

Rare Disease Action Plan for Wales and patients with X-linked hypophosphataemia (XLH)

When the Rare Disease Action Plan for Wales 2022-26 was published last summer, the Welsh Health Circular that accompanied the Plan (WHC-2022-017), 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). Given that the Action Plan is still in its first year of implementation, it is extremely important that the Health Board embeds the Plan's four key priorities, both in financial and operational terms, into their IMTPs

Therefore, could you update me please on:

- 1. How is the Health Board is implementing the Rare Disease Action Plan for Wales and what progress has been made on the four priorities to date, including identifying actions, delivery partners, timelines and outcome measures?**

The Health Board is currently developing a local rare disease action plan to ensure all priorities in the Rare Disease Action Plan for Wales are met. This includes mapping the patient journey to identify any potential pathway developments and/or improvements; and ensuring easy access to information.

The Health Board are also actively engaged and working with the All-Wales Rare Disease Implementation Group to ensure any agreed actions are incorporated into our local action plan.

- 2. How many patients with X-linked hypophosphataemia (XLH) is the Health Board currently treating?**

The Health Board does not hold this information. The Health Board currently commissions tertiary services for patients with this condition from [Cardiff & Vale University Health Board](#) . Therefore, you will need to contact them directly.

- 3. For those patients with XLH, how is the Health Board improving care coordination, as well as access to specialist care, treatment, and medicines.**

Please refer to Q2.