hospiceUK

Mind the Grief Gap:

an independent evaluation
of a virtual bereavement
programme in nine hospices
during the COVID-19 pandemic

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For more information

For more information about this work please contact the Policy, Advocacy and Clinical Programmes team at Hospice UK by emailing policy@hospiceuk.org

About Hospice UK

Hospice UK is the national charity working for those experiencing dying, death and bereavement. We work for the benefit of people affected by death and dying, collaborating with our hospice members and other partners who work in end of life care. Our hospice members influence and guide our work to put people at the centre of all we do. We believe that everyone, no matter who they are, where they are or why they are ill, should receive the best possible care at the end of their life.

About hospice care

Hospices seek to improve the quality of life and wellbeing of those with a life-limiting or terminal illness, helping them live as fully as they can for the time they have left. It aspires to be accessible to all who could benefit and reflect personal preferences and needs. Hospices are rooted in the communities they serve, with each service developed to reflect the needs and the context of its local area. Hospices provide expert care for those in need as well as their family and carers, and care is free at the point of access.

Hospice providers offer a wide range of services to people in their homes, in day services or outpatient clinics, into care homes and hospitals, and through inpatient hospice care. The majority of care provided is to people in their own homes or attending the hospice, rather than just inpatient care.

Table of Contents

1. Executive Summary

The COVID-19 pandemic escalated the need for increased and wider bereavement support services from hospices. Hospice UK, working in partnership with nine hospices across England and guided by a Reference Group, set out to develop a gold standard virtual bereavement support programme.

The programme and its aims

Critically, the programme aimed to 'extend reach' and improve access by:

- Reaching out to people who were previously unknown to the hospice.
- Enabling a system change to create virtual delivery models.
- Ensuring hospice staff had the necessary skills and confidence to provide the required support virtually.

This innovative programme delivered an educational component via taught webinars and facilitated peer-to-peer learning through creating an ECHO™ (Extension of Community Healthcare Outcomes) Network [1]. Over a six-month period in 2020/21, the participating hospices rapidly prototyped models of bereavement support using quality improvement methods to trial and measure impact in 21 discrete projects.

The programme design allowed flexibility to re-focus the education curriculum which was important in the context of the pandemic: moving from an initial hypothesis that staff needed expertise in treating post-traumatic stress disorder to them having a greater understanding and recognition of trauma and the management of onward referral.

Each project was unique having an agreed aim and focus. The pandemic affected all projects without exception. The impact varied for different projects, for example, for some it presented new opportunities and additional drive as people worked towards a common purpose and for some it created barriers to partnership working. Some hospices made the decision to stop projects that were not delivering expected results.

The programme provided hospice project leads with support in extraordinary and challenging circumstances. Quality improvement methodologies acted as a 'forced function' to set aims, identify clear plans, try out ideas and review what was and wasn't working using rapid cycle testing.

Emerging learning

The diversity of the projects and their varied starting points allowed a range of ideas and bereavement support models to be tested in a virtual environment. The learning from the programme identified some key themes:

● Skills development focused primarily on understanding bereavement needs for people experiencing unexpected death in adults during the pandemic primarily through practice development.

● Additional learning about trauma and grief in children and recognising traumatic grief in adults.

● Referrals for bereavement support did not increase as anticipated during the pandemic.

● Upskilling of both providers and bereaved people in the use of ICT (information and communications technology) and videoconferencing should not be underestimated.

● A wide range of bereavement support models appear to work well in virtual environments and people can have a strong preferences about their environment of choice (e.g. face-to-face, telephone, video-conferencing).

The programme successfully tested the viability of how virtual bereavement services could be delivered, even during the most challenging of circumstances; and showed that a community can be virtually or geographically focused. Importantly, a meaningful approach will require hospices to better understand their local communities' needs and who their stakeholders are from the outset.

A step-change in bereavement support

The pandemic has created a step-change in using virtual technology to support each other and improve access. It is vital to continue to build on this learning and measure outcomes. There is rich learning and legacy from the programme including a repository of information available online and an ongoing bereavement community of practice for hospice staff which has been established [2]. Further ECHO™ networks are a potential model to facilitate wider coordination and further development of knowledge and skills.

It is anticipated that the need for bereavement support will rise sharply in the future, and in response this requires increases in capacity and capability at all levels of need. Virtual support is becoming normalised within our society, and with this mind, it is envisaged that a blended approach that builds on virtual technology alongside traditional bereavement support models is important in helping to future-proof services for the longer term. Paying attention to the experiences of bereaved people and understanding their needs and preferences for support is crucial in building sustainable models for the future.

The programme's reach during the six month piloting phase

At least **273** people who were bereaved received direct virtual support from hospice staff or volunteers

187 people in communities gained greater skills and knowledge about supporting people who are bereaved

Social media and website information

Website communication reached over **2,500**
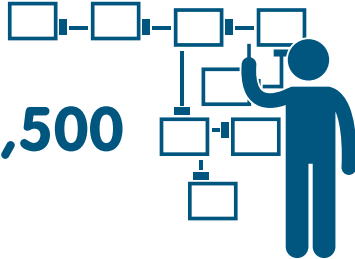
Social media adverts extended reach further e.g. one hospice had a collective reach of **55,000** with two targeted adverts

Bereavement skills gained

At least **52** hospice staff developed their skills in bereavement support

71 hospice volunteers developed their skills in bereavement support

Technology skills gained

At least **38** hospice staff and **74** volunteers developed their confidence and skills in using technology to provide different forms of virtual support.

Perceived confidence of service users' ability to use video conferencing has risen by **24%**

Partnership working

One hospice connected to **250** care homes.
Others' connections included primary schools, premiership football club, carer support organisations
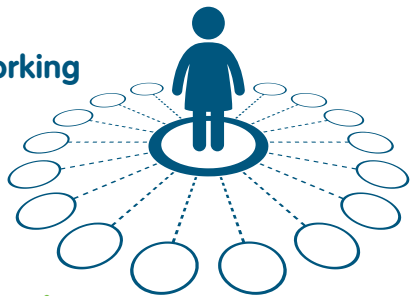
Dissemination of learning

Over **200** individuals accessed the programme learning via the Hospice UK website **(April 21 to Oct 21)**

Three ECHO™ community of practice sessions reaching **30** hospices.

2. Introduction

2.1. The report's aim and purpose of the programme

This report provides an independent evaluation of the lessons learnt from the bereavement programme led by Hospice UK and its impact on bereaved people. Hospice UK worked in partnership with nine hospices with the long-term aim:

> *"to develop gold standard hospice-led bereavement support for the public delivered via virtual technology, so that everyone can get the support they need to cope with the death of their loved ones, wherever they live in the UK."*

The pilot was delivered over six months within a 12 month programme, and its stated aims were to:

- Upskill hospice staff in dealing with symptoms of complex grief and post-traumatic stress disorder (PTSD) brought about by the crisis.

- Train health professionals in the use of new ICT and digital technologies.

- Test the innovative use of virtual technology to transform how hospices can offer bereavement support to the wider public at a distance.

- Reach those who struggle to access traditional bereavement support in the community such as frail older people, full time workers, and those who are house-bound.

- Enable system change in the way that virtual bereavement services are delivered to people in their own homes and in the workplace.

Alongside these aims the programme adopted an approach to enable the participating hospices to rapidly prototype new models of care. The training around the prototyping methodology, bereavement skills and use of technology was provided in a combination of didactic on-line presentations (webinars) and as a Project ECHO™ Network (Extension of Community Healthcare Outcomes) virtual community of practice.

The detailed design of the programme inputs was set jointly with the participating hospices and the Programme Reference Group. This is part of the methodology of a community of practice and ensures that the inputs align to defined learning needs of the participants guided by expert opinion.

The programme was set against the back-drop of the second and third waves of the COVID-19 global pandemic, with the active prototyping phase occurring between November 2020 and April 2021.

As a consequence of the condensed programme time frame, Hospice UK took a pragmatic approach to identify hospice bereavement teams as potential partner organisations. Hospices who had been through an open recruitment process for a previous bereavement programme were invited to put themselves forward. The rationale for this approach was that these organisations were known to have an established bereavement support service in place. As a result, it was expected that they would be able to engage fully and move rapidly to get their projects up to speed within the programme's short timescales.

In total nine hospices participated (see map on page 12).

2.2. Bereavement care

Bereavement is experienced as part of life and does not normally require formal service intervention, and for many people their usual support networks are of sufficient help. However, for some grief can become a serious problem. It can be helpful to meet and talk to others who have been through a similar experience. Some people benefit from specialist help, either from a counsellor or psychotherapist [3].

The bereavement care pyramid [4] is a helpful framework that describes different levels of need for people who experience bereavement (Figure 1). The pyramid outlines the different types of support and services needed at each level, and type of knowledge and skills required to meet the needs.

