Briefing

# Better End of Life 2021

Dying, death and bereavement during Covid-19
Briefing Report

> *"Our parting outside on that extraordinary April day will live with me forever, devastatingly, for all the wrong reasons."*
>
> **Roberta Lovick, whose mother, Doreen Saggers, died suddenly in April 2020**

Published April 2021

The research report accompanying this Marie Curie briefing was produced by an Expert Group of clinical and non-clinical academics from King's College London Cicely Saunders Institute, Hull York Medical School, the University of Hull and the University of Cambridge, along with patients and carers.

The research report draws on unpublished data from the CovPall study (Principal Investigator Prof Irene Higginson). We thank CovPall study team members including Prof Nancy Preston, Dr Matthew Maddocks, Dr Sabrina Bajwah, Prof Lorna Fraser, Dr Mevhibe Hocaoglu, Dr Adejoke Oluyase and Prof Catherine Walshe. We thank the CovPall collaborators and advisors, participants (especially the responding hospices and palliative care services), Patient and Public Involvement (PPI) members and our Study Steering Group.

For more information see https://www.kcl.ac.uk/cicelysaunders/research/evaluating/covpall-study/covpall-study. The CovPall study is jointly funded by UKRI and NIHR [COV0011; MR/V012908/1], with additional support from the National Institute for Health Research (NIHR) Applied Research Collaboration, South London, hosted at King's College Hospital NHS Foundation Trust, and Cicely Saunders International (Registered Charity No. 1087195).

# Introduction

Everyone has the right to the best possible end of life experience, but the reality for far too many people falls far short of what we all hope for and should be able to expect.

The Better End of Life programme – a collaboration between Marie Curie, King's College London Cicely Saunders Institute, Hull York Medical School, the University of Hull, and the University of Cambridge – will examine evidence on the current state of dying, death and bereavement across the four nations of the United Kingdom and propose a policy agenda aimed at helping to ensure that everyone has the best possible end of life experience.

This is a critical moment for improving palliative and end of life care and support. As a result of our ageing population, in 20 years' time there will be 100,000 more people dying each year in the United Kingdom. Demand for palliative and end of life care is set to increase rapidly, as more people live for longer with multiple and complex conditions[1]. New models for delivering palliative and end of life care in the community will be needed to reduce pressures on the NHS and fulfil patient preferences for dying at home. Larger numbers of family members and carers will require support through dying, death and bereavement.

Ensuring people are properly cared for and supported at the end of life must become an urgent policy priority at both national and local level.

The first research report from the programme explores the ongoing impact of the Covid-19 pandemic on dying, death and bereavement in the UK[2].It looks back at 2020, a unique year in history that was marked by the arrival of the ongoing Covid-19 pandemic, but which also provides valuable wider lessons for the longer-term future of palliative and end of life care and bereavement support in our country.

In this briefing, Marie Curie summarises key evidence from the research report and provides commentary on its implications for policy.

This briefing and the research report include selected data from research studies funded by the UKRI, NIHR and others. Marie Curie wishes to make clear that we were not the sole funder of all this research and are extremely grateful for the support given by these other funders for research that is relevant to palliative and end of life care.

## Key findings from the research report

During the pandemic to date, the focus has understandably been on prevention of deaths through infection control, intensive care unit surge capacity planning, treatments to prevent or lessen the severity of SARS-CoV-2 infection, and vaccine development and administration. The impact of the pandemic on the experiences and care needs of the hundreds of thousands of people affected by dying, death and bereavement has had much less scrutiny. Our report seeks to help fill this gap.

The report demonstrates that behind the daily Covid-19 death tolls are real people experiencing tremendous hardships at the end of life. Fewer than one in seven deaths during 2020 was due to Covid-19, while the majority were due to other causes, including long-term conditions and terminal illnesses.

Lockdown and social distancing policies have caused isolation and loneliness during a phase of life where relationships and human contact are of utmost importance. Community care has been stretched at the same time as people may have felt discouraged from seeking hospital care. Many more people have been bereaved during the Covid-19 pandemic and their grieving processes have been profoundly disrupted, leaving many at risk of complicated grief and associated psychological and economic problems.

The report states that in March 2020 the WHO issued rapid guidance on maintaining essential health services during the pandemic. This guidance mentioned prevention, maternity care, emergency care and chronic diseases, but not palliative and end of life care. When the pandemic began, hospices in all four nations found themselves short of essential Personal Protective Equipment (PPE), medicines, equipment and staff and these shortages were made worse by hospices not being viewed as 'frontline NHS'.

Despite this, during Covid-19, palliative and end of life care services have proved to be an essential component of the pandemic emergency response across all four nations. As patients have stayed away from hospices due to visitor restrictions and fear of contracting Covid-19, hospices and community-based services found themselves busier than before in supporting people dying at home and their families and carers. They have educated, upskilled and supported others, and have also taken steps to adapt and innovate their service models.

Palliative care services in hospitals, sometimes also aided by hospice staff, have also found themselves stretched beyond capacity.

### Key research findings

- Behind the daily cumulative number of people who have died as a result of Covid-19 are individuals who have experienced multiple losses during an extraordinary time.
- Fewer than one in seven deaths during 2020 was certified as having been caused by Covid-19; most people have died from other causes. For people living with chronic life-limiting illnesses, the pandemic has had profound impacts.
- Deaths at home increased during the first pandemic wave; notably, this increase was sustained throughout the whole of 2020, outside of the Covid-19 waves.
- Primary healthcare professionals, in partnership with specialist palliative care teams, managed both increased volume and increased complexity of palliative and end of life care need in the community.
- Deaths in hospices fell slightly during 2020. This may be because people with life-limiting illnesses chose not to be cared for in hospices because of visiting restrictions and fear of infection. In response, hospice and palliative care teams shifted resources into the community, supporting people in their homes and in care homes, and providing education and support for other health professionals.
- At the same time, hospice and palliative care services experienced shortages of essential medicines and equipment, meaning they could not always provide the care needed for patients and carers.
- Palliative care teams in all settings increased activity and were stretched to and beyond capacity. These teams made rapid innovations, adapting their services to educate, upskill and support wider health and social care professionals.
- For every person who has died, many more have been bereaved, and the pandemic has profoundly disrupted grieving processes. For many, lockdown, social distancing restrictions, lack of visiting in hospitals and care homes, and shielding have compounded their sense of loss. As a result of deaths that were sudden or required intensive care, and because of the disruption of grieving rituals and social networks, complicated grief is likely to become more common.

Looking forward, palliative and end of life care services will be central to the future provision of health and social care in the UK as our population ages and more people live longer with multiple and complex health conditions. Charitable hospices are the main providers of this care, yet only around 30% of their income comes from government and NHS sources, and the rest from their own efforts. A much more sustainable and resilient funding model is needed to ensure that future needs can be met.

Covid-19 has resulted in a sustained increase in deaths at home in all four nations, but meeting longstanding preferences for home as the place of death beyond Covid-19 will depend in part on wider improvements to the support people are offered in the community at the end of life. Further improvements are needed to fast-track NHS Continuing Healthcare (CHC) in England, as well as an expansion of community nursing services.

Ensuring people are supported to die well in every setting will require a 'whole system' approach that extends beyond the palliative and end of life care sector to include efforts to educate and upskill primary care and social care providers, as well as placing the needs of people at the end of life at the heart of new models of integrated commissioning. Crucially, success will also depend on political consensus emerging around sustainable solutions to the underfunding of social care.

In future, if more people are to be cared for at home at the end of life, attention is needed to ensure carers and family members do not become overwhelmed, as many have been during the pandemic.

Health and social care professionals will need to take steps to proactively identify carers of people at the end of life, assess their needs and ensure they are fully and promptly met.

