

Consensus Research Priorities for Facial Palsy: A Delphi Survey of Patients, Carers, Clinicians and Researchers

Hamlet et al. (2018)
<https://doi.org/10.1016/j.bjps.2018.07.037>

For which topic were research priorities identified?

facial palsy

In which location was the research priority setting conducted?

Europe - United Kingdom

Why was it conducted at all?

Despite the potential negative impact of facial palsy, major gaps in understanding persist surrounding the treatment and care of those affected. Facial palsy is an umbrella term referring to a weakness of the facial muscles caused by various temporary or permanent conditions that affect the facial nerve, for example Bell's palsy, Ramsay Hunt syndrome or Acoustic Neuroma. It is estimated that more than 100,000 people in the UK are affected by facial palsy, which can result in appearance changes alongside a wide range of physical symptoms, including difficulties with speech, facial expressions and eye function. Despite the potential negative impact of facial palsy on psychosocial functioning and quality of life, major gaps in understanding persist surrounding the treatment and care of those affected. Recognising the pressing need to develop a collaborative research agenda with the potential to address these gaps, the charity, Facial Palsy UK sought to conduct a research priority setting exercise.

What was the objective?

to identify priorities for future facial palsy research from the perspective of clinicians, researchers, patients and carers

What was the outcome?

a ranking list of 10 research questions

How long did the research prioritization take?

No information provided.

Which methods were used to identify research priorities?

Delphi

How were the priorities for research identified exactly?

Step 1: Delphi round 1: collecting research priorities via focus groups and survey, asking to propose a maximum of five research topics based on the question: What are the research priorities for facial palsy?, 274 research questions submitted. Step 2: data processing: content analysis: 45 questions remained for prioritization. Step 3: Delphi round 2: with longlist of research topics, participants were asked to rate importance of each question, any questions failing to reach a rating of important or very important amongst 70% of participants were removed from the list for round 3. Step 4: Delphi round 3: participants were asked to re-rate the research topics they wanted addressed within the next 5 years, to that end participants were provided with group ratings from round 2

Which stakeholders took part?

Patients, carers, clinicians and researchers: patient participants were required to have first-hand experience of facial palsy (any origin) or to be a close relative or carer, health professional and researcher participants were eligible to participate if they had at least 6 months experience of working with patients with facial palsy or conducting research in the field. Delphi round 1: 85 participants (67 patients/carers and 18 health professionals/researchers), Delphi round 2: 72 participants. Delphi round 3: 78 participants.

How were stakeholders recruited?

To recruit the expert panel, letters of invitation were sent to all members subscribing to the contact list of the charity Facial Palsy UK and to their Medical Advisory Board. In addition, snowball sampling was used as invitations encouraged health professionals and researchers to share the invitation with suitable others.

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.