

Better End of Life 2021

Dying, death and bereavement during Covid-19
Research 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 Saggars, died suddenly in April 2020

Preface

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 UK. Demand for palliative and end of life care is set to increase rapidly, as more people live for longer with multiple and complex conditions. 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.

This first research report from the programme explores the ongoing impact of the Covid-19 pandemic on dying, death and bereavement in the UK. 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 the UK.

The research report was written by an Expert Group of clinical and non-clinical academics and 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 the research findings and policy recommendations.

“Demand for palliative and end of life care is set to increase rapidly, as more people live for longer with multiple and complex conditions... 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.”

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 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. This research report seeks to help to fill this gap.



Matthew Reed, Chief Executive, Marie Curie

The research shows how Covid-19 was associated with a significant increase in deaths at home across the UK, and also exposed limitations in community support at the end of life. Being able to support people's preferences for place of death beyond Covid-19 will depend on wider improvements to the support people are offered in the place they wish to die. In particular, more support is needed for the delivery of end of life care in community settings, and further improvements need to be made to NHS Continuing Healthcare in England.

Ensuring people are supported to die well at home will require a 'whole system' approach that extends beyond both the end of life care sector and the health sector. Crucially, success will also depend on political consensus emerging around sustainable solutions to the underfunding of social care.

In the 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.

Professionals will need to take steps to proactively identify carers of people at the end of life, assess their needs for both practical and financial support and ensure those needs are met quickly and in full.

The research also reminds us of the scale of bereavement during the pandemic. Meeting the needs of bereaved people, including those experiencing complicated grief as a result of the challenging circumstances of Covid-19, will require increased expansion of existing bereavement support services and action to improve access for groups



such as Black, Asian and Minority Ethnic (BAME) and deprived communities that have been disproportionately affected by the pandemic. Family and friends whose loved ones died of causes other than Covid-19 must not be forgotten.

Looking forward, end of life care services will be central to the future provision of health and social care in the UK. Hospices and community care services delivered by charities are key providers of this care, yet only a small proportion of their income comes from government sources, with the rest from their own efforts. A much more sustainable and resilient funding model is required to ensure that future needs can be met.

Through this study and other research 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. It is critical that the lessons learned during the ongoing pandemic can be applied to policy and practice in ways that help ensure that, in future, everyone has the best possible end of life experience.

Matthew Reed
Chief Executive
Marie Curie

Executive summary

The potential for Covid-19 to cause large numbers of deaths in the UK came to national attention on 16th March 2020, when it was suggested that, without mitigation, over 500,000 people could die from Covid-19 in the UK. During the pandemic to date, there has been an intense focus on the cumulative number of people who have died from Covid-19.

Alongside, the policy focus has understandably been on prevention of mortality through infection control; intensive care 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 who have been – and continue to be – affected by dying, death and bereavement has received little scrutiny.

This report explores the sustained impact of the Covid-19 pandemic on dying, death and bereavement in the UK. It draws on patient and carer perspectives, published literature, and secondary analysis of research and publicly available data.

It is the first in a series and part of a three-year collaborative project between Marie Curie, King's College London Cicely Saunders Institute, Hull York Medical School, the University of Hull and the University of Cambridge.

For a definition of palliative care, see page 14.

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 needs 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 healthcare 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.

Priorities for policy

The Covid-19 pandemic has accelerated the need for palliative, end of life and bereavement care in the UK and exposed weaknesses and achievements in that care. Our recommendations are outlined below.

- **Palliative care services, within and outside of the NHS, must be resourced appropriately.**

The Covid-19 pandemic has exposed systemic weaknesses that must be urgently addressed to meet the rising need for palliative and end of life care in the UK. During Covid-19, palliative care and hospice services, like parts of the social care sector, struggled to access essential supplies, including PPE. Charitably funded services were particularly impacted, as they are often considered outside of NHS supply chains. This impacted care that could be provided to patients. It is essential that palliative care services, whether predominantly within or outside the NHS, are resourced appropriately.

- **Palliative care services have played a front-line role during the Covid-19 pandemic, and this role must be recognised.** These services have relieved distressing symptoms experienced by people with Covid-19; supported people with and without Covid-19 to remain in their homes; reduced pressures on acute hospital services; provided education and support to the wider health and social care sectors; and provided bereavement support to families. In many cases, these services rapidly innovated, shifting resources from inpatient hospices into the community to meet needs.

- **Societal preferences and expectations for dying and death may have permanently changed, and the health and social care system must**

respond accordingly. There was a sustained increase in home deaths in the UK during 2020. Without adequate support and care in the community, dying at home may not be a positive experience. An integrated system-wide approach, including specialist palliative care, primary care and community nursing, and social care is required. Collaborative models of care are required to enable this integrated approach.

- **Care homes must be recognised as providers of palliative and end of life care and supported appropriately.** Deaths in care homes trebled during the first Covid-19 wave. In England, Scotland and Northern Ireland, care homes temporarily overtook hospitals as the most common place to die. More research is needed to understand palliative and end of life care in care homes during Covid-19, from care provider, care home resident and informal family care-giver perspectives.

- **Family members and carers must be recognised as important providers of palliative and end of life care.** Carers and family members need to be supported so that they are equipped with the knowledge, information, skills and resources to care for those close to them.

- **Primary care services need to be recognised as increasingly important providers of palliative and end of life care, at home and in care homes.** Primary care teams of general practitioners and community nurses, working alongside colleagues in care homes and in social care, have been at the forefront of community palliative and end of life care provision, supported by specialist palliative care teams. Resources must be directed to support

the essential, but often overlooked, role of primary care services in end of life care provision.

- **Increased provision of bereavement services is urgently needed.** People bereaved during the pandemic are at risk of complicated grief, which can leave a long legacy of physical, psychological and economic problems, with consequences for individuals and society. Public information on bereavement support options must be improved, and increased provision of bereavement services in areas that have long waiting lists must be prioritised.
- **Data systems must include information on dying, death and bereavement outcomes.** Even basic comparable data on the place of death is not available in all UK nations. Integrated data systems that include information on palliative care delivered by both specialist and generalist providers, including in care homes, are essential.
- **Research that informs care for people affected by dying, death and bereavement during Covid-19 is urgently required.** 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; 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, particularly of those from minority ethnicities and more deprived groups.

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1. Overview of this report

This report is the first in a series and part of a three-year collaborative project between Marie Curie, King's College London Cicely Saunders Institute, Hull York Medical School, the University of Hull and the University of Cambridge.

The project started in January 2021 and aims to examine experiences of dying, death and bereavement in the UK.

The intention of this first report is to examine the impact of the Covid-19 pandemic on dying, death and bereavement in the UK.

The aims are to:

- understand how the Covid-19 pandemic has affected the experiences of people living with serious illness and their carers
- understand how UK mortality patterns changed during the Covid-19 pandemic, in particular the changes in where people die
- explore the ongoing role of specialist palliative care and hospice services in the Covid-19 pandemic, and the contribution of these services to the wider health and social care system response, and identify the key challenges faced
- explore the ongoing role of primary care services in the provision of palliative and end of life care during the Covid-19 pandemic and the challenges they have faced

- identify some of the key challenges faced by those who have been bereaved during the pandemic and by those seeking to provide bereavement care and support
- based on this evidence, make recommendations for health and social care policy to guide provision of care during the ongoing pandemic response and afterwards.

For this report, an Expert Group (see Annex 1) was assembled, comprising 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 early- to mid-career researchers with clinical and non-clinical backgrounds.

The Expert Group was informed by a Patient and Public Involvement (PPI) Reference Group (see Annex 1), which provided guidance on priorities and concerns from a patient and carer perspective. The PPI perspective was enriched by engagement with PPI members through the Cicely Saunders Institute's PPI web-based forum and the Marie Curie Research Voices Group.

The report includes 11 sections. These draw on patient and carer perspectives, published literature, secondary analysis of research data and analysis of publicly available data (see Table 1: Structure of the report, p8)

Table 1. Structure of the report

Section number	Topic	Patient and family perspectives	Published literature	Secondary analysis of research data	Analysis of publicly available data
2	The carer's perspective	●			
3	The impact of the Covid-19 pandemic on dying, death and bereavement		●		●
4	Palliative, end of life and bereavement care during the Covid-19 pandemic		●		
5	Patterns of mortality in the UK during Covid-19				●
6	Activity of specialist palliative care and hospice services during the first wave of Covid-19 in the UK			●	
7	Challenges faced by specialist palliative care services during the first wave of Covid-19 in the UK			●	
8	Changes in community palliative and end of life care provision		●		
9	Impact of Covid-19 pandemic on experiences of bereavement		●		
10	PPI reflections on this report	●			
11	Policy priorities	●	●	●	●

Section 2 draws on the experiences of three carers affected by the pandemic. These perspectives highlight the varied experiences of carers during the pandemic, and how the pandemic has compounded their sense of loss and anxiety.

Sections 3 and 4 draw on a rapid review of evidence, including both UK and international data. The intention was to provide an overview of evidence rather than an exhaustive summary. Details of the method are given in Annex 2.

Section 5 provides an analysis of mortality data for England, Scotland, Wales and Northern Ireland, focusing on the impact of Covid-19 on the place of death. This analysis builds on the methods of a previously published analysis of mortality patterns in England and Wales during the first wave of Covid-19¹, extending this beyond the first pandemic wave and to the four nations of the UK. Details are given in Annex 2.

Sections 6 and 7 explore the activity of specialist palliative care services, using data from the CovPall study of the role and response of palliative care and hospice services to the Covid-19 pandemic. Details of the CovPall study are given in Annex 1, and details of the method are given in Annex 2.

Section 8 explores the activity of primary healthcare services during the pandemic, drawing on data from a survey of GPs and community nurses led by Dr Sarah Mitchell and Dr Catriona Mayland (University of Sheffield).

Section 9 considers the impact of the pandemic on experiences of bereavement. In this section, we draw on interim findings from a UK-wide study of people who have experienced bereavement during the Covid-19 pandemic, led by Dr Lucy Selman (University of Bristol) and Dr Emily Harrop (Cardiff University). We also draw on a survey of practitioners across the UK and Ireland to understand changes in their provision of bereavement care, led by Dr Caroline Pearce and Dr Stephen Barclay (University of Cambridge).

In **Section 10**, Jenny McAleese, a member of our PPI Reference Group tells the story of her husband, Kevin, who died in 2019, and reflects on what the findings of this report mean to her.

Finally, **Section 11** highlights priorities for policy.

2. The carer's perspective

Since the start of the Covid-19 pandemic, there has been an intense focus on the daily cumulative number of people who have died from Covid-19.

Behind the numbers and statistics that make the news headlines are people experiencing multiple losses during an extraordinary time. In this section, we share, with permission, the stories of three carers who have been affected by the pandemic.

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

Covid-19 has had a devastating impact on care homes. While the high number of deaths in care homes has been widely reported, less has been said about the impact of the Covid-19 pandemic on care home residents and their families. PPI contributor Catherine Hall reflects on her and her husband's experiences.

My husband died in August 2020 of Lewy body dementia. He spent the last six weeks of his life in a care home. I had looked after him solely with support from family and friends up to then (my choice).

At first, it was window visiting by appointment only, then it progressed to garden visits once a week, six feet apart, for just one family member. He had not spoken for weeks and did not know who I was.

On one visit, he looked at me and said clearly to me: 'I am dying.' I was unable to comfort him as I could not touch him. I was not frightened of getting Covid-19 or giving it to him. What I was frightened of was being prevented from seeing him again for not following guidelines.

He died a few weeks later. I was allowed to sit with him, and one of my sons was also there when he died. The care at the home was excellent. I had to postpone his funeral for 10 days as I had been in contact with someone who had tested positive for Covid-19, and I was refused a test because I did not have symptoms. Getting tested was not that easy back then.

For every person who has died during the Covid-19 pandemic, many more are living with long-term illnesses. For these people, the pandemic has disrupted the care they receive. Rashmi Kumar is a carer for his mother. He describes his family's experiences during the Covid-19 pandemic.

My mother has a terminal heart and kidney failure conditions. She now lives with us at our home. Before lockdown, my mother received daily community nurse visits, and professional personal care visits three times a day.

