6. 24/7 access

Examples included access either within a service or across a system/area. At system-level, participants advocated for clear signposting for the public and other professionals.

- ▶ **Hospice 24/7 helpline** accessible to staff, individuals, families within the community (A2)
- ▶ **7 day a week face to face service** provided within Trust with a 24/7 advice from palliative care consultants (A2, A3)
- ▶ **Acute intervention team** who are trained to recognise and manage palliative care needs and work closely with ward staff especially during the out of hours period (A2, A3)
- ▶ **Access to medicines for individuals at home** through the promotion of the use of anticipatory medicines, updated palliative care medicine stock list. Supported by the creation of an electronic version of the palliative care Kardex and supported the development of a palliative care pharmacy network (A2, A3, A4)

7. Co-design

This focused on designing services in collaboration with people who have personal and professional experience of palliative and end of life care, including patients/clients and carers. Some case studies mentioned the use of patient user groups for this. Members of the public highlighted that co-design should also enable dissenting voices to be heard.

- ▶ **End of life care strategy development** working across system to co-design with EOL Patient Forum, Carers forums and hospices to foreground people with personal experience (A2)
- ▶ **Carers involved** in a quality improvement project to improve the experiences of carers whose loved one is dying or has died in a care setting. Programme developed by carers and professionals using an experience-based approach; the team visit the care setting and consider the environment and end of life care provision through the eyes of a carer. A summary report provides a platform for service improvement (A1, A3)

8. Leadership

Leadership was demonstrated at a range of levels, from ward-based, team leadership, up to Integrated Care Boards. Leadership was typically expressed as driving vision and strategy. Leaders developed the capacity for innovation, improvement, and staff wellbeing.

- ▶ **Trusts showcasing** their ongoing development of services when writing local reports and presentations, highlighting how by using the Framework it has helped them identify gaps, goals and future strategies (A4)
- ▶ **Local leadership** within an area that champions palliative and end of life care ensuring that they are incorporated into other local strategies or business plans to reduce siloed working (A4, A5)
- ▶ **Team leaders** using the Framework to structure staff meetings and foster a work culture that supports the Ambitions (A5)
- ▶ **Compassionate leadership** that supports staff wellbeing and resilience (A1, A3, A5)



5. Findings and Learnings

To address the research questions, we adopted a theoretical structure to examine how people understand, interpret and implement the Framework. This section outlines the findings generally under this structure. The next section uses the example of community from Ambition 6 to examine this in-depth.

5.1 Understand, Interpret, and Implement

Understand: Across the project, we asked people about the language of the document. We queried what they thought different aspects meant. People spoke about how the Ambitions Framework provides shared language (which is consistent with our [mapping survey findings](#)). For example, they felt the language in the Ambitions made for useful conversation starters when engaging with partners and commissioners. They also acknowledged that each Ambition is broad and vague enough to be refined as needed within a service. This is where the interpretation (below) comes in.

I'm not saying it's not correctly titled, but to me what that means is that [it is not worded as] what that actually means to the general public

Study participant

Even with a sense of shared language we noted differences in how people understood the various ambitions or key words within them. This was most notable around the term community (discussed in more detail in Section 5.2). In our focus group with members of the public, we noted that they were far quicker in pointing out the ambiguity of the language. This indicates that they did not have the same assumptions as many working in the palliative care field about what the Ambitions meant. In the workshop about partnerships, participants claimed it was vital to take time to understand how others make sense of the Ambitions.

Interpret: This aspect builds on 'understand' to see how people make sense of the Ambitions in relation to their own professional and/or personal experience. By asking questions about this, we can observe how people make links between the guidance and what they do, as well as between different parts of the Framework. This is a step people can take to help them begin to identify how they may implement guidance. It enables moving from 'what does it mean' to 'what does it mean for me'. Interpretations are contextual and caveated by experiences. This includes what limitations people perceive.

It's about interpretation of language. It's about interpretation of that word

Study participant

For members of the public, this was often about what they thought should be happening. The ambitions are interpreted as standards. Participants reflected on if and how they had witnessed the kind of care expressed in the Ambitions.

For healthcare professionals and commissioners, people related the Ambitions to different parts of their work. This ranged from patient care to data management and working with others. This could be both in the abstract – 'like this would not work for us now' – or more detailed about what a specific word or ambition meant to them in their work. For instance, this could be how Ambition 1 is about personalising care. People provided examples on how they do this in their daily practice. This included encounters with patients and issues with data management.

Implement: Focuses on how people operationalise the values and foundations found in the Framework – moving from vision to action. We use the term implement to reflect how people talked about making progress with the Framework. By implementation we mean that they are taking steps to change what they do to align their work more closely with the Ambitions. People had different expectations about who should be responsible for implementation, with it being a mixture of higher-level leadership (commissioners, Trust directors) as well as service managers and frontline staff. The former are expected to put in infrastructure and provide strategic vision. For frontline staff, what was key was being supported in order to do the work that was deemed as good palliative care.

