

Development and reporting of research reporting guidelines – who and what are missing?

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Abstract

Objective: The Guidance for Developers of Health Research Reporting Guidelines recommends involvement of multidisciplinary stakeholders. These stakeholders could include those affected by guidelines (eg, patients, carers) and regular end-users of guidelines (eg, publication professionals). We investigated the involvement of these three stakeholder groups in developing research reporting guidelines and the quality of reporting their involvement.

Research design and methods: For this prospective study (September 2016–January 2017), we included every reporting guideline for the main study types, as listed by the EQUATOR Network. We pilot-tested and standardized a data collection spreadsheet to extract data from the corresponding guideline publications. We quantified patient, carer, and publication professional involvement and used statisticians (stakeholders listed in Guidance) as a control group. We assessed reporting quality using the AGREE Reporting Checklist recommendations for documenting stakeholder involvement (ie, name, discipline, institution, location, role) in guideline development.

Results: Of the 33 guideline publications, the mean number of authors was 9 and working group members 45. Statisticians were identified as authors in 24% (8/33) and as working group members in 15% (5/33) of publications. Patients, carers, and publication professionals were rarely identified as being involved, either as authors (0; 0; 0) or working group members (0; 1; 0). Reporting of stakeholder involvement was deficient (eg, for statistician involvement, <25% publications met AGREE recommendations).

Conclusions: Patients, carers, and publication professionals have rarely been involved in developing research reporting guidelines, but could help enhance guideline credibility, dissemination, and use. Guideline developers should consider increasing the involvement of these stakeholders and should also improve the quality of reporting stakeholder involvement.

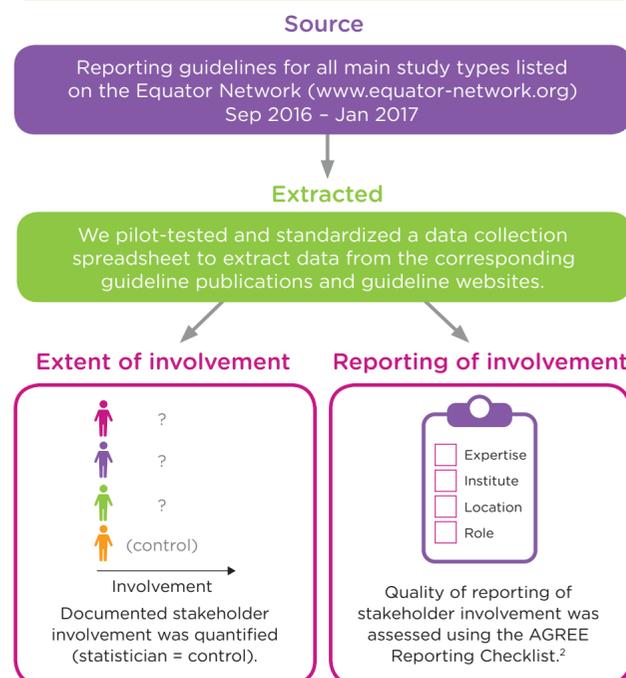
Background

“Most reporting guidelines have been developed by an international multidisciplinary group... participants will usually include statisticians, epidemiologists, methodologists, content experts, journal editors, and perhaps consumer representatives.”

Moher et al. *PLoS Med.* 2010

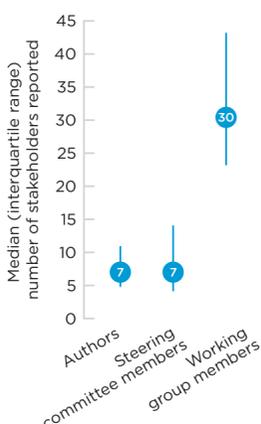
- Developers of research reporting guidelines should involve multidisciplinary stakeholders in the development process and should clearly and transparently document stakeholder involvement.^{1,2}
- Patients and carers are stakeholders who are affected by reporting guidelines.³
- Publication professionals are stakeholders who raise awareness of and adhere to reporting guidelines.⁴
- **Purpose:** To investigate the involvement of patients, carers, and publication professionals in developing research reporting guidelines and the quality of reporting their involvement.

