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Ysgrifennydd y Cabinet dros Iechyd a Gwasanaethau  
Cymdeithasol  
Cabinet Secretary for Health and Social Services



Llywodraeth Cymru  
Welsh Government

Ein cyf/Our ref: MA-P-VG 2796-18

Mark Isherwood AM  
Chair, Cross Party Group on Hospices and Palliative Care  
National Assembly for Wales  
Cardiff Bay  
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4 September 2018

Dear Mark

Thank you forwarding the final version of the Cross-Party Group (CPG) Hospices and Palliative Care Inquiry into inequalities in access to hospice and palliative care.

As you know I attended the CPG group meeting on 11 July to provide an initial response to the recommendations within the report and advised that I would be providing a more formal response once I had had time to fully consider the report over the summer months. Please accept this letter as the Welsh Government's formal response to the CPG report.

I would like to again reiterate my thanks, the secretariat and the members of the CPG for the time that you have taken to consider this often difficult subject and for producing a balanced report that focuses on both good practice as well as highlighting the challenges that need to be addressed.

The Welsh Government aim is for people in Wales to have a healthy, realistic approach to dying and to be able to plan appropriately for the event. We want them to be able to end their days in the location of their choice – be that home, hospital or hospice and we want them to have access to high quality care wherever they live and die, whatever their underlying disease or disability. That is why we continue to provide over £8.4 million annually and have identified end of life care as one of the areas that we will be focusing on in 'A Healthier Wales: our plan for Health and Social care in Wales'.

There are 11 recommendations in total and I will respond to each in the order that they are set out within the report.

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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.

**Recommendation 1.** *The Cabinet Secretary for Health and Social Services should monitor, and have oversight of, progress against shared priorities between the Palliative and End of Life Care Delivery Plan and other Health Delivery Plans.*

**Accept** - This is already happening and many of the mechanisms to implement this recommendation are already in place. The Chief Medical Officer chairs a meeting of all clinical leads on a quarterly basis, Implementation Group co-ordinators are also convened on a quarterly basis and I meet with all 9 chairs of the major health conditions implementation groups together on an annual basis. Each of these meetings includes time for consideration of shared priorities, identification of common areas of interest and to seek opportunities to work collaboratively across the delivery plan agendas.

My officials are represented on all the implementation groups and promote collaborative working through regular attendance at health board medical directors, directors of primary care and director of therapies meetings. All of the implementation groups are chaired by health board/trust chief executives or executive directors and a number of the other health delivery plans such as the cancer, heart conditions and respiratory plans all contain end of life care actions within their plans.

The End of Life Care Board has previously collaborated with the Cardiac and Renal Networks and plans are in place to work with mental health and dementia teams to provide joint training around future care planning.

We will use these mechanisms to continue to seek further opportunities for progressing our shared priorities between end of life care and the other health delivery plans.

**Recommendation 2.** *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.*

### **Accept in Part**

Year on year, numbers of patients on palliative registers are increasing. The palliative care practice register is maintained within the Quality and Outcomes Framework (QOF) and the frequency of multidisciplinary team (MDT) discussion is captured within QOF. The current contract introduced in 2014-15 also supports the review of the delivery of care at the end of life through case reflection to identify service development issues, barriers to the delivery of care and examples of good practice. Practices will develop plans based on population need, while individual health boards will provide updates.

Last year's annual statement of progress for the End of Life Care Plan showed that:

- 10,013 people were registered on a QOF palliative care register; this is an increase of over 62% since 2011-12.
- 11,171 patients received specialist palliative care. This is an increase of 5.4% from 2015-16. Of these, 60% (6,733) patients were under the care of the specialist care team in the 90 days prior to their death.
- 49.3% of all patients' deaths were supported by specialist palliative care, of these 69.2% of people who died from cancer, compared to 51.9% in 2015-16 and 24.6% of patients with a non-cancer diagnosis received specialist palliative care, an increase of almost 8%.

The Annual Statement of Progress estimated that of the 33,000 people who die in Wales each year, around 24,000 of these will require palliative care of some sort. Of these just over 10,000 are recorded on a GP palliative care register (2016-17) and will be in receipt of either supportive or generalist palliative care.

This suggests that GPs in Wales are probably capturing about a third of those with palliative care needs on a primary care palliative care register. Not being on the register does not mean that an individual is not known to the practice, or is not getting adequate palliative care. However, patients not on a "register" may be less likely to be getting comprehensive, co-ordinated, palliative care. Better information should become available when a unified clinical record is introduced.