We found that services are implementing the Ambitions in different ways. This was from focusing on educating staff to larger re-designs of service provision to widen access. Some co-developed community action focused on promoting education and support amongst the population. Sometimes implementation was at the level of educating others about the Ambitions. Importantly for those we spoke to, implementation was not a one-off process. Implementation involves continuous service redesign, evaluation, and collaboration.



We use the language [of the Framework] to try and reframe people's thinking



Study participant

In conversations about implementation people articulated barriers, facilitators, and ambiguity around how to realise the Ambitions. For example, when discussing shared records, people tended to agree that this is a good thing that supports person-centred care. Yet, systems are often determined at a 'much-higher level'. There are also resource implications. In some cases, even if organisations used the same IT system, 'the programmes don't talk to each other'. When people did have shared records, they noted that this required determining who needed what kind of access and when. Additionally, sharing may be limited, often excluding social care or patients/clients themselves. For some, the solution is sharing key documents or aspects of patient notes to ensure coordination around specific care plans.

Here, when people focused on foundations, this helped ground the discussions more about actions. This is because when they discussed the Ambition statements, there was more of a questioning about parameters. Ambition statements were not effective for measuring progress. Many reported to lack confidence and resources to measure progress effectively. Additionally, people reported being able to use the foundations as levers. This could be in business cases or through commissioning processes. People could articulate how a foundation could meet more than one Ambition. They also articulated how the foundations related to wider health and social care goals. The foundations were therefore seen as routes to meeting the Ambitions. This is one reason the Grab-and-Go Guide (Section 5.3) focused on the foundations.

Moreover, the Ambitions were viewed as something that was to be achieved by a collective or system. Discussions of implementation therefore could move between individual action (or action within a service) to how services collaborate and the role of commissioners. Where people found implementation difficult when thinking about the systems, they often cited a lack of two things: leadership and resources. For example, people mentioned that whilst individual hospices could be seeking to meet the six Ambitions, that without more action across the system, there would inevitably be inequity in provision and that more could be done to enable communities to be prepared to help (Ambition 6). Leadership and resources were deemed to ultimately belong to individual organisations, although they could be managed within them.



We have tried to do that [focus on specific Ambitions] and really struggled, whereas with the foundations we've been able to... slot into that topic heading and list a number of actual things that we needed to do



Study participant

Barriers:

Lack of awareness about the Ambitions framework

Lack of leadership

Perceived lack of agency to make changes

Lack of clarity about one's role in realising the Ambitions

Difficulty engaging stakeholders

Deficits in infrastructure and resources

Difficulty measuring progress

Change in personnel

Length of the Ambitions document

Facilitators:

Appreciating progress and existing local action

Dedicated time and resources to work on the Ambitions

Sharing learning and networking

Sharing examples of practice and documents

Being involved at strategic levels

Embedding the Ambitions into meeting agendas and education

Local champions who promote the Ambitions across levels and sectors

5.2 In-depth examination: unpacking Ambition 6 and what is community?

From our previous study, we knew that Ambition 6 was less likely to be the primary focus of those reporting to use the Framework. Yet, people welcome the inclusion of community in palliative and end of life care guidance and policy. In this project, we specifically attended to exploring issues around Ambition 6. We did this via our theoretical structure of understand, interpret and implement.

Understand: People understood Ambition 6 (Every community as prepared to help) in four main ways. This included: public, site, community based on characteristics, and what it means to belong to a community. It was not uncommon for people to speak about community in nostalgic terms. Communities were typically identified as being external to the speaker. People noted that someone could belong to multiple communities, or multiple understandings of community, at any one time.



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.



Study participant

Community as public: This described community in generic terms. Terms included 'general person', 'general public', 'layperson' or 'lay public'. These understandings portrayed communities as homogeneous. Their main characteristic was that they were not identified primarily by a professional role.

Community as site: People defined community by the location, place, or site of community – where they are. This included geographical area, such as a town or city. In some cases, people focused on the 'hyper-local', down to neighbourhoods or street level. People identified charities, churches, schools or even hospitals as being communities; the latter was noted by participants as 'surprising to realise' that the hospital was a community with a population the size of small town. On occasion, people talked about community as contrast to NHS settings, such as social care as being 'community'. Lastly, people spoke of online communities, recognising that these may or may not be tied to a geographical location or place.

Community based on characteristics: Some participants spoke about the groups of people who are considered communities. This was identified by a particular aspect or shared characteristic. Examples include: different ethnic groups, faith groups, marginalised groups, vulnerable groups such as those experiencing homelessness, local interest groups, and volunteers. One participant summarised it as: community of play, community of purpose, and community of identity. Some complexity was added to the previous understandings by noting diverse or intersectional communities. It is important to note though that some of these groupings are based more on the perspective of the person who is defining it

as a community rather than a self-definition by those who are deemed to be part of the community identified. Often these groups were spoken about as being external to the research participants, for example, communities they seek to engage with, rather than reflecting on the communities they are part of.

