

Research Priorities of Patients with Neuromuscular Disease

Nierse et al. (2013)

<https://doi.org/10.3109/09638288.2012.694964>

For which topic were research priorities identified?

neuromuscular disease

In which location was the research priority setting conducted?

Europe - Netherlands

Why was it conducted at all?

It is expected that patient involvement in research will ultimately make practice and policy more relevant to consumers' needs, leading to outcomes that include greater patient satisfaction, improvement in treatment adherence and better acceptance of research findings. In the field of neuromuscular diseases (NMD), patient organizations have since long taken an active role with regard to scientific research. Despite this active engagement with scientific research, no studies have been found that specifically focus on patients' involvement in research agenda setting for NMD.

What was the objective?

to list top priorities for scientific research in order to complement the researchers' agenda

What was the outcome?

a list of 24 research topics

How long did the research prioritization take?

April 2006 - January 2008

Which methods were used to identify research priorities?

focus group; interview; meeting; survey

How were the priorities for research identified exactly?

Step 1: interviews: to collect stories of individual patients. Step 2: data processing: thematic analysis, topic list developed, several research areas identified that were further explored in focus groups. Step 3: focus groups: exchanging experiences and generating shared understandings about possible topics for research, further exploring of research areas. Step 4: survey: participants were asked to rank four research areas and 24 research topics. Step 5: dialogue meeting: between patient representatives and researchers to integrate agendas

Which stakeholders took part?

Patients with neuromuscular disease (NMD). Interviews: 11 participants. Focus groups: 26 participants. Survey: 171 participants. Meeting: 8 patient representatives from the vsn (one father of a child with dmd; one partner of a person with als; six patients with other NMD) and 2 researchers (neurology and md in rehabilitation medicine, who were both not involved in clinical care for the participants).

How were stakeholders recruited?

Participants were approached by the VSN and recruited by the research team. Participants were intentionally sampled for the interviews to achieve a good division of participants over the diagnostic groups.

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.