Some people, particularly those with more complex conditions, will require access to specialist palliative care. In 2016-17, 15,459 patients received specialist palliative care from health boards across Wales; of these, 6,733 patients were referred to specialist care within 90 days of their death. This is an increase in total referrals of 3.3% from 2015-16, but a decrease of 1.4% in those in the last 90 days of life, suggesting the specialist palliative care teams are being involved earlier in patients' final illnesses, as well as more patients accessing specialist input.

Setting targets is not straight forward as QOF data identifies palliative care need only, not the actual diagnosis and whether care is of good quality. Placing greater numbers on a register can not be taken as improvement in care. Clinical data on quality of care will be held as part of the clinical record during the MDT and can be made available through practices.

It is therefore important that we get the right people on palliative care registers. We will consider what actions can be taken to increase the number of people with palliative care need who are on general practice palliative care registers and receiving best possible care.

**Recommendation 3.** *Charitable hospices and health boards should demonstrate how they promote improved awareness of the breadth of hospice and palliative care services.*

**Accept** - Whilst this is not a direct recommendation for Welsh Government, it is one that we are happy to support. Too often people see hospices as simply a place where people go to die with the associated negative connotations, but hospice care is about so much more than that. They provide a wealth of life enhancing services for those in need of palliative care and anything that can improve people's knowledge and understanding of these services is to be encouraged.

**Recommendation 4.** *Health boards should demonstrate how they consider end of life care needs in determining their out of hours coverage and work cooperatively to resource paediatric out of hours services at an all-Wales level.*

**Accept** - Again this is not a recommendation for the Welsh Government but is one we would actively support. The NHS 111 service in Wales will bring together the existing NHS Direct Wales services with the GP out of hours call handling and initial triage. NHS 111 in Wales will offer a single number for accessing out of hours health care in Wales, this will be linked to services that provide out of hours service and sign post patients to these.

111 will provide a real opportunity to co-ordinate and manage the demand of unscheduled care for NHS Wales, meet the needs of patients within their own communities, avoid unnecessary hospital admission and reduce demand on acute hospital services. The 111 number has been rolled out and is available in Abertawe Bro Morgannwg UHB and the

Carmarthenshire area of Hywel Dda UHB. There are plans in place to roll the number out in other parts of Wales later this year.

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

**Accept** – This is something that already happens to a certain extent. Regulations 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. These pooled funds are intended to support improved joint commissioning arrangements. 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.

Regional partnership boards are required to produce an annual report setting out how they have improved well-being outcomes. This would include setting how their pooled fund has supported improved commissioning arrangements.

**Recommendation 6.** *The Welsh Government Ministerial Advisory Group for Carers should address the specific support needed by carers of people at the end of life.*

**Accept** - Last November the Minister for Children, Older People and Social Care announced three national priorities for carers to help focus the work of Welsh Government and our partners in the statutory and third sectors on driving improvements for carers. Those priorities are:-

- Supporting life alongside caring
- Identifying and recognising carers
- Providing information, advice and assistance

The Minister also announced that he would be forming a Ministerial Advisory Group on Carers to target and monitor improvements against the three national priorities. The Group met for the first time on 27 June 2018. It is designed to improve the experience of carers of all types, recognising that carers in different circumstances will have different support needs.

The Ministerial Advisory Group needs to have members who are in a position to drive and influence change and also to be small enough to work effectively as a group. On that basis, it was not possible for large numbers of carers to join this group, nor for every different 'type' of carers' interest to be represented on the group. But that doesn't mean that the group will not pick up on those different needs. The Minister has committed to establishing an Engagement and Accountability Group to support the Ministerial Advisory Group. This group will allow for the representation of a much more diverse range of carers than is possible on the Ministerial Advisory Group itself. Ideas for establishing this group were discussed at the first meeting of the Ministerial Advisory Group.

Welsh Government officials met Catrin Edwards of Hospice UK (Secretariat to the CPG) 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.

**Recommendation 7.** *The End of Life Care Implementation Board should develop a robust action plan to address shortages in community nursing for both children and young people, and adults with palliative care needs.*

**Accept** – Much work has already been done to attract more nurses to Wales. NHS Wales is seeing and treating more people than ever before and our health service is meeting this challenge - in fact there are now more nurses working in NHS Wales than ever before. This should be recognised and celebrated. However, we are not complacent and recognise there are very real challenges around the recruitment of nurses in primary and secondary care and within the third sector that provide support in palliative care and end of life care.

