



Mary  
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Consulting

PPIE Lead  
for the  
Maternity  
and  
Perinatal  
Mental  
Health  
theme

Building ongoing  
communication  
throughout the lifecycle of  
research - reflections of a  
service user PPIE Lead

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# PPIE in research/equity & diversity in involvement



## Researchers

- Data analysts
- Bio-medical
- Social science
- PPI researchers



## Knowledge intermediaries

- ❑ PPI Leads/ co-applicants
- ❑ Advocates for equity and diversity in research
- ❑ Methodologies



## The public

- Individuals
- groups, CICs, charities
- MSLCs/Maternity Voices Partnerships
- Social media networks



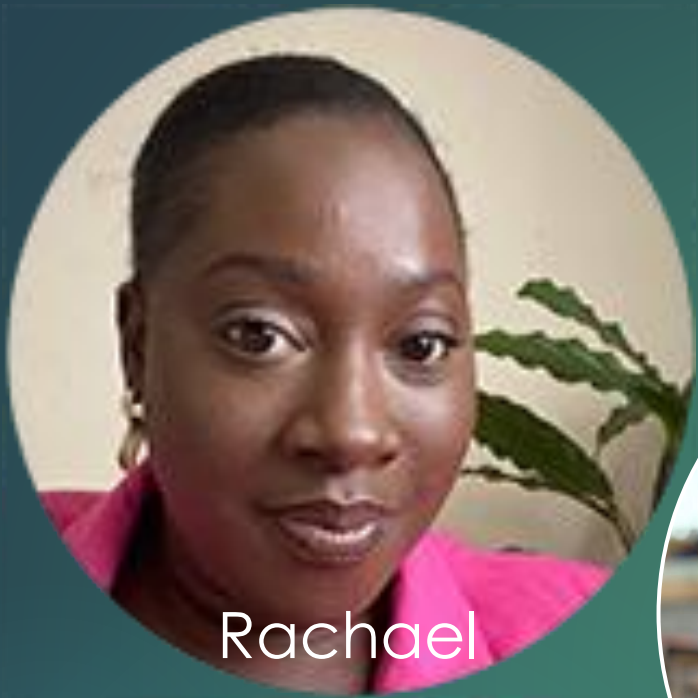
# ARC South London Maternity and Perinatal Mental Health Research

**Current issues in SE London:**  
poorer outcomes for women &  
babies living in areas of social  
disadvantage & from Black, Asian  
and minority ethnic groups

- What are the reasons for this?
- What models of care can help?
- How can care & outcomes for women with mental illness be improved?

We aim to **reduce health inequities** & have a **positive impact** on health & wellbeing of **women & families** in **the local community**





Rachael

Mummy's Day  
Out



Vita

Maternity  
Voices  
Matter



Zenab

National  
Maternity  
Voices

# Different degrees of public involvement

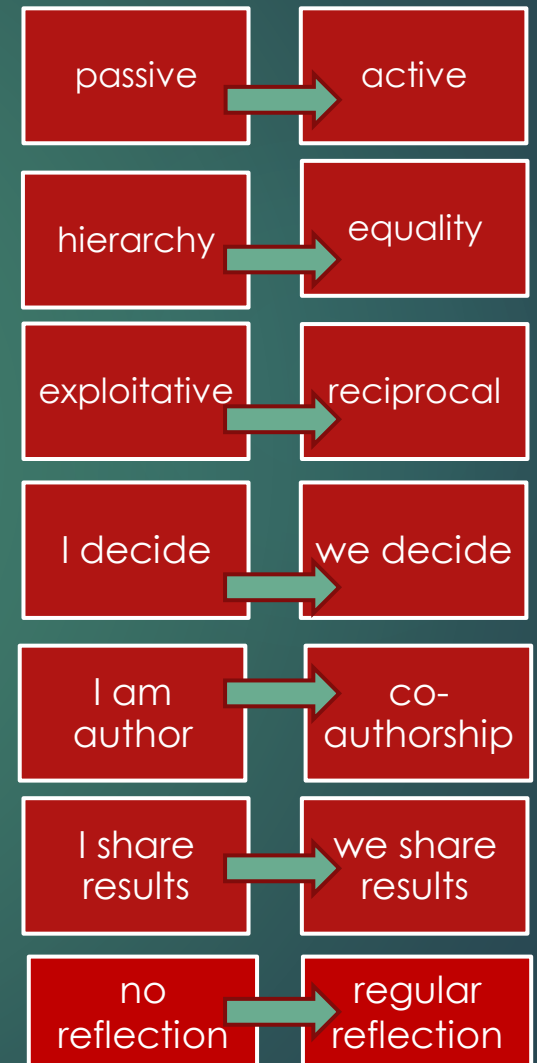
- ▶ consultation
- ▶ collaboration
- ▶ co-production
- ▶ user controlled

Briefing notes for researchers (NIHR, 2021)

# A spectrum of involvement - co-production

“an opportunity for researchers to work with the public *sharing power and responsibility* from the start to the end of the project”

(Wilson et al., 2018).



