

Cafodd yr ymateb hwn ei gyflwyno i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Flaenoriaethau'r Chweched Senedd](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [Sixth Senedd Priorities](#)

HSC PSS 32

Ymateb gan: | Response from: Hospice UK



Question 1: Initial priorities identified by the Committee

The Committee has identified several potential priorities for work during the Sixth Senedd, including: public health and prevention; the health and social care workforce, including organisational culture and staff wellbeing; access to mental health services; evidence-based innovation in health and social care; support and services for unpaid carers; access to COVID and non-COVID rehabilitation services; and access to services for long-term chronic conditions, including musculoskeletal conditions.

Q1. Which of the issues listed above do you think should be a priority, and why?

You can comment on as many or few of the issues as you want.

In your answers, you might want to think about:

- What impact or outcomes could be achieved through any work by the Committee?
- How the Committee might address the issue?
- When any Committee work should take place?
- Whether there are any specific groups, communities or stakeholders that the Committee should involve or hear from in any work?

Context: palliative and end of life care in Wales through and beyond the pandemic

37,789 people died in Wales during 2020, a marked increase on previous years with 3,979 'excess' deaths in comparison with the five year average.¹ Set in context, the COVID-19 pandemic saw palliative and end of life care need **increase to the level of demand that was previously predicted to be reached in 2040**, based on projections taking account of an increasing and ageing population.²

We know that **not all people who needed end of life care during the pandemic will have received the care they deserved**. Access to palliative and end of life care was inequitable prior to the pandemic, with an estimated one in four people missing out on the care they need and with people from racialised and deprived communities noticeably underserved by services. With mounting evidence that BAME communities have been overexposed to, and under-protected from, Covid-19 over the course of the pandemic,³ there is a real concern that the pandemic will have exacerbated this inequity, and others, in the experience of end of life care.

¹ From ONS 'Deaths at home increased by a third in 2020 , while deaths in hospital fell except for COVID-19'
<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/deathsathomeincreasedbyathirdin2020whiledeathsinhospitalsfellexceptfor covid19/2021-05-07>

² Cicely Saunders Institute (2021) 'You matter because you are you: an action plan for better palliative care'
https://csiweb.pos-pal.co.uk/csi-content/uploads/2021/01/Cicely-Saunders-Manifesto-A4-multipage_Jan2021-2.pdf

³ <https://www.runnymedetrust.org/projects-and-publications/employment-3/overexposed-and-underprotected-covid-19s-impact-on-bme-communities.html>

Significant trends, developments and transformations in the delivery of palliative and end of life care emerged during the pandemic. These warrant further inquiry to ensure that the system is rebuilt with lessons learnt to improve experiences of care. Notably, these include:

- **In 2020 deaths in private homes in Wales were 32% higher** than the previous five year average, a trend which is **continuing into 2021**
- **In 2020 deaths in care homes in Wales were 19% higher than the previous five year average⁴**
- Deaths in hospital from causes other than COVID-19 were markedly lower than in previous years.
- There is an **increased need for bereavement support, with an estimated 190,000 people in 2020 alone experiencing a bereavement** with an increased likelihood of a more complex bereavement responses given the “high level of disruption to end of life, death and mourning practices, as well as social support networks”⁵ during the pandemic.

Welsh Government has identified palliative and end of life care as an area for focused improvement. The National Clinical Framework outlines the commencement of a National End of Life Care Programme, recognising that end of life care has cross-over with multiple condition pathways. With the development of a Quality Statement alongside the development of a National Programme, the Health and Social Care Committee will want to designate significant resource to scrutinising this area of work.

This could involve:

- Recognising palliative and end of life care as a cross-cutting health and care concern by ensuring that improving the end of life care experiences of people should be factored into scrutiny work in areas where there is potential cross-over, even when end of life care is not the primary focus of an inquiry
- As part of the Committee’s ongoing scrutiny of the COVID-19 pandemic and its impact on people and the health and care system, palliative and end of life care should feature prominently (see below, under COVID-19 recovery for additional detail). This scrutiny should be ongoing with a view to informing wider COVID-19 inquiries at UK and Wales levels where these are taken forward.
- People with experience of care, including loved ones and carers, should be heard as part of scrutiny of palliative and end of life care policy and provision. Groups representing communities who are known to be underserved by palliative care services or who are more likely to have inequitable access to palliative care should be actively sought to inform scrutiny
- As well as involving palliative care providers, such as hospices and NHS palliative care specialists, primary care and social care professionals will bring valuable insight to scrutiny

⁴ Data taken from ONS ‘Deaths at home increased by a third in 2020 , while deaths in hospital fell except for COVID-19’

<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/deathsathomeincreasedbyathirdin2020whiledeathsinhospitalsfellexceptforcovid19/2021-05-07>

⁵ Harrop E., Farnell D., Longo M., Goss S., Sutton E., Seddon K., Nelson A., Byrne A., Selman L.E. Supporting people bereaved during COVID-19: Study Report 1, 27 November 2020. Cardiff University and the University of Bristol.

