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

National Institute for NIHR Health and Care Research

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

	Children are not involved	Consulted	Collaborate with adult researchers	Child initiated or directed	
Prioritising or identifying the right research questions		Children asked about problems that concern them.	Children and adults jointly prioritise or identify research to address problems that concern them.	Children choose their own research.	
Designing the research		Children consulted about the design of the research.	Children and adults deliberate and jointly decide on the design of the research.	Children decide how the research is designed.	
Managing the research		Children consulted in the management and conduct of the study.	Children and adults jointly steer the project throughout the research process.	Children direct with support from adults how the research is conducted ¹	
Analysis and interpretation		Adults show preliminary findings to children and ask for feedback.	Children and adults work together to analyse data and determine conclusions.	Children analyse data and draw their own conclusions.	
Dissemination of study findings		Adults consult children on how to disseminate findings.	Children and adults collaborate on dissemination and awareness- raising activities.	Children undertake activities to disseminate their findings.	
Implementation		Children consulted about how findings from the research can be implemented.	Children and adults work together on plans for implementing findings.	Children develop and implement an action plan to ensure research taken into practice.	
Monitoring & Evaluation		Children consulted about what they have learned from the process of involvement and impact on the research.	Children and adults work together to monitor and evaluate lessons learned from the process of involvement and impact on the research.	Children develop their own tools t monitor and evaluate lessons learned from the process of involvement and impact on the research.	

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

Within the boundaries of ethics and lay

- Did the authors describe the aim(s) of PPI in the study
- 2a) Is there a description of the methods used for involving CYP? This would include a description of

Figure 2: Analysis framework and rating criteria for NIHR reports

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Insufficient explanation and detail

Sufficient explanation and detail

Some evidence to address analysis guestion

Enough evidence to address analysis question

- 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:

- **a)** the opportunities offered to children and young people, including models and stages of involvement
- **b)** any reported impacts of involvement, and
- c) 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)

- Level of involvement (e.g., consultation, collaboration, child-led
- PPI population (e.g., numbers involved, age group, other demographics and medical condition
- Model of involvement (e.g., development of a Project Advisory Group, focus group, tapped into existing Young Person's Advisory Group, etc
- 2b) Is there a description of involvement in different stages of the research process? This would include:
- What stage of the research process are CYP involved?
- Is this involvement at just one stage of the process or multiple levels

	is any interventent of just one stage of the process of mattiple levels.		
Study results (outcomes) *	3) Is there a description of the outcomes of PPI with CYP? (both positive and negative)		
Impact	4) Is there a description of the impact of PPI with CYP? (both positive and negative). This could include any description of the following impact:	Rating	Code
	of the following impact.	Unmet	U
	 Impact on the study Impact on CYP Impact on researchers Impact on policy 	Partially met	Ρ
Dissemination	5) Is there a description of how CYP supported (or will support) the dissemination of research findings/results?		
Reflections/critical	6) Is there a description of the conclusions and lessons learned from PPI with CYP?		
perspectives *		Fully met	F

Results

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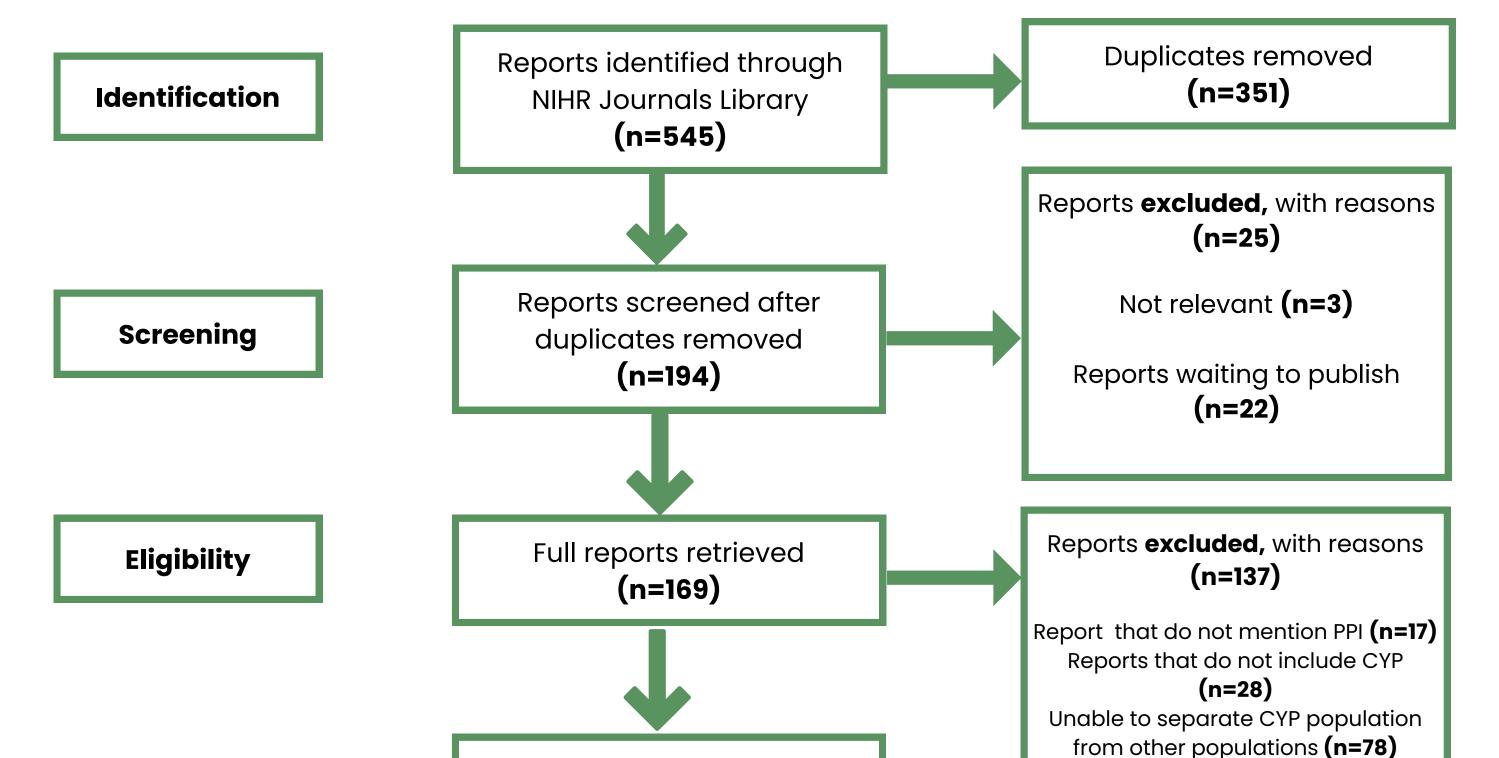
The length of the text to describe PPI with all stakeholders (parents, charities, adults, CYP, etc) varied from one short paragraph to full chapters within the main report or appendices. Of the 32 reports, only four fully met all the criteria for reporting PPI against the NIHR reporting expectations, (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