The circle outside the pyramid highlights that there are many factors that impact a person's experience of bereavement. For example, the circumstance surrounding their loss, their previous life experience, their current social networks and their experience and understanding of bereavement.
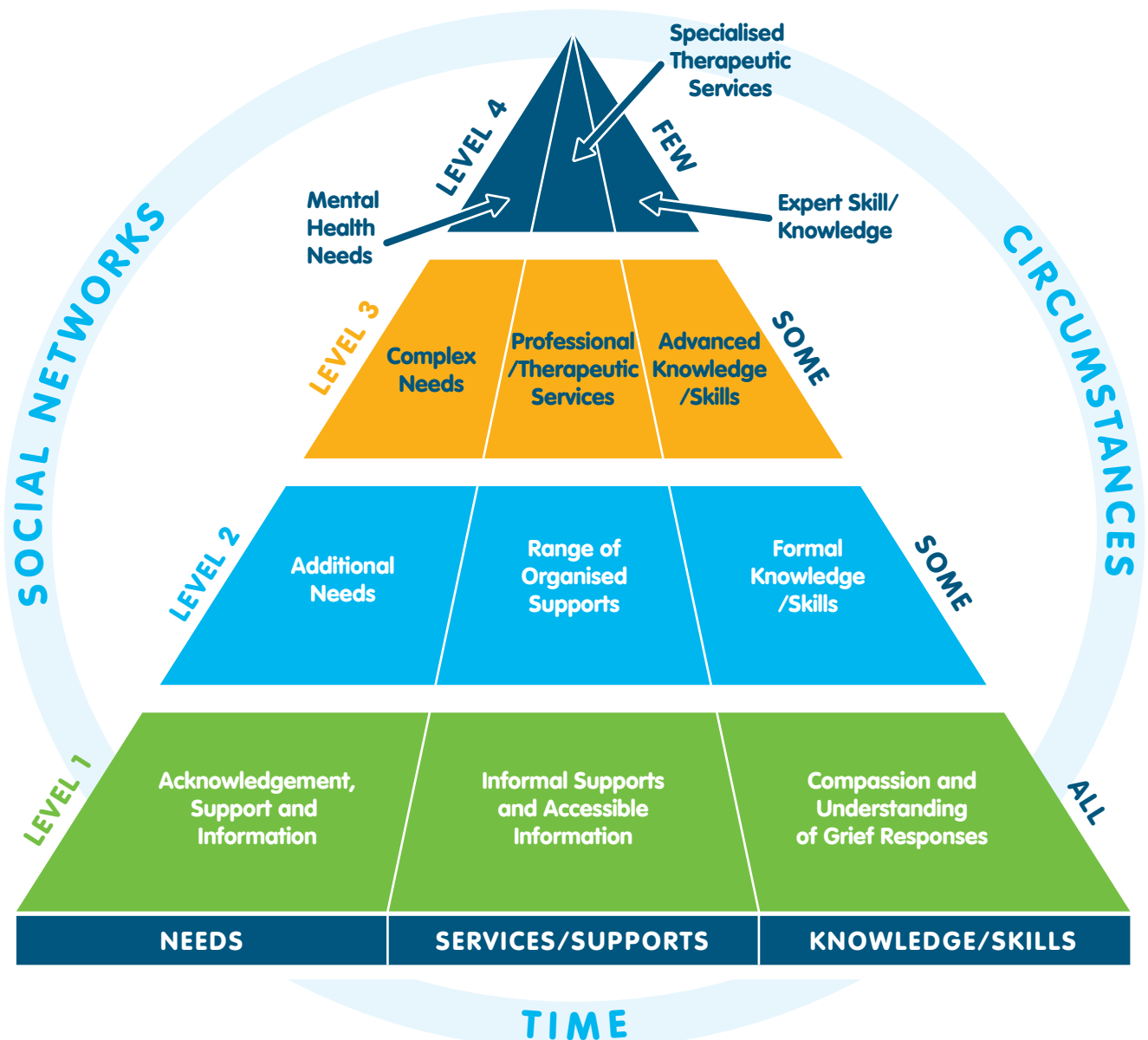
Figure 1 The Bereavement Pyramid based on the one developed by the Irish Hospice Foundation [4]

The pyramid sets out that all people who experience bereavement need level 1 support, for example compassion and support typically provided by their own social networks. Some people will need additional support outside of their social networks **(level 2)** and others may need more intensive support such as counselling **(level 3)**. A few experience complicated bereavement which may require support from a specialist therapeutic service **(level 4)**. A similar four tier framework exists for children where part of the focus is to ensure support is age appropriate [5]. Services and support at all levels may focus on individuals or families.

Hospices are an important provider of bereavement care services in their local health and social care systems, providing support for 72,000 individuals annually [6]. The traditional hospice model provides bereavement support or counselling for family and friends of hospice patients [pyramid level 2 and 3]. There is also recognition that the hospice itself will directly provide level 1 support, acknowledging loss by, for example, sending condolence cards and holding annual memorial services for those who are bereaved. Their approach to providing palliative and end of life care will often help close family and friends prepare for their loss, as death is expected and thus paving the way for easier bereavement.

As well as providing direct support and care, professionals working in the area of bereavement need to be able to recognise complicated grief and refer onwards for specialist help.

Some hospices are also involved in creating bereavement support in the wider community. Some are involved in public health approaches to palliative and end of life care [7] and initiatives such as compassionate communities [8]. These initiatives aim to equip both people

Figure 2 The Programme's timeline next to the global pandemic [23], [24]

who live and work in a community to better understand loss and bereavement and therefore improve the support at level 1. Some hospices are actively involved in training health and care professionals in bereavement support knowledge and skills.

2.3. The national context and the programme timeline

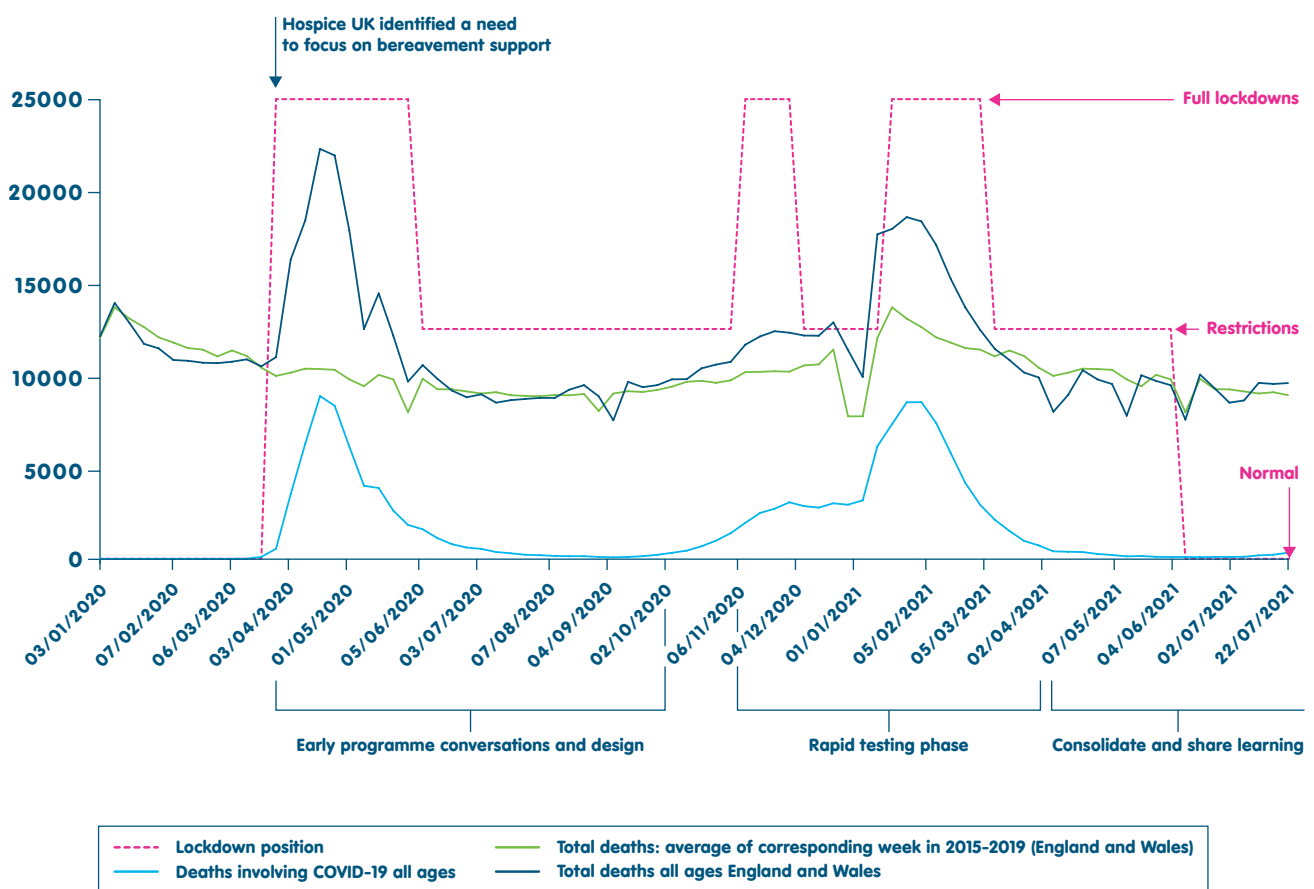In March 2020 the UK nations underwent their first national lockdown restrictions to manage rising COVID-19 infections [see Figure 2]. The immediate priority at this stage was to reduce infections from COVID-19, prevent people from dying from COVID-19 and NHS services from becoming overwhelmed. The graph shows the total number of deaths during the pandemic (dark blue line), next to the usual average for the same time period (green line) and the total number of COVID-19 associated deaths.

It is estimated that for every COVID-19 death, nine people are affected by bereavement [9]. A UK estimate identified that the total number of people bereaved during COVID-19 restrictions in 2020 and 2021 was in the region of one million people [10].

Hospice UK identified that a part of their response to the pandemic would be to work with hospice services in efforts to support those who were bereaved during the pandemic.

National restrictions affected how people were able to say goodbye, how they were able to visit their loved ones and how they could be supported in person by friends and family during their bereavement. There were more unexpected deaths; more people died at home. Experiences varied during the pandemic [11] [12] [13]. Usual support services for the bereaved [14] and those who were lonely as a result of a previous bereavement were disrupted. The impact on people who were bereaved in the UK showed that:

● Only 26% of people surveyed felt supported by healthcare professionals immediately

after the death of their loved one due to COVID-19, and 33% did not feel supported at all.

● 45% of people surveyed were not contacted by the hospital/ care provider after the death of their loved one.

● 51% of people surveyed were not provided with any information about bereavement support at all [15].

The size and the suddenness of the changes meant that those working in bereavement services were working fast to adapt. Existing systems were disrupted, people were furloughed, rules and guidance were rapidly evolving. The research community galvanised efforts to guide decision-making to support bereavement service development in the context of a pandemic. For example one study highlights that the key features of service delivery in situations of mass bereavement are:

● *'Adoption of a proactive service model to seek out those in need.'*

● *'Central coordination of a consistent offer of support with delivery by local organisations.'*

● *'Crisis-specific core competencies for those delivering counselling interventions.'*

● *'An emphasis on structured psycho-education to enable loss and restoration-focused coping and use of support from existing social networks.'*

● *'The use of group-based support for facilitating connectedness and shared understandings.'*

● *'The need for formal risk assessment leading to specialist mental health provision for individuals at high risk of prolonged grief disorder and other mental health disorders.'*

● *'Integration of prospective evaluation alongside service delivery with real-time feedback used to inform practice.'* [16]

These features are important. For example, if central coordination exists in a locality, it is easier for new hospice-led developments to

complement what is already available, and support rapid communication of new and existing offers of support to those in need. This also highlights the role that Hospice UK undertook to communicate and rapidly share learning across hospices.

The final context is a side-effect of the pandemic. Most organisations were impacted by COVID-19 in some way – these organisations ranged from funders, researchers, government departments, health service providers, to community organisations and charities. The impacts included: the practical aspects of lockdown, furlough, staff needing to shield or isolate, home schooling children, funding uncertainty, and family personally affected by COVID-19.

While this was an ambitious programme to deliver in the context of a pandemic, the unique circumstance dictated a need for Hospice UK and its partners to spring into action quickly.

There were implications for the programme with the tight time frame and need for rapid start-up. It is a testament to all involved that they were able to deliver the key aims of the programme during such significantly challenging circumstances. A key learning is to ensure adequate time or create flexibility in the programme timescales in conversation with all partners involved if these circumstances were to re-occur.

