

IIH



**PATIENTS AND
PROFESSIONALS
SETTING RESEARCH
PRIORITIES**

Idiopathic Intracranial Hypertension Priority Setting Partnership

Final Report



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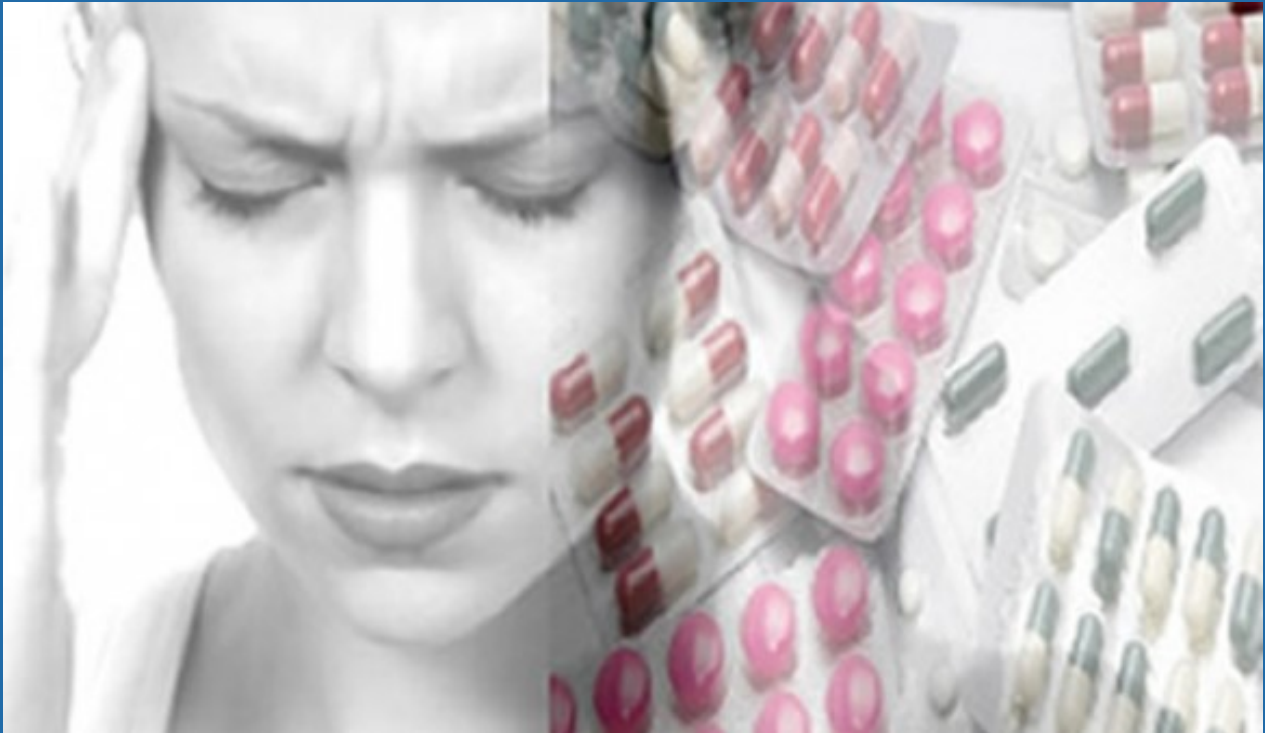
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Acknowledgements

Thank you to the steering group members, our partners and everyone who took the time to complete the surveys and attend the final workshop. Also a huge thanks to the James Lind Alliance advisors for their help in facilitating this PSP.



Why was the Priority Setting Partnership set up?



Idiopathic Intracranial Hypertension (IIH) is a neurological condition of unknown cause defined by increased intracranial pressure (ICP) around the brain without the presence of tumour or disease.

