

## NICE quality standard for rare diseases: RCSLT response

### April 2026

The RCSLT is pleased to see the publication of the [NICE quality standard for rare diseases](#).

We are particularly pleased that this acts on some of the recommendations we made in our response to the [consultation on the draft standard](#). This includes the:

- inclusion of allied health professionals in the healthcare professionals sections;
- addition to the information section that any information provided as part of discussions with a healthcare professional should be age-appropriate and meet the person's accessibility needs;
- recognition of the importance of information being provided in a way that is easily read and understood by people with rare diseases, or with support, so they can communicate effectively with health and social care services, with information being provided in a format that suits their needs and preferences.
- increased reference to NG204 Babies, children and young people's experience of healthcare; and
- referencing of disability and cognitive issues.

On other areas we highlighted – including on data collection, workforce capacity, the geographic and/or condition postcode lottery of access to speech and language therapy – NICE said that they will continue to work with the Rare Diseases Advisory Group to review the quality standard and support implementation.

We hope that that is the case and that this quality standard will facilitate the development of specialised services, and support the delivery of high-quality, person-centred care for those people of all ages with rare diseases who have communication disability, difficulty, or difference, and/or difficulties with eating, drinking, and swallowing, and their families and carers.