

Research Priorities for Rare Neurological Diseases: A Representative View of Patient Representatives and Healthcare Professionals from the European Reference Network for Rare Neurological Diseases

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For which topic were research priorities identified?

rare neurological diseases

In which location was the research priority setting conducted?

Australia - Australia; Europe - Austria; Europe - Belgium; Europe - Bulgaria; Europe - Czech Republic; Europe - France; Europe - Germany; Europe - Hungary; Europe - Ireland; Europe - Italy; Europe - Lithuania; Europe - Malta; Europe - Netherlands; Europe - Norway; Europe - Poland; Europe - Slovenia; Europe - Spain; Europe - Sweden; Europe - Switzerland; Europe - United Kingdom

Why was it conducted at all?

In its position paper on patient involvement in neuroscience research, the European Federation of Neurological Associations (now European Academy of Neurology) sets as a priority that action should be taken 'to ensure that the research community understands what is important to people with health conditions'.

What was the objective?

to collect the opinion of patient representatives and healthcare professionals within ERN-RND on the prioritization of research priorities for rare neurological diseases

What was the outcome?

a ranking list of 5 research areas

How long did the research prioritization take?

No information provided.

Which methods were used to identify research priorities?

survey

How were the priorities for research identified exactly?

Step 1: survey; participants asked to rate importance of five research themes for rare neurological diseases

Which stakeholders took part?

Patient representatives and healthcare professionals: 95 patient representatives, 61 healthcare professionals.

How were stakeholders recruited?

No information provided.

Were stakeholders actively involved or did they just participate?

Stakeholders were mere participants of the research prioritization process; they were not actively involved in the process.