AMBITIONS FOR PALLIATIVE AND END OF LIFE CARE

Mapping Examples of Use in Practice
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1. EXECUTIVE SUMMARY

The Ambitions for Palliative and End of Life Care: a national framework for local action was originally released in 2015 and relaunched in 2021 for an additional five years. Developed through partnership, the Framework provides a vision for action focused on six ambitions underpinned by eight foundations. This report shares findings from a project about how people have used the Framework in England. It involved mapping exercise based on a survey to identify examples of practice of how the Framework.

There are examples of services using the Framework across England. The majority of examples came from hospice and/or specialist palliative care settings. Each person is seen as an individual (Ambition 1) was most frequently identified as a primary focus for services. Each community is prepared to help (Ambition 6) was least frequently identified as a primary focus. The report includes case studies for each Ambition; they have not been evaluated as part of this project and are therefore not presented as examples of ‘best practice’.

The Framework is most frequently being used to provide guiding principles and to support education and training. Examples of use in local policy, commissioning and developing business cases were also identified. Survey respondents identified the Framework as having a role in enabling a process of service development from strategic conception to practical delivery, although there are persistent concerns about how ambitions can be meaningfully operationalised, measured, and resourced.

Overall, the Framework appears to be well received by survey respondents. It is perceived to provide a shared language about what matters in palliative and end of life care.

There is appetite for further education and knowledge exchange about the Framework and how people have used it. More work could be done to embed the use of the Framework in local strategies and partnership development, as well as supporting initiatives to realise Ambition 6.

Suggested next steps include further research; encouraging the use of the Framework at strategy and commissioning levels; additional education, training and knowledge exchange; and focusing on carers and communities. Further in-depth case study analysis and additional research will be conducted by the project team starting in April 2022. This will focus on how a range of stakeholders understand, interpret, and implement the Framework.
2. INTRODUCTION

The *Ambitions for Palliative and End of Life Care: a national framework for local action* was originally released in 2015 and relaunched in 2021 for an additional five years. Developed through partnership, the Framework provides a vision for action around six identified ambitions underpinned by eight foundations. These are outlined in the background section. To date, there has been no large-scale research to examine how the Framework has been implemented within service development and provision.

This report describes the first stage of a project conducted by researchers based at The Open University that examines how people have used the Framework. This stage focuses on the collection of summary-level information concerning how the Framework has been understood and used, including a mapping of examples of relevant local activity. As well as the provision of stand-alone evidence, this stage provides a basis for further research, which will bring together evidence from selected case studies of identified activity with data from focus groups, workshops and knowledge exchange events which explore views and experiences of the Framework across wider palliative and end of life health and social care to further its implementation and development.

Our objectives were to identify:

- where the Framework has been used (geographically and care settings)
- examples of how it has been used
- what ambitions are being addressed
- what foundations were identified as important
- what people thought the Framework enabled them to do
- what challenges people faced in using the Framework.

To address these objectives, we conducted an online survey, as well as reviewed relevant literature and existing information about the Framework. This report documents the findings and implications from this research focusing on the mapping of survey results.
3. BACKGROUND

The Framework was first launched in 2015 after being co-produced by 27 partners, which span health and social care, as well as third-party organisations. The Framework outlines a vision with six ambitions (summarised in the image below) seeking to improve how death, dying and bereavement are experienced and managed, which are underpinned by eight foundations, which are visualised on the next page.

Image provided by NHS England on behalf of the National Palliative and End of Life Care Partnership.

The Framework was relaunched in 2021 for another five years, with the partnership expanding to over 30 organisations. The Framework is the latest in the trajectory of palliative and end of life care policy in England. However, unlike the national End of Life Care Strategy (2008),¹ it is not mandatory and, to date, there has been no central regular evaluation of how the Framework and its ambitions have been understood or implemented. Instead, and in line with a localised approach, service providers can self-assess their provision against the ambitions and share examples of practice through professional peer groups. A 2019 survey on impact of the Framework indicated that organisations felt that the Ambitions Framework was well used, especially for developing local strategies, but that there were issues with implementation.²
In the published literature, we have identified three main ways in which the Framework is discussed. The references cited in this section are provided as exemplars, rather than comprehensively documenting all relevant literature.

Firstly, there are articles that promote the Framework, often in editorial format. Secondly, there are examples of where people have sought to articulate how they have been inspired by the Framework to enact service development and generate service improvements, or develop practice guidance. They illustrate how people have made explicit links between the Framework and their action (either in service design or direct patient/public interaction). The majority of these examples are located in the grey literature, with evidence of them being featured at professional conferences. The current limited volume, and varying forms, of this evidence base precludes a systematic review that might identify key lessons concerning the impact of the Framework to date, or the implications for future development.

