# Impact of Covid-19 pandemic on Hospices (ICoH)
# Staff Cohort Report

**Authors**
Dr John I MacArtney, Marie Curie Senior Research Fellow, University of Warwick
Dr Joanna Fleming, Senior Research Fellow, University of Warwick
Dr Abi Eccles, Research Fellow University of Warwick
Dr Catherine Grimley, Research Assistant, University of Warwick
Helen Wesson, Research Assistant, University of Warwick
Dr Catriona Rachel Mayland, Senior Clinical Research Fellow, University of Sheffield
Dr Sarah Mitchell, Senior Clinical Fellow, University of Sheffield
Shalene van Langen-Datta, Marie Curie Policy Officer
Ruth Driscoll, Marie Curie Head of Policy and Public Affairs, England
Professor Kathryn Almack, Professor, University of Hertfordshire
Professor Jeremy Dale, Professor of Primary Care, University of Warwick
Lynn Tatnell, Patient and Public Involvement representative
Lesley Roberts, Patient and Public Involvement representative

**Corresponding author:** Dr John I MacArtney, john.macartney@warwick.ac.uk

*Please use the following to cite this report:*
MacArtney, J.I., Fleming, J., Eccles, A., Grimley, C., Wesson, H., Mayland, C.R., Mitchell, S., van Langen-Datta, S., Driscoll, R., Almack, K., Dale, J., Tatnell, L., Roberts, L. (2022) *Impact of Covid-19 pandemic on Hospices (ICoH): Staff cohort report*. University of Warwick Press: Coventry. doi: 10.31273/978-1-911675-04-4
url: https://doi.org/10.31273/978-1-911675-04-4

**Main findings**

- Many hospices rapidly adapted their services at the start of the pandemic to support the NHS, delivering new innovative hospice services for their communities. This brought opportunities to do things differently, but staff were concerned that the pandemic might also fundamentally change what hospice care is.

- Staff were worried about the impact that the loss of charitable funding would have on the services they provided and were concerned about the sustainability of hospice funding in the future.

- The loss of volunteers early in the pandemic was a concern for hospice staff, who sought to find ways to involve volunteers with patients and carers via video support groups. However, staff noted that some volunteers only wanted in-person involvement.

- Staff found managing the visiting protections practically and emotionally difficult because of the fluctuating guidelines and variability of practice that the application of individual discretion brought.

- Staff recognised that people with life-limiting conditions and those that care for them were especially vulnerable to Covid-19 and sought to put extra measures in place to support them, including telephone and online video calls. However, while this had some benefits, these measures were not always appropriate for all patients.

- Hospices had to close their day services at the start of the pandemic, but many quickly sought to provide a range of measures to support patients and those that care for them in their homes, from door-step visits to online video support groups.

- Hospices struggled to provide hospice at home at the start of the pandemic, but then recognised the need to start or expand their services, so they could support the many more patients with life-limiting conditions who were dying in their places of residence.

- The use of digital technology such as online video calls were widely adopted across many hospice services, from support groups to one-to-one therapy. Staff found many (unexpected) benefits, including reduced travel time; but, in many instances staff would prefer in-person contact.

- Staff reported feelings of camaraderie at the start of the pandemic, but interviews were strongly associated with experiences of fatigue and poor wellbeing, due to loss of staff and overwork.

- As with other services bereavement support used telephone and video calls to support bereaved carers and family members. Again, in-person support – from one-to-one sessions to providing a supportive space e.g. bereavement café – was recognised by staff to be preferable in many circumstances.

## Implications for practice and recommendations for policy

1. Hospices should explore ways they can bring people with life-limiting conditions, and those that informally and formally care for them, together to explore their shared needs and concerns as a group and be ready to facilitate, engage and listen to them not just as patients and (in)formal carers, but as citizens, who need to continue to have an active voice in society.

2. Hospices need to be sufficiently resourced with skilled staff who able to provide gold-standard palliative care and connect with the full range of health and social services they require, including out-of-hours, to support their patients and carers. In particular:
   a. Staff should be encouraged to experiment with online and in-person day services, so patients have options for accessing support that suit their needs.
   b. Staff should be suitably resourced and supported so that they so that they can provide safe and effective hospice-at-home services 24 hours a day.

3. Include volunteers in Covid-19 safe workforce planning with the aim for them to be able to provide in-person or online support as necessary.

4. Ensure hospice staff are supported through clear strategies for communicating rapid and complex service changes to patients and their carers, in particular relating to guidance on how best to apply visiting restrictions consistently.

5. Staff should ensure that people with life limiting conditions are not marginalised or discriminated against and that the quality of their lives are valued equitably in the application of any (new) guidance or policy.

6. Funding should be available to ensure that staff remain trained and up to date to exploit the advantages of digital resources, so they are comfortable offering them as a one-to-one or group resource, an addition to in-person and telephone support.

7. Recognising that working in hospice services in all settings can be both rewarding and challenging, ensure that staff are supported through a pro-active approach to their health and wellbeing, including fast-track access to mental health and bereavement support if required.

8. Hospices should consider providing a blended approach to bereavement support involving telephone, online video calls and groups, as well as in-person one-to-one therapy and support groups.

## Introduction

In the UK hospices provide holistic healthcare (physical, emotional, social and spiritual), with a focus on quality of life for those who have life-limiting conditions (Clark, 2014; Taylor, 2019). Hospices can provide multi-disciplinary support via a range of services, from (specialist) palliative care in-patient beds, day services (e.g. social and support groups), and out-patients (e.g. specialist palliative care, physiotherapy, breathlessness clinics); to those services offered off-site, such as community nursing services, and/or hospice at home (Hasson et al., 2021; Hospice UK, 2017). Pre-pandemic, most hospice support was premised on being provided in-person, whether that was on an inpatient unit, in a day service, or at the patient's place of residence. However, the pandemic brought rapid and significant changes to how hospice care and support was delivered (Dunleavy et al., 2021). This was not only due to national restrictions, but also because many of those with life-limiting conditions are especially vulnerable to Covid-19, as it could both shorten the amount of life they had, as well as significantly affect their quality of life.

Little is known about what happened to people with life-limiting conditions who were discharged home or who experienced changes to hospice community services during the first lockdown or throughout the Covid-19 pandemic (MacArtney et al., 2021). While each specialist palliative care service and hospice's response to Covid-19 has reflected local conditions, common to all in England has been the theme of adapting large portions of care and support to a now dispersed community of service users (Dunleavy et al., 2021). These changes will have affected how people lived with life-limiting conditions during the pandemic and how they were cared for. Moreover, their experiences could provide insights into the uneven and inequitable affects of the pandemic (Pickersgill, 2020), which may need addressing through changes to policy and practice.

## Background to this report

This report describes the diversity of experiences of hospice staff who worked in operational roles in hospices in the West Midlands during the Covid-19 pandemic. It is one of four cohort reports – the others focus on patients, carers, and senior managers respectively – that form the evidence base for a Policy Report into the impact of Covid-19 on hospices. In these reports we address the nine key themes that were identified as potentially important in our previous collaborative knowledge synthesis (MacArtney et al., 2021) and seek to address some of the policy gaps we identified in our review of recommendations for hospice practice and policy (van Langen-Datta et al., 2022). Together these outputs are the result of an Economic and Social Research Council funded study (grant number: ES/W001837/1). This is one of the first studies to contribute an in-depth exploration of hospice-based experiences of the pandemic to the growing body of knowledge about the effectiveness and effects of changes to hospice services, at regional and national levels in response to Covid-19.

The aim of this report is therefore to explore the effects the Covid-19 pandemic had on the experiences of hospice staff as they sought to provide care and support to people with life-limiting conditions and those that cared for them so that we can identify recommendations for clinical practice and healthcare policy. Drawing on these findings, this report offers **recommendations for hospices and clinicians** who continue to provide care and support for people with life limiting conditions and those that care them during the ongoing pandemic. These recommendations will also be of interest to **local commissioners** who will need to work with hospices in their region to ensure informal carers receive the support they need, and **national policymakers** who will need to ensure the necessary resources and guidance are available.

## Methods

### *Design*

We used an interpretive qualitative approach (Silverman, 2011), as this best allows us to explore and describe the range of patient experiences of hospice care and support during the pandemic.

### *Setting*

The West Midlands is a vibrant and diverse community – including the largest ethnically diverse population outside of London – that is distributed across a range of geographical locations, from inner city to rural areas (Evans et al., 2012; Medland, 2011).

### *Sample and recruitment*

We contacted all 13 non-NHS hospices caring for the adult population in the West Midlands and asked them to recruit participants for the study. Nine hospices agreed and seven successfully recruited participants. Hospice staff were asked to share the participant information leaflet with patients who had used any of their services during the pandemic, i.e. in-patient or community since March 2019. If the patient agreed the hospice would then pass the patient's details to the research team, who would then contact the patient to answer any outstanding questions, ensure they were happy to take part, and arrange a time for the interview.

### *Data collection*

In-depth interviews were conducted by AE, JF, CG and JM via telephone or MS Teams, whichever the participant preferred. The researcher recorded verbal consent before starting the interview. The interview then started with the open question, "Could you tell me a bit about your background and what kind of role you have with the hospice during the pandemic?" Follow-up questions would be in response to the participant's story, but would include prompts on providing services, experiences of different locations of care, concerns about Covid-19, or the impact of the pandemic on their and colleagues wellbeing.

### *Analysis*

The recordings were automatically transcribed via MS Stream, checked by researchers CG and AE and coded in NVivo 1.5 by AE, JF, CG and HW using the anticipatory themes (Braun and Clarke, 2019), developed during the collaborative knowledge synthesis (MacArtney et al., 2021). A sample of collated extracts (approx. 30,000 words) from the coded anticipatory themes were shared with co-authors and collaboratively analysed using the One Sheet Of Paper (OSOP) method (Ziebland and McPherson, 2006) at a knowledge translation workshop to identify any new (sub) themes, as well as any recommendations for practice and policy. JM then summarised the NVivo nodal outputs for each theme and identified any further recommendations. Using the themes identified in our previous study (MacArtney et al., 2021), JM drafted a working paper and shared this with the co-authors for further interpretation and comments.

