

Russell George MS
Chair, Health and Social Care Committee
Senedd Cymru / Welsh Parliament
Cardiff Bay
Cardiff
CF99 1SN

1 February 2023

Dear **Russell**

Prioritisation of the Rare Disease Action Plan for Wales 2022-26

I am writing to the Committee in light of the recent budget scrutiny session that the Committee undertook with Ministers and officials on 11 January 2023.

While it is understood that the Welsh NHS continues to find itself in an extremely challenging and pressurised environment both operationally and financially during this winter period, I am concerned that in the evidence provided by the Health Minister, she failed to prioritise the Welsh Government's commitment to improving the lives of people living with a rare disease in Wales during the forthcoming 2023-24 financial year.

As a founding member of the Cross Party Group on Rare, Genetic and undiagnosed conditions, you will recall when the Rare Disease Action Plan for Wales (RDAPW) 2022-26 was published last summer, the Welsh Health Circular (WHC) that accompanied the Plan, set out clear expectations for Health Boards to facilitate and implement the priorities and actions in the Plan over its lifetime. The WHC said:

*"Health boards should take account of the priorities for rare diseases when planning their services and developing their Integrated Medium-Term Plans (IMTPs)."*¹

However, in the Health Minister's evidence to the Committee, she was unambiguous in stating that she had issued new guidance to Health Boards, for this forthcoming financial year, based on six identified priorities. She said:

*"What we've got to do is to try and give them (Health Boards) an indication of where we'd like them to focus their spend. In the guidelines in preparation for their IMTPs, I've just made it absolutely clear that I want them to focus on six areas."*²

She went on to set out what those six priorities were:

1. Delayed transfers of care
2. Improving access to primary and community care
3. Urgent and emergency care (six goals)
4. Planned care and recovery
5. Cancer
6. Mental Health (including CAMHs)

We know from the *National Clinical Framework: A Learning Health and Care System* published in 2021, that the Government's strategic vision of a health system in Wales is one that is "co-ordinated nationally", because greater central direction helps shape behaviour but is "delivered locally" by those directly responsible for their respective populations, through collaborations, between health organisations and partners. The Government states that this approach "ensures local ownership" and a "thriving innovation agenda."

That means if the Welsh Government does not prioritise and coordinate the delivery of a particular policy agenda with Health Board partners, then there is no formal requirement for those partners to implement that agenda into their medium-term planning cycle.

Given that the RDAPW is still in its first year of implementation, it is absolutely critical that Health Boards do not lose sight of embedding the four key priorities, both in financial and operational terms, into their IMTPs. Those four priorities are:

Priority 1 - Helping patients get a final diagnosis faster

Priority 2 - Increasing awareness of rare diseases amongst healthcare professionals

Priority 3 - Better coordination of care

Priority 4 - Improving access to specialist care, treatment, and medicines

As you know, the Rare Diseases Implementation Group (RDIG) brings together delivery partners to develop and monitor Wales progress. Unlike other clinical implementation groups in Wales, the RDIG has had no core funding to help them facilitate this work; so they are already at a disadvantage. Moreover, as the new NHS Executive, which will bring together all the national clinical programme networks and implementation groups, continues to evolve, this will also impact on the operating function of the RDIG in terms of its monitoring and reporting timelines.

We know that people with rare diseases and their families often face a lifetime of complex care, which is often disjointed and that has a significant and detrimental impact on their education, financial stability, mobility and mental health. Therefore, it is vitally important that the voice of the rare disease community is not lost in this current extremely challenging period. Only by fully prioritising and committing to the comprehensive implementation of the RDAPW, will Wales have the ability and opportunity to achieve significant change and improvement in the care and treatment of people living with a rare disease.

I hope that as a Committee, through your scrutiny deliberations and reporting to the Senedd, you will take this matter into account and request that Government do not lose sight of the many policy commitments it has made beyond the six priority areas highlighted by the Minister, particularly those that effect this particularly vulnerable group of patients and their families.

Best wishes,

A handwritten signature in black ink that reads "Victoria Hayes".

Victoria Hayes

Director of Public Affairs, Northern Cluster, Kyowa Kirin

References

¹ Welsh Health Circular (2022/017), *Wales Rare Diseases Action Plan 2022 – 2026*, Welsh Government, 16 June 2022.
https://www.gov.wales/sites/default/files/publications/2022-06/wales-rare-diseases-action-plan-2022-2026-whc-2022-017_3.pdf
(As accessed on 1 February 2023).

² Transcript of Health and Social Care Committee (Section 8), 11 January 2023.
<https://record.senedd.wales/Committee/13294>
(As accessed on 1 February 2023).