

ORIGINAL ARTICLE

A survey of Delphi panelists after core outcome set development revealed positive feedback and methods to facilitate panel member participation

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Accepted 14 June 2018; Published online 30 June 2018

Abstract

Objectives: The objective of this study was to elicit feedback on consensus methodology used for core outcome set (COS) development.

Study Design and Setting: An online survey of international Delphi panelists participating in a recent COS for clinical research studies evaluating acute respiratory failure (ARF) survivors was conducted. Panelists represented 14 countries (56% outside the United States).

Results: Seventy (92%) panelists completed the survey, including 32 researchers, 19 professional association representatives, 4 research funding representatives, and 15 ARF survivors/caregiver members. Among respondents, 91% reported that the time required to participate was appropriate and 96% were not bothered by reminders for timely response. Attributes of measurement instruments and voting results from previous rounds were evaluated differently across stakeholder groups. When measurement properties were explained in the stem of the survey question, 59 (84%) panelists (including 73% of survivors/families) correctly interpreted information about an instrument's reliability. Without a reminder in the stem, only 20 (29%) panelists (including 38% of researchers) correctly identified properties of a COS.

Conclusion: This international Delphi panel, including >20% patients/caregivers, favorably reported on feasibility of the methodology. Providing all panelists pertinent information/reminders about the project's objective at each voting round is important to informed decision making across all stakeholder groups. © 2018 Elsevier Inc. All rights reserved.

Keywords: Consensus methods; Core outcome set development; Delphi study; Stakeholders; Feedback strategies

1. Introduction

A core outcome set (COS) is a minimum collection of outcomes reported in all studies within a specific field [1,2]. Similarly, a core outcome measurement set (COMS) contains the measurement instruments used to assess outcomes within a COS. Core set adoption improves trial efficiency, facilitates comparisons and meta-analyses within a field, and helps to prevent bias from selective outcome reporting, while still permitting researchers to evaluate additional outcomes of relevance to their study [3,4].

Incorporating input from a panel of diverse stakeholders helps to ensure core sets contain the outcomes and measures that are most valued by patients, families, clinicians, clinical researchers, and research funding organizations.

The modified Delphi consensus methodology is a common way to reach consensus on COS/COMS projects [5,6]. However, a Delphi process, which involves multiple rounds of voting by a large panel of stakeholders, can also be challenging because all panelists must understand fundamental properties of outcomes and measurement instruments to serve as informed voters. Because patients and family caregivers are essential stakeholders but often have no clinical research experience, integrating their input into the Delphi process can be challenging [7,8]. Substantial effort may also be required to ensure a high participation rate among panelists during each round of voting. Delphi moderators must decide how best to prepare panel members for voting, what background information about outcomes

Conflict of interest: None.

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What is New?

Key findings

- After five rounds of voting, >90% of Delphi panelists reported that the time required to participate was appropriate, and they were not bothered by repeated reminders to encourage timely voting.
- While most panelists considered the feedback and results from previous rounds of voting when casting votes, the importance placed on the prior voting of different stakeholder groups varied substantially.
- Without guidance, respondents struggled to correctly identify the properties of a core set approximately 3 months after completion of the Delphi project.

What this adds to what was known?

- All stakeholder groups benefit from repeated guidance on principles for core outcome set development during voting.

What is the implication and what should change now?

- A high participation rate from a diverse international panel of stakeholders including patients and caregivers can be achieved during core outcome set development with real-time provision of pertinent information and timely voting reminders.

and measurement instruments to provide, and how to ensure timely voting.

To help future Delphi moderators navigate these design decisions, we elicited Delphi panel member feedback. We recently conducted a Delphi process to develop COS/COMS that included stakeholders from >16 countries, including acute respiratory failure (ARF) survivors and their caregivers. These stakeholders participated in five rounds of voting and reviewed information on 36 outcomes and 75 measurement instruments. More than 90% of panelists voted in each of the five Delphi rounds. Therefore, we asked stakeholders to report on the burden of participation and reminders to vote in each round and on how they weighed provided background information and feedback from other stakeholder groups when voting. We also asked two questions assessing stakeholders' understanding of key information needed to inform voting.

2. Materials and methods

We conducted a cross-sectional, online survey (Qualtrics, Provo, UT, USA) of 76 stakeholders who recently

participated in an international, two-stage Delphi consensus process to develop both a COS and COMS for postdischarge clinical research studies evaluating ARF survivors [9,10], approximately 3 months after completion of the Delphi process. To develop the survey, we generated questions based on the expertise and experience of the researchers administering the Delphi and reviewed questions asked of panelists in previous evaluations of Delphi processes [11–13]. Survey questions were tested for clarity and readability, with iterative refinement, using input from four ARF survivors/caregivers and six clinical researchers. The final result was a 30-question survey with both multiple-choice and open-ended/free-text questions assessing (1) the burden of Delphi participation, (2) how panelists used background information provided by the research team to prepare themselves for voting, (3) how panelists considered and weighed feedback and voting from earlier Delphi rounds, (4) panelists' understanding of information provided about measurement instrument properties, and (5) panelists' understanding of how COSs are used in research. The complete text of the survey instrument is available at www.improveLTO.com/cos-resources/.

The five-stage Delphi process occurred from January 5, 2016, to October 10, 2016. The Delphi panel included representatives of each of the 21 members of the International Forum for Acute Care Trialists organization, as well as clinical researchers identified through random sampling of a pre-existing database of corresponding authors on studies of ICU survivors, and representatives of clinicians, ICU patients, and caregivers identified by professional associations and patient/family advisory councils [9]. The five rounds of voting were completed in 157 days, with a median number of weeks for response to each round of 1 (interquartile ranges [IQR]: 0–2). Each panelist received an e-mail invitation containing a link to the follow-up survey regardless of their participation rate during the Delphi process. All initial e-mail invitations included the names and affiliations of study investigators and requested survey completion within 5 days. Reminder e-mails were sent to panelists who had not completed the survey on days 7, 15, 28, 35, and 48 after the initial invitation, after which telephone calls and text messages were used to contact nonrespondents.

Survey response rate for this study was defined as the proportion of invited Delphi panel members who subsequently completed the follow-up survey. Responses to multiple-choice survey questions were summarized using counts and percentages for categorical variables, and medians and IQR for continuous variables. Response options to questions about the burden of survey participation, and about considering the voting results from previous rounds and stakeholder groups, used a five-point Likert scale with the following options: strongly agree, agree, neutral, disagree, strongly disagree, and in some cases, not applicable. Likert-scale responses to questions about the importance panel members placed on educational information

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