- Building on the recommendations in the Fifth Senedd Health, Social Care and Sport Committee [Legacy Report](#) to work collaboratively with Cross-Party Groups to increase capacity and expertise, the Cross Party Group on Hospice and Palliative Care can be a source of knowledge to enhance the Committee's scrutiny in this area
- With regards scrutiny of the National Programme, it would be appropriate to consider this after the programme has been established and under way, for example during the second half of the Sixth Senedd term. Until that point, the Committee will be interested in the development of the Quality Statement

Health and Social Care Committee proposed priorities

The health and social care workforce, including organisational culture and staff wellbeing

The health and social care workforce is a cross-cutting issue that should be considered as part of any and all inquiries undertaken by the Health and Social Care Committee. Hospice UK is pleased that the Health and Social Care Committee is undertaking a concurrent inquiry focussing on the implementation of the joint HEIW and SCW workforce strategy and will be responding to this separately.

However, given the impact of the COVID-19 pandemic and steps towards recovery there is a particular window of opportunity emerging to focus on 1) learning from the partnership and multi-disciplinary team approach fostered in some areas during the pandemic as part of the workforce integration agenda, and 2) workforce wellbeing.

- **Multi-disciplinary approach, partnership and an integrated workforce**

There has been significant commentary on the innovation needed to respond to the COVID-19 pandemic as a driver for integration that improves the patient experience. Within end of life care, the [CovPall study](#) identifies pooling of staffing resources, staff flexibility and collaborative teamwork between specialist palliative care services and with other generalist palliative care providers as responses to the increased demand for palliative and end of life care during the pandemic.

This built on, and fast-tracked, the multi-disciplinary and cross-organisational working that existed pre-pandemic within palliative care, with partnerships between hospices, care homes, primary care and NHS specialist palliative care teams in acute and community settings. Revisiting the relationship between the specialist palliative care workforce and the generalist workforce should also feature in learning as we strive to reconfigure services fit to meet greater future need.

There is a need to learn from and explore future models for the palliative care workforce, as well as the wider community workforce. Consideration of this should make up part of any scrutiny of the joint [HEIW and SCW workforce strategy](#), which identifies the ambition that "by 2030 multi-professional and multi-agency workforce models will be the norm."

- **Workforce wellbeing**

Marie Curie's [Better End of Life report](#) notes the significant staff shortages across palliative and end of life care services during the pandemic, with shortages in Wales and London among the highest across UK regions and nations where 60% of services reported staff shortages. There was

therefore a necessity for the palliative care workforce to flex and adapt, with positive consequences for innovations going hand in hand with significant pressures and strains as the workforce struggled with increased demand amidst fewer resources. Several support networks and resources were established in response to the pandemic, including formal schemes such as the partnership [Our Frontline](#) where Hospice UK supports a specialist trauma and bereavement phone service, as well as local arrangements for support, including supervision of care home staff by hospice social workers and bereavement counsellors.

We do not yet know the long term impact of the pandemic on workforce wellbeing. There will be a need to monitor the impact of available and ongoing support at an individual level as well as the wider impact on staff retention at regional and national levels and amongst different specialisms or sectors.

Access to mental health services

Given the context of the pandemic, significant **access to bereavement support** will be needed at an individual and population level. This is against the backdrop of gaps and variations in access to bereavement care as identified in the [Scoping Survey of Bereavement Services in Wales](#), which also found that bereavement care is seldom prioritised within organisations and that there is a lack of access to funding.

Added to this, the CPG Hospices and Palliative Care in the Fifth Senedd in its inquiry into the [Compassionate Cymru programme through Covid](#) heard from BAME community leaders that palliative and bereavement care are not always experienced as accessible by people of colour and awareness of available support is limited. This is coupled with a need for tailored bereavement care and mental health services for people of colour, especially in the context of COVID-19.

The forthcoming National Bereavement Framework will provide focus for improving equal access to bereavement care across Wales. However, the **Committee will be interested in monitoring the implementation of this Framework and accompanying funding on the impact it has on access and outcomes for people needing bereavement care** at a population level. It will be important to hear from people from all regions across Wales as well as from groups representing racialised communities.

Support and services for unpaid carers

Respite and short break care

Increasing the availability of respite and short break care is acknowledged as a Welsh Government priority. The Committee will want to monitor the impact of the Welsh Government £3m short break fund to support carers to continue to care. As part of scrutiny in this area, the Committee may wish to engage with children with life-limited conditions and their families, who rely on short break care from hospices to maintain the whole family's mental health and relationships, and who identified as part of the [Family Voices](#) survey that extra nights of nurse-led respite care as essential to keep them from breaking.