What it means to be in a community: Participants discussed what it meant to be part of a community. This included: self-perception, sense of belonging, loyalty, support, and ways of doing things, including different approaches to death and dying. They related these values to Ambition 6. We noted a shift in terminology within the sessions around whether communities support, care, or help (or a combination of this), and what these terms mean. Some participants started to define Ambition 6 as communities who care rather than communities who are prepared to help. Consequently, there was continuous questioning within sessions about what are communities and what are they expected to be and do.

Interpret: When it came to making sense of how community related to their own service setting and/or personal experience, we found that how people thought about community impacted what they think was or was not possible. Many of the responses identified communities that were external to the speaker/participant. This raised questions of how to engage these communities and whose responsibility this is. Overwhelmingly, people interpreted communities as a source of value –for dying individuals, those important to the dying person, and the communities themselves. Communities are also as a resource that could be drawn on by palliative care services (for both help and financial support,

e.g. for hospice fundraising), although some noted that communities could be a barrier if they restrict access to healthcare services.

When people thought of communities as external, some concluded that Ambition 6 was beyond their own remit. Consequently, they professed it was difficult for them or their service to realise Ambition 6. For example when talking to people working in the acute sector, some of them viewed communities as external to these institutions. For others, communities defined by groups meant that they felt they were overwhelmed by the number of potential organisations and groups they would need to engage with, and that within their current role there may not be capacity to do this either effectively or meaningfully. In these accounts, interpreting community as external lead people to not realise what links and contacts they may already have with communities or community groups.

Fantastic as an aspiration, but much more difficult for me to know what the role of the acute trust is within that.

Study participant

Whilst there was acknowledgment that community groups may already be doing good work, others noted that much of the community engagement work related to the Ambitions still focused on clinical leadership in its interpretation. This means that people were interpreting the Ambition as something that the (palliative care) providers lead on to make a difference within

the community work. However, in our workshop on community, there was discussion about spending time learning from community group leaders and understanding their views and valuing their expertise. This means that interpretations that valued community expertise may look different than interpretations that are clinically focused or driven. Participants warned about viewing community as a solution in these interpretations. They encourage working with and for the communities instead.

The rub was that it was owned in the majority by clinical staff.

Study participant

Some did recognise that they belong to communities, and often that this was multiple and may not always be formal communities. When people adopted this interpretation, they began to speak about their spheres of influence in their day-to-day interactions, including friendships or workplace. When people reflected on their own experiences of community or hearing other people's experiences, they noted that this could be positive and/or negative – and began to challenge the idealistic undertones of community that were present when discussing how people understand community. This shows the importance of not just focusing on how people understand community, which can be idealistic or as a value, and to see how they make sense of it and reflect on it after they have encountered other interpretations.

I think community to me has always been sort of a positive and an inclusive and I think it's only when you start talking about things like marginalised groups and belonging and things like that that you realise actually it can be as much as a negative sort of connotation to some people as it is a positive.

Study participant

Implement: We came across several examples of how people were doing work that addressed Ambition 6. Some of these were badged under compassionate community or community engagement. A core message across this work was that people should investigate what is already going on to avoid duplicating work or effort. Here we provide information about some of the examples and what they did. We also discuss the common barriers and facilitators that people discussed when it came to operationalising and realising Ambition 6.

Case studies

Citizen-led Community of Practice and Support Hub

Focused explicitly on building networks within the community, linking up existing groups and creating a practice of discussion and reflection. The aim was to develop local awareness about dying in a 'subtle, softly' way by providing places and spaces to commune. This enabled people to come together to share their experiences. People can access information about care funding, bereavement support, and other issues linked to the end of life. The behind-the-scenes development work for this began after the Ambitions were launched in 2015, developing a multi-stakeholder involvement group focused on end of life care which created a local strategy (over several years), informed by the Framework and with dedicated leads for each Ambition who could bid for local money for developments.

Working with identified community groups

These were deemed to be under-represented within specialist palliative care within the area, for example ethnic minority groups or people experiencing homelessness. The purpose was to engage with these communities to explore how they understand palliative and end of life care, provide death literacy sessions, and to improve trust between members of community groups and the palliative care services. This helped the professionals understand what was most important to people in these groups, including the variety of preferences, as well as reflect on how some of their practices needed to change to be more accessible. Other people mentioned similar areas of action which involved speaking with community groups to find out what they think about palliative care and begin a series of ongoing community engagement based on that starting point.

