

Response to the Consultation on the COVID-19 Inquiry Aims and Principles

About Scottish Partnership for Palliative Care (SPPC)

SPPC brings together health and social care professionals from hospitals, social care services, primary care, hospices and other charities, to find ways of improving people's experiences of declining health, death, dying and bereavement. SPPC provides a voice for organisations and individuals working in this area, a means of staying informed and connected, and a vehicle for collaboration. SPPC also engages with the public and communities through our Good Life, Good Death, Good Grief alliance.

SPPC was founded 30 years ago and has grown to be a collaboration of over 100 organisations involved in providing care towards the end of life. SPPC's membership includes all the territorial NHS Boards, IJBs, local authorities, the hospices, Third Sector organisations and a range of professional associations.

SPPC works closely with SG officials to facilitate engagement with the sector and to inform and support implementation of SG policy.

COVID-19 Pandemic and Palliative Care

The role of palliative care within a pandemic is to address suffering in all settings both for those who are dying and for those receiving disease modifying intervention. During the COVID-19 pandemic there has been a need to deliver palliative care for people dying with COVID-19 whilst maintaining palliative care services for people living with and dying of other conditions.

The pandemic caused changes to how people were cared for at the end of life and how they died. This had impacts on individuals, their families and the staff and volunteers providing care.

For more background on palliative and end of life care in Scotland please see [*Every Story's Ending, proposals to improve people's experiences of living with serious illness, dying and bereavement*](#). This report published in September 2021 by SPPC presents a comprehensive overview and analysis. Chapter 13 specifically addresses the challenges for palliative and end of life care created by

the pandemic, catalogues the remarkable rapid collaborations and innovations put in place to provide the best care possible. The chapter also makes recommendations for the future.

The Approach and Process of the Inquiry

In its conduct the inquiry should be conscious of the trauma, fatigue and burnout experienced and still being experienced by many members of the public, service providers and decision-makers. The inquiry should first and foremost seek to listen, to understand and to identify learning for the future.

The inquiry should be led by a panel of independent experts, rather than by a single Chair. We propose that the panel should include independent expertise in palliative and end of life care and bereavement.

In gathering and hearing evidence the inquiry should be flexible in its approach and reflect on and accommodate the vulnerabilities of some people who have important evidence to give. It may be appropriate for some evidence to be given in confidential sessions and/or via pre-recorded video. Confidential psychological support should be available to those giving evidence.

It may be appropriate for the panel to make visits around Scotland.

Aims of the Inquiry

The relief of suffering and quality of dying should be a significant concern of the inquiry. Below we propose a range of topics which should be included in the inquiry. In terms of the draft aims of the inquiry these topics relate to direct health impacts of COVID-19, other health impacts and economic impacts.

We've framed these topics in terms of opportunities to learn and do better in future:

1. How pre-pandemic planning could be improved to encompass the need to provide higher levels of palliative and end of life care in difficult circumstances.
2. How the public could be made more aware of, better informed about and fully engaged in anticipatory care planning, including CPR decision-makingⁱ.

3. How changes to the law could improve the security of supply of end of life medications during a pandemic, whilst also reducing waste.
4. How people and their families can be better supported to maintain communication, including saying final goodbyes, in the context of a highly infectious pandemic?
5. How can the spiritual needs of people and their families best be accommodated?
6. How can the significant and long term harms of people dying whilst separated from loved ones be better balanced against other public health harm reduction aims such as controlling infection?
7. What support was and is available to people bereaved during the pandemic and what was/is the level of unmet need and how should these needs be addressed?
8. What were the experiences of people dying at home and their families during the pandemic, and what can be learned for the future? (From the beginning of 2020 until mid-March 2021 the total number of all deaths at home increased by 36% compared to the average number of people who died at home in the equivalent period in 2015-2019ⁱⁱ).
9. What were the experiences of staff supporting the increased numbers of people dying at home during the pandemic? (There was an increase in both the number and complexity of needs of people dying at home creating challenges for GPs, district nurses and other community staffⁱⁱⁱ).
10. How can care homes be better resourced, equipped and supported as key settings providing palliative and end of life care?
11. How can learning and innovation from successful rapid adaptation to maintain palliative care services in the face of

difficult circumstances be embedded and sustained going forwards?

12. What are the economic impacts of the pandemic on Third Sector providers of palliative care and what are the lessons for longer term service sustainability?
13. What are the economic impacts of the pandemic on Independent Sector providers of palliative care and what are the lessons for longer term service sustainability?
14. How can hospices be better engaged and integrated from the outset in the strategic planning and delivery of services? Hospices are major providers of palliative and end of life care, but lie outwith the NHS. Hospices were key leaders and rapid innovators^{iv} in the early responses to the pandemic but experienced difficulties due to a lack of integration with the wider system (for example difficulties accessing PPE^v).

Mark Hazelwood
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ⁱ Understanding and addressing challenges for Advance Care Planning in the COVID-19 pandemic: An analysis of the UK CovPall survey data from specialist palliative care services. <https://www.medrxiv.org/content/10.1101/2020.10.28.20200725v1>

ⁱⁱ *Dramatic increase in deaths at home during the pandemic - No.2* – Blog series. Jan Savinc. Scottish Centre for Administrative Data Research. March 2021
<https://www.scadr.ac.uk/blog-series-dramatic-increase-deaths-home-during-pandemic-no2>

ⁱⁱⁱ *Community end of life care during the COVID-19 pandemic: Initial findings of a UK primary care survey*. Sarah Mitchell et al. MedRxiv. Feb 2021

<https://www.medrxiv.org/content/10.1101/2021.02.15.21251756v1.full-text>

^{iv} This *Scottish hospices: Clinical innovation in response to COVID-19 pandemic Summary of feedback gathered from Scottish hospices end of June-August 2020*. Hospice UK

https://www.hospiceuk.org/docs/default-source/Policy-and-Campaigns/briefings-and-consultations-documents-and-files/scottish-hospices-clinical-innovation-in-response-to-covid_v4-docx.pdf?sfvrsn=0

^v Rapid Evaluation of the COVID-19 Pandemic Response in Palliative & End of Life Care (papers include Scottish data) <https://www.kcl.ac.uk/research/covpall>