COVID-19 led to a devastating increase in deaths across the UK. Over a hundred thousand people have died from the virus alone, not including those dying of conditions that worsened, or were left untreated, due to the pandemic. Many more health and care workers, families and friends supported people at end of life than ever before.

The impacts for people receiving, and providing, palliative and end of life care were devastating. Many people who died during the pandemic did not receive the end of life care they deserved, particularly out of hours. Health and social care workers who provided palliative and end of life care, as well as family carers, were under unprecedented pressure. Moreover, the crisis and drop of income from charitable fundraising exposed the financial fragility of the hospice sector.

However, we have also seen incredible resilience among people providing palliative and end of life care as well as innovation, collaboration and new ways of working within this sector. The pandemic has forced individuals and organisations to adapt, for example by providing more care in the community and online.

It is critical that the sector emerges from this crisis aware of, and able to respond to, the significant and lasting changes that have taken place within hospice and end of life care. For this reason, the All-Party Parliamentary Group on Hospice and End of Life Care is launching a review into the lasting impact of COVID-19 on death, dying and bereavement.

The goals of this review are to:
- Uncover changes in the way palliative and end of life care is being, and will need to be, delivered in England following the pandemic.
- Uncover the experiences people have had of death, dying and bereavement during the COVID-19 pandemic and provide a platform for sharing their stories with Government.
- Understand the lasting impact of the COVID-19 pandemic on palliative and end of life care in England, and the resultant changes in care delivery, and identify solutions that cross-sector partners can implement moving forward.
- Explore the impact of the pandemic on out of hours palliative care provision especially in a crisis.
- Make recommendations to Government and the hospice and end of life care sector that ensure lessons learned during the pandemic, as well as new challenges, are not forgotten and lead to an improvement in people’s experience of death, dying and bereavement.
- Explore whether access and attitudes to palliative care changed for those people who previously had little access, such as those in socially deprived areas or where cultural barriers existed.

The APPG welcomes submissions of evidence to this review from as wide a range of organisations and respondents as possible. This includes but is not limited to:
- Relatives and friends of people who have died during the pandemic and can speak to their quality and experience of care or their own experiences of bereavement.
- Frontline workers whose work has involved providing palliative and end of life care during the pandemic, including staff and volunteers within hospitals, community nursing, care homes and domiciliary care. In particular, we welcome responses from those who have been operating on the front line, and the option exists for submissions to be treated anonymously.
- Organisational leaders whose work has involved facilitating or managing the provision of palliative and end of life care during the pandemic.
- Unpaid and informal carers of people currently living with a life limiting illness.
- Non-medical organisations that have supported bereaved people and/or staff during the pandemic.
- Academics and think tanks with relevant research or findings.
- Charities, professional and membership bodies, unions and campaign and patient groups.
- Representatives from groups known to have had poor access to palliative care such as some BAME communities.

If you have any personal or professional experience that is related to this review then we would like to hear from you. However, we are particularly interested in submissions answering the following questions:

1) What significant changes have you seen in how palliative and end of life care is being delivered as a result of the pandemic that you expect to last into the long-term? Responses to this question could cover:
   - changes to where palliative and end of life care is being delivered, e.g. shifts towards care in the community
   - the use of technological solutions
   - impacts on out of hour care provision
   - changes in the provision of generalist and specialist support

2) What significant changes have you seen in palliative and end of life care needs as a result of the pandemic that you expect to last into the long-term? Responses to this question could cover:
   - any increase in demand for bereavement support
   - changes in the complexity of need and presentation of conditions
   - shifts in need related to the location of the individual requiring care

3) What positive ways of working and innovative approaches to delivering palliative and end of life care have been rolled out during the pandemic that should be supported to grow?

4) What shortfalls in the provision of palliative and end of life care have been exposed by the pandemic?

5) If you are a frontline worker, what has been your experience of working within the field of palliative and end of life care during the pandemic? What were the key
challenges? How might these experiences shape future care you provide and impact your professional and personal life? Reponses to this question could cover:

- practical, emotional and physical challenges of working within COVID-19 related restrictions and guidance such as PPE, additional infection control and visitor restrictions
- changes to the type of care you are expected to provide and the settings in which you work
- impacts of the pressure of the pandemic, and caring for people who have died during this time, on your mental health and any support you have received
- any new positive work habits or ways or working

6) If you are a manager or leader within an organisation that provides palliative and end of life care, what impact has the pandemic had on the operation of your services and your staff? Reponses to this question could cover:

- workforce supply, resilience, mental health and capability and any concerns about these factors in the future
- long-term adaptions in your organisation’s ways of working
- changes in out of hours responses to palliative care emergencies
- any mental health support you have provided for your workforce
- the financial sustainability of your service
- the settings in which you provide care and any associated challenges/opportunities
- investment in and use of technological solutions

7) If you are an informal carer of someone currently living with a life limiting illnesses, what was your experience of providing care during the pandemic? What were the key challenges and what, if any, support did you receive? Reponses to this question could cover:

- the challenges of providing care at home during the pandemic, both in hours and out of hours
- changes in the type of care you were expected to provide and new responsibilities
- any support with care you received from the health and care workforce
- any support for your mental health that you received from Government, the health and care system or your workplace

8) If you are a bereaved family member or friend of someone who died during the pandemic, did your loved one receive good palliative and end of life care? What kind of support did you receive as a result of your bereavement? Reponses to this question could cover:

- positive and negative experiences your loved one had of end of life care
- bereavement support you have received and its quality

9) If you are a non-medical organisation, how have you supported people who have been bereaved during the pandemic? Reponses to this question could cover:

- support provided by bereavement services
- mental health and respite support organised by employers for their own staff
changes in the wellbeing and mental health of staff prompted by the pandemic and their long-term impacts

10) If you are a representative organisation of a group known to have had poor access to palliative care, how has the pandemic impacted access to care and are there any specific impacts of the pandemic on the experience people have had of death, dying and bereavement that are disproportionately or solely felt by members of the group you represent?

Please feel free to only respond to questions that are relevant to your experience and/or expertise. We would be particularly grateful for specific examples, evidence, and references, wherever possible.

The APPG will make every effort to hear and record your experience in a way that is comfortable for you. We would therefore be happy to receive evidence anonymously at policy@hospiceuk.org or alternatively to arrange a phone/zoom call via the same email address.

The word limit for submissions is 2000 words. Unless your submission is anonymous, please clearly state who the submission is from, i.e. whether from yourself in a personal capacity or sent on behalf of an organisation, and include a brief description of yourself/your organisation. Please do not send us confidential information.

Please email your submission to policy@hospiceuk.org with the subject line “APPG review submission”

The deadline for written submissions is 16 November 2021.

About the APPG on Hospice and End of Life Care

The All-Party Parliamentary Group (APPG) on Hospice and End of Life Care brings together MPs and Peers from across the political spectrum to campaign for high quality and accessible palliative and end of life care for all.

The group’s purpose is to raise awareness and promote the needs of adults and children living with terminal or life-limiting conditions, and their families and carers, in Parliament and promote person-centred, evidence-based policies to improve end of life care in all settings, including hospices, hospitals, care homes, and in people's own homes.

Secretariat support to the APPG is provided by Hospice UK.