The final realm of literature we identified provides a more critical analysis of how the Framework (loosely conceptualized as ‘policy’ or ‘guidance’ within these articles) can have meaningful impact. For example, existing interview-based research with Ambitions Partners demonstrates ‘several areas of concern’ as identified by policymakers. These include the understandability of the Framework and specific ambitions, the role of policymakers in implementation, as well as how localism (in terms of care provision and policy settings) may entrench inequalities. The evidence from this literature is consistent with literature concerning both end of life care policy, as well as healthcare policy implementation more generally, in terms of scope and how policy can be operationalised. The key questions raised throughout include how policy is implemented in practice, how one can understand or measure the impact of policy, and what (un)intended consequences there may be from the creation and use of policy.
4. METHODOLOGY

To address project objectives, we developed an online survey to map usages of the Framework. The survey comprised of a mixture of closed and open questions, utilising standardised descriptors (e.g. of geographical areas, care settings) in line with previous palliative and end of life care surveys. Alongside the nature of the work undertaken, survey questions sought information on: primary Ambition(s) guiding the work; how the Framework was understood to enable this work; and, perceived challenges to use of the Framework. Questions were tested against a set of webinar presentations from the Ambitions Partners monthly webinar series that highlights service examples. The entire survey was reviewed and pilot tested by our advisory group, which includes members of the public, academics, and health and social care professionals.

The survey was favourably reviewed by The Open University Human Research Ethics Committee (HREC/4162). It was open between 30th November 2021 and 31st January 2022 on the JISC online survey platform. Invitations to participate in the survey were circulated via email and social media; the invite was included in the NHS England National Palliative and End of Life Care Update newsletter of January 2022 (delayed due to focus on covid-critical activities from November onwards).

To minimise missing data and facilitate withdrawal of data, the platform only collected data from respondents who completed the survey (i.e., clicked ‘submit’). Pilot testing of the survey indicated that it took less than 15 minutes to complete. To aid quick completion of the survey, we did not ask for further details about co-design or evaluation; these can be followed up in future work.

Data for closed questions were analysed to understand frequency. Cross-tabulations were performed to understand the relationship between responses in pairs of closed questions. Answers to the question about policy context were coded by content to produce a quantitative overview. Other qualitative free-text comments were analysed by the lead author to identify recurring themes.
5. RESULTS OF THE MAPPING SURVEY

We received 45 full responses, describing services geographically distributed across England; for each region, between 6-9 examples of services were returned. Other areas of the UK were also represented, with examples received from Wales, Northern Ireland, Scotland, and the Isle of Man (Figure 1). Several services noted that they provided national coverage; these are captured under ‘other’. Most services were either NHS (73%) and/or charitably (57%) funded.

![Figure 1: Location of Service](image-url)
5.1 Settings

Respondents were invited to identify which setting their service related to, with the option of selecting more than one setting. A majority of examples were based in settings involving specialist palliative care and/or hospice care. The full range of options can be viewed in Figure 2.

We received examples of services from all settings listed, and some respondents further specified their settings as: telephone services, services provided in learning disability homes, tertiary centres, and community services or services based in people’s homes.

Approximately half of the examples indicated that multiple organisations were involved with the service. Where respondents selected more than one setting, it is evident that settings outside of specialist services are being supported by specialist palliative care.

Over 70% of respondents indicated that patients/services users/clients/public were involved in the design of the service, and a further 20% said they were unsure.

![Figure 2: Setting of Service](chart)

*could select more than one
5.2 Use of the Framework

We asked about how the Framework had been used to support service design and/or provision; respondents could select more than one option (Figure 3). Most frequently, it was used to provide guiding principles for the work undertaken, with its role in supporting education and training as well as quality improvement also regularly highlighted. In addition, in a significant number of examples, the Framework had been used in local policy, commissioning, and/or business cases.

Most services were established before 2015 (71%), which predates the first launch of the Framework. This suggests that those who responded to the survey are more likely to be using the Framework to be evaluating and revising existing services, rather than designing entirely new services. Most (95.6%) also answered ‘yes’ when asked if the service had been reviewed (e.g., via audit, feedback surveys, formal evaluation and/or research). The remaining responses represented ‘unsure’ and ‘not applicable’, rather than ‘no’. Nearly 50% of respondents said the Framework has been used to facilitate reviews, evaluations, and/or audits.
We asked respondents to identify which factors were needed to design and sustain the service examples that they were reporting on. The factors are aligned to the eight foundations outlined in the Framework. Respondents could select more than one factor. Figure 4 shows the relative importance of each of the foundations across all of the survey responses. The foundation about education and training was identified as important for over 93% of services. Co-design was the least frequent foundation cited; it was identified as important in just over 50% of examples. Overall, most foundations were reported to be needed to design and/or sustain services in 75% or more of all services.