## Results

25 hospice staff recruited from six hospices were interviewed on MS Teams or on the telephone. We sought to recruit frontline staff for this cohort, with a working definition of staff who had operational roles at the hospice i.e. either had regular contact with patients or carers as part of their role, or worked in support services but who were not hospice senior managers. We purposefully recruited to cover a range of hospice roles, collated under four general headings in Table1 to preserve participant anonymity: doctors, speciality trainee and consultants, inpatient and community; nurses including support and care assistants; allied health professionals, including social work and psychological, occupational, physio, and complementary therapists; support services, including administrative and volunteer coordinator roles. 23 identified as female, 24 as heterosexual and one as bisexual; all identified as white-British ethnicity. Age ranges by decade were requested, with the greatest number of participants (n=13) being between 50-59, ranging from seven participants in their 30s and one in their 60s (see Table 1, participant characteristics). Interviews lasted between 30 minutes to 1.5 hours. Interviews provided rich and in-depth descriptions of participants' experiences working for a hospice during the pandemic. The following analysis sought to explore those experiences to identify opportunities to better deliver hospice services and support to those with life-limiting conditions and those that care for them.

| | **n** | **%** |
|---|---|---|
| Participants | 25 | |
| Female | 23 | 92% |
| 18-29 | 0 | 0% |
| 30-39 | 7 | 28% |
| 40-49 | 4 | 16% |
| 50-59 | 13 | 52% |
| 60-69 | 1 | 4% |
| Role | 25 | |
| Doctors | 2 | 7% |
| Nurses | 12 | 48% |
| Allied Health Professionals | 7 | 28% |
| Support services | 4 | 16% |

**Table 1: Participant characteristics**

### Impact of changes to hospice services during the pandemic

In the first months of the UK and England's Government's response to the Covid-19 pandemic significant attention was focused on readying hospitals and intensive care units. At the same time – receiving far less national attention – were the efforts of regional community health and social care services who were preparing for a rapid and significant shift in how they would care and support people (Bowers et al, 2021; Mitchell et al., 2021; Oluyase et al., 2020). This included the non-NHS hospices (Sleeman et al., 2021), which are the focus of this study. Based on the findings from our collaborative knowledge synthesis we anticipated that there would be three main areas of concern relating to how changes to hospice services might affect experiences of those with life-limiting conditions: the impact upon resources and funding; loss of volunteers; and changes to visiting arrangements (MacArtney et al., 2021).

*Impact on resources and funding*
One of the implications of the pandemic was the impact it had on how the various healthcare services were resourced in the community. This had knock-on implications for **how hospice community services worked with other community healthcare providers**. For example, a participant explained:

> "*I've lost count of the times I've gone into the house and I'd have to tell the family that that person is probably going to die tonight. A couple of people have actually died while we were there, because they accessed nobody because of covid. District nurses weren't going out, the clinical nurse specialists weren't going out, GPs weren't going out and still aren't*" (ICOH53, senior nurse).

It was not only the pressures on primary care that posed problems for hospice services. Participants also witnessed patients with Covid-19 diagnosis being discharged back home from hospital, with only immediate family to care for them:

> "*The advice that was given was, you know you can sit with your husband and still live in the same house, but please wear a mask. And that was very difficult for some family members, to still care for their loved ones on their own. And the isolation is not seeing people, although [staff seeing people] was a necessity when it was the end of life*" (ICOH47, nurse).

Nonetheless, as well as acknowledging the difficulties primary care faced, the pandemic had brought opportunities for beneficial changes to ways of working with colleagues in the community. One participant described how the hospices working relationships with GPs had changed during the pandemic, noting some ways they were less accessible as they were not doing home or in-person visits, but had improved in other ways because they were more available through video and telephone calls, "So there's more flexibility is the more modern take of that, and I think that probably won't return back to the traditional [ways of working]" (ICOH61, nurse). Another participant explained how during the pandemic they had "certainly improved communication" and worked more closely with the local hospital, phoning into each other's bed meetings, taking on the whole care of patients in the community, which also helped to "freed the district nurses up and they were grateful of that" (ICOH62, senior nurse).

A participant explained how their local Clinical Commissioning Group (CCG) realised early in the pandemic that clinical generalists in the community were going to be providing a lot of end-of-life care and would need training. In response several hospices worked together to provide a series of webinars on key topics including Advance Care Planning (ACP) and symptom control for GPs, other healthcare professionals in the community, and for care homes. She reflected:

> "*And that was possibly the best decision that we ever made . . . because it was really needed, and so the evidence from it was the loads and loads and loads of people showed up to it*" (ICOH64, senior nurse).

Another initiative one hospice put in place was to support local care homes by providing a palliative and end of life care education programme. This later was merged with a wider programme of support for care homes developed by the Community Healthcare Trust, "it was a really lovely integrated piece of work" (ICOH64, senior nurse). Another participant explained how, during the pandemic the ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) document and process was launched in their area. The hospice was responsible for training local clinicians and while this brought a number of logistical issues, she felt:

> "*We probably reached into more practices where GPs were concerned and more care homes and that doing sort of virtual contact than we could have ever imagined had we just said come to the classroom and here we are. So that certainly made it an impact, so that was, that was a huge sort of investment really as regards the sustainability and embedding where other services are concerned*" (ICOH61, nurse).

However, a participant reflected on what happened to resourcing of some services at the "end" of the pandemic, particularly those that had allowed hospices to provide more integrated support to community services:

> "*I have lots of sadness around this because we did that [community support] and we changed it and we work with CCG's and we worked really closely together and lots of money came out of the woodwork work to be able to support that through covid. And then of course, covid, finished [interviewer name], covid 'ended', yeah, and so did the money and we had to disband our service because nobody would fund it*" (ICOH64, senior nurse).

One result of these resource pressures in community came with the **verification of death** at home**.** A participant said she found the support from General Practitioners (GPs) with this was poor. She described how a GP did not visit a home to verify the death of a patient, instead providing instructions over the telephone to the daughter and granddaughter of what to do. She said the family had told her:

> "*And as much as the service that we gave was wonderful and that lady could die at home with her family around her, the verification, the memory of them having to verify their own family member and will haunt them forever*" (ICOH47, nurse).

Sadly, she explained, "that happened many, many times in the community that, you know verification of death from GPs didn't happen. And we often called a GP for support and the support wasn't there" (ICOH47). She went on to explain:

> "*So normally, the thing is the district nurses were run off their feet so much they also couldn't get to the houses quick enough. The GPs just weren't coming out at all, the district nurses would, you know they were able to do that service, but they were just so run off their feet. It could be hours and hours before they could get there, which was also quite traumatic for the families*" (ICOH47).

The process of verification of death also changed for patients who died in a hospice. A participant explained that new legislation brought in during the pandemic meant that only one doctor was needed to verify, whereas previously it had been two, but the doctor was required to speak (usually on the telephone) with a family member to explain what was being put as cause of death on the certificate. These were often difficult conversations to have and the participant reflected that, “I don't know how family feel about that and whether it feels, whether it feels easier or not [to have the conversation]” (ICOH57, doctor).

The impact on hospice resources and the implementation of various protective measures, such as Personal Protective Equipment (PPE), also had implications for the **ethos and practice of hospice care** for some participants. As one participant summarised, “The pandemic certainly does constrain you from delivering a truly holistic package of care” and this meant, “That closeness for humanity is lost” (ICOH43, support nurse).

A participant reflected how she was aware that staff and patients missed the human connections that were disrupted by the PPE and social distancing pandemic protections:

> “*I still think a lot of people missed the human connection and you know being able to sit here and, you know, we felt it too, being able to hug people and hold their hand*” (ICOH56, AHP).

Another participant explained that she felt that although staff, patients and carers had “gotten used to” PPE, there were still situations where talking to people when dressed in full PPE “I still think that for there are certain people and certain situations where it's still just feels really alien towards” (ICOH26, senior nurse). She went on to reflect how the protections and PPE meant that she could not be tactile – hold hands or put an arm around a shoulder – with carers in ways that she would have done pre-pandemic. In particular, she was wary that if she did, she might be reported for a breach of the rules. While the guidelines have eased a little, she is still not as tactile as she was and is concerned that it, “definitely has impacted the quality of care that we've given” (ICOH26). Similarly, a participant explained that they had to balance the “very clear” guidelines about always wearing masks, with the clinical situation in front of them:

> “*So, you know, there's that kind of element of trying to balance those kind of rules and make sure that you're being legal and safe and still attentive to what the kind of client needs*” (ICOH69, AHP).

As well as the challenges that PPE brought to providing holistic care, participants also noted how the reduced staffing numbers and increase in numbers of patients meant there were time pressures affecting the care they provided. Another participant explained that having multidisciplinary meetings as they had pre-pandemic were no longer feasible, as the administrative support was no longer available in the hospice. However, this did not mean the commitment to holism was lost, as one participant said, “if we lose holism, we're not really providing palliative care” (ICOH61). Another participant said:

> “*I feel that the balance is again upholding the principles, as pioneered by pioneered by Cicely Saunders, but you know the emotional, psychological, spiritual, social elements are just equally as important as physical elements of care for end-of-life patients*” (ICOH43, support nurse).

In practice, a participant explained that if they were with a patient in their home who had a need they could not support, they would not now say “let me get my colleague in or let me refer on”, rather, “if you were in that home and something was needed to be done, you did it” (ICOH61, senior nurse). She noted that this helped build trust with the patient and their carers.

A participant explained that the holistic support they would usually provide on the inpatient unit was “desperately in demand” (ICOH69, AHP). Similarly, a Social Worker at another hospice explained that they were not able to get onto the inpatient ward, as they usually would, as non-clinical staff were banned. As staff on the ward were busy, they were unable to find time to facilitate telephone and video calls so the AHPs could provide the sort of support they usually would give patients. They believed that this lack of contact affected the quality of support that the inpatients received:

> “*You can have a medic dealing with your physical pain all the live long day, but if you've got psychological pain you will, you will remain in pain to some degree, and what the social workers do is help with that psychological pain. We couldn't do that 'cause we couldn't get in there*” (ICOH67, AHP).

As the pandemic went on they, “pushed and pushed and pushed and pushed and pushed until we were allowed back on the ward” (ICOH67).

