Methodological review on Delphi technique: expert definition and retention in rare diseases

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Introduction

- A Delphi approach is a consensus generation methodology, which relies on aggregated opinions of a panel of experts on a given research question. The approach is most useful in research areas where knowledge is scarce. The efficacy of the method relies on multiplicity of rounds and anonymity (**Figure 1**).[1]

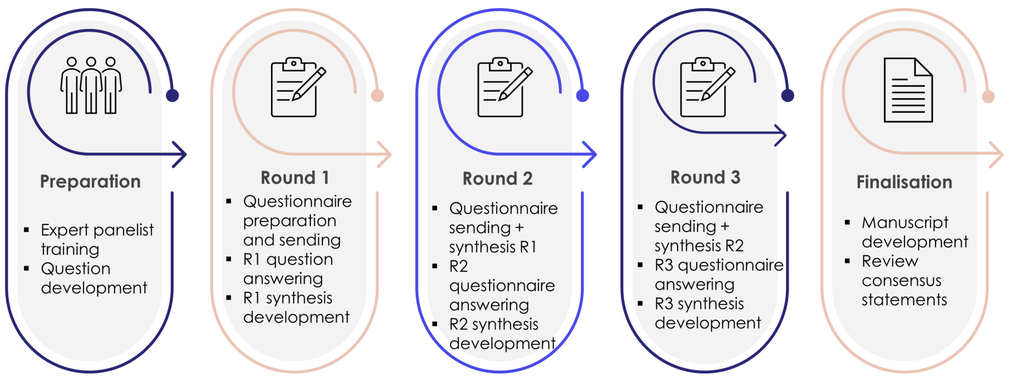

Figure 1: A Delphi technique. The first round establishes the different positions of the KOLs on the several topics in discussion. The second-round highlights the more controversial topics. The third round enables consensus. Topics on which consensus is not reached following round 3 are typically those that are more controversial

- While criteria such as clinical experience and publication history are commonly cited, variability in disease conditions necessitates flexible panel compositions. Effective strategies to mitigate attrition and ensure result validity include purposive sampling, optimized survey layouts, and timely reminders between rounds. These approaches are crucial for fostering consensus and advancing research in the realm of rare diseases, a disease area that may suffer from insufficient stability of results, a low number of specialized panelists, and lack of available treatment guidelines.

Objectives

The objectives were to establish best practices for selecting panel members and enhance response rates in Delphi studies focused on rare diseases, addressing current gaps in criteria for the selection of panel members and participant engagement found in existing literature and personal experiences.

Methods

- **Database Search:** EMBASE and Medline were searched via the Embase.com platform on January 5, 2024, employing a comprehensive strategy to identify pertinent literature concerning the application of the Delphi method in the domain of rare disease research.
- **Article Selection:** A review process was undertaken to select articles that described the utilization of the Delphi method within the context of rare disease research. Articles discussing the use of Delphi panel and discussing the appropriate methods for Delphi panels were considered of interest.
- **Key Focus Areas**: Data was subsequently organized to reflect different topics of the review: establishment of criteria for defining experts, strategies for selecting and recruiting diverse panels, considerations for determining optimal panel sizes, and effective management techniques to ensure participant retention.

Results

- A total of 237 records were identified, in which ten articles that describe the utilization of the Delphi method within the context of rare disease research were ultimately selected.
- To ensure validity and reliability of outcomes, strategies and criteria should be established regarding the selection of experts in Delphi panels. Commonly cited criteria include membership in professional boards, a minimum of two years of clinical experience, involvement in drafting guidelines, and recent publication in high-ranking journals. Moreover, panel composition varies depending on the disease, with an overarching goal of fostering diversity and inclusivity through sampling techniques. Strategies such as including the utilization of online modified Delphi panels and the meticulous optimization of survey layouts are recommended. Further recommendations are shown in Figure 2.
- These proactive measures contribute to the **facilitation of robust consensus-building processes while safeguarding against the potential pitfalls of false consensus** (Figure 2).[2,3]
- Achieving comprehensive disease management guidelines requires assembling expert panels with diverse backgrounds and expertise. Criteria such as clinical experience, involvement in guideline drafting, and recent publications serve as guiding principles in the selection of experts. Moreover, panel composition is intricately tailored to the nuances of each disease, often employing sampling methodologies to ensure a multifaceted representation of perspectives. In tandem with these selection criteria, effective strategies are deployed to enhance engagement and bolster the validity of the deliberative process. These strategies encompass the implementation of online modified Delphi panels, meticulously crafted survey layouts, and proactive measures such as obtaining consent for subsequent rounds and sending timely reminders to participants. Furthermore, inviting missed round participants serves to mitigate attrition and foster sustained engagement throughout the guideline development process.
- By harmonizing these approaches when feasible, stakeholders can collaboratively navigate the complexities of disease management, ultimately culminating in the development of **reliable and relevant guidelines that meet the needs of healthcare practitioners and patients** (Figure 2).[2,3]

