

A Patient-Clinician Partnership to Set Research Priorities for Hyperemesis Gravidarum

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Historically hyperemesis gravidarum (HG) has been under researched and what research has occurred has been of poor quality and little clinical value or relevance to patients. Now, driven by women who have themselves suffered HG the research world is addressing these flaws and striving to produce clinically valuable answers to the most pressing questions.

Objectives:

1. Together with patients and clinicians, work internationally to identify uncertainties about the effects of HG treatments and management which have not yet been answered by existing research
2. Determine by international consensus a prioritized list of those uncertainties, to guide future research
3. To publicize the results of the PSP among researchers, research commissioning bodies and the general public in order to stimulate research in these areas

Methods: An international HG Priority Setting Partnership representing patients and clinicians has followed the established James Lind Alliance (JLA) methodology (outlined in Figure 1). A steering group consisting of patients and clinicians has guided the research. Stakeholders representing patients, their carers and the multidisciplinary professionals involved in HG treatment completed an online survey to gather uncertainties. 1,009 participants took part and submitted 2,899 questions. Questions were then formatted and checked against existing evidence. 65 true uncertainties were prioritized in two stages, first an online survey ranking narrowed the long list to 26 uncertainties. Secondly, a one day workshop prioritized the top ten questions which need addressing by international researchers.

Outcomes: By following the protocol a prioritised list of uncertainties relevant to both patients and their clinicians has been identified which can inform the international HG research agenda, funders and policy makers.

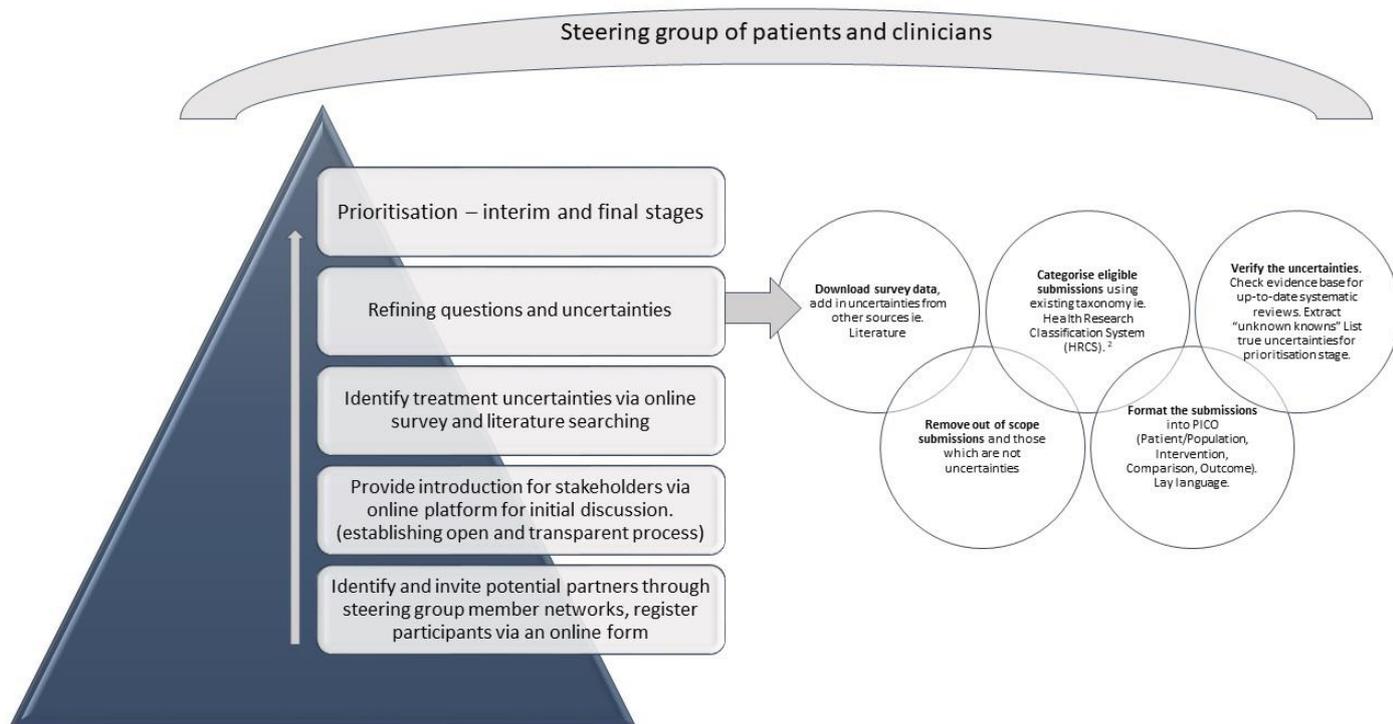


Figure 1: Diagram of the methods for the priority setting process

Keywords

Hyperemesis gravidarum, research priorities, patient clinician collaboration

References

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