Meeting the needs of bereaved people, including those experiencing complicated grief as a result of the challenging circumstances of Covid-19, will require an expansion of existing bereavement support services and action to improve access for groups such as Black, Asian and Minority Ethnic (BAME) and deprived communities which have been disproportionately affected by the pandemic – this as part of wider efforts to address health inequalities. Reforms are also needed around bereavement leave and financial support for bereaved people.

Open access to standardised data on dying, death and bereavement outcomes is essential for measuring, monitoring and improving the quality of care provided across the UK in the future. Further research is also needed to inform better care through dying, death and bereavement.

Through this report and other studies conducted during Covid-19, much more is now known about the vital role played by palliative and end of life care during the emergency response. We hope that the lessons learned during the ongoing pandemic can be applied to policy and practice in ways that help ensure that, in the future, everyone has the best possible end of life experience.

## Methodology

The research report draws on published literature, secondary analysis of research and publicly available data. It includes previously unpublished data on the intensity of activity of hospice and palliative care services in UK nations and English regions, as well as the challenges faced by UK services, drawn from the CovPall study – a multinational observational study of palliative care during the Covid-19 pandemic funded by the UKRI and NIHR.

The research report was carried out by an Expert Group made up of clinical academics in palliative medicine and primary care from King's College London, Hull York Medical School, the University of Hull, and the University of Cambridge, as well as other researchers with both clinical and non-clinical backgrounds.

The Group's work was shaped and informed by a Patient and Public Involvement (PPI) Reference Group and members of the Cicely Saunders Institute PPI web-based forum. It is the insights from these individuals and carers and the professionals supporting them that lie at the centre of our research findings and policy recommendations.

# Selected research findings

**Outside the daily Covid-19 death totals are people experiencing tremendous hardships at the end of life, regardless of cause of death.**
Death rates increased significantly in the UK during 2020. Between 2015 and 2019, on average 604,000 people died each year.  In 2020, the absolute number of people who died was just over 695,000 – an increase of 15% on the previous five-year average.

Most of the deaths that occurred during the pandemic were from non-Covid causes. The report found that the pandemic has had profound impacts on dying people and their families and carers, regardless of cause of death.

For people living with terminal illness approaching the end of life, lockdown and social distancing policies have caused isolation and loneliness during a phase of life where relationships and human contact can be of utmost importance.

Community care has been stretched, meaning people may not have been able to access the support they need. At the same time, the call to 'stay at home, protect the NHS' may have discouraged people with life-limiting illnesses from seeking hospital care when they needed it.

For every person who has died during the Covid-19 pandemic, many more have been bereaved. The report cites one recent study from the USA which estimates that, on average, nine people are bereaved for every one person who died from Covid-19[3]. If Marie Curie applies this to all deaths in the UK during Covid-19, this suggests that up to 6.2 million people may have experienced bereavement over the past year.

For these people, grieving processes have been profoundly disrupted. Social distancing restrictions, lack of visiting in hospitals and care homes, and shielding have compounded a sense of loss and guilt about the death of a loved one.

**Roberta's story**

**During the third week of April 2020, there were 24,691 deaths in the UK. One of the people who died was Doreen Saggers. Here, her daughter Roberta tells her story.**

Lockdown, week four. Just another ordinary April day, or so I thought. That was until my dear 89-year-old mum, whom I had brought to my home for safe keeping, was suddenly taken ill. Recognising heart problems, an ambulance was called. On arrival, the medics, dressed in full space-like uniforms, began work on my delicate little mum. Back-up was soon called, and at one point five people were working to save her life. I remember the deafening sound of what seemed like a metronome as they pumped hard to revive her.

After an hour, the decision was made to take her to the hospital. By then, everything seemed to resemble slow motion. Panic set in as I became aware that I would not be able to go with Mum on what would possibly be her final journey. Inseparable in life, this was a terrible wrench. I was distraught. I should have been comforting her and holding her tiny hand. Instead, I waited at home, alone.

Shortly after arriving at the hospital, my precious mum was pronounced dead. How could this be, that she died in A&E as did my dear daughter years before? At least I was with Louise. My mum was alone. Having devoted my life to helping to improve end of life care following Louise's death, I am devastated that I failed my mum.

Visiting her in the chapel of rest with my brother was so hard as we couldn't kiss, hold hands or hug. I needed this; I needed physical and psychological support, as I'm sure he did too. I fully understand the need for distancing, and we did abide by all of the rules. However, it's very hard having a funeral with just 13 people when possibly 100 would have attended. It was surreal. Even ordering the wicker basket for her burial proved difficult due to high demand. It was only thanks to the unbelievable kindness of the undertaker who travelled across the country to collect one for her that I managed to get something that was right for Mum.

We cannot plan precisely for a loved one's death. However, I could never have imagined such a difficult and heartbreaking experience. Our parting outside on that extraordinary April day will live with me forever, devastatingly, for all the wrong reasons. I know that I am not alone, and many others are also nursing a broken heart.

### There was a sustained increase in deaths at home throughout 2020, even outside of pandemic waves.

More people died at home during Covid-19, even outside of pandemic waves, and this contrasted sharply with previous place-of-death patterns.

Between 2015 and 2019, on average 604,000 people died each year in the UK. Around half of these deaths occurred in hospitals, with the rest occurring at home, in care homes and in hospices.

Marie Curie's own analysis (not contained in the research report) finds that overall, since the beginning of the pandemic in March 2020, deaths at home rose as a proportion of total deaths in Great Britain (England, Wales and Scotland) from 24% to 29%, compared to the five-year average for the same period, while deaths in care homes rose from 22% to 24%, with a corresponding fall in the proportion of hospital deaths from 47% to 42%. It should be recognised that these overall changes in place of death over the course of 2020 conceal significant variation over the course of the year.

The research report found that, in all nations, hospital deaths increased above baseline during the first pandemic wave, many of which were certified as due to Covid-19. Hospital deaths fell subsequently such that there were fewer deaths in hospitals than would be expected during weeks 20-40 of 2020. Hospital deaths again rose above baseline during the second pandemic wave, with a large proportion of these deaths certified as due to Covid-19.

Deaths in care homes increased dramatically during the first pandemic wave, many of which were certified as due to Covid-19. Subsequently, care home deaths dropped to baseline levels. Numbers of care home deaths increased during the second pandemic wave, but less than they had during the first wave.

In contrast, deaths at home increased during the first pandemic wave in all four nations, with relatively fewer deaths certified as being due to Covid-19.

There was a sustained increase in the number of people dying at home in all four nations throughout 2020, with a further increase during the second pandemic wave. Covid-19 was infrequently the cause of death for deaths at home, and there was little difference in this between the first and second pandemic wave.

### Deaths in hospices decreased during Covid-19, but palliative care and hospice teams increased activity and the busiest of these services were those caring for people in the community.

From the first weeks of the pandemic, hospice deaths fell below baseline levels and this was sustained for most of 2020. From the start of the pandemic in March to the end of 2020, hospice deaths in England and Wales fell from 6% to 4% of total deaths.

