Understanding and addressing challenges for advance care planning in the COVID-19 pandemic: An analysis of the UK CovPall survey data from specialist palliative care services.

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Abstract

Background: Specialist palliative care services play an important role in conducting advance care planning during COVID-19. Little is known about the challenges to advance care planning in this context, or the changes services made to adapt.

Aim: Describe the challenges that UK specialist palliative care services experienced regarding advance care planning during COVID-19 and changes made to support timely conversations.

Design: Online survey of UK palliative/hospice services' response to COVID-19. Closed-ended responses are reported descriptively. Open-ended responses were analysed using a thematic Framework approach using the Social Ecological Model to understand challenges.

Respondents: Two hundred and seventy-seven services.

Results: More direct advance care planning was provided by 38% of services, and 59% provided more support to others. Some challenges to advance care planning pre-dated the pandemic, whilst others were specific to/exacerbated by COVID-19. Challenges are demonstrated through six themes: complex decision making in the face of a new infectious disease; maintaining a personalised approach; COVID-19-specific communication difficulties; workload and pressure; sharing information; and national context of fear and uncertainty. Two themes demonstrate changes made to support: adapting local processes and adapting local structures.

Conclusions: Professionals and healthcare providers need to ensure advance care planning is individualised by tailoring it to the values, priorities, and ethnic/cultural/ religious context of each person. Policymakers need to consider how high-quality advance care planning can be resourced as a part of standard healthcare ahead of future pandemic waves. In facilitating this, we provide questions to consider at each level of the Social Ecological Model.

Key words: Palliative care, Hospices, Coronavirus, Surveys and Questionnaires, Pandemics, advance care planning.

Key Statements

What is already known about the topic?

- An important part of palliative care's response to COVID-19 is ensuring that timely and proactive advance care planning discussions occur with patients and their care networks.
- High quality advance care planning is viewed as a process that adopts a holistic, collaborative, and individualised approach.
- Prior to COVID-19, challenges to advance care planning included time constraints, lack of training, fears of taking away hope, limited resources, and insufficient knowledge.

What this paper adds?

- The COVID-19 pandemic exacerbated already-existing challenges to conducting high-quality, individualised advance care planning, including the ability to maintain a personalised approach, and sharing information between services.
- COVID-19-specific challenges to advance care planning exist, including the complexities of decision-making for a novel infectious disease, communication issues, and workload pressures.
- In responding to these challenges, services adapted local processes (prioritising specific components, normalisation and integration into everyday practice) and structures (using technology, shifting resources, and collaboration) of care.

Implications for practice, theory or policy

- COVID-19 has provided an opportunity to re-think advance care planning in which the starting point to any discussion is always the values and priorities of patients themselves.
- Providers and policymakers need to urgently consider how high-quality advance care planning can be resourced and normalised as a part of standard care across the health sector, ahead of future or recurrent pandemic waves and in routine care more generally.
- There are several key questions that health professionals, services, and policy makers ought to consider in working towards this.

Introduction

In March 2020, the World Health Organisation declared Coronavirus (COVID-19) a global pandemic, with an estimated global mortality rate of 3.4%, increasing with age and co-morbidities.(1) The number of patients suffering and dying from COVID-19-related illness is placing huge pressure on healthcare systems across the world.(2) By March 2021, 114,140,104 number of people globally had been diagnosed with COVID-19 and 2,535,520 had died as a result of this infection. (3)

Worldwide, specialist palliative care services have an important role to play in responding to the pandemic and are skilled in delivering person-centred symptom control and making complex decisions in the face of uncertainty. (2, 4, 5) One crucial aspect of decision making in palliative care - and even more so within the context of the pandemic - is ensuring that timely advance care planning discussions occur with both COVID-19 and non-COVID-19 patients (and their families).

Adapting existing person-centred definitions, (6, 7) we define high quality advance care planning as 'timely considerations and activities to best prepare for future care, including: identifying values based on past experiences and quality of life; choosing proxy decision-makers wisely and verifying that they understand their role; deciding whether to grant leeway (and how much) in proxy decision making, and; informing other family of wishes in advance to reduce or prevent conflict'. As a person's preferences and priorities are complex and may change over time, (8, 9) we view advance care planning as a process, not a one-time event or document. (10) In the COVID-19 pandemic, it is crucial that healthcare professionals have high quality and timely advance care planning discussions with patients and their families, to enhance the likelihood of improved outcomes and satisfaction.(11-13) However, this presents multiple challenges.

Patient (unpredictable disease/prognosis, insufficient knowledge of health status, anxiety, and denial), (13, 14) professional (time constraints, lack of communication training/skills, fears of taking away hope), (13-15) and system-wide (limited resources and unclear responsibilities) (14-16) challenges exist to initiating and following-up advance care planning discussions. Currently, however, there is lack of evidence regarding how these issues manifest during the COVID-19 pandemic, or what may be done to address these challenges. Addressing these issues is crucial in optimising the specialist palliative care response to the COVID-19 pandemic and for adapting to future increases in the need for palliative care.(17, 18)

This study aims to describe the challenges that UK specialist palliative care services experienced regarding advance care planning during the COVID-19 pandemic and the changes made to support timely conversations.

Methodology and Methods

Design and participants

The CovPall study is a rapid multinational observational study of palliative care during COVID-19. (19) Given that understandings of advance care planning during COVID-19 are dependent on the cultural and policy contexts in which they are conducted, this paper reports data from the UK nations only through collecting data via a cross-sectional on-line survey of hospice and specialist palliative services in the UK. Services providing hospice and specialist palliative care across inpatient palliative care, hospital palliative care, home palliative care, and home nursing settings were eligible for participation and recruited through palliative care and hospice organisations (Sue Ryder, Hospice UK, Marie Curie, European Association of Palliative Care, Together for Short Lives, and the palliativedrugs.com and www.pos-pal.org network) between April and July 2020. Within these sites, service leads (medical or nurse directors/clinicians) or their selected nominees were eligible to complete the survey.

