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Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol  
Minister for Health and Social Services



Llywodraeth Cymru  
Welsh Government

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David Rees AM  
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National Assembly for Wales  
Cardiff Bay

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17 July 2014

*Dear David,*

**HSC Committee 26 June - Cancer Delivery Plan Inquiry Session**

At the Health and Social Care Committee on 26 June I agreed to provide Members with information on the following;

1. a note on the delivery of treatment and services for patients with neuroendocrine tumours at an all-Wales level, as an example of services being delivered for the less common cancers;
2. confirmation that the technology is in place to support the timely reporting at GP, GP cluster and national levels of the reviews of lung and gastrointestinal cancer cases dealt with by each GP in Wales in 2014;
3. a note to update the Committee on the 'trialogue' discussions of the draft EU regulations on data protection, and the potential impact on cancer research in Wales;
4. the paper submitted by Public Health Wales to the House of Commons Science and Technology Committee's inquiry into National Health Screening;
5. a note on whether there is resource and capacity for bowel scope screening to be provided in Wales.
6. provide your views about the concerns expressed in relation to the iWantGreatCare surveys;
7. set out the actions that you are taking to ensure everyone has equitable services and access to end-of-life care.

1. Neuroendocrine Tumours (NETs) are rare (4 per 100,000) and particularly difficult to diagnose as the symptoms are often identified as other conditions. While there is only one specialist centre in Wales, the Multi Disciplinary Team for Neuroendocrine Tumours, based in Cardiff, supports the diagnosis and advice on treatment options for patients throughout Wales. In delivering treatment patients are referred to various specialist centres across the UK, whilst patients in the Cardiff and Vale LHB area are treated in the Cardiff centre. For rarer cancers, where services can not be delivered by individual LHBs, responsibility for ensuring services across LHBs are delivered will fall to either WHSSC or the Cancer Networks.

2. The current technology allows for GP referral activity to be reported in real time. It does not, as yet, allow for capture of the analysis of pathways of care though this is the ambition of the Cluster work. For 2014/15, GP practices will review the care of patients newly diagnosed with lung or digestive system cancers which will have a specific focus on the diagnostic process, the appropriateness and speediness of the diagnosis and learning points to be used in GP cluster discussion to understand better the patients experience, to identify learning points and to act on that learning.

A workshop is planned for October 2014 to collate the priorities identified by Cluster networks, and this will include priorities for information and technology development for officials to take forward in discussion with NWIS and stakeholders. As part of this, officials will be working with the Cancer Network to explore what data is required at each level to ensure continuous learning and service development. Primary Care Clinical Leads will also be gathering examples of good practice to inform data analysis and reporting in the future. This builds upon the work of individual practices and the Royal College of GPs and Macmillan GP Advisors who are supporting practices and local networks to improve early diagnosis and cancer outcomes.

Key GP cluster themes and actions will be part of GP Cluster Network Annual Report.

3. The Welsh Government does have concerns over the potential impact of the proposed EU Data Protection Regulation on use of data to support NHS service delivery, and particularly the potential damage to health and scientific research.

Scientific research generates many important benefits by improving our understanding of society, health and disease. However, the EU Parliament has recently accepted amendments to Articles 81 and 83 of the proposed Data Protection Regulation as part of a block vote supporting all proposed amendments. These amended Articles as they stand provide a significant threat to health and scientific research - making much research involving personal data at worst illegal, and at best unworkable.

The original draft Regulation set out a proportionate mechanism for protecting privacy, whilst enabling health and scientific research to continue. It included a requirement for specific and explicit consent for the use and storage of personal data, but provided an exemption for research. This approach recognised that individuals' interests can be protected through robust ethical and governance

safeguards, such as approval by a research ethics committee. The amended versions of Article 81 and 83 significantly reduces the scope of this research exemption. The use of personal data in research without specific consent would be prohibited, despite the fact that this research is subject to ethical approval and strict confidentiality safeguards.

If enacted, the current draft of the EU Regulation would put at risk significant Welsh, UK and European investments in research, including genetics, cohort studies, biobanks, disease registries and the use of routinely collected data to support research.

For example, Welsh Government has invested more than £7 million in the Secure Anonymised Information Linkage (SAIL) databank to date, including £3.9 million from the National Institute for Social Care and Health Research (NISCHR). The novel methodologies used by SAIL allows routinely collected data to be anonymised and linked so that it can be utilised for research in a safe and secure way. The capacity and expertise that has been developed to support and enhance the conduct of health and social care research will be seriously undermined, and significant achievements will be left redundant if Article 81 and 83 of the current draft Regulation are adopted.

