

The key messages from our analyses thus far are that:

- Palliative and hospice care services responded actively during the COVID-19 pandemic but were often ignored from national and multinational pandemic responses
- Palliative and hospice care services adopted ‘frugal innovations’ (improvised, unplanned, and low-cost – yet effective - solutions) in responding to the pandemic
- The starting point for Advance Care Planning (discussions of a person’s futures wishes/priorities for care) should always be the values and priorities of patients

More detail can be found in the policy briefs attached to this newsletter.

## An update on progress to date

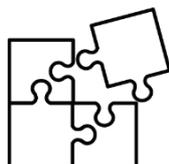
### Paper publications

We have submitted pre-prints of our papers that you can read prior to their publication through clicking the images below



Challenges to Advance Care Planning during COVID-19

Challenges of caring for people dying from COVID-19



Innovations and practice changes in response to COVID-19

### EAPC Conference

Findings from the first part of this project were presented at the 11<sup>th</sup> European Association of Palliative Care World Research Congress (Oct 2020).



Click on the pictures above to view Catherine Walshe’s and Irene Higginson’s oral presentations from the conference

### What next ...

#### Survey research:

- Response of specialist palliative care and hospice services to Black Asian and Ethnic Minority patients dying with COVID-19

Nov-Dec 2020

#### Part 2 of CovPall:

Collect clinical information to understand what palliative care interventions are effective at addressing the symptoms and concerns of people with COVID-19

Tbc – dates?

### Contact

If you have any questions or queries, please contact [palliativecare@kcl.ac.uk](mailto:palliativecare@kcl.ac.uk)

Or visit: <https://www.kcl.ac.uk/cicelysaunders/research/evaluating/covpall-study>



International Observatory on End of Life Care | Lancaster University

**Policy brief summary for challenges of caring for people dying or seriously ill with COVID-19 and recommended actions in planning for a second pandemic wave (the CovPall Study)**

<p><b>What we did and why we did it</b></p>	<ul style="list-style-type: none"> <li>• There is little published information on the care for people who are dying from COVID-19, and those who suffer severe symptoms.</li> <li>• We carried out an online survey of clinical leads of palliative care services in order to understand the response of and challenges faced by palliative care services during the COVID-19 pandemic.</li> <li>• This work is part of the wider CovPall study that aims to understand the multi-national specialist palliative care response to COVID-19.</li> </ul>
<p><b>How we did it</b></p>	<ul style="list-style-type: none"> <li>• An online multinational cross-sectional survey of palliative and hospice care services.</li> <li>• Analysis of responses according to settings, country/region and type of management (charitable or public)</li> </ul>
<p><b>What we found</b></p>	<ul style="list-style-type: none"> <li>• 458 services responded; 277 UK, 85 rest of Europe, 95 rest of the world (1 country unreported);</li> <li>• 81% cared for patients with suspected or confirmed COVID-19,</li> <li>• 77% had staff with suspected or confirmed COVID-19;</li> <li>• Services cared for a surge in patients dying from and with severe symptoms due to COVID-19 in three main categories: patients with underlying conditions and/or multimorbid disease not previously known to palliative care, patients already known to palliative care services, and patients, previously healthy, now dying from COVID-19.</li> <li>• Services provided direct care and education in symptom management and communication; 91% changed how they worked.</li> <li>• Care often shifted to increased community and hospital care, with fewer admissions to inpatient palliative care units.</li> <li>• Despite a very active response palliative care services felt ignored by national health and social care systems and struggled to get equipment and staff.</li> <li>• Shortages were common. Of services, 48% reported shortages of Personal Protective Equipment (PPE), 40% staff shortages, 24% medicines shortages, 14% shortages of other equipment. Considerable time and energy was expended trying to mitigate against the effects of these shortages.</li> </ul>

	<ul style="list-style-type: none"> <li>• Factors associated with increased odds of PPE shortages were: charity rather than public management, inpatient palliative care unit/or home nursing.</li> <li>• UK had higher palliative care staff shortages than other countries.</li> </ul>
<b>What we recommend</b>	<ul style="list-style-type: none"> <li>• There is a need for better recognition and integration of palliative care into national health systems. This is particularly the case for charity managed services and those providing care in people's homes.</li> <li>• The different groups of people severely affected by COVID-19 should be better recognised. A parallel planning approach may be needed for patients with uncertain trajectories.</li> <li>• The role of free standing inpatient palliative care units should be proactively considered in a second pandemic wave: could their staff be diverted to the community (as occurred in some settings in our study), could they be diverted to hospital palliative care teams or care homes (both settings needing additional support), or could units provide an alternative or rehabilitation/step down care from hospitals?</li> </ul>
<p><b>In depth findings can be found in the paper attached entitled:</b></p> <p><i>The challenges of caring for people dying from COVID-19: a multinational, observational study of palliative and hospice services (CovPall)</i></p> <p><a href="https://www.medrxiv.org/content/10.1101/2020.10.30.20221465v1">https://www.medrxiv.org/content/10.1101/2020.10.30.20221465v1</a></p>	