Hospice of the Good Shepherd

Compton Care

Great Oaks Dean Forest Hospice

St Elizabeth Hospice

Saint Francis Hospice (SFH)

Dorothy House Hospice Care

The Mountbattern Group

St Christopher's Hospice

St Wilfrid's Hospice
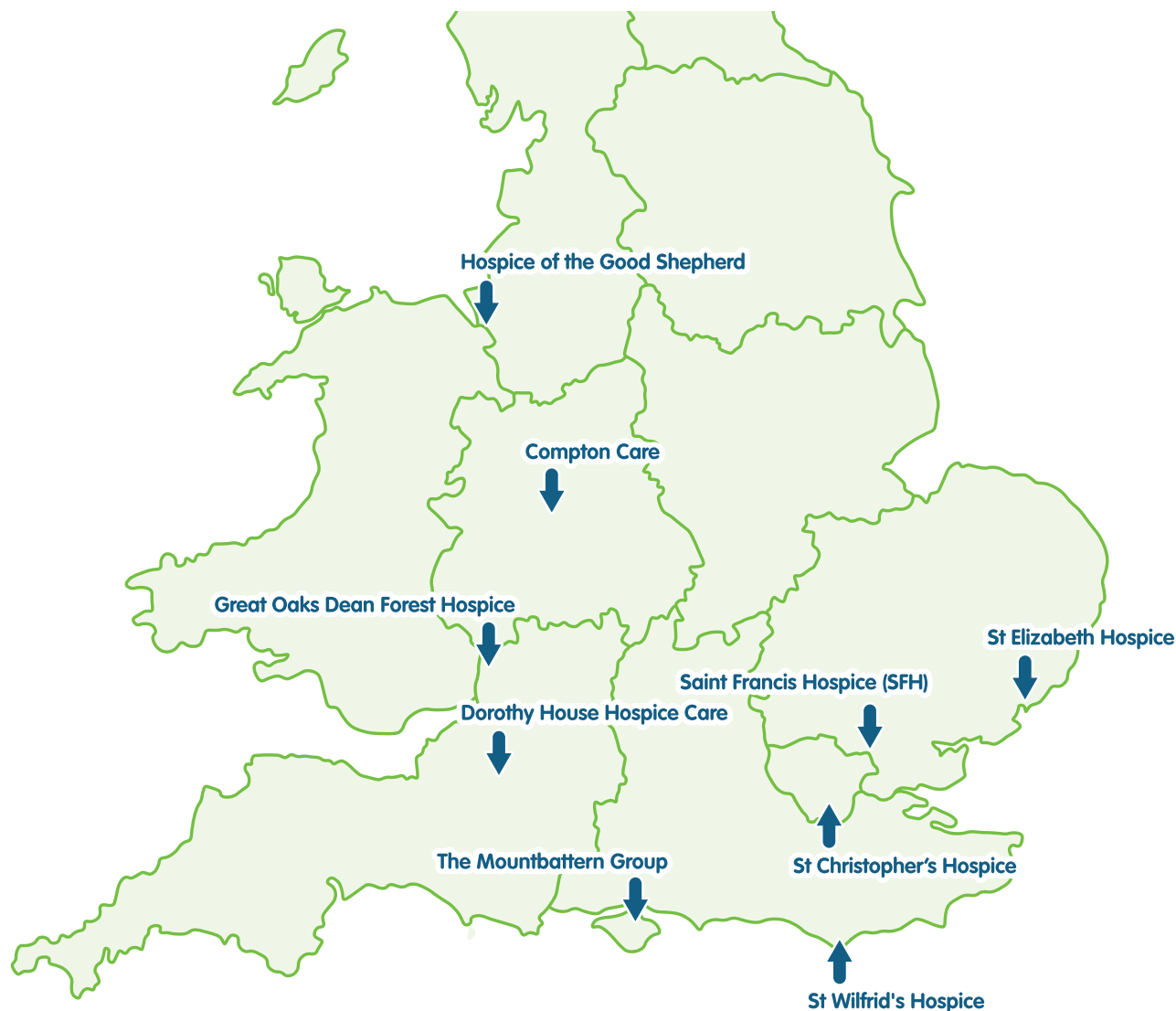
Participating hospices

3. Evaluation methodology

3.1. Available data

Project level data

All nine hospices completed an end of project report (described as a "case study") to a standard pro forma. Seven out of nine hospices provided additional information on request. Some hospices focussed on multiple projects while others delivered one with a single focus. There was also a diversity of starting points and of local contexts across the participating hospices. The hospices developed a bespoke approach to project evaluation in line with the chosen prototyping methodology.

Other sources of project level information included: Hospice UK project lead's notes for individual 1:1 coaching and account of progress reports.

Programme level data

The sources of data include the programme's inputs:

- Webinar and ECHO™ presentations, attendance and supporting documents.
- Minutes of the Programme Reference Group.

Programme outputs and reflections:

- Number of website hits.
- Discussion at a project leads meeting.
- Meetings with the project team.
- A survey of the hospice leads at the start and end of the programme (7/9 hospices).

3.2. Approach

A logic model was developed and agreed to frame the evaluation approach [See Figure 3]. This sets out the context, a description of programme inputs, outputs and outcomes with an exploration of programme assumptions.

There were two areas of focus:

1) Learning from the programme approach and methodology.

2) Learning from the virtual bereavement support and service models and training.

A thematic analysis of the available quantitative and qualitative data was developed, and triangulated.

As each project had a distinct aim, a project specific analysis was undertaken. Firstly, projects were categorised using the bereavement pyramid and project aims were refined with a focus on available outcome measures. The analysis assessed the evidence of benefit, the structural changes, use of technology, learning and the impact of the pandemic [17]. This allowed the thematic analysis to be triangulated with the other sources of data.

In order to quantify the potential programme impact, the total number of bereaved people directly supported as a result of each project was calculated and summed where data were available and relevant. Although there are obvious limitations to this approach, there is evidence that proactively reaching out to people who are bereaved is beneficial [16].

Where projects focused on providing direct support to people who are bereaved, an assessment was made of the available evidence (e.g. analysis of outcome measures, feedback). Some projects used validated outcome measures, others developed bespoke questionnaires. In some instances the hospices

deliberately took an informal approach. To increase the objectivity of the evaluation, where possible, an additional analysis of complete datasets provided by the hospice was carried out. (Instead of a secondary analysis of selected feedback of information provided in the project reports). Where outcome measures were used, it is notable that response rates tended to be low. Working in a virtual environment meant that the hospices were trying out new approaches to distribute and collect questionnaires and feedback forms. In addition, one hospice highlighted that there was a 'lower completion rate' for counselling for people not previously known to the hospice which affected their measurement.

The potential indirect benefits of greater knowledge and skills in the community (professionals, members of the public) and in the hospice (staff and volunteers) was calculated by a combination of information extracted from the project reports and associated evidence, and estimates requested to and provided by hospices in the supplementary data collection. These numbers include knowledge and bereavement skills gained as a result of practice development. Similarly to outcome measures, where possible independent analyses of complete datasets was undertaken.

The prototyping methodology used in the programme prioritises learning as an outcome – therefore a test or an idea that does not work as expected is not considered to be a 'failure' in this context.

In order to evaluate the programme approach, there was a focus on the feedback from the hospice leads on the programme inputs and learning, and evidence the prototyping method approach was applied in practice.

Situation/need	Inputs	Outputs	Outcomes
Aim for nine hospices to bring bereavement support on-line safely and increase their reach to people who would not usually access bereavement services.	**Programme approach (Hospice UK)** • Rapid prototyping methodology. • Skills, training, resources and peer support through ECHO™ Network sessions (6) and webinars (6). • One to one coaching sessions (3 per hospice). • Financial Support.	**Programme** • Nine end of project reports ('case studies'). • Hospices' progress reports. • On-line material. • Toolkit (under development). • Summative learning.	**People who are bereaved** • Number of people supported due to the programme. • Evidence of benefits.
Context Global pandemic	**Programme Reference Group** **Hospices** • Local approach to design, delivery and training. • Use of methodology and collective learning. • Local context (e.g. partnership working).	**Hospice services** Services and support development as a result of the programme.	**Indicators of community support** • Number of people living and working in the community who are better able to support people who are bereaved. • Evidence of benefits. **Hospice staff and volunteers developing their skills and confidence** • Bereavement support. • Virtual provision of support. **Virtual reach**

Assumptions	External factors
• Expected Hospices to need IT equipment. • Expected Trauma and Post Traumatic Stress Disorder training to be a priority for hospice staff. • Expected a 'tsunami' of bereavement need.	Pandemic disruption existing social and professional networks: all organisations affected. Hospice services varied in their pre-pandemic connectedness with local health and social care economies. Local health and social care economies may or may not have 'central co-ordination of bereavement services' [16].

Figure 3 Evaluation logic model

3.3. Evaluation questions

Outcomes: What was the summative potential impact of the programme?

Outcomes: Which projects had measureable impact? Which projects contributed to important learning? What skills and knowledge did hospice staff gain?

Outputs: What is the generalisable learning about the different bereavement models and how they work in the virtual environment?

Inputs: What is the generalisable learning about the prototyping methods? Skills and knowledge gained by the hospices and the overall programme approach?

4. Evaluation of the methodology and programme approach

4.1. Programme governance

The Programme Reference Group included experts on children's bereavement, patient and public involvement and co-design and national/international experts on bereavement. This group's terms of reference included:

- Contribution to the design and delivery of the education curricula.
- Participation in the monthly community of practice ECHO™ sessions to share their expertise and experience.
- Provision of advice and support to the Project Manager and Internal Hospice UK Project group.

The monthly community of practice ECHO™ sessions are designed to enable peer to peer support. In addition to these, the Hospice UK project manager identified the need for additional support and provided 1:1 coaching to the hospice leads.

4.2. Description of the programme inputs

The programme's educational inputs were developed jointly with the participating hospices and the Programme Reference Group during the launch event. The benefits of this method is that it formalises and co-designs the programme inputs as an agreed shared curricular. This is a core methodology in an ECHO™ Network.

Early discussions with the Programme Reference Group highlighted that the programme's original *'reference to Post Traumatic Stress Disorder is unhelpful – these users get onward referral'*. They recommended that instead the emphasis should be about developing understanding about complicated grief, recognising triggers and knowing how to refer to level 4

bereavement support. In addition, these discussions highlighted the importance of virtual supervision of staff and general staff well-being.

The programme delivered twelve half-day sessions in a virtual environment. The content was delivered in either a webinar format (to enable wider sharing) or during the ECHO™ Network [1]. The ECHO™ model is a peer-learning and knowledge sharing approach that increases the capacity of health experts to provide high quality, specialist health care for their patients [18]. It is a distance, technology enabled education model in which people from multiple disciplines can come together in an 'all teach, all learn' environment to address common issues or achieve common goals. There is an emphasis on case based learning.