Ethical approval was obtained from King's College London Research Ethics committee (LRS-19/20-18541). The CovPall protocol is registered (ISRCTN16561225) and these survey results are reported according to STROBE (20) and CHERRIES checklists. (21)

Survey and data collection

This survey was developed through iterations within the CovPall team and piloted in expert and Patient Public Involvement consultations. REDCap was used to securely build and host the survey which aimed to understand how specialist palliative care and hospice services/organisations responded to the COVID-19 pandemic, and comprised of 72 closed- and 94 free-text responses (the full survey is provided in supplementary file 1, and procedures for the survey are provided in supplementary file 2). This paper focuses on the impact of COVID-19 on advance care planning via analyses of two closed-ended and two free-text questions (see Table 1). The responses provided were reflections made by service leads (or their nominees) on behalf of the service/organisation in which they worked. The pandemic started in the UK in March 2020, and data on the number of COVID-19 patients seen were collected between 23/04/2020 to 31/07/2020.

Table 1: Closed and free-text survey questions analysed in this study

Questions taken from section 4 of the survey, titled: 'How have your services changed in response to COVID-19'		
Closed questions	4.13. Would you say you are now involved directly with patients/families in advance care planning? 4.14. Would you say you are now involved advising/supporting others and/or educating about advance care planning?	1. A lot more 2. Slightly more 3. About the same 4. Slightly less' 5. Much less
Open questions	4.15. In what ways (if any) have you changed how you are supporting advance care planning? 4.16. What would you say are the main challenges for advance care planning during the COVID-19 pandemic?	Free text response

Data analysis

Anonymised quantitative data items were summarised descriptively. Free text responses were analysed in NVivo (v12) using a thematic Framework approach. (22) This allowed within- and between- case analyses to be made to explore how key contextual variables related to main themes. The following iterative steps were followed: (1) familiarisation and coding; (2) developing an analytic framework; (3) indexing; (4) charting (by developing matrices to understand differences in main themes across key variables); and (5) interpreting the data. During the development of our analytic framework, we recognised that responses to the challenges to advance care planning free-text question could be understood through using an adapted version of the Social Ecological Model. (23, 24) This model recognises that challenges to advance care planning exist at multiple interacting levels (individual, interpersonal, within teams/services, between teams/services, and national).

We adopted a relativist approach to rigour (25) by using lists of criteria on what researchers agree constitutes high quality qualitative analysis (26-28) as a starting point and then selecting criteria appropriate to the context, purposes, and methodology of this study (table 2).

Findings

Characteristics of survey sample and advance care planning provision

We received responses from 277 UK palliative care services, of which 168 included hospice services (equating to ~76% of hospice services in the UK, (29) see Table 3). Two hundred and forty-eight services reported caring for patients with suspected or confirmed COVID-19, and 16 services reported no suspected or confirmed cases of COVID-19 patients (13 did not provide a response to this question). The number of COVID-19 patients seen ranged from 0-400, (median 14; IQR 5-52). Thirty eight percent of responding services were directly providing more advance care planning and 59% were providing more advice to others about advance care planning. The vast majority (92%) of those who were providing more direct advance care planning were also providing more advice to others about the advance care planning process.

Free text responses

The analysis of free-text responses are divided into two sections. The first section presents six themes and two sub-themes representing the challenges to advance care planning and how these were understood through the different levels (national, individual, interpersonal, within- and between-teams and services) of the Social Ecological Model. Whilst some of these challenges were specific to COVID-19, others were general challenges exacerbated by the pandemic (see Figure 1). The second section presents two themes and five sub-themes representing the changes/adaptations that services made to support advance care planning during the pandemic.

Table 2: List of quality criteria selected for ensuring a rigorous qualitative analysis and how it was fulfilled in this study

Quality criteria	How it was fulfilled
Rich rigor (does the analysis use appropriate theoretical constructs, data, sample, and context?) (27)	We collected and analysed free text responses from 277 palliative care services (~84% of hospices in the UK), drawing on the Social Ecological Model to understand and explain the individual, organisational/structural, and national challenges to conducting advance care planning during the COVID-19 pandemic within a UK context.
Credibility (have thick descriptions and detailed findings been provided?) (26, 27)	A wealth of free-text data allowed for thick description and detail that shows the reader the challenges and changes made to support advance care planning during the COVID-19 pandemic. Quotes and their descriptions are provided to support this.
Width (how comprehensive is the evidence provided?) (26)	Data was collected across all regions of the UK during the first wave of the pandemic, thus presenting a diversity of voices and perspectives (see Table 3 for demographic information of participating services).
Exploiting exceptional data (were contradictory data attended to during analysis?) (28)	During analysis, data that contradicted or questioned the narratives of main themes were attended to and incorporated into the development of themes.
Sincerity (did the research team engage in reflexivity and were they transparent about the research process?) (27)	Each step of the analytic process is outlined clearly. During analysis, the research team offered critical and alternative interpretations/explanations of findings, challenged each other's assumptions, and encouraged introspective (e.g., how each researcher's biases, experiences, and histories impacted the analytic process) and intersubjective (e.g., how interactions between the research team members affected analysis) forms of reflexivity.
Meaningful coherence (does the analysis achieves its intended goals through using appropriate methods?) (27)	We used thematic Framework analysis to understand the research aims and, in the discussion, contextualise research findings in relation to previous literature regarding advance care planning during COVID-19 and palliative care more generally.

Table 3: Demographic information of participating palliative care services and an overview of UK participants' responses to closed-ended CovPall survey questions on advance care planning.