**Policy brief summary for specialist palliative care service innovation and practice change in response to COVID-19.**

<p><b>What we did</b></p>	<ul style="list-style-type: none"> <li>• We mapped and analysed specialist palliative care services innovations and practice changes in response to COVID-19.</li> <li>• This work is part of the wider CovPall study that aims to understand the multi-national specialist palliative care response to COVID-19.</li> </ul>
<p><b>How we did it</b></p>	<ul style="list-style-type: none"> <li>• An online multi-national cross-sectional survey of hospice and specialist palliative care providers.</li> <li>• Statistical analysis included frequencies, proportions and means, and free-text comments were analysed using a qualitative framework approach.</li> </ul>
<p><b>What we found</b></p>	<ul style="list-style-type: none"> <li>• <b><i>Specialist palliative care services have been flexible, highly adaptive and have adopted a ‘frugal innovation’ model when responding to the COVID 19 pandemic. They have been creative by using, adjusting and recombining existing resources, structures and processes to manage the impact of the crisis.</i></b></li> <li>• Changes involved streamlining, extending and increasing outreach of services, using technology to facilitate communication, and implementing staff wellbeing innovations.</li> <li>• Enablers included; collaborative teamwork, pooling of staffing resources, staff flexibility, strong leadership, and a pre-existing IT infrastructure including systems to support telehealth.</li> <li>• Barriers included; fear and anxiety, duplication of effort, information overload, funding, and IT infrastructure issues.</li> </ul>
<p><b>What we recommend</b></p>	<ul style="list-style-type: none"> <li>• <b><i>In addition to financial support, greater collaboration is essential to build organisational resilience and drive forward innovation, by minimising duplication of effort and optimising resource use.</i></b></li> </ul>
<p><b>In depth findings can be found in the paper attached entitled:</b></p> <p><i>‘Necessity is the mother of invention’: Specialist palliative care service innovation and practice change in response to COVID-19. Results from a multi-national survey (CovPall)</i></p> <p><a href="https://www.medrxiv.org/content/10.1101/2020.10.29.20215996v1">https://www.medrxiv.org/content/10.1101/2020.10.29.20215996v1</a></p>	

**Policy brief summary for 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.**

<p><b>What we did</b></p>	<ul style="list-style-type: none"> <li>• The aim of this study was to describe the challenges to Advance Care Planning experienced by specialist palliative care and hospice services at the height of the COVID-19 pandemic, and how services adapted to these challenges.</li> <li>• This work is part of the wider CovPall study that aims to understand the multi-national specialist palliative care response to COVID-19.</li> </ul>
<p><b>How we did it</b></p>	<ul style="list-style-type: none"> <li>• An online multi-national cross-sectional survey of UK hospice and specialist palliative care providers.</li> </ul>
<p><b>What we found</b></p>	<ul style="list-style-type: none"> <li>• 37.9% of services provided more Advance Care Planning themselves; 58.5% of services provided more support to other professionals (less familiar with Advance Care Planning) who were delivering Advance Care Planning.</li> <li>• Challenges to Advance Care Planning were either COVID-19 specific or general challenges exacerbated by the pandemic.</li> </ul> <p>COVID-specific challenges:</p> <ul style="list-style-type: none"> <li>• Rapid, complex decision-making in the face of a new disease</li> <li>• Sensitive and difficult conversations hard to conduct remotely, by video or phone</li> <li>• Increased workload because of COVID-19 and staff sickness</li> <li>• For some people, racing against their deteriorating health over a short timeframe</li> <li>• A national context of fear and uncertainty</li> </ul> <p>General challenges exacerbated by the pandemic:</p> <ul style="list-style-type: none"> <li>• It was hard to maintain an individualised and appropriately tailored approach</li> <li>• Sharing Advance Care Plans between professionals is crucial but limited by different IT and record systems, although some rapid solutions were found</li> </ul>
<p><b>Recommendations:</b></p>	<ul style="list-style-type: none"> <li>• Professionals and healthcare providers should ensure that Advance Care Planning is individualised by tailoring it to the values, priorities, and ethnic, cultural, and religious context</li> </ul>

	<p>of each person.</p> <ul style="list-style-type: none"><li>• Staff need to be provided with adequate training, education, and support in order to conduct high quality and individualised Advance Care Planning. This may be facilitated through drawing on collaborative networks across services and organisations.</li><li>• Policymakers need to consider carefully how high-quality, individualised Advance Care Planning can be resourced as a part of standard healthcare, ahead of future pandemic waves.</li></ul>
<p><b>In depth findings can be found in the paper attached entitled:</b></p> <p><i>‘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.’</i></p> <p><a href="https://www.medrxiv.org/content/10.1101/2020.10.28.20200725v1">https://www.medrxiv.org/content/10.1101/2020.10.28.20200725v1</a></p>	