

Reporting patient and public involvement practice with children and young people in the design and conduct of paediatric health research

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Background



- The active involvement of patients and the public in the design and delivery of health research, rather than as 'subjects' of research has been encouraged (if not required for many years).
- Defining how this is realised in practice, especially where children and young people (CYP) are concerned is limited, partly due to the low level of reporting of Patient and Public Involvement (PPI) in general.
- In April 2018, the National Institute for Health and Care Research (NIHR) advised authors of research it funds to refer to the Guidance for Reporting Involvement of Patients and the Public Checklist (GRIPP2)[1] to enhance the **quality, transparency, and consistency** of reporting PPI activities.

NIHR Reporting expectations:

- If there was no PPI in the study, please state this in your report setting out why this was not thought appropriate or was not feasible.
- What form did the PPI take and at what stages did it occur during your study.
- What impact did PPI have during the study? How was it useful.
- If there was little/no impact of PPI during the study, please say so.
- The way(s) PPI will support dissemination of the results.

Objectives

This research is part of the lead author's PhD research [2]. The aim was to examine in detail the reports held in the NIHR Journals Library that are completed by researchers about the processes of PPI with children and young people. The purpose was to explore the **quality of reporting**, not to assess the quality of PPI. Attention would be paid to:

- the opportunities offered to children and young people, including models and stages of involvement
- any reported impacts of involvement, and
- reported challenges and facilitators to involvement