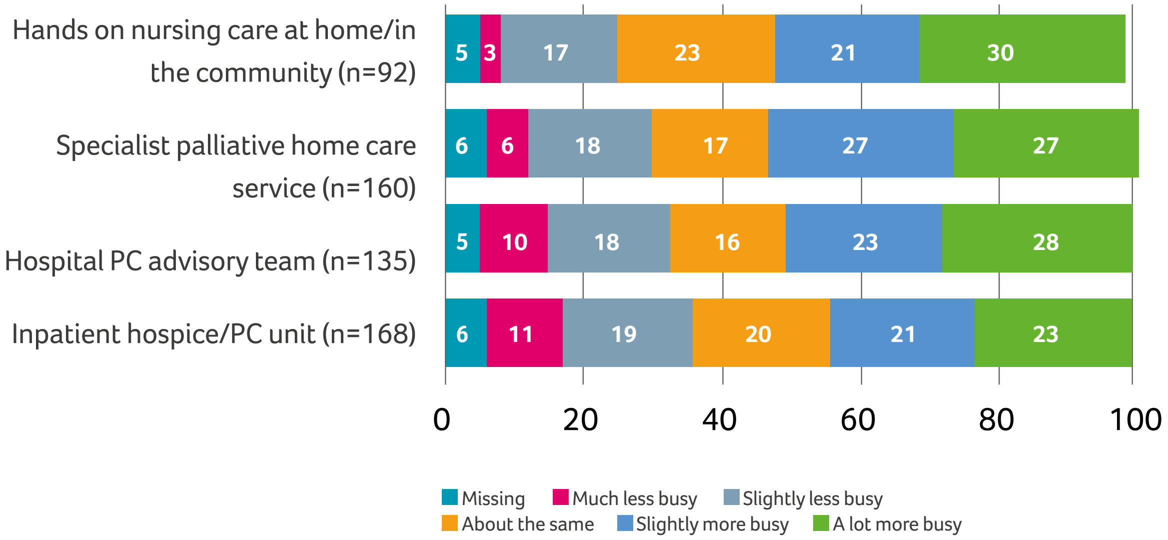
The decrease in deaths in hospices may be due to people with a terminal illness choosing not to be admitted to hospices because of visitor restrictions and fear of contracting Covid-19.

Despite this, data from the CovPall study shows that hospice and palliative care services from all UK nations and English regions reported being busier than before the Covid-19 pandemic. The region with the largest number of services reporting being busier was London, where 69% of services reported being slightly more or a lot more busy. The regions where the smallest number of services reported being slightly or much more busy were the North East and West Midlands – 33% and 34% respectively.

Four main types of service were included in the CovPall study: services providing hands on nursing care at home in the community; specialist palliative home care services; hospital palliative care advisory services; and inpatient hospice/palliative care units. Services providing specialist palliative home care services and hands-on care in the community reported being busier than those providing inpatient hospice care.

## Figure 1
## Activity of hospice and palliative care services in Scotland, Northern Ireland, Wales and regions of England.

> *One hospice unit has closed and the other has had to reduce beds [as they are] too close together. This has led to increase in community workload with more complex and unwell people at home requiring assessment, care coordination, clinical decision making and support.*
> (Scotland)



Due to rounding, percentages may not total 100%.

Figure 1

### Hospices and palliative care specialists educated, upskilled and supported others.

Many services reported increased activity as they intensified provision of care according to escalating needs. Some services opened additional inpatient beds, including in acute hospitals and 'field hospices'. Others extended their hours of operation to meet demand for palliative care.

Some services shifted provision of care, merging services or extending the roles of clinicians to support the wider health care system, including in clinical decision-making. Some inpatient hospice units reported a drop in inpatient referrals, while others needed to close beds due to guidance on infection control. This often prompted a shift in resources from inpatient to community provision where needs were greatest.

Early in the pandemic, there was a lack of guidance to support communication, symptom control and care for people dying from Covid-19. Resources were rapidly developed to support both specialist palliative care professionals as well as wider health and social care professionals in hospital and community settings. These resources included after-death and bereavement care.

Hospice and palliative care services took on new roles in provision of education and training in symptom control for people with Covid-19 to health and social care professionals, including those in hospitals and care homes. Palliative care services also took on broader roles in providing psychological support, and debriefing/reflection sessions for members of staff.

> *We had to quickly teach [health care staff] about palliative care, syringe drivers, large doses of [drugs] and many other aspects of Palliative Care.* (London)

### Hospice and palliative care services adapted and innovated.

Many services increased their use of technology, including telephone and video calls. For some, this had the advantage of freeing up capacity by reducing travelling time. Many services reported large increases in the number of people they were supporting remotely.

Services found they were providing more psychological support to people living in the community who were struggling with the impact of the pandemic. Due to the increase in complexity of need, services reported that remote consultations were often very time consuming.

> *Patients/carer have been more psychologically distressed, and this is requiring more prolonged non face-to-face consultations.* (North East)

Considerable time was spent supporting people to remain in their usual place of care and avoiding hospital admissions where possible. Supporting patients to remain at home required integration with other community services, such as community pharmacies.

> *High level of calls related to anxieties of how patients would get repeat prescriptions, fears of running out of medication. This led to liaising with pharmacies, trying to get patients setup on delivery systems. Updating GP practices with the named pharmacies. Arranging Dosette boxes.* (North West)

### Primary care services did more delivery of palliative and end of life care.

The report cites a UK-wide questionnaire survey of GPs and community nurses during September and October 2020[4]. Responses were received from 559 individuals (387 community nurses, 156 General Practitioners and 16 unspecified role), from all regions of the UK.

This survey found GPs and community nurses reported increased involvement in provision of end of life care in the community during the pandemic. Over half of respondents said that they had cared for patients who had died with confirmed Covid-19, and over two-thirds said that they had cared for patients who had died with suspected Covid-19.

The survey found that primary care teams, in partnership with specialist palliative care teams, managed both increased volume and increased complexity of palliative and end of life care during the pandemic, particularly when patients did not want to go to hospital or to a hospice. Over half of respondents said they provided 'a lot more' or 'a bit more' end of life care than usual.

Respondents also reported managing patients with very complex needs who, pre-Covid-19, might have been admitted to hospital or a hospice.

It was suggested that the Covid-19 pandemic had indirectly enabled a long-term aspiration of increasing the proportion of people who die at home to be realised, even though the increase in volume and complexity of care was a challenge.

> *"We have had more complex patients being managed at home which has been a challenge, whereas if Covid-19 and visiting wasn't an issue they may have been hospice inpatients or even admitted to an acute hospital bed."* (GP, England)[4]

### Care was compromised by shortages of essential equipment, medicines and staff.

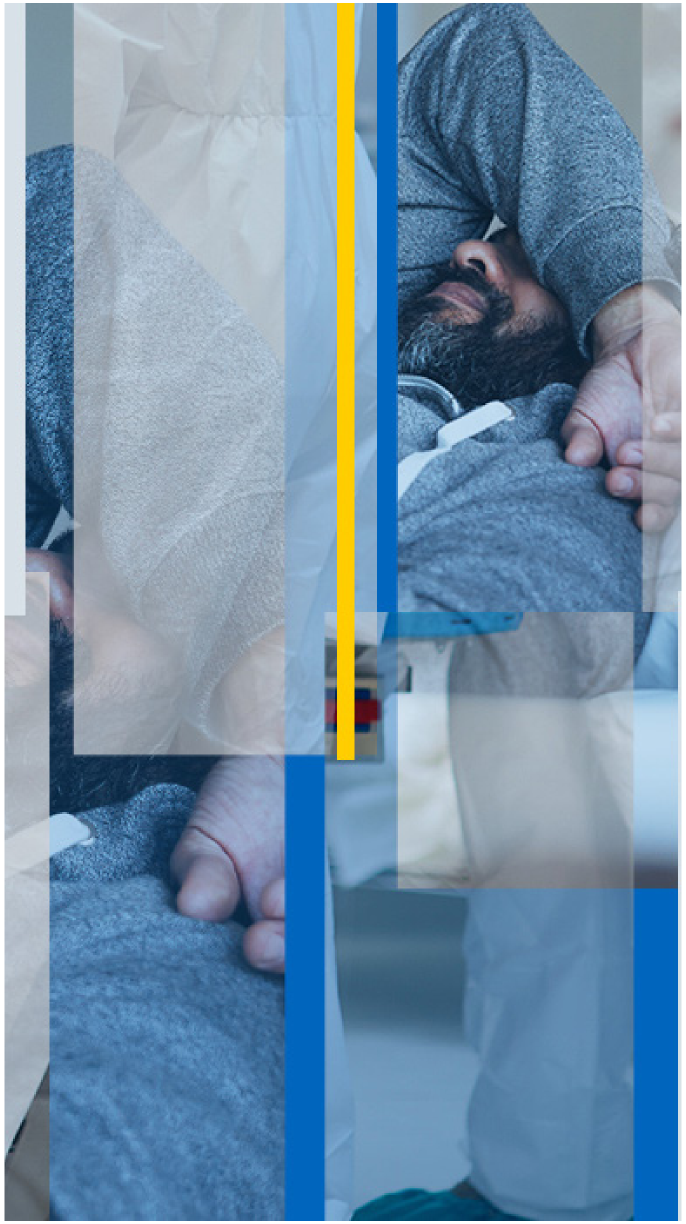
Hospice and palliative care services experienced many challenges during the first pandemic wave that limited their ability to provide direct care to patients and families, or indirect care through educating other professionals in how to support dying people and their carers.

