

Written evidence submitted by the Office of Health Economics (ADY0391)

The [Office of Health Economics](#) (OHE) is a charity and Independent Research Organisation accredited by BEIS. Founded in 1962, OHE is the world's oldest health economics research organisation. As a thought leader and publisher in the economics of health, health care, and life sciences, we work in partnership with Universities, Government, health systems and the pharmaceutical industry to research and respond to global health challenges. We receive funding from a variety of sources published in our Annual Reports, and our team also conduct contract research work through a wholly-owned subsidiary, OHE Consulting Ltd, which gift-aids all of its profits to the charity.

Reason for submitting evidence

We are submitting this evidence in fulfilment of our Charitable Objects, including inter alia the promotion of evidence-based health care policy, by carrying out research on the economics of health, health care systems and the life sciences industry; promotion of effective and efficient use of health care resources, by advancing the use of economic approaches to support decision making; and the facilitation of decision making and awareness of health care policy issues, by encouraging debate and dissemination of relevant health economics research.

As background, OHE Consulting Ltd, was contracted by Dignity in Dying in 2019 to estimate the extent of unrelieved pain in England. We summarise our findings below which we believe are pertinent to the scope of this Committee.

Submission of evidence relating to the question:

To what extent do people in England and Wales have access to good palliative care? a) How can palliative care be improved, and would such improvements negate some of the arguments for assisted dying/assisted suicide?

Unrelieved Pain in Palliative Care in England

In England, in 2017 an estimated 378,427 people received palliative care each year in a range of specialised and generalised services. Overall, the quality of palliative care in England and the wider

UK is regarded as excellent. Despite the excellent provision of palliative care in the UK, it is recognised that not all needs are met, especially within community palliative care.

Yet there is little evidence on the level of unrelieved pain in end-of-life patients, nor any understanding of the extent of this unmet need, even if every patient received the very highest standards of care as currently delivered by hospices. Moreover, there is recognition that the application of current best practice protocols for palliative care, such as the WHO's cancer pain ladder for adults or the NICE guidelines, cannot alleviate pain for all end-of-life patients.

In 2019, we assessed the extent of this unmet need by estimating the number of palliative care patients who would have their pain relieved if 'best practice' was adopted, and some projections of how these numbers may change over time. The study focused on England due to the limited availability of data for the entire UK. However, extrapolations are also provided that estimate the number of end-of-life patients with unrelieved pain in Scotland, Wales, and Northern Ireland assuming similar levels of unrelieved pain as reported in England.

This extrapolation is based upon the 2016 mortality statistics for the UK and assumes both similar levels of palliative care need, and similar levels of unrelieved pain in the rest of the UK as is reported in England. According to this extrapolation, an estimate of the current number of people dying UK-wide with unrelieved pain would be between 19,468 (no relief at all) and 152,038 (partial or no pain relief). Applying this same approach to the number of patients who would still experience unrelieved pain even if they received hospice level care, estimates of the UK figures would be 6,394 people (no pain relief at all) and 61,202 (partial or no pain relief).

The estimates presented in this study assume the levels of unrelieved pain in the last three months of life reported by families and carers of patients dying in hospices in England in the National Survey of Bereaved People (VOICES), which was conducted in 2015 by the Office of National Statistics. We know from the VOICES data that reported levels of unrelieved pain are significantly lower in hospices than in other care settings, including hospitals.

At present, the level of unmet need is large: an estimated 16,130 patients are dying in pain, that is, with pain not at all relieved in the last three months of life. If we were to include only adults over 18, the number of patients who experience no relief from their pain would be 15,996. Our estimate of 5,298 patients who would die without any pain relief at all represents an aspirational, best-case scenario where every patient receives the very highest standard of care as provided in hospices.

If the current levels of unmet need in specialist palliative community care continue, it will result in growing numbers of patients whose pain is unrelieved at the end of life, with a projected increase of 21.7% by 2040 in parallel to the increase in deaths.

All of our findings and detailed information on the methodology are available in an [OHE Consulting Report](https://www.ohe.org/publications/unrelieved-pain-palliative-care-england) which is available at: <https://www.ohe.org/publications/unrelieved-pain-palliative-care-england>

The correct citation for the original study is:

Zamora, B., Cookson, G., Garau, M., 2019. Unrelieved Pain in Palliative Care in England. OHE Consulting Report. London: Office of Health Economics.

Related OHE research

Sampson, C.J., 2016. Identifying Objects of Value at the End of Life. In: J. Round, ed., Care at the End of Life: An Economic Perspective. Switzerland: Adis, pp.103–122. [DOI](#).

Shah, K. K., Tsuchiya, A. and Wailoo, A. J., 2015. Valuing health at the end of life: A stated preference discrete choice experiment. *Social Science & Medicine*, 124, pp.48-56. [DOI](#). [RePEc](#).

Shah, K. K., Tsuchiya, A. and Wailoo, A. J., 2011. [Valuing Health at the End of Life: An Exploratory Preference Elicitation Study](#). OHE Research Paper 11/06. London: Office of Health Economics. [RePEc](#).

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