	Number	%
Total Responses		
	277	100
Role of respondents		
Medical director/lead medical clinician	97	35.4
Nurse director/lead nurse clinician	69	25.2
Other	108	39.4
Did not provide a response	3	-
Countries		
England	225	*81.2*
Scotland	33	*11.9*
Wales	15	*5.4*
Northern Ireland	4	*1.4*
Patients		
Adult only	247	*89.2*
Children only	16	*5.7*
Both	11	*4.0*
Did not provide a response	3	*1.1*
Setting		
Inpatient palliative care unit	168	*63.0*
Hospital palliative care team	135	*49.6*
Home palliative care team	160	*59.1*
Did not provide a response	92	*32.7*
Type of Management		
Charitable/non profit	143	*51.6*
Public	103	*37.2*
Private/Other	16	*5.4*
Did not provide a response	15	*5.4*
Advance care planning	Number of Respondents	%
Directly providing advance care planning		
A lot more	28	*10.1*
Slightly more	77	*27.8*
About the same	134	*48.4*
Slightly less	13	*4.7*
Much less	10	*3.6*
Did not provide a response	15	*5.4*
Advising others about advance care planning		%
A lot more	76	*27.4*
Slightly more	86	*31.1*
About the same	80	*28.9*
Slightly less	12	*4.3*
Much less	8	*2.9*
Did not provide a response	15	*5.4*

Note: information on settings is not mutually exclusive; many responding services delivered palliative care across multiple settings

Section 1: Challenges to advance care planning

National Level

Theme 1: A national context of fear and uncertainty

Advance care planning discussions were challenging because they took place in a national context of fear and uncertainty. Fears across society – alongside national policies on social/physical distancing – provided a contextual backdrop through which challenges at other levels of the Social Ecological Model may be understood.

A major source of fear and uncertainty was that many patients, their families, and healthcare professionals perceived that clinical decisions were being made on the basis of limited resources, rationing of treatments and services, and the government policy to 'protect the NHS'. There was particular concern that people who were older, had comorbidities, were disabled, or from Black, Asian and Minority Ethnic backgrounds were more likely to be discriminated through the adoption of a blanket– as opposed to a person-centred - approach to shared decision-making:

> *'Perception in public that [advance care planning] is about rationing rather than sensible clinical judgement. In young adult/transition work, huge fear among disabled communities and the perception that they will be denied potentially effective interventions due to discrimination'.* [Senior Medical Team Member, Hospital Palliative Care Team, Adult Service, Scotland]

> *'Family and patient concerns around 'blanket' and CPR [cardiopulmonary resuscitation] decisions'.* [Medical Director/Lead Medical Clinician, Hospital Palliative Care Team, Adult Service, England]

Respondents reported that media coverage – regardless of its accuracy - on issues such as blanket/generalised decisions, rationing of treatments, and the role (and limits of) ventilatory support, exacerbated the aforementioned public fears and uncertainties:

> *'My views on advance care planning remain the same as pre-COVID-19; it should be individualised to improve patient care. I have continued to practice in this way. The media*

> *has covered how during the pandemic there have been some cases when the way it has been delivered has led to those at the receiving end feeling as though their focus has been on protecting services as opposed to the individual.'* [Medical Director/Lead Medical Clinician, Multiple Settings, Adult Service, Scotland]

Individual level

Theme 2: Complex decision-making in the face of a new infectious disease

The rapid onset of a novel infectious disease with so many uncertainties meant that decision-making during advance care planning became even more complex and challenging. Uncertainties regarding the clinical trajectory and prognosis of COVID-19 patients contributed to the challenges of advance care planning because COVID-19 seemed to affect people in different ways; recovery, mortality, and outcomes varied between patients making it difficult to use past experience to inform subsequent decisions. Moreover, profound uncertainties of a different order existed that were related to knowing nothing about COVID-19 (e.g., its death/infection rate, or whether it was acute/chronic, etc.):

> *'The uncertainty of response. Patients with advanced disease have survived while those with no underlying medical conditions have died. The ability to know the course of the illness and make informed decisions with patients in light of that uncertainty is challenging. It requires a dynamic approach to decision making which is difficult to sensitively achieve at times of high stress in medical systems.'* [Consultant in Palliative Medicine, Multiple Settings, Adult Service, England]

One aspect of decision making that was particularly complex and challenging was surrounding service provision and treatment options. This included discussing what services and treatments were appropriate/available, predicting how patients may respond to treatments, treatment limitations, and how any decisions on these issues were subject to dynamic changes in a person's health status:

> *'Uncertainty about treatment availability, potential prognosis on an individual level, when to stop medical interventions like CPAP [meaning continuous positive airway pressure*

> *ventilation]/high flow oxygen'.* [Medical Director/Lead Medical Clinician, Hospital Palliative Care Team, Adult Service, England]

> *'Some of the decisions about limitation of treatment may be appropriate while the patient has COVID-19 but may not be if they recover and then experience different health conditions. I wonder if this review process is happening'.* [Medical Director/Lead Medical Clinician, Hospital Palliative Care Team, Adult Service, England]

