**NHS Education for Scotland**

**Transcript of ‘Bereavement During COVID-19: The experiences of those bereaved and the voluntary sector services supporting them’**

**NES Bereavement Conference 2021 session recording**

**Speakers**:

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* Dr Emily Harrop, Research Associate, Cardiff University

**Chair**:Dr Graham Whyte, Associate Postgraduate Dean for Grief and Bereavement, NHS Education for Scotland

Graham Whyte (GW): I'd like to welcome Dr Lucy Selman and Dr Emily Harrop. Morning, there we go. Dr Lucy Selman's an Associate Professor of Palliative and End of Life Care at the University of Bristol. Her research over the last 16 years focused on experiences of serious illness and end of life and bereavement care. And Lucy has been one of the principal investigators of the Bereavement During COVID study, as well as conducting a fellowship on communication and treatment decision-making in advanced kidney disease. She's also very, has been one of the founders of the Good Grief Festival, which is a public-facing initiative that some of you may well have heard of around grief and bereavement.

And Emily is a Research Fellow at the Marie Curie Research Centre in Cardiff. She's a Qualitative Social Scientist working in palliative care, and her primary research interests are bereavement and the support needs of family carers, patient and family experiences living with advanced illnesses, and as I said, she's also co-leading the Bereavement During COVID-19 study. So we're very much looking forward to hearing your thoughts today.

Emily Harrop (EH): Thank you for the opportunity to talk today about our research. Myself and Lucy are both going to be presenting. I'm going to start off by presenting about one side of the study which looked at people's bereavement experiences during COVID-19, and then I'll be handing over later on in the presentation to Lucy who'll talk about voluntary sector experiences.

So I'll start by briefly giving some background to the study. As we entered lockdown in March 2020, a time of rapidly increasing death rates in the UK and across the world, we began to consider the consequences of the pandemic for grief experiences and bereavement support responses. I don't think back then we expected the death rates to have climbed nearly so high, around 143,000 to date in the UK now, or for the pandemic to still be ongoing, but we anticipated there to be considerable repercussions for bereaved people and support systems at this time.

It wasn't just the high numbers of deaths and bereavements that was a concern. Obviously, now estimated around eight and a half million people bereaved in the UK during the pandemic, but also the unprecedented social and clinical restrictions that came into place, and by their nature were likely to act as risk factors for poor bereavement outcomes. These included sudden unexpected deaths, difficult end of life experiences, restricted funerals and mourning practices, limited social support and wider social and economic disruption. And of course, with many of these factors affecting all people bereaved at this time, not just families of those who died from COVID. However, there was very little in the way of evidence from previous pandemics which could, you know inform responses at this time. So that was the context for us, you know, designing and applying for funding for our study, which we were really pleased to get funding from the SRC. And yeah, so the study has two main aims, the first being to document the grief experiences, the support needs and the use of bereavement support by people bereaved during the COVID-19 pandemic, and there are two sort of main strands of work relating to this aim, the first being a longitudinal online survey of people bereaved since the 16th of March 2020 up until January 2021, when we closed the survey. And that's a three-round survey with follow-ups at seven months post-death and 13 months post-death. And then also a much smaller number of qualitative interviews with survey participants.

And then the second aim has been to try and understand the adaptations, the challenges, and then the innovation involved in delivering equitable bereavement support during the pandemic. And we've done this through a cross-sectional online survey of bereavement services, which we conducted from March to mid-May this year, and then also through qualitative interviews with a number of case study organisations to explore these experiences in more depth. And then, you know, running throughout the study, another a real sort of key aim for us has been to make sure that we are really feeding back our results as quickly as we can to try and inform end of life care processes. [*Section of the audio lost*] so that's been critical to this study.

So we have several publications available already and we have another couple of pre-prints that we're going to be releasing very soon as well. I've put the links up here but they can also be found on our easier to remember study website [www.covidbereavement.com](http://www.covidbereavement.com). And today we're going to be talking about results mainly from the second and third papers on this list, as well as not yet released results on the voluntary sector experiences, which Lucy is going to talk about, and some of the more detailed qualitative results that we have on people's bereavement experiences.