They experienced shortages of PPE, other equipment, medication and staff. These shortages were exacerbated by hospices and palliative and end of life care services not being recognised as 'frontline NHS'.

> *"As we are not classed as 'frontline NHS' we were unable to access (masks and gowns) from our local NHS board. .... this was less than satisfactory for 7 weeks, however this has now been resolved."* (Scotland)

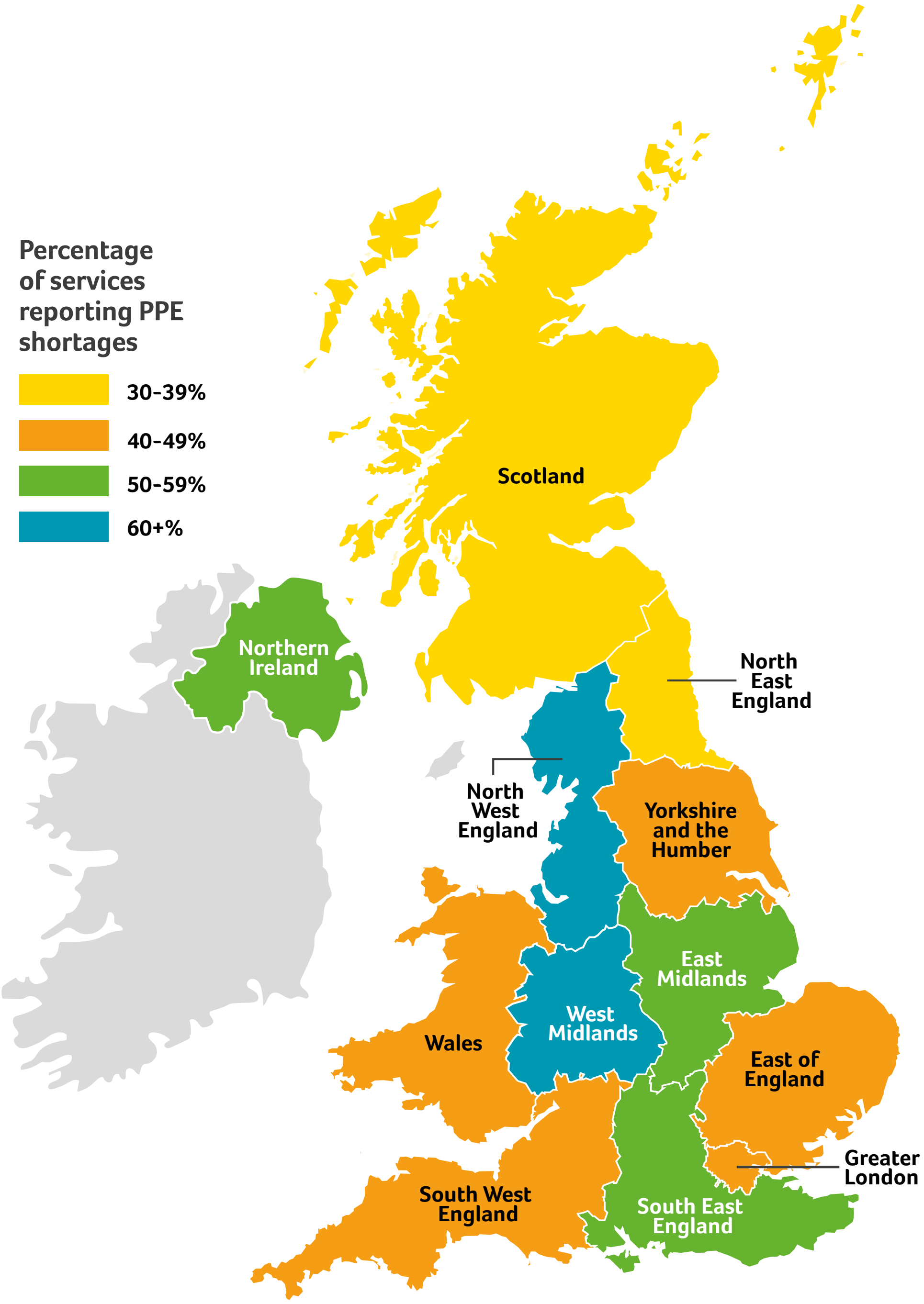
> *We have had problems accessing supplies and being recognised as part of the NHS supply chain. Initial advice regarding hospice setting care was conflicting with regards to what PPE should be worn as we aren't a hospital but neither a care home.* (South East)

> *Some of our nursing staff are undertaking extra work for the NHS so this has impacted on staff available for shifts.* (North East)