Methods

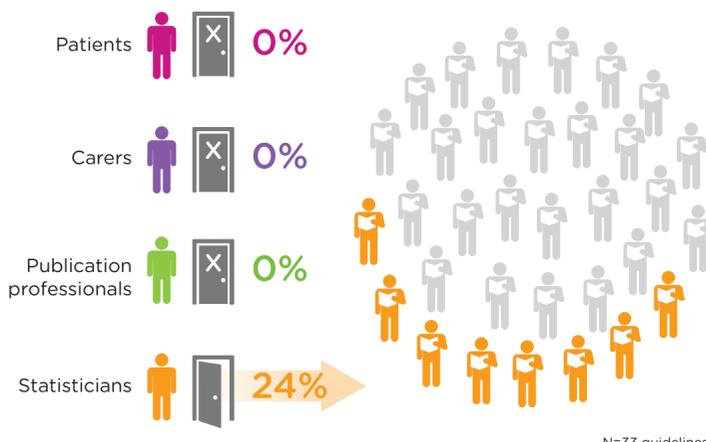


Results

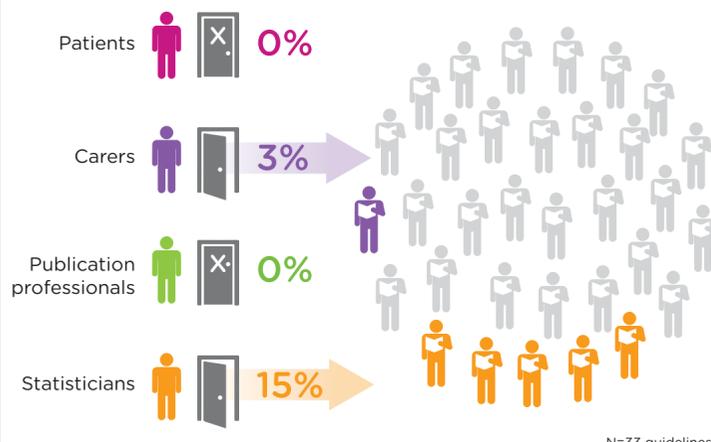
There were 33 guideline publications; most had multiple stakeholders



Patients, carers, and publication professionals were not reported as authors of reporting guidelines



Patients, carers, and publication professionals were rarely reported as members of working groups or steering committees



Reporting of stakeholder involvement was deficient

All stakeholders

- Author information consistent with the AGREE Recommendations was only evident for 9% (3/33) of reporting guidelines.
- Items most commonly not reported were expertise and role.



Statisticians (control)

- Statistician information consistent with the AGREE Recommendations was only evident for 25% (7/28) of reporting guidelines.
- Statisticians were potentially identifiable* as authors of 28 reporting guidelines.



*Inferred from authors' institutes when reporting was not complete or transparent

Carers

- Carer representative information consistent with the AGREE Recommendations was not evident.
- One carer representative was named as a working group member on one guideline.



Publication professionals

- Publication professional information consistent with the AGREE Recommendations was not evident.
- One publication professional was potentially identifiable* as an author or other stakeholder on four reporting guidelines.



*Inferred from our personal knowledge of the publication professional's company name, as reporting was neither complete nor transparent

Conclusions and implications

“...it is also a challenge to get the patient voice in the peer-reviewed literature.”

Alan Weil, Editor-in-Chief, *Health Affairs (Patients' and Consumers' Use of Evidence)*

“It is important to seek feedback and criticism from all stakeholders regarding the reporting guideline[...].”

Moher et al. *PLoS Med.* 2010

- Patients, carers, and publication professionals have rarely been involved in developing research reporting guidelines, but should be as:
 - ✓ Patients and carers are increasingly involved in research.³
 - ✓ Publication professionals can enhance the quality^{5,6} and integrity⁷ of reports, and can promote guideline use.⁴
- Meaningful engagement with these stakeholders could enhance guideline credibility, dissemination, and use.
- Stakeholder involvement and reporting of stakeholder involvement are deficient and need to be improved.
- Guideline developers could contact organizations representing patients and carers (eg, International Alliance of Patients' Organizations) and certified publication professionals (eg, International Association for Medical Publication Professionals, American Medical Writers Association) to initiate meaningful engagement.



Limitations

- Most reporting guidelines were developed before the availability of the AGREE Reporting Checklist.²
- Potential involvement of statisticians and publication professionals had to be inferred because of incomplete and non-transparent reporting.

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