HospiceUK

Extending Frailty Care

Learnings from Hospice UK's **Extending Frailty Care Programme** on developing new care models for older people living with frailty towards the end of their lives.

Acknowledgements

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We would also like to take a moment to remember Sarah Kent (St Christopher's Hospice), who joined us briefly towards the end of the programme. We were deeply saddened to hear of her untimely death and are grateful for the time she spent with us, and for the contribution she made during her short time with the group. We continue to extend our condolences to her colleagues, friends and family.

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HospiceUK

About Hospice UK

Hospice care eases the physical and emotional pain of death and dying. Letting people focus on living, right until the end. But too many people miss out on this essential care. Hospice UK fights for hospice care for all who need it, for now and forever.

We represent the community of more than 200 hospices across the UK. They do everything they can for children and adults living with long-term illnesses or approaching the end of their lives. We do everything we can to support hospices' invaluable work.

Contents

Foreword

It is a cause for celebration that most people will live and die in older age. However, older people are often underserved at end of life. Undertreated in relation to palliative care needs and over treated with interventions that prolong quantity, but not quality of life. People with frailty exemplify the experience of 'ordinary' dying in older age, living with progressive complex care needs across a continuum, with points of intensive need followed by periods of stability. This ordinary dying, the experience for most of us – requires a radical shift in our understanding and response to end of life care. Hospice UK, with the support of the Kirby Laing Foundation took up this challenge.

Hospice UK's Extending Frailty Programme is a vanguard initiative – spearheading the much-needed change required to enable palliative care for all. The programme mobilises the strengths of the hospice movement: helping people to live and die well, in partnership with the person, their loved ones and other services and communities. Innovation is a cornerstone of hospice culture, shaping responses to wrap care around the person and those that matter to them, in the spaces that most people want to live and die 'at home'. Each of the hospice-led projects within this programme took such an approach – using skills and relationships already available to them, in innovative ways to create change.

The 11 projects featured in this programme provide evidence, resources and exemplars for others to utilise and build on. The projects focus on revaluing living and dying rather than an over-emphasis on care in the final days of life, creating different partnerships and integrating palliative care into other social and health care provision. This report is both an encouragement and a clarion call – to the hospice sector and beyond. To integrate and transcend current ways of service provision and ensure all end of life care is age-attuned.

The end of life experience for those we love stays with us – and shapes ourselves and our society. Those who die in older age are as important and worthy of the best support and end of life care we can give, as any other phase of life. The work of the Extending Frailty Care Programme recognises and enables such support. This is a timely publication – the challenge to us all is to reflect, act and be part of the change...

Caroline Nicholson
Professor of Palliative Care and Ageing, University of Surrey

Introduction

The Extending Frailty Care Programme, supported by the generous funding of the Kirby Laing Foundation, brought together 11 hospices from April 2022 to March 2025 to explore innovative approaches to improving care for older people living with frailty, as they approach the end of life.

Through this programme, Hospice UK aimed to create a culture shift in the approach to supporting people with advancing frailty (age 65+) with palliative care needs, resulting in improved quality of life for, and extended reach to, this underserved population.

This report provides a summary of the programme's impact, our learnings, and recommendations for the future.

How we define frailty

Frailty is a distinctive health state related to the ageing process, in which multiple body systems gradually lose their in-built reserves[1] to the point where they are vulnerable to a stressful event that can lead to rapid decline and end of life.

Around 10 per cent of people aged over 65 years have frailty, rising to up to a half of those aged over 85[2].

The growth in the number of people living with frailty is in large part a result of medical advances in improving the management of illnesses that previously would have shortened peoples' lives. The number of people with more than one condition (including dementia) living into older age is increasing year on year[3].

With the rapid rise in the number of people living into their eighth decade and beyond, a whole new set of challenges need to be addressed on how best to support such a population not only to manage their particular illnesses, but to live well.

Terminology: From Advanced to Advancing Frailty:

The original aim of the programme focused on people with advanced frailty, typically reflecting a Clinical Frailty Scale (CFS) score of 6 or higher. However, it quickly became apparent that this terminology presented a practical challenge: many people with advanced frailty were largely housebound, making it difficult to get to them through community-based interventions. In some areas, if a person was seen leaving their home, it was occasionally interpreted as a sign that they no longer required district nursing support, for example – raising concerns about continuity of care.

This highlighted a broader and more complex issue: how to engage with, and support, those living with frailty who are unable to leave their homes. While vitally important, this challenge fell outside the scope and resourcing of the programme. As a result, the decision was made to shift the focus toward advancing frailty – a term better aligned with the programme reach, feasibility, and potential for impact.

Targeting people earlier in their frailty journey (with lower CFS scores) allowed for more accessible engagement, particularly through community-based activities and peer-to-peer messaging. This approach also recognised the evolving nature of frailty, ensuring that interventions remained relevant as individuals' needs increased over time. Encouragingly, as the programme progressed, engagement with people experiencing more advanced frailty grew naturally, reflecting both increased awareness and adaptive learning across participating sites.

The need for this project

Frailty is a leading cause of death in older people[4], and the number of people living and dying with frailty is expected to rise[5].

People with frailty are vulnerable to sudden deterioration due to change (illness, infection, social circumstances, medication) and often will not return to their previous level of independence[6, 7].

Frailty also increases the risk of adverse outcomes, including falls, delirium, disability and mortality.[8, 9, 10]

Older people with frailty typically require integrated services because their needs span both health and social care. This includes palliative care to improve quality of life and address any discomfort, symptoms and concerns. Currently older people with frailty do not receive this care routinely because palliative care services often focus only on people with dominating single diseases like cancer[11]. Also, because dying in people with frailty may be slow and unpredictable, its beginnings may pass un-recognised[12].