People shared a range of common barriers when they discussed what they do or had attempted to do. The main issue was that it could be assumed to be someone else's responsibility. Yet, when asked, people struggled to identify who this should be. Some wanted more community-oriented work at ICB level, adopting a community assets approach. People noted that there could be confusion about community engagement and community fundraising. This may lead to misunderstandings about roles and responsibilities. This could be within an organisation and in communications with external stakeholders. Additionally, there is a risk that individuals become 'the directory' for external links. Other common barriers included structural issues. For example, lack of resourcing for different types of activity (e.g. education) or disproportionate bureaucracy. Examples warned of a lack of technical support to enable communities. This could limit the use of the knowledge communities gain from working with palliative care. People discussed the practicalities of collaborative work. This included the lack of clarity of shared goals, lack of recognition of expertise, and unclear leadership. People question who to involve and how to do this. Participants noted a long period of time is required to build meaningful relationships or networks. Lastly, whilst people noted that there could be pockets of good work there could still be issues of access, sustainability, and scalability.

Participants noted many things that facilitated their work towards realising Ambition 6. People advocated for dedicated time and spaces for community groups to meet together (with or without professional services involved). They noted the need for funding for linking up and networking. Whilst networking may not appear immediately productive, people recommended that this could build and foster relationships. It can be a valuable source of information about what is already happening. Tapping into existing volunteer-based services was cited as a useful starting point. People suggested working with volunteers to enable ownership of community engagement. People spoke positively about examples that valued community-based expertise, spent time listening, and considered ownership. Ultimately, people sought to build trust.

More information

Find out more about this project from OU.



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5.3 Grab and Go Guide: Small Steps, Big Vision

Drawing on the learnings from our case studies, focus groups and workshops, we developed a two-page [Grab and Go Guide](#). The content and design of this was further refined after our two Evidence Cafés. The final version is included here.

We found a wide range of practices and confidence levels when it came to using the Framework, with many people not knowing where to start or how to progress. A focus on foundations enabled people to work towards multiple Ambitions. This is therefore reflected in our choice to focus on the foundations instead of the Ambitions in the guide. This focus on the foundations also reflects the statutory guidance released to ICBs. We added two elements – collaboration and sharing learning – to reflect strong themes from the research that people found invaluable to realising the Ambitions; these were each a theme of a workshop earlier in the study. These additions also help foreground actions that are important to realising Ambition 6, which is not readily identified by participants in the existing foundations.

For each foundation, the guide provides a what, ask, and action. This reflects our approach to understand, interpret, and implement. 'What' is about how the foundation is defined and understood, pointing to what all it can include. 'Ask' is a series of prompts – aimed at a wider, multi-perspective audience – to engage in reflection, identification, and discussion about what people know and do. The 'Action' included are examples drawn from the research. They are provided to illustrate a range of possible action; more examples can be found in the case studies (Section 4).

The intended audience for this guide is broad: from commissioners to front-line workers. This reflects the range of participants in the project. When we asked in Evidence Cafés if and how we should narrow the target audience, participants in a range of roles wanted to make use of or share the document. The Grab and Go Guide is created with a [CC-BY 4.0](#) license meaning that you can re-use and adapt it with attribution for your purposes.



Ambitions research

For more information on how people have understood, interpreted and implemented the Ambitions for Palliative and End of Life Care: a national framework for local action, visit the link below or scan the QR code for reports from the project, workshop slides, and where possible, data.



Visit open.ac.uk/projects

SMALL STEPS, BIG VISION

This is your Grab-and-Go Guide for the Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026 [↗](#)

The framework provides a vision and guidance around six ambitions and eight foundations to improve care. Launched in 2015, it is supported by [over 30 partners](#) and embedded in the [statutory guidance for ICBs](#) linked to the Health and Care Act 2022. Based on in-depth research conducted at The Open University, this guide focuses on the foundations necessary for realising the vision.

For each item, this guide provides: a description, prompts to get you thinking, and examples in action. You can use this guide for your own reflection, to facilitate team discussions, or in work with partners and across systems. We have added two areas to focus on (9&10) to promote collaborative and cross-sector working. This guide helps you to identify areas you can act on - a starting block to turn small steps into the big vision.

1. Personalised care planning

- **What:** Conversations between the person, those close to them and professionals that explore and document the management of their health and care, considering the context of their life, identity and background, as well as family situation. It can include advance care planning and recording of preferences.
- **Ask:** What types of care planning are we already doing? What might improve the quality of the conversations? How could we involve more people in care planning? How equitable and effective is care planning across our system?
- **Example in action:** Advance Care Planning (ACP) education programme across entire locality. Adaptations to ACP documents for people with learning disabilities and culturally sensitive language translations. [Universal Principles for Advance Care Planning](#).

