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Developing our international PPI evidence base through high quality reporting: The evolution and use of GRIPP 2



Our international PPI evidence base

- Evidence, knowledge and learning about PPI are important
- Help us understand what works, why, how and for whom
- Help us grow our practice, based on evidence and tacit knowledge
- Growing body of international peer-reviewed papers and reports about PPI
- Specialist and generic journals that publish PPI evidence

Research Involvement and Engagement, <http://www.researchinvolvement.com/>

Origin of GRIPP

- Systematic reviews of PPI evidence in health and social care research (Brett et al 2014, 2012) and in health and social care provision (Mockford et al 2012)
- Huge challenges with undertaking both reviews: Limited conceptualization of PPI, poor quality of methods reporting, unclear content validity of studies, poor reporting of context and process, enormous variability in the way impact is reported, little formal evaluation of the quality of involvement, limited focus on negative impacts, and little robust measurement of impact
- Poor reporting is not unusual in health research
- The original GRIPP checklist tried to address these key issues (Staniszewska et al 2011)

Evolution of GRIPP2

- We recognised more consistent reporting of PPI would help everyone understand what happened in a study and help with future syntheses of evidence
- But we needed international consensus on the items to report
- We joined forces with EQUATOR, other organisations and public contributors to start on our journey of developing consensus
- EQUATOR 18 step process including a three stage Delphi process that included researcher, policy makers, patients and public contributors
- Feedback from the Delphi at first stage indicated the need for a short form. Rounds 2 and 3 asked for people to indicate which items should be included



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Library for health research reporting

The Library contains a comprehensive searchable database of reporting guidelines and also links to other resources relevant to research reporting.

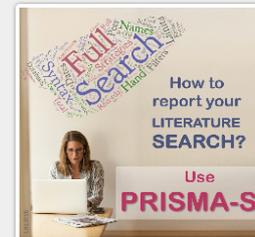
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Reporting guidelines for main study types

- | | | |
|---|---------|----------------------------|
| Randomised trials | CONSORT | Extensions |
| Observational studies | STROBE | Extensions |
| Systematic reviews | PRISMA | Extensions |
| Study protocols | SPRINT | PRISMA-P |
| Diagnostic/prognostic studies | STARD | TRIPOD |
| Case reports | CARE | Extensions |
| Clinical practice guidelines | AGREE | RIGHT |
| Qualitative research | SRQR | COREQ |
| Animal pre-clinical studies | ARRIVE | |
| Quality improvement studies | SQUIRE | Extensions |
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Toolkits

Find practical help and resources to support you in:

- [Writing research](#)
- [Peer reviewing research](#)
- [Using guidelines in your journal](#)
- [How to develop a reporting guideline](#)

EQUATOR highlights

12/07/2021 - [Online course on using reporting guidelines now available in Portuguese](#)



Resumo para publicação de artigos científicos - Instruções simples e práticas para aumentar o impacto e visibilidade da sua pesquisa

The Panamerican Health Organization (PAHO), in partnership with the EQUATOR Network, has just launched the Portuguese version of a free online course about reporting guidelines. The course is aimed at anyone interested in improving the quality of their research for health and increasing

its impact on health policy

26/01/2021 - [Launch of the new Chinese EQUATOR Centre and an interview with the Director](#)

News

[EQUATOR Network Newsletter October 2021](#)
28/10/2021

[EQUATOR Network Newsletter July 2021](#)
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GRIPP SF Items

1. Aims: report the aims of the study
2. Methods: Provide a clear description of the methods used for PPI in the study
3. Results: Outcomes—Report the results of PPI in the study, including both positive and negative outcomes
4. Discussion: Outcomes—Comment on the extent to which PPI influenced the study overall. Describe positive and negative effects
5. Reflections: Critical perspective—Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience

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Methodology | [Open Access](#) | [Published: 02 August 2017](#)

GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research

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Research Involvement and Engagement **3**, Article number: 13 (2017) | [Cite this article](#)

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Abstract

Background

While the patient and public involvement (PPI) evidence base has expanded over the past decade, the quality of reporting within papers is often inconsistent, limiting our understanding of how it works, in what context, for whom, and why.

Objective

To develop international consensus on the key items to report to enhance the quality, transparency, and consistency of the PPI evidence base. To collaboratively involve patients as research partners at all stages in the development of GRIPP2.

Methods

The EQUATOR method for developing reporting guidelines was used. The original GRIPP (Guidance for Reporting Involvement of Patients and the Public) checklist was revised, based on updated systematic review evidence. A three round Delphi survey was used to develop consensus on items to be included in the guideline. A subsequent face-to-face meeting produced agreement on items not reaching consensus during the Delphi process.

Results

One hundred forty-three participants agreed to participate in round one, with an 86%

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RESEARCH METHODS AND REPORTING



GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research

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Additional material is published online only. To view please visit the journal online.
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GRIPP2 (short form and long form) is the first international guidance for reporting of patient and public involvement in health and social care research. This paper describes the development of the GRIPP2 reporting checklists, which aim to improve the quality, transparency, and consistency of the international patient and public involvement (PPI) evidence base, to ensure that PPI practice is based on the best evidence

and consistency of the PPI evidence base. To collaboratively involve patients as research partners at all stages in the development of GRIPP2.

METHODS

The EQUATOR method for developing reporting guidelines was used. The original GRIPP (Guidance for Reporting Involvement of Patients and the Public) checklist was revised, based on updated systematic review evidence. A three round Delphi survey was used to develop consensus on items to be included in the guideline. A subsequent face-to-face meeting produced agreement on items not reaching consensus during the Delphi process.

