

What are the Research Priorities for Idiopathic Intracranial Hypertension? A Priority Setting Partnership Between Patients and Healthcare Professionals

Mollan et al. (2019)
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For which topic were research priorities identified?

idiopathic intracranial hypertension

In which location was the research priority setting conducted?

Europe - United Kingdom

Why was it conducted at all?

IIH predominantly affects overweight women of childbearing age with the incidence of the disease documented to be rising¹⁰ with the increasing prevalence of obesity. In those with severely affected vision, surgery may be indicated. For the majority, it can be a chronic condition, with headaches impacting on the quality of life of patients, and an economic burden. Understanding where research should be directed was a priority for IIH UK, the leading charity for IIH in the UK.

What was the objective?

to identify gaps in knowledge that matter most to key stakeholders (patients, carers and clinicians) and to indicate where future funding should be placed

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?

JLA method

How were the priorities for research identified exactly?

Step 1: setting up PSP: survey constructed by steering group. Step 2: collecting research questions: via survey, 2405 questions submitted. Step 3: data processing: responses refined, evidence check, duplicate questions removed, resulting in longlist of 48 indicative questions verified by study lead. Step 4: interim ranking: via survey, participants were asked to identify and rank their top 10, resulting in shortlist of 26 questions. Step 5: final prioritization: workshop: series of discussions and rankings

Which stakeholders took part?

People with iih, carers, family and friends, and healthcare professionals. Survey: 356 participants. Interim ranking: 512 participants. Workshop: healthcare and non-healthcare professionals.

How were stakeholders recruited?

This survey was advertised by partners, IIH UK and steering group members.

Were stakeholders actively involved or did they just participate?

Stakeholders not only participated but were also actively involved in the research prioritization process: They were part of a steering group. The steering group consisted of representation from IIH UK, patients and all the major specialities associated with IIH. The members oversaw the process, designed the survey, and were involved in data processing.