Many people with frailty want their care to be in their home environment. They have similar palliative care needs to people with cancer[13] and, when asked, tend to prioritise quality over length of life[14]. However, management of frailty can be sub-optimal leading to missed intervention opportunities and additional healthcare costs[15]. Living well with frailty – and dying well when the time comes – requires care that is connected, respectful, and shaped around what matters most to the individual.

About the Extending Frailty Care Programme

The hospice sector already has a rich and valuable knowledge of interventions that can ameliorate the experience of frailty, such as Holistic Needs Assessments, medication reviews, exercise programmes, and social events to provide connections and reduce loneliness. Therefore, our focus was on applying and sharing this knowledge more consistently, to change the way frailty care is delivered in practice. One of the aims of the programme was to test new care models in the communities where people with frailty are living, necessitating collaboration with relevant partner organisations.

The proposal included using our established regional hospice and palliative care networks, the collaborative learning and support methods of Project ECHO[16] and the latest expertise in UK clinical frailty management, to create, evaluate and disseminate a portfolio of new service models in care delivery for older people with frailty. By adopting a translational approach — applying established methods for developing and embedding new models of care in local contexts — we aimed to improve the lives of people living with frailty.

The programme design

The programme was structured into three phases over a period of 36 months, with specific aims and activities:

- **Phase one:** Engaging sector experts in co-creation of frailty-attuned care models – months 0 to 12
- **Phase two:** Testing new frailty care models with hospice partners – months 13 to 30
- **Phase three:** Evaluating findings and sharing knowledge – months 30 to 36

The inputs, outputs and outcomes of the programme are shown in the logic model in **figure 1**.

The timeframes were later revised to shorten phase one to six months and extend phase two for testing with hospice partners to 24 months. This change was possible because knowledge about effective interventions had developed rapidly in the two years since the original proposal, enabling us to shorten the 'scoping' phase with academics and service improvement experts – the Expert Reference Group (the ERG) – and allow more time for hospice partners to test and evaluate the identified service models.

Figure 1. Extending Frailty Care Programme Logic Model

Programme Aim: To create a culture shift in the approach to supporting people with advancing frailty (age 65+) with palliative care needs, resulting in improved quality of life for, and extended reach to, this underserved population.

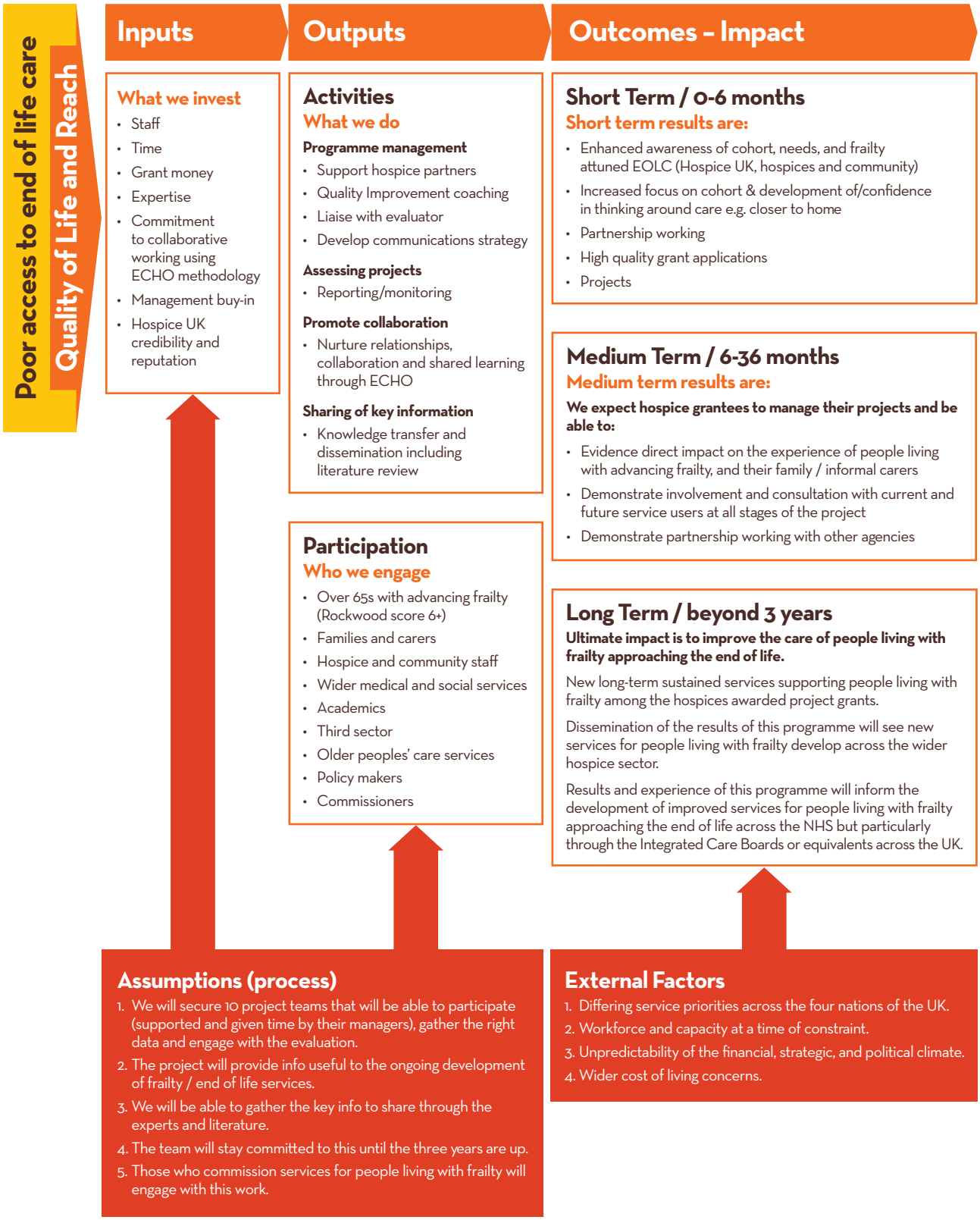


Figure 2. Programme Timeline

Phase 1: Set-up Apr 22 to Sep 22

Expert Reference Group ECHO network meetings

Hospice UK Programme Manager appointed.

