

The Rt Hon. Baroness Hallett DBE
Chair, UK Covid-19 Inquiry

6 April 2022

Dear Baroness Hallett,

We are writing to express our concern that the significant increase in deaths in private homes during the pandemic is missing from the draft terms of reference of the COVID-19 Public Inquiry and to make the case for its inclusion as an area of focus.

There have been over 100,000 excess deaths in private homes across the UK since the beginning of the pandemic. Only 9-12% of these deaths 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. These statistics include the number of children and young people who died at home during this period

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. Most worryingly, we 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 may have died at home since the beginning of the pandemic without the palliative and end of life care they needed.

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 as well as cases where families have reached breaking point from taking on significant caring responsibilities. However, it is unclear just how many people have had such traumatic experiences and how widespread gaps in the provision of care may be, nor what it might mean for the future.

Since early 2020, deaths in private homes have been consistently high, 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. This increase does not appear to be a

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short-term trend, with the impact ongoing, and therefore it is of utmost importance that it is a specific line of investigation within the COVID-19 Public Inquiry.

Government, health and care systems and frontline workers need information on what is behind this increase and how well people have been supported in order to better support those dying at home now and in the future. Together, we implore you to ensure the COVID-19 Public Inquiry investigates this surge in deaths in private homes by amending the terms of reference to include explicit mention of this increase.

Yours sincerely,

Craig Duncan, Interim Chief Executive, Hospice UK
Simon Blake OBE, Chair, Dying Matters
Caroline Abrahams CBE, Charity Director, Age UK
Fiona Carragher, Director of Research and Influencing, Alzheimer's Society
Joseph Carter, Head of Devolved Nations, Asthma + Lung UK
Sarah Mistry, Chief Executive Officer, British Geriatrics Society
Chris Jones, Chief Executive, Care & Repair Cymru
Karolina Gerlich, Chief Executive Officer, Care Workers' Charity
Joanne Anning, Chair, Childhood Bereavement Network
Dr Hilda Hayo, Chief Admiral Nurse and CEO, Dementia UK
Adrian Richards, Chief Executive Officer, Disability Focus
Dr Jane Townson, Chief Executive, Homecare Association
Trystan Pritchard, Chair, Hospices Cymru (represents 15 hospices in Wales)
Eve Byrne, Director of Advocacy, Macmillan Cancer Support
Sam Royston, Director of Policy and Research, Marie Curie UK
Chris James, Director of External Affairs, Motor Neurone Disease Association
Dr Marilyn Relf, Chair, National Bereavement Alliance
Charlotte Augst, Chief Executive, National Voices
Sarah Scobie, Deputy Director of Research, Nuffield Trust
Dr Crystal Oldman CBE, Chief Executive, Queen's Nursing Institute
Nik Hartley OBE, Chief Executive Officer, Spinal Injuries Association
Katie Chappelle, Associate Director for Wales, Stroke Association
Heidi Travis, Chief Executive, Sue Ryder
Judi Rhys MBE, Chief Executive, Tenovus Cancer Care
Dr Amy Proffitt, President, The Association for Palliative Medicine
Jacqueline Cannon, Chief Executive, The Lewy Body Society
Georgina Carr, Chief Executive, The Neurological Alliance
Andy Fletcher, Chief Executive, Together for Short Lives
Dr Kate Woodthorpe, University of Bath
Dr Julie Rugg, University of York
Charlotte Gill, Director of Policy, Public Affairs and Communications, VoiceAbility