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ORIGINAL ARTICLE

Existing evidence summarization methods cannot guarantee trustworthy patient decision aids

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Abstract

Objectives: Our aim was to evaluate how organizations that develop patient decision aids conduct their evidence summarization process and assess whether their current processes provide sufficient information to instill confidence that patient decision aids are trustworthy and up to date.

Study Design and Setting: We identified 23 organizations from a public inventory of patient decision aid developers and included only organizations that have produced five or more tools. These organizations were asked to complete a 17-item survey and to share relevant documents.

Results: Of the 23 organizations, 18 completed the survey, and 15 were eligible for analysis. Most organizations reported using existing systematic reviews and clinical practice guidelines. Seven of 15 had a documented approach for summarizing evidence, but the documents offered varying levels of detail. Common steps identified are tool-relevant question formation, search strategies, evidence appraisals, and updating policies.

Conclusions: Organizations do not use a standardized process to summarize evidence for the patient decision aids that they develop. This is problematic, given that the information they contain is known to influence patients' decisions. Further attention to how organizations summarize evidence for these tools is required. © 2018 Elsevier Inc. All rights reserved.

Keywords: Decision aid; Evidence; Process; Reporting; Guidelines

1. Introduction

Patient decision aids are being promoted as tools to facilitate shared decision-making [1], despite concerns about their uptake in practice [2]. Patient decision aids have significant impact on patient knowledge and can influence patients' treatment or screening decisions [1]. It is, therefore, important that the information they contain is accurate, as free from bias as possible, and kept up to date in a systematic way. These are difficult tasks to accomplish

Ethics approval and consent to participate: This study was reviewed and did not require oversight by the Institutional Review Board, of the Committee for the Protection of Human Subjects at Dartmouth College.

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Conflicts of interest: Professors M-A.D. and G.E. are consultants to ACCESS Community Health Network in Chicago. M-A.D. and G.E. have developed the Option Grid patient decision aids. This study analyzed the methods of the Option Grid Collaborative, which no longer exists. Option Grid patient decision aids were licensed to EBSCO Health in April 2017. G.E. and M-A.D. receive consulting income from EBSCO Health. G.E. has edited and published books that provide royalties on sales by the publishers: the books include Shared Decision Making (Oxford University Press) and Groups (Radcliffe Press). He has in the past provided consultancy for (1) Emmi Solutions LLC who develop patient decision support tools; (2) National Quality Forum on the certification of decision support tools; (3) Washington State Health Department on the certification of decision support tools; (4) SciMentum LLC, Amsterdam (workshops for shared decision-making). G.E. owns copyright in measures of shared decision-making and care integration, namely CollaboRATE, IntegRATE, and Observer OPTION. These measures are freely available for use. V.M.M. is an investigator with the Mayo Clinic Shared Decision Making National Resource Center. This center makes conversation aids and places them online for free; neither V.M.M. nor the Center derives any income from these tools. V.M.M. was a coauthor of the IPDAS guidance on evidence synthesis. M.D.D. and C.R. have nothing to declare.

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What is new?

Key findings

- Organizations do not use a standardized process to summarize research evidence for the patient decision aids they develop, despite the existence of suggested approaches and the existence of methods for creating trustworthy clinical practice guidelines.

What this adds to what is known?

- The realization that more rigorous methods are required to ensure that patient decision aids contain trustworthy evidence.

What is the implication and what should change now?

- We have identified the need for patient decision aid developers to give more attention to evidence summarization processes.

and are very similar to the challenge of producing trustworthy clinical guidelines [3−5]. In addition, those who produce patient decision aids have the additional task of identifying concerns or outcomes that are relevant to patients, topics where research is often sparse or nonexistent.

Patient decision aids are also expected to portray evidence about options in ways that are accessible to patients and in formats that facilitate comparisons, such as similar time-horizons, similar denominators, and in risk communication methods that do not typically have to be considered by organizations that produce clinical practice guidelines. It could also be argued that the responsibility to produce high-quality evidence summaries is greater for patient decision aid organizations than for those who produce guidelines for professionals, given the potential to directly impact patients' decisions and behaviors. Professionals can reasonably be expected to discriminate high- from low-quality summaries of evidence or to use their judgment when assessing evidence contained in guidelines or similar documents. Tools produced for use by the public need higher standards or, at the very least, similar standards to those used by producers of high-quality clinical practice guidelines. As more agencies and policies suggest the use of patient decision aids across many countries [6], the need for producers to be clear and transparent about how their tools are developed has arrived.

The importance of developing standards for evidence summarization has been clearly articulated [3]. The International Patient Decision Aids Standards (IPDAS) Collaboration has included six criteria related to the use of up-to-date scientific evidence in the IPDAS checklist [7]. However, neither the IPDAS instrument, the IPDAS minimum standards, nor a recent appraisal [4] offers additional information or guidance on the necessary steps that should be taken when attempting to select and synthesize evidence-based information for patient decision aids [8,9].

The use of rigorous systematic evidence review, in addition to the inclusion of an explicit description of the development process and disclosure of potential conflicts of interests, has been recognized as a key issue in the development of trustworthy clinical practice guidelines [5]. Clear standards and agreed strategies to summarize evidence have resulted in guidelines that are increasingly trustworthy [10]. When examining whether patient decision aid developers addressed potential conflicts of interest, there was a clear need to improve the processes and apply consistent polices [11].

Health policy developments in many countries indicate a growing interest in shared decision-making and a parallel need to develop patient decision aids. In response, new developers are emerging, while research foundations and device and pharmaceutical companies are considering how best to develop patient decision aids in their areas of interest. However, it is unclear what methods for the summarization of evidence are being followed by patient decision aid developers. Furthermore, there is currently no means to assess the quality of evidence summarization used to populate patient decision aids or the extent to which evidence summaries are updated to reflect new research findings. Given these uncertainty, the aim of our study was to evaluate how organizations that develop patient decision aids conduct their evidence summarization process and assess whether their current processes provide sufficient information to instill confidence that patient decision aids are trustworthy and up to date.

2. Methods

2.1. Design

We administered an online survey between January 27, 2017 and February 24, 2017, to a sample of organizations known to develop patient decision aids. The Committee for the Protection of Human Subjects at Dartmouth College reviewed the project and determined no requirement for monitoring the involvement of human subjects by the Institutional Review Board. We used the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) for reporting our findings (Appendix A).

2.2. Population

For the purpose of this study, we created a public online inventory of patient decision aid developers, maintained at https://goo.gl/s2tjwj. Colleagues in the field of shared decision-making were invited to check the inventory for missing organizations, using email listservs, and by using a specific shared decision-making network hosted on Facebook (700 members). When we could identify no further

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