

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

Anna Selva^{a,b,c,*}, Andrea Juliana Sanabria^b, Sandra Pequeño^b, Yuan Zhang^d, Ivan Solà^{b,e}, Héctor Pardo-Hernandez^{b,e}, Clara Selva^{f,g}, Holger Schünemann^d, Pablo Alonso-Coello^{b,d,e}

^aClinical Epidemiology and Cancer Screening Department, Corporació Sanitària Parc Taulí, Parc del Taulí 1, 08208, Sabadell, Spain

^bIberoamerican Cochrane Centre, Biomedical Research Institute Sant Pau (IIB Sant Pau), Barcelona, Spain

^cResearch Network on Health Services in Chronic Diseases (REDISSEC), Spain

^dDepartment of Clinical Epidemiology & Biostatistics, McMaster University, Hamilton, Ontario, Canada

^eCIBER Epidemiología y Salud Pública, (CIBERESP), Spain

^fPETRO Research Group, Spain

^gDepartment of Social Psychology, Autonomous University of Barcelona, Barcelona, Spain

Accepted 25 May 2017; Published online 1 June 2017

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 downfalls 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)

Funding: This work was supported by a research grant from the Instituto de Salud Carlos III (FIS PI14/02006 to P.A.-C.). P.A.-C. is funded by a Miguel Servet research contract from the Instituto de Salud Carlos III (CP16/00137).

Conflict of interest: A.S. is a doctoral candidate in Public Health and Methodology of Biomedical Research, at the Department of Paediatrics, Obstetrics, Gynaecology and Preventive Medicine at Universitat Autònoma de Barcelona, Spain.

* Corresponding author. Tel.: +34-93-553-7808/7814.

E-mail address: annaolid@gmail.com (A. Selva).

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.

frameworks (<https://ietd.epistemonikos.org>), an evolution of the previous Evidence to Decision table [6], that facilitate a structured approach for moving from evidence to a recommendation (or a decision) [7–9]. Among the suggested criteria to take into consideration when adopting these frameworks, two are particularly relevant to patients' views: (1) considering whether there is important variability or uncertainty on how patients—or those affected by the recommendation or the decision—value the main outcomes (desirable and undesirable) and (2) considering whether the intervention is acceptable to patients and other stakeholders.

Considering patients' views is an important aspect but often ignored by guideline panels [10–13]. To date, there has been little guidance on how to incorporate this aspect into clinical guideline (CG) development [14]. To our knowledge, no previous assessment of how guidance documents for clinical guidelines address this issue has been completed. Hence, to address this shortcoming, we conducted a systematic review of guidance documents for clinical guidelines to identify and describe the proposed methods to incorporate (1) patients or their representatives and (2) patients' views when developing clinical guidelines.

2. Methods

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].

2.1. Search strategy

We run 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.

Download English Version:

<https://daneshyari.com/en/article/5121698>

Download Persian Version:

<https://daneshyari.com/article/5121698>

[Daneshyari.com](https://daneshyari.com)