It was noted by some participants that the quality of hospice care that was provided in the pandemic “ebbed and flowed,” (ICOH26) as one said, which participants found “frustrating” and “demoralising” (ICOH26 and 30). A participant reflected on how her training in palliative care had set high expectations to provide “gold standard care,” because if that opportunity was missed, “it is gone forever, literally because they've died”. However, not being able to fulfil these expectations left her with:

> “*a sense of real dissatisfaction that this is just this just isn't palliative care. This isn't what we, are specialised at doing. This is just care. This is, you know, we doing basic care. Nobody got neglected. Nobody got, you know there was no malpractice or harm. But that's not what we're about. We're not about firefighting. We're about providing like an excellent service for people. And we're about providing a service that doesn't just accept kind of the status quo but goes beyond that*” (ICOH26, senior nurse).

However, other participants were less sure that quality of care had been affected. One participant said of the community support she provided, “I think our care standards stayed the same” (ICOH74, support nurse) and another said, when asked one participant said the inpatient unit, “I don't believe it did, no. I mean patients for it was fairly business as usual.” But, “I think in the community I would say yes it did change” (ICOH62, senior nurse). She explained:

> “*quality is about giving time and doing that stuff, those things that for example, the NHS can't provide. You know that that extra, sort of personal touch, and I think some of that got lost a little bit because we were we, I mean, we were busy*”.

Another participant said that they did not believe the pandemic affected the quality of care people got in the community. However, she went on to note that what was needed was funding for more staff:

> "*There's nothing worse for a nurse than to hear that somebody has, you know died alone at home, when we know if there was more support they that would never have happened*" (ICOH47, senior nurse).

A participant reflected on the difference between the start of the pandemic and **the ongoing situation at the time of the interview** (approx. 18 months into the pandemic). She explained that in the first lockdown some patients who were admitted to the inpatient unit had no visits by any healthcare service previously, "we could easily be the first doctor that they'd seen in months," and so came in with a long lists of unmet needs. Unfortunately, she was not seeing things improve, "And to be honest with you, it's getting worse. 'cause, yeah, everything is broken now . . . [because] so many months in, it's the wider problems with, you know, staff" (ICOH48, doctor). Another participant explained that they were aware that "district nurses, these people they're leaving in droves as well because they've had enough" (ICOH53, senior nurse) and this meant she had a larger caseload, which she had to manage mostly by telephone calls. However, assessing people on the telephone was not easy as patients would not always give a complete picture because, "they think you're busy, so they think they don't need [you] to come out" (ICOH53).

However, the new ways of working during the pandemic have also brought improvements to how services worked together, as one participant explained communication with other services had improved, as the following participant said:

> "*I think some of our communication with other departments has maybe sort of improved a little bit. Because everybody, you know, feel that little bit of, well, we're all kind of sort of stuck in this, so I think you can sort of, is a bit easier to sort of just ring up and go what's going on with this sort of thing and that. So I think maybe that's a little bit easier*" (ICOH34, nurse).

The Covid-19 pandemic and associated protections put in place, including lockdowns and social distancing rules, had a significant **financial impact on hospices**. This is because most hospices are dependent upon charitable funding to stay financial viable, so the pandemic meant that as well as not being able to hold fundraising events, hospices had to close their high-street shops. As the following participant explained, they were worried that the hospice might not be able to continue providing its services:

> "*a lot of hospices are running on charity, and without all of those things [charity fundraising events] that we need, I think a lot of people were quite frightened that they weren't gonna have a job at it at the end of it, and we're not at the end, actually, so…*" (ICOH30, AHP).

A participant explained that the pandemic hit just as the hospice was getting ready to do its annual fundraising appeal events. They therefore had to cancel all the in-person activities and quickly come up with an emergency appeal as "damage limitation" (ICOH42, support services). Although most staff we spoke to were not involved with the details of the hospices finances, they were dealing with the consequences, as a participant explained what the hospice continues to need is, "More resources. We need more people. We need more beds" (ICOH34, nurse). She went on to say:

> "*I just think we could have done so much better if we had much more comprehensive palliative care in this country, and it wasn't seen as an add on and it wasn't a charity, it was if it was mainstream*" (ICOH34).

*Loss of volunteers*

Many hospices are fortunate to be supported by volunteers who, pre-pandemic, would help with a range of roles from patient transport, assisting support groups, fund raising, and administration. However, many people were unable to volunteer because of both the lockdown and the protections many hospices put in place meaning they were closed to non-essential clinical staff. As well as this, a participant said, "All the volunteers stopped coming in, a lot of them are sort of more elderly and a lot of them had to isolate" (ICOH60, nurse).

One participant's role specifically involved managing the hospices volunteers. She explained how they all had to stop working with the hospice at the first lockdown, "whether that was within fundraising or within the shops, and especially obviously within the hospice" (ICOH42, support services). However:

> "*As things went on, there was certain things that you know, we were like, actually we really need some volunteers to support us with this 'cause we just haven't got enough staff and so there was certain roles that we, certain roles that kind of came back*" (ICOH42, support services).

This included providing in-person support to patients and carers within day services, recognising that the lack of in-person contact was "it's only adding to the isolation that they're already feeling" (ICOH42).

There were therefore two issues to address, supporting the volunteers who had lost an important social network, and how to (re)engage the volunteer workforce in the current pandemic circumstances. The first issue was addressed by using one-to-one video meetings, which allowed the hospice to stay in touch with volunteers, as well as organise larger events with them than had been possible before the pandemic. The participant said, "before it was all about geographical location", and went on to explain that she could now do "a big virtual conference for the week, which we could open up to every volunteer that had, obviously, IT access" (ICOH42, support services).

The participant also explained how later in the pandemic she was able to get the volunteers involved in providing telephone calls and video support groups with patients and those that cared for them. However, not all volunteers were happy to provide support online:

> "*It was difficult to get a lot of volunteers to embrace the digital side of things because, you know, it was not stuff that we've never done before . . . it was kind of difficult to get some people to embrace it . . . And there's still some people now that were like, 'no, it's not for me. Zoom, Teams, it's not for me'. But most people seem to be embracing it*" (ICOH42, support services).

The participant went on to say that she was aware that some people stopped volunteering for the hospice as, "the whole reason they volunteered was to see people and to get out of the house for themselves, you know, it's just social thing for a lot of them as well" (ICOH42).

*Changes to visiting arrangements*

The following participant set the context for the limitations to visiting arrangements, saying that hospices were places that "want to open our doors to everybody and anybody you know, pets, children, you know, extended family" (ICOH26, senior nurse). Another participant reflected on the difference the limitations on visitors made:

> "*I like having 10 million relatives coming and going, you know, I like the social side of a hospice. That's what [we] do . . . and make us so much different to a hospital . . . [but] we've had to put our patients first and discuss, and protect everyone from covid. So we understand why it's been done, but obviously it's still cruel doing that*" (ICOH74, support nurse).

The rationale for having no visitors at the start of the pandemic and during the first months made sense to most participants, especially as they saw news reports at the time of hundreds of people dying each day, "you know without that going on in the background, I think it even felt like the right thing to do" (ICOH57, doctor). Even so, some hospices were letting one family member visit when someone was at the very end of life. A participant reflected on the hospices decision to allow at least one visitor, even during the first lockdown, and the difference that made to some families transferred to the hospice from hospitals:

> "*To my knowledge, you know, nobody was denied access to and support of a loved one while they were on our ward, which I'm really proud of and I think you know, it was a tough call, I think, for the leadership to balance risk – with risk to staff and risk to patients, with the benefits of having visitors. And I think they made the right call. I'm proud of that, that fact, and you know, as I said earlier, we had people coming from acute hospital settings and their family hadn't seen them for 10-12 weeks and then they came in here and their family could see them. And you know that that was amazing*" (ICOH67, AHP).

As the pandemic progressed different hospices would have different rules on who could visit, if any at all, and how many could visit at one time, as one participant said, "It changed almost weekly. It felt like 'cause I think we were trying to work out what to do" (ICOH46, senior nurse). One participant reflected on the impact those limits on numbers had saying, "picking two people to visit your loved one. Which two do you pick? Yeah, and I think a lot of people would have a lot of guilt on that as well" (ICOH74, support nurse).

The changing number of people allowed to visit was also noted to be an issue for some staff. A participant explained some of the difficulties they had with managing visiting numbers, which were always caveated by being open to the discretion of the senior nurse on the ward, saying it is, "so wide for interpretation because what my discretion is completely different to another nurse's discretion and also that is a reflection on your view of the pandemic" (ICOH26, senior nurse). She went on to say:

> "*Because the patients want to see consistency. And if one patient in one room has got eight people and another has got only six. You know and believe me they find*

> *out these things, they see them coming in and out . . . you've got to be consistent or otherwise you create another you know whirlwind of emotions amongst relatives*" (ICOH26).

Things could be further complicated if discretion was allowed when a patient was believed to be very close to death, but then stabilised or even improved a little, as one participant described:

> "*Sometimes you might find yourself in the position of, you'd have a patient who you thought was deteriorating in the last couple of days, and you might allow the visitors to come and then you know, several days later, the person still hasn't died, and they perhaps rallied a little bit. And then you're thinking, okay, so do we actually need to, you know, stop the stop the family visiting again, which obviously is incredibly painful*" (ICOH57, doctor).

One participant noted another difficulty was when young children wanted to visit inpatients, as they were not vaccinated. However, if the nurses were able to "argue it clinically" then they would be supported and:

> "*then 10 minutes you know, just come in, say hi and you know, take some photos. We'd have the social workers make some memories with them, and then the visit would be over*" (ICOH62, senior nurse).

There were wider implications to the limits of visitors that the participants noted. At the time of interview hospices still had limits on the number of people who could visit, as one senior nurse said, "I think it still continues to put people off coming in" (ICOH26). Another participant reflected how she was aware that some patients had not wanted to come in because of the visiting protections:

> "*A lot of our patients have not wanted to come in because of the restrictions, because we still obviously have some restrictions for visiting. So it's meant that more of our patients that would normally have come to us as staying in their community*" (ICOH34, nurse).

One participant observed that, "I think a lot of people found it very hard to let [family members] be admitted 'cause they couldn't visit" (ICOH60, nurse). She went on to say:

> "*I think it's really hard knowing that they can't come and see you, knowing that you're dying. You could potentially die on your own if we're busy. We can't just sit there and then they're obviously sat at home, just waiting for the phone call to say, I'm really sorry they've passed away. And I think that obviously the patient that's died obviously isn't going to remember, but that the family members have to live with that for the rest of their lives. And I think that's quite difficult*" (ICOH60).