Evaluation consultant appointed.

Expert Reference Group (ERG) assembled to inform our approach.

Thematic analysis undertaken to distill 10 models of frailty-attuned care for hospices to test.

Phase 2: Implementation Oct 22 to Sep 24

Hospice grantee partners ECHO network meetings

Grant-funded 11 hospices to deliver projects testing the 10 models of frailty-attuned care.

11 project leads recruited, visited and coached/supported by Hospice UK Programme Manager.

Monthly ECHO meetings delivering peer to peer support, QI learning and external insight from experts in the field.

Quarterly meetings with external evaluator.

Phase 3: Share Oct 24 to Mar 25

Sector-wide Frailty Care ECHO/Community of Practice

Findings presented at Hospice UK National Conference.

Abstracts from the 11 projects published in BMJ.

Relaunched ECHO network as sector-wide Community of Practice to share learning.

Web resources updated for other hospices.

Programme evaluation completed.

Future

Sector-wide Frailty Care ECHO/Community of Practice

Seek new ways to build on what we have learned.

As a result, the revised programme ran as follows:

Phase one: months 0 to 6:
Co-creation of frailty-attuned care models

- Establishing a Steering Group to oversee governance of the programme.
- Engaging a dedicated Programme Manager to support participating hospice partners, drive the project forward and ensure data and finances were processed in a proper and timely way.
- Appointing an evaluation consultant and devising the Evaluation Framework.
- Engaging a multidisciplinary ERG, including individuals from academia, geriatric and palliative care, general practice, commissioning, and care settings such as hospices and care homes across the four nations, to provide insight and guidance on identifying frailty-attuned care models for testing.
- Developing a suite of resources to support participating hospices to test the new care models.

Phase two: months 6 to 30:
Testing new frailty care models with hospice partners

- Defining the grant allocation criteria and launching a call for grant applications.
- Selecting 10 hospices and/or community palliative care providers to form a Frailty Community of Practice and test the new models of care identified in phase one.
- Holding Frailty ECHO Network sessions to share learning and development in real time between participating hospice partners.
- Upskilling participating hospice partner staff in Quality Improvement (QI) methodology, to ensure the new care models are implemented effectively.
- Providing additional support for participating hospices via site visits, online coaching and Progress Sharing days for hospice partners to present and discuss their progress with each other.

Phase three: months 30 to 36:
Evaluating findings and sharing knowledge

- Compiling and sharing learnings with recommendations for the wider sector.
- Refining and updating Hospice UK's frailty resources with learnings from the project evaluation, so these can be used and shared by all hospices and providers across the UK, including care homes and NHS partners.
- Sharing programme learnings via traditional academic dissemination including journals, abstracts at Hospice UK's National Conference, and with other relevant organisations around the UK.

The evaluation approach

An independent evaluation consultancy, Whole Systems Partnership (WSP), was appointed during phase one of the programme. The programme Evaluation Framework, developed in collaboration with WSP, was implemented in phase two. WSP met with the selected hospices after each set of data submission was completed, and evaluation and data collection were ongoing throughout the project.

The aim of the Evaluation Framework was to answer the following question:

What models of care will enable a culture shift in the approach to supporting people with advancing frailty (65+) who have palliative care needs, resulting in improved quality of life for, and extended reach to, this underserved population?

Each of the selected hospices operated in their own context and were therefore not directly comparable with one another, however, a set of evaluation questions was applied irrespective of context to determine the following:

- Success or otherwise of extending reach into the cohort of those with advancing frailty in the local catchment area.
- The extent to which new and more collaborative approaches to such service delivery is improved.
- The extent to which there is increased awareness in hospices of care models to support older people living with advancing frailty.
- Success or otherwise of peer support networks to support workforce in providing appropriate frailty-attuned care models.
- How emerging knowledge is translated and implemented in each locality and beyond to enable and enhance knowledge transfer.

Before selecting pilot sites, Hospice UK worked with the ERG to identify a range of frailty-attuned care models, resulting in the selection of ten models for potential testing. This formed part of the criteria for selecting the grantee partners.

The ten frailty-attuned models of care identified for testing:

Identification and management of frailty for patients who have palliative care needs and/or are approaching end of life regardless of level of complexity.

New models of working, such as establishment of virtual wards or new information sharing strategies so that patient data flows between hospice; hospital; community; care homes, voluntary sector and social networks including family members.

Upskilling of staff to support caring for people with frailty such as training hospice and domiciliary/residential care staff around difficult conversations and the management of slow decline in the context of frailty.

Working in partnership across health care settings, to support people, both before and after a crisis, to avoid unwarranted hospital admission or other place changes due to an underlying, unaddressed palliative care concern.

Improving the patient and service users journey to make navigating the health and social care system easier, by reducing the number of 'touch points' or creating contact models such as single point of access.

Enhance palliative rehabilitation and strengths-based approaches.

Mitigating risk by working in partnership with patients and service users, for example by considering in advance interventions such as de-prescribing and/or environmental factors such as those related to falls.

Support for people with advancing frailty **who are reluctant to engage** with palliative care.

Working in partnership with volunteers in a **Compassionate Communities** approach to develop frailty awareness which will support people with advancing frailty in their personal environments and communities.

Working in partnership with **domiciliary and residential services** providing end of life care, such as a 24-hour response service for patients approaching a phase of clinical transition or unpredicted or rapid deterioration that requires medical intervention.

Saint Michael's Hospice in North Yorkshire created a new Care Connector role responsible for delivering personalised care to people in their homes. For up to a period of 12 weeks, the Care Connector conducted one-on-one visits and regular 'check in' phone calls.

