

Psychological Supports for People living with a Rare Disease in Ireland: An Online Survey Based Study

Study Summary

People living with rare diseases have reported high unmet support needs for access to psychological services despite the significant impact rare diseases have on mental health. The National Rare Diseases Office (NRDO) developed a research study to explore experiences in accessing psychological supports in the Republic of Ireland, and ways in which supports can be improved.

An online survey designed by the NRDO in collaboration with Irish rare disease patient organisations was distributed to people living with rare diseases. Complete responses were received from 142 individuals (87 adults and 55 children).

People living with rare diseases reported a need for psychological supports at all stages of their patient journey. Participants indicated that a rare disease has an impact on educational, social, and financial aspects of daily living. A lack of understanding of the rare disease by healthcare professionals (“Their condition is very hidden so can be overlooked and not taken seriously”), extended waiting times and the financial burden (“The medical costs are so high that we are left with little left over financially to access care or help”) of accessing supports were key themes identified by participants.

A full study report will be published in the [Irish Journal of Medical Science](#).