

LETTER TO THE EDITOR

Delphi panelists for a core outcome set project suggested both new and existing dissemination strategies that were feasibly implemented by a research infrastructure project



Although many fields of research are developing standardized core outcome sets (COS) and associated core outcome measurement sets (COMS) to help mitigate heterogeneity in outcomes evaluations, there are multiple barriers to their dissemination and uptake. These barriers include a lack of involvement of relevant stakeholders in developing COS/COMS; disagreement among researchers, clinicians, and policymakers; and lack of buy-in and incentives among users and stakeholders [1–3].

We report a case study on dissemination of a COS/COMS created, via a modified Delphi consensus process, for clinical research studies evaluating acute respiratory failure survivors' long-term outcomes after hospital discharge (known as the “ImproveLTO project,” www.improveLTO.com) [4,5]. Our specific objectives were to (1) report dissemination ideas solicited from the Delphi panel members, via a survey conducted 3 months after the consensus process, (2) describe and compare these ideas with actual dissemination activities undertaken, and (3) evaluate the potential impact of dissemination activities on new registrations to the project web site containing COS resources. Further information on study background, methodology, and strength/limitations is available in an online [Supplementary Material](#).

Of the 70 respondents, 50 (71%) provided text-based ideas for disseminating the COS/COMS (respondent characteristics in [eTable 1](#)). Eighty-seven dissemination ideas, representing 45 unique ideas, were generated by the respondents, with each suggesting a median (IQR) of 1 (1–2) ideas. These dissemination ideas represented 7 different categories ([Table 1](#)). Our project has conducted dissemination activities in all 7 categories (see [Table 1](#), for examples of project activities). These activities of the ImproveLTO project demonstrated subsequent increases in the project's web site registrations ([eTable 2](#)). Electronic communications (via e-mail, podcast, electronic newsletter, and social media) were followed by relatively high numbers of new web site registrations per dissemination activity, similar to the impact of live presentations to research groups and at conferences ([eTable 2](#)).

Existing recommendations to promote COS/COMS update include (1) promoting awareness among stakeholders; (2) networking with stakeholder organizations; (3) creating incentives from payers; (4) gaining endorsement from funders, journal editors, and systematic review organizations; and (5) ensuring a quality framework for consensus process around COS/COMS development [3]. Only one of these was not suggested by our survey respondents: endorsement from systematic review organizations. Moreover, our survey respondents suggested ideas not in existing recommendations: educational activities, publications, Web-based resources, and social media promotion. We found that electronic modes of dissemination (eg, social media efforts and e-mails to stakeholders/professional groups) were associated with a high number of new registrants to the project web site and might be a cost-effective way to reach new stakeholders when compared to live presentations that can be more resource intensive.

In conclusion, respondents generated a variety of valuable suggestions for dissemination of the ImproveLTO core outcome set, which both aligned closely with existing guideline recommendations, and included unique suggestions. Dissemination activities were associated with new registrants for the project web site that includes the COS/COMS resources. Understanding how stakeholders learn about COS/COMS is an important step toward improving uptake and the efficiency of clinical research.

CRedit authorship contribution statement

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Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.jclinepi.2019.05.026>.

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Table 1

Thematic categories for core outcome set dissemination suggested by survey respondents and actual dissemination activities of the ImproveLTO^a project

Dissemination category	Panel members suggesting ideas, N (%)	Example suggestions by panel members	Example activities conducted by ImproveLTO ^a project
Disseminate to professional associations/research groups	35 (50)	Dissemination and circulation through special interest groups, clinical bodies, professional bodies, societies Prepare promotional statement (1–2 paragraphs) with hyperlink to web site/article with full report; then have stakeholders promote this by posting with newsletters for relevant organizations Web sites of relevant professional organizations and patient support groups/groups associated with this research	E-mail to organizations, including International Forum for Acute Care Trialist and its member organizations, National Institutes of Health's National Heart Lung and Blood Institute, Johns Hopkins Clinical Research Network among others. Podcast with American Thoracic Society Presentations to professional and research groups, including American Thoracic Society, National Institute of Child Health and Human Development's Collaborative Pediatric Critical Care Research Network meeting, Singapore-Australian & New Zealand Intensive Care Society, Asia Pacific Intensive Care Forum, Society for Critical Care Medicine Discovery Network Newsletter broadcast using Society of Critical Care Medicine and Johns Hopkins Medicine Flyers at Association for Clinical & Translational Research Conference 2018, ATS 2017 Washington DC, ATS 2018 San Diego
Online COS resources	12 (17)	Well-advertised, free-access, Web-based dissemination Create a web site—online resources Create a core set free app	ImproveLTO web site ^a : https://www.improvelto.com/coms/ InFACT web site: https://www.infactglobal.org/campaign-1/ Trial Innovation Network: https://trialinnovationnetwork.org/
Publication	10 (14)	Ask journal editors to put it on their Web page for instructions to authors Incorporate into clinical practice guidelines of post-intensive care syndrome Circulation of the results, publications to clinical practice guidelines, and standards writing groups.	Core Outcome Set— <i>Crit Care Med.</i> 2017; 45:1001-1010. Core Outcome Measurement Set— <i>Am J Respir Crit Care Med.</i> 2017; 196:1122-1130. Understanding patient-important outcomes after critical illness: a synthesis of recent qualitative, empirical, and consensus-related studies. <i>Curr Opin Crit Care.</i> 2018. 24:401-409.
Social media	9 (13)	Use of LinkedIn, Twitter, and other Social Media Outlets	ImproveLTO twitter account: @ImproveLTO Tweets and other social media dissemination from/by ATS Critical Care (@ATSCritCare), Society for Critical Care

(Continued)

Table 1. Continued

Dissemination category	Panel members suggesting ideas, N (%)	Example suggestions by panel members	Example activities conducted by ImproveLTO ^a project
Educational	9 (13)	Core training programs (eg, university—undergraduate/postgraduate training). Collaborate with organizations that offer continuing education units to demonstrate the methodology Conduct webinars	Medicine (@SCCM), National Heart, Lung, and Blood Institute (@nih_nhlbi, @NHLBI_LUNGDir) Journal Club with American Thoracic Society
Funding bodies	7 (10)	Use of core outcomes set (COS) could be advocated for in funding opportunity announcements of the study of acute respiratory distress syndrome Get funders and journals to mandate the COS Direct invitation to a specific funding body to present	NHLBI Red Alert: News from NHLBI Clinical Research Resources for Evaluating Long-Term Outcomes of Acute Respiratory Failure Patients. <i>Am J Respir Cell Mol Biol.</i> 2017;56:vi. Understanding & Measuring Patient-Important Outcomes NIH/NHLBI Identifying Clinical Research Priorities in Adult Pulmonary Critical Care, Bethesda, MD (Presentation NHLBI at Bethesda, MD)
Proof of uptake	5 (7)	Follow-up study examining rate of use of a portion or all the core outcome set moving forward. Demonstrating use of COS would help publishing in impactful journals	Publications and protocols using the core outcome measurement set can be found at https://www.improveLTO.com/publications-coms-minimum/

^a Free resources available at the web site (www.improveLTO.com) include educational videos, outcome measures and tools, new publications, relevant upcoming events, and conferences.

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