Involving diverse communities in research - insights and learning from a co-production training event

Dr Abigail Easter, Senior Lecturer
Agnes Agyepong, Maternity Voices Partnership Chair at Guy's and St Thomas' Hospital
Mary Newburn, Patient and public involvement (PPI&E) Lead

Maternity and Perinatal Mental Health research

Inside Research Seminar,

3 November 2021

NIHR | Applied Research Collaboration South London

Involving diverse communities in maternity and perinatal mental health research – insights and learning from a co-production training event.

Authors: Ahmed E, Newburn M, Moltedo V, Umutoni K, Agyepong A, Silverio SA, Sandall J and Easter A.

NIHR Applied Research Collaboration South London. 2021.

https://bit.ly/3mkpU2P

# ARC Maternity and Perinatal Mental Health Research

- **Current issues in SE London:** poorer outcomes for women & babies living in areas of social disadvantage, with mental health difficulties or from Black, Asian & minority ethnic groups

  - What are the reasons for this?
  - What models of care can help?
  - How has the COVID-19 pandemic affected these health inequalities?

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

- Involve women, communities and relevant organisations in our strategy from the beginning of our work

ARC South London Maternity & Perinatal Mental Health Theme: Our work, so far..

RESEARCH PROJECT   5 May 2020

Investigating maternal and perinatal outcomes among women from Black, Asian and Minority Ethnic groups
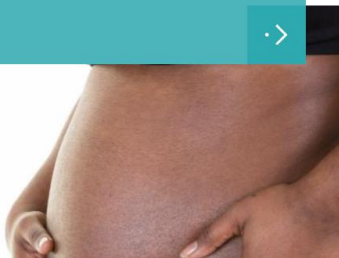
CORE RESEARCH PROJECT
15 Sep 2021

The ASPEN Study: Attempted suicide in the perinatal period: A study of life-threatening suicide attempts during pregnancy and early motherhood

CORE RESEARCH PROJECT
10 Dec 2020

The impact of the Covid-19 pandemic on the health and care of women experiencing mental illness and domestic violence and abuse, during pregnancy

ADOPTED PROJECT   4 Aug 2020

The changing maternity care study: How has virtual and remote care changed maternity care practices during Covid-19?

CORE RESEARCH PROJECT
5 May 2020

Models of maternity care for women living in areas of ethnic diversity and social disadvantage
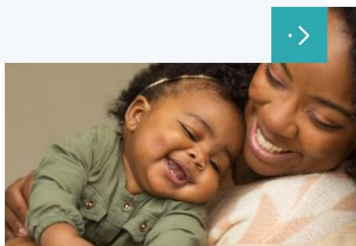
CORE RESEARCH PROJECT
5 May 2020

Investigating the factors surrounding life-threatening self-harm and attempted suicide in the perinatal period among women with mental illness

ADOPTED PROJECT   5 Aug 2020

The experiences of parents who suffer pregnancy loss and whose babies die during the pandemic

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PPIE - Patient & Public Involvement & Engagement
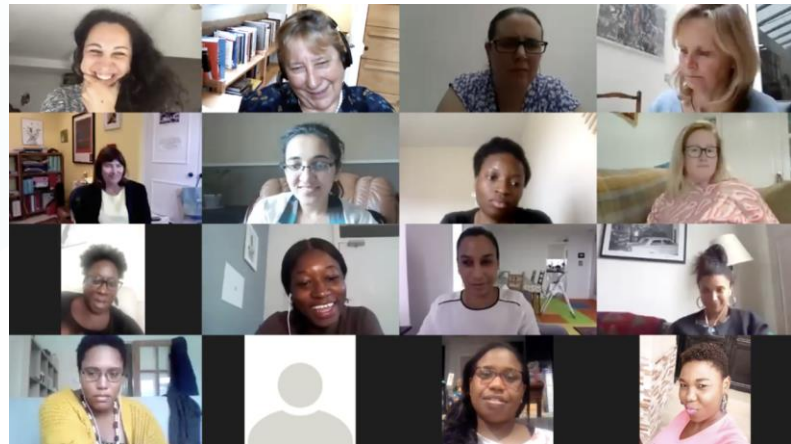
- **We include** service users, networks, communities, & charities using existing and new connections, social media and London Maternity Voices Partnerships

"Our research aims to improve the health and wellbeing of women and families by identifying who has additional needs, and by improving the healthcare management, support and clinical monitoring of women at risk of severe morbidity and mortality during and after pregnancy. Community involvement in the research really helps us to get this right."