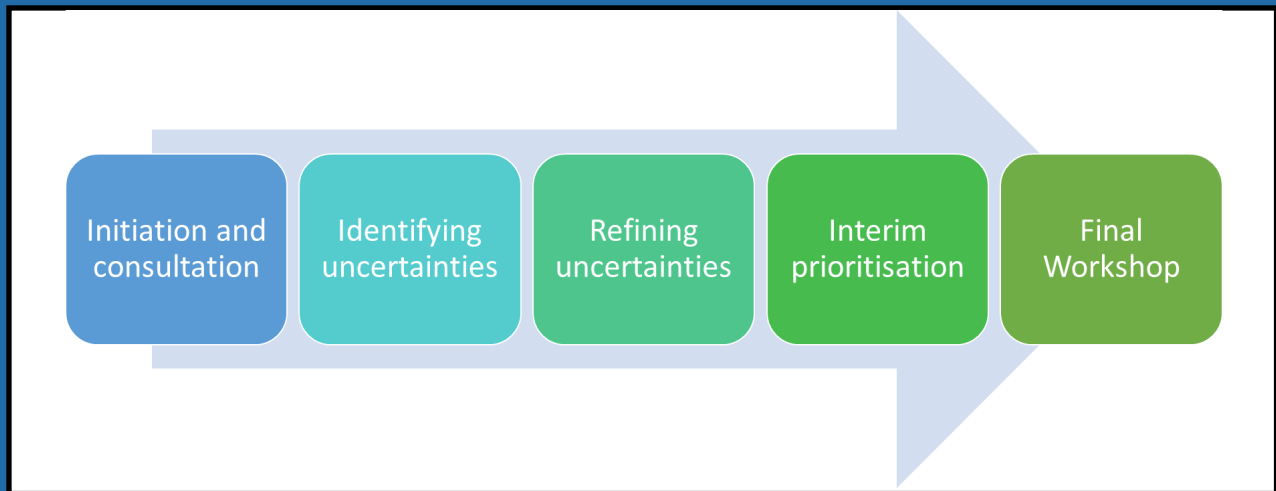
IIH predominantly affects overweight women of childbearing age and in the last decade, an estimated 24,000 people have been diagnosed with IIH in the UK, which is predicted to rise with the increasing global prevalence of obesity.

The condition causes significant morbidity, with up to 25% of patients losing vision permanently and the majority experiencing disabling headaches. In those with severely affected vision, surgery may be indicated. However for the majority, it can be a chronic condition with increased healthcare costs, impacting quality of life and the ability to work.

IIH is under researched and a recent Cochrane review (2015) found insufficient evidence to recommend or reject any current treatments used for treating people with IIH. There are currently no national clinical guidelines for the diagnosis and treatment of IIH, meaning that there is huge variation across the country.

By bringing together individuals with IIH, carers and healthcare professionals in this partnership, we hoped that the research priorities with the best outcomes for individuals with IIH and those treating them would be identified.

An overview of the process



Initiation and consultation

A steering group was formed in February 2017 and key organisations were invited to become partners. Maryrose Tarpey was our James Lind Alliance Advisor and guided us through the process.

Members of the steering group:

Krystal Hemmings — PSP lead
Alexandra Sinclair— Clinical lead
Michelle Williamson—Project coordinator
Dr Clare Herd — Information specialist

Patient representatives: Martin Plowright,
Norma-Ann Dan, Amanda Denton, Rachel
Bennett



Clinical representatives: Anita Krishnan, Susan Mollan, Jayne Best, Arun Chandran,
Ahmed Toma, Kamal Mahawar, Julie Edwards, Caroline Rick

Partners



FIGHT FOR SIGHT
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OF BRITISH
NEUROLOGISTS



An overview of the process

Identifying uncertainties (1st survey)

The purpose of the first survey for the priority setting partnership was to collect uncertainties from individuals with IIH, carers, friends and family and healthcare professionals.

The steering group decided to focus on adults (16+) only and sought out questions that individuals would like answered by research in the following areas:

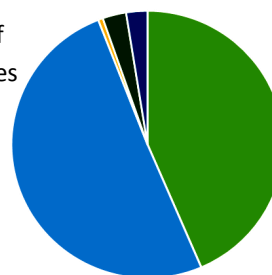
- The causes of IIH
- The diagnostic process
- Management of headaches, vision and weight
- Care provision for individuals with IIH

Participants were also given an opportunity to submit questions outside of these areas.

The online survey ran between May and August 2017, it was advertised on the IIHUK website and partners and steering group members sent the survey out to their networks, via email, newsletters and social media.

