

THE ECOSYSTEM OF EVIDENCE

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Artificial intelligence and digital transformation
in research and healthcare

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#EBHC2026

Trends in patient and public involvement in health research 2000-2024

Bibliometric Analysis

Colin Macarthur MBChB, PhD
Senior Scientist
SickKids Research Institute
Toronto, Canada

30th 1996-2026 GIMBE EVIDENCE FOR HEALTH

Background 1

Patient and public involvement (PPI) in health research

NIHR | National Institute for Health and Care Research



"Research carried out 'with' or 'by' members of the public, rather than 'to,' 'about,' or 'for' them"

Background 2

PPI in health research is a global social movement

NIHR | National Institute for Health and Care Research

pcori

CIHR IRSC
Canadian Institutes of Health Research | Instituts de recherche en santé du Canada



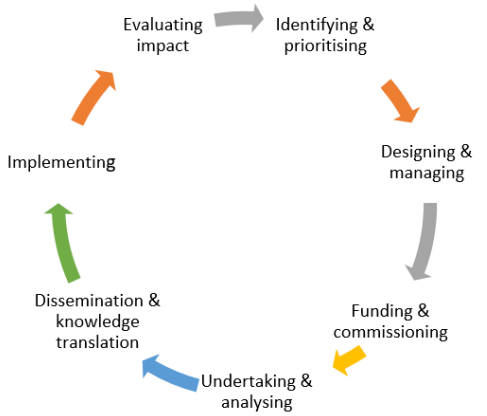


Strategy for Patient-Oriented Research
SPOR
Putting Patients First

Background 3

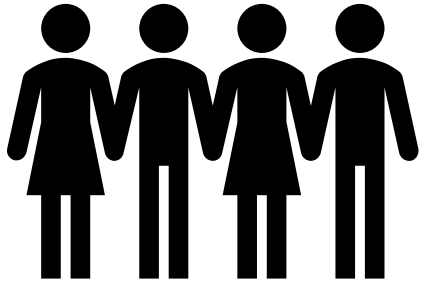
Perceived benefits of PPI

1) Research Process



- Relevance
- Feasibility
- Recruitment and retention
- Dissemination

2) Research Team



- Understanding of clinical condition, patient experience
- Motivation

3) Patient Partners



- Skill development
- Empowerment
- Altruism

Background 4

Patient and public involvement (PPI) in health research

- Few data on trends in PPI in health research
- Boote et al. *Health Expectations* 2012;18:44-57
  - Bibliometric review (1995-2009), no denominator, no estimate of trends
- Vanneste et al. *BMJ* 2025;389:e082697
  - Published RCTs (2015-2023), 4 journals, PPI prevalence 18%, significant ⇧ trend

