Ministear airson Slàinte Phoblach is Slàinte Bhoireannach
Jenni Minto BPA

Minister for Public Health and Women's Health
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To:

Clare Haughey MSP, Convener, Health Social Care and Sport Committee

By email
hscs.committee@parliament.scot

29 October 2025

Dear Clare,

EXTENSION OF THE UK RARE DISEASES FRAMEWORK

I am writing to you to confirm that the Scottish Government has, along with the governments of Wales and Northern Ireland, agreed to a one-year extension of the UK Rare Diseases Framework, as proposed by Ashley Dalton MP, Parliamentary Under-Secretary of State for Public Health and Prevention, in a letter to each of her counterparts dated 26 August 2025.

The UK Rare Diseases Framework was co-developed by all four nations as a result of extensive community engagement, and published in January 2021, with an intended lifespan of five years. Within this timeframe, each nation has produced and implemented their own Action Plan which support the Framework's four priorities: faster diagnosis, greater awareness among healthcare professionals, better care co-ordination and improved access to specialist care, in their respective healthcare systems. Scotland's Action Plan for Rare Diseases was published in December 2022, and our Progress Report was published in August 2024.

Tha Ministearan na h-Alba, an luchd-comhairleachaidh sònraichte agus an Rùnaire Maireannach fo chumhachan Achd Coiteachaidh (Alba) 2016. Faicibh www.lobbying.scot

Scottish Ministers, special advisers and the Permanent Secretary are covered by the terms of the Lobbying (Scotland) Act 2016. See www.lobbying.scot

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Discussion is now underway between officials from all four nations, and in the Framework governance groups, as to what should follow the current Framework on its expiry in January 2026. We have agreed that a one-year extension to the existing Framework provides a practical mechanism to maintain continuity in governance, avoid a gap in four-nations collaboration, and ensures stakeholders remain engaged while future policy options for 2027 are developed. Importantly, we understand that the purpose of the extension year is transition - enabling the four nations to consult widely with stakeholders and plan the next steps in a way that reflects community priorities.

In the meantime, we will continue to implement Scotland's Action Plan under the governance of our Rare Disease Implementation Board, to ensure that the lives of people living with rare conditions in Scotland continue to improve.

I hope this information is of use to you and your colleagues in the committee.

Yours sincerely,

Jenni Minto MSP

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