This all changed abruptly in March 2020, when the community nurse and professional care visits suddenly stopped without any communication. My wife and I had no other options but to step up to manage all my mother's personal care needs. We also experienced great difficulties accessing our GP surgery, including 'out of hours' support. This was very stressful and challenging for us. We were very lucky as we have two nieces who are doctors and they were able to help and guide us on what to do and how to manage her medications.

The situation started to improve by mid-April (2020). Home visits by community nurses started with one visit every week. We were also able to access support from our GP by phone. However, personal care support was still not available.

In July 2020, my mother's health unfortunately deteriorated to a critical condition. My wife and I were unable to care for her at home and she had to be temporarily admitted to a care home. This caused us and my mother great concern because we were not allowed to visit her, and she suffered great loneliness and anxiety. We were all, including my mother, very relieved to have her back at home with us in August.

Our situation is now a little better, and in some ways better than before the pandemic. We have direct access to our GP by telephone and through digital consultations. We are receiving regular community nurse home visits three times per week, which increase when my mother's health becomes unstable. Professional personal care support also re-started - but we have reduced these visits to 'once a day'.

A big plus for us has been that my family and I now feel that we are better informed in how best to provide my mother's palliative and end of life care. We have also decided that my mother will now spend her last days with us (at home).

We were lucky and very fortunate to have good support and guidance in the family. I fear how some people (and their loved-ones) might be coping without access to similar support, especially those who may not be able to communicate their difficulties or challenges.

3. The impact of the Covid-19 pandemic on dying, death and bereavement

‘How we die remains in the memory of those who live on.’ – Dame Cicely Saunders

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

In 2020, the absolute number of deaths in the UK increased to just over 695,000 as a result of the Covid-19 pandemic²⁻⁴. Of these, just under 90,000 deaths were certified as having been caused by Covid-19, while 606,000 deaths were from other causes (Table 2)⁵.

For people living with life-limiting illnesses and approaching the end of life, the pandemic has had profound impacts. 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, slogans such as ‘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. Data

Table 2. Deaths 2015-2020 by UK nation

	Scotland	Northern Ireland	Wales	England	UK
Deaths					
2015	57,579	15,548	33,198	495,309	601,634
2016	56,728	15,430	33,066	490,791	596,015
2017	57,883	16,036	33,248	498,882	606,049
2018	58,503	15,922	34,406	505,859	614,690
2019	58,108	15,758	33,183	496,370	603,419
2020	64,824	17,424	37,790	575,407	695,445
Covid-19 deaths^a	6,702	1,830	4,945	75,782	89,259
Non Covid-19 deaths^b	58,122	15,594	32,845	499,625	606,186

^a Number of deaths of people whose death certificate mentioned Covid-19 as one of the causes

^b Total deaths minus Covid-19 deaths

from the USA estimates that, on average, nine people are bereaved for every one person who died during the Covid-19 pandemic⁶. For these people, grieving processes have been profoundly disrupted⁷. Social distancing restrictions, lack of visiting in hospitals and care homes, and shielding are likely to compound a sense of loss and guilt.

Complicated grief may be more common as a result of sudden deaths, ICU care, isolation, and disruption of social support networks. This can be associated with physical, psychological and economic problems for bereaved caregivers⁸.

During the pandemic to date, there has been an intense focus on the daily cumulative number of people who have died from Covid-19. Alongside, the policy focus has understandably been on prevention of mortality: through infection control, ICU 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 who have been – and continue to be – affected by dying, death and bereavement has had little scrutiny.

4. Palliative, end of life and bereavement care during the Covid-19 pandemic

The potential for Covid-19 to cause large numbers of deaths in the UK came to national attention on 16th March 2020, when it was suggested that, without mitigation, over 500,000 people could die from Covid-19 in the United Kingdom⁹.

From the start of the pandemic, while the likelihood that many people could die was acknowledged, there was little focus on the need for palliative care. 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 care¹⁰.

In part, the paucity of attention on palliative care as part of the pandemic response, was a result of there being very little evidence to guide these recommendations. A rapid review in March 2020 identified just ten academic papers on palliative care during viral epidemics, most of which were from experiences during the SARS and Ebola epidemics in Asia and Africa¹¹. Just one study from Europe (Italy) was identified.

For a definition of palliative care, see page 14.

4.1 Current evidence on palliative, end of life and bereavement care during the Covid-19 pandemic

Knowledge has increased dramatically since March 2020; we now know much more about palliative, end of life and bereavement care during the Covid-19 pandemic.

Palliative care is an essential part of the Covid-19 pandemic response

For people with severe Covid-19, relief of symptoms and psychosocial support is essential and appropriate. Palliative care should be available in all settings where people with Covid-19 may be cared for, including in hospitals, care homes and homes, and should not be considered only when people are close to death.

Internationally, specialist palliative care teams have experienced a surge in the number of people they care for as a result of the Covid-19 pandemic. However, these teams felt ignored by national and international policy responses and often lacked equipment, staff and medicines¹².

People with severe Covid-19 may deteriorate suddenly, and with rapidly escalating symptoms

Breathlessness, agitation and delirium are common symptoms among people with severe Covid-19^{13,14}. Alleviating these symptoms is an important part of care, irrespective of prognosis or the other treatments being considered¹⁵. While these symptoms usually respond to standard doses of symptom control medication (such as morphine for breathlessness and midazolam for agitation),

syringe pumps (a medical device that delivers low doses of medication continuously through a small needle under the skin) are often needed to ensure symptoms are as well controlled as possible¹³.

The Covid-19 pandemic has changed where people die, impacting on people with and without Covid-19

During the first pandemic wave, there were large increases in the number of people who died in care homes, in hospitals and at home in the UK¹. Deaths in hospices reduced, partly because people chose not to be admitted to hospices because of visitor restrictions. Some people with chronic life-limiting illnesses avoided being admitted to hospices and hospitals because of fear of contracting Covid-19¹⁶.

Palliative care and hospice services implemented rapid changes in response to Covid-19

Internationally, specialist palliative care and hospice services made rapid adaptations in response to the pandemic¹⁷. Frequently, these adaptations were so-called 'frugal innovations'; changes implemented included streamlining, extending and increasing outreach of services, and using technology to facilitate communication.

Many hospice services reported increasing provision of care in the community, where people wanted to be cared for. These adaptations enabled provision of care to people with Covid-19, as well as people with other life-limiting conditions.

Community services innovated rapidly in response to increasing needs

Early in the pandemic, there were rapid changes in practice and policy relating to anticipatory prescribing (prescribing of medication for common end of life symptoms, in advance of clinical need) in the community.

A survey of 261 community practitioners across the UK and Ireland found changes to local guidance and practice¹⁸. Many of these changes related to enabling informal carers to administer end of life medication, to avoid patients at home suffering lengthy delays to symptom relief.

The need for bereavement support has increased

The pandemic has been associated with a profound disruption in dying, death and bereavement experiences⁶. Being severely ill with Covid-19 may lead to distressing symptoms, intensive care admission, and sudden deterioration and death⁷, all of which are associated with increased risk of complicated grief.

The wider circumstances of the pandemic caused interruption of social support networks through social isolation and shielding, disruption to death rituals from visiting restrictions in hospitals and care homes and not being able to attend funerals and wakes¹⁹, and co-occurrence of additional stressors such as economic difficulty, all of which may further disrupt the grieving process. These factors are likely to increase the need for bereavement support²⁰.

Care homes are essential providers of palliative, end of life and bereavement care

Care home deaths in England and Wales increased three-fold during the first pandemic wave¹. While deaths in care homes have been much scrutinised, most of this scrutiny has been on infection control and prevention²¹. Understanding experiences of dying, death and bereavement in care homes, and provision of palliative and end of life care, has been relatively unexplored.

The needs of people from ethnic minorities and disadvantaged groups require further exploration

While inequalities in relation to ethnicity and socioeconomic group have been well described during the pandemic, less is known about how ethnicity and deprivation influence care for people who are dying and those bereaved²².

Palliative care is treatment, care and support for people with life-limiting illnesses, and their families, friends and carers. Palliative care aims to identify and relieve the symptoms and concerns that people living with life-limiting illnesses experience, whether physical symptoms such as breathlessness or pain, or emotional, social or spiritual concerns. It is estimated that more than 75% of people who die in the UK have palliative care needs^{23, 24}.

Palliative care may be delivered by a range of health professionals, including general practitioners and community nurses, and by a wide range of services and care providers.

The term '**specialist palliative care**' is used to describe care that is delivered by multidisciplinary teams for whom this is the main focus of their role. Specialist palliative care teams work across community, acute hospital and hospice settings. As well as providing direct hands-on care to people living with life-limiting illnesses and their families and carers, specialist palliative care teams have an important role in indirect care through providing education and training to health and care professionals.

A common misunderstanding is that palliative care is only relevant when people are dying. However, the relief of suffering is an essential component of care for all patients with a potentially life-threatening illness and can be provided alongside other medical treatments.

5. Patterns of mortality in the UK during Covid-19

People's experience of dying, death and bereavement are profoundly influenced by i) changes in place of care and death, and ii) changes in services received.

In this section, we report patterns of mortality, including the place of death in England, Wales, Scotland and Northern Ireland during the Covid-19 pandemic to 12th February 2021. We include people who died from Covid-19 and those who died from other causes. Full details of methods are given in Annex 2.

5.1 Deaths in the UK: baseline deaths, deaths due to Covid-19 and additional deaths

To understand patterns of mortality during the Covid-19 pandemic in the UK, we defined the following mortality categories, consistent with a previous study of mortality patterns in England and Wales¹:

Average deaths – Deaths that would be expected to occur in a typical year without a pandemic, calculated using the average number of deaths that occurred in the same period from 2015–2019.

Baseline deaths – Deaths officially registered during the pandemic up to and including the number of expected deaths, but excluding deaths certified as with or from Covid-19.

Covid-19 deaths – Deaths officially registered with Covid-19 on the death certificate. This includes deaths where Covid-19 was suspected but not confirmed through a laboratory test.

Additional deaths – Deaths officially registered that are in excess of average deaths but are not accounted for by deaths certified as being from Covid-19. This group might include deaths due to Covid-19 but not recorded as such, or deaths indirectly related to the pandemic – for example, through avoidance of hospital care.

Weekly deaths in the UK peaked during week 16 of 2020, from a baseline of 11,854 deaths to a total 24,691 deaths, of which 9,509 were certified with Covid-19 on the death certificate.

Following the first pandemic wave, the number of deaths remained close to baseline with very few Covid-19 or additional deaths for several months.

Towards the end of 2020, the number of Covid-19 deaths started to rise, and total deaths once again rose above average.

There were fewer additional deaths during the second wave, likely as a result of more comprehensive testing.

Note that dips in average and reported deaths in weeks 22, 35 and 52/53, correspond with bank holidays, and are a reporting artefact.

Figure 1 shows all deaths registered in the UK during the Covid-19 pandemic between week 11 of 2020 and week 6 of 2021 (7th March 2020 to 12th February 2021 in England, Wales and Northern Ireland, and 9th March 2020 to 14th February 2021 in Scotland).