2. Shared records

- **What:** The person and those who are caring for them can access records, such as care plans. It can include electronic systems to facilitate sharing across health and social care providers. It can refer to records created and shared by the person and those important to them.
- **Ask:** What information needs to be shared? How do we currently share information? What barriers do we currently have in accessing information within or across organisations? Does the person, or those important to them, have access to the records in a version that they understand?
- **Example in action:** Treatment escalation plans accessible across different services in an area. Linked up IT systems between acute and primary care using [Palliative and End of Life Care Information Standard](#).

3. Evidence and information

- **What:** The collection of data that can be used locally and nationally to understand service provision and evaluate interventions. It can include using and being involved in research.
- **Ask:** What routine data is being collected and how do we use it? Where are we currently using evidence to inform our actions? Are we collating and listening to a wide range of voices through feedback? Do I know how to make sense of the information I collect?
- **Example in action:** [National Audit of Care at End of Life](#) (NACEL) and local mortality data to inform action plan, including address inequities in access. The [Integrated Palliative Care Outcome Scale](#) (IPOS) for patient care.

4. Involving, supporting and caring for those important to the dying person

- **What:** Focusing on those around the dying person, such as family, friends and carers. It includes supporting them in their caring role, pre-bereavement and bereavement care. It involves understanding peoples' social context, cultural background and support networks, and how they want to be treated and respected.
- **Ask:** Have we mapped who is important to the (dying or bereaved) person and what resources/capacities they have to provide care or support? Does our language reflect how people talk about those important to them, including acknowledging their relationship? How are we working in partnership with people important to the dying person, carer and/or bereaved person? How do we support those who will be bereaved?

- **Example in action:** Befriending service for carers and bereaved. Bereavement Help Points for information. Using [NICE guidelines on supporting carers](#).

5. Education and training

- **What:** Education of staff and/or volunteers, ensuring they are competent in their knowledge about good end of life care and that this is maintained. It includes focusing on skills sets and quality assurance of training.
- **Ask:** What do people already know about end of life care? Are we making good use of free educational resources? How can we invest in and embed training across our system?
- **Example in action:** [National e-learning programme End of Life Care for All](#) (e-ELCA) with over 120 free online modules. End of Life Care Facilitator providing education across acute and community providers in an area, recording of who is trained. Palliative Care team using Ambitions Framework to structure education for all Trust staff.

6. 24/7 access

- **What:** System-wide access to end of life care support, including symptom management, at all hours and days of the week. This does not mean that each service must always be available, but that there is accessible and equitable coverage across a system/area to meet needs.
- **Ask:** Where would we direct someone out-of-hours? Who might need access to services out-of-hours and why? Are existing out-of-hour services accessible for all groups of people?
- **Example in action:** Hospice 24/7 helpline accessible to staff, individuals, and families. Use of [Ambitions self-assessment](#) to identify gaps in service provision.

7. Co-design

- **What:** Designing services in collaboration with people who have personal and professional experience of palliative and end of life care, including patients and carers. Methods of engagement can be creative, participatory, and experience-based. Co-design should embrace diverse views and not be limited to service provision commissioning decisions.
- **Ask:** What knowledge do I have about co-design? Who are we involving (individuals and organisations)? How do people want to be engaged with? Who is best placed to facilitate co-design processes? In what ways do we actively involve people in designing a service and making decisions about how we provide care? How are we learning from people's lived experiences, their support needs, and what care and support they access and want to access?
- **Example in action:** Project focusing on bereaved carers providing Trusts with insights on how to improve physical and support environments for end of life care and post-death experiences.

8. Leadership

- **What:** People and organisations who have the capacity and remit to identify what needs to happen, communicate visions, and motivate others to realise the Ambitions. Leadership is not limited to those with formal positions of authority.
- **Ask:** Who am I expecting to take this forward? In what ways can I instigate change? How can I support others to realise the Ambitions? What strategic leadership is needed for system-level changes?
- Example in action:** Trusts showcase their ongoing development of services when writing local reports and presentations, highlighting how using the Framework has helped them identify gaps and goals. Team Leaders include the framework in regular meetings, fostering working cultures that support the Ambitions. Development of compassionate leadership that supports staff wellbeing and resilience.

9. Collaboration and partnership working

- **What:** Working with others (within and beyond your organisation) on a common goal. Partnership may involve sharing resources and responsibilities.
- **Ask:** Who do we need to be working with? How knowledgeable are our potential partners with the Ambitions or end of life care? Have we discussed our expectations about roles and responsibilities? What barriers do we have to working together?
- **Example in action:** Hospice uses the Framework when working with partners to facilitate sharing goals and best practice under different themes, with dedicated time for networking and relationship building.