The Ministry of Justice is leading negotiations with EU on behalf of the UK in order to find a way to ensure that the Regulation can protect valuable research while protecting privacy. Welsh Government officials in NISCHR have provided briefing, along with other UK health departments, Research Councils and medical research charities, to support Ministry of Justice in lobbying for change to the proposed EU data protection regulation.

The EU Justice and Home Affairs Council is currently working towards an agreed position for the EU Council on the draft Regulation, with the next meeting of the Council scheduled for October 2014. Once the EU Council formally adopts a position on the draft Regulation, trilogue discussions between the Parliament, Council and Commission will begin.

Welsh Government officials will continue to support Ministry of Justice colleagues in raising the issue of the damaging implications and influencing a change to the current proposed Regulation as the legislation passes through the EU Council and trilogue processes.

In my oral evidence I suggested that the Health and Social Care Committee might consider sending a letter to the Minister for Justice to encourage efforts to lobby against the amendments to Articles 81 and 83 of the draft EU Data Protection Regulation.

4. A copy of the Paper by Public Health Wales to the House of Commons Science and Technology Committee's inquiry into National Health Screening is attached at Annex A

5. In March 2010, the UK National Screening Committee (UK NSC) recommended the introduction of flexible sigmoidoscopy (FS) to the existing bowel cancer screening programme. This recommendation was followed by a commitment from the Department of Health to invest £60m for the development of a FS screening service in England. The pilot of FS screening for people aged 55 years in England started in March 2013 and is rolling out incrementally aiming to achieve national coverage by the end of 2016.

Scotland started a pilot in January 2013 in four health boards and is currently inviting people aged between 59 and 61 years of age. The pilot will be time limited and formally evaluated before a decision on the way forward is made. There are no plans to implement FS in Northern Ireland.

A decision to introduce FS as a screening programme in Wales has not been made. Currently, PHW is working with Professor Wendy Atkin, who led the original trial in 2010, to ascertain the potential impact of a FS screening programme on the population of Wales. This work will inform the feasibility of having such a programme that complements the existing bowel screening programme.

Flexible sigmoidoscopy only looks at the left side of the bowel, where the majority of polyps and bowel cancers start, therefore faecal occult blood (FOB) screening still needs to remain to cover cancers arising in the right side of the bowel.

The Wales Screening Committee discussed FS at its June meeting. The benefits of this screening intervention were recognised, however it was agreed that implementing such a service in Wales would be challenging given the current low uptake of bowel screening by FOB, and within the current endoscopy provision.

6. We recognise the importance of the patient voice in improving services, particularly at the end of life when understanding the needs of the individual are essential to providing effective services. As the Marie Curie report 'Listening to Dying People in Wales' states, our Delivering End of Life Care Plan emphasises the strong role patient and family feedback plays in improving services.

The Marie Curie Palliative Care Research Centre (MCPCRC), Cardiff University, recently undertook a study of [iwantgreatcare](http://www.iwantgreatcare.co.uk) to;

- o Establish whether the questionnaire is understandable in terms of content, wording and sentence structure;
- o Explore whether the questions are pertinent to participants;

As a result of this study a number of changes to the survey are being made to drive up participation and make the survey tool more user friendly. This includes simplifying its user interface and removing complex wording from the document. The survey remains a good tool for capturing in real time the views of patients in the service, the changes made following review will drive up participation.

7. Actions to ensure equitable end-of-life care services are set out in the Delivering End of Life Care Plan. Some achievements in this area include:

- Establishment of seven-day working by clinical nurse specialists and access to Consultant advice 24/7 throughout Wales.
- Funding for specialist and respite hospice beds and development of Hospice at Home services.
- Improving access 'out of hours' to emergency drugs and an anticipatory prescribing programme, through 'Just in Case' boxes.
- A funding formula for specialist palliative care services, ensuring a minimum level of specialist service across Wales (£6.4m distributed by Welsh Government to support services).
- Healthcare support workers appointed into specialist acute teams to assist in meeting patients' priorities at the end-of-life by supporting families, maintaining dignity and respect for patients in the terminal phase, particularly in busy acute settings.
- Formalised links throughout Wales between clinical nurse specialists and nursing homes to support staff caring for residents with end-of-life care needs.
- Development of a palliative care clinical information system.
- A national patient evaluation programme (Iwantgreatcare)
- Wales palliative care website with open access providing information on all aspects of clinical care and strategic work programmes.
- Development of a GP short course in palliative care

*Best wishes,*

*Mark.*

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