They helped patients to:

- set individual goals
- engage with social groups
- arrange meal deliveries
- connect with wider services depending on their needs (such as NHS, adult social care and voluntary services).

At the end of the 12-week programme, patients reported feeling empowered to manage their symptoms more effectively at home. Working with the Care Connector also helped them feel able to discuss Advance Care Plans with loved ones.

The Hospice UK Grants team administered grants to 11 hospice partners to test the new frailty care models. We envisaged that there would be enough high quality grant applications from our 209 member hospices to ensure that the programme would be evaluated across different socioeconomic, urban, rural and ethnically diverse settings.

Although the programme was open to hospices in all four nations of the UK, unfortunately none from Northern Ireland or Wales met the selection criteria on this occasion.

The 11 hospice-led projects focused on a mixture of preventative and rehabilitative support for people with advancing frailty as well as opportunities to have conversations that often led to the completion of an Advance Care Plan (ACP).

The projects, all of which included an element of partnership working by design, are listed in Figure 3 (see page 13).

Figure 3. Hospice partner projects

Organisation	Region	Project	Activities	Care model tested
ellenor	Gravesend	Care home rehabilitation	An outreach programme of seated exercise classes in care homes to improve strength and mobility and reduce falls among frail patients	Enhance palliative rehabilitation
Highland Hospice	Inverness, Scotland	24/7 helpline, education in care homes	Frailty in Care Homes 24/7 clinical helpline with remote ECHO education support in the Highlands of Scotland	Working in partnership to reduce avoidable admissions
Isabel Hospice	Welwyn Garden City	Compassionate Communities	Addressing Frailty: a Community Development approach to living well with frailty, through collaboration and coordination of hospice care and local services	Working in a Compassionate Communities approach
Prospect Hospice	Swindon	Virtual ward	Establishing person-centred proactive patient centred decision-making working in collaboration with the Swindon community virtual ward	Improving patient and service user journey
Saint Michael's Hospice	Harrogate	Care coordinator/ pathway streaming	Frailty Care Connector: providing personalised support for people living with advancing frailty	New models of working
St Barnabas Hospices	Worthing	Rehabilitation and patient journey	Rehabilitative palliative care to identify and provide proactive planning, care and support to older people living with frailty	Enhance palliative rehabilitation
St Catherine's Hospice	Crawley	Outreach/ education	Supporting older people at risk of advancing frailty to live well: A collaboration between St Catherine's Hospice and Leith Hill GP Practice	Identification and management of people with frailty
St Christopher's Hospice	London	Residential care home, education and family support	The Connections project: Living and dying well with frailty	Working in partnership with domiciliary and residential services
St Clare West Essex Hospice	Hastingwood	Domiciliary care	New Frailty Lead role, to provide education, training and support to domiciliary care workers supporting people living with advancing frailty at end of life	Working in partnership with domiciliary and residential services
Strathcarron Hospice	Denny, Scotland	Prisons	Identifying and Supporting Frail People in Prisons: introducing frailty screening and management to support the ageing prison population	Identification and management of people with frailty
Trinity Hospice and Palliative Care Services	Blackpool	Community pathway/ partnership	Blackpool Extended Community Frailty Partnership / Specialised Frailty Nurse	Working in partnership to reduce avoidable admissions

The project leads at each participating hospice benefitted from calls with WSP, who acted as a 'critical friend', highlighting progress and learnings that would be of interest to others across the sector. Often these discussions revealed that the project leads had underestimated and underreported their successes.

The Programme Manager also held 1:1 coaching calls with the hospice partners to reflect on challenges such as recruitment or resources, and on the QI process, paying particular attention to measurement, impact, and planning routes through any difficulties.

To improve communication and facilitate data sharing, a Microsoft Teams channel was also created.

The hospices universally selected to use – although not always exclusively – the nine-point Rockwood Clinical Frailty Scale[17] (CFS) to assess people's level of frailty, where a score of five or above indicates that the person is living with frailty that requires some assistance. All participating hospices reported working with individuals who had Rockwood Clinical Frailty Scale scores of 4 and above, with a significant proportion falling within the moderately frail range (scores of 5 or 6).

All projects had to amend their approach to the levels of frailty according to the Rockwood scores, because the model they were delivering was too challenging for people with severe frailty. This was an unintended consequence of the design of the programme, as the goal to work more in the community meant that the support offered by the pilot sites was geared to people who were more able.

"Having the Palliative Care Helpline (PCH) available to Scottish Ambulance Service clinicians when attending care home residents is invaluable as they are able to provide professional-to-professional support, especially in the out-of-hours period when other support is difficult to access. With this support, the clinicians are able to provide person-centred care and direct the patient and care home to the most appropriate care in the right place."

Highland Hospice, Palliative Care Helpline (PCH) Project

"On returning for the second session, a carer with responsibility for assessing care packages shared that she had received a referral for someone discharged from hospital that stated they had a Rockwood Frailty score of 7. She was proud to be able to recognise this and fully understand the person's level of need and felt empowered to discuss this with the family and demonstrate their level of knowledge and competence, thus reassuring them."

St Clare Hospice, Domiciliary Care Project

The programme results

The programme achieved its overall aims, with frailty now more central to hospice work. For many of the hospice partners, the projects have become 'business as usual'.