So I'll start by giving a brief overview of our participant characteristics in our baseline survey of bereaved people, so this was the first survey round, and it's these results I'm going to be talking about today. We had 711 people take part in the survey. Almost 90% of the participants were female, so it was very under representative of men, and our mean age was 49. Just over half of participants had lost parents, followed by a partner or spouse, and around 5% self-identified as from a minority ethnic background, so we were underrepresented here as well. The most common cause of death was from confirmed or suspected COVID-19, followed by cancer, with most people dying in a hospital. But participants were represented across geographical area in the UK, and also socioeconomic status and levels of education.

So, in the first part of the baseline survey, our participants were asked about their experiences of end of life care. Experiences were mixed, but a fairly high proportion of people experienced what would be considered a suboptimal end of life care, which you can see in the overall responses to these questions. So, 22% of respondents said they were never involved in decisions about the care of their loved one, although 22% said they were always involved. 18% said they were not at all informed about the approaching death, with 32% said they were fully informed and 35% felt not at all supported by healthcare professionals immediately after the death. 45% were not contacted by the hospital or care provider after the death, and 48% were not provided with any information about bereavement support.

In the survey, we also wanted to identify the extent of what could be considered pandemic-specific death in early bereavement experiences. We included six items in this relating to contact and saying goodbye prior to the death as well as funeral restrictions and social isolation. And we can see here that the restrictions placed on family visiting in health and care settings, funerals and everyday social interaction affected almost all participants in some ways, with 50%, so half of people having five or six of these experiences. And with the most commonly reported of these were restricted funerals by over 90% followed by limited contact with other close relatives or friends at around 80%, and then also 67% of people reporting loneliness and social isolation.

In our statistical analysis, we wanted to identify different factors affecting these experiences of end of life care and early bereavement, and one of the factors that we found was related to place of death, so where they died, whether it was hospital or care home, hospice, or home setting to be a key factor. Deaths in hospitals and care homes increased the likelihood of being unable to visit prior to death, say goodbye, and having limited contact with other friends or family in the last days of life, I suppose, as you might expect, really. Hospital deaths also decreased the likelihood of knowing the contact details for the responsible care professional. So we saw on the previous slide, that was, you know, that was quite a problem for people. People whose relatives died in hospice or at home were more likely to be involved in care decisions and feel well-supported by healthcare professionals after the death, so they had slightly better experiences on these outcomes. And hospice deaths also increased the likelihood of being given bereavement support information, and this was least likely for care home deaths.

Other factors that we found to have statistically significant effect on these end of life outcomes were cause of death, whether the death was expected or not, and the relationship of the person to the deceased. So, bereavement due to COVID-19 compared to all other types of death decreased the likelihood of being involved in care decisions and feeling well supported by healthcare professionals after the death, and it also increased the likelihood of being unable to say goodbye. Interestingly, and perhaps more surprisingly, we also found that COVID-19 deaths were associated with higher levels of social isolation and loneliness as well as limited contact with relatives and friends. Expected deaths, for example cancer or other terminal illnesses were associated with higher likelihood of feeling involved in decisions and being informed about the patient condition, as well as feeling well-supported by healthcare professionals following the death. If the deceased person was the partner or a child, then the bereaved person was also more likely to know the contact details for the responsible care professional, were more likely to be able to visit and be given bereavement support information. However, we also found that being a bereaved partner strongly increased the odds of social isolation and loneliness. They're much more likely to experience social isolation and loneliness after the death, which again, you know, you might expect this to be the case.

So, I'm now going to talk a little bit about some of the themes from the qualitative free-text data. So these were where participants wrote about their experiences in the survey. And these provide really illustrative examples of the huge strain and the challenges that the health systems faced during the pandemic. We can see this in the often, you know, really quite detailed descriptions that people gave us of communication problems that they experienced with the different healthcare settings. People describe difficulty getting information about their loved one, sometimes due to not being able to find out where they were or to be able to get the correct contact numbers for the wards, or people, or due to their calls not being returned and there being quite infrequent updates on the patient condition.

People also gave examples of misinformation concerning the patient's condition and care, as well as hospital policies and processes for matters such as visiting or PPE requirements, collecting belongings and death certificates, which cause people quite a lot of stress and upset. And some people also gave examples of what they considered to be insensitive language and behaviours, as well as a lack of involvement in care or treatment decisions.