10. Sharing learning

- **What:** The process of exchanging information and insights with others with the intention of achieving a common objective or goal over time. It can involve acquiring new knowledge and skills as well as becoming part of a community.
- **Ask:** Where can I find out about what others are doing? How can I tell others about what my organisation does and lessons learned? In what ways do I reflect on what others have done and try it out in my own practice? Am I open to learning from people with different experiences, perspectives, and roles (including from non-professionals)? What is needed to facilitate more intentional learning in the environments I am part of?
- **Example in action:** Involvement in workshops and networking events, including sharing documents and case studies (e.g. FutureNHS). Feedback learning to one's own team through meetings and learning events.

Interested in knowing more? Link up with your local ICB or palliative care team. Your local contact is:

Footnote: This guide has been developed by Dr Erica Borgstrom, Claire Henry MBE, Dr Joanne Jordan and Dr Una St Ledger of Open Thanatology at The Open University. Marie Curie funded this research. For more information project findings and outputs, visit: <https://tinyurl.com/ambitionsframework>. For more resources about the Ambitions, check [FutureNHS](#). This guide does not replace statutory or [NICE guidelines](#).
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5.4 Answers to the research questions

1. How do people understand the Ambitions Framework?

Overall, people understand the Framework as outlining good end of life care and what services should strive for. For members of the public, they understood the Ambition statements more as what should be happening rather than aspirational. Professionals talked about the Framework as providing a shared language. Yet, participants had different understandings and interpretations about what aspects meant, especially when considering how to realise the Ambitions in practice. This variation is not linked to the participants' role, location, or previous experience; we observed variation across and within all data collection methods and participant groups. Ambition 6 (All communities are prepared to help) was focused on, to illustrate the variation in understanding and the impact this has on interpretations and action (see Section 5.2 for more detail).

In focus groups, we asked about the order of the Ambitions. Some people had no preference or did not think the order changed their understanding of the Framework. Others felt that Ambition 6 should be the first one listed. They thought other ambitions were more likely to naturally be progressed if Ambition 6 was prioritised. They noted that it may not be prioritised if listed last. Ambition 1 (Each person is seen as an individual) and Ambition 3 (Maximising Comfort and Wellbeing) were understood to be closely linked and requiring prioritisation.

2. What lessons can be learned from in-depth case studies of how people have interpreted and operationalised the Ambitions Framework?

Whilst people understand the Framework to be applicable

to all people and all settings, we heard mostly from those working in or with palliative care. When making sense of the Framework in relation to their own role, people predominantly spoke about it in terms of implementation (something that they need to do) rather than guiding principles.

People have been working towards all Ambitions. As with our previous mapping survey, we noticed that some Ambitions have been more readily addressed compared to others. Through our discussions with case studies, we found that when people focused on the foundations, rather than just the six ambition statements, that they felt more empowered. They were able to identify the possible levers for change. They noted that working on a foundation could impact multiple ambitions. Even so, people spoke predominately about the Ambitions, rather than the foundations or the Framework more generally. These six statements were an orienting point.

We saw three main approaches to operationalising the ambitions. Participants did not express a single or 'best' way for this.

Strategic: One approach was to adopt the Framework as the main way of organising services at strategic level. This could be from using it to structure strategy and communications, to explicitly citing it in business cases and aligning it to institutional values (e.g. aligning to NHS Trust values). Those who adopted this approach often found the self-assessment tool helpful and tended to focus on their work on a service-level; it was not uncommon for several projects to be developed as a result of this. In some instances, people and services were able to provide leadership in their local area and for this approach to be adopted by others within

the area. When thinking about the future landscape of care, this approach was the one that people hoped ICBs would adopt.

Statements rather than Framework: The second approach was similar to the first but tended to focus on specific Ambition statements rather than the entire framework (i.e. to avoid overwhelm) and typically focused on a specific service. This approach viewed implementation as more incremental, typically building on either existing 'good practice' and/or identified areas in need of improvement (e.g. from an inequality assessment or CQC report). Here people expressed interest, and in some cases involvement, in collaborative working across the system; this could be difficult due to weak ties, lack of resources, and/or perceived one-way communication. In some cases, the focus on a particular ambition resulted in generating new networks and partnerships, especially if this was deemed to sit largely outside of healthcare providers (i.e. community work).

Complimentary: The third approach was to be aware of the Framework but not draw on it heavily for strategic decision making or internal or partner communications. Whilst this approach appreciated the values and purpose of the Framework, it was viewed to predominately compliment service values rather than replace them; they also preferred the flexibility offered by orienting their services around business values rather than the Framework. Here the self-assessment tool was not necessarily helpful for generating action. People who adopted this approach, however, did still value hearing about other services and developments and being part of wider systems discussions about improvements across the sector.

3. What key insights, including identification of gaps, can be shared across contexts to further the implementation of the Ambitions Framework?

A recurring message arising from case studies was that it took time to operationalise the Ambitions. This involved taking time to understand what they meant for them locally. This included time to assess their current offering (either using the self-assessment tool or other means of benchmarking their service). Time to develop relationships with partners and time to secure funding was also required. Partnership and collaboration were deemed to be the most difficult to predict in terms of time required.