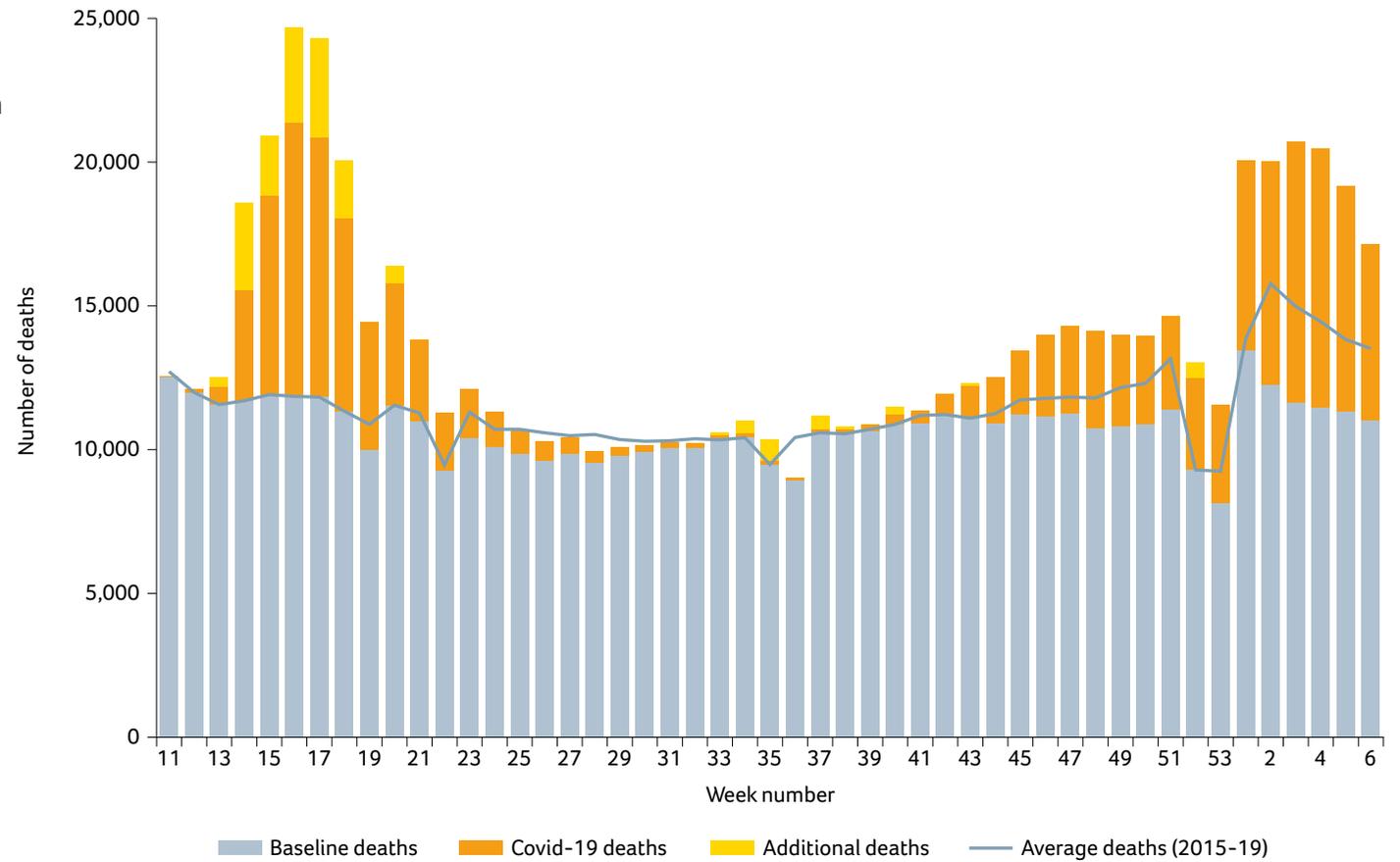


Figure 1

Data for the four nations show similar patterns. In the following graphs, numbers of deaths have been standardised per 100,000 population to make them more comparable. While the mortality patterns are similar in England, Wales, Scotland and Northern Ireland, the total numbers of deaths are smaller in Wales, Scotland and Northern Ireland, giving a more 'noisy' baseline.

Figure 2 shows all deaths registered during the Covid-19 pandemic in the nations of the UK between week 11 of 2020 and week 6 of 2021 (7th March 2020 to 12th February 2021 in England, Wales and Northern Ireland, and 9th March 2020 to 14th February 2021 in Scotland).

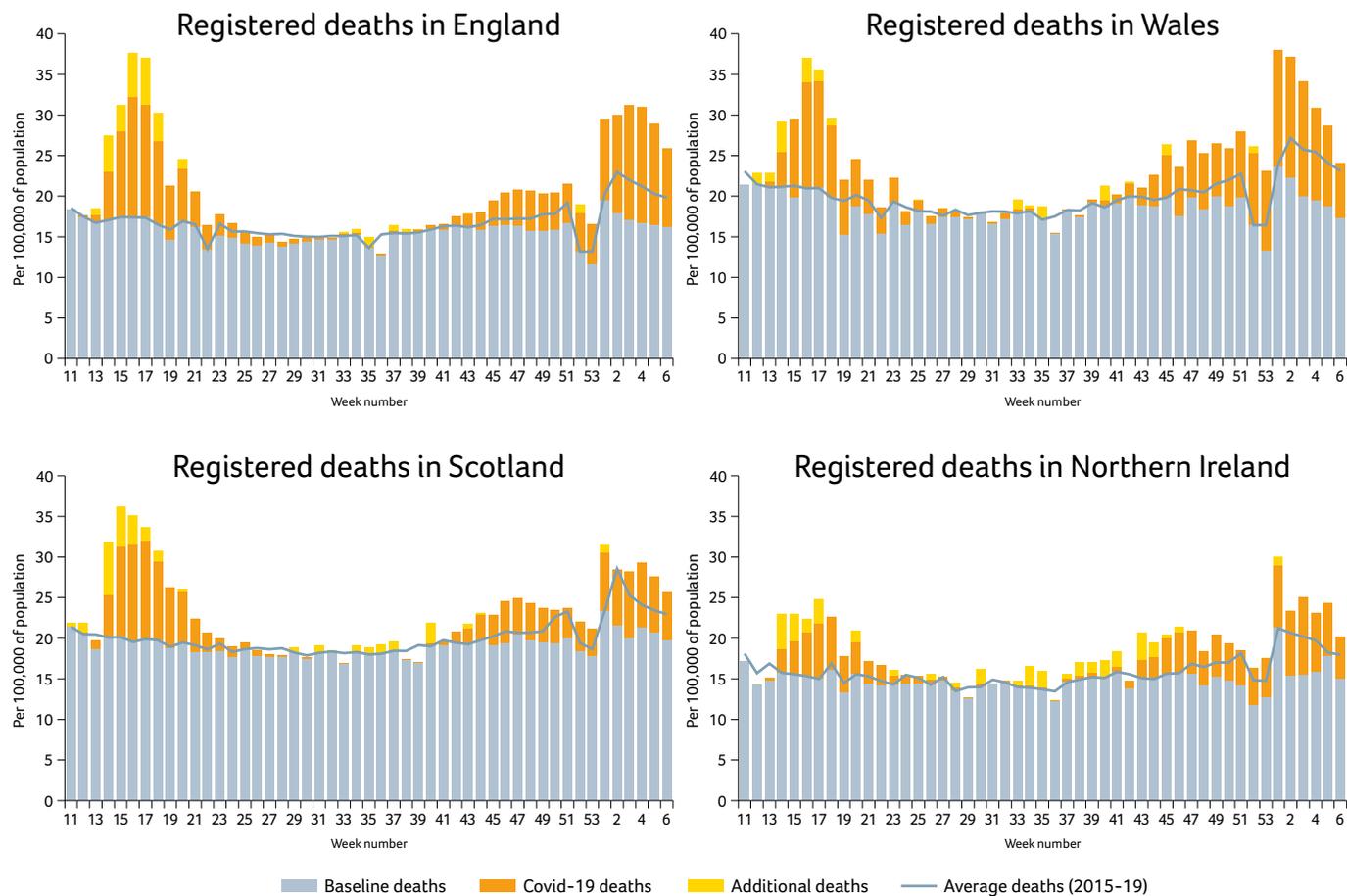


Figure 2

5.2 Change in place of death (total deaths) compared to previous five years, for England, Wales, Scotland and Northern Ireland

To understand the impact of the Covid-19 pandemic on where people die in the UK, the weekly number of deaths in hospitals, at home, in care homes and in hospices was examined. Deaths were identified as those due to Covid-19 and those from other causes. To enable comparison across nations, deaths were standardised per 100,000 population. The dark grey line indicates the average number of weekly deaths in that setting (2015-2019).

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 many deaths certified as due to Covid-19.

Figure 3 shows deaths in hospitals per 100,000 population between week 11 of 2020 and week 6 of 2021 (7th March 2020 to 12th February 2021 in England, Wales and Northern Ireland, and 9th March 2020 to 14th February 2021 in Scotland).

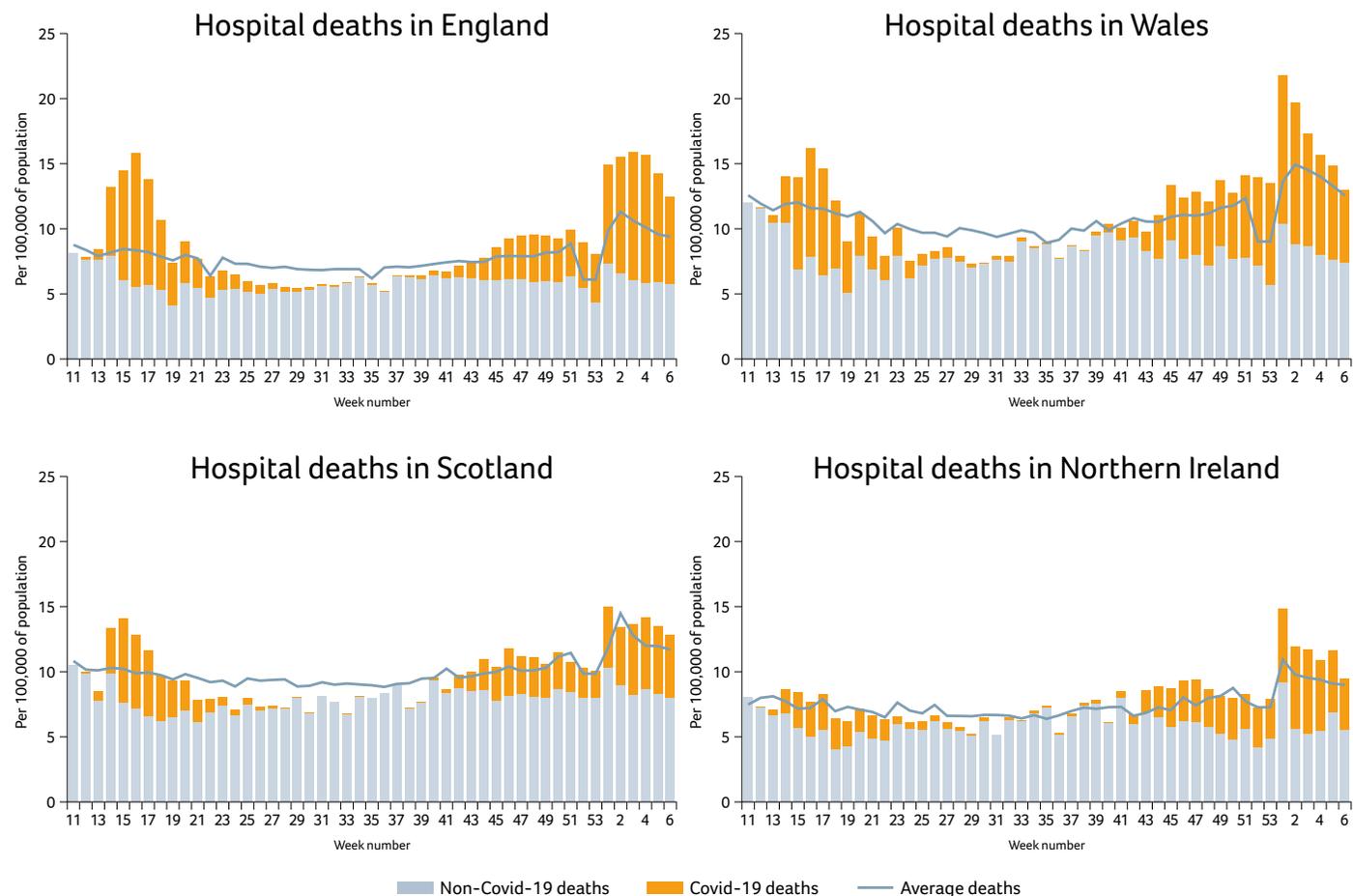


Figure 3

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 registered cause of death for deaths at home, with little difference in this between the first and second pandemic waves.

Figure 4 shows deaths at home per 100,000 population between week 11 of 2020 and week 6 of 2021 (7th March 2020 to 12th February 2021 in England, Wales and Northern Ireland, and 9th March 2020 to 14th February 2021 in Scotland).