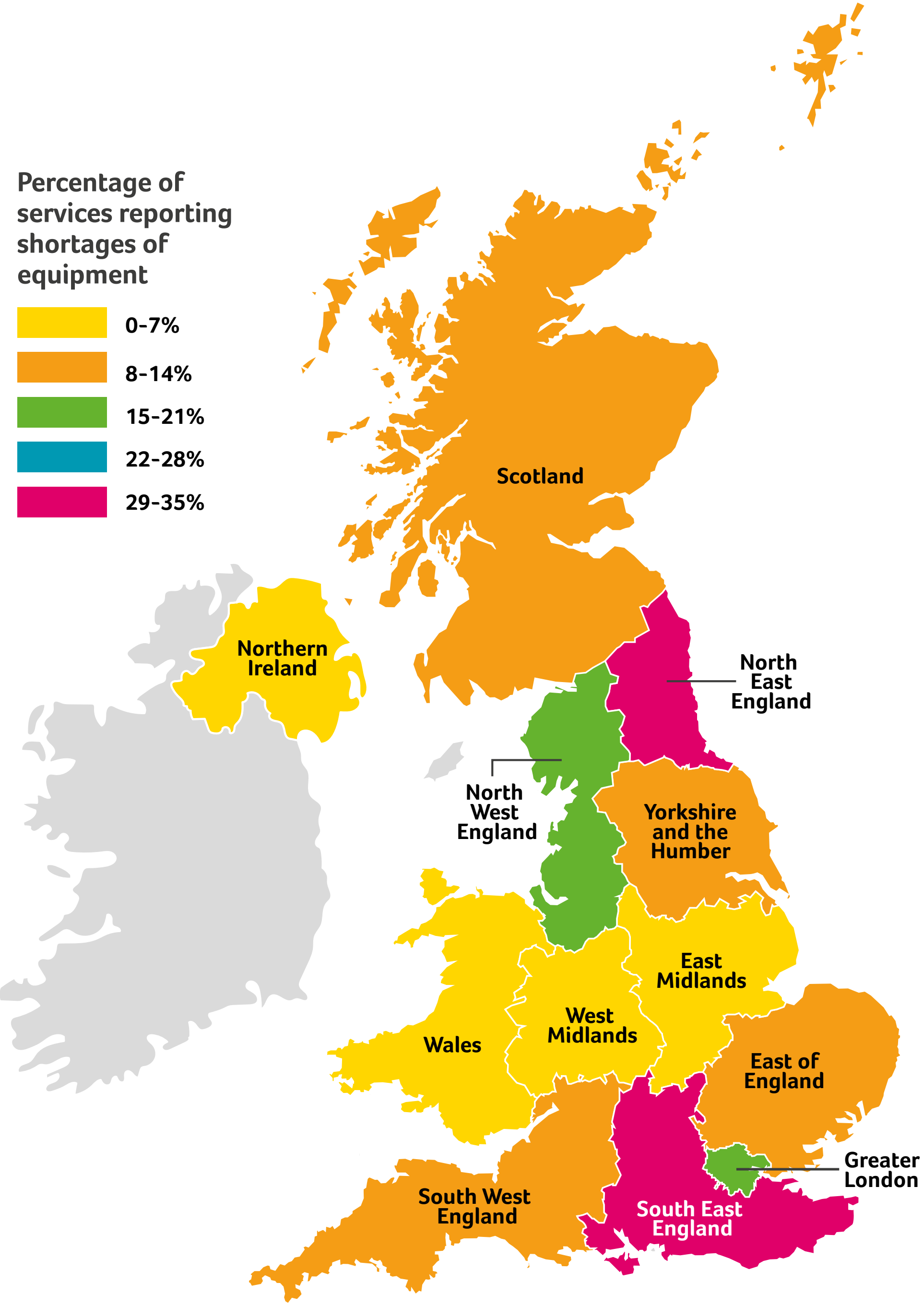
## Figure 2
## PPE shortages

Shortages of PPE were most common in the North West of England and the West Midlands, and included shortages of masks, aprons and face shields as well as other essential equipment including cleaning products, waste disposal products and body bags. Training regarding PPE and 'fit' testing to ensure correctly fitted masks was also limited. Services adopted creative approaches to procuring PPE, through social media appeals and local networks, but procuring adequate PPE was extremely time consuming and reduced the ability of services to provide direct patient care.



## Figure 3
## Equipment shortages

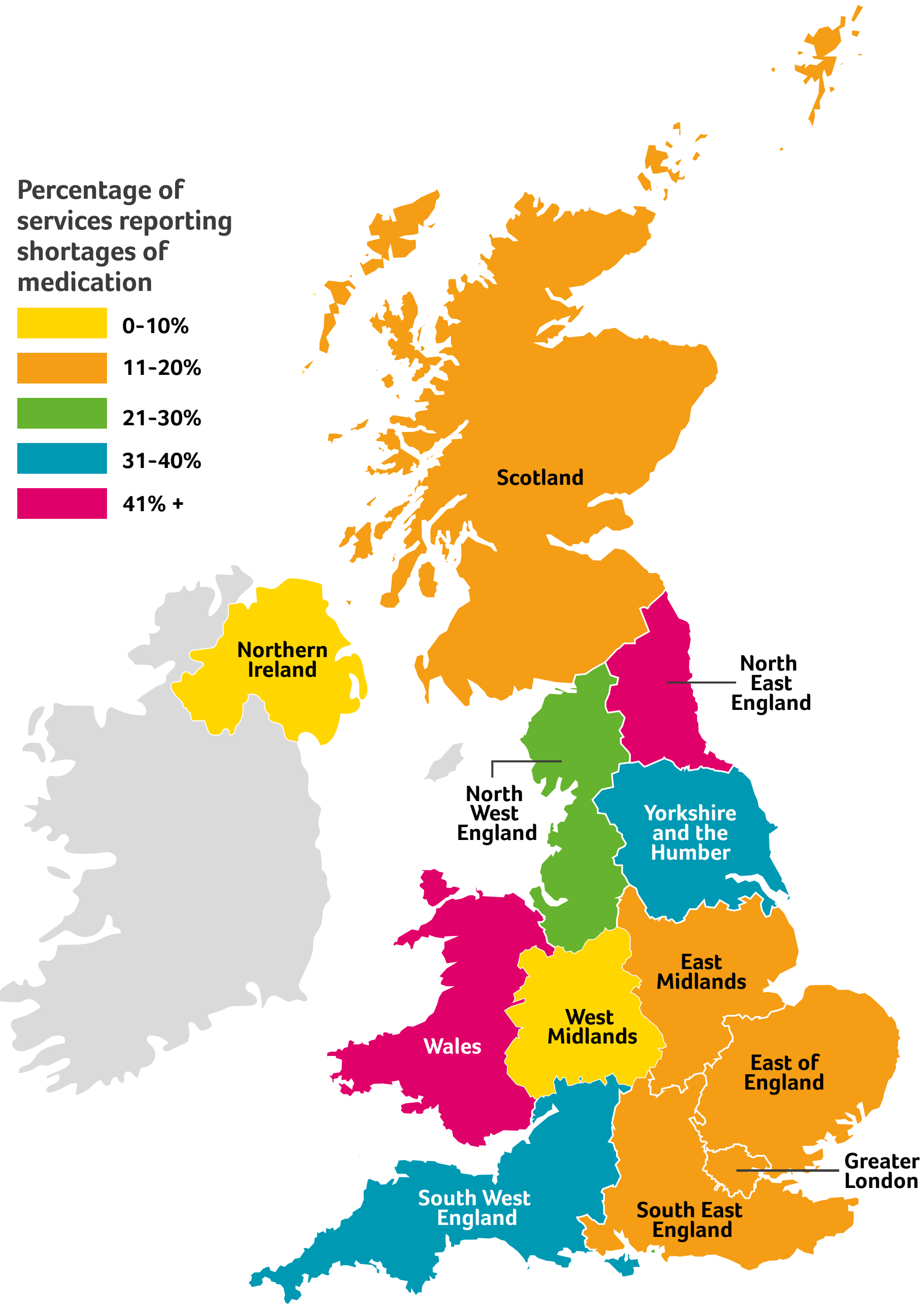
Where equipment shortages were mentioned, they most commonly related to syringe pumps and the associated lines/needles needed. Services worked together to source and share equipment, but in some cases, services did not have enough syringe pumps to address patient need, meaning that some patients may not have had their pain and other symptoms fully controlled.