Another participant reflected on her experiences during the pandemic of listening to patients and carers worries about calling the hospice for advice, in case it led to an admission to the inpatient unit or hospital, which they were fearful of because of the risks of contracting Covid-19. She said:

> "*They would rather be at home and struggle with their symptoms, or leave it to the last minute to call in for support. You know, we found that actually we're*

> *trying to reverse issues that could have been done more easily, you know with longer time to play*" (ICOH61, nurse).

These concerns were felt to be disproportionate to the actual risks in the hospice, especially as the pandemic went on, as one participant explained that the protections put in place in her inpatient unit meant that since the first few months of the pandemic, there had been no Covid-19 transmission between staff and patients or patient-to-patient.

Some of the issues staff faced with visitors were that they were not aware of the protections in place when they arrived from hospitals or the community:

> "*We've had to really drum it into the referrers. You must emphasise the restrictions on visitors because the problem came when people came in and didn't realise there were restrictions, and then we're like, 'oh, I would have stayed at home if I don't know that this was the situation'. So we were really trying to drum it into people. You must tell them so that they know what they're coming into*" (ICOH26, senior nurse).

Although several participants noted that family members could be understanding about the visiting limitations and be "astonishingly gracious about it" (ICOH57, doctor), it was not always the case, as participant reflected, "staff having to become like security guards for the unit didn't work" (ICOH26, senior nurse). Another participant described some of the difficulties staff faced enforcing the visiting protections:

> "*It did bring a lot of animosity towards the staff. You know, so two relatives for one patient, you know, yet all the things like, well, she's got four children you know, and unfortunately we did see patients who died with two relatives in the room and two looking through the window. And that has an effect, I think on most of the staff because that was beyond your control*" (ICOH63, senior nurse).

Looking back she felt that:

> "*I think you know the last, the last hours of somebody's life if very important to those remaining. And I think you know, as a guide, I think they probably should have been allowed immediate family, no matter how many*" (ICOH63).

One participant wondered if visiting protections could not have been amended sooner, once testing and Personal Protective Equipment (PPE) were widely available. Another participant discussed the ongoing rationale for the need for the visitor limitations, which she felt was shifting:

> "*[At the start of the pandemic] it was about protecting relatives and patients. But as it's gone on I think, really, the protection is about staff now . . . They haven't got the capacity for staff to go off sick at the moment, you know, we're really, really struggling with staff numbers and retention and so now I think the restrictions on visitors really, if I'm honest, is about staff because they just don't want staff going off with it*" (ICOH26, senior nurse).

*Quality of care*

The second major theme that our previous work identified as needing further examination was how the pandemic affected the quality of how care was provided in hospices and how it was experienced by people with life-limiting conditions and those that cared for them. To understand this further we looked at how demographic characteristics or geographical location might affect care, the experiences of care in the inpatient unit, as part of day and outpatient services, and as part of hospice at home services. We also looked to see what changes to care were enacted because of the pandemic and how these were experienced. Finally, we asked participants about the (pre) bereavement support the hospice had provided.

*Demographies and geographies of care.*

The Covid-19 pandemic affected everyone, but it affected some groups more than others. In this theme we look at how the pandemic was understood to have affected participants because of who they are or because of the places in which care and support were (or were not) available to them. In particular, people with life-limiting conditions were particularly at risk of Covid-19 severely affecting the quality of the life they had left, as well as shortening that time. We therefore looked to see if there were any disproportionate or inequitable effects in the way the pandemic affected people caring for those who were dying and what additional support hospice put in place to help compensate for that. For example, one participant explained that at the start of the pandemic the hospice stopped the support it provided to homelessness support organisations. However, they quickly realised this was a mistake and were able to restart in September 2020 and provide:

> "*online education programs, [we] did lots of online networking and support with existing providers and provided forums for them to do that and walk to the streets*" (ICOH64, senior nurse).

Hospice staff were aware that people with life-limiting conditions might be experiencing a disproportionate amount of isolation as most would be 'shielding' i.e. taking extra precautions to avoid social interaction as they were Clinically Extremely Vulnerable (CEV) to the effects of Covid-19. As one participant explained, she found people with life-limiting conditions and those that cared for them struggled with accessing care because of their fears of Covid-19:

> "*I think people were scared. I think people were scared to have people come in their house and I think that maybe people were saying 'no' to other places that did do community visits because of that nervousness. I think people felt abandoned. I think that people didn't have the help. People got a lot worse over that time period because they weren't able to access their GP. You know, they weren't able to go to hospital appointments*" (ICOH75, AHP).

To help with this, hospices sought to (regularly) contact patients and those that cared for them by telephone and video calls. We explore the practicalities of these forms of contact below. However in this section we consider the issues around equity of access to hospice support via telephone and video calls. As the following participant described, the pandemic brought forward the use of video calls to support patients and carers, and had opened-up new ways to support people that they previously would not have been able to help:

> "*So we've sort of picked up on some of those more isolated people I'd say – that haven't got family [or] can't drive – that we are still providing a service for, that*

> *we wouldn't have necessarily done before the pandemic and we will continue to see. We won't just rule them out as 'no, you're not appropriate for our group'. We will see you in another way if we can*" (ICOH46, AHP).

Who the patient or carer was and how their condition affected them played an important part in whether they could access support via telephone or video calls. One participant reflected that the pandemic had helped with changing some perceptions:

> "*I think the other thing that's a myth busted for us is, you know, people of a certain age can't use technology. Well, that's nonsense. Absolute nonsense. Total ageist nonsense*" (ICOH62, senior nurse).

Another participant explained the different ways that different groups reacted to various forms of support provided, either by telephone, video call or in-person:

> "*It's really interesting because at first, pretty much everybody all hated telephone and they didn't like it and they wanted to do it face-to-face [in-person]. But as time went on more people prefer telephone and especially we saw the trend with men, and definitely younger men, by phone because you have that anonymity still and felt almost freer to cry and get upset when you can't see their face. So yeah actually it had some big advantages and now that we are back working in the hospice we still have that free blended approach*" (ICOH56, AHP)

A participant explained that the move to telephone and online support was particularly difficult for some of the people he supported, for example those who may be experiencing domestic abuse:

> "*It's kind of quite a big disruption to kind of therapeutic support for a few, especially my more – for want of a better word – my complex clients, where actually there was a big benefit for seeing them in a kind of safe place out of their home, out of their home environment and stuff, and that that obviously completely stopped*" (ICOH69, AHP).

He went on to explain that he had to be very careful on the calls and keep them "bland", saying, "So yeah you could we kept contact and that kind of thing; but it wasn't therapy. It was just check in calls" (ICOH69). This participant described how he had therefore sought to return to in-person one-to-one support as soon as it was possible to do so. However, this was not always possible for some patients:

> "*Because they were clinically vulnerable and didn't feel safe to come in and were self-isolating and that that kind of thing and so I mean I had one client with MND [Motor Neurone Disease], for example, whose speech was deteriorating significantly so couldn't do phone, couldn't do video call. Needed to come in, but at the same time just didn't feel safe to*" (ICOH69, AHP).

Another participant explained how some of the changes put in place disadvantaged some groups access to hospice care:

> "*And the people who are disabled or hard of hearing or what have you and phone online doesn't work for them, didn't have any options for them during lockdowns then. We couldn't do anything, so we were referring them to other counselling services that could do face to face appointments at the time*" (ICOH56, AHP).

*Places of care: hospice care day and out-patient services*

We asked the staff we interviewed about their experiences of what happened with day and out-patient services at the hospice during the pandemic.

A participant reflected on conversations he'd had with patients and those that cared for them about the role of the day services and having a social space to go that was there for people because they had a life-limiting condition, and what it meant to lose that:

> "*I think that to me has really shown how really important that that sort of provision of it is, you know, stuff that's not even about the complex psychological or complex medical stuff. But just about that kind of background, emotional support, that background society, social support*" (ICOH69, AHP).

As several participants described, those social spaces that the hospice provided had to be closed at the start of the pandemic, with staff at some hospices being transferred to other roles, with the day service patients allocated to another member of staff in a different department. Another participant explained how her hospice had closed the day services and that:

> "*I don't think well ever get that back, so they're going to evolve what the day services was. So that's going to be a really good thing, an improvement to what it was, so that's something to look forward to*" (ICOH50, AHP).

A participant explained that although there were reservations about the practicalities and quality of care and support that could be provided via video and telephone calls, "the alternative was cancelling everyone and not giving anyone any form of support and that just wasn't an option really" (ICOH56, AHP).

There were a range of initiatives put in place by different hospices to remain in contact and support those patients and those that cared for them at the start of the pandemic. However, one participant was upset to realise that, compared to other hospices, her hospice did not put any measures in place, saying, "we didn't even, I didn't get to [do] nothing" (ICOH53). In contrast a participant at another hospice said that one thing that helped during the pandemic lockdowns were the outreach visits they were able to do to people's homes – standing outside to speak with them – as they provided a useful way to find out what needs were not being met:

> "*I think the outreach with people, I think that's really important and doing that in meaningful ways to people, finding out what it is that they need, or what they require, and listening to that, not just telling them this is what we can offer you*" (ICOH75, AHP).

Most hospices, including that of ICOH53, put in place a telephone or video call support service during the first lockdown. We discuss one-to-one telephone and video call support below (*Telephone check-ins* and *Digital palliative healthcare support* respectively), but here we look at the use of video support groups in relation to the day and outpatient services.

The implementation of online support groups was new to many hospices and one participant explained that she had done her own research into ways online support groups might best help patients and carers, as well as people who had been bereaved during the pandemic. There were also issues with rapidly implementing online support groups, as another participant explained how he felt “they were poorly coordinated. They would ask staff members at a moment’s notice, ‘Oh can you do this?’” (ICOH43, support nurse)

For people with some conditions the video support groups were seen to be less successful, as one participant reflected on the online fatigue and breathlessness support groups that she had helped coordinate, saying:

> “*I don't think that that is the best way to continue on because I think people miss out on that peer support, but I think at the time people were really grateful that we were getting in contact with them, giving them information*” (ICOH75, AHP).