Methods

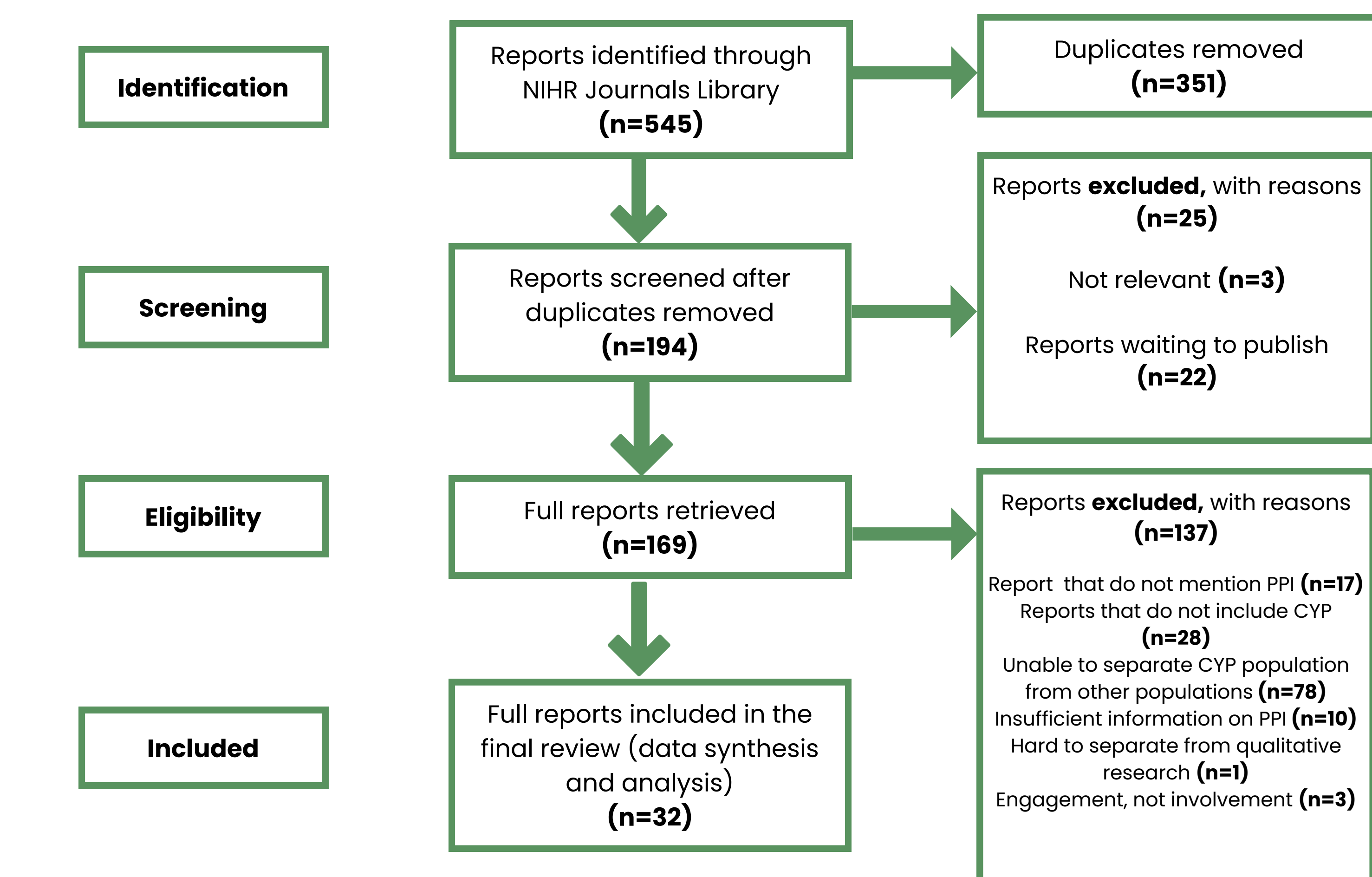
Inclusion criteria

- Study population included children and young people between the age range of 0-24 years
- PPI activities occurred with children and young people aged 0-24 years
- Any interventional or observational study

Exclusion criteria

- Not relevant (study population didn't include 0-24 years)
- Reports published prior to April 2018
- Reports waiting to publish
- Reports that do not mention PPI
- Reports that do not include children and young people in PPI activities
- Unable to separate CYP population from other populations (e.g., parents or carers)
- Insufficient information on PPI
- Describes 'engagement' not involvement
- Hard to distinguish between the actual research methods and PPI.

PRISMA Flowchart



Qualitative content analysis and **Framework analysis** techniques were used to analyse the data. A small group from the NIHR Paediatric Incubator was formed (led by the lead author) to iteratively test tools (see Figures 1 and 2) to assess the level and quality of reporting of PPI with children and young people. Further workshops with wider members of the Paediatric Incubator have taken place and a workshop with Young Peer Researchers has been planned for mid-October.

References

- Staniszewska S, Brett J, Simera I, Seers K, Mockford C, Goodlad S, Altman DG, Moher D, Barber R, Denegri S, Entwistle A, Littlejohns P, Morris C, Suleman R, Thomas V, Tysall C. GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. *BMJ*. 2017 Aug 2;358:j3453. doi: 10.1136/bmj.j3453. PMID: 28768629; PMCID: PMC5539518.
- <https://bit.ly/3fjxp97>

