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Rare Disease framework for improving the lives of people living with rare conditions in the United Kingdom.

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Potential competing interests: No potential competing interests to declare.

Source

Mitchell, A. E. P., & Butterworth, S. (2024). Designing an accessible and equitable conference and the evaluation of the barriers to research inclusion for rare disease communities. *Community and Interculturality in Dialogue*, 4, 106.

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The lack of equality, diversity and inclusion in rare diseases is known to create a lack of fairness and equal opportunities for people with rare diseases. This lack of representation prevents those who support and provide health care for this community from fully understanding the safety and effectiveness of new treatments.

In 2021, the “Department of Health and Social Care published the new United Kingdom (UK) Rare Diseases Framework. ^[1]^[2] This document details the government's commitment to improving the lives of the 3.5 million people living with rare conditions in the UK. ^[1]^[3] The framework emphasised the need to listen to the patient's voice and identified four key priority areas to bring about change: helping patients get a final diagnosis faster, increasing awareness of rare diseases among healthcare professionals, better coordination of care and improving access to specialist care, treatments, and drugs.” ^[1]

A related definition explains the equality, diversity, and inclusion considerations for rare disease communities^[4], as well as the cultural concepts of distress in rare disease conditions^[5] and improving the lives of people living with rare conditions^[6].

References

1. ^{a, b, c} Andrew E. P. Mitchell & Sondra Butterworth. (2024). *Designing an accessible and equitable conference and the evaluation of the barriers to research inclusion for rare disease communities. Community and Interculturality in Dialogue, vol. 4, 106* .
2. [^] Department of Health and Social Care. (2021). *The UK Rare Diseases Framework*. GOVUK.
3. [^] Rare Disease UK. (2020). *Illuminating the Rare Reality*.

4. [^] Andrew E. P. Mitchell, Federica Galli, Chris Keyworth, Elena Vegni, et al. (2022) *Editorial: Coronavirus Disease (COVID-19): The Mental Health, Resilience, and Communication Resources for the Short- and Long-term Challenges Faced by Healthcare Workers*. *Front. Psychol.*, vol. 13 . doi:10.3389/fpsyg.2022.904328.
5. [^] Andrew E.P. Mitchell. (2023). *Rare mental health conditions showing cultural concepts of distress*. doi:10.32388/zsvd86.2.
6. [^] Andrew E. P. Mitchell. (2024). *Rare Disease framework for improving the lives of people living with rare conditions in the United Kingdom*. DOI 10.32388/L82AJG.