Model of involvement

Involvement at different phases of the research

- 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

Reported Dissemination Evaluation demographics 10 (gender, ethnicity Management Prioritisation etc) of CYP (other than age ranges) was weak for most reports Design Analysis & interpretation Implementation No involvement Average low levels of involvement age 7-25 Evidence of involvement 2. Reported impacts Impact on researchers Impact on CYP Impact on research Built capacity for undertaking Optimised the quality of the research Confidence building Skills & Knowledge effective PPI More insightful research grounded in CYP Interaction with YP's enthusiasm to be involved was **Research skills** expertise infectious! other YP Public speaking Influenced inclusion criteria, search terms & Reinforced the importance of Interaction with skills beneficial features of the research involving YP HCPs Vocational or Acceptability of research tools and methods of Emotionally motivated by the value Sense of belonging employability skills administration of involving YP Acceptability of study documentation/consent 3. Reported challenges and facilitators Pre-existing relationships (networks) PPI budget Bereavement Accomodating CYP availability

Included

Full reports included in the final review (data synthesis and analysis) (n=32)

Insufficient information on PPI (n=10) Hard to separate from qualitative research (n=1) Engagement, not involvement (n=3)

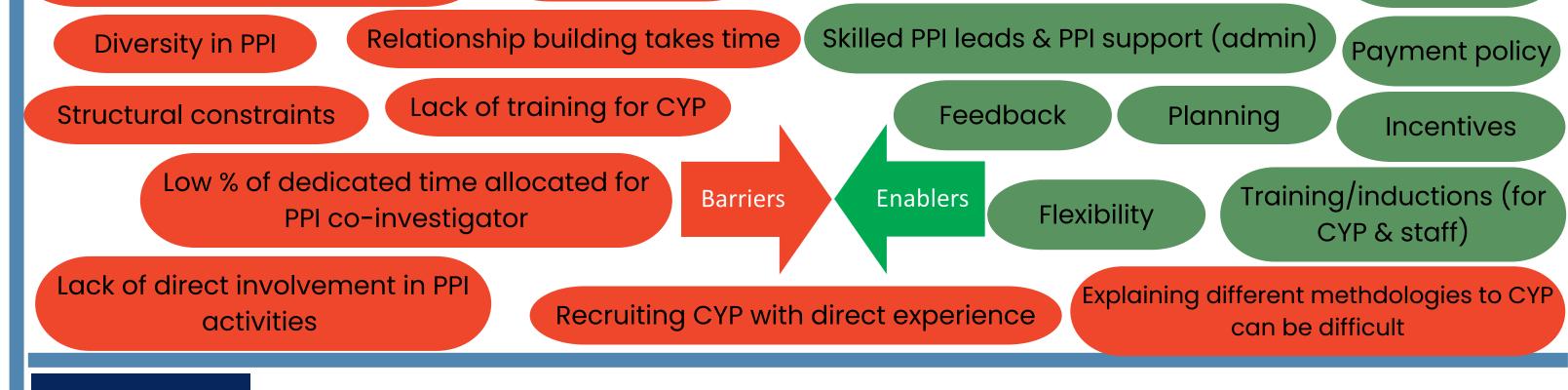
Qualitative content analysis and Framework analysis techniques were used to analyse the data. A small group from the NIHR Paediatric Incubator was formed (led by the lead author) to iteratively test tools (see Figures 1 and 2) to assess the level and quality of reporting of PPI with children and young 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

1. 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.

2. https://bit.ly/3fjxp97

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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.