![Figure 4: Foundations](image)

*could select more than one
**data scaled according to frequency

We received two ‘other’ items (not included in Figure 4 data visualisation); respondents noted the need for resources (including specific kinds of staff) and carers. The inclusion of ‘carers’ as an other category may suggest that the terminology about ‘those important to the dying person’ is not always immediately interpreted as including carers.
5.3 Wider Policy Context

To understand use of the Framework in a wider policy context, a free text box asked about other policy, guidance and frameworks supporting the design and/or delivery of services. Thirty-four responses were received, subsequently coded by content (Figure 5). The most frequently named item was NICE guidance, followed by One Chance to Get it Right (also identified as Five Priorities)\(^\text{13}\) and Care Quality Commission (CQC) frameworks and reports. Several other end of life care reports and the National End of Life Care Strategy are seen to have a legacy, with respondents noting their ongoing use. The ‘other’ category included 18 different items; each mentioned a single time. These included, but are not limited to, the Compassionate City/Civic Charter,\(^\text{14}\) The Lantern Model of Care,\(^\text{15}\) individual pieces of research or service user feedback, and AgeUK quality specifications.

**Figure 5: Other policy, guidance and frameworks**

*data coded from free text qualitative responses

- NICE guidance
- One Chance to Get it Right (Five Priorities)
- CQC Items
- Local policy or reports
- Our Commitment to you for End of Life Care
- Gold Standard Framework
- Other
6. FINDINGS FOR EACH AMBITION

This section is ordered according to the six ambitions. Alongside a summary of overall findings for each ambition, we provide a case example for each ambition to illustrate how they have been used to develop and/or support local level work. Examples have been selected according to the primary guiding ambition as identified by survey respondents, reflecting the geographical spread in England and variety of care settings in which such work has been undertaken. We have purposively selected examples that showcase services that address a broad understanding of palliative and end of life care and wide range of working. They have not been evaluated as part of this project and are therefore not presented as examples of ‘best practice’.

Image provided by NHS England on behalf of the National Palliative and End of Life Care Partnership.
Ambition 1: Each person is seen as an individual

Ambition 1 was most frequently identified as the primary ambition that best matches the service reported on (24 out of 45 examples). People most commonly reported using Ambition 1 to provide guiding principles, support quality improvement, and support education and training. In terms of the settings in which Ambition 1 was primarily used, the three most frequently cited were: specialist palliative care, educational/training settings, and hospice. In terms of the factors that were perceived as necessary to design and/or sustain a service where Ambition 1 was primarily used, the most frequently cited were: personalised care planning, education and training, and (equally) those important to the dying person as well as evidence and information. When used in combination with other ambitions, it was most frequently combined with Ambition 3, although all other ambitions were also represented.

Case example for Ambition 1: Children’s Hospice Setting – Acorns
A children’s hospice in the Midlands that was set up before 2015 provides inpatient and community care, supporting children and families. They have noted that the Framework provides a synergy between their organisational values and behaviours, which they can further build on, especially in enabling all staff to be prepared to care. They have recently completed a review of services and want to explore further how they can use the Framework to embed change.
Ambition 2: Each person gets fair access to care

Ambition 2 was identified as the primary ambition in three cases. In each case it was used differently, namely, as guiding principles, to support quality improvement, and (equally, in combination) as a tool for review and to support education and training. In terms of the settings in which Ambition 2 was primarily used, the most frequently cited was hospice care, with other settings (primary care, secondary care, care homes, specialist palliative care, domiciliary care, education and training providers, and community organisation) being equally represented. Examples citing Ambition 2 as their primary ambition therefore tended to highlight services that worked across or with different settings and partners. In terms of the factors that were perceived as necessary to design and/or sustain a service where Ambition 2 was primarily used, the most frequently (equally) cited were: personalised care planning, shared records, education and training, and co-design. When used in combination with other ambitions, all were equally represented.

Case example for Ambition 2: Integrated Care System (ICS) - Nottinghamshire
An integrated care system has used the Framework to understand the current delivery of palliative and end of life care across the whole of a geographical area. They undertook a self-assessment using the Framework to inform the ICS strategy; they have found the self-assessment tool beneficial for service development. They identified that they are currently working in partnership with a wide range of providers, commissioning and directing primary, secondary, and third sector services in the area. They co-design and evaluate services. The Framework is used for guiding principles, in commissioning processes and local policy, for service design and quality improvement, and for education and training. A challenge has been to gain agreement to underpin services against the Framework rather than a locally developed agenda.
Ambition 3: Maximising comfort and wellbeing

Ambition 3 was the second most frequently cited primary ambition, with 12 service examples provided. The three most frequent ways people have used the Framework in services focusing on Ambition 3 were guiding principles, quality improvement, and service design. When identified as the primary ambition, for Ambition 3 the most frequently cited settings were: specialist palliative care, hospice, and then equally across care homes, education and training providers, and community organisations. We did not have any examples of it being used in pharmacy or housing. The three most frequently cited factors needed to design or sustain a service listing Ambition 3 as their primary ambition were: shared records, education and training, and leadership. For respondents that identified Ambition 3 as the primary ambition for the service, they also noted that it Ambitions 1, 2, and 4 were also applicable to a higher degree than Ambitions 5 and 6. This represents a picture of services potentially being organised around principles of person-centred care.

