

**Dedicated funding, people and time - the game changers for PPIE in health data research: a reflection on our public involvement in the Networked Data Lab in Grampian.**

**Sharon Gordon, NDL PPI Co-Lead**

**Boyd Ross, Aberdeen Centre for Health Data Science (ACHDS)  
PPIE Group Public Partner**





# ACHDS

Aberdeen Centre for Health Data Science



# Grampian NDL public involvement framework

Co-developed a framework for patient and public involvement and engagement (PPIE) with the Health Foundation, NDL PPI leads and public partners, based on existing guidance<sup>1,2</sup>



1 NIHR INVOLVE guide v1

2 Aitken et al. 2019 Consensus Statement on Public Involvement and Engagement with Data Intensive Health Research

# Dedicated funding: set up ACHDS PPIE Group

**Nurse Parents** Tennis  
Analytical Chemist in environmental health Accountant Cycling Dogs/pets  
**Grandchildren** IT Systems Consultant Parents with dementia  
Pharmaceutical industry Maths tutor Retired Charity work  
Lots of volunteering Social Care  
Undergraduate student Aberdeen Football Club **Children**  
Professor of Engineering Work part-time



10 Public contributors - *thank you!*

# Access to children and young people's mental health services analyses - PPIE

**ACHDS PPIE Group:** 11 Online and hybrid structured discussions

**Advocates for children and young people** – parents, carers and people working with children and families in the community:  
Three online structured group discussions (with 9, 16 and 6 people) and one 1:1 meeting



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Boyd

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Notes

76%

Prioritizing aspects of a topic

Designing an analytical plan

Analysing & interpreting

- helped prioritise topics and research questions
- reassured the team these were important questions to ask with the data available
- sense-checked results and interpretations
- Suggested **who** the team should share the results with



Gordon, Sharon



boyd Ross



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# Improved communication with the public

- Suggested **Who** the team should speak to next and **how**
- Practical feedback on clear communication with the public:
  - use graphs rather than tables but chose the simplest graph – better still use a mix of graphs and infographics
  - one graph per slide
  - have the take-home message in words
  - use higher resolution and bigger fonts





# Key reminders from the PPIE Group

- Talk to the people the results impact most – the research must be **relevant**
- We're OK with health data being linked in safe havens for **valuable** research to benefit society – **tell us** about the benefits
- Be open about the quality and limitations of the data – don't overinterpret - **don't over egg the pudding!**



## Undertaking PPI&E activities



## Dissemination

HSR UK The voice of UK Health Services Research

Conferences Events Publications Opportunities Membership Viewpoints

Workshops

### Demystifying Patient and Public Involvement and Engagement in health data research: early lessons from a framework approach

CONFERENCES  
Conference 2022  
Conference 2021  
Plenaries  
Presentations  
Workshops

#### Session chair:

- Fiona McKenzie, Human-Centred Health

#### Contributors / presenters:

- Olivia Ross-Hurst, Programme Officer, The Health Foundation
- Lynn Laidlaw, Patient Partner working with The Health Foundation
- Dr Magdalena Rzewuska, Research Fellow, University of Aberdeen
- William Ball, Research Fellow, University of Aberdeen
- Alan Johnstone, Public Contributor working with NHS Grampian / University of Aberdeen
- Norman Deans, Public Contributor working with NHS Grampian / University of Aberdeen
- Joanna Dundon, National Clinical Informatics Lead - Public, Digital Health and Care Wales
- Claire Newman, Public Engagement Officer, Swansea University
- Lesley Bethell, Chair of Compassionate Cymru
- Dot Williams, Patient Partner working with Swansea University

Lay summaries

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.....  
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- ✓ Study Approvals
- ✓ Grant Applications

### RESEARCH

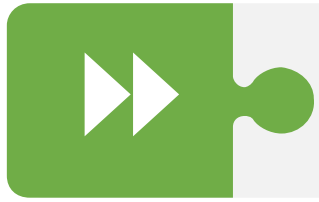
### Open Access



## Inequalities in children's mental health care: analysis of routinely collected data on prescribing and referrals to secondary care

William P. Ball<sup>1</sup>, Corri Black<sup>1,2</sup>, Sharon Gordon<sup>1</sup>, Bárbara Ostrovska<sup>3</sup>, Shantini Paranjothy<sup>1,2</sup>, Adelene Rasalam<sup>2</sup>, David Ritchie<sup>2</sup>, Helen Rowlands<sup>1</sup>, Magdalena Rzewuska<sup>4</sup>, Elaine Thompson<sup>2</sup>, Katie Wilde<sup>5</sup> and Jessica E. Butler<sup>1\*</sup>

## Reviewed/co-authored publications



## Implementation

*..and impacts!*

Feedback to key stakeholders at the local level:

23 Feb 2023:

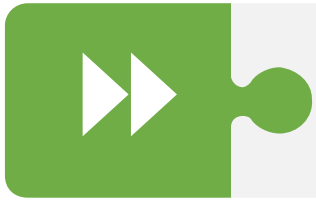
‘...help families that need help to navigate the systems better to find the help they need..’

...provide ‘...better mental health training for staff working with children and young people so they can provide better support...’

06 Dec 2023:

‘..I delivered training in trauma...3 weeks ago...’

‘...LIAM training is about to be offered to Youth Workers and PSAs ...and will be evaluated by end of 2024 ...’



## Implementation

*..and impacts!*

23 Feb 2023:

Development Manager for Youth Work at ACC attended our workshop....

...and used the info we provided from the analysis to support his case for **investment in 2 new members of his team.**

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8 Key reminders from the PPIE Group:

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12 Dedicated people: PPIE funding creates PPIE Champions

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Boyd:

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## Dedicated people: PPIE funding creates PPIE Champions

### Reflections from our PPI partners:

*I feel my input is **valued and acted upon** when appropriate.*

*I find the work to be very satisfying as a means of "giving something back" in my retirement."*

*"..one of the most important things for me has been the privilege to work with such amazing people to **make research more accessible** since I know that for many it's seen as a black box not meant for them."*



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# Dedicated people: PPIE funding creates PPIE Champions



Reflections from researchers:

‘getting it ...[our research..] right’ and  
‘..getting it across right..’

‘... [the PPIE Group] input was very  
insightful and had **a major impact on the  
final version** of the application.’

‘...PPI is now incorporated [costed in] at  
**every stage...**’

Dedicated PPIE funding supports dedicated people to dedicate the time to make it happen and to strive to do it more and better...

# Dedicated funding, people and time - the game changers for PPIE in health data research: a reflection on our public involvement in the Networked Data Lab in Grampian.

Dr Magdalena Rzewuska Díaz and Dr Sharon Gordon (NDL PPI Co-Leads, Phase 1)

Aberdeen Centre for Health Data Science (ACHDS) PPIE Group: Norman Deans, Alan Johnstone, George Murray, Bārbala Ostrovska, Debora Paterson, Boyd Ross, Carol Vermeulen, Lynn Laidlaw, Joyce Paul, Grace Revell

Advocates for children and young people.

**NDL Grampian Team:** Dr Jess Butler (NDL Lead, NHSG), Professor Corri Black (NDL Lead, UoA/NHSG), Raul Berrocal-Martin (NDL Analyst UoA), Dr Frank Popham (NDL Analyst-NHSG), Dr Will Ball (NDL Analyst, UoA Phase 1), Irmina Zborowska (NDL Administration Co-Ordinator), Gail Mew (ACHDS Administration Co-Ordinator)