## Figure 4
## Medication shortages

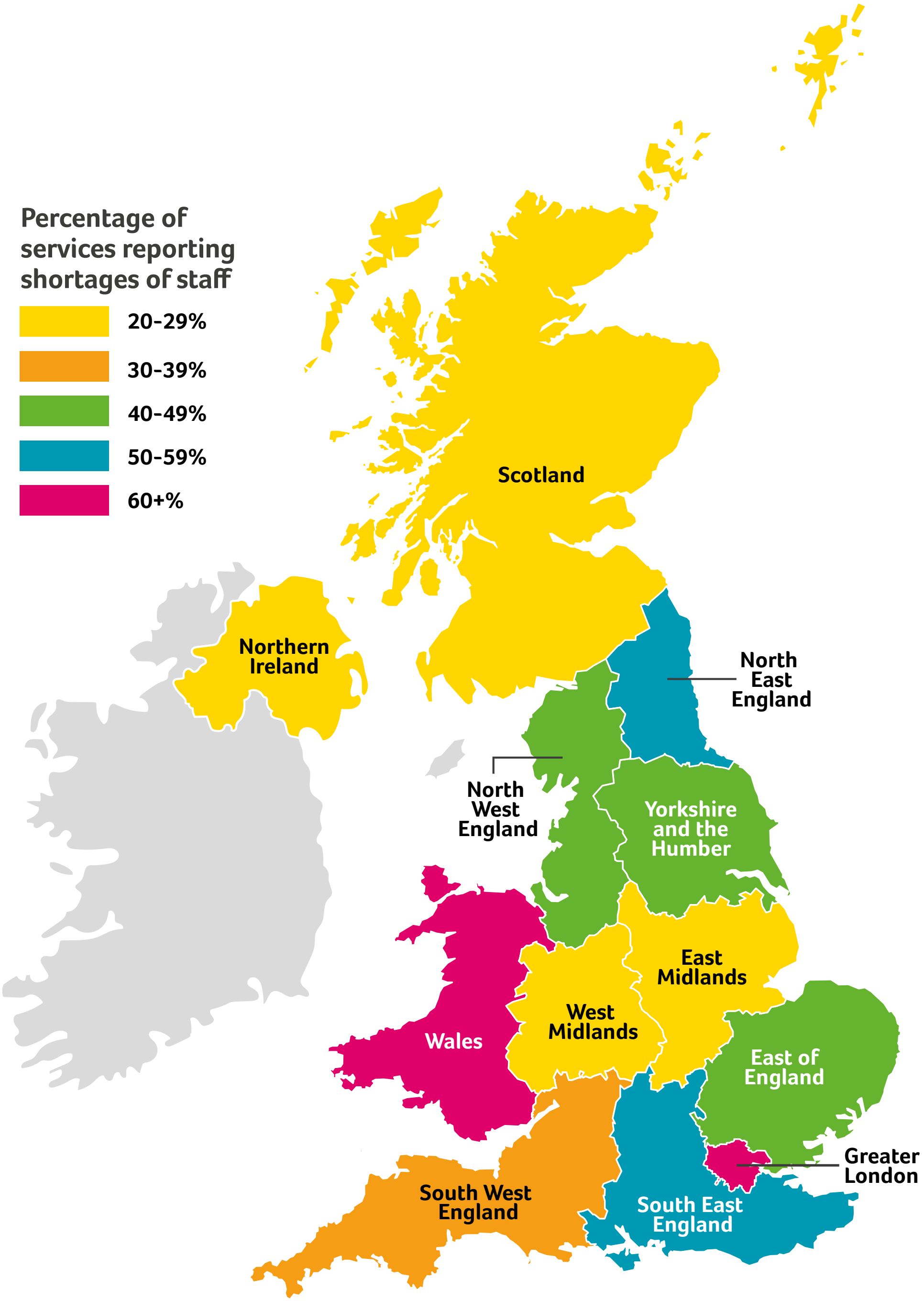
People with Covid-19 frequently experience distressing symptoms, most commonly breathlessness and agitation. Irrespective of prognosis, medicines, including morphine, may be needed for control of symptoms.

The majority of services surveyed did not report shortages of key medicines during the pandemic. The exceptions were Wales and North East England, where 53% and 42% of services reported experiencing shortages of key medicines. Of the 63 services that reported shortages of medication, levomepromazine, midazolam and alfentanil were most commonly mentioned.



## Figure 5
## Staff shortages

Staff shortages were most common in Wales and London, where 60% of responding services reported staff shortages. Shortages were a result of shielding, self-isolating and sickness due to suspected Covid-19. In some cases, staff were redeployed from palliative care into other roles. Access to Covid-19 testing in hospice settings was limited, which compounded staff shortages.



## More people are now at risk of complicated grief.

A recent study in the United States cited in the research report has estimated that for each person who dies from Covid-19, nine people are bereaved – be that a grandparent, parent, sibling, spouse or child[3]. If Marie Curie applies this to all deaths in the UK during Covid-19, it suggests that as many as 6.2 million people may have experienced bereavement over the last year.

Drawing on data from 532 bereaved respondents from across the UK, one study (Harrop et al)[5] found negative end of life and bereavement experiences were common. More than half (56%) of respondents said they were unable to visit their loved one prior to death, while two-thirds (67%) said both that they were unable to say goodbye as they would have liked, and that they experienced social isolation and loneliness.

The study found that while the experiences of respondents varied, problems with communication were common. Almost one in four (23%) respondents said they were 'never' involved in decisions about the care of their loved one; 17% said they were not at all informed about the approaching death; and half of respondents (51%) said they were not provided with any information about bereavement support.

Of respondents who had tried to obtain support from a bereavement service, over half (56%) experienced difficulties accessing these services. Challenges included long waiting lists, limited availability, and a lack of information about where to get support. Some people who had been bereaved through non-Covid-19 causes reported feeling less entitled to support.

## Bereavement support services adapted and innovated.

Another study cited in the report[6] explored in depth the delivery of care for 805 people bereaved during Covid-19 in the UK and Ireland.

Respondents reported major changes in the provision of bereavement care. The greatest change was through the use of telephone, video and other forms of remote support. Prior to the pandemic, telephone and video had been used rarely but became the primary mode of support.

Frequently reported was the impact of restrictions on funeral arrangements; reduced opportunities for face-to-face interaction made it difficult to identify people who might need support.

> *"We are beginning to see more extreme reactions from people who were bereaved before the pandemic and who had begun to find ways of living in their altered world, but who now find that most of the outlets that they were using to help themselves are now closed to them."* (Hospice Social Worker)[6]

The survey also highlighted the need to ensure support is not limited to people bereaved during the pandemic. Several respondents highlighted the needs of people who had been bereaved before the pandemic, for whom restrictions led to an escalation in support needed.

> *"I have found families who have lost a member during the pandemic feel their loss is not as big as that of people dying of Covid. Or as important."* (Hospice Social Worker)[6]

# Policy recommendations

Based on the research report, Marie Curie makes the following policy recommendations:

**Palliative and end of life care services, within and outside of the NHS, must be sustainably funded.**
Hospice and palliative care services have proved to be a vital component of the emergency response to Covid-19 and will be central to the future provision of health and social care in the UK as our population ages and more people live longer with multiple and complex health conditions. Yet, both prior to the pandemic and during it, this sector has been treated as 'not frontline NHS'.

Charitable hospices are the main providers of specialist palliative and end of life care across the UK, yet only around 30% of their income currently comes from government sources. The remainder is raised through community fundraising, charity shops and their own investments.

Sharp reductions in charitable income during Covid-19 have been compensated for by emergency grant funding by governments in all four nations, but a much more resilient and sustainable funding model is urgently needed to ensure we can meet challenges of rising demand for services beyond Covid-19.

**Dying people must be better supported to die in the place of their choosing.**
Prior to the pandemic, just 7% of people expressed a preference for dying in hospital, yet nearly half of deaths typically took place in hospitals[7]. This was despite likely cost savings to the NHS from preventing hospital admissions and supporting early discharge for people at the end of life, and the priority successive governments in all four nations of the UK have placed on supporting people to die in their place of preference, where possible.

The pandemic has resulted in a sustained increase in deaths at home in all four nations, but meeting preferences for home as the place of death beyond Covid-19 will depend in part on wider improvements to the support people are offered when being cared for in their own homes at the end of life.

In England, Fast-Track Continuing Healthcare (CHC) is a free care package for patients to enable them to be cared for outside of hospital at the end of their lives if their condition is deteriorating rapidly and may have entered a terminal phase. Marie Curie's research into the state of Fast-Track CHC since 2017[8] has revealed delays and failures in putting these packages in place as well as a postcode lottery of variable performance in different parts of England.