Case example for Ambition 3: Befriending
AgeUK in Worcestershire provide a specialist befriending service. It was set up in 2020, in the context of the COVID-19 pandemic to support those caring for family at end of life and those bereaved. It offers older people friendship and regular contact. The service is partnered with local hospices. They have used the Framework to provide them with guiding principles and values. Compared to other case examples for Ambition 3 that focused predominately on the dying person and total pain management, this case exemplifies a broader understanding of who can benefit from comfort and support.
Ambition 4: Care is coordinated

Respondents provided three examples that list Ambition 4 as the primary ambition. The most frequent ways people have used the Framework in services focusing on Ambition 4 were as a tool for review, and then equally as guiding principles, business case, to identify partner organisation, and for education/training. When identified as the primary ambition, for Ambition 4 the most frequently cited settings were: primary care, and then equally across secondary care, care homes, social care, and specialist palliative care. We did not have any examples of it being used in community hospitals, housing, or mental health. Whilst there was a low number of responses for this Ambition, this highlighted gap may mean that coordination of care may not be reaching these other areas of service/care as consistently.

The most frequently cited factors needed to design or sustain a service listing Ambition 4 as their primary ambition were: evidence and information, leadership, and then (equally) personalised care planning, those important to the dying person, and co-design. It was most frequently combined with Ambition 1, although all other Ambitions were also represented across examples which had listed Ambition 4 as their primary Ambition.

Case example for Ambition 4: North Tyneside Clinical Commissioning Group
A Clinical Commissioning Group in the North East work in partnership across primary care, community services, secondary care, social care, out of hours, ambulance services and with patient representatives. They commission palliative care services and have used the Framework to co-develop an end of life development group. The Framework has provided clarity and a structure to design services, using the headings in the document. Co-development has been key to enabling ownership by different partners, and the language in the Framework is viewed to be ‘vague’ enough that they can adapt it to local needs.
Ambition 5: All staff are prepared to care

Respondents provided two examples that used Ambition 5 as the primary ambition for the service example. The three most frequent ways people have used the Framework in services focusing on Ambition 5 were guiding principles, quality improvement, and education/training. When identified as the primary ambition, for Ambition 5 the three most frequently cited settings were: secondary care, education and training providers, and then (equally) across primary care, social care, care homes, hospice, community hospitals, and specialist palliative care. We did not have any examples of it being used in ambulance, pharmacy, voluntary sector, housing, mental health, prisons, domiciliary care, and community organisation. The most frequently cited factors needed to design or sustain a service listing Ambition 5 as their primary ambition were: education and training, and then equally, personalised care planning, shared records, evidence and information, those important to the dying person, 24/7 care, and leadership. Co-design was not mentioned as a factor that was needed. For respondents who identified Ambition 5 as the primary ambition for the service, all of the other ambitions were equally represented when asked what else was applicable to the service except Ambition 6. There were no examples that had Ambition 5 as their primary Ambition that also considered Ambition 6 relevant. This may mean there is a gap in how people consider the potential for Ambition 5 and Ambition 6 to be interconnected. This may be partially explained by the low number of examples received for both Ambition 5 and Ambition 6.

Case study for Ambition 5: End of Life Care Facilitator providing hospital education
A hospice employee leads commissioned teaching sessions within an acute hospital in Plymouth via an honorary contract. These sessions are aimed at newly qualified staff, such as nurses as part of their induction, and for apprentices; staff educated also includes doctors, medical students, support staff, and managers. Bespoke training is provided to wards to refresh and update their knowledge and the facilitator has partnerships with specific departments (such as oncology). Dying Matters Awareness week events are held within the hospital and there is a monthly drop-in for patients, staff, and public to learn about advance care planning and to provide supportive literature.
Ambition 6: Each community is prepared to help

Only one example was provided that listed Ambition 6 as the primary ambition for the service example. The most frequent (equality weighted) ways people have used the Framework in services focusing on Ambition 6 were guiding principles, cite in local policy, identify partner organisations, and education/training. When identified as the primary ambition, for Ambition 6, all setting examples were equally selected, and included: primary care, voluntary, mental health, education and training provider, and community organisation. We did not have any examples of it being used in: secondary care, social care, care home, community hospitals, ambulance, hospice, pharmacy, housing, specialist palliative care, prisons, or domiciliary care. The most frequently cited factors (equally cited) that were needed to design or sustain a service listing Ambition 6 as their primary ambition were: personalised care planning, evidence and information, those important to the dying person, education and training, co-design and leadership. Both shared records and 24/7 care were not listed as factors.