Aims

Primary

- To determine prevalence and trends in PPI in health research

Secondary

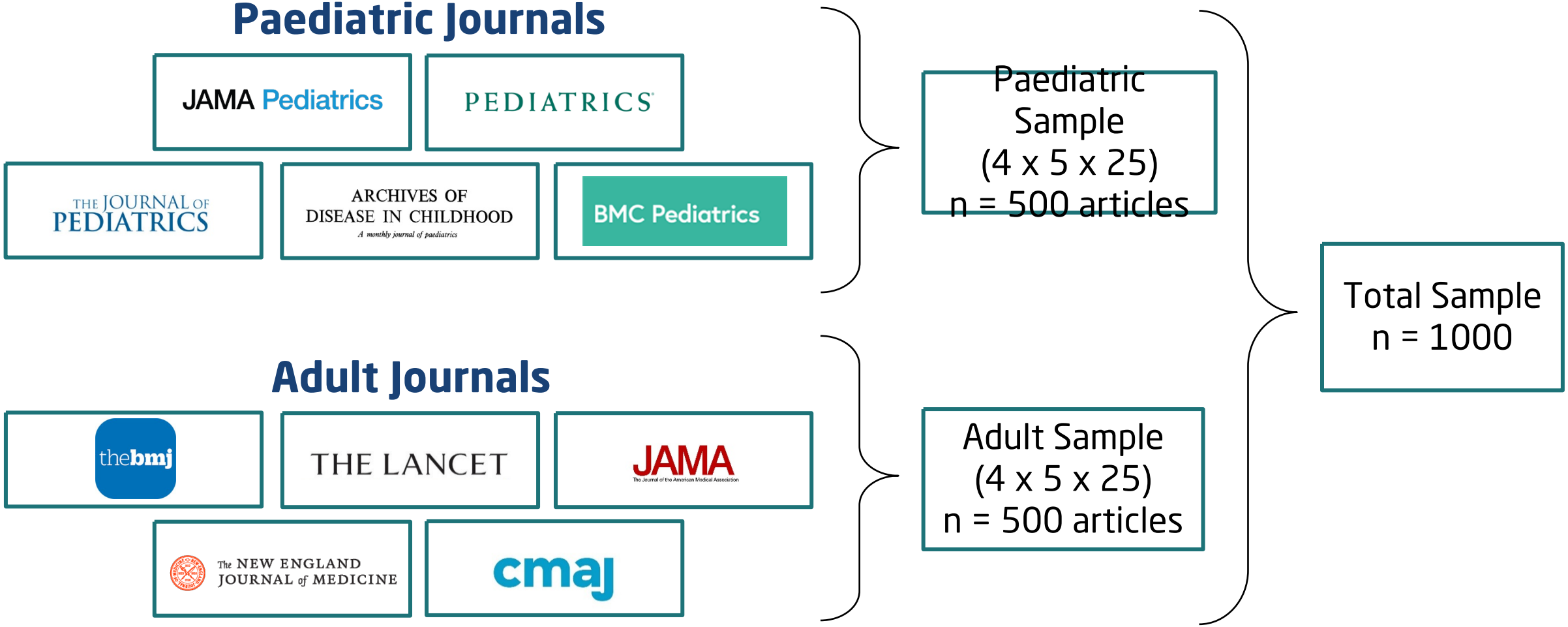
- To compare adult and paediatric trends
- To examine ‘level’ of PPI involvement over time

Methods 1

Study Design and Analysis

- Bibliometric analysis of peer-reviewed, empirical research publications
- All study design types
- Over 25 years (2000 to 2024)
- Published in 10 general medical journals
- Log linear regression analysis to assess trends over time

Methods 2


Paediatric Journals
JAMA Pediatrics
PEDIATRICS
THE JOURNAL OF PEDIATRICS
ARCHIVES OF DISEASE IN CHILDHOOD
A monthly journal of paediatrics
BMC Pediatrics
Adult Journals
thebmj
THE LANCET
JAMA
The Journal of the American Medical Association
The NEW ENGLAND JOURNAL of MEDICINE
cmaj
Paediatric Sample (4 x 5 x 25) n = 500 articles
Adult Sample (4 x 5 x 25) n = 500 articles
Total Sample n = 1000

Methods 3

Nature of PPI

- **Who** was involved, **how**, and **when**?
- IAP2 level scored 1-4

IAP2 LEVEL	CONSULT	INVOLVE	COLLABORATE	EMPOWER
Example	Seek feedback and take views into account.	Work with patient partners in research design and conduct.	Partner with and share responsibility in research design and conduct.	Lead some or all aspects of design, conduct, and dissemination.
Score	1	2	3	4