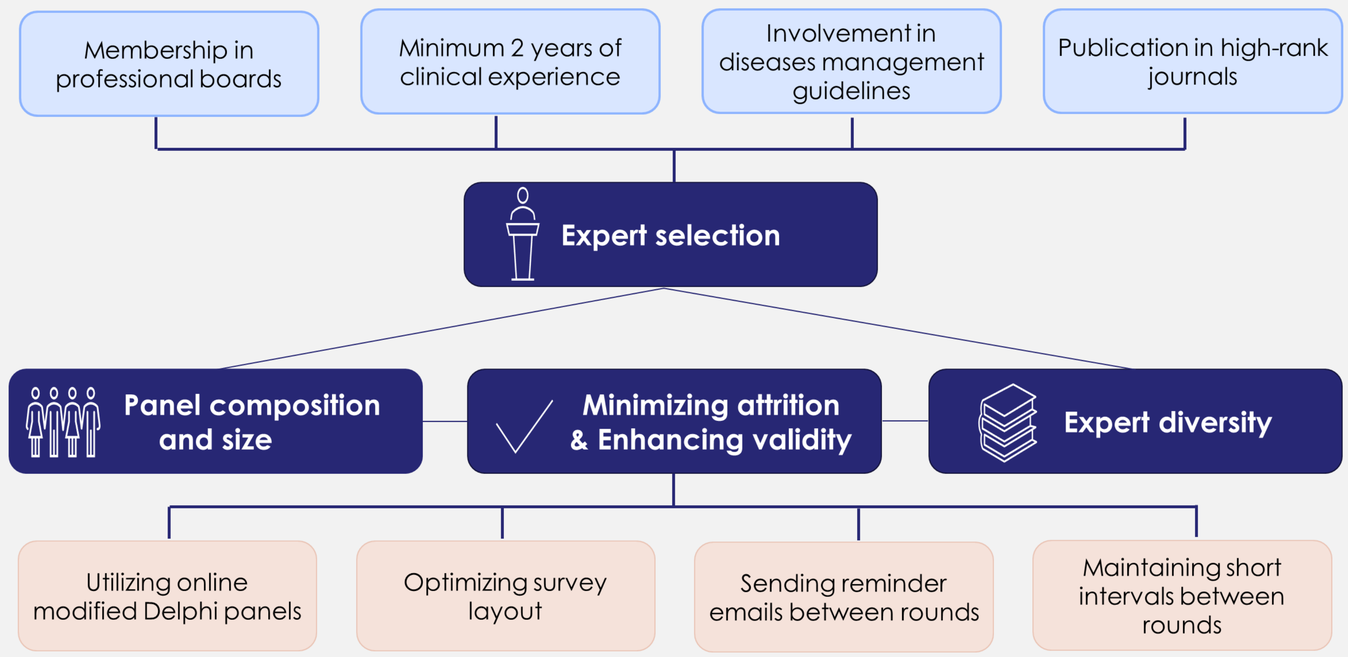

Figure 2: Criteria and Strategies for Selecting and Maintaining Expert Panels in Disease Management Guidelines Development

Conclusions

- The literature provides a comprehensive overview of best practices and challenges associated with employing the Delphi method in the realm of rare diseases, contributing to the advancement of research methodologies in this field.
- Many challenges are raised when using the Delphi technique. Researchers need to adapt the method to suit their disease field and study aim. Online modified Delphi panels are increasingly used by researchers worldwide and represent a promising and rigorous research technique in healthcare.

References
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Disclosures
- AC, PK, PA, and LB are all employees of Amaris Consulting UK Ltd. and they do not have any disclosures.