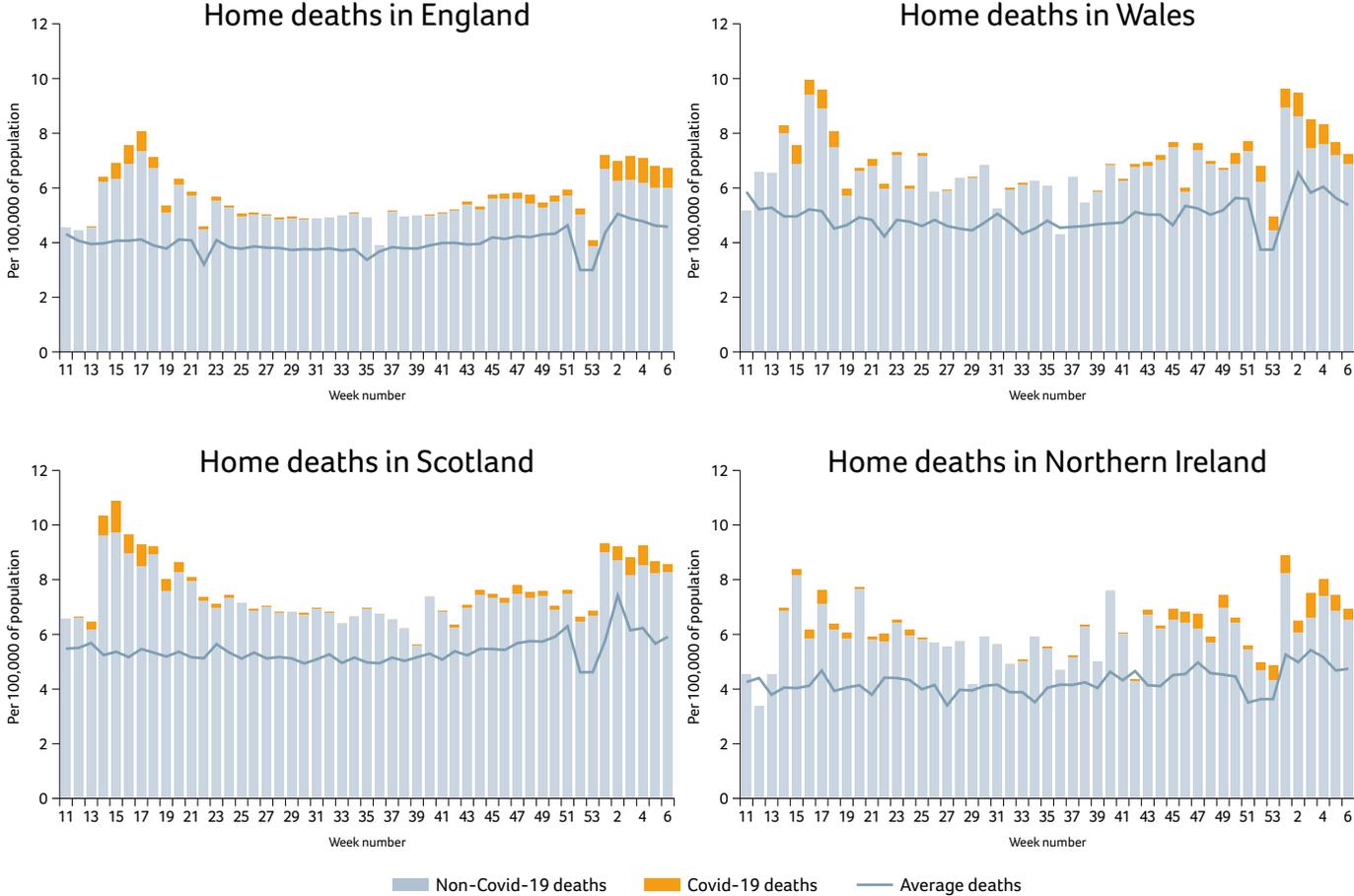


Figure 4

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 the increase was less than during the first wave.

Figure 5 shows deaths in care homes per 100,000 population between week 11 of 2020 and week 6 of 2021 (7th March 2020 to 12th February 2021 in England, Wales and Northern Ireland, and 9th March 2020 to 14th February 2021 in Scotland). In Scotland, hospice deaths are included with care home deaths.

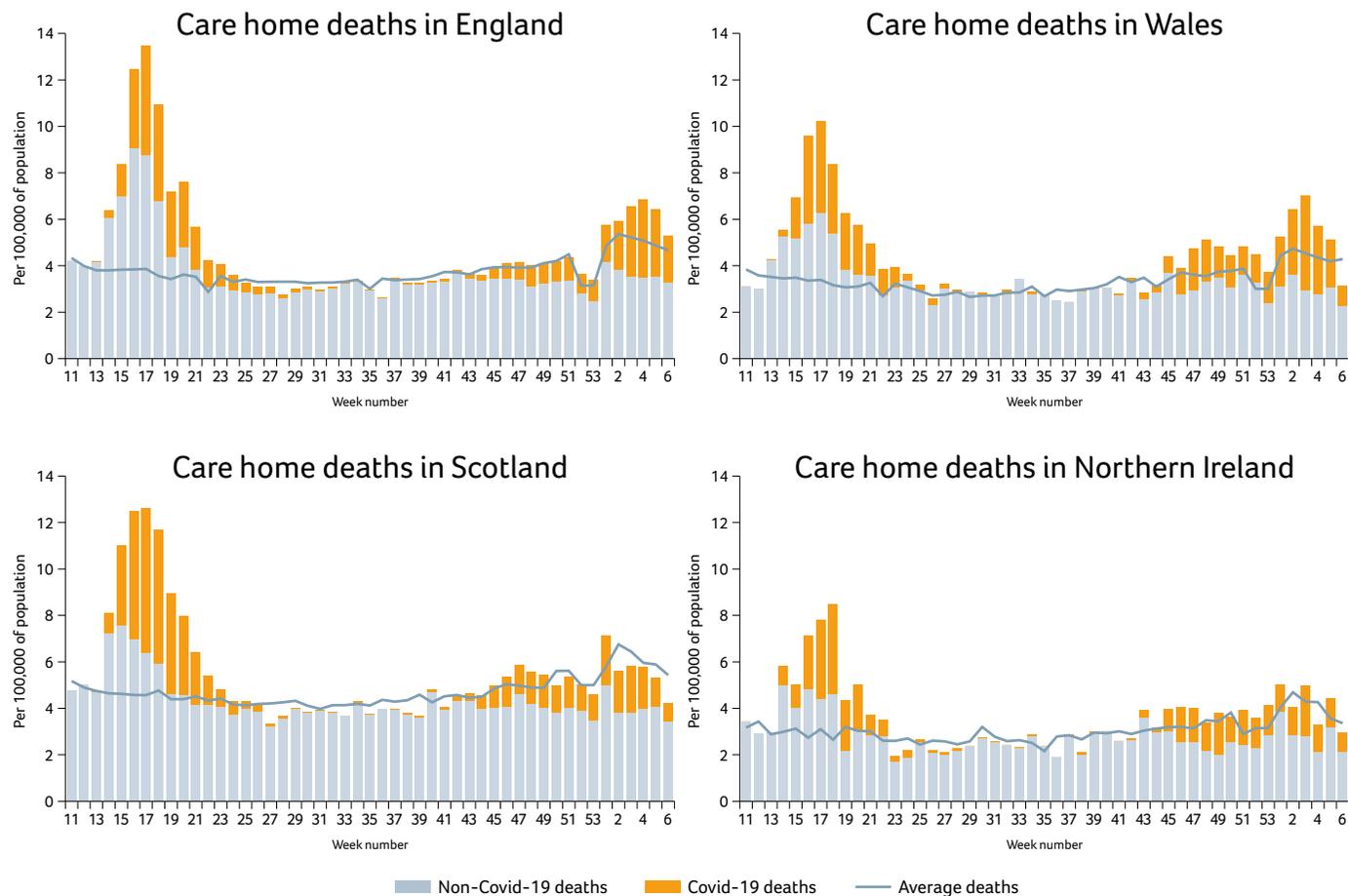


Figure 5

In contrast, from the first weeks of the pandemic, hospice deaths fell below baseline levels and this was sustained for most of 2020. A small proportion of deaths occurring in hospices were certified as caused by Covid-19. Note that disaggregated data on hospice deaths are not available for Scotland.

Figure 6 shows deaths in hospices per 100,000 population between week 11 of 2020 and week 6 of 2021 (7th March 2020 to 12th February 2021 in England, Wales and Northern Ireland). In Scotland, hospice deaths are included in other place of death categories, so not reported here.

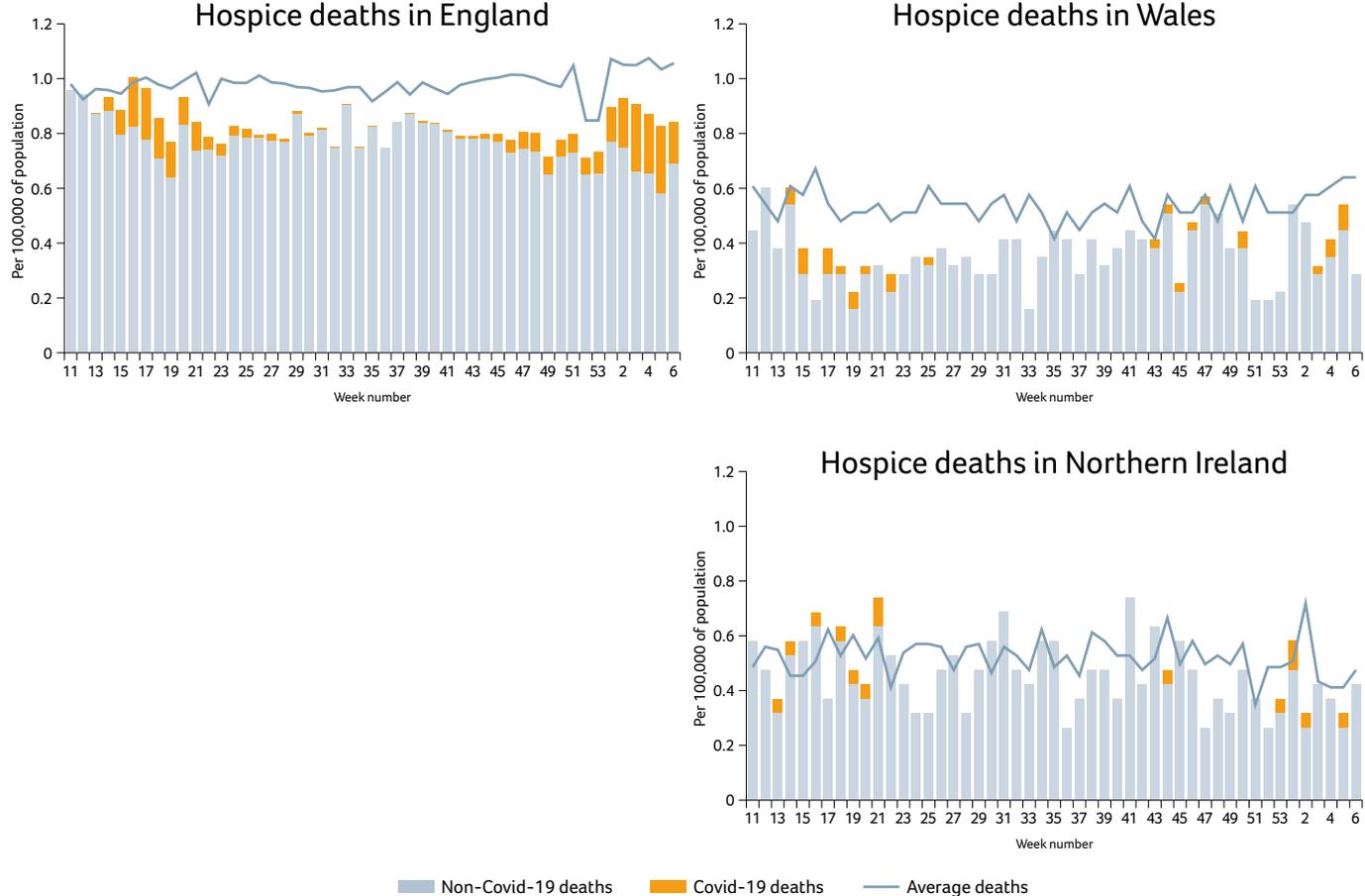


Figure 6

6. Activity of specialist palliative care and hospice services during the first wave of Covid-19 in the UK

The place of death only represents one aspect of people's experience of dying and death. While hospice deaths fell during the Covid-19 pandemic (as described in section 5.2), this does not reflect the total activity of hospice and palliative care services.