However, there were more positive examples given too, and descriptions of these more positive experiences tended to include a sense that staff were doing their best, that they were showing compassion and kindness despite the really difficult sets of circumstances that they were in. If there were flexible, more flexible visiting arrangements, these were commented on very favourably, and also relatives feeling that they were kept well-informed about their loved one's condition and care. Quite often, these, more better experiences were related to hospice care or specialist palliative care involvement, which, you know, is consistent with the quantitative data that I've just described, but not always, and actually the extract we can see here from the daughter was from the bereaved daughter who lost a parent to COVID-19 in hospital. You can see that there were some positive examples in these settings too, with this quote really highlighting how much that feeling of being given time and empathy meant to families going through this. People always also gave quite detailed descriptions of the impacts that these end of life experiences then go on to have on their grieving process. People described the, you know, quite long-lasting distress and guilt that they felt by being unable to say goodbye or to be able to provide comfort to the, to their family member. And for some also, people also described, you know, the trauma of when they were able to witness the death remotely, this was quite a traumatic experience for some people.

And as you can see in this extract from a bereaved sister being unable to host what would be considered conventional funeral services or, you know, wakes, being unable to share stories and celebrate the life of their loved ones was also, you know, highly distressing at the time, but also causing more long-lasting feelings of guilt and regret. And people talked about how this made it quite difficult for them to find closure and begin to grieve when they felt they hadn't had, hadn't been able to have the kind of send off that they would've wanted to. And people commented also about the distress they felt when having to travel to the crematorium alone in some cases, having to sit apart from other family members, and also returning home to empty houses was also, you know, a deeply distressing experience for people. Similarly, there were lots of examples given of how lockdown and social distancing restrictions during early bereavement disrupted the support that they needed from friends and family, also perceived to be affecting their grieving process.

So people, in their comments, people bereaved by COVID-19 also described what could be considered additional anxieties and stresses and these related to things like anxiety relating to catching or spreading the virus to other more vulnerable family members, you know, worrying about further bereavements and the distress caused by other people questioning the, the virus, questioning the virus and not observing social distancing rules. People felt very angry towards how they perceived the government to be handling the pandemic and to not have done enough to prevent it and also to the behaviours of other people. So it had quite an alienating effect on them really and compounded their feelings of social isolation and loneliness. And the need to share experience with others who had been through the same was also commented on quite widely with lots of people reflecting on just how unique this experience was and the difficulties that anyone else would've faced trying to understand what they were going through. And we can see this anger and this fear expressed in this quote from a daughter whose mother died of COVID, and the perceived obstacles that this was creating for them in their grieving process. As she quite powerfully writes, you know, "How can I grieve when I'm terrified and trying to protect her sons?"

So what do we know about how these experiences have affected people's need for support and their sort of vulnerability? To quantitatively investigate people's supports needs, we've looked at people's perceived needs for help across 13 practical and emotional domains using a five point scale measuring high to no level of need. And this table shows the percentage of people experiencing high or fairly high-level needs for each of the items. And we can see that emotional support needs were, you know, higher than practical needs, and that between 50 to 60% of people reported high or fairly high needs in six of the emotional domains. And these included help with processing feelings surrounding the death and loss, anxiety and depression, and needs relating to communicating and connecting with friends and family. Which would suggest, you know, considerable needs for social and emotional support as well as for more formal grief-focused support. So are people getting the support that they need? Well, this triangle depicts the public health model of bereavement care, which is very similar to the NICE three-component model which some people may also be familiar with. The diagram given here gives pre-pandemic estimates of the proportions of the bereaved population in low-risk groups, so around 60%, moderate risk groups around 30%, and high risk groups around 10%. So that's how you would normally expect the population, bereaved population to be distributed. And then this was confirmed in a 2015 Australian survey, which is where this diagram's taken from, which gives the confirmed proportions in red.

But the reason I'm showing it here is it's quite useful for sort of illustrating the different types of support that typically needed by different groups of people with different levels of need. So the bottom tier, tier one, the low-risk group includes universal access to information on grief and available support as well as informal support from social and community networks. The second tier for those with moderate needs includes structured reflective support, which is often led by trained volunteers, or it can be in individual or group settings. And then the third tier includes specialist grief, mental health and psychological interventions, which would be targeted at the small minority of people identified as at high risk of prolonged grief disorder.