For the one example that listed Ambition 6 as its primary Ambition, Ambition 1 and 3 were also cited as applicable (which are person-centred). The gap of other ambitions here is more likely due to low response rate rather than indicative of other ambitions not being considered relevant for community-oriented service examples. In total, 25 examples listed Ambition 6 as either a primary or secondary ambition. Additionally, it should be noted that whilst not many examples were provided for Ambition 6 as a primary ambition, the qualitative data across several questions indicated that people were considering and working with it in terms of compassionate communities. The qualitative data indicates that respondents viewed it as strategically significant that community approaches were included in the Framework.

Case study for Ambition 6: Citizen-led Community of Practice in East of England
Growing out of a social support hub, the Community of Practice spans a 20-mile area that is frequently subjected to being ‘in-between’ other services. Funding is provided by the local clinical commissioning group to support a compassionate communities initiative. The aims of the project have been to connect local assets that could support people and families experiencing long-term or terminal illness and generate a culture where people could take an active role in supporting others. This has been shaped by the Community of Practice members according to their perceived strengths. Members included people from education, funeral industry, voluntary sector, churches, local charities, local councils, art sectors, volunteers, and people undergoing cancer treatment. The project has worked with an academic at the local university to help design and evaluate the service. It has used the Compassionate City Charter\textsuperscript{14} as a template but rebranded it as a civic charter.
7. WHAT PEOPLE SAID

The survey included several open questions discussed in detail below. All quotes have been anonymised and participant IDs are included to demonstrate that quotes have been used from a range of participants.

7.1 What the Framework has enabled

We asked respondents to tell us what the Framework had enabled them to do that they may not otherwise have done. Across all 41 responses received, we identified seven main themes, which capture perceived benefits of the Framework. In summary, these are:

• provides and legitimises end of life care values
• raises awareness of particular issues
• enables communication through provision of shared and inclusive language
• facilitates partnership working, including service users and information sharing
• enables the identification of priorities for service and strategy development
• facilitates the measurement of progress
• enables access to funding.

The Framework was considered to provide a “guiding vision and principles” (ID:729) which legitimatises or justifies particular approaches to palliative and end of life care such as, for example, communities being prepared to care (Ambition 6). Such statements were viewed as an explicit endorsement by NHS England of an underpinning set of values to inform local level activity. Additionally, the Framework was seen as being important for raising awareness about the “need and importance” (ID:149) of palliative and end of life care, especially for “raising the profile and complexity” (ID: 678) of its wide role and multiple levels and settings of provision.

Several respondents emphasised how the Framework has “facilitated more focused and inclusive conversations” (ID: 858) by providing a “shared language” (ID:149). This shared language was considered to facilitate partnership working across the wider palliative and end of life care system, as illustrated in the following statement: “The Framework is a very useful guide we use when talking to commissioners / funders / the public about how care for people and their families can be improved.” (ID:934). Several different ways in which a shared language supported partnership working were described, such as, for example, in
Of all identified themes, that concerning the role of the Framework in enabling a process of service development from strategic conception to practical delivery was most frequently articulated. Several examples of this process were described, including use of the Framework to (re)develop local strategies, set the agenda for operational meetings, identify areas for development, and question service design. Some respondents noted their use of the Self-Assessment Tool to facilitate this process. More specifically, the Framework was described as a “benchmark” (ID:371) and to provide a “baseline to measure progress against” (ID: 229). In this regard, several respondents highlighted the Framework’s role in consolidating the perceived value of service evaluation, with one claiming that it has “brought audit and review into everyday practice” (ID:024) and another that “it has enabled me to give a very clear account as to what good looks like within the organization [sic]” (ID: 477). Lastly, a few respondents noted that they have been able to use the Framework to secure additional funding for new or widening service provision.

“IT HAS ENABLED ME TO GIVE A VERY CLEAR ACCOUNT AS TO WHAT GOOD LOOKS LIKE WITHIN THE ORGANIZATION”

Of note, the themes outlined above were not mutually exclusive, so that, for example, respondents could write about the importance of the values legitimated through the Framework being useful for the development of partnership working, which was further facilitated through the Framework’s provision of a shared language in which service developments could be grounded. Moreover, whilst Ambitions 6 (about communities) was identified least frequently as a primary guiding ambition, in open text comments it was this Ambition that was commonly explicitly endorsed, often being linked to the notion of compassionate communities.