Theme lead: Jane Sandall CBE, professor of social science and women's health, King's College London

"PPIE is about empowering those very people who are at the heart of research in healthcare by giving them a voice."

Vita Moltedo, co-founder member of Maternity Voices Matter

https://www.arc-sl.nihr.ac.uk/research-and-implementation/our-research-areas/maternity-and-perinatal-mental-health/about-our-0

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Why Black women are not engaging in research and what can be done to change this

Agnes Agyepong

RACISM

How to combat bias p6

Modified Delphi
What is chronological bias and how can it affect your study? p9

Measurement error
Methods to avoid misclassification when interpreting results p21

Quantitative study
When and how to use factorial design in nursing research p26

11 March 2021 / Vol 29 issue 1

Why bias is key to stopping institutional and structural racism in healthcare and research

Institutional racism not only damages our health, it can kill, and it does

Agnes Agyepong
Posted 12 February 2021 - 12:17

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BIAS

Let me get straight to the point. Systemic and institutional racism is affecting the lives of black and brown people right now, across the world in adverse ways. In the healthcare sector it not only damages our health, it can kill, and it does.

The need to address and have important, sometimes uncomfortable, conversations on how we can tackle systemic and institutional racism in healthcare has become a topical issue heightened by the murder of George Floyd at the hands of police. Recorded for all to see, his cries of: 'I cant breathe!' reverberated around the world leading to the largest protests in history, and the global Black Lives Matter movement, which saw between 15 million and 26 million people worldwide protest inequalities.

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Research & implementation

Home > News & insights > Blog and commentary

Service user involvement in maternity and perinatal mental health research

Agnes Agyepong, parent engagement programme manager at Best Beginnings and Guy's and St Thomas' NHS Foundation Trust Maternity Voices Partnership Chair discusses why Black women are not engaging in research and what can be done to change this?

BLOG AND COMMENTARY

29 Sep 2020   At no time in British history has there been such a keen interes

How we can all play a role in bringing about change
Questions for introspection

- **Are our leadership teams reflective of the types of audiences we are trying to reach?**

- **What Black researchers are we working with on this project?**

- **What Black networks are we reaching out to and co-producing with?**

- **Are we funding our partners adequately?**

- **Is our approach transactional or relationship led?**

- **How are we collaborating with and amplifying the voices of those who are already doing the grassroots work within the community?**