There was a balanced response to the survey with 356 people responding, they submitted 2405 questions in total.

A breakdown of survey responses



- Health or Social Care Professional (155)
- Person with IIH (180)
- Carer/former carer of someone with IIH (2)
- Friend/family member of someone with IIH (10)
- Other (9)

Refining uncertainties

Between August 2017 and March 2018 the 2405 questions were processed and narrowed down to 48 true uncertainties, which can be found at <http://www.jla.nihr.ac.uk/priority-setting-partnerships/IIH/>

During this process questions that were deemed to be out of scope or unanswerable were removed. The list was redefined and similar questions were grouped together. Finally the list was checked against published research and questions that had already been answered by research were also removed.



An overview of the process

Interim prioritisation (2nd survey)

The 48 questions were distributed in a second online survey between March and April 2018 and individuals were asked to select and rank their top 10. The survey was completed by 401 individuals with IIH, friends or carers and 111 healthcare professionals. The rankings were reverse scored and the total scores for the two groups were calculated separately to ensure an equal weighting. A final list of 26 prioritised questions were selected, which included the top 10 for both groups. These questions were taken forward to the final workshop.



Final workshop

The final workshop took place at the Royal College of Ophthalmology in London on the 27th of April 2018. The day was overseen by three JLA advisors and involved individuals with IIH, their carers, healthcare professionals and PSP partners.

Participants were asked to rank the top 26 questions before attending the final workshop and this helped to facilitate the initial discussions, by highlighting the areas of most and least importance to a wide range of individuals. Working together throughout the day, we easily came to a consensus on the rankings for all 26 questions, with an agreed top 10 priorities.

Top 10 research priorities in IIH

- 1 In the individual with IIH; what causes the disease, the symptoms and the progression of the disease?
- 2 What are the biological mechanisms of headache in IIH and why in some do headaches continue even after papilloedema has resolved?
- 3 Can new therapies for IIH be developed which are effective, safe, and tolerable and potentially help with weight loss as well as reducing brain pressure?
- 4 What is the biological explanation for the differences between rapid visual loss compared with gradual visual loss in IIH and how can this be predicted?
- 5 What are the best ways to monitor visual function?
- 6 Can IIH biomarkers (tests in body fluids for example urine, saliva, blood, or brain scans) help diagnosis, predict the risk and guide therapy decisions in IIH?
- 7 What are the hormonal causes for IIH and why is IIH primarily associated with female sex?
- 8 What medications are effective and safe to treat IIH headaches?
- 9 With regard to weight loss in IIH: how much is needed to treat IIH and how quickly does it work? What is the best, safest and most acceptable method to achieve this in the short and long term? Additionally, does the initial Body Mass Index (BMI) of the patient have an effect?
- 10 Which is the best type of intervention to treat IIH and when should surgery be performed?

Next Steps



“ It’s a privilege to work hand in hand with the IiH patients. As a team we can prioritise the research agenda and drive progress for this devastating condition ”

Alexandra Sinclair (Clinical lead)

Our hope for this project was that it would help to guide future research into IiH, ensuring that relevant and focused research results in the best outcomes for individuals with IiH and those treating them.

We followed the James Lind Alliance framework as this is a guided and reproducible process, known to be the gold standard in research prioritisation by major research funding bodies.

Therefore to ensure that future research into IiH is focused on the highest priority areas, we encourage research funders to consider the priorities identified as part of their research strategy and prioritise funding towards these. We also encourage researchers to focus their efforts on addressing the highest priority questions, which will not only ensure that these key areas are addressed but will also strengthen grant applications.

Further information about this project can be found at: <http://www.jla.nihr.ac.uk/priority-setting-partnerships/IiH/> or on the IiH UK website (<https://www.iih.org.uk/>). Once available, this will include a full list of all of the verified uncertainties identified by the PSP and details of any existing systematic reviews.

Please help us to raise awareness of the outcomes of this PSP and the need for more research into IiH by sharing this report with your contacts and tweeting us at #IiHtop10.

If you have any comments or questions please contact either Krystal Hemmings (krystalhemmings@iih.org.uk), Alexandra Sinclair (a.b.sinclair@bham.ac.uk) or Michelle Williamson (shellywilliamson@iih.org.uk).