Incorporating patients’ views in guideline development: a systematic review of guidance documents

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Abstract

Objectives: To assess how guidance documents for developing clinical guidelines (CGs) address the incorporation of patients’ views in CGs.

Study Design and Setting: Systematic review to identify the methodology provided in guidance documents for incorporating (1) patients or representatives and (2) patients’ views in the CG development process. The search was performed in 2017 in five databases. Two authors selected the studies, and data extraction was double-checked.

Results: We included guidance documents from 56 institutions. Of those, 40 (71.4%) recommended the inclusion of patients or their representatives, mainly for developing recommendations (14/40, 35.0%); reviewing the final version (13/40, 32.5%); formulating clinical questions (13/40, 32.5%); defining the scope and objectives (10/40, 25.0%); and dissemination and implementation (10/40, 25.0%). Concrete methods on how to incorporate patients were provided by 47.5% (19/40) of institutions. Forty (71.4%) institutions provided additional strategies to incorporate patients’ views. The majority (30/40, 75.0%) suggested sources for obtaining these views (consultation with patients [24/40, 60.0%], using panels’ judgment [10/40, 25.0%], conducting de novo research [10/40, 25.0%], or a systematic review [9/40, 22.5%]).

Conclusion: Although most institutions suggest incorporating patients and their views when developing CGs, little detail is provided on how to do this. Institutions should provide more guidance as this could have a positive impact in guideline applicability. © 2017 Elsevier Inc. All rights reserved.

Keywords: Practice guidelines; Patient preference; Patient views; Patient participation; Evidence-based medicine; Methods

1. Introduction

Clinical guidelines are statements that include recommendations based on a systematic review of the available evidence, providing the benefits and downsides of alternative care options [1]. Clinical guidelines have the potential to facilitate informed decision making, improve patient care, and optimize the use of available resources [1,2].

When drafting recommendations, clinical guideline panels need to make judgments about several criteria, including the decision about the balance of the effects for the main outcomes, desirable and undesirable. To achieve this, it is important that they consider the views of those affected by the recommendation, typically the patients. This is especially significant as the relative importance (value) that patients place on health care outcomes often vary and may differ from those of clinicians [3,4].

The GRADE working group has initially referred to this concept as “patients’ values and preferences” [5]. GRADE has recently developed the Evidence to Decision (EtD)
What is new?

Key findings

- Although guidance documents suggest the incorporation of patients and/or their views in the guideline development process, little detail is provided on how to actually do this.
- There were no differences in the inclusion of patients or their views by type of institution, geographical region, or year of publication.
- There is important variability in the terminology used to refer to this aspect of guideline development.

What this adds to what was known?

- This survey is the first to critically review the available guidance, provided by clinical guidelines’ guidance documents, for how to incorporate patients and their views.

What is the implication and what should change now?

- Increasing clinical guidelines’ applicability—more structured and explicit guidance—as well as research is needed in this area.
- The terminology in this field should be standardized to improve communication.

We registered the protocol of this systematic review in PROSPERO (http://www.crd.york.ac.uk/PROSPERO; registration number CRD42014013869). We report the results of the review according to the PRISMA statement [15].

2. Methods

We ran an exhaustive search in MEDLINE (via PubMed, from 1966 to August 2013), the G-I-N library (http://www.g-i-n.net) and The Cochrane Methodology Register. We updated the search in January 2017. The search strategies are available in Appendix A at www.jclinepi.com. We reviewed the bibliography of included documents, the web sites of relevant organizations identified in previous research projects [16–18], and run a search in Google. The searches had no language restriction except the Google search, which was limited to English.

2.2. Inclusion criteria and study selection

We included the latest available version of guidance documents for guidelines (also referred as Methodological Handbooks), published from 2003 that provided guidance on the development process of clinical guidelines, and were produced by institutions responsible for CG development. We excluded documents that only reported methodology for adapting, endorsing, or updating clinical guidelines. Two authors (A.S. and A.J.S.) independently assessed documents for eligibility, initially reviewing titles and abstracts, and then the full text of those deemed eligible. Disagreements were solved by consensus and, if needed, with the help of a third reviewer.

2.3. Data extraction

We developed and pilot-tested a case report form (CRF) using REDCap (Research Electronic Data Capture), a secure, Web-based application designed to support data collection for research studies [19]. The CRF is available from the authors on request.

We extracted the following data from eligible documents: main characteristics of the document, developing institution, year of publication, guideline development group composition, inclusion of patients or patient representatives in the guideline development process, methods used to include them, explicit consideration of patient’s views, and sources and methods to obtain them. One author (A.S.) extracted the data, while another reviewer checked the data for accuracy (A.J.S., S.P., and C.S.). Disagreements were solved by consensus and, if needed, with the help of a third reviewer. By consensus of two of these three authors (A.J.S., A.S., and C.S.), we collected and provide the most relevant quotations that were illustrative of the different aspects evaluated.