However, another participant explained that the day services experiences and successes with video support groups meant they would be able to provide a more balanced approach in the future, adaptable to the needs of patients and carers:

> “*We can do that as a blended approach so that you know we can do a program for people that can get there [to the hospice] and we don't have to worry about all them . . . And those that can't, well look, we know we've proven that we can do this as an online program, so ‘yay!’, let's carry on and do that. So real wins with that*” (ICOH64, senior nurse).

During 2021, several hospices sought to reopen the in-person day services in some format. A participant explained how they piloted re-opening some day service support groups over the summer of 2021, asking patients and carers to attend smaller groups, for a six-week period, and doing a lateral flow test before arriving. However, the pilot ended on week three when only two people came to the group:

> “*That was a little bit of a disaster, 'cause I think people were just frightened to come in. We're asking them to lateral flow test, a lot of them, just it freaked them out a little bit, I think*” (ICOH46, AHP).

They changed the structure to one three-hour session and “they seem to feel a lot happier with that, feel more comfortable” (ICOH46).

One of the issues faced when re-opening was the limitations on the number of people who could be in a room together. A participant explained that this limited the day services the hospice could provide onsite, especially for those who had been discharged from a particular day or outpatient service, but still needed a space to socialise. This led to trade-offs about who got to use the limited available space, as the following participant said:

> “*So that could have gone better, but, I don't know how, you know, we've got a limited amount of rooms and it's kind of cherry picking who needs are greater. I don't agree with all the cherry picking either, you know, but whether that's I have a particular favourite group and they're not seen enough, or you know I'm not understanding the rationale behind which group gets to use that room today*” (ICOH30, AHP).

### *Places of care: hospice at home*

The pandemic meant that more people with life-limiting conditions were being cared for and dying at home. For one hospice this meant that they had to develop a hospice at home team:

> "*One of the few good things that has come out of the pandemic is that the hospice now has a hospice at home team, which ,you know, they are the nurses and health care assistants who go out to provide personal care for patients in the last days of life*" (ICOH48, doctor).

However, during the first three months of the pandemic another participant recalled how she had to replace the in-person visits she had booked in with telephone calls:

> "*Just to check in with them to check that they were okay, and then to reassure them that we would come out and see them as soon as we would be as soon as we were allowed to*" (ICOH45, senior nurse).

She explained that as a provider of one of the hospice's condition specific services, she was still allowed to do "essential" visits, which included new patients and six-month reviews and as a result she was able to "feed that quite important information back to the palliative care nurses" (ICOH45).

Providing hospice at home services at the start of the pandemic posed a number of issues for hospices. One hospice stopped providing night sitters (unlike some other hospices in the region), when patients were less able to rely on family members supporting them during the lockdown:

> "*I felt that we were letting down these people these people were still in need of our services. That was these services, which . . . our service users and their families really rely on . . . that they actually had less support, their own support networks had been diminished, that for us to also withdraw our support I felt was an extremely, that was a very wrong decision to have made*" (ICOH43, support nurse).

The participant said that this decision was reversed a few months later.

Other hospices reduced their services, as a participant shared her concern about the impact of the pandemic on services during the first lockdown, before it was possible to test for Covid-19:

> "*Prior to testing patients, that the hospice sort of ran down a little bit in numbers, so I always thought in that time we were supporting people enough. I know the community teams were doing their very best. But then once testing was up and running, I think we supported the palliative population as we would have done normally really*" (ICOH45, senior nurse).

However, for some hospices it was felt that there was a reduction in demand for hospice at home support, as one participant noted that during the first year or so of the pandemic many patients and families were reluctant to have hospice at home teams in their residence. The hospice repurposed those staff to provide support in other ways:

> "*Our hospice at home services that weren't doing as much hospice at home 'cause people didn't want them in their house, to be able to do some of the follow up*

> *calls and some check in calls and do a little bit video conferencing*" (ICOH64, senior nurse).

Another participant reflected on the decision for the community nurses and doctors not to visit patients in their homes that was taken at the start of the pandemic and the impact that had on patients and staff:

> "*You know they're being told by [hospice] that you can't [visit], you know, that you're not allowed to go and help them. Where does that leave them? I mean, you know, absolutely awful. But yeah, as I said, things have changed, unfortunately very, very slowly. So although it's been, you know, it's taken an extra 12 months, I'd say, for them to start getting back to what they should have started doing 12 months ago and in that time lost they've lost staff*" (ICOH48, doctor).

The fluctuating service provision had an impact on the expectations of people with life-limiting conditions and those that care for them, as one participant reflected how better communication with patients and their families during the pandemic was needed as, "our website was still saying we do this, but actually we're going out and saying 'but during these times we can only do this'" (ICOH61, senior nurse).

A participant explained how some patients and their families had been left unsupported on their own at home for long periods of time with little or no support either via telephone, video or in-person. She described the impact that had on her and the families she supported, when she was allowed out to visit them:

> "*So, you know, and that there's a lot of people or they haven't seen anybody [healthcare] for weeks and weeks. So nobody has had that conversation about death and dying to them. So when you go there, as you can imagine, they're not prepared for it. And there's me, the angel of death going in saying, 'you need to get the family here' or you know. Luckily for me, I'm experienced with conversations like that. But, you know, you do walk out – as experienced as I am – and I walked out and I sat in the car and like because, yeah, they've got young teenage kids screaming in the house 'cause dad's gonna die tonight, you know. So yeah. This yeah, it's horrific to be fair, its horrific and I pity the people who have got somebody poorly at home, I really do*" (ICOH53, nurse).

For those hospices that were providing hospice at home services, staff also had concerns about going to people's homes, as the following participant – transferred into the hospice at home service as part of a pandemic reshuffle of staff – explained:

> "*But again there was that fear, I think, I'm going into houses with, you know, very little PPE. You know, we just really had, these masks and the visors and an apron. And yeah, you were going into a house. And yes, I think that was really difficult for most of the staff 'cause it's different, isn't it? Its change and I think that that's quite frightening in itself on top of everything else that was changing and that was happening, I think it was stressful for people*" (ICOH34, nurse).

Although limits on visitors was primarily an issue hospice staff faced on the inpatient unit, it was also something that hospice staff experienced when visiting a patient's home where they found several family members with the patient. A participant said:

> “*Because obviously everybody should have been keeping away, but you just have to make that that call that judgment on the day and think, this is the last time of being with their family members. But sometimes the patient would also say, I don't want any of them to put themselves at risk. So even in their last dying days they were concerned, they don't want everybody mixing. It was a very difficult times for families and patients to make the right choices*” (ICOH47, senior nurse).

*Digital palliative healthcare support*
Hospices had to quickly adapt many of their services to the new pandemic landscape. For many this meant starting or increasing the use of digital technologies, which mostly involved using video platforms. As one participant said, “it has pushed some of the services into using technology in a much more robust way” (ICOH62, senior nurse). Another participant explained how her hospice had raised money to purchase more tablet computers, which “were difficult to get hold of ‘cause everybody was doing it” (ICOH62, senior nurse).

A participant explained how the pandemic and use of video calls brought ways of supporting inpatients that were not considered before. She explained how a patient’s sister lived in another country, but:

> “*For the whole time she was in [country], every night at 7:00 o'clock they'd bring the iPad through and she could talk to her sister, virtually. Now, I don't think that would have probably happened before the pandemic*” (ICOH46, AHP).

Another participant explained how the greater use of video calls had helped them support children, who struggled to have conversations over the telephone. She went on to explain that, for the adult support groups she ran she had found:

> “*For some people it’s kind of intrusive being in their own home, but for others, it's the ease that they can just log on and then log off and then at home and they don't need to go anywhere*” (ICOH56, AHP).

Video calls also had the obvious benefit over telephone calls of being able to see the patient, so staff were better able to assess the person’s condition, which was “far better than doing just a telephone assessment” (ICOH48, doctor). However, the use of video calls had its limitations, as the following participant explained, “but when you're not feeling your best, you don't really want to be on camera, do you? And when you're that weak, do you want to talk?” (ICOH63, senior nurse). Another participant reflected on what was lost and what was gained through the move to using telephone and video consultations with patients, noting how it made seeing the patient easier, especially now they were more comfortable doing telephone and online consultations, but that they missed being in the room with the patient:

> “*But I think for palliative care it's, I mean for me you know, where I get my energy from is from seeing the patients. So for me, that's always been the best part of the job. And, you know, in terms of it's a difficult job to do, to do it over the phone without that connection, you know, that that real connection it is, you know, it's really hard. So yeah, so remote stuff is kind of good because it means that we have more things that we're able to offer and, you know, [now] we're not quite so*

> *uncomfortable doing things over the phone or doing things remotely than we were*" (ICOH48, doctor).

As another participant reflected, he had now adapted to using video calls, when previously he was unsure they could work to provide support to people who were dying or to those that were caring for them. While he had some reservations about their suitability on all circumstances, he said:

> "*In fact, in some situations it's better actually seeing someone remotely is better than not seeing them at all or seeing someone remotely who might otherwise be greatly fatigued, for example, coming to see you, you know. Again, it's giving us the tool and that that kind of balance*" (ICOH69, AHP).

*Changes to services that worked, changes that did not work.*

The pandemic brought a range of changes to how hospices worked and meant that hospices were continually having to adapt as the pandemic situation and protections changed. We asked participants about what had changed – for better or worse – at different points during the pandemic. While many participants were able to reflect on what they thought had, or had not, worked some shared the following participants comment, "I still feel like people are still working out whether we handled it right or not" (ICOH26).

The **start of the pandemic and the first lockdown** brought rapid change for many participants, and there was a sense of camaraderie as one participant said, "you pull together in a crisis don't you? And that's just what we all did" (ICOH45, senior nurse). Another participant said, "we really pulled together and really looked after each other" (ICOH60, nurse). One participant reflected:

> "*I think the resilience of the staff worked really well because they were just all thrown, everybody was thrown into this new world where you have to think different, protect yourself and protect everybody around you. I think everybody worked extremely well in that situation*" (ICOH47, nurse).

