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 to commit to collective development of a quality standard as part of their rare disease action plans.**

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 progress over time in improving 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.

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 the development of a quality standard for rare disease to improve equity of care for rare diseases across all four UK nations, and its goal for 2023 is to see each of the four UK nations' implementation boards commit to collaborative development of a quality standard as part of their rare disease action plans.

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 services when necessary.
- Access to patient centred support and care co-ordination – 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.

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.

What can you do?

By lending your support through Tweets and writing letters, we can show the UK Government that there is widespread support for a rare disease quality standard.

For further information 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, UCL, National Specialty Advisor for Metabolic Disorders
- Phillippa Farrant, Adult Support Worker for Wolfram Syndrome UK
- Sue Millman, CEO, Ataxia UK
- Tony Lockett, Co-Founder and Principal Investigator at MEDQP
- Dr Lucy McKay, CEO, Medics 4 Rare Diseases
- Natalie Frankish, Policy and Engagement Manager for Scotland, Genetic Alliance

Case study:

Quality standard for rheumatoid arthritis

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, seen in secondary care and start definitive treatment. The National Early Inflammatory Arthritis Audit, a mandated national audit of 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.