Coproduced researcher/service user training

Participatory appraisal methodology

Key questions

- How can researchers work with diverse communities?
- How can we share power?
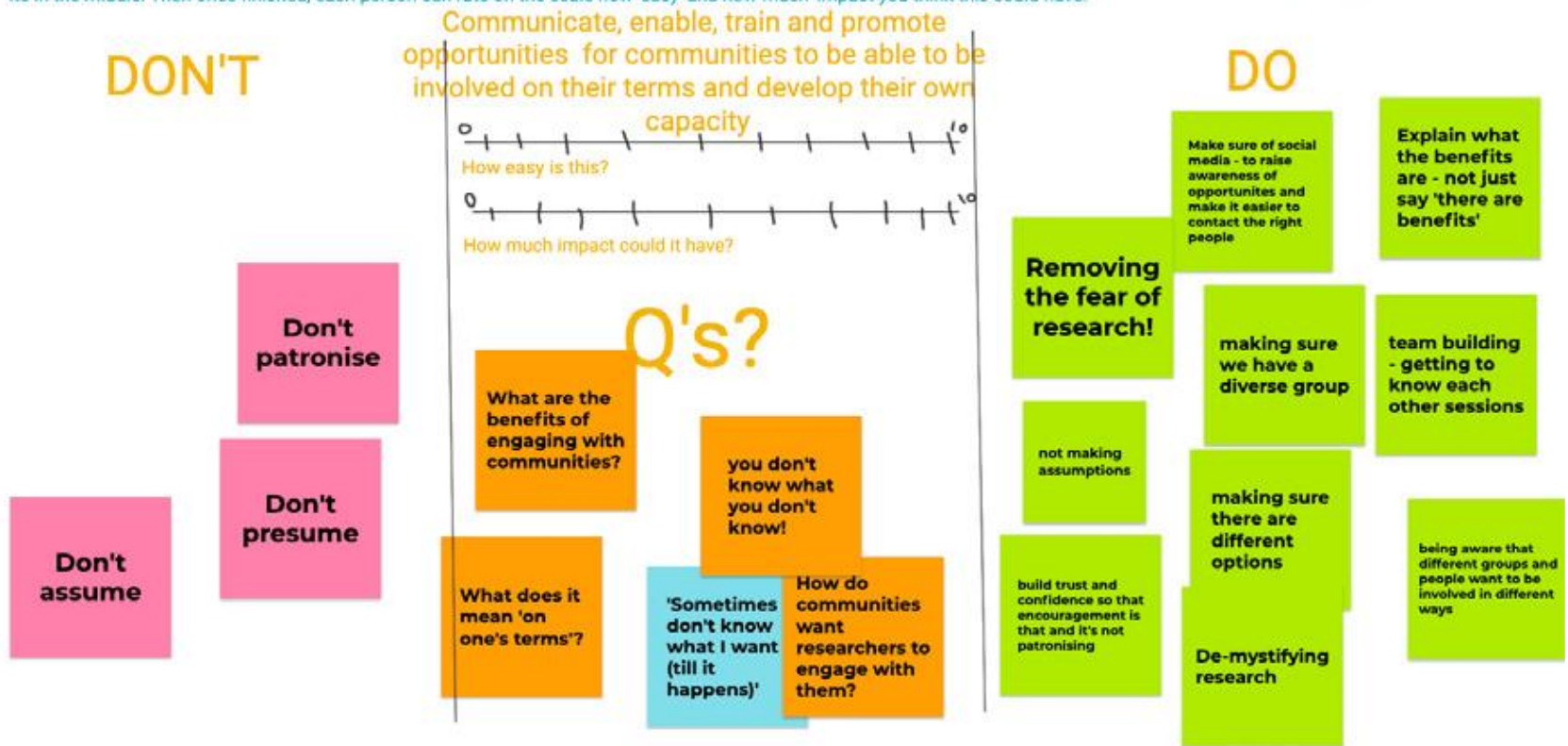- How can we overcome barriers to PPIE within research systems and culture?

Spider diagram – an illustration of barriers and potential solutions

The H form

How can we implement these solutions?

H-Form: Discuss this solution... write what we could 'do' in green post-its on the right, and 'dont's' in pink on the left. If you have any questions write them in yellow post-its in the middle. Then once finished, each person can rate on the scale how 'easy' and how much 'impact you think this could have.

Communicate, enable, train and promote opportunities for communities to be able to be involved on their terms and develop their own capacity

DON'T

DO

How easy is this?

How much impact could it have?

Q's?

Don't patronise

Don't presume

Don't assume

What are the benefits of engaging with communities?

What does it mean 'on one's terms'?

you don't know what you don't know!

'Sometimes don't know what I want (till it happens)'

How do communities want researchers to engage with them?

Make sure of social media - to raise awareness of opportunites and make it easier to contact the right people

Explain what the benefits are - not just say 'there are benefits'

Removing the fear of research!

making sure we have a diverse group

team building - getting to know each other sessions

not making assumptions

build trust and confidence so that encouragement is that and it's not patronising

making sure there are different options

being aware that different groups and people want to be involved in different ways

De-mystifying research

Themes – Dos (and don'ts)

- **Community-focus**
- **Communications**
- **Funding**
- **Trust**
- **Power imbalance**
- **Diversity**

"Technical or formal language being used, which works for ethical approval and might score highly for 'respectful' can seem distant and cold and therefore either nothing to do with me, or positively alienating"

(workshop participant)

Recommended actions:

- Ensure information is short and clear

- Get community advice on communications

- Plan outreach activities carefully

- Ask which social media platforms are best

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" Money and funding came up… not having the money to do things properly, not having the resources… wanting to do things better, but not being able to do it. "

(plenary discussion)

Recommended actions:

- Plan PPIE funding in detail
- Apply for adequate funding
- Be clear about all work that needs funding
- Budget for team building and training

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" We also spoke about trust being very, very important, and providing information and representation at all levels of decision making, as well as adequate funding "

(plenary discussion)

Recommended actions:

- Be respectful and appreciative

- Work together with reciprocal benefits

- Build trust with key community influencers

- Support active development of research by community members

- Ask: "Are we sharing power? What can we do differently?"