A participant gave an example of how different staff pulled together, with support staff who:

> "*Started doing PPE bags for all the clinical staff, you know, making up little bags of masks and aprons and gloves, and everybody sort of rallied really, to support the ward and those who are having patient contact*" (ICOH45, senior nurse).

Another participant recalled how the start of the pandemic and implementation of the Personal Protective Equipment (PPE) and social distancing protections took some getting used to for all, "the poor patients were confused. I think we were confused" (ICOH62, senior nurse). The rapid changes meant that one participant felt there was, "a lot of, kind of, just ambiguity about our roles I guess, but at the end of the day, we just tried to keep our head down and do what we've always done and that's provide palliative care to those people that needed it" (ICOH26, senior nurse).

Staff from each of the hospices described the different ways that their organisation changed, adapting to the needs of their local community, as well as working with the resources they had available. A participant from one hospice described how the day services space was quickly converted into an inpatient unit, in preparation for the surge of patients at the start of the pandemic:

> “*So where the innovation was concerned, you know, yeah, we made that happen. We converted our day hospice into a bedded unit. So you know, we made things happen quickly and we acted in a way that we were asked of very rapidly and there was no, there was no real red tape. There was no, everybody was willing to make that happen*” (ICOH61, nurse).

Another hospice helped the NHS by accepting any terminally ill patients the hospitals needed to discharge, regardless of their specialist palliative care or hospice needs. A participant described how they were worried that this meant people who did have complex palliative needs were therefore not getting access to hospice care:

> “*It just felt like some people could have would have been better off in in a different environment and then other people that needed our sort of help then weren't able to 'cause obviously we have limited capacity*” (ICOH34, nurse).

Some hospices responded to the predictions of high death rates from Covid-19 by radically and rapidly changing their model and service provision to become an end-of-life care centre for those dying from covid. However, the number of deaths did not materialise. As one participant said:

> “*From a staff nurse option that whole thing just didn't work at all because their whole plan was that it was going to be this kind of end-of-life covid centre. But they had like literally one or two patients. It was they had all this staff. They had hardly any patients in it and the time and resources it took to set up and for us to vacate and then to come in it was it was such a big ordeal and actually they just didn't get the numbers of patients through that they wanted and that they foresaw*” (ICOH26, senior nurse).

She went on to explain it was:

> “*because it was just such a new service, there wasn't the kind of infrastructure there for referrals and nobody knew where to refer them to because it was just all completely new, so it was only really ever going to work by clinicians that knew exactly what was going on. And so I think there were stumbling blocks all the way through that decision making process, and I think it had the potential to be really effective*” (ICOH26).

Another participant described how, at the start of the pandemic, funding streams and processes for discharging patients from hospitals were changed, which meant the social care leads could were able to better work with hospices to coordinate the needs and funding for patients. As a participant said:

> “*It just it just meant people got home quicker and got what they needed and were able to access hospice at home services and personal health budgets and whatever they needed to get home. So yeah, so that was a real win*” (ICOH64, senior nurse).

However, even though this was seen as a significant improvement the previous arrangements are “now is back in place and everybody is moaning about it again” (ICOH64).

A participant summarised how many of the changes at the start of the pandemic meant that, “we almost shifted from a proactive to reactive response” (ICOH61, senior nurse). As another participant described, some of the rapid response systems they put in place to support people at home meant that more proactive planning and management of patients, including Advance Care Planning, were not being done. She explained:

> “*So I would say the model shifted from working all together, just providing urgent response and having to kind of work the narrative around that to go back to planned care, do it in a different way because we need to be able to release some of the staff and continue with a level of urgent response*” (ICOH64, senior nurse).

As well as the new systems and processes for patient referral, there were new practices to get used to, as a participant working on a hospice inpatient unit described:

> “*There was a very, very strict way of doing everything. Very, very strict. You had to enter the ward at a certain place. You had to leave it at a certain place, you had to wash your hands. You had to be assessed for washing your hands. You had to take you had to don and doff your PPE in a certain way. Then you know, I think things like that. It was very strict and I think everybody just in the end just fell into it*” (ICOH45, senior nurse).

During the pandemic hospices sought to work with each other in innovative ways, with some hospices merging services and sharing staff across sites. As well as the difficulties of rapidly changing roles, this brought practical stresses for those staff involved, as one participant observed:

> “*But I think it was quite stressful for the staff 'cause obviously the ones that had come over from [region] found it difficult to be on a different site. And even though the roads weren't busy 'cause it was, you know very quiet at the beginning, I think people found it quite difficult to travel if they weren't used to traveling*” (ICOH34, nurse).

The new ways of working also brought new clinical dilemmas for staff. For example, one participant reflected on situations she faced with inpatients who needed suction to help remove phlegm, which if it was not removed could lead to the patient choking and dying. She explained that pre-pandemic this would have been something she would have done without thinking. However, suction was an aerosol generating procedure and the guidance banned the use of suction without the use of a type of mask that was unavailable to her at the time (FFP 3). In many cases she did not know if the patient had Covid-19. But she was told, that had she used suction, she would not have been sanctioned. This left her in a moral quandary:

> “*In that situation, if you're happy to do so, you can do it. But if another nurse is in there and you know they don't want to, then they don't have to. But that leaves you in a position, knowing that if he choked to death and you did nothing. It just it just didn't sit very right like the guidance for that wasn't right. So you're giving me a choice that I'm in this situation, this man choking, and I don't know if you've got covid or not. If I suction him, I could potentially catch it, but if I don't, he could choke to death. That's a very difficult. Putting the choice on you*” (ICOH60, nurse).

The first weeks and months of the pandemic involved continual updates to the local and national situation, including new amendments to guidance. A participant whose role had changed due to the pandemic explained how, at her hospice, they used WhatsApp messenger group chats including “all aspects of the nursing team were, regardless of you know what grade or job description they had,” to share latest NHS England guidance and other advice:

> “*So communication was fantastic, because obviously you've got people working different shifts different hours, you've got ourselves who were sort of on loan to the ward, if you like; but we all had access to this information*” (ICOH45, senior nurse).

As the pandemic situation stabilised somewhat, staff were able to reflect on the changes put in place and consider longer-term plans. One participant explained how the “blitz spirit” that motivated much of the early response from staff changed over time, recognising that “that's not quite working” and the need to adapt as, “We're in this for the long haul now aren't we?” (ICOH64, senior nurse). This led to some staff returning to their previous roles and the reintroduction of closed services, such as day services. Another participant explained that it was the introduction of testing that was a significant change that helped the hospice return to more normal ways of working:

> “*I think we were lucky when testing came in because that changed everything. Absolutely everything, that changed, and it just meant that we could operate a bit more safely and not that we weren't operating safely, but at least instead of guessing we knew for certain about individual patients. And certainly the hospice run, I say normally, as normally as it could once testing came into play. So that was invaluable for us really*” (ICOH45, senior nurse).

As well as the somewhat temporary or short-term adaptations hospices put in place, participants described the **longer-term effects** that the pandemic appeared to have on them and the hospice. Some of these were positive, as one participant explained how, because of the pandemic, the hospice was using social media more to hold memorial events and provide video tutorials, “Its embracing technology for the first time in the hospice’s history” (ICOH56, AHP). Another participant explained how the pandemic had affected their capacity to fundraise, but also instigated their increased use of digital and online methods of fundraising:

> “*It kind of gave us a bit of kick up the bum and we've really speed up in that sense and caught up with the other big [charities] I’d say. So you know, we've invested a lot in our digital fundraising and like I say just be more innovative with it. So we raised money that we never would have thought about raising money in a way before*” (ICOH68, support services).

The pandemic also forced hospices to be innovative with “some of the new ways that we've, you know, thought about kind of raising funds and stuff like that that's been quite positive” (ICOH42, support services). Another participant said that pre-pandemic she was aware that she and her clinical colleagues were aware they needed to improve their IT skills:

> “*I think the fact that we all had to very quickly upskill on technology was quite positive . . . we were sort of thrust into this world of well, ‘you gotta get your head around [it]*” (ICOH67, AHP).

Other participants reflected how the pandemic had allowed them and other staff to make changes to the clinical work they were doing:

> “*I think prior to the pandemic it was a well trodden path and this is how things are and you don't change them and it's how we've always done things whereas the pandemic gave you freedom to kind of rip up the rule book really, start scratching away that you never would have been able to*” (ICOH56, AHP).

Similarly, one participant explained how, when she returned to her pre-pandemic role her team reviewed some of its ways of working and communicating saying, “Looking back, it made us do things differently, but actually probably for the better” (ICOH45, senior nurse). In particular, for one participant the pandemic brought the realisation that much of hospice care was premised on in-person service delivery and that alternative ways of working were possible:

> “*So when that one thing [in-person delivery] is taken away from you, [you] can’t think then. So I think anyone designing a service should have different tools to use and then you wouldn't have been landed in the that problem, we have them because you've got different things that you can lean on*” (ICOH56, AHP).

Some participants were more ambivalent about the implications of some other changes that had taken place. A participant reflected that:

> “*I feel that [the pandemic] was, yeah, this is one of the things that I think covid is being used as a bit of a tool to bring about changes, that would probably not have been considered [otherwise]*” (ICOH43, support nurse).

Another participant was worried about how the effects of staff fatigue from losing staff members as the pandemic went on meant that “there have been times when patient care has been detrimentally affected” (ICOH26, senior nurse). Several participants also noted that the pandemic had affected the usual routes to diagnosis, treatment and support that patients and those that care for them might usually access. As one explained:

> “*I think in this this is born from that first kind of lockdown, is we're getting patients referred towards who are late, that sat at home that couldn't access hospital appointments that that didn't appear to the GP with worries and indications of early illness. So the referrals are coming in poorlier, later, you know missed opportunities, possibly as well and complex levels of loss*” (ICOH61, senior nurse).

One participant was particularly concerned about her experiences of the health service – personal and professional – throughout the pandemic so far:

> “*So I think patients stopped being the priority and I think figures started to be the priority and I don't think people realise the impact that was having for patients and their family. I think it was more like ‘oh, you know, when you're wanted or when it looks good for us to treat you with well [we’ll call you], but when you*

> *need us, we've got all these things in place, which means we can't be there for you"*" (ICOH75, AHP).