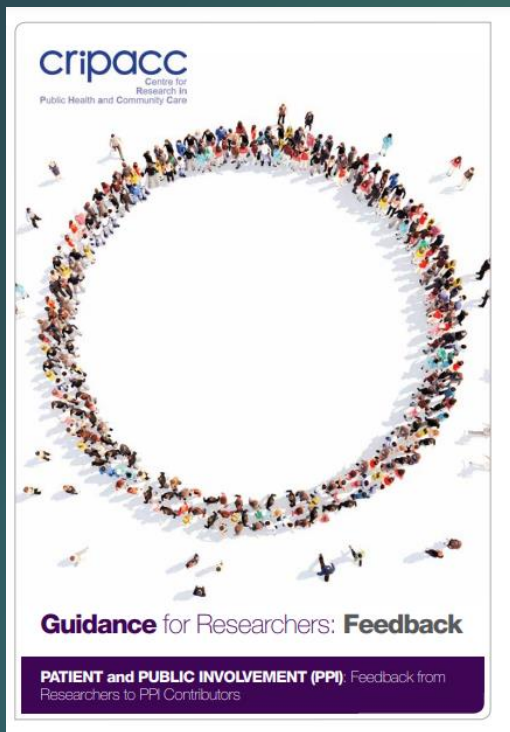


# GRIPP2 – a framework to guide how we work

Five elements	RELAX study (Reducing Levels of AnXxiety)	What we will do	Approve review &/or Report
<b>Aims</b>	Identify clear objectives of PPI in the study	<b>Written PPIE Plan</b>	
<b>Methods</b>	Provide a clear description of methods for PPI in the study	<b>3 online workshops Advisory group meetings</b> (King's MVP, indivs, charities)	
<b>Study results</b>	Outcomes – report the <b>results of PPI in the study</b> , including positive and negative outcomes	<b>Keep a log of comments, questions and requests. Minutes</b>	
<b>Discussion and conclusions</b>	Outcomes – Comment on the extent to which PPI influenced the study overall. Describe positive and negative effects	<b>Ask for regular feedback from Researchers</b>	
<b>Reflections/ critical perspective</b>	Comment critically on the study, reflecting on the things that went well and the things that did not, so others can learn from this experience.	<b>Collate reflections from: PPIE-AG, Researchers and TSC members</b>	

Staniszewska et al (2017) developed [GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research](#)

# Researcher feedback form



<b>NIHR</b>   Applied Research Collaboration East of England		<b>Public Involvement Group</b>	
		<b>Feedback Form</b>	
<p>Dear [Name],</p> <p>To allow us to improve our research, please complete the following form. We are interested in knowing how helpful our comments are to you. Your feedback on the proposal or documents you asked us to review will be used to improve our research. Completion of this form will also be helpful to you when completing the Patient and Public Involvement (PPI) sections of funding application forms and providing project updates if funded.</p>			
Project Title:			
Name and contact details of lead researcher (including institution & email address):			
1) Overall, how helpful were the comments received from [PPI group] members?		<b>Please circle/underline one response:</b>	
		Very helpful      Quite helpful      Not helpful	

► <https://arc-ee.nihr.ac.uk/researcher-feedback-form>

# Models of Maternity Care for Women with Multiple Long-Term Conditions During Pregnancy, Birth and the Postnatal Period

## Specific changes

- multiple health conditions
- sickle cell
- midwifery care / continuity
- methodology

Zoe Vowles, Midwife Research Assistant ARC-SL  
Pre-doctoral








Dr Brittannia  
Volkmer, Clinical  
Trial Coordinator  
**RELAX study, KCL**

# Summary

How to achieve public and community involvement throughout the life of research?

1. relationships
2. resources
3. reciprocity
4. reflection



Life-Threatening  
Attempted Suicide in  
the Perinatal Period

A study of women's experiences of life-threatening suicide attempts during pregnancy and early motherhood

Currently, suicide is one of the leading causes of death in pregnant women and new mothers (MBRRACE-UK 2019). Suicide is under-researched and too often misunderstood - your contributions to this project will help us provide better support in the future.

**If you**

- Are over 18;
- Attempted suicide during or in the year after your pregnancy;
- And you attempted suicide between one and five years ago.

**Please consider contacting the study team.** We are looking to find ways to prevent future deaths by suicide, and by sharing your experiences, you can teach us new ways to help.

If you participate, the study will provide compensation for your time. We will discuss how to

Please contact  
**Maternity-Studies**  
**@kcl.ac.uk**  
for more information

If you require urgent support with your mental health, please call the NHS 111 helpline, the Papyrus-UK helpline on 0800 068 4141, or

# References

- ▶ CRIPACC, Guidance for Researchers: Feedback from Researchers to PPI Contributors. 2018. [https://www.clahrc-ee.nihr.ac.uk/wp-content/uploads/2016/05/Guidance-for-Researchers-PPI-Feedback\\_2018.pdf](https://www.clahrc-ee.nihr.ac.uk/wp-content/uploads/2016/05/Guidance-for-Researchers-PPI-Feedback_2018.pdf) email: [e.j.mathie@herts.ac.uk](mailto:e.j.mathie@herts.ac.uk)
- ▶ NEWBURN M, SCANLON M, PLACHCINSKI R, MACFARLANE A J. Involving service users in the Birth Timing project, a data linkage study analysing the timing of births and their outcomes. *Int J Popul Data Sci*. 2020 Nov 2;5(3):1366. doi: 10.23889/ijpds.v5i3.1366. PMID: 34007886; PMCID: PMC8121135.
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- ▶ RELAX study (REducing Levels of AnXxiety in Pregnancy) <https://arc-sl.nihr.ac.uk/research-and-implementation/our-research-areas/maternity-and-perinatal-mental-health/reducing>
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- ▶ WILSON P, MATHIE E, POLAND F, KEENAN J, HOWE A, MUNDAY D, KENDALL S, COWE M, STANISZEWSKA S, GOODMAN C. How embedded is public involvement in mainstream health research in England a decade after policy implementation? A realist evaluation. *Health Serv Deliv Res* 2018; 23(2). <https://doi.org/10.1177/1355819617750688>