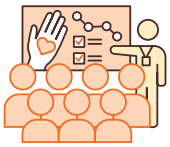
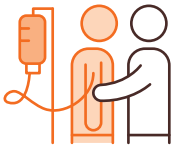
Case studies provided by the project leads from participating hospices, highlighted the following themes:

- Increased feelings of wellbeing among individuals
- Greater awareness of support available beyond the walls of the hospice building
- Care home staff feeling the right support was given and coordinated well for the benefit of the resident
- Improved general recognition of frailty leading to better coordinated care for patients
- Carers benefited from training and were better equipped to help their loved one
- Enhanced ACPs for patients

The service models

As part of the grant application process, hospice partners were asked to align their projects with one of the proposed frailty care models. However, as the work progressed, each hospice's learning and impact extended well beyond the initial model outlined in their funding proposal. Many of the hospice partners evidenced impact across several of the frailty care models by the end of the programme (see Figure 4). This was likely due to evolutions in their thinking brought on by peer-to-peer support provided during the programme, facilitated by the flexibility of the QI methodology that underpinned it.

Figure 4. Impact of hospice partner projects across the frailty attuned-care models

Frailty care models	Projects with high impact	Projects with medium impact
 Identification and management of people with frailty	6	3
 New models of working (e.g. virtual wards)	5	5
 Upskilling of staff (e.g. in domiciliary or residential care)	7	1
 Working in partnership to reduce avoidable admissions	0	2
 Improving patient and service user journey	2	2
 Enhance palliative rehabilitation	4	3
 Mitigating risk (e.g. falls prevention)	3	4
 Support for people with advancing frailty who are reluctant to engage	4	1
 Working in a Compassionate Communities approach	6	0
 Working in partnership with domiciliary and residential services	6	1

The hospice-led projects

The external evaluator found that across the projects, reach into local populations varied from 1% to 20% of the estimated number of people with potential to benefit. This highlights both the scale of unmet need and the potential for greater reach over time – particularly with sustained funding, more flexible implementation periods, and systems better attuned to supporting this work.

The projects demonstrated benefits across a range of needs and settings:

▶ St Barnabas Hospice

Integrated frailty care[18] into its usual services through the 'Living Well' Programme. The programme is now a regular offering, with increased staff awareness improving the identification of frailty.

▶ St Catherine's Hospice

Developed a five-week programme[19] to help people with frailty manage their health and plan for future care, while connecting them with local support services. They partnered with their local Primary Care Network (PCN) to ensure its sustainability, and now their project lead offers consultancy and frailty education to other PCNs, as well as groups like Age UK East Grinstead and My Care Matters.

▶ St Christopher's Hospice

Adapted its approach to working with care homes[20], increasing care planning and medication reviews, which greatly benefited frail individuals. This project prompted a review of the relationship between bereavement and frailty.

▶ St Clare Hospice

Provided training to domiciliary carers[21], enabling them to spot early signs of frailty and initiate crucial end-of-life care discussions. They developed strong relationships with local care providers and established a training package that will continue to be provided in the future.

▶ ellenor

Focused on seated exercise programmes[22] for care home residents, improving their wellbeing and satisfaction with care. They are looking to expand these programmes and offer training to care home staff to reach more people.

▶ Highland Hospice

Set up a helpline for care homes[23], preventing unnecessary hospital admissions for frail individuals. Strong partnerships with care homes and the Scottish Ambulance Service were key to the project's success. They plan to expand the service, focusing on professional clinical decision-making for potential hospital admissions.

▶ Isabel Hospice

Fully integrated frailty care into its regular services alongside its 'Living Well' programme, leading to a cultural shift where frailty is assessed for all patients. They used alternative wording such as 'Ageing Well' to improve engagement and are now expanding the programme[24].

▶ Saint Michael's Hospice

Focused on empowering people with frailty to live fuller lives with the support of a Frailty Care Connector[25] who providing personalised support for people living with advancing frailty. Participants reported feeling supported and empowered. The hospice is exploring ways to continue this valuable work.

▶ Prospect Hospice

Integrated frailty care into its virtual ward system[26], identifying and supporting people with frailty in need of palliative care. This approach proved highly effective in managing frailty and reaching individuals new to hospice care.

▶ Strathcarron Hospice

Developed a multidisciplinary team to support frail people living in prison, transforming care plans and coordination. Education across different levels in the prison made a significant impact, and they are considering rolling out this model to other prisons in Scotland.

▶ Trinity Hospice

Built partnerships[27] with care homes and healthcare providers, using Quality Improvement (QI) methodology and electronic care planning tools to improve frailty care. This approach streamlined care coordination and allowed the hospice to secure funding for further expansion.

Strathcarron Hospice in Scotland developed a project to help care for individuals affected by frailty in a men's prison[28, 29]. Working in the prison, the hospice:

- selected a specific screening tool (the Edmonton Frail Scale[30]) to help identify frailty among the prison population
- developed a prison-specific needs assessment tool to assess the holistic needs of people identified as moderately or severely frail.

They established forums and focus groups with NHS healthcare staff, carers from social care agencies and peer carers (fellow prisoners trained to support those living with frailty). This approach ensured that all stakeholders contributed to an individual's care delivery. Attendees reported having improved their knowledge, confidence and skills in managing patients with frailty.

Strathcarron's work in the prison has also led to:

- a monthly speech and language frailty clinic being set up in the prison
- easier access to palliative care medication
- motion sensors and night lights being purchased to help those who were falling overnight.

Partnership working

Despite experiencing time and resource pressures, partner organisations selected by hospice project teams were generally enthusiastic and ready to engage. Community partners including GPs, care homes, and other health partners such as Integrated Care Boards (ICBs), found the work to be valuable according to WSP's evaluation, and as a result have developed stronger relationships with the hospices.

Care providers, in both residential and homecare settings, also reported better relationships with hospices, as well as improved health and wellbeing for their service users.

Interestingly, non-hospice partners were more positive about the extent to which partnership working had improved through the programme, compared to the hospice teams themselves, although both groups saw benefits. This suggests an unacknowledged appreciation and need for the services provided by hospices.