The curricula and inputs to enable "clinical upskilling", in order of presentation, were:

- Grief and grieving in a pandemic.
- Bringing bereavement services online.
- Bringing services online during the COVID19 pandemic.
- Wellbeing and self-care.
- Voices of lived experience.
- Children and grief.
- Current bereavement research relevant to the pandemic.

In addition to this content:

- Hospice leads presented their project's updates as part of the 'case discussion' to facilitate peer learning.
- Hospice UK staff gave a number of presentations on the prototyping methodology described in the next section.

The Hospice UK project manager provided additional support via 1:1 coaching and support / catch up calls with the participating hospices.

4.3. Description of prototyping methodology inputs

Rapid prototyping: quality improvement methodology

The first ECHO™ session set out the core quality improvement methodology based on the Model for Improvement (see Figure 4).

The model for improvement is an intuitive framework [19]. It consists of two parts: first answering three key questions and second testing out change ideas in practice using 'Plan Do Study Act' cycles of change. [25]
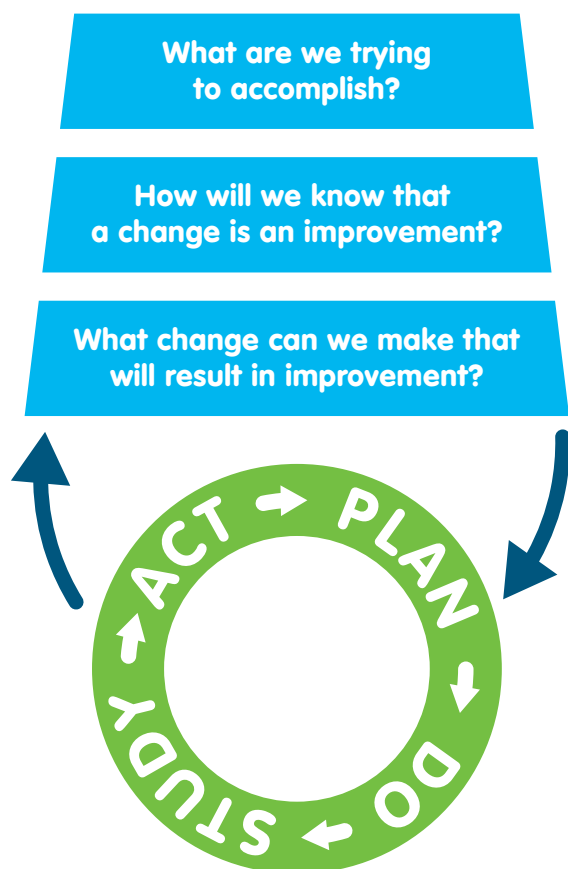

Figure 4 The Model for Improvement developed by Langley et al [19]

Additional Quality Improvement tools were also highlighted in the first ECHO™:

- 30-60-90 day action planning.
- Having a shared purpose and aims statement including setting 'SMART' outcomes.
- Measurement for improvement.
- Stakeholder analysis, mapping, communication approaches with stakeholders.
- Levels of engagement with service users with an emphasis on co-production.

These were reviewed in the second ECHO™ session with an additional tool highlighted:

- Driver diagrams.

The final ECHO™ session focused on the sustainability model.

A reporting framework and approach was set out in the first ECHO™ session.

4.4. Evaluation of the programme inputs

4.4.1. Prototyping Method: Quality improvement methodology

Skills gained by project leads

Figure 5 shows the before and after analysis of the project leads' confidence in using quality improvement methodologies of the baseline and follow up survey.

Proportionally more people were either moderately confident or very confident at the end of the programme.

These comments are snapshot reflections in the moment, collected four months after the active prototyping phase of the projects.

The feedback **after the programme** for those that were moderately or very confident highlighted the following:

The benefits of the training (2/4)

> "Again, attending the training and presentations has been a great help." 〃

> "Good training – very helpful." 〃

The tools and approach (1/4)

> "The tools provided by the project have enabled me to think differently and recognise what is useful to quality improvement." 〃

With one saying they found the tools *"cumbersome"*. (1/4).

For those who were only 'slightly confident' or 'somewhat confident', this reflected their steep learning curve or the potential barrier of new terminology not connecting with existing knowledge and approaches:

> "This is new in the methods chosen so with anything new it's understanding what is being asked." [Somewhat confident] 〃

Reflections on quality improvement methods from the 'end of project reports'

The thematic analysis of the relevant content to the answers of three questions from the "end of project reports" gives a more nuanced picture of what the hospice leads found most and least useful about quality improvement methods.

A key learning was that the methodology overall created a '**forced function**' to reflect, review and build evidence and keeping the project on track (5/9 hospice leads) for example:

> [We] "hadn't thought through how we would measure progress, building evidence for the difference we would make." 〃

> "They helped us to think about things we hadn't thought about in regards to the planning, delivery and sustainability of the project." 〃

> "Not surprisingly being 'forced' to slow down and consciously consider the improvement cycle felt a tad laborious. However, with hindsight, certain aspects were certainly worthwhile." 〃
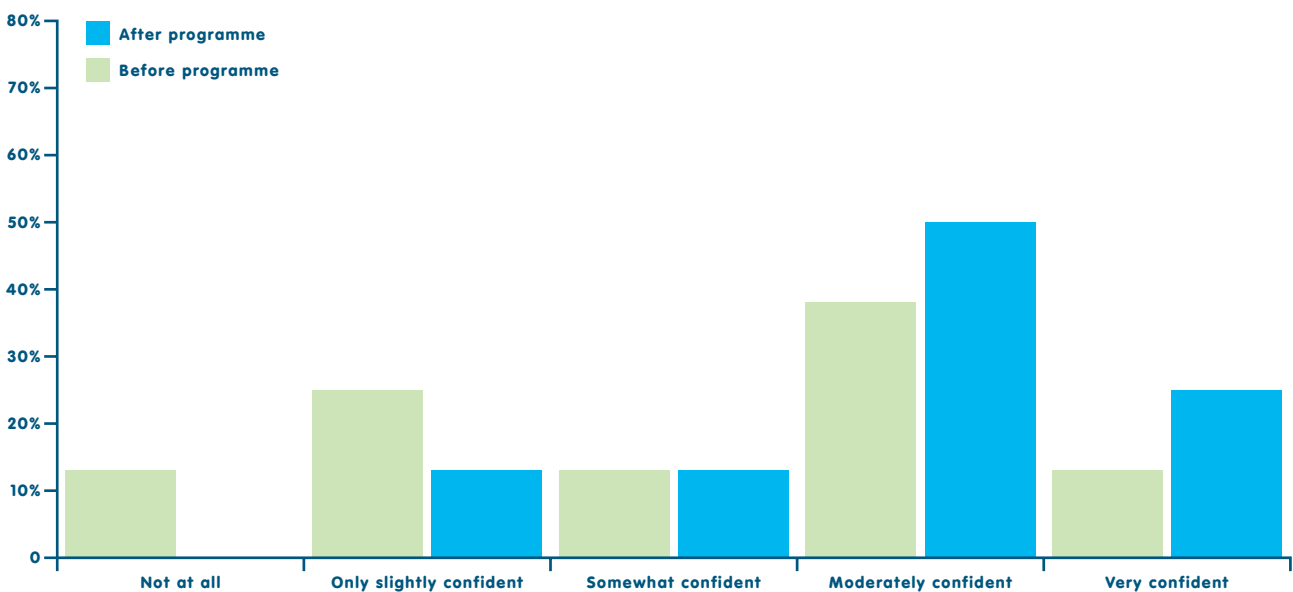

Figure 5 The change in project leads' confidence in using quality improvement methods

"… The tools have enabled us to stay on target and helped us structure our regular meetings. The process of reviewing progress has been encouraging."

There was a sense that some tools and/ or reporting were 'cumbersome' or 'time consuming' (4/9), for example:

"They take time to complete so they can feel like additional 'work'."

"Using the Quality Improvement tools could sometimes feel like an extra task."

There were reflections about the steep learning curve for those unfamiliar with the methods (3/9), in particular in the programme's context and tight timeframes.

"Getting used to the tools and ensuring using them correctly."

"Lack of time to investigate and study in depth the full benefits of the tools in the timespan of the project. We believe we could have made even better use of these tools if we had additional time to explore them."

"The contrast for the practitioner to be part of a fast-moving dynamic project, whilst maintaining a safe, contained space for the client to work through turbulent emotions is challenging. "

Another hospice lead highlighted that the approaches are tools and not masters.

"In essence such concepts can be a useful tool, as opposed to a definitive rule, for embedding theory into existing practice. There's a balance to be struck with all this sort of stuff so long as we remain mindful that using such tools must not inhibit the organic progress or creativity inherent in most projects."

The issue is that experience and expertise allows mastery of a tool, and everyone needs to start somewhere.

There was diversity in preferences around which tools were most useful.

Five highlighted the importance of identifying and developing relationships with key stakeholders and working with them, for example:

"Stakeholder analysis was crucial at the start, even though, in retrospect, I feel we could have been more adventurous in our thinking about who the stakeholders were."

"Scope your community and community leads, get names and contact numbers before sending information out … attend meetings in the Trust and local services."

Communication is part of establishing good relationships with stakeholders, 4/9 highlighted the importance of communication.

Six hospice leads highlighted the importance of planning with the 30/60/90 day action planning approach being specifically mentioned by four of the six, for example:

"30,60,90 was useful, particularly at the start of the project to help order thoughts and to get down on paper all that needed to be done and to make sure this was achieved and put in extra measures in place if not."

Four highlighted the importance of understanding bereaved people's perspectives, although specific methods were not highlighted.

> *"That what we think bereaved people need and what they actually want can be at odds.*

This site listened to their peer support group when the group indicated they would prefer to meet without external facilitation rather than wait. The feedback was that the group "really enjoyed being left to 'get on' with it." The key learning for the hospice lead was:

> *"Listen to those you serve! Avoid paternalism!"*

Another site who had attempted to reach out to Black, Asian and Ethnic Minority communities reflected that they found it *"Difficult to reach the communities we wanted to; there needs to be [more] learning about these communities and their needs."*

Three highlighted the importance of having clear aims and 'SMART' objectives, while five commented on 'Plan Do Study Act Cycles' of change either by name or by practical application. Some felt they already approached improvement in this way and formalising the method felt like an additional hoop.

> *"We established weekly meetings where we used the Plan, Do, Study, Act technique as a framework for our discussions."*

Two highlighted the evaluation approach in measurement for improvement and the benefits of *"Evaluating as you went along and making changes there and then."*

Two highlighted the usefulness of driver diagrams, one highlighted the sustainability tool and two highlighted the benefits of carrying out "risk assessments".

Peer learning through ECHO™ and support to the leads

The ECHO™ community of practice helped the project leads to learn from each other and helped them to feel supported (3/9).