So in our study, we found that just over half of our participants demonstrated high or severe vulnerability in grief using the Attitude to Grief Scale, and strikingly, that 74% of participants in these two high-risk groups were not accessing the type of formal tier two or tier three support, so the two top tiers in the triangle, which, based on this model and previous evidence, might be expected to help them, so it would suggest [*Section of the audio lost]*. We also felt that this next finding stood out that only 29% of respondents in our sample reported not to have needed bereavement services because their friends and family provide them with enough support, which is obviously quite a big difference from the 60% estimation in tier one of the pre-pandemic triangle. And I'm now going to go on to sort of briefly discuss some of the difficulties people have faced with both formal and informal sources of support during the pandemic.

Okay, so what explains this relatively low uptake of formal support despite apparently high levels of need? We found that as many as 60% of the people hadn’t tried to access support from bereavement services, including around a half of those in high-risk groups, but we also found that of those who had sought support, 56% experienced difficulties accessing these services. And reasons that people selected to explain why they didn't try included 27% of people feeling uncomfortable asking for support, and 18% being unsure if it will be of help to them. 15% of people said that the support that they wanted wasn't available to them whilst 14% reported a lack of knowledge of how to access this type of support and, you know, this relates to the finding on the slide also that 50% of people hadn't been given any information about bereavement support.

More detailed insights were provided in the qualitative data, particularly around the availability of appropriate support and what is appropriate support. Although many of the people who received telephone or web-based support described positive experiences, we also found that a fair proportion of people felt, described how they felt uncomfortable discussing sensitive and personal matters remotely. Some people also perceived a need for COVID-19 loss-specific support rather than more generic bereavement support which reflected the kind of complexities of pandemic bereavement. And people also talked about needs for culturally relevant and group-specific support for those with similar experiences. And then another interesting, you know, sad pandemic-specific barrier that we identified in the qualitative data were examples of people who lost elderly parents to long-term illnesses and sometimes also to COVID-19, who explained how they felt less entitled or worthy of support given the perceived greater needs of others and the heavy demand being placed on services as a result of the pandemic.

Most, so yes, most people were supported by friends and family, around 90%, but around 40% of people also reported difficulties getting this support. A quarter of people reported that their friends or family were unable to support them in the way that they wanted, whilst a fifth of people reported feeling uncomfortable asking for help. And a number of themes were again identified in the qualitative data, which helped explain and expand on some of these statistics. The first of these related to difficulties connecting and communicating with friends and family and the challenges posed by social distancing and lockdown requirements. People described how they missed being able to hug their friends and family as well as difficulties they experienced talking openly about their feelings, especially over the phone or internet. And a general lack of understanding and empathy was commonly described. And as this quote from a bereaved daughter illustrates, people also described how the exceptional nature of COVID bereavement, including the anger associated with it, made it impossible for other people to understand, really affecting their loneliness and isolation. And due to the widespread stress caused by this pandemic, people also worried about adding to the emotional and mental health burden of friends and family who had their own issues to deal with.

So to briefly conclude this first part of the presentation, we feel that these results, you know, first and foremost, highlight the exceptionally difficult sets of experiences associated with pandemic bereavement, with high levels of disruption, of disruption to end of life, death and mourning practices, as well as people's social networks and coping mechanisms. We've identified quite high-level needs for emotional and therapeutic support and also described significant difficulties that bereaved people face getting these met. So, yeah, whilst in some respects, we feel that our results elaborate on pre-pandemic inadequacies with formal and informal support, they also suggest some new pandemic-specific challenges. And yeah, based on these findings, we've made three sort of key recommendations for improving the support available for bereaved people. First for increased resourcing and provision of services as well as the tailoring of services to meet the diverse needs and backgrounds of bereaved people including support, which is culturally and crisis competent, and group-based support for those with shared experiences and characteristics. Secondly, to raise awareness and understanding of different support options and how they can help. Information on grief and bereavement services need to be provided proactively following a death and made available in online and community settings, with GPs and other primary care providers better resourced to signpost to appropriate support. And finally, following compassionate communities types approaches, we also recommend expanded provision of informal community-based support and activities to help with the high levels of loneliness and isolation experienced whilst longer-term education and society-level initiatives are needed to improve how we communicate and support people experiencing death, dying and bereavement. And I'm going to hand over to Lucy now.