Advancing professional development and upskilling of the sector

The programme significantly strengthened the skills of project leads, equipping them with a robust foundation in QI, leadership and change management. Throughout the duration of the programme, clear increases were observed in participants' confidence and competence in stakeholder engagement, planning and evaluation. The project leads developed effective communication skills, including delivering compelling elevator pitches – and gained valuable insights into key organisational functions such as finance, communications and recruitment. Crucially, they also learned how to effectively embed change by involving their wider teams through inclusive communication and the practical application of QI methods.

For many project leads, this was their first experience of structured education using ECHO methodology or preparing written abstracts for publication. All of them subsequently presented their work at the Hospice UK National Conference – either on the main stage or as part of a well-received workshop event – further building their confidence as authors and agents of change.

> ***"I've met some absolute rockstars of the hospice world during this project... The insightful knowledge that they have shared with us – you can't put a cost on that."***
>
> *Andy Lowden, ellenor Project Lead*

This sense of connection and inspiration was echoed across the programme, contributing not only to individual development but to a strengthened professional community, motivated to lead change.

Importantly, this professional growth extended beyond immediate project teams. Project leads actively applied and shared their new learning

externally, supporting the upskilling of colleagues across the wider sector. An example of this ripple effect is evident in the data gathered to illustrate the experience of domiciliary care staff working in partnership with St Clare Hospice.

Domiciliary Carers and St Clare Hospice: Training delivered through this project resulted in a measurable increase in knowledge and confidence among domiciliary carers. Reported knowledge of frailty rose substantially, from an average baseline of 6.5/10 to 9/10. Furthermore, 83% of carers stated they would definitely change their practice following the training. Feedback from participants was highly positive, including comments such as: "Will be able to identify frailty a lot better and manage clients with it", "Better awareness of recognising frailty and where to go for help", and "Using knowledge gained in advising service users as to what is available."

This case study clearly illustrates the broader impact of the programme: it not only enhanced the skills and confidence of project leads but also created a beneficial cascade of knowledge transfer to front-line carers. The tangible benefits for patients and carers, staff morale, and overall quality of care underscore the significant value of this programme.

The ECHO sessions and Community of Practice

Over the course of the programme, a total of 20 ECHO online learning sessions were successfully completed, providing stimulating discussions, new ideas and problem solving among the 11 hospice partners, and then latterly to a broader network of professionals. These sessions fostered the growth in confidence and authority of the participants. They were recorded for those who had registered but were unable to attend live, or who just wanted to watch them back. Notably, attendance was consistently high, fostering a strong sense of team spirit and psychological safety. This environment, underpinned by the quality improvement methodology, enabled open challenge and reflection, particularly through the use of real-time case study presentations to explore emerging challenges; this was reinforced by a committed and enthusiastic Programme Manager, whose curiosity and strong belief in the Extending Frailty Care Programme inspired and sustained the group.

The ECHO meetings, as well as face-to-face meetings such as the two Progress Sharing days with the hospice project leads, created opportunities for mutual support between the hospice partners. The creation of a Microsoft Teams channel proved helpful in facilitating confidential data sharing between individual hospice teams, the evaluator, and Hospice UK. It also enabled broader peer-to-peer

exchange around the challenges of the work. However, as the platform was introduced part way through the programme, it caused some initial frustration due to the learning curve involved.

Some sites went above and beyond the expectations of the programme by visiting one another to share learning and observe different approaches in practice. While this was not a formal requirement, the fact that these visits took place – despite widespread staffing and time constraints – was a testament to the commitment and enthusiasm of those involved.

Data gathered through feedback about the ECHO meetings themselves was positive. Project leads valued the opportunity to connect, reflect and learn from one another. Several requested that the sessions be extended from 90 to 120 minutes to allow more time for discussion, so this change was made. Although feedback was occasionally described as "mixed," evaluations throughout the programme consistently indicated strong engagement and appreciation for the sessions. Some of the variation may have stemmed from the staggered entry of teams into the programme, which created a natural diversity in learning needs and familiarity with QI approaches. While the iterative nature of QI was initially unfamiliar to some, the material was intentionally delivered in manageable segments to support those new to the methodology. Over time, the emerging masterclass-style delivery of the QI co-facilitated with a colleague from University College London, was especially well received, and played a key role in building confidence and capability across the hospice partner teams and on reflection, this approach may have been more helpful earlier in the programme.

Programme governance

The Steering Group meetings were effective at bringing careful governance to the programme, particularly in terms of funder requirements, site engagement and risk factors.

The inclusion of the ERG led by Professor Max Watson and Professor Caroline Nicholson added wider perspectives and expertise to the programme. Its input to the grant criteria helped to shape and clarify the type of project applications the Hospice UK team was hoping to attract, and the ERG continued to provide valuable feedback.

Programme challenges

As with any ambitious, system-wide improvement initiative, the programme encountered a number of challenges that offer valuable insights for future delivery and support:

Need for more realistic goal setting

Many participating hospices were engaging in this type of frailty-focused quality improvement work for the first time. In some cases, initial grant applications reflected optimistic projections around the number of patients that could be reached, and the scale and pace of engagement with external partners. The realities of delivering complex change within stretched and under-resourced services – many facing wider system pressures – meant that some projects needed to recalibrate expectations over time.

Workforce delays to project initiation

Recruitment challenges – already a significant issue across the sector – led to delays in project initiation and affected timelines for delivering training, embedding new ways of working, and achieving planned outcomes. In some cases, staff leading the work were simultaneously building confidence in QI or project management skills, often while managing competing clinical or leadership responsibilities or navigating staff reorganisations and cuts. Despite these constraints, all 11 projects were ultimately completed. This was supported by flexible programme management, tailored one-to-one coaching, site-visits, and adaptive approaches taken by project teams, who remained committed to improving care for people living with advancing frailty.

There were delays linked to organisational change and staff turnover. Where key individuals left during the set-up phase, continuity was at risk – yet teams worked hard to maintain momentum and share knowledge internally.