> *"Delivering this project through the Quality Improvement and attending the webinars and ECHOs have supported us to share ideas around bereavement support and the issues faced by other organisations – we are not on our own!"*

> *"The monthly phone call was also very helpful and the coaching received was useful, developing our understanding further."*

> *"Collective learning has helped predict or avert as pitfalls as [much as] possible."*

The meeting with seven project leads highlighted a strong sense of a virtual learning community and a desire to share their learning to others.

Using video conferencing

Figure 6 illustrates a shift in confidence around using video-conferencing. For some it was clear that this was still a new area for them while others have been using the media for a while: for example *"I have worked in bereavement for 15 years and have provided online counselling for the past 4 years"*. This is an enabler for an ECHO™ Network as it is a peer support model.

Two of the three people had less experience of the format. One indicated a shift in their confidence to work using video conferencing.

> *"I feel that without the project I would not have been half so willing to give Zoom a go with clients and now I wonder why it's never been part of our offer to families as, while it can never replace face to face 1 to 1, it works for those who are less mobile, have no transport or live on the periphery of our catchment area, it also has enabled us to support families no matter where they are located."*

One undertook additional training to work online.

The hospice leads were also asked to reflect on the confidence of their service users to use video conferencing. Figure 7 reflects a substantial shift in perspectives and in confidence.
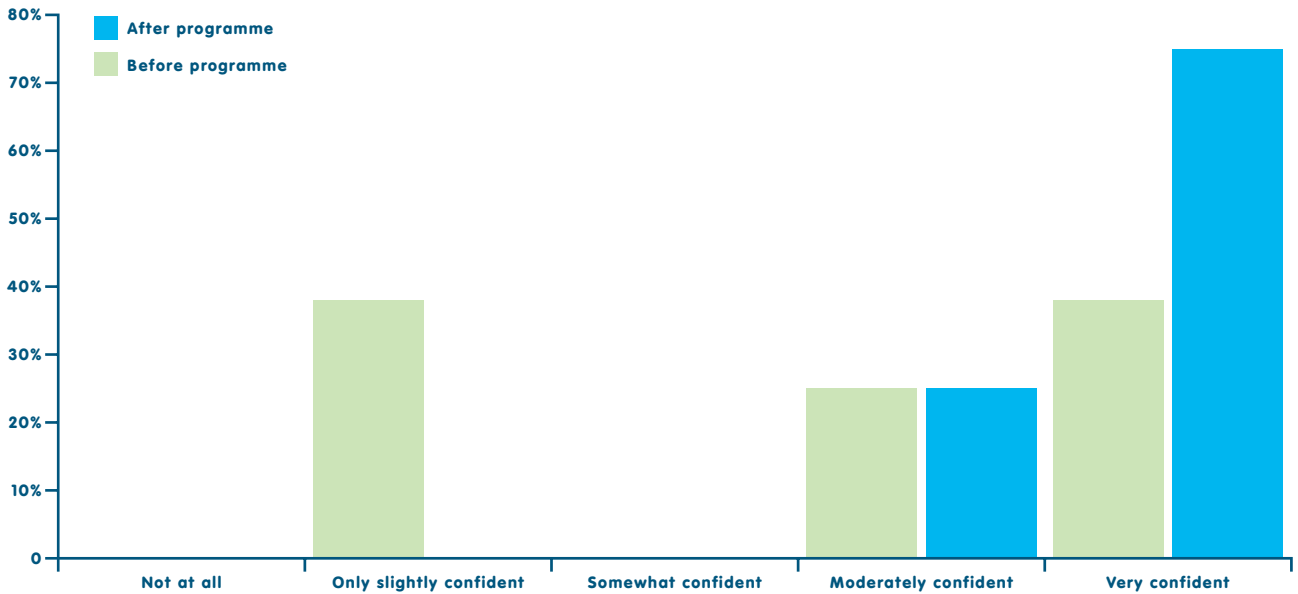

Figure 6 The change in project leads' confidence in using video conferencing to provide services to people who are bereaved
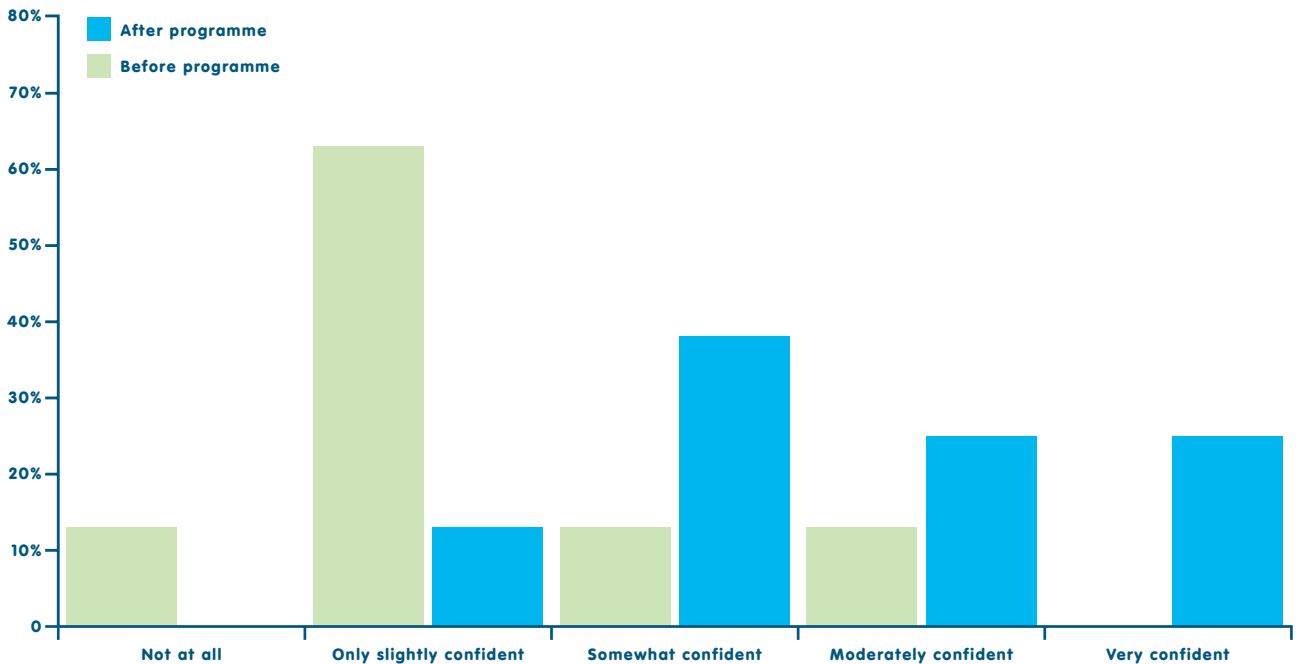

Figure 7 The perception of change in confidence of service users to use video conferencing to receive services

As one person commented on before the programme started, this is a difficult question to answer and without trying video conferencing it isn't possible to know what is possible and acceptable.

> "I can't answer that question, it's too broad and assumes that a knowledge about each one of my clients in terms of their ability and confidence which I have not explored."

All seven comments are included below as they reflect the breath of preferences, confidence and inter-generational perspectives.

Only slightly confident:

> "Only some take up the offer of video-conferencing services. They opt for telephone support over online support."

Somewhat confident:

> "This often depends on age of client and whether they are [ICT] confident generally. I have noticed an increase in confidence with most population groups over the past 18 months."

Moderately confident:

> "I don't actually think it's a question of confidence but a question of preference. Some people simply prefer face-to-face."

> "For our clients who have embraced this medium I would say they are growing in confidence but there will always be some who struggle with technology as well as those who don't have access to it and don't want it."

Alongside this the pandemic was creating a disruptive impact on society in their use of technology with more people using systems such as Zoom to keep in contact with family and friends.

5. Learning and impact of the virtual bereavement models

The nine hospices established 20 discrete bereavement support projects and a number of hospices included developing their website as a discrete project, which collectively have been described as an additional (21st) project.

We have categorised the projects according to Bereavement Care Pyramid levels, Figure 8 summarises and groups these projects at the different levels of support. The thematic analysis of the individual projects is available from Hospice UK [17].

_____
1 The number excludes two projects' figures – for definitional reasons.

5.1. Summative impact across the projects

At least 273[1] people who were bereaved received direct support from hospice staff or volunteers during the six month active project period who would not otherwise have received support.

It is worth noting that some hospices had substantial time lags from the project starting to the service or support being operational.
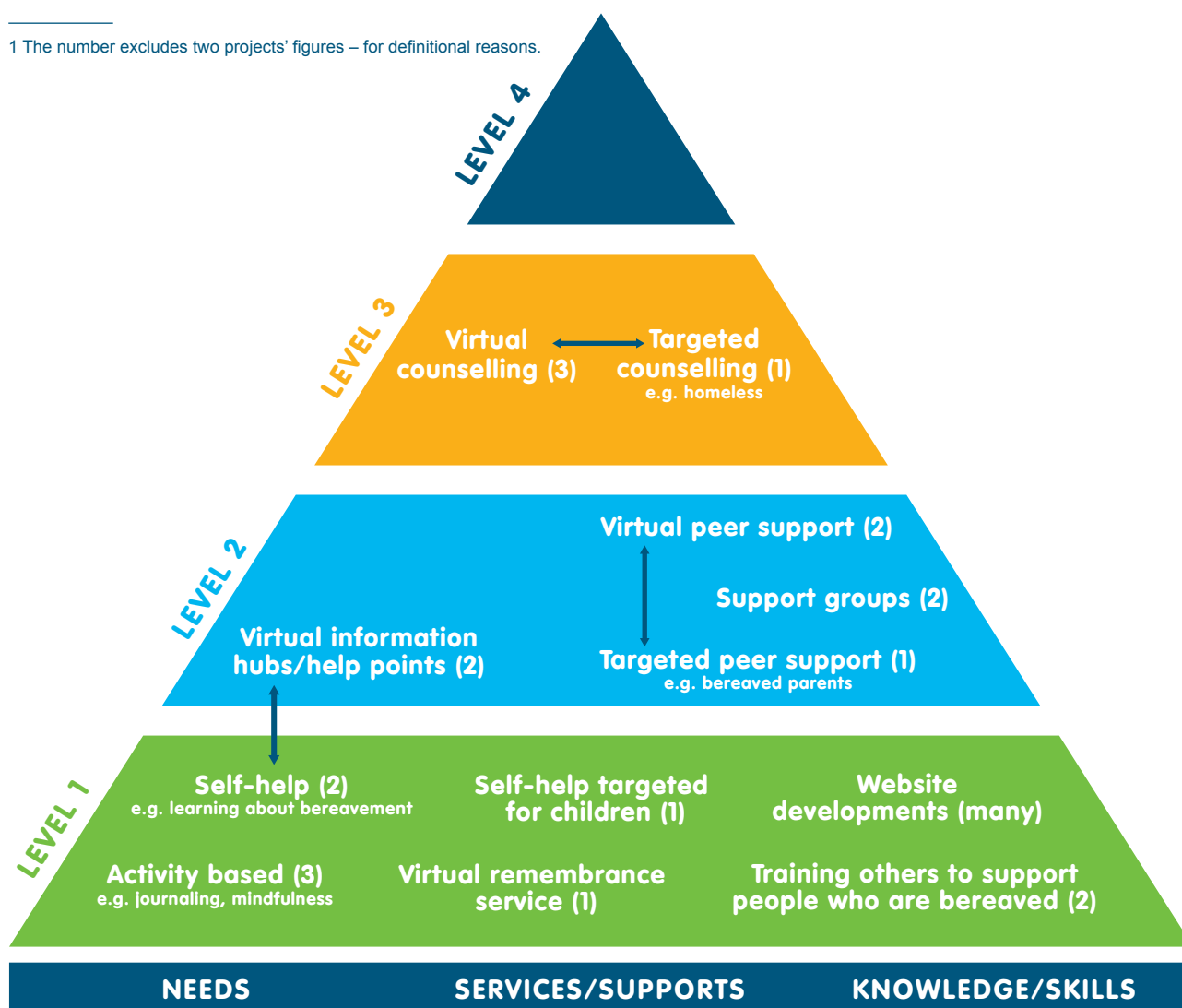