In this section, we use data from the CovPall study to report how hospice and palliative care services in the UK responded to the challenge of providing care during Covid-19.

The CovPall study is a multinational observational study of palliative care during the Covid-19 pandemic that aims to understand the response of, and challenges faced by, palliative care services (see Annex 1 for information).

As part of the CovPall study, an online survey was distributed electronically to palliative care and hospice providers between April and July 2020. Any palliative care service, whether in hospital, community or hospice settings, was eligible to submit data. For more details on the CovPall survey methods, see Annex 2.

Findings from the CovPall survey focusing on innovation¹⁷, advance care planning²⁵, and the international response¹² have been reported elsewhere. For this report, we present previously unpublished data on (i) the intensity of activity of hospice and palliative care services in the UK, and (ii) the challenges faced by UK services in terms of access to essential medicines, equipment (including PPE) and staff shortages (section 7).



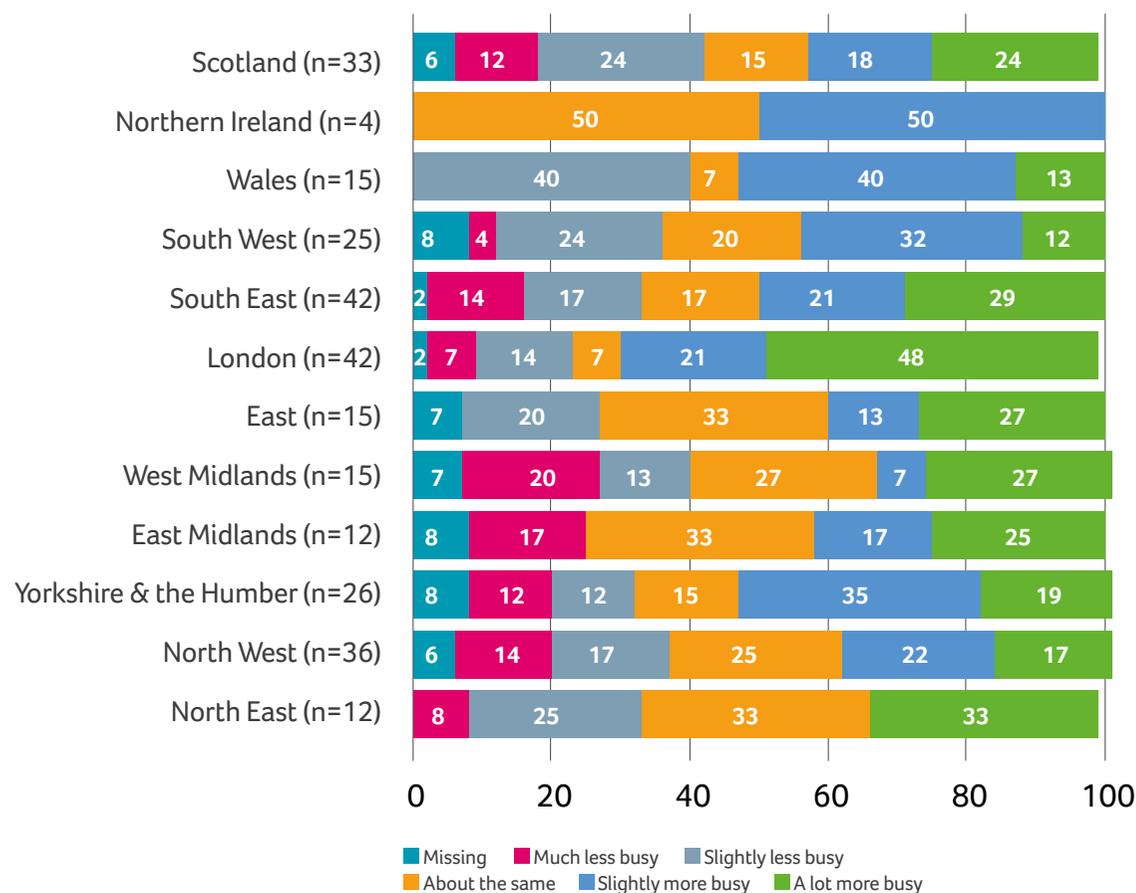
6.1 Intensity of activity of hospice and palliative care services in England, Wales, Scotland and Northern Ireland

The CovPall survey included data from 277 UK services: 225 in England (12 North East, 36 North West, 26 Yorkshire & The Humber, 12 East Midlands, 15 West Midlands, 15 East, 42 London, 42 South East, 25 South West), 15 in Wales, 33 in Scotland and 4 in Northern Ireland. Half of services were charity managed (143, 52%); 103 (37%) were publicly managed.

The CovPall survey asked hospice and palliative care providers, “Would you say overall you are more busy or less busy than before the Covid-19 pandemic?” on a five-point scale, and invited free text responses to the subsequent question, “Why is this?”

Services from all UK nations and English regions reported being either slightly more or a lot more busy than before the Covid-19 pandemic. The region with the largest number of services reporting being more busy 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 a lot more busy were the North East and West Midlands (33% and 34% respectively).

Figure 7 shows activity of hospice and palliative care services in Scotland, Northern Ireland, Wales and regions of England.



Due to rounding, percentages may not total to 100%.

Figure 7

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 community services tended to report more busyness than those providing inpatient hospice care.

Many respondents to the survey provided more than one service type.

Figure 8 shows activity of hospice and palliative care services in the UK according to the type of service provided

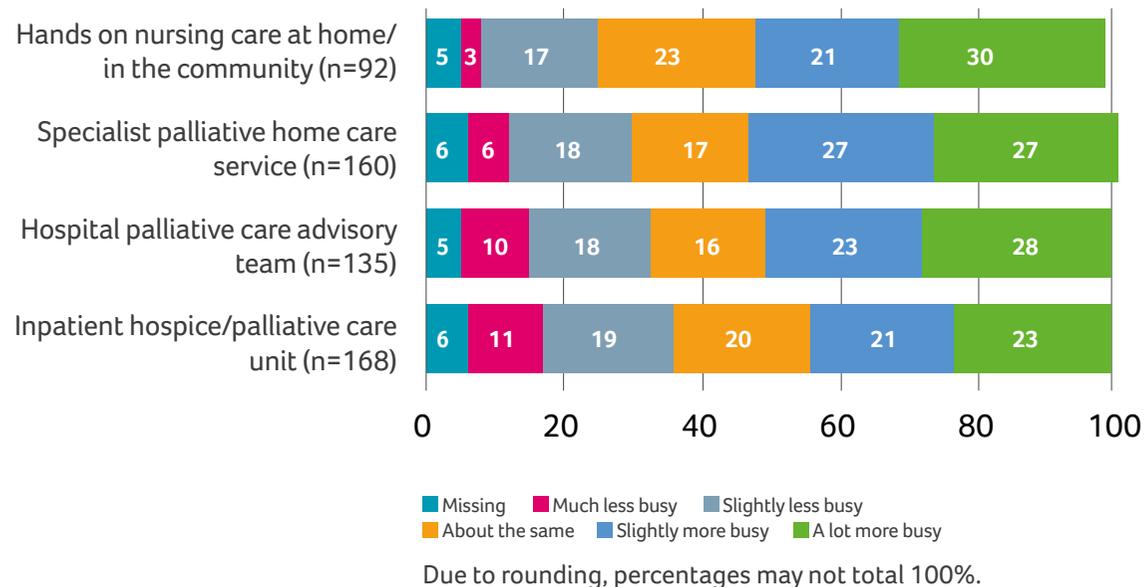


Figure 8

6.2 What contributed to hospice and palliative care services' activity?

Analysis of free text comments identified themes that contributed to services' activity and additional workload during the Covid-19 pandemic.

6.2.1 Shifting resource in response to escalating needs

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.

"We quickly realised [there] would be increased demand for palliative care, and opened a palliative care ward with 24 beds, and had consultant Palliative Medicine ward rounds 7 days a week." (Yorkshire & The Humber)

"New 7 day week service, consultant and CNS on call... Nursing 10am - 8pm Consultant 10am - 10pm." (Northern Ireland)

"New field hospice set up on site." (London)

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.

"We merged the community service with hospice at home to deliver care to all patients 40% AKPS or less." (Wales)

"Duties extend[ed] to running general medical wards and forming part of ward cover on top of usual palliative care on call. [Palliative care doctors] part of clinical decision making group for difficult cases." (London)

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.

"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)

6.2.2 Educating, upskilling and supporting

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.

"We have also been engaging in much more education to healthcare professionals across all settings, including the care homes." (Wales)

"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)

"Hospital teams were initially quieter, but used time to intensively educate." (Wales)

Palliative care services also took on broader roles in providing psychological support, and debriefing/ reflection sessions for members of staff.

"We visited all the wards with patients who have Covid-19 to meet staff and offer support, as determined by the staff members. This has included: teaching – symptom control, including end of life care. Debrief/reflection sessions. Communication skills, particularly supporting communication over the telephone. We contact medical staff on all [Covid-19] cohort wards on a daily basis to discuss care of any patients who are dying and offer to see where needed." (Yorkshire & The Humber)

"When the [service] was less busy [the staff] significantly increased their education provision and psychological support." (South West)

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.

"We have also developed resources to support staff – Guidance for the care of a patient dying from Covid-19; resources for telephone communication; Care after death; Chaplaincy staff support." (Yorkshire & The Humber)

“We have been working to develop and then implement guidance and teaching to others and are developing new integrated care pathways e.g. bereavement with other providers.” (London)

6.2.3 Telephone and remote working

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.

“We have found an increased number of calls from patients requiring general psychological support as they struggle with the uncertainty of the situation.” (Wales)

“Outpatient telephone reviews instead of outpatient clinics more time consuming and challenging. Frequently more support required than usual – patients and their families have struggled with isolation.” (North West)

Considerable time was spent supporting people to remain in their usual place of care, and avoiding hospital admissions where possible.

“We are supporting patients to remain in their usual place of care, home or care home. Patients/carer have been more psychologically distressed, and this is requiring more prolonged non face-to-face consultations.” (North East)

Supporting patients to remain at home required integration with other community services, such as community pharmacies. One service reported helping people at home obtain food.

“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 name pharmacies. Arranging Dosette boxes.” (North West)

“Increase in social support needed at home such as fetching medications, food parcels etc.” (Yorkshire & The Humber)

7. Challenges faced by specialist palliative care services during the first wave of Covid-19 in UK

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 others.