Lastly, one respondent noted that the Framework has not enabled them to do anything differently, describing the ambitions as “fairly obvious and uncontroversial” (ID: 653).
7.2 How others could use the Framework

We asked respondents how they think others could use the Framework and related documentation. Of the 32 who responded, a majority reflected on how they had used it themselves. From these responses, the following themes were identified:

• mapping gaps/self-assessment/audit
• benchmarking and quality improvement
• enhanced data collection
• framing education/professional development
• business case development
• service design and delivery plans
• policy documents
• dissemination to local care settings and providers.

Many of the responses resonate with the themes identified in the previous section, such as the provision of a shared language. Of note, respondents recognised that the Framework supports what is captured in the National Audit of Care at the End of Life. Some respondents highlighted a need for enhanced promotion and use of the Framework in training and other strategic service development/review contexts, including regular operational meetings, suggesting that not everyone is aware either of the Framework, or its importance. Relatedly, in noting that they have used the Framework multiple times, one respondent cautioned against change in order not to undermine the Framework’s current value. Additionally, others noted potential tensions between the overall NHS England approach to palliative and end of life care and that of compassionate communities, but that the Framework can still be meaningfully used in local policy development.
7.3 General comments about the Framework

Towards the end of the survey, respondents were offered the opportunity to share further thoughts about the Framework. Within the 26 responses received, the Framework was regularly endorsed, and frequent statements made concerning use of the Framework in multiple different ways. The responses to this question are useful for further research, implementation, and policy work. From the responses, the following themes were identified:

• possible future development of the Framework
• operationalising the ambitions
• audience/Reach of the Framework.

Suggested areas for future development of the Framework included: a possible change of name since “Ambitions implies possibly not achievable” (ID:933). This respondent suggested that such a change would also help make explicit that the content of the Framework should be seen as a requirement rather than an idealised version of what should happen. Another respondent highlighted a need to be open to the possibility of change to the Framework, noting that a reluctance to do so could stifle sustainable innovation. Several respondents suggested that more work could be done to use the Framework at both a national and local level to drive funding and other resources, including a national steer to Integrated Care Systems. Others expressed a hope that the Framework (or updated version) will be used past 2023, indicating a desire for stability.

“AMBITIONS IMPLIES POSSIBLY NOT ACHIEVABLE”

The general comments indicate that the Framework is viewed positively: setting out clear priorities and providing a structure to review services. However, a recurrent theme raised was how these priorities can be operationalised. Relevant detail was felt to be lacking. Further, whilst some respondents considered that the Framework was helpful for aligning operational objectives, it did not help them to address barriers to equitable care. Continuing difficulties in coordinating care, particularly in under-resourced contexts, were also highlighted. More broadly, some respondents noted that it can be “daunting” to operationalise the Framework alongside other policy and organisational documents, so that, where possible, it should be explicitly aligned with other regulatory activity, such as Care Quality Commission inspections. Suggestions were provided for how operationalisation could be improved included providing more case examples, shared learning, and networking opportunities.

Finally, to address concerns that people who work outside palliative and end of life care are insufficiently aware of the Framework, respondents suggested the creation of scaled down, more “user friendly” versions, targeted at those who are non-specialists in the field.
8. DISCUSSION

The survey generated a range of evidence concerning use of the Framework across England, which provides valuable summary level insight into current and past work, and understandings of the Framework, including how it might be further developed to aid implementation. Relevant work was described for a range of care settings, with that undertaken in specialist palliative care and hospice settings predominating. This may be expected due to the focus of the survey and professional population likely to engage with the Framework. However, our findings are encouraging in that they suggest that the Framework is being seen as relevant to service commissioning and development across wider palliative and end of life care, and the potential for uptake in social care, domiciliary care, ambulance, prisons, and pharmacy, as well as community organisations.

Ambition 1 (Each person is seen as an individual) was the most frequent focus of attention by survey respondents, followed by Ambition 3 (Maximising comfort and wellbeing). Both ambitions reflect a wider, and longer-standing, discourse in palliative and end of life care about holistic, person-centred care. Since many of the service examples described in the survey were started prior to the publication of the Framework in 2015, it may be that, to some extent at least, the Framework is being used to legitimise ongoing work, providing a national framework in which to contextualise this work. It may also indicate that the respondents have found limited scope to develop new services due to resource pressures, and instead are adapting existing services.

Further research would enhance understanding of the extent and nature of the impact of the Framework on service development commenced post 2015, particularly in the context of the COVID-19 pandemic and beyond, and the sustainability of this.