RESULTS

143 participants agreed to participate in round one, with an 86% (123/143) response for round two and a 78% (112/143) response for round three. The

ABSTRACT

BMJ: first published as 10.1136/bmj.j3453 on 2 August 2017. Downloaded from <http://www.bmj.com/> on 13 November 2021 at 13:21

1: Aim Report the aim of the study	To develop international consensus on the key items to report to enhance the quality, transparency, and consistency of the PPI evidence base. To collaboratively involve patients as research partners at all stages in the development of GRIPP2
2: Methods Provide a clear description of the methods used for PPI in the study	Three patient partners were recruited to the research team to assist at all stages of the development of and consensus process for the GRIPP2 guidelines. They were involved in refining the focus of the research questions, in developing the search strategy, in interpreting results, in discussions identifying the need for development of guidelines, and in selecting the items for the original GRIPP checklist. The patient partners helped recruit participants (n=60/143) to the Delphi survey through snowballing techniques. They helped pilot the electronic survey for the first phase of the Delphi survey consensus process and helped other patient reps with technical aspects of completing the online survey, hence improving the response rate in each round of the Delphi. They also worked with the researchers to collate comments from each Delphi survey round, to adapt items, and to feed back to the participants for the next Delphi survey round. They checked comprehension of changed items and comments from the lay perspective. The patient partners took part in the consensus workshop, alongside five other patients (n=8/25 in total) to agree consensus on items not reaching consensus and to adapt wording where items were not clear. The patient partners contributed to edits of the paper and are coauthors.
3: Results Outcomes—Report the results of PPI in the study, including both positive and negative outcomes	<p>PPI contributed to the study in several ways, including:</p> <ul style="list-style-type: none">• Collating initial evidence• Identifying items for the GRIPP checklist• Considering the evidence and their wider experience—the patients highlighted the importance of including items referring to the context and processes of PPI, suggesting that this affected the impact that PPI had on research• The patient partners, along with other patient organisations and charities, recruited nearly half of all participants for the Delphi survey• The patient partners helped other patients with the technical aspects of completing the online survey, improving the response rate in each Delphi survey round.• The patient partners checked the comprehension of the changed items and comments from the lay perspective between rounds and were integral to helping the researchers keep to the scheduled time of the Delphi survey• Throughout the write-up phase for both the results paper and the methods paper the patient partners contributed to the lay sections and contributed to edits of the paper
4: Discussion Outcomes—Comment on the extent to which PPI influenced the study overall. Describe positive and negative effects	<p>Patient and public involvement in this study was very effective and influenced important aspects of the study, based on the impacts in section 3. This might have been related to several factors. Firstly the patient partners had received training around research methods in previous studies, and were actively involved in a patient and public involvement group attached to the University of Warwick. In addition, the researchers were experienced at involving patient partners in their research.</p> <p>The right processes were in place, as the patient partners were involved from the beginning of the study allowing them to help shape the study from the start allowing them to contribute fully to the study. Having the right context, with a collaborative research team, funding to finance their time, and a supportive attitude of their involvement from EQUATOR and other collaborators, also assisted in the positive impact that PPI had on this study. Pre-existing relationships with patient partners and patients who attended the collaborative consensus event provided a vital context for embedded PPI.</p> <p>However, there were limitations. The methods used to gain consensus had been developed and tested for reliability and validity by EQUATOR in the development of previous guidelines, which limited the possible input from the patient partners in identifying or developing methods to gain consensus on GRIPP2. Furthermore, the time for feedback between Delphi survey rounds was short, and organising times where both researchers and patient partners could meet was difficult. In similar future studies, scheduling of these meetings in advance of the Delphi survey might overcome this limitation.</p>
5: Reflections	The PPI in the study was embedded as far as possible into the methods for developing consensus. While not a formal part of EQUATOR

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Evolution of GRIPP2

- All reporting guidance evolves (e.g. CONSORT for trials) and colleagues have been exploring how GRIPP2 could change in the future
- Our plan is to secure funding to review GRIPP2 and identify new candidate items
- Moreover, we recognise that GRIPP2 still sits in an academic context
- GRIPP2 had public involvement in the study and in the Delphi, but is it still based on academic concepts of reporting and academic methods of creating consensus
- These academic concepts are important, but the world of reporting (across all health research) may need a step change to consider patient-important reporting

Patient important reporting

We have done some early work exploring what patients and public contributors would like to report about their involvement

Its clear patients and public contributors want a role in reporting

Early signals are that the concepts of important are different from the academic way of thinking about reporting

Patient-Important Reporting –

Let The People Speak! (and do some writing too...)



GRIPP2 reports PPI. The PPI Partners in the study should be helping to report it. Do researchers encourage and support this? (Do funders or journal editors?)

Does GRIPP2 capture the **patient perspective** of how we **add value** to the research, in design, delivery and dissemination (and often implementation too)?

Short term - ask patients to help to complete GRIPP2 to show what they do report and to see if that is what they want to report

Medium term – consider patient-relevant (patient-authored?) guidance on patient-important evidence/items to report.

Long-term – next iteration; involve patients experienced in using GRIPP2 and those who aren't; consider if we need a separate iteration

Your thoughts and experiences

We would like you to better understand your experiences of GRIPP2 and we have a poll as part of the session

But we are also interested in hearing about your experiences and thoughts about reporting PPI so please email Sophie.Staniszevska@warwick.ac.uk

We would also be interested in your thoughts about how reporting about patient and public involvement evolve in the future?

How can we build a strong evidence base to guide practice built in good quality reporting?

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THANK
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