

**Supplementary material B**  
Information provided for participants before health care professional  
item generation survey (Delphi round zero)

Dear Pre-Delphi Participant,

Thank you for participating in this important initiative.

A recent Cochrane review on interventions for HS identified a total of 30 disparate outcome instruments across 12 RCTs. There is no consensus on which domains and endpoints should be used in trials.

There are several methodologic problems related to HS measures:

- Domains and outcome instruments have not been comprehensively defined.
- Most outcome instruments have not been developed with the collaboration of relevant stakeholders, including patients.
- Most outcome instruments have not been sufficiently validated for construct validity, reliability, sensitivity to change, or feasibility.
- There is significant heterogeneity in use of measurement instruments in observational studies and trials.
- Instruments developed for the research setting may not be applicable to or feasible in the clinical care setting.
- These issues result in challenges in the interpretation of results and indirect comparisons across studies.

One proposed strategy to addressing these issues is to develop core outcome sets (COSs). A COS is a list of outcomes that should be reported in all clinical trials for a specific condition, with the goal of reducing reporting bias, decreasing heterogeneity, and ensuring that outcomes reported are relevant to all stakeholders.

The aim of this study is to develop a COS suitable for all interventional HS trials. Generally, this process involves two main phases. The first phase involves identifying which domains should be measured and reported in all clinical controlled trials (what to measure: the core domain set). The second phase is to identify the instruments that should be used to assess these domains (how to measure: the core outcome measurement set).

This survey is a component of the first phase. In this Pre-Delphi round, we wish to identify items which experts feel are relevant and important to the disease, regardless of whether you believe these items should be measured in a clinical trial, and regardless of whether there is an existing measurement instrument to address the item listed.

The Expert item generation from this nominal exercise will be combined with the results of two qualitative studies which have yielded items of importance directly from HS patients, and with the results of a systematic review of the literature. The combined list of items will be distilled into domains which we will seek to prioritize by consensus in order to achieve a core outcome set. The list of candidate domains will be presented to you in the first Delphi round.

For additional information on COS development, please refer to the articles which we have sent by email. Please do not hesitate to contact us, if you have any questions.