Omissions from the draft terms of reference:

There are several significant omissions from the terms of reference, which consist of the lack of mention of 1) the rise in deaths at home during the pandemic, 2) the role the voluntary sector played in responding to the pandemic and 3) identifying lessons learned that support the recovery and future development of the health and care sector.

The numbers of people dying at home have been increasing for some time, but this trend has been accelerated by the pandemic. In February 2022, the UK reached the milestone of 100,000 excess deaths in private homes since the beginning of the pandemic, compared to the five-year average. These statistics include the number of children and young people who died at home during this period. According to the annual Child Death Review Data Release for 2021, among the children for whom reviews were carried out, 438 died at home in 2019/20 compared to 530 in 2020/21, an increase of 21%.

3% of the total deaths at home during the pandemic were directly related to COVID-19, with the majority caused by dementia, cancer and heart disease. However, the number of deaths at home was undoubtedly accelerated by COVID-19 and people’s experiences were likely impacted by the effects of the pandemic.

Whilst surveys often show that most people want to die at home, this rapid shift in place of death, at a time of unprecedented pressure for the health and care system, is highly concerning. There is so much that we do not know about the experiences of people who have died at home, their loved ones and the frontline workers who cared for them.

We do not know whether people died at home by choice or if they stayed home out of fear of COVID-19 infection, being refused visitors in hospital, or putting pressure on the NHS. We also do not know whether these people had ‘good deaths’ or if the health and care system was sufficiently equipped to care for them. We believe that many thousands of people may have died at home since the beginning of the pandemic without the palliative and end of life care they needed and that their experiences need to be considered within the Inquiry, in addition to the experiences of people who died in care homes and hospitals.

We are aware of cases where people have died at home alone, struggled to access pain medication and been referred to specialist palliative care services much later than they should have been during the pandemic as well as cases where families have reached breaking point from taking on significant caring responsibilities. We are also aware of providers, such as hospices, who have rapidly shifted their services into the community to support people dying at home during the pandemic. It is unclear just how many people have had traumatic experiences of dying at home over the last two years, how widespread gaps in the provision of generalist and specialist palliative and end of life care in the community may be and what further support is needed moving forward.

This is particularly pertinent to the Inquiry because the rise in deaths at home is clearly not a short term trend and will have ramifications for the future provision of palliative and end of life care. The number of deaths in private homes has been consistently high since early 2020, even when lockdown restrictions have been eased. During the early 2021 lockdown, an average of around 1000 excess deaths a week
were taking place in England and Wales and numbers have remained high across the UK far beyond peaks in COVID-19 infection. In 2022 so far, around 4,000 people have died at home across the UK every week. The impact of the rise in deaths in people’s own homes is ongoing, and therefore it is of the utmost importance that it is a specific line of investigation within the COVID-19 Public Inquiry.

Another omission from the draft terms of reference is that the examination of the economic response to the pandemic does not include the £395.8 million spent by UK and devolved Governments to support charitable hospices during COVID-19. This funding to purchase extra capacity within the hospice sector enabled hospices to better support their local health and care systems in responding to COVID. For example, the Department for Digital, Culture, Media & Sport reported that the NHS received the benefit of £323 million in capacity in return for NHS England’s initial grant of £155m in 2020. Of this “70% was used to support more than 40,000 patients and accordingly relieve the NHS of managing these patients’ care during the pandemic”.

In addition to supporting the wider system, Government funding was vital to the survival of a sector that relies on charitable giving to fund essential end of life care. Prior to the pandemic, an average of 34% of adult’s hospice funding and 18% of children’s hospice funding came from the Government, with hospices across the UK having to raise £3.1 million of charitable income every single day. In 2020, COVID-19 restrictions and donor confidence prompted a funding crisis in the hospice sector, resulting in a 40% drop in hospice fundraising in 2020-2021.

The pandemic exposed the fragility of funding for palliative and end of life care, which is currently delivered by a patchwork of public, private and not-for-profit services. If it weren’t for the emergency Government funding for hospices, many would have struggled to survive, support their local systems to respond to the crisis and, most importantly, provide vital end of life care to the people who need it. It is clear that a system whereby hospices rely on bake sales, marathons and charity shops to fund essential care is not sustainable and the COVID-19 Inquiry has an opportunity to explore the lessons learned from the emergency funding provided to hospices during the pandemic and make recommendations to Government and the health and care sector.