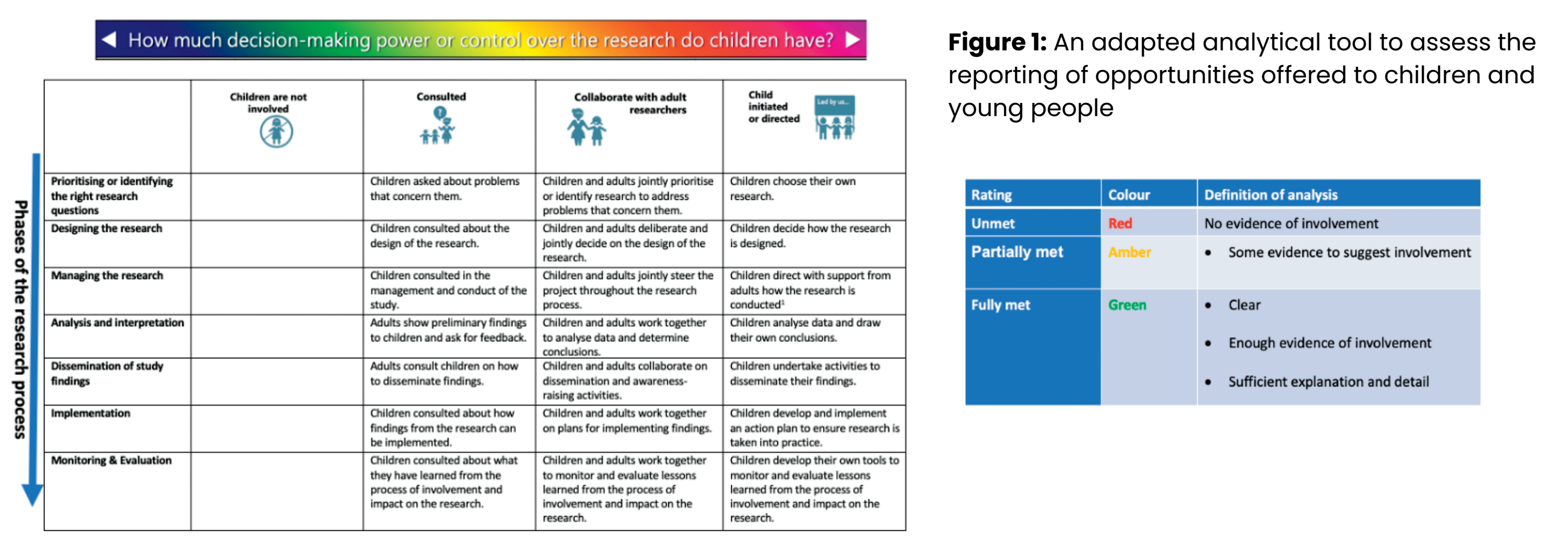


Figure 1: An adapted analytical tool to assess the reporting of opportunities offered to children and young people

Rating	Colour	Definition of analysis
Unmet	Red	No evidence of involvement
Partially met	Amber	Some evidence to suggest involvement
Fully met	Green	Clear Enough evidence of involvement Sufficient explanation and detail