During the first six months of the pandemic, NHS England fully funded all new CHC packages and removed the requirement for a needs assessment to take place in hospital before a person could be discharged from hospital. We welcome indications from the UK Government that it may allow CHC assessments to take place after discharge in future.

In addition to this change, measures to improve discharge in all four nations will need to be accompanied by improved training and resourcing for community services, and better sharing of good practice and performance data if the needs of patients and their carers are to be properly assessed and fully met.

**A whole system approach is needed to deliver palliative and end of life care.**
Ensuring people are supported to die well in all settings will require an approach that includes the whole health and social care system, not just the palliative and end of life care sector. This must include specialist palliative care clinicians, as well as a focus on resourcing, educating and upskilling non-specialist primary care and social care providers in palliative care approaches, and creating new and innovative service models.

As part of this approach:

- everyone nearing the end of their life should be offered the opportunity to set out in a plan their wishes for the end of their life

- quality standards for end of life care and support in community services and primary healthcare should be adopted in each nation

- population-based approaches to commissioning must take account of demand for and costs of palliative and end of life care.

- integrated health and social care systems will need to place the needs of people at the end life at the centre of their governance, staffing and commissioning arrangements.

The success of a whole system approach to palliative and end of life care in the community will also depend on political consensus emerging around sustainable solutions to the underfunding of social care in all four nations of the UK.

### The Hospices of Birmingham and Solihull service

Several hospices provide specialist palliative and end of life care to the diverse communities that populate the Birmingham and Solihull area, but. prior to the pandemic, each had different offers of support out of hours with no part of the area covered by a comprehensive out-of-hours specialist palliative care service. Each hospice also had its own referral pathway, creating confusion among professionals about how to make a referral.

Without a single point of access, patients struggled to know how to get support and often had to dial 999 to get help with distressing symptoms such as pain and breathlessness. This typically resulted in people being admitted to hospital because they could not obtain the care and support they needed in their home.

When in mid-March 2020 the number of cases began to peak, each individual hospice faced the prospect of being overwhelmed by the twin pressures of more patients coming their way at the same time as more of their staff were going off sick.

To respond to these challenges, a new model was developed out of informal conversations held during a leadership training course that took place on the eve of the pandemic. These conversations were built on long-standing and positive working relationships between local professionals.

Known as 'Hospices of Birmingham and Solihull' (HoBS) the new model amalgamated the staffing resources of the specialist palliative and end of life care sector in Birmingham and Solihull through the creation of a single point of access. Key partners included St Mary's Hospice, John Taylor Hospice, Marie Curie West Midlands, and Solihull Macmillan Team (University Hospital Birmingham Community).

Direct pathways were also set up to St Giles Hospice and Birmingham Community Healthcare Trust along with University Hospitals Birmingham, West Midlands Ambulance Service, Continuing Healthcare Team, District Nursing teams and other voluntary sector providers through Birmingham Voluntary Services Council.

Professionals wishing to make a referral for palliative and end of life care were provided with a single phone number to call, and they would then be connected immediately to the right service. Referrals could be made at any time of the day or night, with a specialist palliative care nurse always on hand to assist with emergency and complex cases.

These hospices managed to realise their long-held ambition of a fully integrated hub offering personalised end of life care in the midst of a pandemic. However, looking forward, there is concern that the staff shortages that prompted the creation of HoBS could return in worse form once normal NHS services are resumed.

*"The biggest impact on staff is now. It is far worse than at the beginning... When all this is over, we really need to face the bigger challenge of having the right workforce in place."*
(Marie Curie staff member)

Source: Marie Curie

## The services available to a patient calling HoBS

**HoBS**

1 **Social**
- Personal health budgets
- Voluntary sector
- Fast track/ care package
- Patient choice
- Signposting
- Day hospice services

2 **Care**
- Day hospice services
- Hospice @ home
- Links with district nurses & GP
- Clinical nurse specialist
- Palliative care consultant

3 **MDT**
- Speech and language therapy
- Occupational therapy
- Pharmacists
- Physiotherapists
- Occupational therapy

4 **Support**
- Admission to IPU – carer crisis
- Advice to other healthcare professionals
- Bereavement team
- Support for each other

5 **Rapid Response**
- Hospice @ home
- 24/7 service
- Hospital admission avoidance
- Rapid discharge home for EoL

### Families and carers must be supported to play their part.

Prior to the pandemic, people with a terminal illness were frequently admitted to A&E departments several times during the final year of their lives, often because the situation at home had reached crisis point. In future, if more people are to be cared for at home at the end of life, attention is needed to ensure carers and family members do not become overwhelmed, as many have done during the pandemic.

Health and social care professionals will need to take steps to proactively identify and record details of carers of people at the end of life because many do not identify themselves as such, and this creates challenges around ensuring they have appropriate access to education and support.

Everyone who provides care for someone who is approaching the end of life should have their needs assessed and the recommendations of this assessment must be actioned by local authorities. Where needed, carers should also be supported to balance caring and work responsibilities and to access financial support, such as Carer's Allowance and Carer's Allowance Supplement in Scotland as quickly as possible.

### Increased provision of bereavement support is urgently needed.

Meeting the needs of bereaved people, including those experiencing complicated grief as a result of the challenging circumstances of Covid-19, will require increased funding to improve access to bereavement support services, especially for groups such as Black, Asian and Minority Ethnic (BAME) people and deprived communities who have been disproportionately affected by the pandemic. Attention is also needed to ensure the needs of people bereaved through non-Covid-19 deaths are fully met

Further work is needed to ensure bereavement support services are properly signposted and have clear referral pathways. Staff and volunteers may require specialist training to support people through the physical, psychological and economic difficulties associated with complicated grief. Additional funding will be required to expand provision and ensure equality of access.

Wider reforms are also needed to ensure family members and carers are fully supported through bereavement. Currently only parents who lose a child under the age of 18 are legally entitled to two weeks' paid bereavement leave, and this right should be extended to other close family members. The UK Government must also proceed quickly to act on recent High Court and Supreme Court judgments and extend eligibility for Bereavement Support Payments to unmarried partners, to remove discrimination on grounds of marital status.

### The Companions Service

The Marie Curie Companions Service was developed to support people who are dying and their families while the person is in hospital. People who are dying in hospital may have few or no visitors and, if people are visiting, those people can often feel overwhelmed. Volunteers provide emotional support and respite as well as practical help.

With the suspension of hospital visiting in March 2020, the service was adapted to provide support by telephone instead of face-to-face and to meet the more complex needs of next of kin during Covid-19. It was also expanded through virtual volunteer recruitment and management to respond to increased demand for support.

New restrictions on hospital visiting and rules on social distancing and funerals left many next of kin suddenly cut off from the social contact that would ordinarily have supported them through their loved one's death. Many also struggled to navigate complex new remote arrangements for resolving practical matters such as death registration and notifying banks of a death.

Demand for the service increased as the number of people dying rose during pandemic waves. Beginning in April 2020, capacity was increased by additional volunteer recruitment, enabling the Companions Service to expand its reach and support more than 3,000 next of kin of people cared for by the Marie Curie Nursing Service across the whole of Wales and Southern England.

Successful expansion of the service demonstrates that bereavement support volunteers can be recruited, trained and supported virtually. Volunteers living all over the UK signed up to join the service, despite living many miles from its direct beneficiaries.

> *"The reward comes from building the relationship. I've seen one lady I support go from a very raw emotional state from losing her husband of 70 years to feeling happy because spring is arriving and she has been booked in for her vaccine."*
> (Companions Service Volunteer)

Lessons from the service are now being applied to another project deploying volunteers remotely to help people complete advance care plans setting out their wishes for the end of life for sharing with their GP, but the service has worked much less well for people with dementia.