Numerous people reported that they experienced setbacks, lack of replies, and change of external personnel delaying progress. To address this, participants viewed tenacity and tapping into existing networks as key.

In various stages of the project, people talked about the self-assessment tool. For some, this was useful to do within a service to identify gaps. For others, it was useful to do across an area (ideally sharing the tool and what people submitted in the form of workshops). However, we found that people were unsure of how to measure progress beyond gap analysis. For example, people noted that there were often changes in measures or evaluation strategies, which made it difficult to do year-on-year assessments or to know what was 'best' for their context. People mentioned NACEL and sought to align things with this where possible to reduce duplication in workload. This also indicates that people value national direction and indicators that enable comparison; they look towards NHS England for generating and promoting these. Support for measuring and understanding progress, including sharing learning, can be provided by a range of actors, with Ambitions partner

organisations being perceived as well positioned for this.

Since the Health and Care Act (2022) people expected to see more system-level work within ICS and ICBs. At the time of data collection many of these were still in early development. People hoped to see links between the Framework and local developments. They wanted clearer systems-thinking to address the Ambitions and foundations. This is because many felt it was difficult for a single service to continuously address all of the Ambitions in any given geographical area. This is because many of the foundations required collaborative working across services.

4. What challenges and opportunities are there for transferring learning from select case studies?

One of the main challenges that consistently arose in the research was a tension between focusing on specific service development and a more systems-wide approach, often with leadership at a higher level supporting and driving development in end of life care. Where systems-level work was occurring, this was often building on previous networks and relied on key people retaining institutional memory and relationships. They also tended to have dedicated workload attributed to this type of working. It takes time to develop this way of working, which is not readily applicable to other areas, and hence why in some instances it may be pragmatic to focus on service-level development. We found that some case studies reported successfully developing a programme of work over years. To do this they prioritised a small number of changes or innovations at any one time.

In the project, we found that people who engaged with the research found the project group sessions useful. They valued networking, sharing

learning, and developing a deeper understanding about the Framework. In attending, people often expressed an expectation to hear details about a case study. In our observation of the dynamics, however, what people responded to most was talking with others. This enabled them to think through general issues or approaches, rather than a step-by-step overview. Very detailed examples could lead to responses where people thought that what occurred elsewhere was not applicable to their context. Or there was a perceived lack of information that would enable meaningful change. On occasion, people requested others share strategy documents or presentations with them directly or meeting up 1-1 for further discussions. People also valued hearing that others have found it difficult to implement aspects of the Framework. This was especially around difficulties with partnership working (within and beyond palliative care). Hearing this reassured them that their approaches were not necessarily wrong if they found it difficult to make progress with potential partners.

People noted the need for ongoing engagement with the Framework in order to successfully implement it. Where the Framework is embedded in local strategy and communications, there is implicit on-going learning and engagement with Framework. During the Evidence Cafés, people expressed a desire for more information about the Framework. They wanted easy to access information, prompts, and examples. People suggested an app that could incorporate the Framework, linked out to key documents, and help people connect. People noted FutureNHS and webinars as useful, but these may at times feel exclusive or not open to the public. This clinical focus is also reflected in that most of the case studies were driven by adult palliative and end of life care services. Therefore,

there are further opportunities for sharing learning across and beyond the sector, including in paediatric palliative care, social care, and with voluntary services.

Our focus on Ambition 6 showed the importance of attending to how people understand and interpret community. The ways in which people think about community influence what kinds of actions they think are possible. There is a difference between community engagement and education, and collaborative working involving communities.

Challenges:

Tension between focusing on local or specifics and need for systems approach

Takes time to create changes

Lack of detailed examples but also detailed examples can feel limiting to learn from

Opportunities:

Leadership driving systems-wide approach

Build on existing networks

Dedicate workload to realising the Ambitions

Develop a programme of changes over time

Facilitate sharing learning and networking

Talk about the difficulties

Embed the Framework in local strategy and communications

Share the Framework beyond palliative and end of life care services

Realise how interpretations of Ambitions impacts action, especially around community

