



Llywodraeth Cymru  
Welsh Government

PUBLICATION, DOCUMENT

# Refresh of the rare disease action plan 2022 to 2026 (WHC/2023/041)

A refresh of the NHS's actions and measures to improve care and outcomes for rare diseases in Wales.

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**Required by:**

- all health boards
- Health Education and Improvement Wales
- Welsh Health Specialised Services Committee (WHSSC)

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# Enclosures: Wales rare diseases action plan refresh 2022 to 2026

## Summary

The purpose of this Welsh health circular is to highlight the publication of the 'Wales rare disease action plan refresh (2022 to 2026)'.

## Action

Health boards and NHS trusts, where appropriate, are asked to work with WHSSC, Rare Disease Implementation Group (RDIG), third sector and other relevant organisations to facilitate and implement the priorities and actions outlined in the Wales rare disease action plan.

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

## Wales rare diseases action plan refresh

**The 'Wales rare diseases action plan refresh 2022 to 2026' is available on the NHS Executive's website.**

On January 9 2021, the 'UK rare diseases framework' was published. Following this the 'Wales rare disease action plan' was published in June 2022 to outline the approach taken within Wales.

In 2023, the NHS Wales Executive was launched. Within this new organisation

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RDIG will develop into a Wales Rare Disease Implementation Network (WRDIN). The aim remains the same, to bring together delivery partners to develop and monitor Wales's version of the new action plan. The four main priorities have been identified in the UK Framework:

- 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

This framework sets out the actions needed to improve outcomes in these priority areas.

Whilst the framework remains a UK-wide document, each of the four UK nations operates its own delivery or implementation group / network responsible for drafting and monitoring nation-specific action plans. Tailored to the needs of individual populations, while working together through the UK Rare Diseases Framework Board, the national teams ensure as much alignment across the four nations as possible.

As part of the agreement within the UK Rare Disease Framework Board, Wales, Scotland and Northern Ireland decided to do a refresh each year as opposed to England who publish a new plan each year.

Within the Wales Rare Diseases Action Plan, each priority is outlined with background information, actions, stakeholders / delivery partners, timelines and outcome measures.

Over the cycle of the action plan, WRDIN will meet regularly to oversee and report on action progress and provide a platform for objective measurement of the success of the plan. WRDIN and partners will work with the UK four nations and other equivalent groups to ensure best practice is considered for the

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implementation of the plan in Wales. WRDIN will also work with health boards and partner organisations as a mechanism for the development and progress oversight of the Wales action plan.

This document will be published via the NHS Executive, endorsed by Welsh Government.

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