In future, staff hope to be able to offer dying people and their next of kin a choice of support in the form that suits them best.

> *"It's the least we can do for people at the end of life."* (Marie Curie staff member)

Source: Marie Curie

### Data systems must include information on dying, death and bereavement

Open access to standardised data on dying, death and bereavement outcomes is essential for measuring, monitoring and improving the quality of care provided across the UK in future. Currently, much of this data is either not collected, limited in scope or not available to the public in usable formats. Even the most basic place of death data is not available in all parts of the UK.

The new Health and Social Care White Paper from the UK Government proposes a duty on NHS Digital to have regard to the system improvement benefits of sharing data that it holds when exercising its functions and developing data standards. This duty should be used to deliver integrated data systems that include information on palliative and end of life care delivered by both specialist and generalist providers, in all settings including private homes and care homes in England.

### New research is needed to inform better care through dying, death and bereavement

There has been a rapid growth of knowledge during Covid-19. However, many gaps in this knowledge still exist, and must be addressed through high quality research. These gaps include: the reasons underlying the shift towards home deaths during the pandemic and the implications for patients and family carers; the education needs of the community care workforce with respect to providing increasing palliative and end of life care at home; the best ways to provide palliative and end of life care in care homes; the impact of specialist palliative care services on the wider health system, including hospital admissions and place of death; and the experiences of dying, death and bereavement during Covid-19 of people from BAME groups and deprived communities.

Palliative and end of life care research remains grossly underfunded, with only 0.21% of non-commercial health-related research funding spent on palliative and end of life care research (2018 figures) and with many evidence uncertainties remaining unanswered. In addition to the above research gaps identified, it will be important to investigate whether there has been a change in research priorities of patients, carers and health and social care professionals as a result of the pandemic.

Through this research and recent studies by others, much more is now known about the vital role played by palliative and end of life care during the emergency response to the ongoing Covid-19 pandemic. We hope that lessons learned about palliative and end of life care during the pandemic can be applied to future policy and practice in ways that help ensure everyone has the best possible end of life experience.

### Marie Curie policy recommendations:

| **Governments across the UK must review funding for palliative and end of life care services, within and outside the NHS, to ensure that support is resilient and fit for the future.** | |
|---|---|
| **Support for people to die in the place of their choosing** | • Improve resourcing of palliative and end of life care in the community by primary care services and community nursing teams<br>• Continuing Healthcare (CHC) Assessments should be allowed to take place in the community<br>• End the postcode lottery of delays and failures in fast-tracking CHC in England<br>• Share good practice and performance data on fast-track CHC and quality of care provided in private homes and care homes |
| **A 'whole system' approach to palliative and end of life care** | • Offer everyone the opportunity to set out their wishes for the end of life and ensure these plans are shared and followed by service providers<br>• Adopt quality standards for end of life care and support in all settings, including care homes and private homes<br>• Account for costs of and demand for palliative and end of life care in population-based approaches<br>• Place the needs of people at the end of life at the centre of integrated health and social care systems<br>• Build political consensus on a sustainable solution to social care funding in each UK nation |
| **Support for families and carers** | • Proactively identify and (with their permission) record carers of people approaching the end of life because many do not identify as such<br>• Ensure every carer is offered a fast-tracked needs assessment and that recommendations are acted upon promptly and in full<br>• Support carers to balance caring and work responsibilities and to access financial support such as Carer's Allowance and Carer's Allowance Supplement in Scotland |

| | |
|---|---|
| **Increased provision of bereavement support** | • Increase funding for bereavement support services<br>• Prioritise support for groups hardest hit by Covid-19 including BAME and deprived communities<br>• Ensure the needs of people bereaved through non-Covid-19 deaths are fully met<br>• Signpost services clearly and adopt clear referral pathways<br>• Provide specialist training in complicated grief to staff and volunteers<br>• Extend the right to bereavement leave to all close family members<br>• Act on a recent court judgment by extending eligibility of Bereavement Support Payments to unmarried partners |
| **Data systems must include information on dying, death and bereavement** | • Ensure providers share data openly to support system improvement in palliative and end of life care<br>• Ensure information is made available on both specialist and generalist care provision in all settings, including private homes and care homes |
| **New research to inform better care for people experiencing dying, death and bereavement** | • Support research to investigate:<br>  • the reasons underlying the shift towards home deaths during the pandemic<br>  • the education needs of the community care workforce with respect to palliative and end of life care at home<br>  • the best ways to provide palliative and end of life care in care homes<br>  • the impact of specialist palliative care services on the wider health system<br>  • the experiences of dying, death and bereavement during Covid-19 of BAME groups, deprived communities and other groups<br>• Increase funding for palliative and end of life care research<br>• Investigate the changing priorities of patients, carers and health and social care professionals |

# References

1. Etkind, S.N., Bone, A.E., Gomes, B., Lovell, N., Evans, C.J., Higgingson, I.J., Murtagh, F.E.M. How many people will need palliative care in 2040? Past trends, future projections and implications for services. BMC Med 15, 102 (2017). https://doi.org/10.1186/s12916-017-0860-2

2. Sleeman, K.E., Murtagh, F.E.M., Kumar, R., O'Donnell, S., Cripps, R.L., Bone, A., McAleese, J., Lovick, R., Barclay, S., & Higginson, I.J. (King's College London, Cicely Saunders Institute; Hull York Medical School, University of Hull; and University of Cambridge, UK). Better End of Life 2021. Dying, death and bereavement during Covid-19 Research Report. London (UK): Marie Curie. 2021 April. https:// www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2021/better-end-of-life-research-report.pdf

3. Verdery, A. M., Smith-Greenaway, E., Margolis, R., & Daw, J. (2020). Tracking the reach of COVID-19 kin loss with a bereavement multiplier applied to the United States. Proceedings of the National Academy of Sciences, 117(30), 17695-17701. https://doi.org/10.1073/pnas.2007476117

4. Mitchell, S., Oliver, P., Gardiner, C., Chapman, H., Khan, D., Boyd, K., Dale, J., Barclay, S. & Mayland, C. (2021). Community end-of-life care during the COVID-19 pandemic: Initial findings of a UK primary care survey. MedRxiv: https://doi.org/10.1101/2021.02.15.21251756

5. Harrop, E., Farnell, D., Longo, M., Goss, S., Sutton, E., Seddon, K., Nelson, A., Byrne, A. & Selman, L.E. Supporting people bereaved during COVID-19: Study Report 1, 27 November 2020. Cardiff University and the University of Bristol. Available at: https://2158a728-76d2-4aee-b2a8-646f37e9b97e.filesusr.com/ugd/26b83b_43690ce0978740548d92096c8c10ff7f.pdf [Accessed 16 February 2021].

6. Pearce C, Honey JR, Lovick R, Zapiain Creamer N, Henry C, Langford A, Stobert M, Barclay S. 'A silent epidemic of grief': a survey of bereavement care provision in the UK and Ireland during the COVID-19 pandemic. BMJ Open. 2021 Mar 3; https://bmjopen.bmj.com/content/bmjopen/11/3/e046872.full.pdf

7. NatCen Social Research, 'British Social Attitudes Survey 30: Dying/Discussing and planning for end of life' https://www.bsa.natcen.ac.uk/media/38850/bsa_30_dying.pdf

8. Marie Curie, When time really matters: Fast track care at the end of life, 2018. https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2019/when-time-really-matters-fast-track-care-at-the-end-of-life.pdf

**For more information:**
Ruth Driscoll
Ruth.Driscoll@mariecurie.org.uk