

Vaughan Gething AM  
Minister for Health and Social Services

18 January 2019

Dear Vaughan

At its meeting on 13 December 2018, the Health, Social Care and Sport Committee held an evidence session with members of the Hospice and Palliative Care Cross-party Group (CPG) to discuss the findings of its report *'Inequalities in access to hospice and palliative care: challenges and opportunities'*.

After the session, Members asked that I write to you highlighting the following areas of concern:

### **Data collection**

The CPG reported difficulties in collecting and coordinating data on palliative care use, both for adult and paediatric services. While individual patient level data on specialist palliative care use is recorded, which can provide insight into the number of specialist palliative care services provided at health board and national levels, it cannot provide an accurate figure of the number of people receiving specialist palliative care as many people will access more than one service, including from different providers.

We note that, in accepting Recommendation 9 of the CPG report, you have given a commitment to continue to routinely review data collection mechanisms and take action to improve systems for identify gaps in data *as and when opportunities arise*. However, given the importance of robust data in planning future service provision, we would urge you to increase the priority given to this work.

### **GP Palliative Care Registers**

We note the CPG recommendation that the Welsh Government and End of Life Care Implementation Board should establish a target for increasing the number of people on General Practice Palliative Care Registers and introduce measures to monitor their effectiveness in supporting adults with all life-limiting conditions.



However, in their evidence to Committee, representatives of the CPG told us that they were unclear what it means for people who are put on the register – is this a trigger for them to be referred to appropriate services or to receive appropriate services through their GP. We would therefore appreciate clarification on the benefits to the patient of being included on the GP register.

Further, we would seek assurance that patients are fully consulted prior to their inclusion on the register.

### **Pooled budgets**

Recommendation 5 of the CPG report states that Regional Partnership Boards should make use of pooled budgets to support the delivery of palliative care in care homes.

In accepting this recommendation, you say that this is something that already happens to a certain extent as regulations made under Part 9 of the Social Services and Well-being Wales (Act) 2016 require that regional partnership boards established pooled funds in relation to their care home accommodation functions from April 2018. The Welsh Government would expect therefore that these pooled funds would already include meeting the costs of any identified palliative care costs when care is commissioned.

However, representatives of the CPG told us it would appear that this is slow in progressing, and regional partnership boards are only just beginning to think in terms of pooled budgets. We would therefore ask you to ensure regional partnership boards progress this with pace.

### **Bereavement support**

The CPG report highlights the necessity of appropriate bereavement support (including pre-bereavement support) for families and carers through and beyond their caring journeys. Despite the importance of this service to those affected by death and dying, the CPG told us of cut backs in bereavement support, particularly specialist bereavement counselling, from both the statutory and third sectors. Hospices continue to offer this vital service but report increased pressure on the services they provide in response to service closures elsewhere.

Your response to Recommendation 6 of the CPG – *The Welsh Government Ministerial Advisory Group for Carers should address the specific support needed by carers of people at the end of life* – states that Welsh Government officials met Catrin Edwards of Hospice UK on 17 July and discussed how the interests of carers of people at the end of life could be represented in the Engagement and Accountability Group.



We would appreciate an update on this work.

### **Community nursing**

The CPG report highlights issues around workforce pressures – specifically shortages of GPs, district nurses and community paediatric nurses who coordinate and deliver the day-to-day care of people with palliative care needs in the community.

In evidence to the Committee, representatives of the CPG told us that “district nursing is absolutely the bedrock of care for people at home and if there was one thing that we could change that would make a massive difference for people to be cared for at home for as long as possible, it’s investment in district nursing.”

In light of this, and representation we have received from the Cross-Party Group on Nursing and Midwifery, the Committee has agreed to undertake a short inquiry into community and district nursing.

I look forward to receiving your response to the issues raised above in due course.

Kind regards



Dr Dai Lloyd AM  
**Chair, Health, Social Care and Sport Committee**