Using the foundations listed in the Framework, respondents were asked about those required to develop and sustain their service. Of those identified, ‘Education and training’ was the most frequently cited (identified in 93% of cases). Qualitative data from the survey indicates that education and training should be ongoing to improve (and maintain) quality of care. This also includes education which secures widespread awareness and understanding of the Framework. Our findings suggest the value of considering the education and training needs of different groups of stakeholders across the entire spectrum of care and within communities. Such consideration could encompass, for example, how needs may differ, how they might be addressed, and how stakeholders can be empowered to provide ongoing education and training, including making use of existing materials. Whilst this foundation is identified in the Framework as fundamental to all ambitions, it is particularly pertinent for
Ambition 5 (All staff are prepared to care) and Ambition 6 (Each community is prepared to help) given the knowledge and skills required to meet these ambitions in practice.

The role of those important to the dying person, such as carers, was identified by 75% of respondents as important in the design and/or sustainability of their service. Due to the nature of the survey details in how this is envisioned and works in practice is not available at this point. Service examples tended to focus predominately on the dying person, although some respondents described their provision of carer and/or bereavement support. Discussions within the advisory group about the data and case studies indicated concerns that when using the Framework, service designers/providers/commissioners may be relying on informal carers without adequately supporting them. There is potential to enhance this element of the Framework within a broader prioritisation of its underlying mission, particularly given the known importance of carers in the provision of end of life care, and the impact of their experiences on longer-term health and social outcomes, including grief.

Respondents repeatedly identified a key enabler of their service development activity to be the language provided by the Framework. A shared language was thought to enable conversations across sectors, with partners, and with the public. That said, the term ‘ambitions’ was, on occasions, critiqued for its potential to imply that any work undertaken may strive, but never be able, to achieve, its guiding ambition(s). Whilst this critique was offered by only a few respondents, it parallels other comments made more frequently concerning the difficulty of operationalising the six ambitions and being able to use them in a way that translates into identifying and measuring progress. The Framework therefore appears to function primarily at the level of guiding principles and values, including those of appraising current service provision, rather than providing explicit targets or benchmarks that might underpin such appraisal. Additionally, respondents regularly noted that the Framework did not provide what they considered to be meaningful guidance on how to significantly reduce barriers to accessing palliative and end of life care. Given these issues, further development of the Framework that might bridge the gap between values and action is suggested, particularly around operationalisation of the ambitions, and evaluation of the work in which they are involved.

The self-assessment tool (which is not part of the Framework document but designed based on it) had been used by several respondents, with some finding it very useful for gap analysis and encouraging the use of the tool more broadly. Respondents had either used the tool individually, or in groups as a shared activity. Examples of how the self-assessment tool has been used included: assessing individual service against the six ambitions, assessing a
range of services (e.g. commissioning area), devising individual action plans for lead end of life care staff, and providing a structure to group discussion and co-design. Qualitative data from the survey and discussions with our advisory group, however, indicate that even when self-assessment is undertaken, issues may remain around suitable resourcing to develop or adapt services to meaningfully address any identified shortfalls in provision. It should be noted that most service examples in the survey received funding through the NHS and/or charity, where budgets may be limited and/or unpredictable. There could be further support for people on how to use the self-assessment tool to identify gaps and develop business cases based on this assessment.

The theme of co-design and co-production is strong within the Framework, with co-design featuring as a foundation for the ambitions and co-production being the acknowledged method through which the Framework was developed. By its very nature, co-design encompasses a broad and growing landscape of activity and often the terms, as well as co-creation and collaboration, are used interchangeably.19,20 Over 70% of respondents said that patients/services users/clients and/or the public were involved in the design of the service. Yet, just over half of respondents (53%) cited co-design as required to design or sustain their service; this was the least frequently cited foundation out of the eight listed in the Framework. It was also not a frequent topic in the qualitative data. Our findings suggest that the ethos of co-design and co-production has not necessarily carried over into service development and delivery of the examples submitted. Given this diversity and the potential confusion and lack of confidence these concepts may engender, should the Ambitions Partners wish co-design to be fundamental to the enactment of the Framework, the wide range of stakeholders potentially involved in palliative and end of life health and social care service provision need to know what it means, how it can be undertaken, and what it can achieve. There is, therefore, scope for policy and implementation work around ensuring that relevant knowledge, understanding, and skill development in co-design are supported.

Perceived limitations in awareness of the Framework suggests a need for improved availability of and access to the document, as well as enhanced referencing and explicit signposting to the Framework throughout a potentially broad range of national and local policy-related documents. The current issues around accessing the document (behind a login or found via several Partner websites) may mean that it is less readily available to non-NHS organisation or potential new partners, especially when people are seeking to develop local partnerships. There is scope to develop supporting materials for a range of audiences which describes what the Framework is, why it matters, and how it can be used, including to improve services and experiences. This could include but need not be limited to short videos, workshops, dedicated information sessions with community organisations, social media posts, and publications in range of outlets drawing on the reach of the Ambitions Partners.
Our findings indicate considerable scope and appetite for enhanced sharing of practice and mutual learning. Approximately 20% of respondents reported using the Framework to draw on specific examples, and/or to identify partner organisations. It is important to note that people use the list of the Ambitions Partners to know who has a vested interest and commitment to working on improving care in this field. Developing more knowledge exchange and partnerships was also a theme in the qualitative data with people both willing to share their experiences and keen to learn from others. The ability to use the Framework to learn how others have operationalised the six ambitions, to foster partnerships and to support commissioning are all particularly pertinent in the context of the ongoing development of Integrated Care Systems.