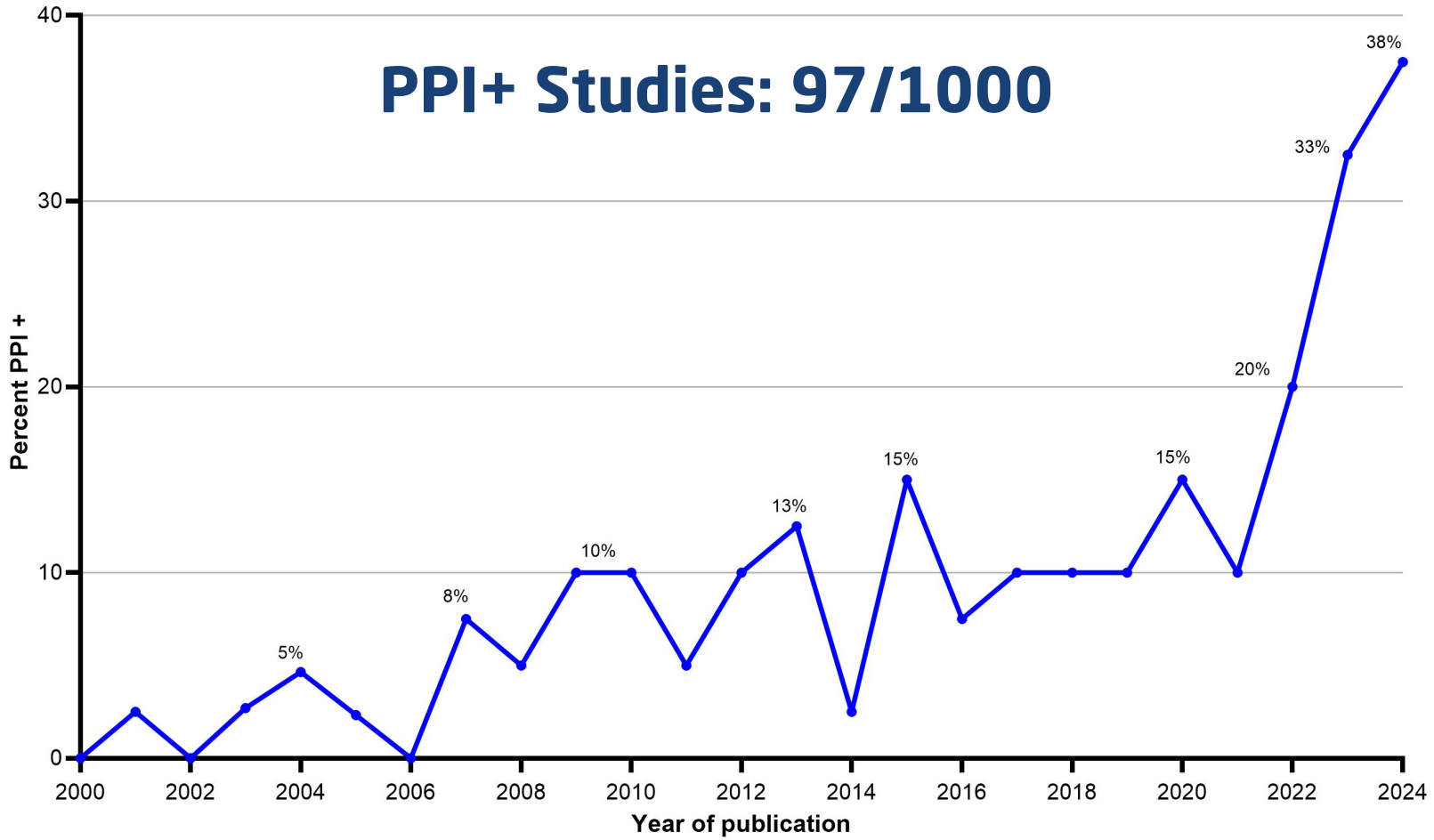


IAP2 Spectrum of Public Participation (modified). International Association for Public Participation (2018)

Results 1

Trend over time:

On average, **14% increase** in PPI+ articles per year
(OR 1.14, 95% CI 1.10-1.18, p<0.001)



