



This is a repository copy of *Including young children in the development and testing of patient reported outcome (PRO) instruments: a scoping review of children's involvement and qualitative methods*.

White Rose Research Online URL for this paper:

<https://eprints.whiterose.ac.uk/201425/>

Version: Supplemental Material

Article:

Gale, V. orcid.org/0000-0001-7472-2039 and Carlton, J. orcid.org/0000-0002-9373-7663 (2023) Including young children in the development and testing of patient reported outcome (PRO) instruments: a scoping review of children's involvement and qualitative methods. *The Patient - Patient-Centered Outcomes Research*, 16 (5). pp. 425-456. ISSN 1178-1653

<https://doi.org/10.1007/s40271-023-00637-8>

This version of the article has been accepted for publication, after peer review (when applicable) and is subject to Springer Nature's AM terms of use, but is not the Version of Record and does not reflect post-acceptance improvements, or any corrections. The Version of Record is available online at: <http://dx.doi.org/10.1007/s40271-023-00637-8>

Reuse

Items deposited in White Rose Research Online are protected by copyright, with all rights reserved unless indicated otherwise. They may be downloaded and/or printed for private study, or other acts as permitted by national copyright laws. The publisher or other rights holders may allow further reproduction and re-use of the full text version. This is indicated by the licence information on the White Rose Research Online record for the item.

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.



eprints@whiterose.ac.uk
<https://eprints.whiterose.ac.uk/>

Article Title: Including young children in the development and testing of patient reported outcome (PRO) instruments: a scoping review of children's involvement and qualitative methods

Journal: *The Patient – Patient-Centred Outcomes Research*

Authors: Victoria Gale and Jill Carlton

Affiliation: The University of Sheffield, School of Health and Related Research, Sheffield, UK

Corresponding Author: Victoria Gale vargale1@sheffield.ac.uk

Online Resource 2 – Search strategies for online databases and decision tree used to guide full text screening

Search strategies for online databases:

Search concepts:

- Population – young children aged 7 years and younger
- PRO instruments – standardised questionnaires that measure subjective health from people's own perspectives without interpretation by others
- Development and/or testing of PROMs, or development of a conceptual framework for a subjective health concept – concept elicitation, content generation, cognitive testing, content validity testing
- Qualitative methods – methods that collect qualitative data and use qualitative analysis techniques

All search terms were free text unless otherwise stated.

Medline via Ovid:

| | Concept | Search terms |
|---|--|---|
| 1 | Population | Child (<i>medical subject heading</i>) OR child health (<i>medical subject heading</i>) or "children" |
| 2 | PRO instruments | "patient reported outcome*" OR "instrument" OR "measure" |
| 3 | Development/testing of PROMs or concept elicitation | "develop*" OR "content validity" OR "concept elicitation" OR "cognitive" |
| 4 | Qualitative methods | Qualitative research (<i>medical subject heading</i>) OR "interview*" OR "focus group" |
| | 1 AND 2 AND 3 AND 4 | |

Embase:

