Briefing: Rare Disease Forum Independent Advisory Group on quality standards

Key messages

- The Independent Advisory Group is calling for the development of a quality standard for rare disease, to improve equity of care for rare diseases across all four UK nations.
- A quality standard, which includes statements on what good care looks like for rare disease, would act as an incentive for the NHS to drive improvements in care and outcomes for rare disease.
- The goal is for each of the four UK nations' rare disease framework implementation boards and delivery partners to commit to collective development of a quality standard for rare disease, and for work to begin on this before the end of 2023.

Why is a rare disease quality standard so important?

We believe a quality standard for rare disease could drive improvements in care. At present there are no real measures in the nation specific action plans for the UK Rare Diseases Framework to demonstrate improvement over time in issues that we know really matter to people living with rare disease. Quality standards have been shown to improve care by demonstrating what good looks like. They set out clear actions for commissioners and all healthcare providers and provide measures that can be audited to show how individual services are performing.

The call is particularly timely given the pressures on NHS services across the UK. Under these circumstances, when staff time is limited, and waiting lists are high, it is easier for rarer and more complex conditions to be overlooked. In addition, new strategies for more common conditions, such as the Major Conditions Strategy in England or the Scottish Cancer Strategy, will contain metrics and measures of success which the NHS will be held to account on. The development of a quality standard is vital to ensure that there is also an incentive to focus on rarer diseases, and to prevent the gap in outcomes between rarer and more common conditions continuing to increase.

What is the IAG?

The Independent Advisory Group for quality standards was formed out of the UK-wide Rare Diseases Forum which was set up to inform the implementation of the Rare Disease Framework. The group is made up of a mixture of patient organisations and clinicians who came together to explore the creation of a quality standard for rare disease. The group is chaired by Sue Farrington, Co-Chair of the Rare Autoimmune Rheumatic Disease Alliance (RAIRDA) and Chief Executive of Scleroderma and Raynaud's UK. The full membership of the group can be found below.
The group's objective is for each of the four UK nations' rare disease framework implementation boards and delivery partners to commit to collective development of a quality standard for rare disease, and for work to begin on this before the end of 2023.

What should a quality standard include?

A quality standard could include statements on what 'good looks like' in areas that we know are important for all rare diseases. These could include:

- Timely diagnosis (where the symptoms have a known cause).
- Timely access to available treatments and new treatments being tested in clinical trials.
- Ensuring treatment is delivered in the appropriate place – including access to specialist and specific services when necessary.
- Access to patient centred support and care coordination – from the start of the patient journey and including follow-up.
- Access to psychological support across the pathway.
- Having a good patient experience.
- Having appropriate and timely discussions around end-of-life care and referral into palliative care.

Case study: The 2013 NICE quality standard for rheumatoid arthritis (updated in 2020) contained quality statements which set how long it should take for someone with suspected inflammatory arthritis to be referred to secondary care, to be seen in secondary care and to start definitive treatment. The National Early Inflammatory Arthritis Audit, a mandated national audit against the quality standard, which is part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP), has shown consistent improvements in national performance against the quality statements since 2018.

How should the standard be developed?

We are asking for the National Institute of Clinical Excellence (NICE), through their quality standard programme, and Health Improvement Scotland (HIS), through their standards programme to work with this group to develop a rare disease quality standard.

The IAG, and other supporters of this call, want to work alongside NICE and other Rare Diseases Framework delivery partners, to develop the quality standard. We are committed to this and are currently looking at commissioning research to develop quality statements which focus on the areas for improvement set out above. However, to ensure the methodology and output of this work will align with the current process for quality standard development, we need ongoing input from relevant stakeholders, and their commitment to working alongside us.

How can you get involved?

To find out more information about how to support this work or if you would like to meet with a member of the group please contact Anna Coupland, RAIRDA Secretariat (anna@principleconsulting.org.uk).

Appendix

Independent Advisory Group membership

Sue Farrington, Chair, Independent Advisory Group, Co-Chair, Rare Autoimmune Rheumatic Disease Alliance, Chief Executive, Scleroderma and Raynaud's UK

Dr Graham Shortland, Consultant Paediatrician/SWAN Lead, Cardiff and Vale UHB, Member of Wales RDIG

Dr Peter Lanyon, Co-Chair, Rare Autoimmune Rheumatic Disease Alliance, Consultant Rheumatologist, Nottingham University Hospitals NHS Trust

Emma Kinloch, Chair, Salivary Gland Cancer UK

Dr Robin Lachmann, National Specialty Advisor for Metabolic Disorders, University College London Hospitals

Phillippa Farrant, Adult Support Worker for Wolfram Syndrome UK

Sue Millman, CEO, Ataxia UK

Tony Lockett, Senior Lecturer in Pharmaceutical Sciences, Centre for Pharmaceutical Medicines Research (CPMR), King's College London

Dr Lucy McKay, CEO, Medics 4 Rare Diseases

Natalie Frankish, Policy and Engagement Manager for Scotland, Genetic Alliance