Results 2

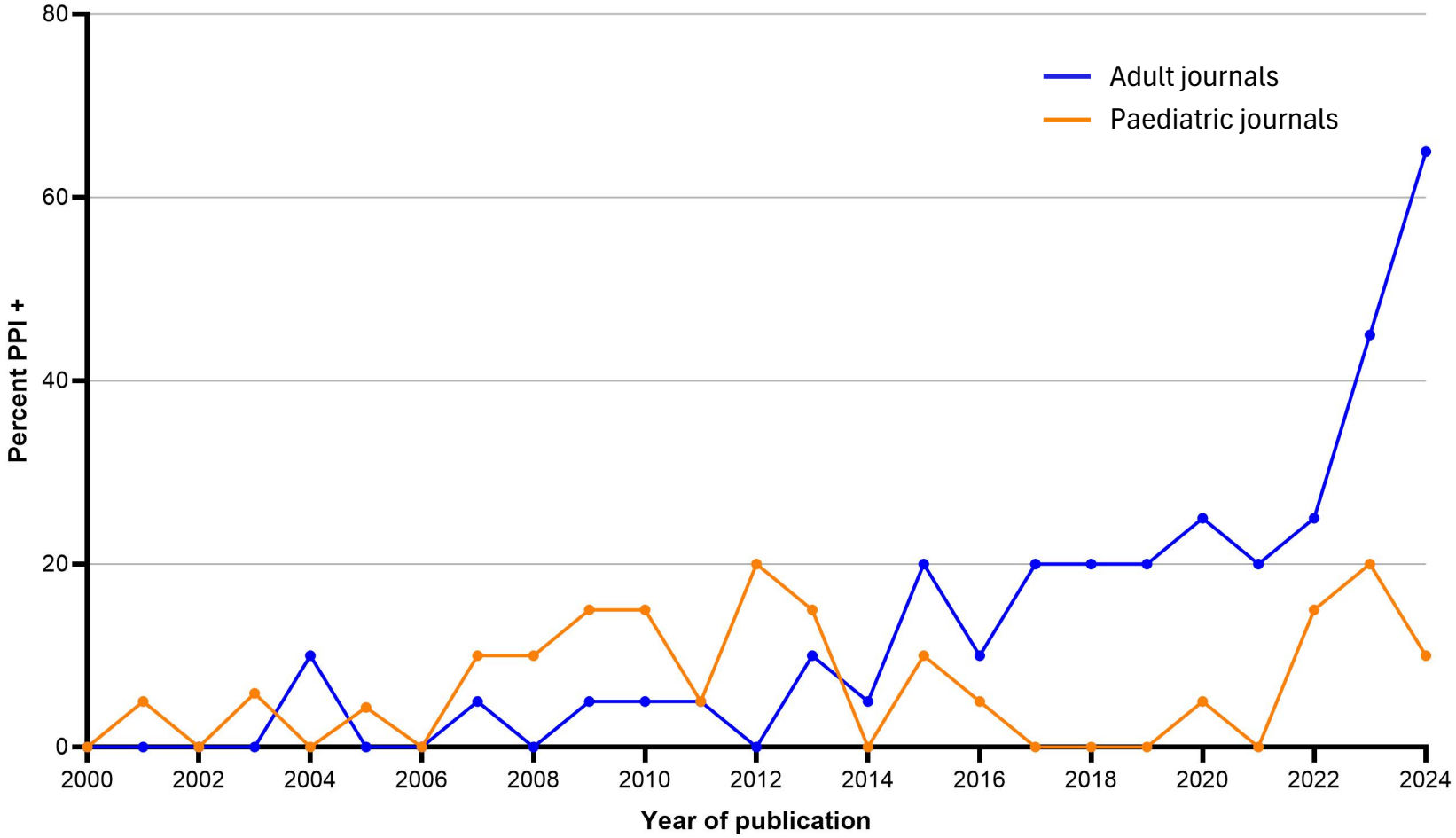
Trend over time **ADULT**:

On average, **24% increase** in PPI+ articles per year (OR 1.24, 95% CI 1.17-1.31, p<0.001)

