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WELSH HEALTH CIRCULAR

Llywodraeth Cymru
Welsh Government

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For Action by:	**Action required by:** (insert date)
All Health Boards, HEIW, WHSSC	Ongoing

Sender: Prof Chris Jones, Deputy Chief Medical Officer, Health & Social Services

HSSG Welsh Government Contact(s):

Caroline Lewis, Major Health Conditions Senior Policy Manager, Nursing and Quality, Health & Social Services, Welsh Government, Cathays Park, Cathays, CF10 3NQ. Tel No: 03000 258953. Email: Caroline.Lewis@gov.wales

Enclosure(s): None

Wales Rare Diseases Action Plan 2022 – 2026

Summary

The purpose of this Welsh Health circulate is to highlight the publication of the Wales Rare Disease Action Plan (2022-2026).

Action

Health boards and NHS trusts, where appropriate, are asked to work with Welsh Health Specialised Services Committee (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

The Wales Rare Diseases Action Plan 2022-2026 is available at the following links:

English: https://collaborative.nhs.wales/implementation-groups/rare-diseases/
Welsh: https://cydweithrediad.gig.cymru/grwpiau-gweithredu/clefydau-prin/

To demonstrate ongoing commitment to the rare diseases community the governments of all 4 UK nations have worked together to design a new UK Rare Diseases Framework (January 2021) identifying four key priorities for improving quality and availability of care, addressing health inequalities, and improving the lives of people living with rare diseases.

The four key priorities are as listed:

- Priority 1 – Helping patients get a final diagnosis faster.
- Priority 2 – Increasing awareness of rare diseases amongst healthcare professionals.
- Priority 3 – Better conditions of care.
- Priority 4 – Improving access to specialist care, treatment and drugs.

As part of the UK Framework, a Wales focused action plan has been developed by RDIG. RDIG has brought together stakeholders, health board, third sector and patient representatives to contribute towards the development of the plan.

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

This plan was developed during the COVID-19 pandemic and there is still an ongoing need to provide NHS services differently both in the pandemic response and to tackle the harm on the system caused by COVID-19. Access to support, information, care, and treatments have become more difficult due to the effects of the pandemic as services have been disrupted due to increased waiting list and delayed diagnosis.

Over the cycle of the action plan, RDIG will continue to meet regularly to oversee and report on action progress as well as keep the process in constant review. It will provide a platform for objective measurement of the success of the plan. RDIG and partners will work with the UK four nations and other equivalent groups to ensure best practice is considered for the implementation of the plan in Wales. RDIG will also work with health boards and partner organisations as a mechanism for the development and progress oversight of the Wales action plan.

Any changes to the Wales Rare Diseases Action Plan will be considered on an annual basis and a number of developments will be subject to agreement of available resources and ongoing, and successful, business cases.