

A Patient-Clinician James Lind Alliance Partnership to Identify Research Priorities for Hyperemesis Gravidarum

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For which topic were research priorities identified?

hyperemesis gravidarum

In which location was the research priority setting conducted?

international

Why was it conducted at all?

There are many uncertainties surrounding the aetiology, treatment and sequelae of hyperemesis gravidarum (HG). Prioritising research questions could reduce research waste, helping researchers and funders direct attention to those questions which most urgently need addressing.

What was the objective?

to identify and rank the top 25 priority research questions important to both patients and clinicians for hyperemesis gravidarum

What was the outcome?

a ranking list of 26 research questions

How long did the research prioritization take?

March 2018 - November 2019

Which methods were used to identify research priorities?

JLA method

How were the priorities for research identified exactly?

Step 1: setting up PSP: steering group developed and agreed on the study protocol. Step 2: survey: collecting research questions: participants were asked to submit up to five questions regarding any aspect of hyperemesis gravidarum research such as diagnosis, prognosis, treatment and the organization of care, 1009 participants from 26 countries (938 patients/carers, 118 professionals with overlap between categories) submitted 2899 questions. Step 3: data processing: thematic coding of submission, 66 indicative questions formulated, check against evidence, resulting in 65 indicative questions. Step 4: interim ranking: via survey: participants were asked to rate importance of each of the 65 indicative questions, 1115 participants from 32 countries took part, lack of healthcare professional representation was discussed with the steering group and a strategy to adjust for this was designed, question ranks were analyzed and sorted by participant type, the first 21 questions were ranked above 25 by both patients and professionals and were automatically included, an additional 4 that healthcare professionals had ranked above these 21 were then included, 1 questions was additionally added, resulting in 26 shortlisted questions that went to the workshop for final ranking. Step 5: workshop: final prioritization: participants were divided into three groups and across two sessions were switched around so that the balance of groups was always evenly distributed with an equal mix of patients and professionals, participants were presented with all 26 indicative questions in conjunction with the rank the indicative question had gained after the survey round, small groups ranked questions, results were collated, plenary consensus on top 26

Which stakeholders took part?

Patients, carers and multidisciplinary professionals. Survey: 1009 participants: 938 patients/carers, 118 healthcare professionals (with overlap between categories). Interim ranking: 1115 participants: 9% healthcare professionals, 3.6% carers. Workshop: 19 participants: 10 healthcare professionals and 9 patient representatives.

How were stakeholders recruited?

The online dissemination of the survey followed an agreed social media strategy using the various partner organization's platforms. Those steering group members who distributed paper copies within clinics accepted responsibility for collecting completed surveys and returning them to the lead researcher. Potential participants for the final consensus workshop were invited via email. Specifically, participants of the earlier surveys who had requested further information on the project were emailed as well as registered delegates for the ICHG. Additionally, the workshop was advertised on social media through charity partner platforms and directly via email and word of mouth to steering group member contacts.

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 patients and clinicians from a range of professions involved in the care and treatment of HG: 5 patient representatives and 10 clinical representatives (3 OB-GYNs, 1 obstetric physician, 1 pharmacist, 1 dietician, 1 nurse, 1 midwife, 1 general practitioner, 1 clinical psychologist) and 1 JLA advisor.



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