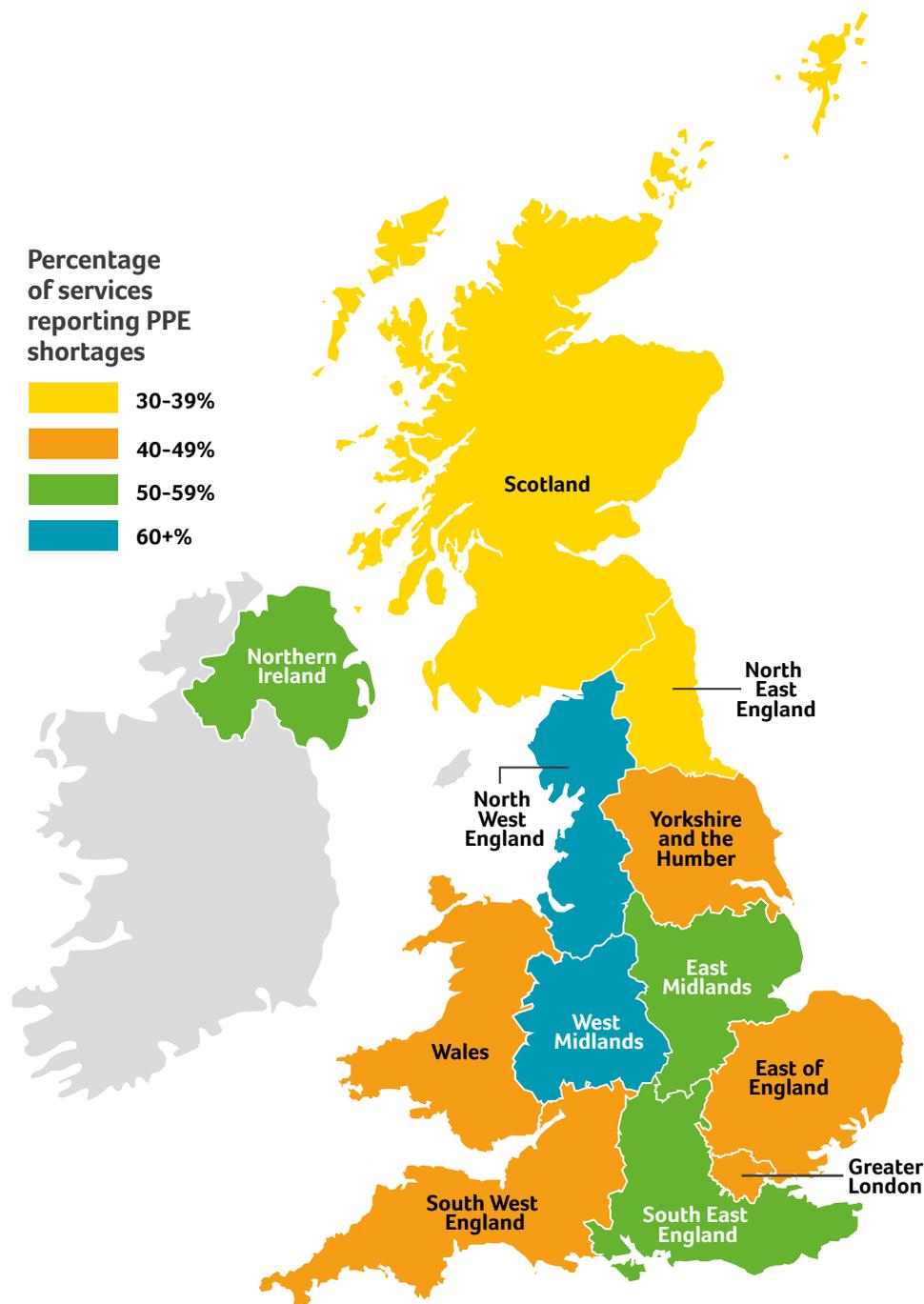
In this section, we report on the challenges faced by UK services, specifically relating to shortages of Personal Protective Equipment (PPE), other equipment, medication and staff. As in section 6, the data in the section come from the CovPall survey, which was undertaken between April and July 2020.

7.1 Shortages of Personal Protective Equipment (PPE)

Shortages of PPE were experienced by 33% to 61% of UK services, most commonly in the North West of England and the West Midlands. A particular issue was not being recognised as ‘front line NHS’.

“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)

“Masks and gowns – as we are not classed as ‘frontline NHS’ we were unable to access from our local NHS board. this was less than satisfactory for 7 weeks, however this has now been resolved.” (Scotland)



PPE shortages included 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 fitting masks was also limited.

"All types of PPE (at different stages because of total lack of co-ordination) access to cleaning, waste disposal products and body bags." (South East)

"Initially difficulty accessing all items of PPE, this is now resolved. Difficulty accessing fit testing for FFP3 masks. Also difficulty getting advice re donning and doffing of PPE within the community setting – all training has been focused around hospital setting." (Wales)

Services adopted creative approaches to procuring PPE, through social media appeals and local networks.

"Tried to liaise with procurements services, NHS suppliers/CCG's/local hospitals, appealing to local community through social media liaising with community groups and other organisations. Drawing on local networks available to us e.g. GP surgeries, schools, dentists, vets, local hardware companies, beauticians." (South East)

Procuring adequate PPE was extremely time consuming and reduced the ability of services to provide direct patient care.

"FFP2 masks initially, now gowns & FFP3 masks, only half of regular order delivered for aprons & gloves at one point. Multiple daily phone calls from ward manager & deputy, CEO raised it at CCG & with MP, ongoing daily phone calls." (West Midlands)



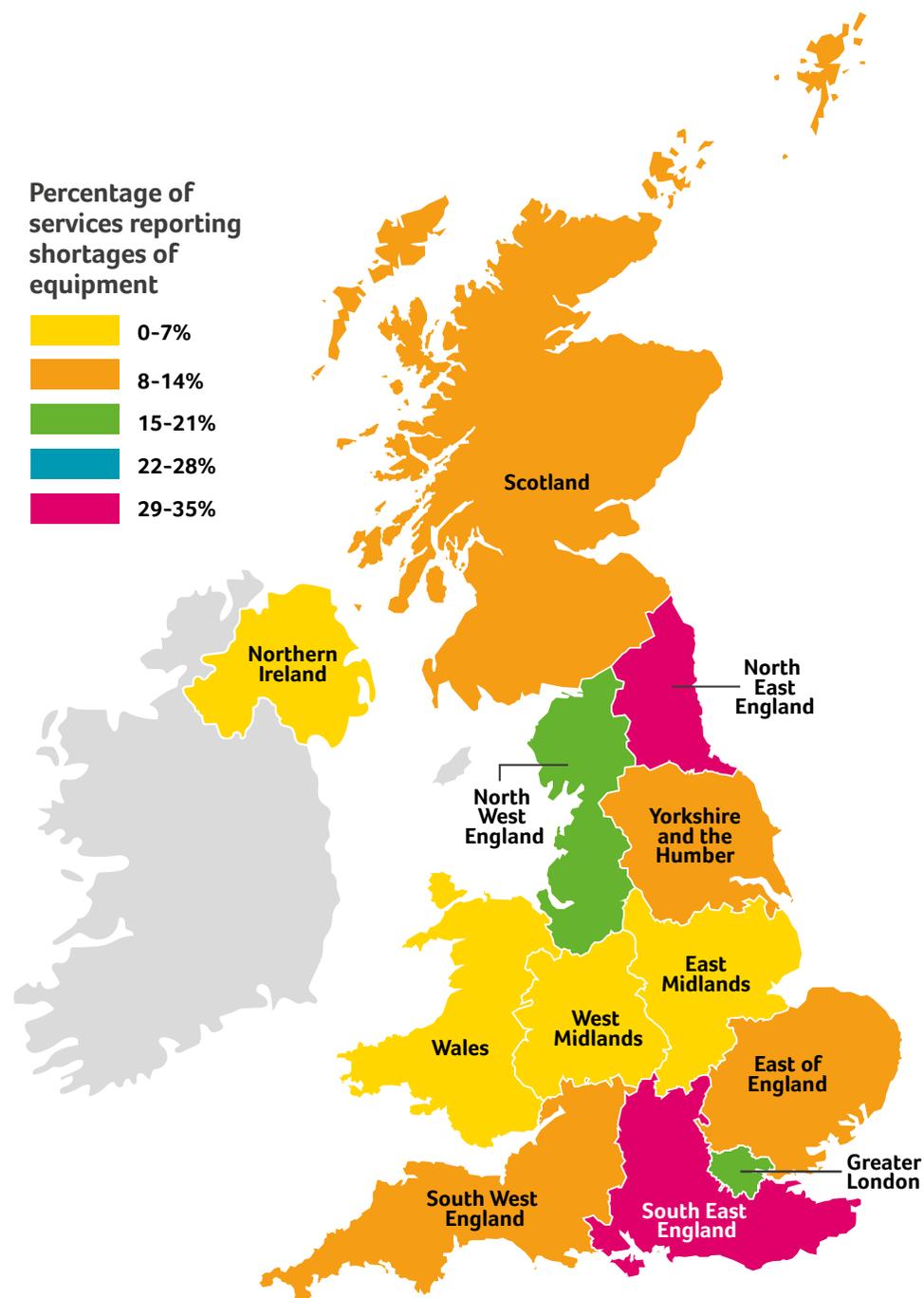
7.2 Shortages of equipment

Relatively fewer services reported shortages of equipment, though this was most common among services in the North East and South East of England. 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. In some cases, services did not have enough syringe pumps to address patient need, meaning that some patients may not have had good control of their symptoms.

“Syringe pump lines and butterfly needles - ordered on NHS supplies, but not delivered as PPE deliveries were the priority. We borrowed from other wards and used other products.” (North West)

“Shortage of syringe pump lines. Issues with version 3 McKinley T34 syringe pumps with very short battery life (<24h).” (Scotland)

“We ordered 20 additional T34 syringe drivers early March 2020 but due to supply issues these did not arrive. In reality there were only 2 days during peak when we did not have sufficient T34 syringe drivers for need.” (London)

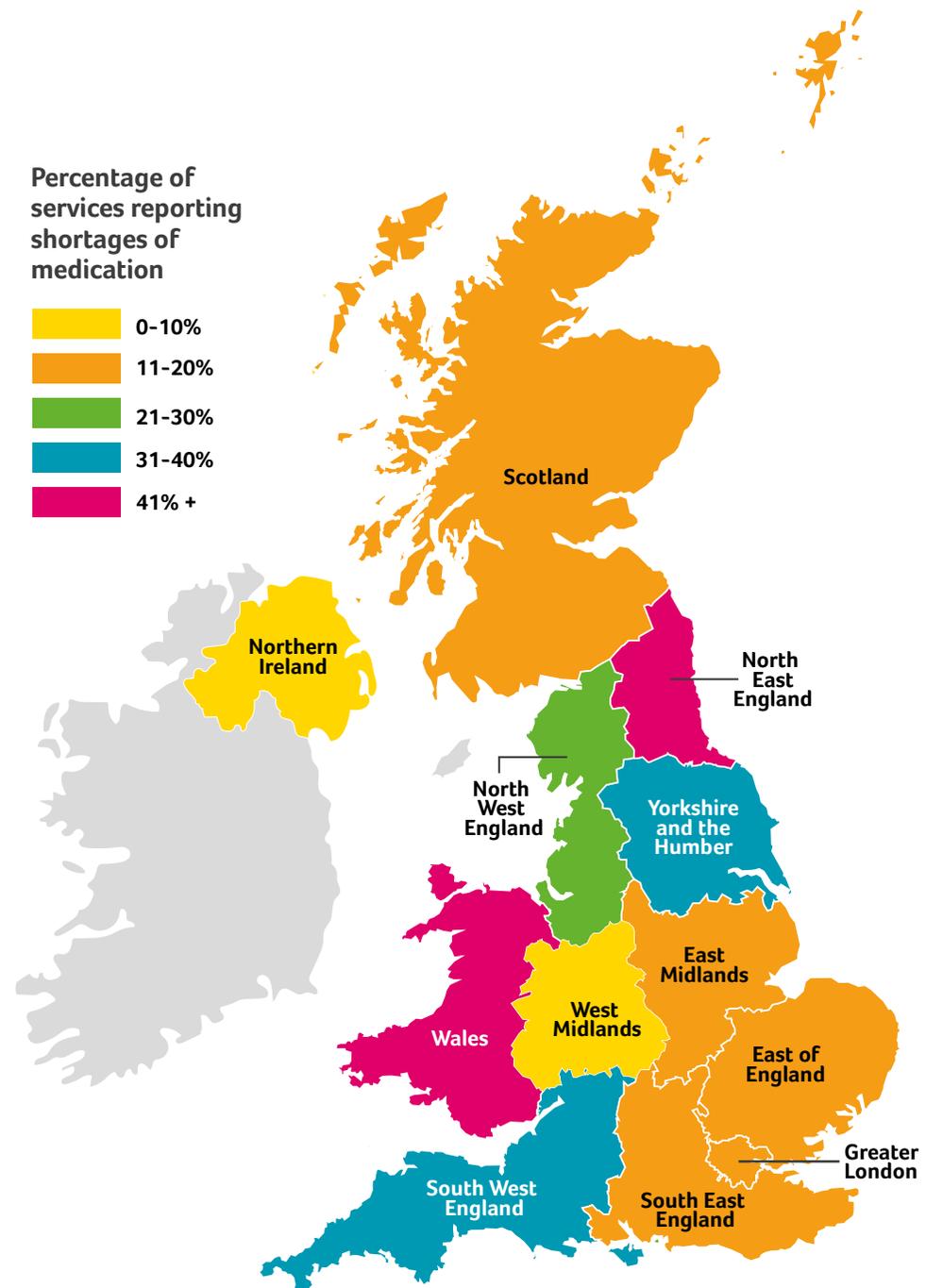


7.3 Shortages of medication

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. Among the 63 services that reported shortages of medication, levomepromazine (35), midazolam (16) and alfentanil (11) were most commonly mentioned.