The Welsh Government is committed to actively supporting health boards to meet the needs of the Nurse Staffing Levels (Wales) Act and understand what sufficient staffing looks like and will continue to work with health boards & trusts across Wales on approving Integrated Medium Term Plans recognising that our workforce underpins services. Section 25A of this Act sets out the NHS health boards and trusts duty to have regard to providing sufficient nurses to allow time to care for patients sensitively. It also clarifies that this applies both where nursing services are provided *and* where they are contracted or commissioned. This includes services commissioned to provide palliative care and end of life care.

However, it is a reality that there is a shortage of registered nurses not only here in Wales and the UK, but internationally with all developed countries reporting shortages in registered nursing staff. We continue to increase the level of investment in the future workforce of NHS Wales. In December 2017 there was an announcement of a £107m package to support education and training programmes for healthcare professionals in Wales. This represents a £12m increase on the package agreed for 2017/18 and will enable more than 3500 new students to join those already studying healthcare education programmes across Wales. The total number of people in education and training places for 2018-19 will be 9,490 compared to 8,573 in 2017-18.

This package includes a 10% increase in the number of nurse training places – an extra 161 – which will be commissioned in 2018-19. This is in addition to the 13% increase in 2017-18; the 10% increase in 2016-17 and the 22% increase in 2015-16 and continues our investment in nurse education numbers. In addition we are maintaining the student bursary for 2019-20 demonstrating our commitment to nursing – the condition for students who receive the bursary to commit to working in Wales post qualification, includes working in hospices as well as the NHS. We also provide help for staff to return to practise with funding up to £1,500 and we have retire-and-return schemes which enable us to utilise the experience these staff have.

In 2014-15 we were commissioning 24 district nurses training places, this increased to 41 places in 2015-16 and increased again to 80 places in 2017-18, this is over a tripling of our commissioned places. Further to this in 2018-19 additional resource through the Plaid Cymru budget compact of £1.4m has been set aside to support the release of community nurses by health boards to train as district nurses and to maximise the opportunity the additional commissioned places has provided.

We also launched in May 2017 our national and international campaign “*This is Wales: train, work, live*”, extended to nursing, resulting in significant interest from overseas nurses as well as from nurses across the UK. We have already started to see nurses recruited into NHS Wales as a result of this campaign and we will continue to work with our health boards to build on these early successes.

We will work with the End of Life Care Board to consider what further steps can be taken to address shortages in community nursing for both children and young people, and adults with palliative care needs.

**Recommendation 8.** *The Welsh Government should introduce enhanced mandatory training in palliative care for hospital-based clinical staff.*

**Accept in Part** – To train all hospital based clinical staff in palliative care would not be practical or necessary. However, it is accepted that more can always be done to increase the number of professionals trained.

The call for mandated training in all areas of clinical care has to be considered within the overall context of the mandatory training programme which is already substantial and is principally aimed to ensure the safety of patients, health professionals and NHS Wales. However, where staff identify end of life care training as part of their appraisal, we would expect health boards to facilitate such training.

Health boards also receive funding from the Welsh Government and the End of Life Care Board to increase capacity in specialist palliative care teams with a specific intention, not only to provide direct care, but to create learning opportunities across the spectrum including both structured and non structured training for all care givers.

In 2015-16, the Welsh Government provided funding to create the 'serious illness conversation' training programme which acknowledged that staff without specialist training frequently cared for patients with end of life care needs and required specific training to enable them to recognise the patient was dying and to equip them with the skills to begin the relevant conversation. To date, this successful programme has reached 542 professionals including WAST and prison service teams. In addition, a number of online training programmes have been made available, including a bespoke online training programme for WAST and Talk CPR video books provided to each GP practice in Wales. In addition a GP 'Short Course' in palliative medicine has successfully trained approximately 500 GPs throughout Wales in basic specialist palliative care knowledge and skills

Many health and care professionals are required to undertake specific qualifications before they are able to practice. It is important to understand the contents of the current education and training programmes and to assess whether it is a matter of changes to these programmes or additional training that is required. For instance there is a plan at UK level to increase the palliative care content of postgraduate training in general (internal) medicine, following the 'Shape of Training' review report published in 2013. A wider analysis of what already exists is needed. On the basis of this analysis we will consider what more can be done in terms of training in palliative care.