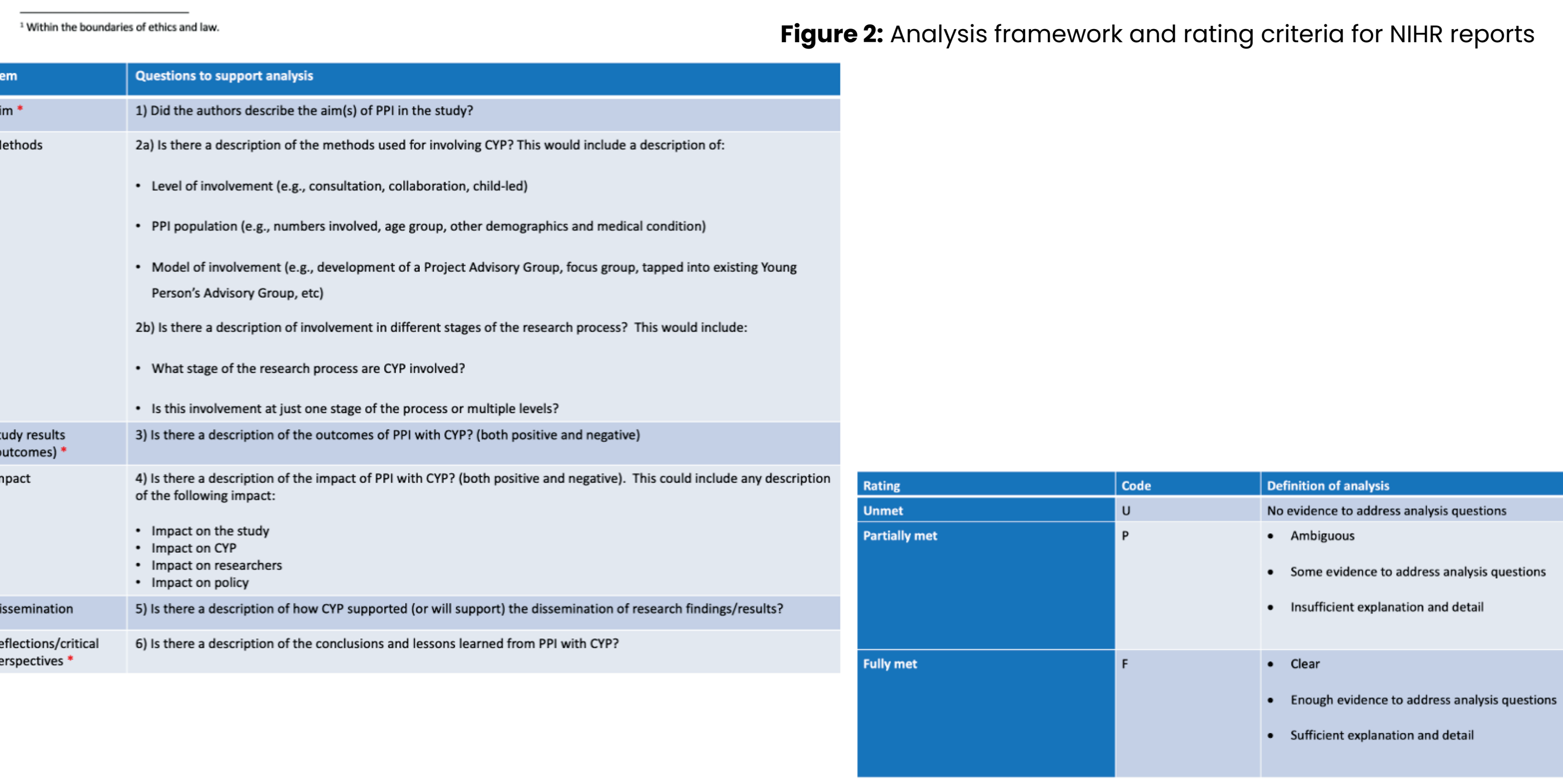
