

The First UK National Blepharospasm Patient and Public Involvement Day; Identifying Priorities

Murta R. et al. (2020)

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For which topic were research priorities identified?

blepharospasm

In which location was the research priority setting conducted?

Europe - United Kingdom

Why was it conducted at all?

Patients' wishes for more information about blepharospasm were apparent, but could not be fulfilled during busy clinics. Furthermore, a tendency for blepharospasm patients to feel isolated due to their lack of confidence performing their daily activities was noted.

What was the objective?

to cultivate a more informed patient group via active dialogue, help clinicians more effectively prioritize research and to facilitate peer-to-peer support for affected patients and public

What was the outcome?

a ranking list of 11 research topics

How long did the research prioritization take?

No information provided.

Which methods were used to identify research priorities?

survey; workshop

How were the priorities for research identified exactly?

Step 1: survey: before participants could register for workshop they had to fill in survey. survey prompt was: I hope research in blepharospasm will find out more about, participants then given 4 optional answers that had to be ranked, participants also asked: What question(s) about the symptoms, diagnosis and treatment of blepharospasm would you like to see answered by research?. Step 2: data processing: 119 suggestions made, resulting in 11 research topics. Step 2: workshop: discussion and ranking of topics

Which stakeholders took part?

Patients and public. 105 participants.

How were stakeholders recruited?

Participants were recruited as participants of Blepharospasm Day.

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.