Theme 3: Maintaining a personalised approach

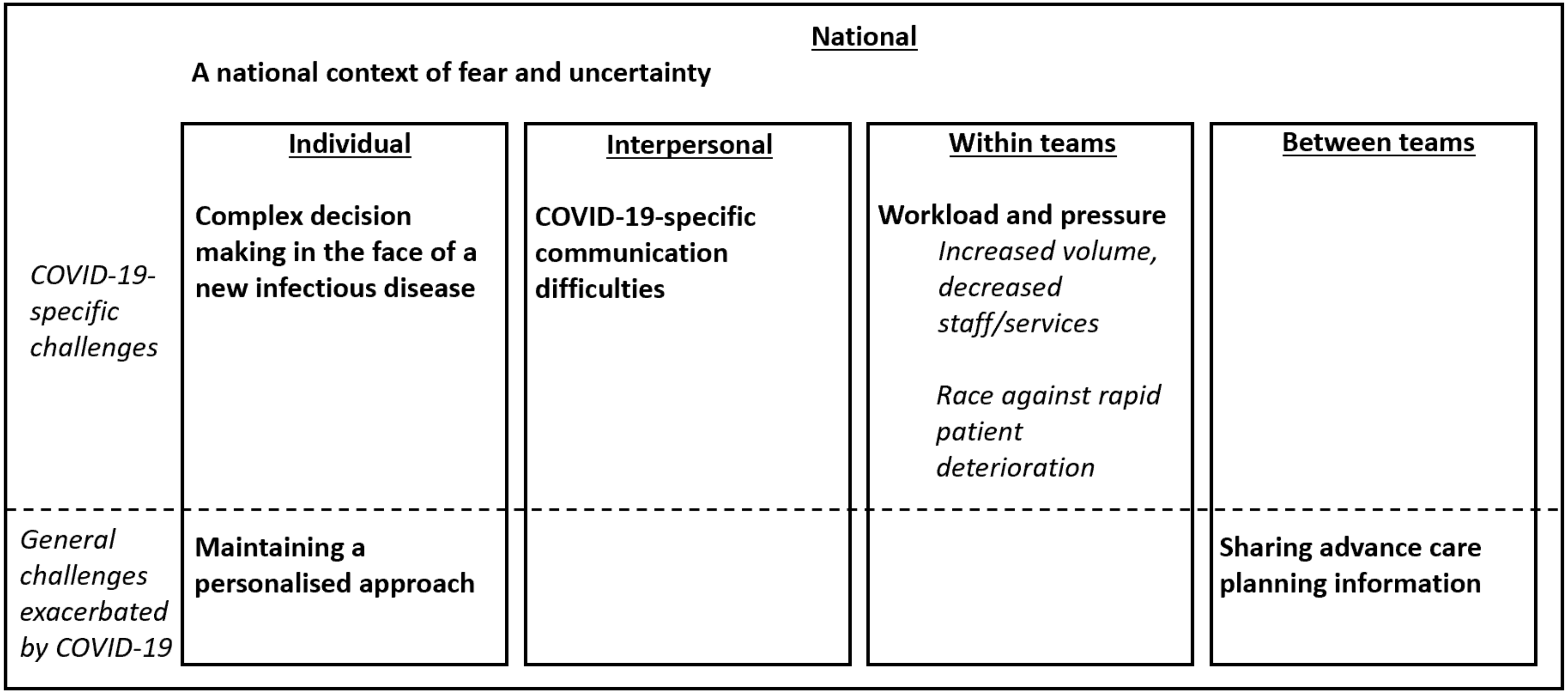
Respondents reflected on how the abruptness of the pandemic made it difficult to avoid advance care planning becoming a 'tick-box' exercise in which generalised decisions were made:

> *[One main challenge was reported as] 'avoiding advance care planning becoming part of a tick box culture and remaining a meaningful conversation about what is important to a patient, ensuring the promotion of advance care planning is for the benefit of the patient and not motivated by limited resources.'* [Medical Director/Lead Medical Clinician, Multiple settings, Adult Service, Scotland]

A prominent challenge to maintaining an individualised approach – particularly with regards to preferred place of care/death - was that advance care planning discussions were occurring in the context of limited choices regarding discharge options. This was either because some services refused to accept COVID-19 patients or because there was a reluctance in being discharged to settings where there were COVID-19 positive patients and consequent visiting restrictions:

> *'Care options are different - not able to access care homes or the hospice as preferred place of care/death, especially in the first 5 weeks'* [Consultant in Palliative Medicine, Home Palliative Care Team, Adult Service, Wales]

Figure 1: An overview of the **themes** and *sub-themes* that represent the challenges to advance care planning in the context of COVID-19, and how they relate to the different levels of the Social Ecological Model.



National

A national context of fear and uncertainty

	Individual	**Interpersonal**	**Within teams**	**Between teams**
COVID-19-specific challenges	**Complex decision making in the face of a new infectious disease**	**COVID-19-specific communication difficulties**	**Workload and pressure** *Increased volume, decreased staff/services* *Race against rapid patient deterioration*	
General challenges exacerbated by COVID-19	**Maintaining a personalised approach**			**Sharing advance care planning information**

Note: This diagram is representative of findings related to section 1 only (the challenges to advance care planning

Interpersonal Level

Theme 4: COVID-19-specific communication difficulties

Policies on physical/social distancing and the use of personal protective equipment presented COVID-19-specific communication challenges. A common communication challenge reported was having remote and telephone advance care planning conversations. Lack of face-to-face contact meant that many healthcare professionals felt that they had lost some of the 'tools' that were integral to their practice during these exchanges:

> *'The reduced face-to-face contact and social distancing feels like we have had our tools taken away from us - emphasizing the importance of advanced communication skills - listening and responding appropriately, ensuring clear understandable language… The ward teams have needed to give bad news over telephone contact which is not usual practice - advance care planning over the telephone is markedly harder than it is face-to-face.'* [Macmillan Specialist Nurse, Hospital Palliative Care Team, Adult Service, England]

These lost 'tools' included the ability to draw on non-verbal clues (e.g., physical touch, reading the environment/patient cues), and develop trusting/respectful relationships prior to conversations; things deemed fundamental in managing the sensitivities, compassion, and nuances of advance care planning conversations:

> *'Not being able to have face-to-face discussions when having sensitive conversations, not being able to physically touch patients and their loved ones who may crave physical comfort such as a hug or hand being held.'* [Nurse Director/Lead Nurse Clinician, Multiple Settings, Adult Service, England]

> *'Staff finding it difficult to have those conversations with people who they haven't met before and having to do it remotely feels impersonal and harsh.'* [Medical Director/Lead Medical Clinician, Multiple Settings, Adult Service, England]

Even if face-to-face discussions were possible, personal protective equipment acted as a physical barrier which made it difficult to use non-verbal communication to display compassion/empathy or provide physical forms of comfort:

> *'Personal protective equipment has been a challenge as it is difficult to see facial expressions or comfort a family member during difficult, distressing discussions.'* [Nurse Director/Lead Nurse Clinician, Multiple Settings, Adult and Children Services, England]

Regardless of whether discussions were remote or face-to-face, an overarching challenge to communicating advance care plans during the pandemic was the difficulty of involving families in conversations.