Lucy Selman (LS): Thank you very much, Emily. I'm really delighted to be with you here today and I'm going to spend the next few minutes talking to you about some of the findings from our survey of bereavement services, which, as Emily flagged at the beginning, was really aiming to understand the impact of COVID-19 on voluntary and community sector bereavement services. The survey included participants from 147 bereavement services and we included services which were part-funded by the NHS, but not those wholly within the NHS, as we were particularly interested in exploring the impact on charitable bereavement services, which really play a key role in the sector in the UK. Participants were usually managers or bereavement leads or counsellors and we asked one person per organisation to complete the survey, going to others as needed for additional information for key questions within the survey. So 53% of the bereavement services represented serve specific counties or smaller regions such as clinical commissioning groups. 16% were UK-wide, and we had one service which was specific just to Scotland. 36% of organisations were hospice or palliative care services, 15% national bereavement charities or NGOs and 12% local bereavement charities. 68% of the services provided support following all causes of death and 33% after specific causes of death. So these are things like life-limiting conditions, sudden death, suicide, stillbirth and neonatal death.

There were real variations in how referrals had changed during the pandemic, so 46% of services said that demand was higher than usual and 35% that demand was lower than usual. We actually have more detailed data which we'll be unpicking over the next few weeks which really explores the patterns of referrals throughout the pandemic because many services saw a drop initially at the beginning of the pandemic and then later on an increase later in the later months of 2020 and in early 2021. In terms of the waiting lists, you can see here on the pie chart, 40% reported they had no waiting list, 20% that their waiting list was less than three weeks and 26% a waiting list of between two and four months, sorry, three weeks to two months, and 8.2% two months to four months.

So one of the main aims of the survey was to explore the impact of COVID-19 on services and what was really clear was that services had really done a huge amount in terms of changing their services and introducing new services. So 78.2% said they changed their services completely due to COVID-19 or adapted them, and over half said they'd introduced new services. In particular, as you'd expect, there was a significant reduction in the provision of all face-to-face support, and this included, for example, peer group meetings, which fell from 50% of services offering those to just 4.1% during the pandemic. Facilitated group meetings, so this would be with a trained coordinator, these dropped from 78% to 11%. One-to-one support, similarly from 87% to 27%, and specialist mental health intervention from 44% to 16%. In addition, online and telephone provisions saw major increases. So these are some of the data for the online support and we saw a rise from just 8.8% of services offering online one-to-one support to 83% of services offering that. Facilitated group meetings were offered online. This jumped from 4.1% of services offering these up to 56%, and online mental health specialist intervention from 3.4% up to 36%.

We were particularly interested in exploring equity and access to bereavement support, as there's evidence from previous research that not everyone who could benefit from support actually accesses it, for a whole variety of different reasons. We asked people if there were groups of people with unmet needs who they thought did not currently access their services before the pandemic, and over two thirds reported that this was the case. And the most frequently mentioned groups were people from black and minority ethnic communities followed by sexual minority groups, deprived communities living in poor areas, and men. Compared with before the pandemic, 3.4% of services said they were seeing more people from black and minority ethnic groups, 52% were seeing the same proportion, 66.1% were seeing fewer, and 38% didn't know or didn't collect this data. And this is obviously particularly important and I think quite powerful because we know that the pandemic has had such a disproportionate impact on people from black and minority ethnic communities.

We explored in the survey, especially in the qualitative free text, the challenges involved in providing bereavement support during the pandemic, and many of these challenges were related to this huge shift to online and telephone support, which I've described. There's a real emotional impact on staff and volunteers, with potentially high levels of burnout described. There was an increased need for supervision and real struggle sometimes in providing therapeutic support in the context of lockdown from home. The volume of clients had, in many cases, increased, and if the volume hadn't increased, what almost always had increased had been the complexity of their needs, that people reported anecdotally higher risks of suicidal ideation and prolonged grief disorder or other poor bereavement outcomes like depression and anxiety, and but also a huge amount of anger associated with being bereaved at this time, especially where the death has been caused by COVID-19.

Services had also experienced challenges in implementing staff training, the kind of training they need to provide related to providing online therapeutic support, but also things like safeguarding, and that all had to shift to online provision. IT use had been a real struggle for some. Clients were not necessarily familiar with the technology that was being used or might have had difficulty accessing support which required often one-to-one support to enable them to access the technology that they needed. Some of the volunteers, also some, especially the older volunteers also struggled with the move to using online technology. Not always, of course, but that was obviously an issue which people had had to really grapple with and provide additional training for volunteers, for example.