Financial processes and grant management

While external financial pressures were a factor, the programme also revealed specific internal challenges around processes and capacity. Hospice project leads were sometimes unfamiliar with accurately costing backfill arrangements or aligning internal financial procedures with the programme's funding requirements. In at least one hospice, pay adjustments to align with Agenda for Change had

not been included in the original bid, requiring the finance team to address the shortfall.

Some projects struggled to engage patients quickly enough to meet the programme's schedule for documentation and claims submissions; additional support was needed to ensure finance teams submitted documentation in formats or timeframes that differed from usual internal processes.

These challenges often reflected the wider pressures hospices are under, as well as unfamiliarity of this type of grant-funded improvement work for many teams. Regular reminders and targeted support from the Hospice UK team helped ensure all projects remained on track, but this experience highlights the importance of clear, early guidance and capacity-building around financial administration in future programmes.

Partnership-building

Engagement with external stakeholders and partners – essential for achieving integrated models of care – often took longer to establish than anticipated. Building trust and shared understanding across different services is a time-intensive process, and future programmes would benefit from longer lead-in periods to support relationship-building. Interestingly though, the evaluation demonstrated that external stakeholders valued the work even more than the hospices themselves.

Reaching people

Some hospices found that working with people at the most severe end of the frailty spectrum (Rockwood 7+) was more complex than anticipated – in fact, impossible within the time limits of the programme. As a result, most projects focused their interventions on people living with moderate frailty (Rockwood 4 to 6), where earlier support could be offered and sustained, aiming then to achieve a cascade effect that would reach people with more advanced frailty. A valuable insight from the Isabel Hospice project lead highlighted how a person's Rockwood score can shift dramatically – from 4 to 7, for example – after just one fall. This underscores the importance of engaging people with moderate frailty earlier as a key part of the hospice offer. The programme team remained cognisant throughout that people with Rockwood scores of 7 and 8 also require attention and renewed focus.

Processes and reporting

Lastly, while many teams appreciated the value of structured improvement approaches, the complexity of some programme tools and reporting requirements occasionally created an administrative burden. Some teams felt that elements such as the logic model and data spreadsheets could have been more user-friendly or streamlined for ease of use in practice.

The programme outputs

To date, learning from the programme has been shared at a number of conferences and through publications, with continued efforts underway to reach broader audiences and extend the impact.

Hospice UK National Conference 2024

All project leads from the 11 participating hospices responded to the call for papers for Hospice UK's annual National Conference, held in November 2024 in Glasgow. Abstracts from all projects were selected; 10 for the poster exhibition and one for an oral presentation.

The National Conference included two sessions focused on the Extending Frailty Care programme. The first featured presentations by Professor Caroline Nicholson, a leading authority on frailty and palliative care from the University of Surrey, Peter Lacey from WSP, two hospice teams, and the Hospice UK Programme Manager. The session was streamed online and covered the context and urgency of the programme at this time, the key details of the programme set-up, the findings of the independent evaluators, and most importantly gave two of the eleven hospice teams the opportunity to present their work in granular detail. It led to an interactive Q&A session about the successes and challenges of the programme and a firm call to action to build on this work within the broader hospice sector.

The second session was an interactive workshop and panel discussion, during which project leads from the 11 participating hospices shared their experiences of implementing QI initiatives to test the new approaches. Hospice UK collaborated again with a colleague from University College London Hospitals to run this session, and we were delighted by participation from colleagues at the Care Quality Commission, who expressed interest in working with Hospice UK on future improvement initiatives.

Publications and events

All 11 abstracts selected for Hospice UK's National Conference were published by BMJ Supportive & Palliative Care[31], enabling learnings from the programme to reach a global audience.

Furthermore, the Programme Manager has collaborated with other subject matter experts to contribute to a new chapter on frailty care for a revised edition of a textbook, due for publication next year. Notably, this will be the first time that the reference text will feature a dedicated section on frailty and as such marks a significant step forward in recognising its importance within palliative care. This contribution will support the wider dissemination of best practice and help promote more consistent, compassionate care for people living with frailty across the healthcare system.

The Programme Manager also co-authored an article for the Nursing Times on the subject of recognising dying[32], which can be especially difficult in older people with frailty, and had the opportunity to promote public understanding of terminal lucidity and end of life experiences through a **BBC Radio 4 interview with Emily Knight**[33], which helped raise awareness and educate the public on some of the complexities of the dying process.

Hospice UK has actively engaged with a range of conferences to share learning from the programme, using these platforms to connect with stakeholders and advocate for improved care practices.

The Programme Manager contributed to this by presenting at selected events, and promoting the work through networking and informal engagement at others – including the Rennie Grove Peace Hospice Online Conference, the British Geriatrics Society Conference at Olympia, the St Francis Hospice Ethics Conference, the Nightingale Hammerson Care Homes Conference, and Saint Christopher's Hospice Conferences in October 2024 and February 2025. This work continues with, for example, plans to spotlight the work at the National Clinical Hospice Leaders' Conference and at an upcoming All-Ireland Institute of Hospice and Palliative Care meeting.

Web resources

Findings from the individual hospice sites and from WSP's evaluation report were collected to produce a series of **web resources** that were published on Hospice UK's website in March 2025.

These resources highlight how hospices and the wider sector can deliver frailty-attuned models of care in practice.

Additionally a short film, titled **'Brian's Story'**, was filmed at Isabel Hospice in Welwyn Garden City and published on Hospice UK's website. The film aims to raise public awareness and highlight the importance of frailty care, while directing viewers to support resources that offer information about how hospices can provide frailty care.

The programme learnings and recommendations

The Extending Frailty Care Programme has demonstrated that it is possible to deliver meaningful, person-centred support and education for people living with frailty who have palliative care needs.

Care that is not solely about medications or clinical interventions, but also about human connection, autonomy, familiarity, and dignity. Through this programme, hospices have begun understand the possibilities to extend their reach, so that more people living with frailty can hope to receive the right care, in the right place, at the right time. The programme also underscored the importance of collaborating with services tailored to meet the specific needs of people living with frailty.

