

It is difficult to search for patient and public partner co-authors of systematic reviews.

The Problem

Patient and public partners are described using a variety of terms. Further, patient and public involvement in research is often poorly reported, despite the emergence of guidance such as GRIPP2 and ACTIVE Framework. These factors make searching for reviews co-authored by partners challenging.

Our overview explores where such reviews are published and how they describe patient and public partner authors, with the goal of making these reviews easier to find.

Methods

Inclusion criteria: systematic or scoping reviews:

- published in English, 2011-present
- on health topics
- in which at least one author is clearly identified as a patient or public partner*

*per NIHR INVOLVE's definition - patients, potential patients, carers, others interested in a health topic who are not professional researchers

We searched:

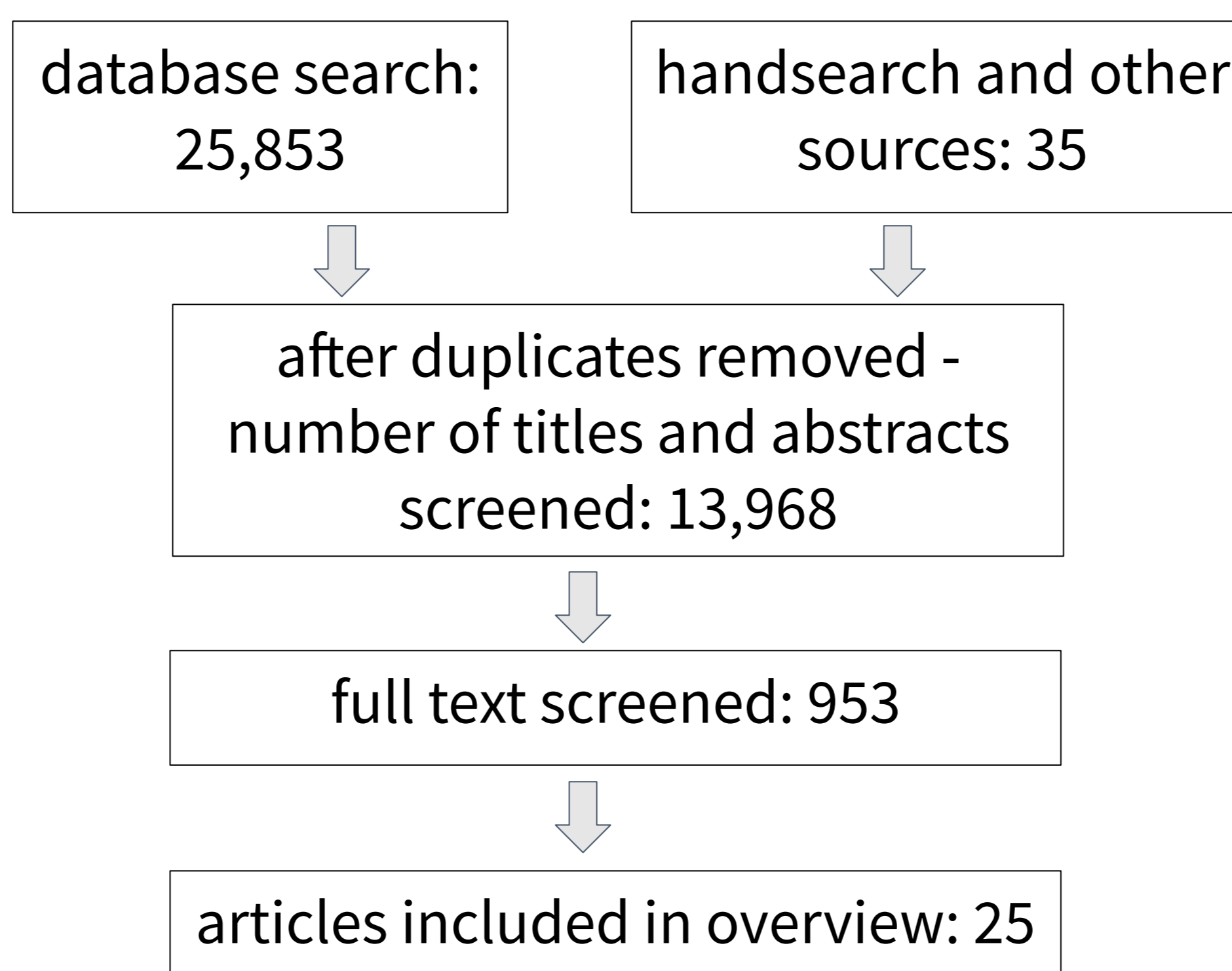
- MEDLINE (Ovid)
- EMBASE (Ovid)
- Cochrane Database of Systematic Reviews (Ovid)
- CINAHL
- PsycInfo
- CAB Direct

We built on published search filters for patient and public involvement (PPI) and for systematic reviews, enhanced with terms used in a gold standard set of 80 papers.

We also handsearched selected databases and journals specializing in PPI.

Preliminary Results

Search results:



When screening titles and abstracts, we included articles which either stated they incorporated PPI, or were on topics which would likely involve patients. When screening full text, some co-authored articles may have been excluded because the patient/public partner was not explicitly identified.

Author affiliations used by patient and public partners include:

- citizen researcher
- patient representative
- patient adviser
- caregiver representative
- expert by experience
- members of a patient panel or organization

What terms do you use to describe patient and public partners?

Do you have an example of a partner-authored systematic or scoping review to share?

References

NIHR INVOLVE (2012). Public involvement in systematic reviews: Supplement to the briefing notes for researchers. tiny.cc/5sj1cz

ACTIVE: Authors and Consumers Together Impacting on eVidEnce. training.cochrane.org/ACTIVE

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Patient and public partner authorship on systematic and scoping reviews: an overview of reviews



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