

Vaughan Gething AC/AM
Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol
Minister for Health and Social Services



Llywodraeth Cymru
Welsh Government

Ein cyf/Our ref MA-P/VG/0346/19

Dr Dai Lloyd AM
Chair, Health, Social Care and Sport Committee
National Assembly for Wales
Cardiff Bay
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19 February 2019

Dear Dai,

Thank you for your letter of 18 January 2019 regarding the HSCS Committee evidence session on the cross-party group inquiry into inequalities in access to hospices and palliative care. I will respond to your points in the order you have raised them.

Data Collection

Capturing data at such a sensitive time in people's lives is never going to be easy. However, I do acknowledge that there are gaps in end of life care data collection in Wales and we are working closely with NWIS and the End of Life Care Board to improve the quality of data collected. This includes:

- Considering the future for CANISC, the data collection tool used for end of life care in Wales. Design and implementation of functionality to replace CANISC will provide an opportunity to collect information in the course of documenting the care provided to patients, as well as enhancing the ability to extract this information for secondary uses. It is expected that when this functionality is available, there would be both additional, and more accurate information available about the care that is provided by Wales' Specialist Palliative Care Teams.
- Using the VOICES in Wales pilot project to explore the feasibility of implementing a national survey of bereaved carers by incorporating initial data collection, and invitation and consent to participate, with the process of death registration and the new Medical Examiners' Service.
- Supporting health boards to participate in the National Audit of Care at the End of Life (NACEL) which focuses on the quality and outcomes of care experienced by those in their last admission in acute, community and mental health hospitals throughout England and Wales. This includes a case note review of inpatients in hospital in the last few days and hours of life and an organisational level audit covering service models, activity, workforce, finance quality and outcomes. Both carer and staff views have also been captured for the first time in this audit and we

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Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

will work closely with health boards to ensure that the recommendations are taken forward in a timely manner. We will also be providing feedback to NHS Benchmarking, the provider responsible for delivering the audit to improve the quality of future audits and to ensure that they more adequately reflect Welsh structures. The National Summary report for England and Wales is scheduled to be published on 22 May 2019.

GP Palliative Care Registers

In relation to the benefit of palliative care registers, you are right in your suggestion that being placed on the register serves as a trigger for an appropriate set of actions from the primary care team and for onward referral for relevant support. These actions might include but are not limited to: more frequent reassessment by GP or district nurse; benefits advice; advance care planning; discussion of preferred place of care or other preferences. They are not specific as they will be tailored to individual need. However, the common thread is the identification of need and the timely response to it.

The CPG also questioned the value of palliative care registers and the End of Life Care Board is currently considering what measures it can take to monitor their effectiveness including discussing with academics whether a piece of research could be commissioned.

In terms of seeking assurance that patients are consulted prior to being placed on a palliative care register, this information is only being used and disclosed for direct care so would be covered by existing GP information sharing arrangements, unless it involved sharing information outside of the healthcare team in which case, additional patient consent would be sought.

Pooled Budgets

In terms of progressing pooled budgets with pace, we have recently consulted on draft amendment regulations to:

- Part 9 of the Social Services and Well-being Act 2014, in order to: Provide additional clarity that all local authorities and the health board within a partnership must contribute to the establishment of a single regional pooled fund;
- Specify the focus of pooled funds is limited to care home accommodation for older people.

The consultation closed in October 2018 and officials are in the process of preparing full advice on the consultation responses received.

Additionally, to promote the establishment of pooled funds the Welsh Government had commissioned the Institute of Public Care (IPC) at Oxford Brookes University to undertake an independent review of pooled funds. The independent review supported the potential benefits of pooled funds between local authorities and health organisations and highlighted ways they could help to improve people's wellbeing. Furthermore, the Welsh Government has commissioned Association of Directors of Social Services (ADSS) Cymru to develop a range of practical tools to support regional partnerships.

Bereavement support

The study to identify and gather information on structured bereavement services available in Wales is progressing well. Marie Curie Palliative Research Centre are undertaking this work and have conducted a literature review to identify key themes and questions used in previous bereavement scoping exercises and evaluations to aid development of a bereavement survey. The survey has been amended following peer review and is now being tested with key stakeholders within the field of bereavement support prior to being finalised. It is anticipated that the survey will go live in February 2019 and run for a period of up to 8 weeks. An interim report is expected in the spring, with the final report expected in the autumn.

With regards to carer representation on the Ministerial Advisory Group, I can confirm that a small group has been tasked with developing proposals for how the Engagement and Accountability Group will work with the Ministerial Advisory Group. We expect a paper outlining the relationship between the two groups to be brought to the next meeting of the Engagement and Accountability Group, likely to be April or May. As officials have previously discussed with Catrin Edwards, we remain committed to including a representative of the needs of carers for those at the end of life on the Engagement and Accountability Group.

District Nursing

Thank you for the information on your plans to conduct a short inquiry into community and district nursing. Our approach in 'A Healthier Wales', is about access to the right care at the right time from the right source of help at or close to home. Through our Primary Care Model for Wales, which supports the vision set out in A Healthier Wales, the Welsh Government is committed to investing in the wider primary care team, including district nurses who provide the core universal nursing care service at home.

I would also like to inform you that my officials have written to health board Chief Executives and asked them to set out how they intend to address the specific recommendations for health boards within the Cross-Party Group Report. My officials will continue to monitor progress on these and all the other recommendations in the report.

Yours sincerely,



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