Given concerns about accessibility of the Framework and reaching audiences outside of the NHS, there is scope to develop networking and shared learning spaces outside of NHS and Department of Health systems. Since most examples came from hospice or specialist palliative care settings, there is also the opportunity to foster this knowledge exchange in other settings and/or for it to be seen to be led by those that are not specialising in palliative care but nevertheless invested in the ambitions.

Overall, the findings from this project indicate that the Framework is being used across England. Whilst it is predominately reported to be used in specialist settings, there is scope for the Framework to be used in a wider range of services and settings given its relevance. Education and training are a strong theme throughout the data, which requires both ongoing support, potential for further knowledge exchange activities, and increased accessibility to the Framework. The Framework is seen to support service design through its shared language and related self-assessment tool. There is a gap in terms of how useful people find the Framework in terms of helping them understand how to operationalise, measure, and resource high quality end of life care to all in line with the ambitions. The ethos of co-design and co-production has not necessarily carried over into service development and delivery of the examples submitted. Whilst Ambition 6 received the fewest number of examples citing it as a primary focus, the topic of compassionate communities was positively reported on. In conclusion, there are several opportunities and potential strategies for improving the use and implementation of the Framework which could foster knowledge exchange and partnerships.
9. SUGGESTED NEXT STEPS

At a broad level, survey findings offer a valuable steer for further work to understand more fully the issues raised, as well as the policy and implementation work that might help to address these issues.

The use and adoption of the Framework could be improved by several suggested next steps. We advise the that commissioners and local policymakers are encouraged to cite and use the Framework to underpin local service design and delivery, including attending to how the foundations listed in the Framework are being met or implemented. The self-assessment tool may be useful for this activity. However, some further investigation may be beneficial to understand how people are using it to inform how to support others in using it as well as the links between self-assessment and resource allocation. Focusing on this level of commissioning and design could help bridge the gap between values and action, including in areas to reduce health inequalities.

Education, training, and knowledge exchange were recurrent themes in the analysis. Ideas on how to address these areas are in the discussion, including improving access to the document, creating public-facing/non-specialist materials, education about co-design, and providing more opportunities for service providers to learn from each other in how they have used the Framework. There is potential to build on the noted positives of the Framework – such as language and partnership approach – to facilitate these activities.

There are two areas based on the data that the Ambitions Partners could focus on to improve how values could be further realised. One is about how to involve and support those important to the dying person, often thought of as carers although this term may not always be appropriate. This includes not only recognising their potential role as a partner in care delivery but also their needs and experiences in their own right, and their involvement in co-design. There could be more research and engagement work to understand what this can look like, especially considering diversity and inequality in access to care.

More could be done to support initiatives that focus on communities being prepared to help (Ambition 6). For example, links between Ambition 5 (all staff are prepared to...
care) and Ambition 6 could be further explored. Staff live and work in communities and can play vital roles in formal and informal community leadership. Encouraging a connection between these two ambitions could support partnership development, community education, and foster compassionate community activities. Overall, a stronger focus to support greater community engagement while continuing to drive existing well performing ambitions.

ENCOURAGING A CONNECTION BETWEEN AMBITION 5 AND AMBITION 6 COULD SUPPORT PARTNERSHIP DEVELOPMENT, COMMUNITY EDUCATION, AND FOSTER COMPASSIONATE COMMUNITIES

In terms of research, as a team, we are about to start a second phase of this project (funded by Marie Curie). This phase will involve in-depth interviews focused on up to 20 case studies identified through the survey, including services established since 2020. The project will also involve new data collection to garner in-depth knowledge concerning how people understand, interpret, and implement the Framework. Part of this work will include knowledge exchange events and report dissemination. This phase is for 12 months beginning April 1st, 2022. There is potential for additional research beyond this project, such as to focus on specific ambitions and education.
10. ACKNOWLEDGEMENTS

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This research and report were produced by Dr Erica Borgstrom, Dr Joanne Jordan and Claire Henry MBE (OU honorary fellow) from The Open University. They are members of Open Thanatology, The Open University’s interdisciplinary research group that promotes the study and education of death, dying, loss and grief across the life course. To learn more about Open Thanatology, visit https://wels.open.ac.uk/research/areas/open-thanatology or follow on Twitter @openthanatology.

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11. REFERENCES

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