Trend over time

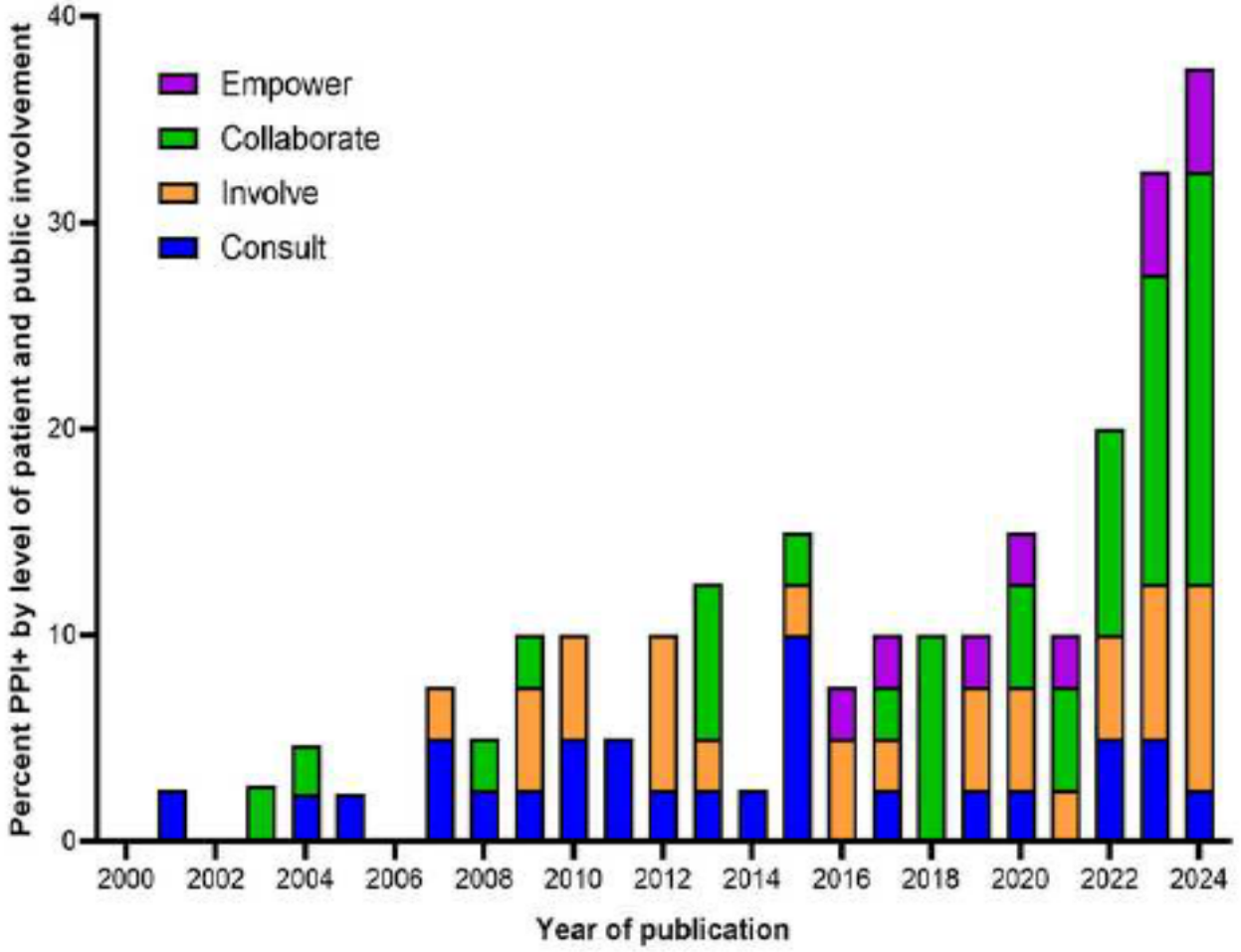
PAEDIATRIC:

On average, **5% increase** in PPI+ articles per year (OR 1.05, 95% CI 1.01-1.10, p=0.03)



Results 3

Trend in IAP2 'level' of PPI in health research, 2000 to 2024



Limitations

- Reporting of PPI was neither standardized nor consistent which may have led to misclassification
- Data on PPI involvement (type of activity and level) was limited to review of the published information only (we did not contact authors)
- Potential for bias in the sampling strategy, given overrepresentation of articles from journals with fewer articles published per year
- Reviewers were not blinded to type of study nor journal

Conclusions

- The prevalence of PPI+ research articles increased significantly from 0% in 2000 to 38% in 2024
- PPI+ research articles increased significantly over time in adult journals but not in paediatric journals
- Among PPI+ studies, mean IAP2 scores increased over time, suggesting deeper levels of engagement of patients and the public

[Cowley S, Borkhoff CM, Buchanan F, Akbar S, Hattangadi N, Sunner R, Cunningham J, Macarthur C. Trends in patient and public involvement in health research 2000-2024. *Research Involvement & Engagement* 2026;12:118]