Figure 8 Project groupings next to the Bereavement Pryamid with number of projects in brackets

For example, one hospice lead reported that recruitment took much longer than anticipated, so the sessional worker did not start until March 2021 to provide out-of-hours counselling.

A number of projects took an indirect approach to supporting people who were bereaved during this period, for example building skills in the community, including professionals who are supporting people who are bereaved.

In total 187 people gained greater skills and knowledge about supporting people who are bereaved as a result of the programme.

Acknowledging loss. One hospice live-streamed their annual bereavement service, 52 people attended the event live and there were an additional 250 website hits afterwards. More people attended in 2020 than 2019.

Social media and website information. A number of hospices had projects that either focused on improving information on their websites as a separate project or included website developments to support the communication of their project. The collective communication reach is over 2,500 including 200 unique views to the Hospice UK project resource page (Apr - Oct 2021). Some projects ran social media adverts for their projects which extended the reach even further, for example one hospice had a collective reach of 55,000 with two targeted adverts.

Bereavement skills gained. At least 52 hospice staff developed their skills in bereavement support through the programme, which includes the hospice leads who attended the Hospice UK training, other staff who attended local training and practice based development through the programme. At least 71 volunteers developed their skills in bereavement support, this included a range of roles and includes volunteer counsellors through the programme. Alongside the learning shared from the Hospice UK training, the methodology reinforced the practice based learning, for example:

"There is direct contact with bereaved people as part of the project so there was learning in listening to people bereaved during the pandemic and the particular issues facing them eg. no funerals etc., in facilitating break out rooms, in the process of evaluating after each session using PDSA concepts."

At least 38 hospice staff and 74 volunteers developed their confidence and skills in using technology to provide different forms of virtual support.

These numbers highlight the importance of volunteers in bereavement support. Although this was not a specific area of focus, their varied roles included counsellors, trained facilitators for peer support, 1:1 peer support, putting memorial bags together.

5.2. Level 3 virtual counselling support

Four projects focused on level 3 support for people who are bereaved through 1:1 counselling services.

There is evidence that the projects were successful in achieving the majority of their aims and all increased their capacity to provide additional support. In total **84** people received counselling as a result of the programme. Ad hoc comments reviewed were positive. The 'Did Not Attend Rates' in the homeless project was low for the client group (4% DNA and 12% DNA and cancellations).

In terms of extending reach, there was a focus on increasing counselling capacity to respond to an expected increase in demand, opening out services to the wider community beyond people who are known to the hospice. One project targeted people who find it difficult to receive services in-hours, one targeted 'vulnerable communities' (described as elderly

people and, Black and Minority Ethnic Communities), one hospice targeted homeless communities and the final hospice targeted 'non-hospice' clients.

Two projects used outcome scales with the intention to measure benefits [CORE and Attitude to Grief Scale], one used a bespoke approach to fit with their client group.

One hospice piloted a new role of 'Counselling Bereavement Co-ordinator' who managed the referrals as well as providing additional counselling capacity. This allowed time for the existing counsellor to focus on strategic long-term capacity planning. This hospice also recruited a sessional worker to provide out-of-hours service. The staff needed to be skilled-up in ICT as the usual ICT support contract hours were 9-5. This hospice said they were using the project to pilot and evaluate new roles as it was anticipating a need to increase capacity long term.

One hospice faced a number of challenges to attract referrals from targeted 'vulnerable communities' (care homes community, Black and Minority Ethnic communities). Their reflection was that they were unable to use their usual approach to reach out to communities due to the pandemic and being in 'lock down'. They did, however, extend their reach beyond usual hospice clients. They also reported an emotional toll on the administrator who acted as the first point of contact.

The pandemic had an impact on extending reach in some of the projects. Where this was an issue, one of the causes appeared to be around engaging stakeholders at an early stage and/or stakeholders being subsumed by the pandemic. The disruption meant usual forms of relationship building was not possible. In these geographical areas, there may be opportunities to improve co-ordination of bereavement support across providers.

Counselling for people who are homeless

A number of factors enabled this project to provide 62 sessions to seven people who were homeless despite a number of challenges.

One enabler was the counsellor's skills and approach:

"The counsellor was a trauma informed integrative counsellor, with additional online training. In particular, they offered flexibility, working with a chaotic group and not enforcing rigid appointments. Sessions had 30 minutes booked free afterwards to allow for late attendees, or those who may turn up early. This group do not wait! In the main they offered a single session model of working, always with the offer of more sessions when needed, but aimed at making use of each individual contact in case it was the only contact."
Hospice Project Lead.

Another enabler was the ability of the hospice staff to develop close and practical working relationship with other agencies. This helped practical support for clients in some of the arrangements (access to a private space for counselling, printing materials, ICT, etc.).

The hospice found they needed to have clear boundary management as they did not accept Tier 4 referrals.

The project has received additional 12 months funding from the Local Authority.

"It's given me the new version of me. It's given me confidence, a new lease of life. You have helped me find myself. I feel proud of myself."
Client Feedback

Another hospice reflected that there was: *"[a] challenge to ensure continued flow of referrals as without it there would be no case for continuing the service. We put particular effort into raising awareness regarding the new project, both amongst professionals and potential service users."* They went onto describe: *"Our early experience of setting up bereavement support for our community bereaved in May 2020 had been about needing to step forward on our own, without partners. In the early chaos of COVID we had found it impossible to identify other local or national partners for a [joined-up] response to the anticipated tsunami in bereavement need, despite all efforts. However, by the time this project phase started, from November 20 onwards, we were able to re-focus on the integration of our service with the broader system. No doubt by then the broader system had also begun to work less chaotically."*

All the hospice virtual counselling services attracted clients from outside the hospice community and therefore extended their reach to some extent. A generic reflection (excluding the counselling project for people who are homeless) was one of practice development: *"The counsellors have heard grief and loss that have been different to what they are used to".* There was a reflection that the counselling revealed pre-existing trauma for some clients. For example, another project lead reflected: *"We did not know the people referred, and some had not heard of us. We therefore, were accessing another set of community that needed the skills and services we were providing. We were also entering into traumatic grief, which is not unusual for our core service but not consistent. With this project it was consistent, and reaching a community that has been impacted by previous traumas and abuse in their life that they had not spoken about."*

Overall, the hospices said they had raised their profile within their wider communities, one commented that there was now greater integration and connection of their services with others, in part to avoid duplication.

Case vignette of a person receiving counselling as a result of the project

- 57 year old female.
- Mother died January 2021 aged 89 years in hospital.
- Client did not get to say goodbye to her mother who she cared for.
- Client was told by the hospital that her mother was "getting better" and will be ready to be discharged. To then be contacted to say she had died.
- The client has many questions, which are unresolved. In the session she is hysterically crying, and cannot accept the word "forever".

Thinks she is guilty for not pushing to have her mother be cared for by her rather than be admitted to the hospital.

Julie's experience of counselling

Julie approached the hospice on the advice of her GP, struggling to come to terms with her mum's death last year. She said:

"The bereavement support was quickly arranged and I was put in touch with J, who has been absolutely wonderful; I couldn't speak more highly of her."

Julie's GP had explained how even though you may be very close to your family it can be helpful to speak to someone outside your family or friendship network.

Julie told the hospice lead:

"We had our conversations over Zoom which has worked really well despite my original concerns. I was able to share some difficult memories and emotions I had bottled up and this was tiring. Strangely though I felt refreshed after speaking to J. She was very understanding and has helped me to see that there is no right or wrong way to grieve. It has been so helpful not to be judged and to be able to talk openly.'

Shared with permission from Julie.

5.3. Level 2 virtual bereavement support

The three groupings of projects identified at level three were: virtual peer support groups, support groups, and virtual information hubs. The differentiation between level 2 and level 1 support may overlap with some of the 'self-help' models having a greater or lesser level of support.

There were three **virtual peer support group** projects developed by two hospices. Peer support groups are groups that meet, generally weekly for a time limited period facilitated by a member of staff or suitably qualified volunteer.

One hospice ran two different peer support projects, developing one as a group targeted at bereaved parents of adult children. The targeted group emerged as a result of feedback and the hospice identifying this group as having specific needs. Matching the type of bereavement was beneficial.

This hospice ran five peer support groups in total during the period (three open, two for parents). The feedback was positive and this is a good illustration of using improvement methodology in practice.

> *"I think it is possibly better if you match up the type of bereavement. Although I agree that no one kind of loss is more important to another I think it's easier to bond if it's a shared situation."*
> **attendee at generic peer support group**

The facilitators said they found it hard to "let go" and "not fill" in the silences. They reflected their presence "forced people" to talk about their bereavement, when left to their own devices may have a different emphasis in their conversations. It is possible that that enabling a group to "form" in the virtual environment is more difficult. The project created a number of insights as its evaluation for the general group focused on understanding people's expectations.

> *".. I wasn't sure how the group would work through Zoom. It worked okay though."*
> **Peer support feedback**

> *"Isolation is [the] biggest problem with COVID, video calls don't solve it, but it's all there is."*
> **Peer support feedback**

> *"Zooming makes it much harder to read visual cues."*
> **Peer support feedback**

The bereaved parents peer support group showed the value of "trusting the process" by connecting bereaved people together to let them know they are not alone.