A participant reflected on what the changes to provision of hospice care might mean for the future:

> "*I feel like it's really changed the face of palliative care. And I think that we're as a Hospice are moving much more towards like what their calling acute palliative care. Which is still palliative care patients, but with more acute needs*" (ICOH26, senior nurse).

She went on to say that while she understood how this development had come about, it was a different approach to palliative care at the hospice than the one she started with many years previously:

> "*You know when your heart is in end of life palliative care in the way that I feel my career has been, I you know it's hard to kind of see that that's a positive thing because you know you want to, you want to carry on just giving, really you know niche care to certain groups of people, you don't necessarily want to expand it open wider*" (ICOH26)

As the pandemic went on it also had an **impact on staff working practices and wellbeing.** Some participants welcomed how the pandemic had normalised practices of working from home and how this provided flexibility, especially for those staff who worked in administrative support roles or lived some distance from the hospice. A participant explained how they could see benefits to new hybrid ways of working:

> "*I do think that that is the best of both worlds, in as much as you get to speak to people you interact and build a team, because we are a team, even though we have specific roles that don't really overlap that much. I mean, it's just nice for the social interaction. But I achieve loads more when I'm at home, loads more*" (ICOH71, support services).

It was not just the support staff that were working from home at the start of the pandemic. A participant explained that at the start of the pandemic the Clinical Nurse Specialists (CNS), who would ordinarily visit patients in the community, were also working from home a lot. However:

> "*We recognised fairly quickly that without the support of each other being back in the office, so they were suffering the psychological effects of isolation. So we brought them back into the office. So actually, within the hospice with anybody that was an administrative role, went out and worked from home, but actually we still kept the clinical staff in and together, and we took over a lot of the admin buildings to be able to be covid safe within the workplace*" (ICOH64, senior nurse).

A participant reflected how staff welfare had been somewhat forgotten at the start of the pandemic – including for those who were furloughed or were working from home:

> "*But I also think nothing could have been changed about that. I think their attention was on, how are we going to get the money? How are we going to keep everyone safe? So I think that was quite right, but I think in hindsight we should have been looking after people, staff earlier . . . I mean just kind of keeping that*

> *connection with people on a daily basis and having those kind of social calls and the importance of doing that*" (ICOH56, AHP).

To help keep staff – especially those working from home or who were furloughed – connected with the hospice one participant explained how she put together an email newsletter to share with hospice staff, collecting good news stories:

> "*Because we kind of thought people need a bit of an uplift at the moment and there's so much doom and gloom going on, maybe we need to start talking about some of it . . . it seemed to get a good a good reception, yeah, I think it was quite appreciated*" (ICOH68, support services).

As already noted, working through the pandemic took its toll on many staff, as one participant explained that although at the start there was a "all hands on deck" attitude at the start, as time went on staffing levels became compromised, "there's just the sense of absolute fatigue within the team of, like their resilience to just keep going during the, you know stresses of it" (ICOH26, senior nurse). Another participant reflected on the morale and wellbeing of the staff on the inpatient unit at her hospice:

> "*But you know, they are worn out, staff are worn out, because we've had you know staff off with covid and other sicknesses. And the girls have stepped up and done extra shifts and everybody's knackered. For want of a better word, everybody is knackered, emotionally and physically yeah*" (ICOH53, senior nurse).

She went on to provide her understanding of the hospice's financial situation and the added stresses that brought, "The hospice isn't sustainable, you know, it's not rocket science, so everybody, you can imagine everybody on tenterhooks [about their] jobs" (ICOH53, senior nurse).

One hospice moved their pre-pandemic in-person Schwartz rounds, which are a multidisciplinary forum for staff to come and share experiences of the emotional and social impact of their jobs, to support staff. This had a knock-on benefit, as one participant explained:

> "*But it means that we've actually now opened that out to wider teams across the organisation, so our nursing teams in the community are, and other fundraisers who weren't attached to the hospice. So he's just been quite a nice way to bring more people together 'cause obviously anyone can join it online now. So, I think that's been another small benefit of the pandemic*" (ICOH68, support services).

A participant noted that, although they felt management could have handled some things better, they were also under a lot of pressure and such judgements about what worked, could only be made in hindsight:

> "*And the [management] were burned out as well, you know, and there's gotta be that understanding as well. It can't have been easy for any of them either. So, I do admit that some things could have been done better, but I don't think they could have been with what we knew then*" (ICOH56, AHP).

As described above, many hospices brought in **telephone check-ins** for patients and those that care for them during the first lockdown and during most of the first year of the pandemic. A participant who helped provide the telephone support service at her hospice explained:

> "*We had to put a lot of things in place very quickly. We had to adapt the service very quickly, do some training for the volunteers, training for myself and my colleagues to get upskilled on telephone support*" (ICOH30, AHP).

For example, a participant explained one of the difficulties they had when providing support on the telephone was when they left "a big, long silence while you're waiting for somebody to sort of talk to you, [it] is difficult because, you know, people jump in and it 'oh, you still there?'" (ICOH34, nurse). Nonetheless, in the telephone check-ins and support lines were seen as a success. A participant explained one of the benefits that telephone support brought:

> "*I think the telephone support has been really, really useful because it's widened our geographical offer. You know 'cause anyone can access us now and we used to be governed by our boundaries. We're not now. That seems to have gone out the window and we've worked with people in London, Wales, Germany. So that is fantastic. I love the fact that if we've got a mum . . . and her daughter lived in Germany, we [can] work with the daughter as well because we don't have that restriction anymore*" (ICOH30, AHP).

As well as the geographical flexibility she explained that telephone support allowed more flexibility for service users as to what time they could speak with staff, making it more accessible. The participant described how some patients and carers were initially resistant to telephone support, but she would offer it on a trial basis, with the possibility of in-person counselling should they wish. However, "up to now I've had no one that I haven't been able to work with on the phone, so you know it's worked one way or another it's worked" (ICOH30, AHP). However, the times the telephone service was available had changed from an evening finish to mid-afternoon, which the participant concerned them, "I don't particularly like because I think it's it stops a lot of people being able to access it" (ICOH30).

Another participant who made many calls to patients and carers during the first year of the pandemic reflected on that experience:

> "*In some ways it was very difficult because people shared a bit too much over the phone. They hadn't been seen by a lot of the medical establishment because of the way things were happening. So we got a lot of the offloading and a lot of, you know, we were trying to signpost and pick up a lot of people that were really struggling. A few people that we've had to sort of signpost on because we were worried, you know, they've said that they're going to take their lives and things because I think they felt so desperate. So it it's been a big learning curve for us that last year*" (ICOH46, AHP).

A participant explained the impact they felt the introduction of the 24/7 helpline had on staff and patients, noting that it was a service they had wanted to get in place for a while, but that it was now replacing a form of care that was not available at that point in the pandemic:

> "*So although there was that small gain, they lost, you know that huge benefit of having the continuity [of care]. But it was awful for the nurses because they were, you know, they had to give up ownership for those patients and hand it over to this helpline and not really knowing, you know, how well it was going to work and these are vulnerable people*" (ICOH48, doctor).

Another significant limitation of telephone only assessments related to safeguarding. A participant explained that they were not made aware of any that they had missed so far in the pandemic, but:

> "*I have to reflect on the fact that they're probably, you know, it's likely that there were safeguarding issues that perhaps we didn't see, we weren't aware of, we didn't know about because we weren't seeing people face-to-face*" (ICOH67, AHP).

One of the inherent limitations of telephone calls is that you are not able to see the person at the other end. A participant explained how this limitation to telephone check-ins, in contrast to their usual way of working which involved visiting people in their homes, affected her role:

> "*If they let you into their house, if you can see how they're living and because people's concerns and abilities to cope are different, they, not everybody has the same base level that they're coming from, so it's difficult when you're on the phone because you can't see them in their own environment. If somebody is telling you they're not coping. Actually, are they really, really not coping, or is it just compared to how they were before?*" (ICOH75, AHP).

Overall, the telephone check-ins and support were welcomed as a necessary but limited stop-gap. The following participant summarised the feedback she had from people with life-limiting conditions and those that cared for them about telephone calls, saying:

> "*They just loved that face-to-face and they all used to say you know telephone communication is fine but you can't beat face-to-face. And we very much found that*" (ICOH45, senior nurse).

Another participant said:

> "*The telephone support has been like invaluable and we will be continuing with that, and we have seen an increase in people accessing like our information and support line and stuff. But there is still, there is still the want and need for that proper human contact*" (ICOH42, support services).

A participant explained that now she had the necessary PPE she would always go out and see a patient who was referred to her, even if they had Covid-19, because, "You can't tell through the phone if someone is dying, can you?" (ICOH48, senior nurse).

*Impact on bereavement support*

Several staff that we spoke to were directly involved in providing (pre) bereavement support to those people that cared for patients at their hospice. We asked them how the pandemic had affected their work.

A participant explained that they started a new service of telephone calls to bereaved relatives of those who died on the inpatient unit, because patients were both arriving and dying within days and because of the visiting limitations. “So we started sort of making those calls to people, which was a new thing from the from the pandemic and, actually, that's another thing that's carried on” (ICOH67, AHP).

Another participant explained that he provided supervision and support to several staff who would ordinarily provide psychological support to patients on the in-patient unit. However, those staff were not able to access the wards because of the protections in place at the time:

> “*They were very distressed by this, because they knew that they weren't able to provide that support to clients and there were very distressed clients. obviously because you know they were dying alone away from their families. And they can go in and offer that kind of support and they were doing the bereavement calls afterwards and so having to listen to the families kind of stories*” (ICOH69, AHP).

As with other services, some hospices sought to use telephone calls and video support groups to provide support. One participant described an online bereavement support group that she and a colleague had been able to put into place in the first year of the pandemic and that had continued as protections at the hospice eased. Reflecting on the difference being online made she said:

> “*I think that's fantastic because again, would people have come to it? And I'm not sure. Would people have made that physical journey? It just makes it so much easier 'cause it’s on Zoom*” (ICOH30).

However, while the first cohort of the video support groups met in the evening, subsequent groups had to meet within office hours due to a hospice wide decision to stop evening support services, removing what the participant felt was a key benefit of online support groups:

> “*When we came out of lockdown a lot of people had to go back to work, so those were people who couldn't access us [in daytime sessions]. And as I say I, I've worked with people who've finished work and sat in their car to have their session. I don't, I don't like that, but I like the fact that they can still have a session [because it is online]*” (ICOH30, AHP).