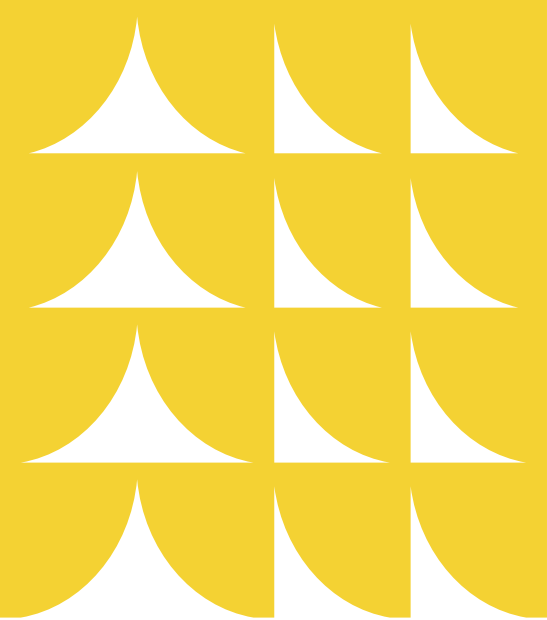


6. Discussion

This research examined how people understand, interpret and implement the Ambitions Framework. It incorporated a wide range of case studies to understanding the kinds of approaches that people have adopted. There is considerable variation in how people have sought to implement the Framework. Learning across them is, therefore, at a high-level rather than about detailed, evaluated processes. Attending to the case studies helps identify links between what people see as the problem, what interventions are undertaken, and what outcomes are.^[9]

People often see the problem as palliative and end of life care is not consistently being delivered at a good level to all people who need it. The Framework is seen as one intervention, by providing guidance on how to address aspects of care. From this though, people and organisations are tasked on deciding what further interventions to take. Across all stages of the project, participants acknowledged that this was a complex step. Some felt more confident in identifying gaps and actions or had more stability within their leadership and structures to enable action. The Framework encourages localism. As such, a variation in outcomes is expected and apparent. However, people were unsure if this variation could increase inequalities across the country. Additionally, services are not consistently measuring or evaluating interventions besides regular audits.

There are two main limitations of the study regarding the case studies. Firstly, we were mainly able to recruit case studies from individuals and organisations with palliative care as one of their primary interests. There is limited knowledge about how, for example, local authorities have implemented the Framework. Secondly, the consent procedure means we cannot identify case studies by name in this document. We appreciate that readers may want this level of detail. However, we wanted participants to feel that they could speak candidly and address challenges. This is often easier if they know that their account can be anonymised.



7. Recommendations

There are several key recommendations arising from the project. These have been distilled from lessons learned across all stages.

1. For the Framework to be adopted more outside of adult palliative care teams and hospices, more needs to be done to raise awareness and knowledge of the Framework in these other sectors. Participants viewed that Integrated Care Boards are well placed to facilitate this at a strategic level.
2. Focus on the foundations to drive action. The Grab and Go Guide (Small Steps, Big Vision) provides prompt questions and examples to help people to think about the kinds of actions they could take.
3. Collaboration and partnership working enables the Ambitions to be realised on a system-level. This takes time, resources, and relationship building. It requires understanding a range of perspectives, experiences, and knowledge. The Framework can provide structure for this, but one needs to check how others are understanding and interpreting the language.
4. Expand opportunities for sharing learning about the Framework and examples of practice. This could be within Ambition partners, in other spaces, and within teams.
5. When focusing on community, realise that how people understand the term impacts what they envision as possible and who they believe is responsible for realising Ambition 6. People seeking to implement Ambition 6 need support for reflection, information gathering, and relationship building.

We have not specified who is responsible for each recommendation, as several of the recommendations are relevant to policy makers, Ambition partners, commissioners, practitioners, and service settings. Participants identified Integrated Care Boards and End of Life Care Facilitators as key positions for realising the Ambitions and these recommendations. However, from the case studies we can see that people across levels and roles can have the agency to enact these recommendations.





8. Conclusion

This project sought to examine how people understand, interpret, and implement the Ambitions Framework. We identified a range of case studies from across sectors. Most had palliative care team or hospice input. Across the case studies, we found evidence of people working towards all Ambitions and embedded all eight foundations. The extent to which the Ambitions are realised in any one location varied. All case studies stated that more progress is needed. We developed a Grab and Go Guide (Small Steps, Big Vision) to translate insights from the project into a document. People can use this for reflection, discussion, and action-planning.

We found a range of confidence in using and implementing the Framework. Leadership and resources were defined by participants as key to drive implementation. How people interpret specific Ambitions impacts what actions they think are possible. For example, understanding community as something external to oneself or one's service can hinder action. Sharing learning and hearing about others' experiences, including challenges, expanded what people thought was possible.

Further work is needed to realise the Ambitions to their full potential. People expect that Integrated Care Boards will enable more action and increased partnership working. Additional research is warranted to understand the ongoing development and sharing of practical learning.

More information

Find out more about this project from OU.



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9. Acknowledgements

This project is about the use of the Ambitions for Palliative and End of Life Care: a national framework for location action published by the National Palliative and End of Life Care Partnership. The latest version for 2021–2026 was released in May 2021.

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This report is dedicated to Tony Bonser. Tony was involved in many palliative and end of life care projects and public engagement during his lifetime. His valuable contributions to this project helped shaped project design and interpretation of early findings. Tony died in December 2022.

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More information

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