> *"I felt slightly overwhelmed with the grief within the room, but also a sense of relief that we were amongst people who truly understood the loss we all feel."*

The other hospice's project offered peer support to 46 people. Their reflection was that it was more stressful for clinicians to work on-line so it is important to support this aspect. The hospice recommend having ICT on hand for the initial group. They said they felt many people did not want to access the group, preferring individual support via phone or face to face.

Two other hospices had projects that created **virtual bereavement information hubs**. Bereavement information hubs are usually volunteer facilitated "drop-in" sessions to learn more about bereavement. Some people may choose to attend more than once to gain support from peers. It is a more informal model than peer support.

One hospice aimed to create targeted information hubs: one for men and another for care home staff and residents' families. Neither attracted the anticipated interest. The planned information hub for care homes was affected by the pandemic and highlighted

the importance of developing relationships with key stakeholders before starting projects. The planned information hub for men was trialled but did not gain sufficient interest, the proposed reason is that men would prefer face to face sessions. This hospice decided to focus its efforts on other projects that were gaining more traction.

The other hospice aligned their information hubs' development with local carers organisations. This hospice provided 68 people with support and their information hubs were led by hospice volunteers and people working in the carer organisations. There was ad hoc positive feedback from attendees. This approach set out a clear shared aim and built upon existing relationships. The carer support organisations contributed to advertising and communicating the sessions to people who could benefit. The hospice delivered three online training sessions for 30 volunteers, including those working for the carer organisations on 'listening skills' that were well evaluated.

Two comments reflect the feedback:

> "great help to those who attend and us as an organisation in terms of the support we can offer. A great joint venture with sharing of expertise and skills. We hope very much we can continue to support carers in this way".
> **Attendee from the carer support organisation.**

> "Only comment is would like more online training occasionally as its difficult for me to get to [the hospice]. I have to catch several buses. …. But would look forward to when we could all meet up again."

The hospice had 454 unique views of the dedicated information page about the hubs. The bereavement team worked closely with their ICT team to source tablets for volunteers or visitors to provide access. The ICT team were also able to help people on how to use zoom if needed.

2 Paired students t-test

5.4. Level 1 virtual bereavement support

There were a range of projects providing level 1 virtual bereavement support. Two hospices developed a public health approach and **virtually trained people in the local community to support those who are bereaved.** The potential benefits of this approach is that it creates capacity for support for everyone who is bereaved and new reach into communities. One of the projects was open to members of the public, so may have trained people who were themselves bereaved.

One of the projects demonstrated a statistically significant[2] increase in participants' confidence in supporting bereaved adults and to signposting complex grief and post-traumatic stress disorder (n=5 of 30 participants). They also developed an information sheet on the local and national bereavement support options for the attendees. There was a lot of interest in their course and it has helped the hospice to create a stronger connection with the local area's bereavement forum.

What I will do differently:

> "Have more of a plan in place to encourage clients to talk about their grief e.g. talking about their memories but also encouraging them to be present."
> **Feedback after attending a Hospice-led virtual training course**

The other project's feedback also indicated that the workshop has increased confidence to support people who are bereaved. This project's success was based on creating a partnership with their local premiership football club. The football club's staff, who work in the community, attended the training and enabled an opportunity for staff working in primary schools to attend training. They had an ambition to extend their reach to men, and a long-term benefit of the project is connecting bereavement to the

football club's mental health programme for men and a longer term partnership. They benefited from the 'Children and grief' webinar to develop the content of their workshop for schools.

Examples of feedback are:

> "Very informative, and I liked that it is very real and honest. The ladies who ran the session were great too – friendly, approachable & open!"

> "I had already gone through the experiences with my own children losing their dad so I was more intrigued as to how you would tackle grief. I was really pleased as you were spot on. My daughter is now 4 years forward and a wiser 14 year old. She believes schools are not prepared or equipped in general when it comes to this topic. She has seen many children since her dad died having to experience what is essentially a 'social stigma' and to watch teachers handle it in a terrible way. I would like all schools to have this training as compulsory."

Staff working in both projects gained experience of developing and delivering an interactive course, and technical aspects of the virtual platform for the first time

Two hospices had projects that targeted a 'health literacy' model for people who are bereaved – **a 'self-help' approach.** One project did not attract the expected audience in their first workshop (n=3) for bereaved people known to the hospice and decided to discontinue. The other hospice used on-line booking so people could refer themselves (via Eventbrite) or could be referred by others, and multiple communication streams to advertise their sessions. Word-of-mouth was powerful. 43 per cent of the audience represented 'extended reach'. The feedback indicated attendees better knew what to expect from their bereavement (n=38, 53 attended, 77 booked).

With the gift of hindsight, the hospice lead wished they had done real time monitoring on how people found out about the session. *"During busy, pandemic times, it was difficult to get hold of the 'right' people in the system. Once information was sent we did not know how this was being disseminated."* This would have identified earlier that the hospital was not generating the anticipated interest. It was clear from the project report that the leads reviewed all feedback they received and adjusted their approach in line with 'PDSA' methodology. This hospice also created a system to loan out iPads and provide support for people who did not have access to technology. They felt their learning and confidence in working virtually had grown so much they were now in a position to consider more formal peer support and structured therapy groups.

> "Very informative. Felt relaxed. The small group session was very helpful, was good to hear other people's stories and add your comments."
>
> "I enjoyed speaking openly to 'strangers' as I have founded it hard to confide in those around me who wish to support me - especially some of my friends as they respond with 'oh yes I am missing him too."
>
> "The time in the breakout rooms was really valuable. It was nice to be able to speak to others going through a similar situations."
>
> **Feedback from virtual workshops**

> "People are thirsty for connection. Anything that helps people to connect is worth following up."
> **Hospice project lead.**

This project appeared to create some new connections: social prescribers, the Job Centre and local drug and alcohol service. The project initially thought that it may have generated new

referrals for their bereavement services. An analysis of the data[3] shows that there was an unusual referral pattern, possibly fewer referrals occurring during periods of 'lockdown'.

There were three projects, developed by two hospices that had **activity based groups** as a way to connect people in their bereavement. There were two writing groups and one mindfulness taster sessions. Two of the projects were emergent and set up due to the growing confidence of working in the on-line environment. One project had a formal outcome evaluation that demonstrated improvements (CORE and Grief Intensity scale). The ad hoc feedback for the other projects was positive.

One of the hospices researched the topic and designed their course from scratch. Their observation is that naturally not everyone will write in-between the weekly sessions. They made a physical connection to the participants by providing pens and journals. This hospice felt they have a greater understanding of the therapeutic benefits of writing.

My memories are like a river—that is influenced by the weather of my mood.

Sometimes the river is bright, sparkling and invites me in to float around but usually once I'm in the river it changes and becomes rough with waves that wash over me and currents that threaten to pull me under.

Generally, I look at the river from a distance—attracted to it but scared off by the risk of wading in and it changing again. So I watch and loiter nearby, wondering how long it'll be before I can just jump in and swim with the same carefree feeling of the past.

Writing after session 4.

"I'd like to thank everyone for the group – it's helped me to feel less mad and a little less alone."
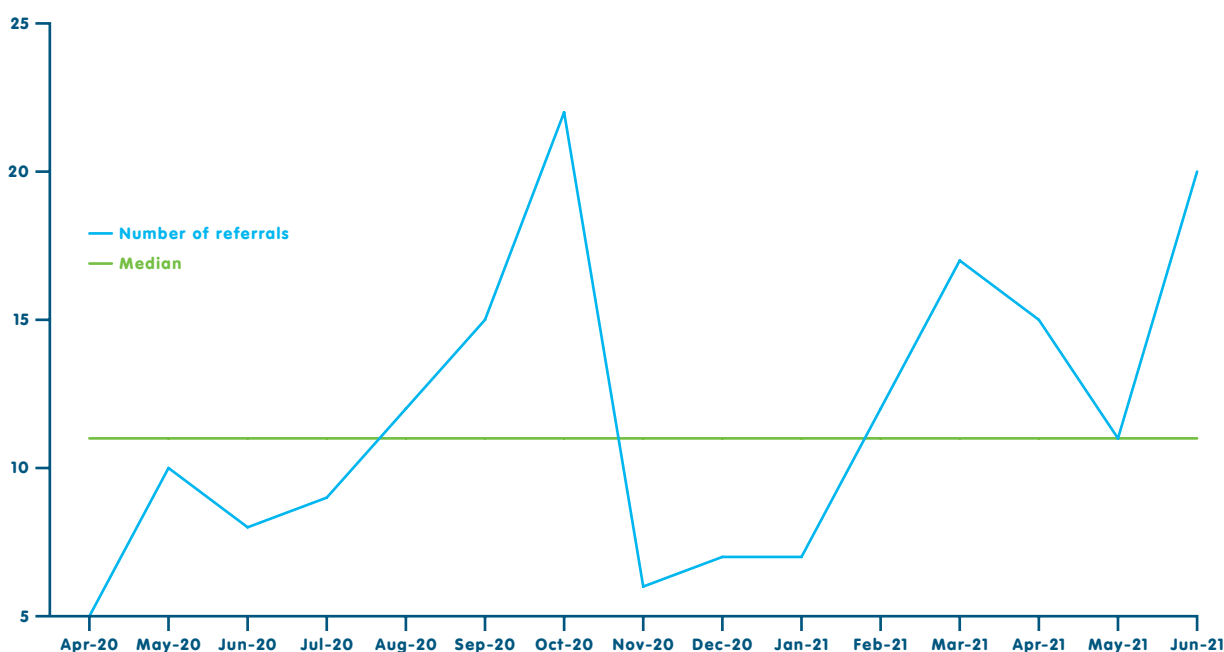
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3 Run chart analysis: too few runs

Figure 9 Number of bereavement referrals in one hospice

> *"Despite being on screen in our little boxes, I do feel a connection to others as we write together. A little bit more of people's stories unfold each week. These moments feel like an outstretched arm. An invisible thread into their world, and a bridge of connection to the outside world. I have missed connection so much, which makes me extremely grateful for this space."*

> *One site commented on their journal writing group: "Each group will be its own thing, and content/ timings may be tweaked accordingly for maximum effectiveness. And another commented that you need to 'enable the groups to support each other."*

The mindfulness course encouraged people to do daily practice and acted as a monthly taster session. An example of feedback showed the potential benefit:

> *"A daily practice has helped in many ways. Through times of panic, fear, anxiety, overwhelm, helping to slow down my brain and be in the moment … having your guided recording is perfect."*

One of the challenges highlighted was advertising and marketing – how do you spread the word about new services that are open to all [in lockdown]? Although technology was felt to be a challenge and barrier for some, it was also felt that it could enable access for others. The hospice lead's reflection was:

> *"Trust the process, a reminder rather than a learning that human connection is the key element to support and healing."*

Another **self-help group** was *virtual storytelling for children under the age of eight.* The target audience was children and their parents for whom virtual 1:1 counselling via Zoom or telephone, has not been appropriate. They posted a series of four 'story time videos', supporting information and live web chat on-line. Five hundred and fifteen people watched the videos in total and they have received ad hoc positive feedback from professionals. However, their livestream event was not well attended. The hospice created good partner relationships with their local university and opened up the opportunity for future digital projects. There was substantial learning for the hospice which noted *at the start of the service [the hospice] had little presence on social media,* and found that it was a time resource project – time to script, film and edit. Lockdown created additional practical hurdles.

