

QE 20

Ymchwiliad i Fil Iechyd a Gofal Cymdeithasol (Ansawdd ac Ymgysylltu) (Cymru)

Inquiry into the Health and Social Care (Quality and Engagement) (Wales) Bill

Ymateb gan Marie Curie

Response from Marie Curie

Written Evidence from Marie Curie

Health and Social Care (Quality and Engagement) (Wales) Bill Consultation

Background

Marie Curie is the UK's leading charity for people affected by terminal illness. We deliver palliative and end of life care directly to people across the UK both in their own homes and in our nine hospices and we run an information and support service which helped over 50,000 people last year. We are also the largest charitable funder of palliative and end of life care research in the UK and we campaign to improve access to and the quality of palliative and end of life care.

In 2018 in Wales, Marie Curie delivered 80,347 hours of care to 2,402 patients through the local health boards. The UK Information and Support Team based in Wales took over 8,000 calls, and thousands more web chat enquires, asking for support and guidance. Marie Curie's Information & Support service provides support and advice to people living with a terminal illness, and those who care for and support them.

Potential barriers to the implementation of the provisions and whether the Bill takes account of them

While previous reviews have led to 'A Healthier Wales' placing an emphasis on the importance of engagement with local citizens, the creation of a Citizen's Voice Body is a crucial step in achieving that goal, and therefore needs to be done with great consideration to the voices involved. It needs to take account of the local knowledge and experience that could be lost through the process of transforming the Community Health Council's into one national body.

While Marie Curie is supportive of the creation of a Citizen's Voice Body, we believe it is of vital importance that the voices of patients who are less able to share their experiences are taken forward appropriately. Every year in Wales, it is estimated that 32,000 people die, and of those, over 6,000 do not have access to the palliative care that they need.

Due to the national nature of the Citizen's Voice Body, there is a strong potential for this body to highlight needs of all citizens in Wales, removing cross border issues, and thinking purely within Health Board regions. This could allow broader decisions. We believe that wherever a patient is in Wales, they should have access to the same level of palliative care and support, putting an end to the post code lottery of end of life care.

While this is clearly an issue that needs more national attention, ensuring that patients along with their carers and bereaved living with a terminal illness are represented on the Citizen's Voice Board is a challenge that needs to be met. Carers of patients experiencing the end of life care process are often the spokespeople for the patient, and should be

incorporated into the board, but provisions should also be made for the patients themselves to contribute.

Therefore, we recommend that health and third sector organisations be allowed to feed into the process of creating the citizen's voice board, and the make up of the citizens chosen to participate.

Unintended consequences of the Bill

NHS England has long benefited (though the survey has now been ended) from a national survey of bereaved people, to discover the experiences of the last three months of the end of life care. The VOICES survey provided valuable data into what needed to be improved to ensure that services were both safe and good quality. We hope that a consequence of ensuring that a duty of candour is implemented, will be that more research is conducted in Wales. This should not just be outcome based but also include the real lived experiences of health services in Wales.

As previously mentioned, transforming Community Health Councils into a single body with a national vision is a key step in ensuring a clearer view of health services across organisational boundaries. It also has the potential to address the balance of 'power' and resource between NHS Wales bodies and the voice of the patient. However, an unintended consequence may be a loss of local data and expertise, at least initially. While Marie Curie is supportive of moving the vision nationally, we believe that further investment in feedback from patients across Wales, needs to be considered. A potential solution to this issue, as stated within the explanatory memorandum, is the increased focus on IT infrastructure behind the board, to raise the profile and increase engagement from local users. This could continue to expand to further encouragement of feedback, and outreach surveys.

If you require more information, please don't hesitate to contact

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