> *'The restrictions on visiting make it more difficult to involve families and often the family haven't seen the patient for some time and don't have that visual cue of how unwell they are.'* [Medical Director/Lead Medical Clinician, Hospital Palliative Care Team, Adult Service, England]

There were concerns that people from ethnic minority groups may have been disproportionately affected by these communication difficulties:

> *'it is much harder in those patients/families that you haven't seen face-to-face, and particularly when there are cultural or language barriers or capacity issues preventing a conversation with the patient.'* [Medical Director/Lead Medical Clinician, Specialist Palliative Home Care Service, Adult Service, England]

Within teams and services level

Theme 5: Workload and pressure

Sub-theme 1: Increased volume, decreased staff and services.

The increase in the number of patients who needed advance care planning discussions (for new referrals and reviewing patients already on their caseload) meant that teams had to work longer, harder, and quicker to ensure that timely advance care planning discussions occurred:

> *'Volume of people who need them [advance care planning discussions].'* [Medical Director/Lead Medical Clinician, Multiple Settings, Adult Services, England]

> *'The numbers involved, particularly [in the] care home sector.'* [Consultant in Palliative Medicine, Multiple Settings, Adult Service, Northern Ireland]

Exacerbating this was a decrease in the availability of healthcare professionals and auxiliary staff (due to absence, deployment to other services, and understaffing):

> *'Staff availability for distribution. Reaching all required professionals, some of the other professionals are working differently so may not be as available, also potential increase in staff absence may present a challenge.'* [Nurse Director/Lead Nurse Clinician, Multiple Settings, Children Service, England]

> *'More difficult to conduct [advance care planning conversations] as not seeing patients earlier in their prognosis as no day care facilities.'* [Registered Manager/Outreach Clinical Lead, Multiple Settings, Adult Service, England]

Sub-theme 2: A race against rapid patient deterioration

Compounding an increased workload and pressure was the rapid clinical deterioration of COVID-19 patients which resulted in a perpetual race against time to engage in discussions before they became too ill, lost capacity, or died:

> *'There wasn't time for advance care planning with patients with COVID-19 - prognosis was sudden and very short.'* [Nurse Director/Lead Nurse Clinician, Hospital Palliative Care Team, Adult Service, England]

> *'The hospital palliative care team have had an increase in referrals of very unwell semiconscious/unconscious patients with severe respiratory failure and high O2 requirements who are imminently dying and too unwell to engage in advance care planning. (Most would be too unwell for transfer even if they wanted this). There has been a decrease in less unwell cancer/and non-COVID-19 patients, non-cancer referrals where advance care planning may be more possible.'* [Medical Director/Lead Medical Clinician, Hospital Palliative Care Team, Adult Service, England]

Because of this, many respondents spoke about how advance care planning conversations felt rushed and forced, rather than spending the necessary time needed to adopt a holistic and person-centered approach to discussions:

> *‘advance care planning was needed to be done quickly and it wasn't always done at the right time, right place, or by the right person.’* [Consultant in Palliative Medicine, Hospital Palliative Care Team, Adult Service, Scotland]

Between teams and services level

Theme 6: Sharing advance care planning information

A pre-existing challenge exacerbated by COVID-19 was the sharing of advance care planning information between services. Different services often used different electronic systems that did not allow for seamless transfer of patient advance care planning information:

> *‘The ability to share information between primary and secondary care services, out-of-hours services, and a mixture of Local Authority and privately owned care homes.’* [Consultant in Palliative Medicine, Multiple Settings, Adult Service, Wales]

Section 2: Changes to support advance care planning

Theme 1: Adapting local processes

Sub-theme 1: Prioritisation of escalation planning and DNACPR conversations

One adaptation was to prioritise certain components of advance care planning (such as treatment escalation plans, DNACPR (Do Not Attempt Cardio-pulmonary Resuscitation), Recommended Summary Plan for Emergency Care and Treatment forms) felt to be of particular importance during the pandemic:

> *‘Frailty nurses have been involved in ensuring that [many] residents in residential care in [locality] have an advance care planning & treatment escalation plan. Historically advance care planning for patients known to hospice is high. However, we are ensuring that all*

> *patients on the Inpatient Unit & the community [register] have treatment escalation plans.'* [Nurse Director/Lead Nurse Clinician, Multiple Settings, Adult Service, England]

Sub-theme 2: Normalisation and integration of advance care planning

Another adaptation to local processes was an explicit effort made by services to integrate and embed advance care planning discussions into everyday clinical practice. This meant proactively initiating, reviewing, and updating Advance Care Plans for all people who were admitted to their service during the pandemic (including COVID-19 and non-COVID-19 patients) alongside ensuring that advance care planning discussions were routinely reviewed in multidisciplinary team meetings:

> *'Actively reviewing the outpatient caseload and community caseloads and targeting people without an advance care plan and broaching this with them more robustly.'* [Medical Director/Lead Medical Clinician, Multiple Settings, Adult Service, England]

Respondents reflected on the pragmatic and practical steps taken, including having conversations earlier and integrating discussions as a routine practice that was completed on patient referral, admission, and discharge:

> *'Routinely including the option of advance care planning for all new referrals. Completing treatment escalation planning forms for patients in the community and on discharge from the hospice.'* [Consultant in Palliative Medicine, Multiple Settings, Adult Service, England]

Theme 2: Adapting local structures

Sub-theme 3: Using technology to support advance care planning

One structural change that was made to support advance care planning discussions was the use of technology. Despite the challenges reported on having virtual and telephone discussions, many respondents reflected on how using these technologies as a form of communication was a way in which they adapted to the pandemic:

> *'Doing more advance care planning over the telephone which staff have had to adapt to doing. Patients are understanding the need of social distancing and the impact of COVID-19.'* [Head of Quality Improvement, Multiple Settings, Adult Service, England]

Services also used technology to support advance care planning by refining information technology systems. Predominantly, this included the implementation and documenting of advance care planning on patients' electronic record and/or adapting electronic forms so that they were COVID-19-specific:

> *'We have had advance care planning discussions on the phone and via video consultations, we have completed 'paper' advance care planning documents electronically.'* [Community Advanced Nurse Specialist, Home Palliative Care Team, Adult Service, England]

> *'[Name of system] was used where possible which was a new electronic way of recording advance care planning discussions that had just been finalised for use.'* [Consultant in Palliative Medicine, Hospital Palliative Care Team, Adult Service, Scotland]

Sub-theme 4: Shifting resources

Some respondents reported shifting resources between services as a means to adapt to increased advance care planning demands. This was usually through delegating certain staff members with the specific responsibility of taking an active role in supporting advance care planning discussions:

> *'Clinical nurse specialist team taking on a much more active role in supporting these conversations.'* [Medical Director/Lead Medical Clinician, Multiple Settings, Adult Service, England]

> *'Much work from the day hospice team supporting people who have had a General Practitioner letter about DNACPR [Do Not Attempt Cardio-pulmonary Resuscitation] and who wished to discuss it further.'* [Senior Medical Team Member, Inpatient Palliative Care Unit, Adult Service, England]

Sub-theme 5: Adapting fast through collaboration

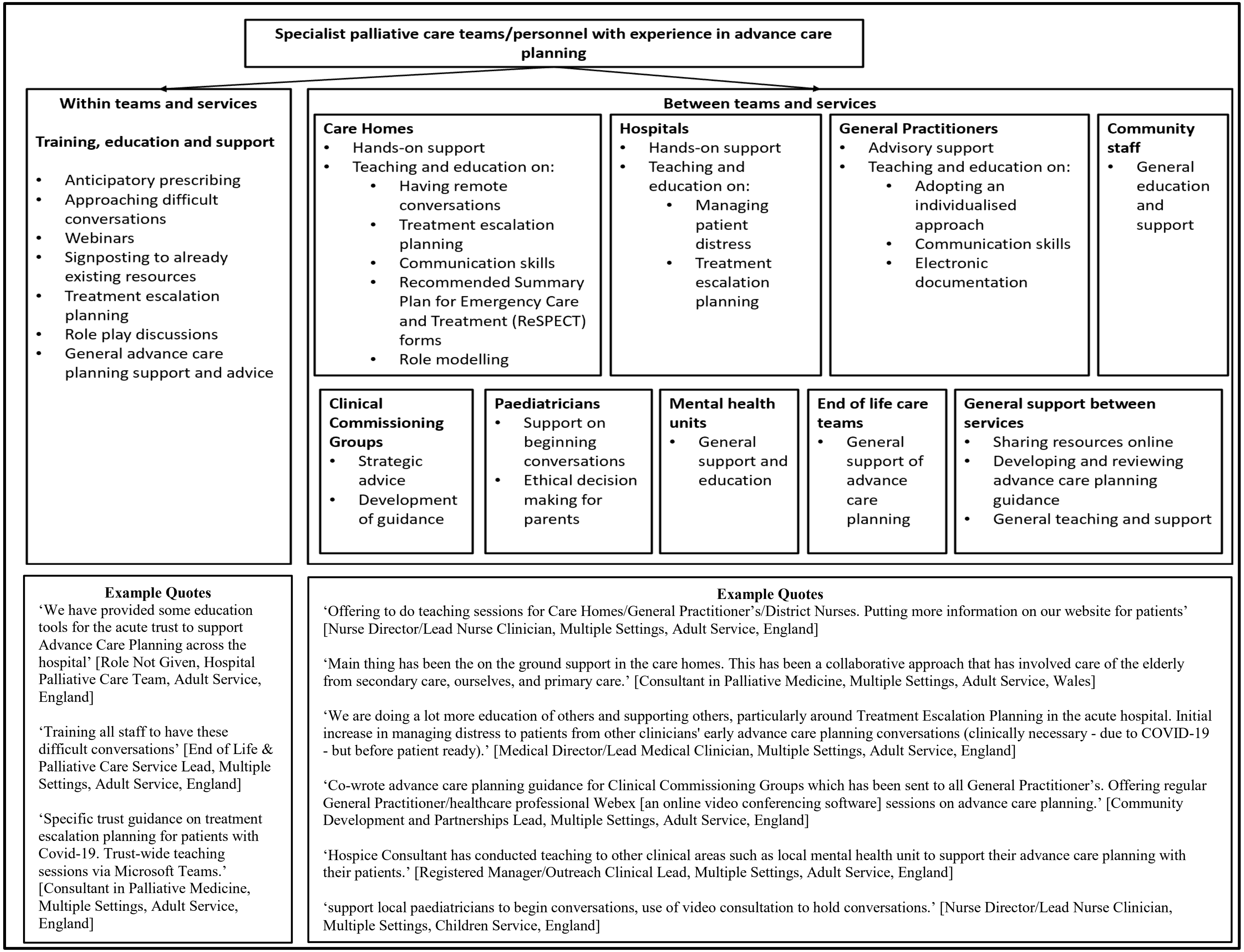
A common change that services made to support advance care planning during COVID-19 was establishing new, or developing already-existing, networks of support and integrated working within and between teams and services. A heavy emphasis was reported on using these networks to adapt fast through collaboration, usually by drawing on the knowledge and skills of specialists in palliative care who were experienced in advance care planning. The networks formed and types of collaboration that occurred were considerable. An overview of these collaborative changes with quotes can be seen in Figure 2.