Over half of the services reported financial challenges including the cancellation of fundraising events but also sometimes tight deadlines and restrictions related to the COVID-specific grants that they could apply for. In some cases, they experienced a lack of volunteers who were able to work, especially volunteers who were older. Some of them may have had to shield, for example, but also things like, you know, high levels of sickness and homeschooling having an impact on volunteers' ability to contribute at this time. As services kind of opened up and were able to start providing face-to-face support again, they often encountered difficulties accessing appropriate facilities where they could be sure that they could maintain social distancing restrictions, for example, and other COVID-secure requirements.

Interestingly, 93% of services also reported there'd been positive changes during the pandemic. Many of these related to widening access to their services and reach of their services. So for example, others who maybe were unable to access face-to-face support were suddenly able to access support online, because the provision was so much more extensive, and some clients also preferred online support, especially younger people. Of course, this does also raise the issue of how to support people who don't prefer online support, as Emily mentioned, in the work package one data, there were clearly some people who struggled with online and telephone support and really wanted to be seen face-to-face. And this was also reflected in the data from services, so people did recognise, for example, that there were older people extremely isolated who wanted to be seen face-to-face. The introduction of new services was also seen as a positive and there were some really creative and innovative services that had been introduced, not just bereavement support calls but also walking groups so people could be outside and in safer environments than face-to-face within a building. Online relaxation and meditation, online remembrance services and bereavement cafes, or informal meetings online. Many of the services said they'd really embraced digital technology and that that had been a real positive that they would take forward. Enabling goodbyes through memorial events, for example, was often new to them, but something they could really see the benefit of. Many services, so 47% reported there'd been local and regional initiatives to coordinate services, which was a real benefit that they wanted to take forward also.

So I've just presented some very preliminary data. We're still in the process of analysing this data, but what we've seen really is that these rapid and major shifts in bereavement support provision as well as notable challenges, especially around the impact of providing online support from home and telephone support from home on staff and volunteers and operational and financial difficulties. However, almost all services also reported positive changes, and one of the next steps is going be really learning from these positive changes and trying to take those forward. Over two thirds of the services did recognise inequity in who currently accesses support, and black and minority ethnic groups were most frequently recognised in this regard. During the pandemic, proportions of black and minority ethnic clients have not seemed to increase despite the disproportionate impact on these population groups.

So what we need to do next in terms of recommendations is really carry forward the positives, like local and regional coordination, while trying to understand better and alleviate the challenges. There's a need to invest in training and staff and volunteer support as well as digital provision of services and understanding whose needs are not being met, including things like digital exclusion. We need to assess and respond to unmet needs for formal bereavement support among disadvantaged groups, and crucially, routinely collect client data to determine and ensure equity.

Before I end, I wanted to flag again the UK Commission on Bereavement which Donald Macaskill highlighted this morning. Emily and I are really honoured to be on the steering group for the Commission, which launched in June. There's going to be a review of written and oral evidence and a report will be produced in 2022 by the Commissioners. To sort of start identifying some of the key issues in terms of policy-making going forward, we held a round table in October. We're delighted that the Commission is chaired by Dame Sarah Mullally, the Bishop of London, and to have such an incredible group of Commissioners working on this project including, of course, Donald Macaskill. The calls for evidence are currently open. If you search the UK Bereavement Commission online, you can find out how you can submit your own written evidence. There's two different calls, one for professionals and one for organisations, and that includes people conducting research in this area. And then the second call is for individuals who've been bereaved in the last five years, and both of those written calls close at the end of the year, and we'd be really grateful if you could share the calls widely in your networks. In order to increase the reach of these calls, we're also exploring alternative engagement methods for children and young people and people with learning difficulties. Independent Age is taking evidence over the phone via their main telephone advice line for anyone who prefers to give their evidence verbally. On Thursday evening, key learning disability stakeholders are taking over the Commission's Twitter account, and those responses during that takeover will be used as evidence. If you want to look up the Commission on Twitter, it's @theUKCB. And we're also currently fixing plans for workshop activities for children and young people which will be offered through schools, youth and faith groups. In addition, there'll be oral evidence sessions in December and January.