“At the height of the pandemic [we] had difficulties in the community accessing just in case injectable medications including morphine & haloperidol. Difficulties obtaining methadone for injection in [the] community.” (East Midlands)

“We have received a memo to avoid use of alfentanil on the general wards as ITU were in need and there was a shortage. However we have not yet needed to consider this drug (so far) as a therapeutic option.” (Wales)



7.4 Shortages of staff

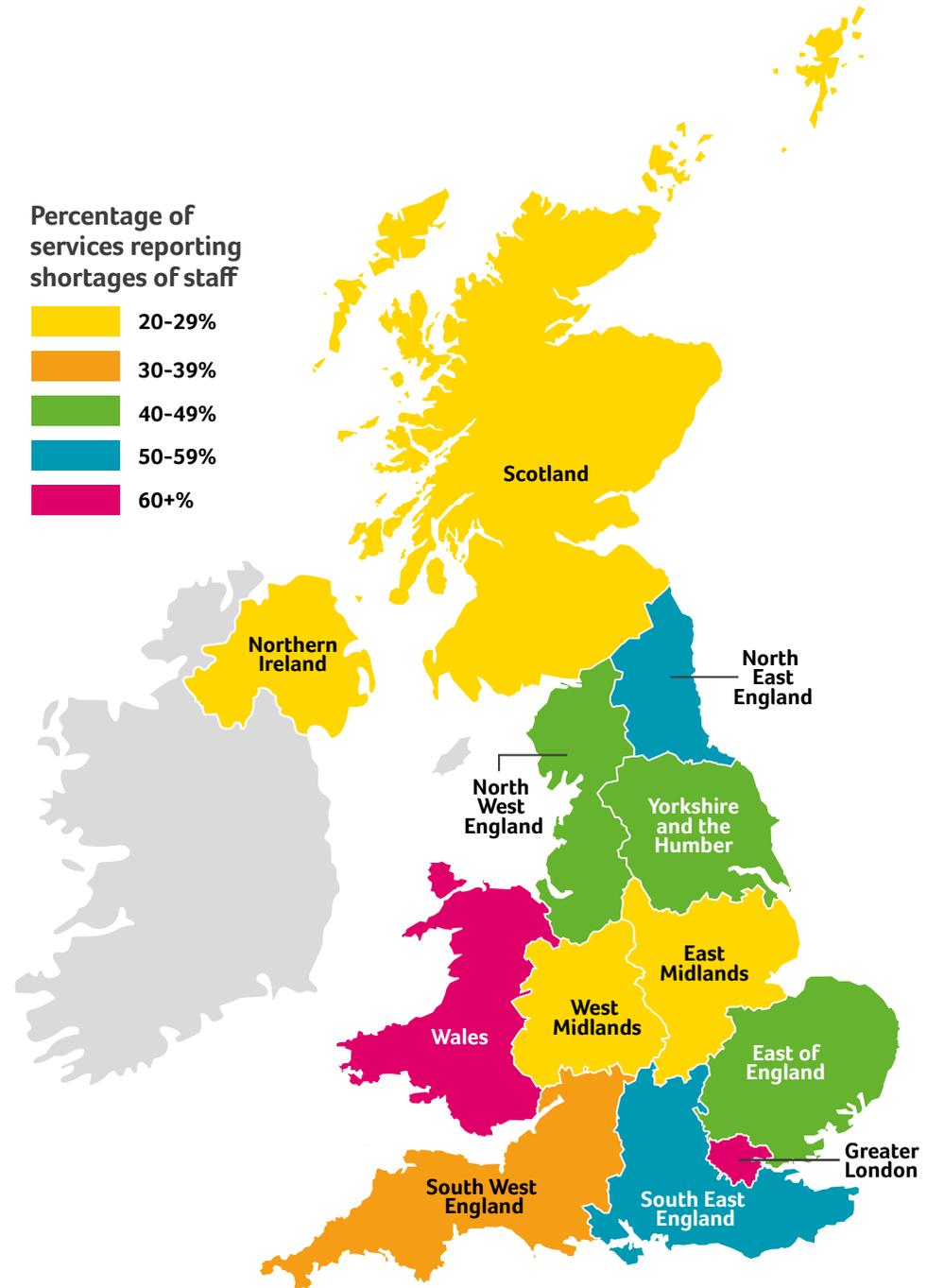
Staff shortages were most common in Wales and London, where 60% of responding services reported staff shortages. Shortages were a result of shielding, self-isolating and sickness. In some cases, staff were redeployed from palliative care into other roles.

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

“Ward staff cohort had a period of 42% sickness. Therapy team, community team and doctors all had a period of high sickness rates during last 2 months. One staff member on ITU. Various staff took retirement.” (South West)

Access to Covid-19 testing in hospice settings was limited, which compounded staff shortages.

“About 20% staff absent through the whole crisis due to shielding, furlough, self isolation and actual illness. Local hospital were nearly first to set up testing and we have been lucky enough to have access very rapidly to tests for staff or family members. This has helped to get some people back to work. People have been redeployed into other roles.” (North West)



8. Changes in community palliative and end of life care provision

Sections 5, 6 and 7 highlighted the sustained increase during 2020 of people dying at home and described the shift of specialist palliative care services into the community to address these changing needs. Here, we describe how primary healthcare services have responded to the need for palliative and end of life care during the pandemic.

In this section, we draw on data from a survey of primary healthcare professionals co-led by Dr Sarah Mitchell and Dr Catriona Mayland (University of Sheffield), based on the CovPall survey. The data are currently published as a pre-print and are undergoing peer review¹⁶.

Mitchell et al carried out a web-based, UK-wide questionnaire survey of GPs and community nurses during September and October 2020. Responses were received from 559 individuals (387 community nurses, 156 General Practitioners and 16 unspecified role), from all regions of the UK.

Respondents to the survey reported increased involvement in provision of end of life care in the community during the pandemic. Over half of respondents (296 of 557 who responded to this question, 53%) said that they had cared for patients who had died with confirmed Covid-19, and over two-thirds (371 of 554 responses, 67%) 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 (322 of 554 responses, 58%) said they provided ‘a lot more’ or ‘a bit more’ end of life care than usual. For GPs, this involved more use of remote consultations and involvement in advance care planning.

Community nurses were more likely to report providing face-to-face care, symptom control, bereavement support and support for family carers. Respondents also reported managing patients with very complex needs who, pre-Covid-19, might have been admitted to hospital or a hospice:

“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)

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 for services. One community nurse wrote:

“I feel more patients stayed at home for non-Covid related end-of-life care. Which was good. Think the staff that were at the front line went above and beyond to keep patients at home. Patients and families did not want admission as then they could not see family etc. and then die without family there. Staying at home was seen as best option for most patients and families, even if it was tiring.” (District Nurse, England)

9. Impact of Covid-19 pandemic on experiences of bereavement

The Covid-19 pandemic has profoundly disrupted dying, death and bereavement experiences.

People bereaved during the pandemic (whether because of Covid-19 or another illness) are at risk of experiencing complicated grief, as a result of deaths that were sudden or required intensive care, because of disruption of grieving rituals and social networks, and isolation in bereavement. This poses physical, psychological and economic risks to the bereaved.

A study from the United States has estimated that for each person who dies from Covid-19, nine people will experience the death of a close relative (a grandparent, parent, sibling, spouse or child)⁶. Here we report on how Covid-19 has affected the experience of bereavement in the UK.

In this section, we draw on two UK-wide surveys. First, a survey of people who have experienced bereavement during the Covid-19 pandemic, led by Dr Lucy Selman (University of Bristol) and Dr Emily Harrop (Cardiff University)²⁶. Second, a survey of practitioners in the United Kingdom and Ireland, led by Dr Caroline Pearce and Dr Stephen Barclay (University of Cambridge)²⁷. Both surveys have been published elsewhere, and key information from those publications is summarised here.

9.1 Experiences of people who have experienced bereavement during the Covid-19 pandemic

Drawing on data from 532 bereaved respondents from across the UK, Harrop et al found negative end of life and bereavement experiences were common: 56% of respondents said they were unable to visit their loved ones prior to death, 67% said they were unable to say goodbye as they would have liked, and 67% experienced social isolation and loneliness²⁶.

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

In free text comments, respondents described more positive care experiences. These included a sense that staff were doing their best and showed compassion and kindness. These experiences were often associated with hospice or specialist palliative care involvement.

In this study, over half of participants demonstrated high or severe levels of overall vulnerability in grief. More overwhelming grief and higher support needs were particularly associated with deaths that occurred in hospital. Including family members in decisions about the care of their loved ones decreased family members' emotional support needs and their vulnerability in grief.

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.

9.2 Experiences and views of practitioners concerning changes in bereavement care during the Covid-19 pandemic

The survey led by Pearce and Barclay explored the delivery of care for people bereaved during Covid-19²⁷. This was an online survey of the experiences and views of practitioners carried out between 3rd August and 4th September 2020. In total, there were 805 respondents from practitioners working in hospice, community and hospital settings across the UK and Ireland.

Respondents reported major changes in their 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.

"We were not using video call before Covid and rarely offering counselling by phone, but this is now primary to our service." (Hospice Bereavement Service Manager)

Frequently reported were the impact of restrictions on funeral arrangements; reduced opportunities for face-to-face interaction produced difficulties when identifying bereaved people who might need support.

“Visiting restrictions have meant much less face to face contact. For example I have talked with a spouse in the car park at social distance.” (Palliative Medicine Doctor)

Similar to the survey by Harrop et al, this study identified differences in perceptions of loss and need between people bereaved as a consequence of Covid-19 and those bereaved as a result of other conditions.

“We’ve been unable to see as many family members face-to-face as we normally would, so it’s been harder for us to identify people.” (Hospice Social Worker)

“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)

The need to manage more complex forms of grief as a result of the pandemic was identified.

“These are just more difficult cases to tackle, and the isolation – not having been able to visit a loved one in hospital who’s subsequently died – exacerbates this.” (General Practitioner)

“We have at times entered territory/topics that are new and we do not have the answers to.” (Hospice Family Services Manager)

The survey also highlighted that the need for 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.

“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)



10. PPI reflections on this report

Section 9 highlighted that the need for bereavement support is not only relevant to people whose loved ones die from Covid-19 and is not limited to people bereaved during the Covid-19 pandemic.

Here, we provide a PPI member's reflections on this report.

The pandemic has impacted on the grief experiences of people bereaved from all causes, during and prior to the pandemic. Here, Jenny McAleese tells her story and reflects on the findings of this report.

Kevin was, is and always will be the love of my life. We were soul-mates and just got each other, despite the age-gap of 16 years. We brought out the best in each other, loved each other's company and made each other laugh: we were a great team. Kevin taught me how to love, how to live and how to die.

Kevin was diagnosed with terminal prostate cancer in May 2016. His diagnosis came completely out of the blue and turned our world upside down.

Nothing prepares you for the devastating news that the person you love more than any other is terminally ill. Equally, nothing prepares you for the gut-wrenching agony of grief, even if the death is expected. I miss him so much it sometimes quite literally hurts, as if someone is squeezing my heart.

Kevin spent just over two weeks in our local hospice before he died. I spent most of every day by his side. He had always been very clear that his preference was to die in the hospice, so I was relieved that his wish had been met.

Two days before Kevin died, I was able to get into bed with him and just snuggle up for an hour with the door closed and our favourite music playing: this was a precious hour I'll never forget. After Kevin died, a friend and I sat with him quietly and that too was an important intimate time.

For the first year after Kevin died, I kept myself busy. I went to my yoga classes, began body balance classes and even started playing tennis again. I went out for coffee, breakfast or dinner with whichever friend invited me, went to stay with friends and family, had people to stay with me. I went to films, concerts and plays. I found being at home on my own unbearable.

Alongside the social activities, I had some grief counselling and also attended a fortnightly Bereavement Group, where I met many of the people I had known in the Carers' Group. We met in a local café and shared laughter and tears in equal measure, those further on in the grieving process supporting and encouraging those of us at the beginning of the journey. It wasn't long before I was arranging evening meals out for the group; we all struggled to eat on our own.

My sister came to stay with me for the first anniversary of Kevin's death, 13th March 2020. At this point, I felt relieved and rather proud of myself for having survived the first year. I was blissfully ignorant of the fact that the second year is harder than the first and that Covid was about

to deny me access to all the people and activities that had enabled me to survive this first year.