Discussion

Using the Social Ecological Model, our findings demonstrate how the COVID-19 pandemic exacerbated already-existing challenges to conducting high-quality and timely advance care planning. At the individual level, the main challenge was maintaining an individualised approach (13) and making complex decisions in the face of extreme clinical uncertainty. (13, 14, 30) At the within- and between-teams level, racing against rapid deterioration (31-33) and sharing of advance care planning-related information (13, 34) were reported as challenging. Though clinical uncertainty about COVID-19 had similarities to other critical illnesses, (32) the depth of uncertainty in an infectious disease of which almost nothing was known was of a different order in this pandemic, bringing unique challenges to advance care planning.

This study shows how COVID-19-specific challenges made delivering high quality advance care planning difficult. These occurred at individual (limiting choices of place of care/death), interpersonal (COVID-19-specific communication difficulties), within-teams (a rapid increase in the volume of advance care plans combined with sudden decrease in healthcare and auxiliary staff members and services) and national (delivering advance care planning in a national context of fear and uncertainty) levels. The Social Ecological Model illuminated how a national context of fear provided a contextual backdrop through which the various challenges are better understood.

Figure 2: An overview (with example quotes) of the collaboration networks that were established and developed during COVID-19 and how these were used to support advance care planning.



Specialist palliative care teams/personnel with experience in advance care planning

Within teams and services

Training, education and support

- Anticipatory prescribing
- Approaching difficult conversations
- Webinars
- Signposting to already existing resources
- Treatment escalation planning
- Role play discussions
- General advance care planning support and advice

Between teams and services

Care Homes

- Hands-on support
- Teaching and education on:
    - Having remote conversations
    - Treatment escalation planning
    - Communication skills
    - Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) forms
    - Role modelling

Hospitals

- Hands-on support
- Teaching and education on:
    - Managing patient distress
    - Treatment escalation planning

General Practitioners

- Advisory support
- Teaching and education on:
    - Adopting an individualised approach
    - Communication skills
    - Electronic documentation

Community staff

- General education and support

Clinical Commissioning Groups

- Strategic advice
- Development of guidance

Paediatricians

- Support on beginning conversations
- Ethical decision making for parents

Mental health units

- General support and education

End of life care teams

- General support of advance care planning

General support between services

- Sharing resources online
- Developing and reviewing advance care planning guidance
- General teaching and support

Example Quotes

‘We have provided some education tools for the acute trust to support Advance Care Planning across the hospital’ [Role Not Given, Hospital Palliative Care Team, Adult Service, England]

‘Training all staff to have these difficult conversations’ [End of Life & Palliative Care Service Lead, Multiple Settings, Adult Service, England]

‘Specific trust guidance on treatment escalation planning for patients with Covid-19. Trust-wide teaching sessions via Microsoft Teams.’ [Consultant in Palliative Medicine, Multiple Settings, Adult Service, England]

Example Quotes

‘Offering to do teaching sessions for Care Homes/General Practitioner’s/District Nurses. Putting more information on our website for patients’ [Nurse Director/Lead Nurse Clinician, Multiple Settings, Adult Service, England]

‘Main thing has been the on the ground support in the care homes. This has been a collaborative approach that has involved care of the elderly from secondary care, ourselves, and primary care.’ [Consultant in Palliative Medicine, Multiple Settings, Adult Service, Wales]

‘We are doing a lot more education of others and supporting others, particularly around Treatment Escalation Planning in the acute hospital. Initial increase in managing distress to patients from other clinicians' early advance care planning conversations (clinically necessary - due to COVID-19 - but before patient ready).’ [Medical Director/Lead Medical Clinician, Multiple Settings, Adult Service, England]

‘Co-wrote advance care planning guidance for Clinical Commissioning Groups which has been sent to all General Practitioner’s. Offering regular General Practitioner/healthcare professional Webex [an online video conferencing software] sessions on advance care planning.’ [Community Development and Partnerships Lead, Multiple Settings, Adult Service, England]

‘Hospice Consultant has conducted teaching to other clinical areas such as local mental health unit to support their advance care planning with their patients.’ [Registered Manager/Outreach Clinical Lead, Multiple Settings, Adult Service, England]

‘support local paediatricians to begin conversations, use of video consultation to hold conversations.’ [Nurse Director/Lead Nurse Clinician, Multiple Settings, Children Service, England]

These worries may be viewed through the ‘four horsemen of fear’ concept (35) in which COVID-19 precipitated bodily, interpersonal, cognitive, and behavioural fears. These fears were brought into advance care planning conversations by patients, their families, and health professionals, disrupting their ability to engage in advance care planning conversations as effectively as they would have liked.

In adapting to these challenges, services made changes to structures and processes of care. There is already evidence of the benefits of some of these, such as having earlier advance care planning discussions(13, 36) and training aimed at facilitating healthcare professionals’ skills/confidence in communicating advance care plans. (37-39) Recent work has also demonstrated the feasibility and effectiveness of having virtual discussions with patients/families during COVID-19, (40, 41) and resources have been developed to support healthcare professionals to navigate the challenges and sensitivities of virtual difficult conversations. (42-44)

However, some changes induced by the pandemic, such as reducing advance care planning to specific components were less helpful. This is because advance care planning is a nuanced, contextual, and multi-component process that needs continual revisiting as a person’s illness progresses; not a one-time event/document, not least because preferences and priorities may change. (6-8, 10, 12, 36, 45-48) Delivering ***all*** of the multiple components of advance care planning, and delivering them well, is important to ensure inclusive, holistic, and individualised care that focuses on what matters most to patients. (49) Whilst understandable in the pandemic context, emphasis on discrete components of advance care planning may jeopardise the individualised and holistic qualities essential for the delivery of high quality and comprehensive advance care planning, and runs the risk of making advance care planning a ‘tick box exercise focused on a predetermined list of preferences’.(45) This is a concern raised by the public and clinical communities. (45, 50, 51)

