

1. About Hospice UK

- 1.1 Hospice UK was founded in 1984 and is the leading charity supporting hospice and palliative care throughout the UK. Our vision is hospice care for every person in need and our mission is to enable hospice care to transform the way society cares for the dying and those around them.

2. About this response

- 2.1 Hospice UK welcomes the opportunity to provide evidence to the Equalities, Local Government and Communities Committee to support its scrutiny of the Public Services Ombudsman (Wales) Bill.
- 2.2 This response draws on the experience of hospices in Wales supporting and caring for people with terminal or lifeshortening conditions, and from the knowledge and experience of Hospice UK working at a national level for people with palliative care needs. We have limited our comments to those issues affecting people who need hospice and palliative care.

3. Context

- 3.1 The Social Services and Well-being (Wales) Act 2014 made amendments to the Public Services Ombudsman (Wales) Act 2005 to the effect that the Ombudsman's remit was extended to cover unresolved complaints about independent palliative care and social care.
- 3.2 Hospice UK and independent hospices in Wales welcomed this change, which provided additional channels of redress for patients and families in circumstances of heightened distress and vulnerability.
- 3.3 The Bill as currently drafted reinstates the 2014 changes. It further sets out the legal framework for complainants to make oral complaints and for the Ombudsman to conduct Own Initiative Investigations in relation to social care and independent palliative care, as per the proposed framework for listed authorities.

4. Part 5: Investigation of complaints relating to other persons: Social Care and Palliative Care

4.1 Patient pathways and integration

- 4.1.1 People receiving palliative care from Independent palliative care providers (hospices) are almost invariably referred to this service from the NHS following treatment for a lifeshorting or terminal condition.
- 4.1.2 A person accessing care from an independent palliative care provider is likely also to be accessing care and support from a range of services simultaneously, including: the NHS through GPs, District Nurses and specialists in secondary care; social care, including domiciliary care or within a care home.

- 4.1.3 The service pathway of a person cared for by an independent palliative care provider is very likely to include NHS, and possibly private health provider, input.

4.2 An equalities approach: regional service provider variation

- 4.2.1 Palliative care in Wales is provided by a mix of independent providers and NHS providers. With reference to inpatient facilities in particular, a local population will often be served *either* by an NHS provider *or* an independent hospice.
- 4.2.2 The Bill as drafted creates a standalone investigation regime for independent palliative care providers (and social care providers). This is separate from the mainstream investigation regime that applies to NHS palliative care providers.
- 4.2.3 Under the Bill as drafted, a complaint made to the Ombudsman by a person supported by an NHS palliative care provider will follow a different investigation regime from a patient receiving equivalent treatment from an independent palliative care provider.

4.3 Issues and inconsistencies requiring clarification

- 4.3.1 The proposed framework where independent palliative care (and social care) follows a standalone investigation regime from the mainstream investigation regime for NHS and private healthcare providers does not appear to follow the principle of “investigat[ing] a whole complaint” (50, Explanatory Memorandum) that has led to the preferred option (Option 2) in relation to “extend[ing] the Ombudsman’s jurisdiction to allow investigation of complaints in a public/private health service pathway” (50). There may be occasions when a person’s complaint about an independent palliative care provider can be best investigated in relation to their care pathway in its entirety, which may also include NHS care.
- 4.3.2 The Explanatory Memorandum sets out that the separate investigation regimes had been taken forward in the current drafting of the Bill in light of the Fourth Assembly’s Finance Committee’s recommendation, despite responses to the consultation on the draft Bill that strongly recommended one integrated system. It notes that
- This was because of the specific nature of social and palliative care and the fact that merging the two regimes would create one very complex and intricate regime. (26)
- 4.3.3 Given the already integrated nature of a service pathway for a person receiving palliative care from an independent provider, Hospice UK is unaware of any specific features of this service that makes it incompatible with a mainstream investigation process by the Ombudsman. We welcome any clarification in this area.
- 4.3.4 With respect to the complexities and intricacies of merging the two regimes, Hospice UK understands from evidence given by the Chair of the Finance Committee, Simon Thomas AM, to the ELGC Committee in Evidence Session 1 on 29 November 2017 that this would have involved complex and technical drafting of legislation. There was also a view that mainstreaming the investigatory regimes was inappropriate given that the Assembly had taken a decision to include independent palliative care and social care within the Ombudsman’s remit as recently as 2014. We would welcome further information about the complexities and intricacies of integrating the investigatory regimes to enable us to comment further on this issue.
- 4.3.5 Failing to integrate the investigation process for all providers in this Bill could be seen as a missed opportunity to improve seamless, integrated provision for complainants. However, Hospice UK does not, in principle, object to a separate investigatory regime for independent palliative care providers (and social care) if the burden of bureaucracy is placed on the Ombudsman and its office rather than the complainant, providing that:

- 4.3.5.1 People escalating complaints to the Ombudsman in relation to independent palliative care providers have the same rights and access as people escalating complaints in relation to NHS providers.
- 4.3.5.2 Clear guidance is provided, both for people escalating complaints and for hospices who will direct persons to the Ombudsman, about how to present a complaint about a service pathway that may include the independent palliative care provider, NHS and social care provision.

5. Definition of “palliative care service” could exclude some users from Ombudsman’s services

- 5.1 Hospice UK is concerned that there is the potential that some people cared for by hospices – those receiving palliative care services in their broadest sense, as well as carers supported prior to and during bereavement – could be excluded from access to the Ombudsman’s services due to the narrow definition of palliative care as set out in the Bill.
- 5.2 Independent palliative care providers take a holistic approach to palliative care. This encompasses a range of person-centred services for both the patient and their carers. Hospice care places equal emphasis on someone’s clinical, physical, emotional, social and spiritual needs and responds by offering diverse care services such as complementary therapies, bereavement support as well as expert clinical care.
- 5.3 In the Bill as currently drafted the Ombudsman may investigate a complaint that relates to an independent palliative care provider if “the independent palliative care provider has received public funding [...] in respect of a palliative care service that it provides in Wales.” (43(2))
- 5.4 Hospices receiving public funding are likely to receive this to deliver a palliative care service with a narrower definition than that adopted by the hospice movement, namely to provide clinical and physical care only.
- 5.5 63(2) states that a “‘Palliative care service’ means a service the main purpose of which is to provide palliative care”, which provides little clarity on what falls within the remit of this definition.
- 5.6 A potential solution is to move away from the specific type of care to the type of provider, e.g. “a non statutory provider of health and care services who has received statutory funding in the last three years”.

6. Own initiative investigations

- 6.1 People in receipt of palliative care, and their families, who are facing end of life are at their most vulnerable and should be afforded all protections to ensure that their care, or the care of a loved one, is not jeopardised, or seen to be jeopardised, by raising a concern. We therefore support the Bill’s policy intention to “protect the most vulnerable” (EM, 16) through the introduction of new powers to the Ombudsman to investigate on own initiative, where criteria are met.
- 6.2 We welcome the inclusion of criteria 45(2)(a) (parallel to 5(2)(a)), which cites the case of “vulnerable or disadvantaged person[s]” who may feel unable to make a direct complaint either to the independent palliative care provider or Ombudsman for fear of “sustain[ing] injustice or hardship in consequence” of making that complaint.
- 6.3 Own initiative investigations must always work in favour of vulnerable and disadvantaged persons. We therefore agree that any changes to the criteria set out in

primary legislation should be subject to the Assembly's affirmative procedure, as per 45(5).

- 6.4 Again, should separate investigatory frameworks for independent palliative care and other listed authorities be retained, people in receipt of care from independent palliative care providers must have the same recourse to the Ombudsman as those receiving palliative care from the NHS.
- 6.5 Further clarification regarding the remit of the Ombudsman and the relevant inspectorate – whether Health Inspectorate Wales or Care and Social Services Inspectorate Wales – is required to ensure there is no duplication of efforts in investigating failures of services or care through “Own initiative investigations”. Hospices registered as charities are also accountable to, and regulated by, the Charity Commission, which issues rules and guidance on delivering public services.