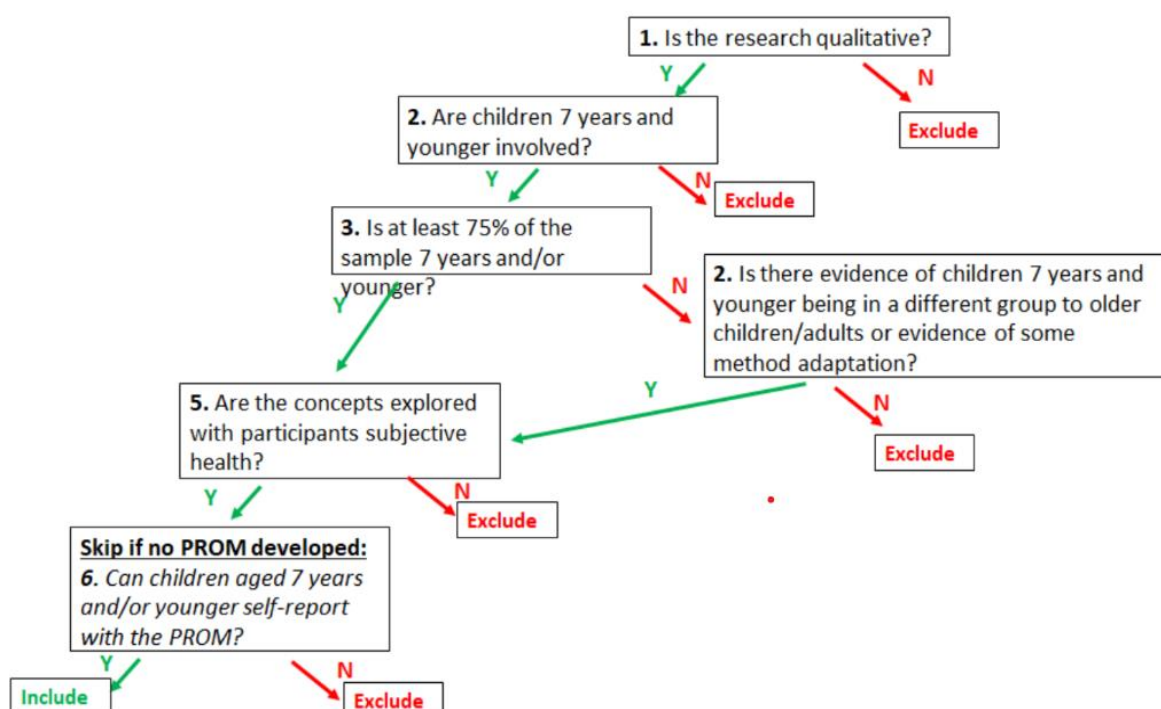
| | Concept | Search terms |
|---|--|---|
| 1 | Population | Child (<i>medical subject heading</i>) OR child health (<i>medical subject heading</i>) or "children" |
| 2 | PRO instruments | "patient reported outcome*" OR "instrument" OR "measure" |
| 3 | Development/testing of PROMs or concept elicitation | "develop*" OR "content validity" OR "concept elicitation" OR "cognitive" |
| 4 | Qualitative methods | Qualitative research (<i>medical subject heading</i>) OR "interview*" OR "focus group" |
| | 1 AND 2 AND 3 AND 4 | |

CINAHL

| | Concept | Search terms |
|---|-------------------|---------------------|
| 1 | Population | "Child" |

| | | |
|----------------------------|--|--|
| 2 | PRO instruments | "patient reported outcome*" OR "instrument" OR "measure" |
| 3 | Development/testing of PROMs or concept elicitation | "develop*" OR "content validity" OR "concept elicitation" OR "cognitive" |
| 4 | Qualitative methods | "Qualitative" OR "interview*" OR "focus group" |
| 1 AND 2 AND 3 AND 4 | | |

Decision tree used to guide full text screening:



Following a discussion between the two reviewers, 2 studies were included on the assumption that children *up to* the age of 8 years were included (i.e., 7 years and 11 months); one study was inconsistent in how the youngest age group was referred to, sometimes as 5-7 years, others as 5-8 years [1]; and the other reported conducting focus groups within United Kingdom (UK) school Key Stage 1 (KS1) which is 5-7 years, but in the appendix this was reported as 5-8 years – it was assumed that this meant up to 8 years [2].

Examples of studies that appear to meet the inclusion criteria but do not are:

- Rebok et al [3] – this was a cognitive interviewing study that had involved children aged 5-11

years. 62% of the sample were aged ≤ 7 years. Despite a high level of methodological detail, there was no evidence of children aged ≤ 7 years being interviewed in their own groups or evidence of methodological adaptations specific to them. As it was not possible to ascertain exactly how children ≤ 7 years had been involved, this study was excluded.

- Kamat et al [4] – this study involved children up to 12 years in concept elicitation and cognitive interviews. There was evidence of adapted methods for children aged ≤ 7 years. All inclusion criteria were met aside from the PROM being developed for children ≤ 7 years would not have enabled them to self-report – it was intended to be an ObsRO.

References:

1. Wiener L., et al. Child and parent perspectives of the chronic graft-versus-host disease (cGVHD) symptom experience: a concept elicitation study. Support. Care Cancer. 2014; <https://doi.org/10.1007/s00520-013-1957-6>
2. Markham C, et al. Children with speech, language and communication needs their perceptions of their quality of life. Int J Lang Commun Disord. 2009; <https://doi.org/10.1080/13682820802359892>
3. Rebok G, et al. Elementary school-aged children's reports of their health: A cognitive interviewing study. Qual Life Res. 2001; <https://doi.org/10.1023/A:1016693417166>
4. Kamat S, et al. Novel Questionnaires for Assessing Signs and Symptoms of Eosinophilic Esophagitis in Children. J Allergy Clin Immunol. 2022; <https://doi.org/10.1016/j.jaip.2022.02.049>