Considerations for clinical practice and policy

COVID-19 has provided an opportunity to re-think advance care planning in which the starting point to any discussion is always the values and priorities of patients themselves. Initially, these discussions are likely to be broad in nature, with their focus then narrowing in line with the more immediate concerns of individuals. (49)

Some changes to support advance care planning were temporary and may be dropped post-pandemic (such as shifting of resources and focusing on specific components of advance care planning), but innovative changes that showed promise may be amplified and sustained. Changes such as learning fast through collaboration, training to support advance care planning, the integration of advance care planning into everyday clinical practice, and use of virtual technology are important to maintain as the need for palliative care is estimated to rise considerably (18) and need for advance care planning will not be able to be met by specialists alone. (52-54) In facilitating these changes, Table 4 provides questions for health professionals and policymakers – in the UK and beyond - to consider when conducting advance care planning during a pandemic and in clinical practice more generally. These are detailed in accordance with each level of the Social Ecological Model and are designed as a means to ensure that organisational/service structures, resources, and support are in place so that: (i) healthcare professionals are adequately skilled/trained to complete high quality and timely advance care planning; and (ii) their work environments are conducive to engaging in high quality advance care planning. Most importantly, policymakers in any given country need to consider how high-quality advance care planning can be resourced as a part of standard care.

Strengths, limitations, and future research

This is the first study that provides insight and understanding - based on the reflections of a large sample - on the impact that the COVID-19 pandemic had on the ability of UK hospice and palliative care organisations to engage in timely and high-quality advance care planning discussions, alongside the changes to practice that were made to adapt to these. The timely delivery of the survey enabled capture of changes across the peak of the first wave of COVID-19 in the UK.

Advance care planning is influenced and moderated by contextual and cultural-dependant factors. (55, 56) Whilst many of the findings of this paper may be applicable in these contexts, more research that explores international and cultural differences regarding advance care planning during COVID-19 is needed. Survey data was collected at a single time-point and so the processes through which challenges to advance care planning changed over time, and the longer-term impact, sustainability, and effectiveness of changes are not always clear. Moreover, this survey was completed by service leads, thus some of the responses provided may not have always reflected the views of other professionals/staff who worked in their organisations.

Conclusion

Many challenges to providing high quality advance care planning during COVID-19 pre-dated the pandemic, whilst others were COVID-19 specific, or markedly exacerbated by the pandemic. Professionals and healthcare providers need to ensure advance care planning is well-founded for individuals, and genuinely tailored to their values and priorities, and attuned to their ethnic, cultural, and religious context. Policymakers for health and social care need to consider carefully how high-quality advance care planning can be resourced and normalised as a part of standard healthcare ahead of future pandemic waves.

Table 4: Multi-level considerations for conducting high-quality advance care planning during a pandemic and clinical practice more generally.

Level	Who	Questions to consider
Individual	*Healthcare professionals*	• Is the starting point for advance care planning discussions based on the values and priorities of patients themselves and their care network? • Is advance care planning being treated as a nuanced, contextual, and multi-component process that needs continual revisiting as a person's illness progresses, rather than a one-off event/document? • Is advance care planning being treated as a multi-component process that considers: ▪ Identifying values/priorities based on past experiences and quality of life? ▪ Choosing proxy decision-makers and verifying that they understand their role? ▪ Informing family and friends of wishes in advance to reduce/prevent conflict? • Is advance care planning considering both improvement and deterioration in illness (parallel planning) to encompass genuine uncertainties?
Interpersonal	*Service providers/organisations*	• Do you have systems and protocols in place that supports advance care planning discussions taking place through various means, including: ▪ Face-to-face with personal protective equipment (if appropriate)? ▪ Virtually/telephone? • Have you considered distributing advance care planning information in the most commonly non-English speaking language for your area?
Within-teams	*Service providers/organisations*	• Has your organisation embedded advance care planning into key points of everyday practice, including: ▪ At referral/admission? ▪ Within multi-disciplinary team meetings? ▪ At discharge? • Have staff (specialist and non-specialist) been provided with adequate training, education, and support on the importance of, and best ways to conduct advance care planning (including with ethnic, cultural and religious groups relevant for your area)? • Have you supported/built staff capacity to successfully provide advance care planning virtually?
Between-teams	*Service providers/organisations*	• Are you part of a collaborative network in which support for and integrated working within and between teams and services is used to facilitate advance care planning?

National	*Policy makers; service providers/organisations*	- In line with the above, have you considered how high-quality advance care planning can be resourced and normalised as a part of standard care across the health and social care sector?

Author Contributions

IJH is the grant holder and chief investigator; KES, MM, FEM, CW, NP, LKF, SB, MBH and AO are co-applicants for funding. IJH and CW, with critical input from all authors, wrote the protocol for the CovPall study. MBH, AO, and RC co-ordinated data collection and liaised with centres, with input from IJH. AB, FEM, and LKF analysed the data. All authors had access to all study data, discussed the interpretation of findings and take responsibility for data integrity and analysis. AB, FEM, and LKF drafted the manuscript. All authors contributed to the analysis plan and provided critical revision of the manuscript for important intellectual content. IJH is the guarantor. Sites who contributed to this work can be found in supplementary file 3.

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Conflicts of Interest
None of the authors have any conflicts of interest to declare

CovPall Data Sharing Statement

Applications for use of the survey data can be made for up to 10 years, and will be considered on a case by case basis on receipt of a methodological sound proposal to achieve aims in line with the original protocol. The study protocol is available on request. All requests for data access should be addressed to the Chief Investigator via the details on the CovPall website (https://www.kcl.ac.uk/cicelysaunders/research/evaluating/covpall-study, and palliativecare@kcl.ac.uk) and will be reviewed by the Study Steering Group.

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