

## Welsh Government consultation

### White paper: Rebalancing care and support

#### Hospice UK response

March 2021

#### About Hospice UK

Hospice UK is the national charity working for those experiencing dying, death and bereavement. We work for the benefit of people affected by death and dying, collaborating with our hospice members and other partners who work in end of life care. Our hospice members influence and guide our work to put people at the centre of all we do. We believe that everyone, no matter who they are, where they are or why they are ill, should receive the best possible care at the end of their life.

#### Palliative care need

As expressed in the analysis within the consultation document, there is a growing need for care and support in all populations. Largely due to our ageing population, as well as people of all ages living longer with more complex conditions, palliative care need is projected to increase by 42 per cent over the coming two decades.<sup>i</sup>

#### Palliative care as integrated care

Palliative and end of life care is an exemplar of a multiagency system involving: the NHS, social care, the voluntary sector (notably, charitable hospices, communities, families, and carers).

For context:

- Around 16 per cent of all people who die, will die in care homes, and will require end of life care in this setting<sup>ii</sup>
- Charitable hospices provide care for more than 12,700 people each year, with 9,150 people cared for in their own home or care home, often supported by domiciliary care and unpaid carers.<sup>iii</sup>
- Children's hospices across Wales collectively provide more than 1,000 short breaks, or respite, to children and their families each year. This care primarily fulfils a social care need but often the hospice is the only setting that can accommodate the child's specific nursing care needs.<sup>iv</sup>

The reality of the provision of palliative and end of life care – with many people cared for at the end of life in care homes or supported with personal care in their own homes, means that palliative care straddles health and social care in practice.

This is especially important to recognise, as where the “complexity” of the social care system can lead to poor outcomes is when people struggle to access the right care, when they’re transferred between services, or after they’re discharged. There is room for improvement within the social care sector to ensure seamless transitions between care settings and examining and highlighting the good practice within the palliative and end of life care sector is a critical step.

Complexity does not, however, necessarily serve as a barrier to improvement. Cross-sector or cross-specialism working can lead to cross-fertilisation of ideas within a local or regional health and care system. There are extensive examples of hospices engaging in providing educational support and training to other parts of the social care system, such as care homes and other community-based social care providers.

### Commissioning, and charitable hospices as providers of social care

As well as being part of an integrated system, working alongside social care providers, charitable hospices will be amongst the 1,000 providers referenced in the consultation document as part of the social care landscape.

Charitable hospices received a total of £5.7m in statutory funding in 2019, primarily through service level agreements or commissioned specialist palliative care services from health boards. Some people, though not all, cared for by integrated hospice at home services will be people who have been assessed as requiring their care and support needs to be met by Local Health Boards through Continuing Health Care budgets. A very small proportion of hospice funding will come through commissioned services from local authorities. The remainder of hospice income – around £33.3m in 2019 – is fundraised from local communities as well as trusts and funds.

Some charitable hospices providing hospice at home services are already recognised as social care providers registered with Care Inspectorate Wales to provide domiciliary care. They do this by combining their expertise in palliative care with personal care to meet the particular needs of people in the last weeks and days of life.

There will be other hospices, not yet recognised by local authorities as potential suppliers, that can form part of the solution to meeting greater and increasing need for palliative and end of life care in the community. As such, we welcome an approach that aims towards achieving a more diverse provider base that can provide new and alternative models of care, based on what matters to people.

### Regional Partnership Boards’ design and structure

For the reasons outlined above, we welcome proposals that facilitate more effective partnership working between health boards and local authorities whereby Regional Partnership Boards will be given the legal status to commission integrated services.

In this way, RPBs can serve as a conduit for linking the two sides of the equation for supporting people in their own home who need palliative or end of life care, where there is a recognised health and care need.

## Real-time population, outcome measures and market information to analyse needs and service provision

We welcome Welsh Government's proposed intelligence-led approach. However, as yet, palliative care need, and planning to meet that need, does not feature on Regional Partnership Boards' Population Needs Assessments. Given the existing need for palliative care and the projected increase in need in the coming decades, as outlined above, this is a significant omission that needs to be addressed in future population needs assessments.

We encourage partnership working with service providers, existing provider networks such as Hospices Cymru, and Hospice UK in Regional Partnership Boards' commissioning of research and mechanisms to collect this information to inform and build their evidence base regarding palliative and end of life care. There is a considerable existing body of research in this space that Welsh Government would benefit from examining prior to further investment.

Hospice UK has developed a population-based needs assessment tool, [PopNAT](#), which enables decision-makers to plan for the future, identify unmet need, and to innovate services based on intelligence about the end of life and palliative care needs of the local population. We encourage Welsh Government and Regional Partnership Boards to make use of this and other existing tools which identify gaps in provision and enable practical action based on evidence.

We are concerned that the proposed cycle of information collection is only every five years. The past year has clearly demonstrated the speed with which demographic and population need changes can occur. We encourage Welsh Government to adopt a more reactive and responsive approach.

We encourage Welsh Government to take into account the fact that providers are, and will likely continue, to face increased demand and pressures in the wake of Covid-19, they are also likely to receive growing demands to provide data. As such, we encourage Welsh Government to adopt a streamlined approach that does not lead to duplication and unnecessary burden on providers.

## Further information

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<sup>i</sup> Etkind, S.N., Bone, A.E., Gomes, B. et al. How many people will need palliative care in 2040? Past trends, future projections and implications for services. BMC Med 15, 102 (2017). <https://doi.org/10.1186/s12916-017-0860-2>

<sup>ii</sup> ONS Dataset: 'Deaths from selected causes by place of death and place of residence in Wales, 2016'

<sup>iii</sup> Hospice UK (2021) 'Hospice Care in Wales: activity and need', based on hospice activity data 2018-19

<sup>iv</sup> Hospice UK (2021) 'Hospice Care in Wales: activity and need', based on hospice activity data 2018-19