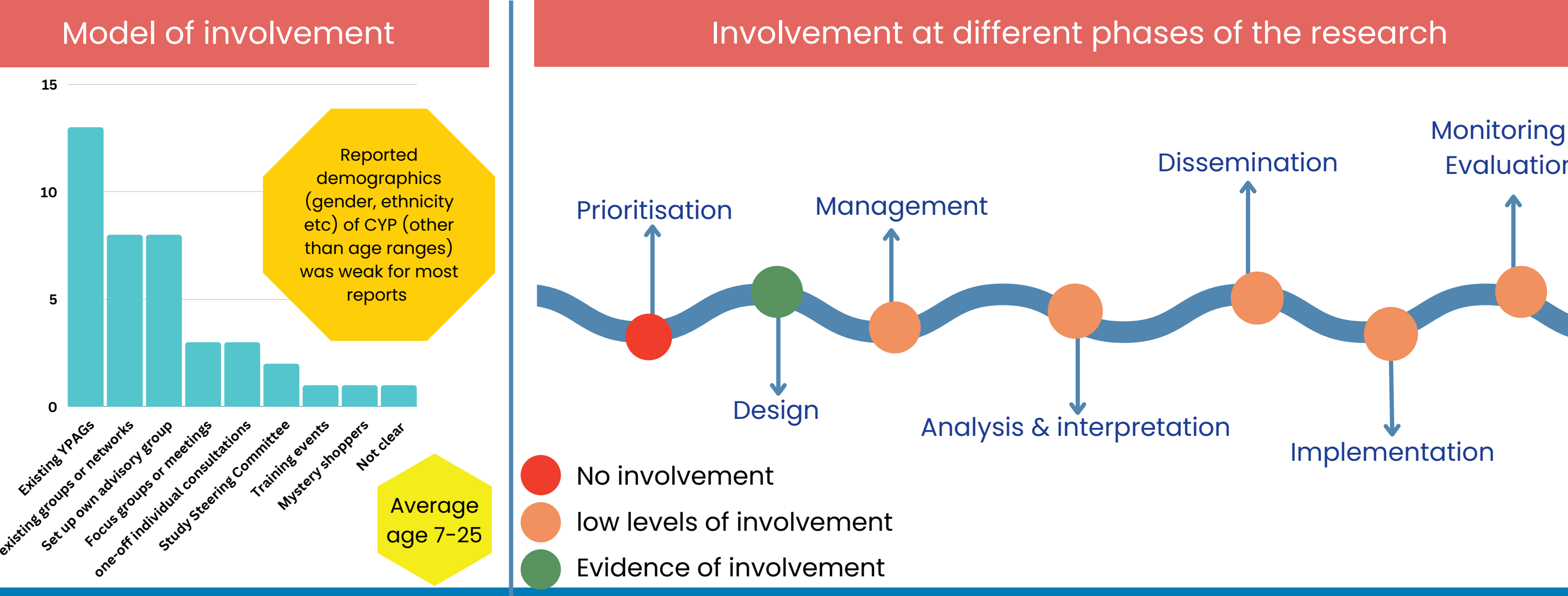