There is a feeling that there is a place for this type of resource to be posted online to aid communication about grief and loss with children. As the project was not able to be evaluated or co-designed with parents or professionals working with children, it is difficult to know what proportion beyond the four people who gave feedback, felt it helped them. The hospice plans to reconnect with schools and others who work with children in the future. All the videos remain in the public domain.

One hospice used the programme as an opportunity to do a live stream of their annual **remembrance service**. They also posted the video of the service online to allow people who could not attend live to see and comment if they wish. More people attended (52 compared to 40 in the previous year) and they had 248 views in total on YouTube. One of their top tips is *"Don't be afraid to try new things i.e., technology".*

A number of the hospices updated the bereavement information pages on their websites. For some this was focused on wider communication about their project, while others focused on either refreshing or updating the information for self-help and getting bereavement support. Some hospices developed on-line booking systems for people to access their support.

6. Discussion and learning

The programme refocused its aims in response to the requirements and recommendations of the hospices and expert Reference Group. The result is a diverse range of projects focusing on delivering direct or indirect virtual support to people who are bereaved. The diversity provides a rich platform for learning.

The demand for bereavement and counselling services is likely to continue. Increasing capacity at all levels is important, ensuring there are mechanisms to give or refer on for extra support if needed.

6.1. Virtual technology and providing support to people who are bereaved

More than 270 bereaved people have been directly supported through this pilot programme. A range of different support models have been developed and tested in a virtual environment with indications of benefits. There is "no single gold standard" bereavement support delivered via virtual technology, instead a range of support models and approaches that appear to work:

● Counselling including counselling for people who are homeless.

● Peer support models for bereaved groups.

● Bereavement information hubs.

● Skilling up professionals about bereavement.

● Developing health literacy, self-help and general knowledge and how to support people who are bereaved.

● Activity based groups.

● Live streaming and/or posting video of rememberance services.

One hospice lead, after reviewing and reflecting on feedback from one of her projects said said: *"this encouraging feedback highlights that group-based video support can help people feel connected, happier and more at peace."*

This hospice described their starting point as *"our experience and confidence in delivering such support in a virtual context was limited but we knew that technological innovations provided a good option to explore as a solution."*

Some people will prefer face-to-face support others may prefer virtual. A blended approach will avoid creating barriers to either preference. The potential advantages of the virtual environment is it:

● Extends *'the reach'* for those who are unable to travel easily (physically or because of time constraints).

● Could create more opportunities to connect people with similar interests or experiences together.

● Effective way to train and support professionals to develop their skills and knowledge without the cost of travel and hosting and to connect expertise.

● Potential to save travel time for staff, volunteers and patients.

● Some people prefer the virtual environment and for them it has become the norm.

The disadvantages include:

● Communication isn't as easy and there is no opportunity to offer 'touch' to give support. This may affect the ability of new groups to form.

● Implications for staff support and well-being, especially when combined with substantial home-working.

● The extra resource and cost to loan out ICT equipment for those who don't have access and supporting those who are not confident.

● Some groups need two facilitators or at least one facilitator and an administrator to support the technical aspects.

● Training and adaptation is required – it's not as simple as transferring what you do face-to-face to a virtual environment.

Central to this is the insight *"Trust the approach"*. The emphasis is on bringing people who are bereaved together to enable the support regardless of mode of delivery. As working and living in the virtual environment has become part of many people's lives, continuing bereavement support and training through this media should continue to be part of the bereavement support offer from hospices.

Practical tips: virtual environment for groups

- Design the session to be interactive and allow for the group to form.

- Overbook sessions to accomodate last minute cancellations.

- Advertise an earlier start time than actual start time in order to start on time.

- Invest in training for administrative staff to support ICT.

- Ensure there is someone (e.g. administrator) to manage technical/ support aspects before and during the session.

- Return rates for electronic evaluations are low if you send these out after the training session - incorporate time for this at the end similar to face-to-face training.

- Use group emails to manage enquiries / Eventbrite or online booking saves time.

- Be adventurous in marketing for open courses and encourage word-of-mouth.

- Ensure you have a mechanism to support people who need more help.

- Don't underestimate basic internal ICT processes/ different proficiencies of practitioner and recipients of bereavement support.

6.2. Training and skills development

One hundred and twenty three hospice staff and volunteers have developed their skills and understanding around bereavement. The emphasis moved away from hospice staff dealing with symptoms of complex grief and post-traumatic stress disorder to being able to recognise symptoms of complicated grief and be able to onward refer. The programme has gone beyond hospice staff in this respect, with professionals working with bereaved people having a greater understanding of this. It appears that for some bereavement during the pandemic is exposing previous trauma that is affecting their bereavement.

The greatest area of development has focused on practice learning in providing support for people who are not known to the hospice where their loved one has died of an unexpected death.

Another learning point is from the training provided on childhood grief. This generated an understanding that it is important for all bereavement services in hospices to understand grief in childhood as well as adulthood – families who are bereaved often consist of adults, young people and children of all ages. This is regardless of being an 'adult' or 'child' hospice service provider.

The programme also highlighted the potential role hospices have to work with communities and professionals to develop their confidence in supporting people who are bereaved. This is an important development opportunity to increase capacity in particular in level 1 and level 2 support and enabling people to come forward in the future. The virtual environment has the opportunity to widen access, keep venue costs down and reduce travel time.

*"Going forward we will look at offering a mixture of online and face to face training as we recognise that **online training can be more accessible** for professionals."*
Hospice lead.

6.3. Extending the reach beyond traditional hospice community

The majority of the hospices were able to reach beyond their traditional hospice community. While some projects did not reach specific targeted groups, they have contributed to the collective learning.

The barriers occurred when there were few pre-pandemic relationships with potential partner organisations and it was unclear who was the lead. The pandemic prevented the usual approach of meeting community groups and services such as care homes to understand needs and create practical working relationships.

Practical partnership working with other frontline services can enable greater access to services as seen in the homelessness project to provide counselling to a community who experience multiple challenges and barriers to access counselling. The model and approach the hospice developed may be replicable.

Similarly information hubs being co-delivered with carer support organisations enabled one hospice to reach out to carers in their communities.

Realising the potential to connect with a football club foundation enabled one hospice to quickly align its project focus and create a 'shared purpose' with the foundation's 'improving mental health for men' and 'health of children' programmes. This collaboration extended their reach out to men and primary schools.

It felt that as teams created a reputation for providing good models of support or training, new opportunities and connections were created. An example is of one hospice being invited to present a webinar to 250 care home leads.

There is still a need to learn around creating effective virtual support with Care Homes, and Black and Minority Ethnic Communities. Other providers in the community such as Home Care may also benefit from proactive support.

6.4. Enabling system change to provide virtual bereavement support

A number of projects faced challenges in connecting with and/ or communicating their projects to wider stakeholders, and these challenges were amplified by the pandemic. There was a sense that in some geographies it was unclear who was taking responsibility for "central co-ordination of locally delivered bereavement support" [16]. Creating this is important for the future, especially if the demand for support and services grows as expected.

ECHO™ Networks are a potential model to offer an infrastructure for locality coordination and developing knowledge and skills. Or different models such as buddying or areas of particular common developmental interest. It is important that all organisations reach out and create a clear shared purpose.

Innovative partnerships outside traditional health and social care services have enabled new reach and bypassed some of the pandemic barriers experienced by other hospices. Hospices have the advantage of agility compared to larger organisations.

6.5. Programme approach and prototyping methodology

The ECHO™ network and programme approach provided an important and safe learning environment for the hospice leads. It enabled peers to share knowledge and experience and supported rapid learning and sustainability.

The model for improvement is a recognised and established methodology in use in health services in the UK and internationally. When used well, the approach provides rigour and flexibility to evolve and learn about what works and doesn't work in the local context [20]. The combination of the short lead in time for the programme and the additional challenges of the pandemic reduced the time available for

all leads to optimise their understanding of the method. However, there was good evidence that the approach helped – creating a 'forced function' to plan and carry out real-time evaluation. Some specific tools were viewed as being particularly important such as stakeholder mapping and management.

The programme learning reinforces the importance of co-design and understanding all stakeholders' perspectives to develop change ideas. In addition, there is some specific learning about how to collect outcome measures in the virtual environment. For example, aim to integrate feedback or outcome measurement data collection into the session, use short and simple measures for the feedback (e.g. grief attitude scale, one or two open ended questions). Across a programme, there are benefits to work towards consistent yet meaningful measurement for similar interventions to optimise learning about what works.

There is a recognition that rapid prototyping takes time and resource, some of the new models needed additional staff to be recruited to work alongside the existing services.

7. Conclusions

There are positive indications that the programme benefited a number of people who are bereaved and people who support those who are bereaved, and skilling up hospice staff and volunteers to provide bereavement support in a virtual environment. It has created a boarder remit and included training people working and living in communities to support the bereaved.

The design of the programme allowed the hospice leads to develop projects that met their understanding of local needs within the programme timescales. This was in the context of extended national lock-downs which disrupted many practical aspects of life. Although some feedback indicates a wish to return to face-to-face bereavement services and support, it is clear the pandemic has created a step-change in use of virtual support and virtual working. The world hasn't stayed still. Many organisations and hospices outside this programme have been using video-conferencing and virtual working. This programme provides additional insights and a replicable methodological approach using the learning shared in the Hospice UK online resources [2].

The need to develop and increase the capacity and capability of bereavement care and support at all levels of need as part of the response to the pandemic remains [13]. A blended approach that builds on virtual support and training models alongside face-to-face support models is important to future-proof services and support for future generations. Hospices have a lot to offer as they focus on 'extending their reach' beyond the traditional hospice clients as part of a shared aim to reduce inequalities in bereavement [21]. They have expertise and existing connections to communities and professionals. A meaningful approach will require hospices to be proactive, understand their local communities' needs, what is already

on offer and opportunities for partnership working that can facilitate and enable improved outcomes. A community can be virtually or geographically focused, where people live, work or socialise.

"The pandemic is going to impact on millions of people's grief for many years to come. It is imperative we ensure that bereaved people receive the correct support for their needs to prevent prolonged grief disorder and other problems."
Dr Lucy Selman, 2021. [22]

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