I have no idea how I would have coped with Kevin's illness, his deterioration or with bereavement had these occurred during the restrictions imposed on us by the Covid-19 pandemic. Kevin would not have been able to access the care and support he needed, and I doubt that, without this and time spent with family and friends, he would have been able to remain as positive as he did and live as long and as well as he did. As for coping with my grief in isolation, that doesn't bear thinking about.

Sometimes, during this pandemic, it feels as if only Covid-19 deaths have been counted, or have mattered. What about all the people who have died from other illnesses, and those bereaved? This report shows that there were more than six times as many non-Covid deaths as Covid ones in 2020, yet the focus remains on Covid. It saddens me that people who have been bereaved from conditions other than Covid-19 felt that they were less entitled to support.

For me, this report has important messages.

First, society needs to face up to death – to talk about it, normalise it and ensure that people have the opportunity to express their wishes, and plan for the death that they want. I feel so glad that Kevin was able to have the death that he wanted. It has brought me much comfort. Sadly,

during Covid, many people have not had this opportunity.

Second, we hear the NHS strategy frequently referring to living well and ageing well, but there also needs to be an emphasis on people dying well, in their place of choice. Death is, after all, part of life.

Third, palliative care, wherever and by whatever organisation it is provided, must be recognised as an essential part of the overall pattern of NHS services and resourced accordingly. It horrifies me that hospices were spending time trying to source PPE when that time could have been spent on patient care.

Last, we need to ensure those bereaved during the Covid-19 pandemic get access to bereavement support as a matter of urgency. I can't bear to think about how I would have coped after Kevin died without my family, friends and support groups. I hate to think how many people might be experiencing grief and struggling on their own right now.

11. Policy priorities

In 2018, it was projected that, by 2040, care homes could overtake hospitals as the most common place to die in England and Wales²⁸. In 2020, this became a reality. The Covid-19 pandemic has accelerated the need for palliative, end of life and bereavement care in the UK and exposed weaknesses and achievements in that care. Here, we make recommendations to ensure that the highest quality care can be provided to all those who are affected by dying, death and bereavement, during the pandemic and beyond.

Specialist palliative care services, within and outside of the NHS, must be resourced appropriately.

The Covid-19 pandemic has exposed systemic weaknesses that must be urgently addressed to meet the rising need for palliative and end of life care in the UK. During Covid-19, palliative care and hospice services, like parts of the social care sector, struggled to access essential supplies, including PPE, during the first months of the pandemic. Charitably funded services were particularly impacted, as they are often considered outside of NHS supply chains. This impacted on care that could be provided to patients. It is essential that palliative care services, whether predominantly within or outside the NHS, are resourced appropriately.

Palliative care is an essential part of the Covid-19 pandemic response.

Palliative care services have played an essential front-line role during the Covid-19 pandemic. These services have relieved distressing symptoms experienced by people with Covid-19, supported

people with and without Covid-19 to remain in their homes, reduced pressures on acute hospital services, provided education and support to the wider health and social care sectors, and bereavement support to families. In many cases, these services rapidly innovated, shifting resource from inpatient hospices into the community to meet need.

Societal preferences and expectations for death and dying may have permanently changed, and the health and social care system must respond accordingly.

There was a sustained increase in home deaths in the UK during 2020. While we do not fully understand this shift, we do know that home is the most commonly expressed preferred place of death for people with life-limiting illnesses. The NHS Long Term Plan includes dying in the preferred place of death as a quality measure²⁹. However, without adequate support and care in the community, dying at home may not be a positive experience. An integrated system-wide approach, including specialist palliative care, primary care and community nursing, and social care is required. Understanding the community care workforce and education needs is essential. Collaborative models of care are required to enable this integrated approach.

Care homes must be recognised as important providers of palliative and end of life care.

Deaths in care homes trebled during the first Covid-19 wave. In England, Scotland and Northern Ireland, care homes temporarily overtook hospitals as the most common place to die. While there has been significant attention on care homes during Covid-19, the focus has been on infection control. Much more research is needed to understand palliative and end

of life care in care homes during Covid-19, from care provider, care home resident and informal family care-giver perspectives.

Family members and carers must be recognised and supported.

The pandemic has meant many families and carers have had to provide care, when professional care was not available in the community or at home. Carers and family members need to be supported so that they are equipped with the knowledge, information, skills and resources to care for those close to them. This includes knowing how to access health and social care when needed.

Primary care services are increasingly important providers of palliative and end of life care, at home and in care homes.

Deaths at home and in care homes have increased during the pandemic: in both settings, primary care teams of General Practitioners and community nurses, working alongside colleagues in care homes and in social care, have been at the forefront of care provision, supported by specialist palliative care teams. All of these services have rapidly adapted to meet the increased need for palliative and end of life care. Much more research is needed to understand primary care provision of palliative and end of life care during Covid-19. Resource must be directed to support the essential, but often overlooked, role of primary care services in end of life care provision.

Increased provision of bereavement services is urgently needed.

The Covid-19 pandemic has had profound impacts on experiences of bereavement in the UK and the support needed. People bereaved during the

pandemic are at risk of complicated grief, which can leave a long legacy of physical, psychological and economic problems, with consequences for individuals and society. However, people are often not aware of bereavement support options, and where they exist they can be hard to access. Public information on bereavement support options must be improved, and increased provision of bereavement services in areas that have long waiting lists must be prioritised.

Data systems must include information on dying, death and bereavement outcomes.

Data on dying, death and bereavement outcomes is essential to understand and improve the quality of care provided across the UK. Too often, this data is either not collected or is limited in its scope. Even basic comparable data on the place of death is not available in all UK nations. Integrated data systems that include information on palliative care delivered by both specialist and generalist providers, including in care homes, are essential.

Research that informs new care for people affected by dying, death and bereavement during Covid-19 is urgently required.

There has been a rapid growth of knowledge during Covid-19. However, many gaps in this knowledge still exist, and must be answered 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 those from minority ethnicities and more deprived groups.



Annex 1 Report preparation

The report was produced by an Expert Group of clinical and non-clinical academics and researchers.

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Annex 2. Details of the methods used in sections 3-7

Sections 3 and 4 – UK deaths 2015-2020 and rapid review of evidence

UK mortality data

Data on UK deaths for 2020 (including Covid-19 deaths) was retrieved from official weekly death statistics, according to date of registration, from:

England and Wales – <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/weeklyprovisionalfiguresondeathsregisteredinenglandandwales>

Scotland – <https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/vital-events/general-publications/weekly-and-monthly-data-on-births-and-deaths/deaths-involving-coronavirus-covid-19-in-scotland>

Northern Ireland – <https://www.nisra.gov.uk/publications/weekly-deaths-statistics-northern-ireland-2020>

Northern Ireland – <https://www.nisra.gov.uk/publications/weekly-deaths-statistics-northern-ireland-2020>

Design

Rapid review.

Inclusion/Exclusion criteria

Population – patients, carers, health care professionals, wards, units and services

Intervention – palliative care, hospice care, end-of-life care

Context – Covid-19

Findings – data on any aspect of palliative and end of life care during Covid-19

Study design – case series, cross-sectional studies,

cohort studies, intervention studies, systematic reviews (opinion pieces, editorials, service descriptions and narrative reviews were excluded)
Language – limited to English

Search strategy

We searched MEDLINE [2019-2021] and medRxiv [01 Dec 2019 – 19 Jan 2021]. We completed the search on 19 Jan 2021. Our search strategy is listed below:

MEDLINE – (palliative care OR palliative medicine OR palliative\$.mp. OR hospices OR terminally ill OR terminal care OR hospice\$.mp. OR end of life.mp. OR EOL.mp OR terminal*.mp. OR dying.mp) AND (Covid* OR exp pandemics OR pandemic\$.mp. OR epidemic\$.mp. OR epidemics OR exp disease outbreaks OR disease outbreaks Or coronavirus OR coronavirus.mp. OR exp coronavirus infections OR SARS.mp. OR SARS-CoV-2.mp. OR SARS virus OR Severe Acute Respiratory Syndrome).

medRxiv – (palliative care) AND (Covid). Search was limited to articles in the subject of palliative care.

Study selection

One researcher (RLC) ran all searches and screened all articles in Excel (Microsoft Corporation, Redmond, WA) using titles and abstracts. Full texts were screened by RLC and KES. Included studies were not quality appraised.

Analysis

We conducted a narrative synthesis.

Section 5 – Examination of patterns of mortality in the UK during Covid-19

Design

Descriptive analysis of publicly available routinely collected data from England, Wales, Scotland and Northern Ireland, following methods of Bone et al.¹

Data sources

Publicly available data published online by the Office for National Statistics (ONS), National Records of Scotland (NRS) and Northern Ireland Research and Statistics Agency (NIRSA) were used to provide information on weekly death registration data, including Covid-19 deaths and historical weekly deaths. These data identify deaths where Covid-19 was mentioned on the death certificate. Guidance specifies that Covid-19 is an acceptable direct or underlying cause of death and can be documented without diagnostic proof.

The number of deaths in each nation was described by week. The week number refers to the week within the calendar year – for example, week 1 is the first week of January, which allows for comparison between the same period in previous years. Small differences exist in the numbering system between nations. To allow for comparison across the UK nations, the NIRSA data was re-numbered such that the week ending 10th January 2020 was re-numbered week 2 (consistent with ONS data for England and Wales). The NRS data for Scotland runs Monday to Sunday so each ‘week’ is two days out of sync with the data for England, Wales and Northern Ireland (which runs Saturday to Friday). This could not be adjusted for.

The data for England and Wales were separated into region of usual residence in the dataset. Therefore, it was necessary to combine these to give the numbers for England as a whole. Deaths of those resident outside England and Wales or those records where place of residence is missing or not fully coded are not included in this data.

Analysis

The definitions used during the analysis of the data were:

Average deaths – Deaths that would be expected to occur in a typical year without a pandemic, calculated using the average number of deaths that occurred in the same period from 2015–2019.

Baseline deaths – Deaths officially registered during the pandemic up to and including the number of expected deaths, but excluding deaths certified as with or from Covid-19.

Covid-19 deaths – Deaths officially registered with Covid-19 on the death certificate. This includes deaths where Covid-19 was suspected but not confirmed through a laboratory test.

Additional deaths – Deaths officially registered that are in excess of average deaths but are not accounted for by deaths certified as being from Covid-19. This group might include deaths due to Covid-19 but not recorded as such, or deaths indirectly related to the pandemic, for example, through avoidance of hospital care.

The mortality categories above were calculated as follows:

1. Average deaths: We used the average number of deaths over the previous five years (2015–2019) for the corresponding week, as supplied by the ONS, NRS and NIRSA. Data for week 52 was used as a proxy for week 53.

2. Baseline deaths: We used the total number of deaths, minus deaths from Covid-19. Where the value for baseline deaths was in excess of the average deaths, these were defined as additional deaths.

3. Covid-19 deaths: We used information published in weekly datasets, by age.

4. Additional deaths: For each week, additional deaths were calculated by subtracting baseline and Covid-19 deaths from the total number of deaths.

For each of the mortality categories above, deaths were calculated per 100,000 of population for each nation, in order to allow for comparison between nations. The population estimates of the UK nations for mid-2019 was used for this adjustment.

Sections 6 and 7 – Analysis of CovPall data

Study design

A multi-national observational study of palliative care providers during the Covid-19 pandemic. The survey included closed and free text responses. This report is limited to responses from the UK.

Inclusion criteria

Services providing palliative care.

Procedures and questionnaire

Palliative care services were identified through

palliative care and hospice organisations. Clinical leads or their nominee were invited via email, with an attached information sheet and a link to complete the survey online via REDCap. Services also had the option to complete the survey as a Word document or by telephone/video conferencing with a member of the research team. Data were anonymised before analysis [12, 17, 25].

Analysis

Contingency tables were used to understand levels of busyness and shortages by nation (for Wales, Scotland and Northern Ireland) and region (for England). Content analysis was used to explore free text comments to understand activities of services and experiences of shortages of PPE, staff, medicines and equipment.

Ethical approval

The survey received ethical (Institutional Review Board) approval from King's College London Research Ethics committee (LRS-19/20-18541); study sponsor: King's College London; co-sponsor: King's College Hospital NHS Foundation Trust, registered ISRCTN 16561225.

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

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