Figure 2: Analysis framework and rating criteria for NIHR reports

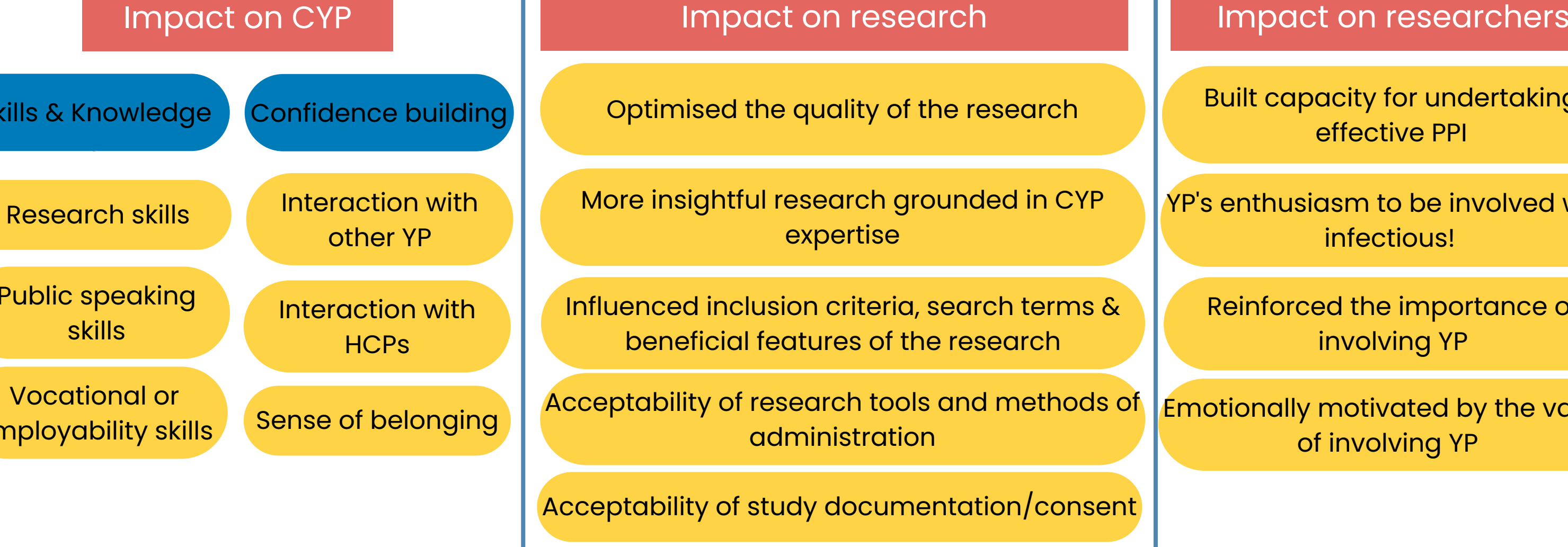
Results

The length of the text to describe PPI with all stakeholders (parents, charities, adults, CYP, etc) varied from one short paragraph to full chapters within the main report or appendices. Of the 32 reports, only four fully met all the criteria for reporting PPI against the NIHR reporting expectations, (and also the GRIPP2SF criteria). All the reports focused specifically on describing how CYP were involved in the phases of the research process, and less attention was paid to describing the impact of involvement. The challenges and facilitators of CYP involvement were reported in sixteen reports.

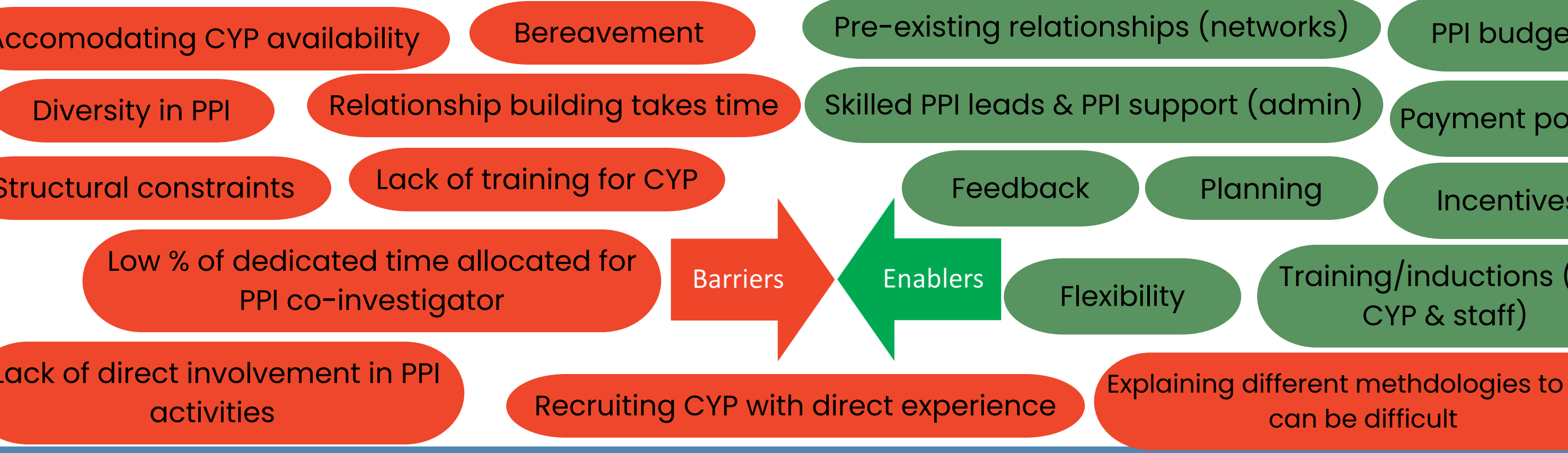
1. Reported opportunities offered to children and young people



2. Reported impacts



3. Reported challenges and facilitators



Discussion

- Despite NIHR guidance and the GRIPP2 checklist, the quality of reporting of PPI with children and young people (and in general) was found to be suboptimal.
- A full description of the demographics (gender, ethnicity, etc) of CYP was weak for most reports. Most mention the age ranges of CYP (between 7-25 years) but it is not clear from the reports the breakdown of ages for each activity.
- The majority of researchers who accessed existing YPAGs tended to provide minimal information about PPI activities and its impact.
- Only 3 research projects formally evaluated or self-reflected on PPI activities with CYP.
- Findings from this review will inform the development of simplified reporting guidelines for researchers that are informed and endorsed by CYP.