This work has improved the quality of care provided, raised the profile of frailty within the hospice and palliative care landscape, and strengthened the confidence and skills of those leading change. It has also deepened local partnerships and laid the groundwork for more sustainable, joined-up systems of support.

Programme design: key learning points

- Early preparation and engagement are essential. Securing buy-in from people close to or in the role that will be leading the project, senior leaders and local champions at the outset can increase momentum and clarity of purpose.
- In a project such as this, project leads required flexible, ongoing access to training in QI, evaluation tools, and project management due to staggered project start dates and varying levels of experience.
- Actively share progress across the wider organisation to foster collective ownership and engagement. In line with quality improvement methodology, when stakeholders feel connected to the journey, they are more likely to offer support and respond constructively if challenges arise.
- Celebrating successes proved to be a powerful driver of energy and momentum, reinforcing team morale and contributing significantly to the sustainability of the programme.

Overall programme learnings

The programme catalysed a culture shift in how hospices understand and deliver care to people living with frailty.

- Project leads were upskilled in leadership and QI, and many gained their first experience of presenting work at a national level.
- Individuals receiving care reported increased wellbeing, and greater awareness of the support available through hospices. For instance, several hospice teams – including Isabel, St Barnabas, Saint Michael's and ellenor – demonstrated that

timely, person-centred interventions could help stabilise or slow deterioration in people living with frailty. Despite unchanged Rockwood scores, people with frailty showed maintained or improved function in areas such as mobility, independence, falls prevention, and emotional wellbeing.

- Front-line carers and partners across sectors developed a stronger understanding of hospice services and how to access them.
- There was measurable improvement in access to care for underserved communities within hospice catchment areas.
- Stronger relationships were built with system partners, enhancing collaborative working and local visibility of frailty care models relevant to the hospice sector.

Recommendations for the future

For the hospice sector:

- **Acknowledge and embrace the overlap between frailty care and palliative care**

  Hospices should bring their palliative expertise earlier and alongside the frailty care delivered by GPs, district nurses, care homes, domiciliary care and geriatricians. Local partnership models should work to flex the organisational boundaries for people living with frailty where possible. This might involve hospice staff going into care homes or working alongside GPs. Staffing models should also become more fluid, e.g. hospices employing geriatricians or palliative specialists working in neighbourhood health teams. For patients living with frailty who may not have a life-limiting condition, hospices can bring expertise to their care, rather than take over their care. By working in this way, hospice care at home and living well services can play their part in keeping patients out of hospital and in preventing social isolation and loneliness.

- **Strengthen relationships with neighbourhood health team providers.**

  The partnership models developed through the programme, particularly with primary care, community services, the care sector, and ICBs, demonstrated tangible benefits. There is now an opportunity to consolidate and replicate these models, using what has already worked to support broader system goals. In England, frailty, palliative and end of life care are front and centre of the current NHS Neighbourhood health guidelines[34]. Hospices should be part of their local neighbourhood partnerships to deliver these, and access potential funding.

- **Invest in ongoing training and development in frailty care.**

  To sustain and build on the progress achieved, and be fit to meet future palliative care and population health needs, it will be essential to embed training and development into existing structures. This includes ongoing access to project management, quality improvement, and frailty-focused education – not as one-off investments, but as part of a culture of continuous learning that equips teams to lead change and respond effectively to complexity. This can often be achieved through smarter use of existing resources, peer-led learning, and low-cost, high-impact approaches such as Communities of Practice.

- **Utilise and share the outputs from the programme more widely.**

  Hospice partners developed training offers, handbooks, templates and tools as part of this programme. Participating hospices can share these as they see fit, both across the hospice sector and with other local service providers.

  By becoming part of frailty-focused Communities of Practices like Hospice UK's, hospice staff can share their experiences of how others are implementing these recommendations, and learn from each other about how they are supporting people living with frailty.

  We recognise that this work is unfolding in an exceptionally challenging financial environment. However, much of what was achieved in this programme was through collaboration, shared learning, and making thoughtful use of existing tools and relationships. By continuing to embed this kind of approach, and building innovative partnerships with other local providers and partners, hospices can contribute to wider system goals, often without significant new spend.

Next steps for Hospice UK

The Extending Frailty Care Programme has laid strong foundations for sustainable change – not only in how hospices care for people living with frailty, but in how they collaborate, lead, and innovate across systems. These foundations are already being embedded across Hospice UK's wider strategic work, with clear opportunities and ambition to extend the programme's reach and deepen its impact.

Building on this momentum, Hospice UK will:

- Consolidate learning from across the programme – particularly from the 11 test sites, but also from other hospice teams who have made progress over recent years – to inform future service design and innovation.
- Continue to grant-fund hospices, and offer those hospices support in project management, QI and evaluation methods, equipping hospice teams to lead and measure change with confidence.
- Strengthen and grow our new Frailty Care Community of Practice. This approach has proven to be one of the most valued elements of the programme, providing a trusted space for shared learning, peer support, and the spread of practical innovation. Our Community of Practice will continue to amplify the programme's learnings by encouraging ongoing communications and publications – including discussions, case studies, further abstracts and conference attendance.
- Deepen engagement with national bodies and charities focused on supporting people living with frailty, as well as relevant Royal Colleges such as the Royal College of Nursing and Royal College of General Practitioners. This will support hospice relationship-building with local community services, PCNs and voluntary organisations.
- Maintain a focus on sustainability, by continuing to track and promote the long-term impact of the 11 grantee hospices.

This is not the end of the journey – it is a strategic turning point. By continuing this work, Hospice UK will help hospices play an important role in community-based care for people living with frailty – ensuring they are recognised, included, and compassionately supported at every stage of their care.

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