So I'd just like to end with acknowledging my co-PI, Emily Harrop, and our incredible research team based at both University of Bristol and Cardiff University. We have an extensive network of really helpful advisors as well throughout the country. I'm really grateful to them. And the Economic and Social Research Council for funding. As Emily mentioned, we have a study website, [www.covidbereavement.com](http://www.covidbereavement.com), where you can find out more about what we're doing. Thank you very much.

GW: Thank you very much, Lucy and Emily. That was very interesting to hear the results of those studies and to, I suppose, get some of the evidence backing up some of the experiences that Donald was talking about earlier. For a few questions coming in, I think you probably answered some of them there with that last slide, somebody just from a practical level was wondering about the best way of accessing the study and if they wanted to look at it in more detail, would that be going via the website, or what would it be?

LS: Yeah. Yes, I think that's the best way. So on the website, we have a tab on reports. We also have a tab for sort of various media engagements that we've done as well, so yeah, you can find out more about the study then. And Emily also mentioned, we've got a couple of other pre-prints that will be coming out over the next weeks as well, which we'll post there once they're ready.

GW: That's great, thank you. And someone was asking about the slides, they will be put up with this recording on our website as well when they're wanting those. Again, it probably links into some of your recommendations, maybe Emily, in the first half of the presentation, someone was asking about the, I suppose, the equity of support in terms of where people die, and a perception that a family death in a care home was different in terms of level of support that they got from somebody that had been in a hospice setting, so, and what we can do to, to make that more equitable across the piece. I don't know if there's anything in addition you wanted to mention about that.

EH: Yeah, I mean, that is something that we found, is that obviously people, yeah, people, care homes in particular, people are less likely to get given information around bereavement support compared with hospices, who obviously often have their own bereavement support team. So you can see how it's, it makes, you know, makes sense that that is the case. Although it's, you know, good that that's the case, you can see how that happens. So I think, you know, our main recommendation is that, you know, everyone really needs to be given better information around bereavement support options. And you know, this needs to be done through different channels, really, so, I mean, you know, GPs need to be better equipped to signpost people to bereavement support options. I think GPs often don't, aren't always aware of the different services in their areas, so there's issues around coordination, so publicising services, and just better, yeah, better promotion of support online and in other community settings for people less likely to, you know, search online, whether, you know, like, pharmacies, or through, you know, libraries. I think, you know, there just needs to be a much broader range of ways in which people can access information on how to get, how to get bereavement support if they want it.

GW: Okay, well, thank you. And somebody else was asking just in relation to the volunteers that were providing the bereavement support, whether they, do you have any figures on whether they had frontline experience in terms of looking after people who were dying from COVID or did they have personal experience, or were they completely separate? I don't know if that's something that came up or not.

LS: So the survey that we conducted with bereavement services was generally completed by sort of managers and coordinators of bereavement services. But we did ask them to go and speak to other people in the organisation who would have key information for certain questions. So for example, we had questions around the impact on staff and volunteers and we asked them to go and actually speak to the coordinators of the volunteer services and the volunteers themselves. We're also doing some in-depth case studies, which Emily mentioned, so around 10 services, we've done in depth interviews with key people in the organisation. And in those case studies, we've always tried to include frontline volunteers and staff providing care during the pandemic to really try and capture those experiences. Most of the bereavement services, of course, like the volunteers initially didn't have specific training in COVID-19 bereavement, but all of them would've had some kind of training. You know, if you work in a hospice as a, as a bereavement support worker, you are provided with training and support. And I think what we saw was just that the bereavement services themselves suddenly had to do an awful lot of training and additional support and supervision to make sure that their volunteers felt safe and equipped to provide bereavement support in this really challenging, personally challenging, and in terms of client needs, also challenging situation.

GW: Okay, there's a few more questions coming through but probably in the interests of time, I think we'll have to leave it there. So thank you, Emily and Lucy, for a very interesting presentation.

The film was produced in November 2021 and can be found at [www.sad.scot.nhs.uk](http://www.sad.scot.nhs.uk/) or <https://vimeo.com/677710901>

For more information visit [www.sad.scot.nhs.uk](http://www.sad.scot.nhs.uk/) or contact SupportAroundDeath@nes.scot.nhs.uk

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