We would also like to emphasise the importance of including the role the voluntary sector, including hospices, played in responding to the pandemic and the impact of the pandemic on non-acute and non-NHS care settings within the terms of reference. Hospices stepped up during the pandemic to support health and care systems to provide palliative and end of life care and cope with a huge volume of death. For example, hospices used their in-patient and community capacity to provide care for people with complex needs and reduce the pressure on, and improve capacity in, acute settings, with many hospices also expanding their capacity. Hospices also offered training and support to generalist colleagues, for example those working within care homes. A free and confidential bereavement, trauma and emotional support counselling service for frontline workers was also provided by Hospice UK and delivered by Just B. It is vital that the COVID-19 Public Inquiry’s investigation of the response of the health and care sector across the UK to the pandemic includes all system partners, including the voluntary sector, and this should be made explicit in the terms of reference.

We also believe that there are wider lessons to be learned from Covid-19 than informing the UK’s preparedness for future pandemics and that the terms of reference should include within its scope lessons learned for the future provision of health and care, particularly for people at end of life. During the pandemic, we have seen incredible resilience among people providing palliative and end of life care as well as rapid innovation and new ways of working. The pandemic drove individuals and organisations to adapt, for example by providing more care in the community and online. The pandemic also swept away many of the barriers to integrated working in health and care, allowing services across the public, private and voluntary sectors to work together as a whole system. Lessons from this rapid transformation and integration of services should not be forgotten and should inform the future development of integrated
health and care systems. Similarly, cases of poor palliative and end of life care experienced must guide health and care systems’ recovery from the pandemic and their future provision of care.

There is a particularly pressing need to learn lessons from people’s experiences of palliative and end of life care during the pandemic because we expect to see more people dying in 2031 than at the height of the pandemic and reach a mortality of nearly 800,000 across the UK in 2040. The volume of death that health and care systems were coping with during the pandemic is set to become normal, making it vital that systems learn from their pandemic response and explore whether current capacity, training and integration is sufficient to support expected increases.

**Issues or topics the Inquiry should look at first**

Hospice UK does not have a position on which issues or topics the Inquiry should look at first but does believe that the Inquiry should start reaching out to people with lived experience, including those who have been bereaved and cared for people at end of life during the pandemic, as soon as possible. There should be constant outreach to, and conversations with, people with lived experience throughout the entire Inquiry process.

**How the Inquiry should be designed and run to ensure that bereaved people or those who have suffered serious harm or hardship as a result of the pandemic have their voices heard**

It is vital that the COVID-19 Public Inquiry invest proper time, resource and energy into listening to the perspectives of people with lived experience, including those who have cared for people at end of life during the pandemic and been bereaved. Ensuring people with lived experience’s voices are heard within the Inquiry, particularly those from excluded communities, will require the Inquiry to proactively reach out to communities and local organisations, such as hospices, conduct one-to-one conversations with people about their experiences and work with them to explore how they can contribute to the Inquiry’s aims in a way that feels meaningful to them.

Individuals who have been bereaved during the pandemic or suffered serious harm or hardship are likely to have less time to dedicate to engaging with the Inquiry through formal means, such as this consultation. Therefore, the Inquiry team needs to ask people how they would like to share their views and experiences and adapt to these requirements.

We would recommend that there is specific staff resource dedicated to reaching out to people with lived experience, briefing them on the aims of the Inquiry, working with them to contribute their views and experiences and ensuring that they feel heard. We would also recommend that the Inquiry aim to ensure that every public hearing includes the voice of someone with lived experience. People with lived experience who contribute to the Inquiry should also be given the opportunity to review its report(s), and how they are represented, before publication.

Hospice UK’s Dying Matters campaign aims to open up conversations around death, dying and bereavement. This includes platforming the voices of people with lived experience of death and dying and supporting them to share their stories. Hospice UK provides Secretariat services to the APPG on Hospice and End of Life Care, which is currently running its own inquiry into the lasting impact of COVID-19 on death, dying and bereavement. We are also supporting the Senedd Cross-Party Group for Hospice and Palliative Care’s deep dive into experiences of end of life care during the pandemic. People with lived experience have contributed to these inquiries through written means and by giving oral evidence at private virtual meetings of the groups. Hospice UK would be pleased to support the Inquiry by reaching out to its network, through its Dying Matters campaign and its work with the APPG on Hospice and End of Life Care and Senedd Cross-Party Group for Hospice and Palliative Care, to encourage those with lived experience to engage with the Inquiry team.