This participant also explained that while an online bereavement support group can provide a focused programme of support over a period of weeks, what is often needed afterward is a space of mutual support after the online programme finished. This could be something like:

> “*A good grief cafe where people could access a social space and we haven't been able to do that. So for me that still feels really important because there's kind of a time when you finish working with people, but they're still desperately lonely and they still need people that they can relate to*” (ICOH30, AHP).

This was something that online groups could not yet replicate:

> “*We can't open a zoom room and sit there for like two hours hoping somebody turns off and breakout rooms, we wouldn't have enough people to manage it if people wanted to break off, and you know, like you would in a cafe and have a chat*” (ICOH30).

**Summary of findings**

Hospice staff recognised that people with life-limiting conditions and those that care for them were especially vulnerable to Covid-19 and the effects of the protection measures put in place. Staff sought to put extra measures in place to support them, including door-step visits, increased telephone check-ins and online video support groups. However, staff were worried about the impact that the loss of charitable funding would have on the services they provided and were concerned about the sustainability of hospice funding in the future. The pandemic also included suspending the roles of most volunteers, closing day services, and limiting the number of visitors to inpatients. This last change was one of the most emotionally and practically difficult measures to manage, particularly because of the fluctuating guidelines and variability of practice that the application of individual discretion brought. While staff reported feelings of camaraderie at the start of the pandemic, the interviews – some conducted 18 to 20 months after the first lockdown – were strongly associated with experiences of fatigue and poor wellbeing, due to reduced staff numbers and overwork.

Many hospices also adapted their services at the start of the pandemic to support the NHS. This brought opportunities to develop new ways to deliver services to their communities and do things differently. This included expanding their services so they could support the many more patients with life-limiting conditions who were dying in their places of residence. Hospice staff also experienced a rapid expansion and use of telephone and video calls to replace in-person care and support. Staff noted several advantages to the new ways of working, in particular allowing for greater access to hospice services. However, staff were concerned that some changes might also be fundamentally changing what hospice care is, moving it away from in-person holistic centred care.

**Summary of the implications for practice and recommendations for policy**

The pandemic has affected the emotional and psychological wellbeing of many staff, and they may be in need of ongoing support from managers and colleagues. If hospices are to continue to provide holistic person-centred care and support for people with life-limiting conditions and those that care for them, they will need to be sufficiently resourced with skilled staff who are (again) given the opportunity to provide gold-standard palliative care. This will include experimenting with forms of online and in-person inpatient, outpatient, day and bereavement services, as well as 24-hour hospice-at-home services. As hospices continue to adapt to the changing Covid-19 environment it will be important to ensure hospice staff – including volunteers – are supported through clear strategies for communicating rapid and complex service changes to patients and their carers. Staff will particularly need support as guidance changes on how best to consistently apply visiting limits and protections.

It will be important as the pandemic continues that staff ensure that people with life limiting conditions are not marginalised or discriminated against and that the quality of their lives are valued equitably in the application of any (new) guidance or policy. Hospices are well placed to develop ways to bring people with life-limiting conditions, and those that informally and formally care for them, together to explore their shared needs and concerns as a group and be ready to facilitate, engage and listen to them not just as patients and (in)formal carers, but as citizens, who need to continue to have an active voice in society.

## Conclusion

This is one of the first studies to provide in-depth exploration of a range of hospice staff experiences of the Covid-19 pandemic, as it included doctors, nurses, allied health professionals, and support service staff. We found that during the first lockdown staff experienced rapid changes to the way they worked, but they rallied to support their local communities and the NHS. Many changes – including enforcing visitor limits to inpatient units and reduction in support offered at home – were emotionally difficult to implement and staff may have ongoing need for support. Hospice staff were welcoming of many changes to their working practices, including greater use of online video calls, particularly when they improved access to hospice services for patients and carers. However, staff explained that hospice care is predicated on being an in-person service and they were keen to return to this whenever it was safe to do so. Hospice staff will therefore have to continue to find the right balance between Covid-19 and the pandemic protections and ensuring people with life limiting conditions are afforded the best quality of life in the time they have left.

## Funding statement

‘The Impact and implications of Covid-19 on the relational, social, and healthcare experiences of Hospice care in the West Midlands’ (ICoH) study was funded by Economic and Social Research Council (ESRC) as part of the UK Research and Innovation’s rapid response to Covid-19 (grant ref: ES/W001837/1). Marie Curie staff were acting as consultants, with their time funded by the ESRC grant.

## Acknowledgements

The Research Team would like to thank all the participants who took part in this study, who so generously gave us some of their time to speak with us.

## References

Bowers, B., Pollock, K., Oldman, C. and Barclay, S. (2021) 'End-of-life care during COVID-19: opportunities and challenges for community nursing', *British Journal of Community Nursing January 2021,* 26(1), pp.44-46. DOI: 10.12968/bjcn.2021.26.1.44

Braun, V., Clarke, V., Hayfield, N. and Terry, G. (2019) 'Thematic Analysis', in Liamputtong, P. (ed.) *Handbook of Research Methods in Health Social Sciences*, pp.843-860. DOI: 10.1007/978-981-10-5251-4

Clark, D. (2014) 'Palliative medicine as a specialty', in *End of life studies blog*. *Accessed 30/6/20* [Online]. Available at: http://endoflifestudies.academicblogs.co.uk/palliative-medicine-as-a-specialty/.

Dunleavy, L., Preston, N., Bajwah, S., Bradshaw, A., Cripps, R., Fraser, L. K., Maddocks, M., Hocaoglu, M., Murtagh, F. E., Oluyase, A. O., Sleeman, K. E., Higginson, I. J. and Walshe, C. (2021) ''Necessity is the mother of invention': Specialist palliative care service innovation and practice change in response to COVID-19. Results from a multinational survey (CovPall)', *Palliative Medicine*, pp.814-829. DOI: 10.1177%2F02692163211000660

Evans, N., Menaca, A., Andrew, E. V., Koffman, J., Harding, R., Higginson, I. J., Pool, R., Gysels, M. and Prisma (2012) 'Systematic review of the primary research on minority ethnic groups and end-of-life care from the United Kingdom', *Journal of Pain and Symptom Management,* 43(2), pp.261-286. DOI: 10.1016/j.jpainsymman.2011.04.012

Hasson, F., Jordan, J., McKibben, L., Graham-Wisener, L., Finucane, A., Armour, K., Zafar, S., Hewison, A., Brazil, K. and Kernohan, W. G. (2021) 'Challenges for palliative care day services: a focus group study', *BMC Palliative Care,* 20(1), pp.1-9. DOI: 10.1186/s12904-020-00699-7

Hospice UK (2017) *What does the public think about hospice and palliative care? Key findings from ComRes survey*, London: Hospice UK. https://professionals.hospiceuk.org/docs/default-source/What-We-Offer/publications-documents-and-files/comres-paper-201704aa70124ccd608dad24ff0000fd3330

MacArtney, J. I., Eccles, A., Fleming, J., Grimley, C., Mayland, C. R., Mitchell, S., van Langen-Datta, S., Driscoll, R., Almack, K., Dale, J., Tatnell, L. and Roberts, L. (2021) 'What do we know about the impact of the Covid-19 pandemic on hospices? A collaborative multi-stakeholder knowledge synthesis [version 1; peer review: 3 approved].', *AMRC Open Research,* 3(23), p.23. DOI: 10.12688/amrcopenres.13023.1

Medland, A. (2011) *Portrait of the West Midlands*, London. Available at: https://www.sustainabilitywestmidlands.org.uk/wp-content/uploads/portraitw_tcm77-2260021.pdf.

Mitchell, S., Oliver, P., Gardiner, C., Chapman, H., Khan, D., Boyd, K., Dale, J., Barclay, S. and Mayland, C. R. (2021) 'Community end-of-life care during the COVID-19 pandemic: findings of a UK primary care survey', *BJGP Open,* 5(4). DOI: 10.3399/bjgpo.2021.0095

Oluyase, A. O., Hocaoglu, M., Cripps, R., Maddocks, M., Walshe, C., Fraser, L. K., Preston, N., Dunleavy, L., Bradshaw, A., Murtagh, F. E. M., Bajwah, S., Sleeman, K. E. and Higginson, I. J. (2020) 'The challenges of caring for people dying from COVID-19: a multinational, observational study of palliative and hospice services (CovPall)', *Journal of Pain and Symptom Management,* 62, pp.460-470. DOI: 10.1016/j.jpainsymman.2021.01.138

Pickersgill, M. (2020) 'Pandemic Sociology', *Engaging Science, Technology, and Society,* 6, pp. 347-350. DOI: 10.17351%2Fests2020.523

Silverman, D. (2011) *Interpreting qualitative data: a guide to the principles of qualitative research.* London: Sage.

Sleeman, K. E., Murtagh, F. E. M., Kumar, R., O'Donnell, S., Cripps, R. L., Bone, A., McAleese, J., Lovick, R., Barclay, S. and Higginson, I. J. (2021) *Better End of Life 2021. Dying, death and bereavement during Covid-19. Research report.*, London (UK): Marie Curie. DOI: 10.21203/rs.3.rs-535007/v1

Taylor, R. (2019) 'Perspectives on hospice and palliative care though a UK lens', in *The Value of Death blog*. Accessed 30/6/20 [Online]. Available at: https://commissiononthevalueofdeath.wordpress.com/2019/09/19/perspectives-on-hospice-and-palliative-care-though-a-uk-lens/.

van Langen-Datta, S., Mayland, C. R., Mitchell, S., Driscoll, R., Dale, J., Fleming, J., Eccles, A., Grimley, C., Wesson, H., Almack, K., Tatnell, L., Roberts, L. and MacArtney, J. I. (2022) 'The impact of Covid-19 on hospices: A systematic integrated review and synthesis of recommendations for clinical practice and policy [version 1; peer review: 0 approved]', *AMRC Open Research,* [In press].

Ziebland, S. and McPherson, A. (2006) 'Making sense of qualitative data analysis: an introduction with illustrations from DIPEx (personal experiences of health and illness)', *Medical Education,* 40(5), pp.405-14. DOI: 10.1111/j.1365-2929.2006.02467.x