Question 2: Key priorities for the Sixth Senedd

Q2. In your view, what other key priorities should the Committee consider during the Sixth Senedd in relation to:

- a) health services;**
- b) social care and carers;**
- c) COVID recovery?**

You can comment on as many or few of the issues as you want.

In your answers, you might want to think about:

- What impact or outcomes could be achieved through any work by the Committee?
- How the Committee might address the issue?
- When any Committee work should take place?
- Whether there are any specific groups, communities or stakeholders that the Committee should involve or hear from in any work?

a) Health services

The Fifth Senedd Health, Social Care and Sport Committee [Legacy Report](#) recommended that the Health and Social Care Committee in the current Senedd provide scrutiny on the following areas which affect the lives of people approaching the end of life:

- the development of Quality Statements to replace major health conditions delivery plans, including the End of Life Care Delivery Plan
- GP Clusters
- Dementia pathways
- Extension of the Nurse Staffing Levels (Wales) 2016 Act to paediatric inpatient settings and in the community, including by conducting post-legislative scrutiny on the implementation of the Act.

We urge the Committee to consider these in their forward work plan.

b) Social care and carers

Sustainable resourcing of social care

The needs of people with terminal and life-limiting conditions will not fit neatly into either health or care categories, with the majority of people accessing care that would be understood as meeting a social care need alongside their health needs.

People towards the end of life face significant variation in the funding of their care, often dependent on the place of their care, with some funded through the NHS, others in social care settings funded through Continuing Healthcare, self-funding in full or in part for the social care aspect of their care, and others receiving their care for free funded through charitable sources such as hospice care.

For these reasons, the sustainable resourcing of a palliative and end of life care system fit for the future – to be inquired into as part of the National End of Life Care Programme – is bound up with discussions about the future resourcing of our social care system.

The Committee will be interested to pursue the proposals for a future settlement for social care in Wales, in the context of the UK Government Health and Social Care Levy, and should include consideration of increasing end of life care needs within this work. Alongside the End of Life Care Programme Board, the Committee may wish to involve Hospice UK in this work as the future resourcing of palliative care is an ongoing focus for us.

c) COVID recovery

As part of ongoing scrutiny of the impact of the pandemic on health and care in Wales or to inform wider inquiries into the handling of the pandemic by national governments, the Committee should prioritise hearing the voices and experiences of people affected by death, dying and bereavement. Learning and transformation of the health and care system as part of COVID-19 recovery must be informed by the lived experiences of those who have used and will use the services going forward.

The Cross Party Group on Hospice and Palliative Care is undertaking a deep dive into the experiences of end of life care at home during the pandemic, with a view to hearing the stories and testimonies of families and carers alongside those of the frontline workforce. This deep dive aims to cast a light on the significant gaps in knowledge about how the increase in people dying at home during the pandemic has been experienced by people and families. This includes understanding whether, for example, people had access to pain and symptom relief, had care from the right professionals at the right time, or if families felt supported and were able to access bereavement care if they needed it.

Collaborating with the Health and Social Care Committee to take forward the initial themes, findings and outcomes from this deep dive will enable this, as yet unheard, aspect of the pandemic to inform scrutiny and learning through the COVID-19 recovery.

Question 3: Any other issues

Q3. Are there any other issues you wish to draw to the Committee's attention?

Health inequalities

Hospice UK is part of the Health and Wellbeing Alliance (Wales) and we endorse the Alliance's call for an inquiry across all Senedd Committees on tackling health inequalities in Wales. In line with the Alliance's work we agree that:

"Meaningful progress will require coherent efforts across all sectors to close the gap and an inquiry undertaken by all Senedd Committees will enable Committees to consider what action each Welsh Government department is doing to tackle the root cause of health inequalities and put forward recommendations around where improvements are needed." (Health and Wellbeing Alliance)

Hospice UK's most recent work in this space has demonstrated the broad areas where people experience unequal access to care, see [Equality in hospice and end of life care: challenges and change](#) (2021), as well as a focus on the unequal access to appropriate palliative and end of life care for imprisoned people, see [Dying behind bars](#) (2021). The latter will have particular relevance to the Committee as it monitors the Welsh Government's response to the Fifth's Senedd's Health, Social Care and Sport Committee report on [Health and Social Care provision in the adult prison estate in Wales](#). This body of evidence builds on the Cross Party Group on Hospices and Palliative Care inquiry into [Inequalities in access to hospice and palliative care](#) (2018) during the Fifth Senedd, which highlighted multiple barriers that serve to proliferate inequity in access to hospice and palliative care. While the Welsh Government accepted all recommendations in this inquiry, some recommendations remain in progress, which requires ongoing monitoring and scrutiny.

Hospice UK will continue to prioritise tackling inequalities in access to palliative and end of life care in its own work during the coming year, focusing on marginalised groups including racialised communities. We are keen to share the findings of our research and policy recommendations with the Committee as part of their ongoing scrutiny in this area.