

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

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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 the workshop they had to fill in a survey. The survey prompt was: "I hope research in blepharospasm will find out more about...", participants were then given 4 optional answers that had to be ranked, participants were 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.