**Recommendation 9.** *The Welsh Government and End of Life Care Implementation Board should identify gaps in data collection on adult and paediatric palliative care needs, and take steps to fill these, to ensure service planning and design is based on need.*

**Accept** -. The Social Services and Well-being (Wales) Act requires local authorities and health boards to jointly undertake an assessment of the population to determine the care and support needs in an area. Once this assessment has taken place, consideration to how palliative care will be provided will need to be taken into account based on existing services. Not all patients with palliative care needs require specialist input – things like access to voluntary hospice care and levels of additional community support will also be considered.

Welsh Government through the End of Life Care Board has allocated funding to work with NWIS to improve data collection through the transfer of the Canisc module onto an updated platform. Residual funding from 2017-18 was allocated to voluntary hospices to work with the Canisc lead on the End of Life Care Board to improve the ability to access key systems and consequently improve data collection and analysis in this area.

Establishing actual need on a real time basis is very difficult for two reasons. Firstly, that need is very much dependant on an individual, their circumstances (e.g. where they are living, are they alone, do they have complex co-morbidities) and their illness and its prognosis which is much harder to predict in some diseases than others.

Secondly, there is a significant difference between specialist palliative care and end of life care with the former needing to be provided by a palliative care specialist and the latter invariably provided by a generalist or other specialities with the support of a palliative care specialist if necessary hence the 24/7 on call rota of consultants and Clinical Nurse Specialists.

Research undertaken by the Cicely Saunders Institute puts need at around 75% of the dying population. The End of Life Care Board annual report suggests that around 49.3% are being seen within specialist care only.

We will continue to routinely review our data collection mechanisms and take action to improve our systems for identifying gaps in data as and when opportunities arise.

**Recommendation 10.** *The End of Life Care Implementation Board should support health boards and NHS trusts to improve their accountability by developing consistent reporting criteria to measure progress against meeting national palliative care priorities.*

**Accept** – This is something we already do. Annual reporting mechanisms changed in 2017 with health boards being required to submit annual progress reports to the End of Life Board rather than published annual reports. Health boards use a template to provide this information and focus on local priorities, achievements and areas for improvement. These will vary according to local need and resource. Health boards are required to report against specific reporting criteria which is then used to inform the annual report submitted by the End of Life Care Board to the NHS Chief Executive.

Data for palliative care is managed via the 'Canisc' system and the current Canisc data provides shared reporting measures which can be compared. More work could be done for health boards to be more consistent in how they produce their reports to enable comparison and ensure that their report should be easy to find on their websites.

The Acute Hospitals audit undertaken in 2016 and repeated in 2018 provides good data and allows comparison between Health Boards and with NHS England.

**Recommendation 11.** *The Welsh Government and End of Life Care Implementation Board should ensure that the funding of charitable hospices is regularly updated to ensure it is based on current local population need and prevalence data.*

**Accept in Part** - The funding formula was developed in 2009 and used as the basis for increased funding to provide an equitable platform on which to deliver palliative care throughout Wales. Funding at this time was allocated to voluntary hospices directly from the Welsh Government through the End of Life Care Board and also through service level agreements with Health Boards.

In June 2014, the First Minister confirmed in a statement that from 2015-16 all funding would be transferred to Health Boards for future allocation. The then Minister for Health and Social Services agreed to this funding being ring-fenced for three years, ending in 2017 and many voluntary hospices will have renegotiated funding with their individual Health Boards. Voluntary Hospices are also able to benefit from clinical support such as Palliative Medicine Consultants and Pharmacy Services teams employed within NHS Wales and other forms of statutory funding such as Wanless funding which is recurring. In addition, for patients who

meet continuing healthcare criteria, hospice at home providers are able to access this funding.

The current position is that funding for charitable hospices in all its forms has been devolved to health boards and we expect that they will develop their plans in line with the priorities of the end of life care delivery plan in place at the time. There are a number of variables that make need for charitable capacity different across health boards. These include the extent to which the NHS has specialist palliative care beds and community based services, the characteristics of the population in particular its age profile and the pattern of existing charitable provision.

We will work with the End of Life Care Board to review the way in which funding is allocated, in doing so moving away from the use of an arbitrary formula (which might work for one area and not another) to a system that is based on local determination of need.

Yours sincerely

A handwritten signature in black ink that reads "Vaughan Gething". The signature is written in a cursive style with a large initial 'V' and a long, sweeping tail on the 'g'.

**Vaughan Gething AC/AM**

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Cabinet Secretary for Health and Social Services