**Terms of Reference**

**Patient and Public Involvement and Engagement Strategy Group**

**Maternity and Perinatal Mental Health Research**

1. **Our goal:**  is a culture of active patient and public involvement and engagement (PPIE) in maternity and perinatal mental health research, where research is carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them, and in which strong links and networks are developed with individuals and organisations to ensure that Black, Asian and Minority Ethnic communities are at the centre of the research in south London, and that those living in poverty, facing disadvantage and with socially complex lives are well represented and supported to be involved in research.
2. **Purpose**:
   1. **To advise** on ways of working towards our goal, for example by co-producing agreed values and good practice for collaborative, partnership working.
   2. **To promote diversity and inclusion** in research, among researchers, research participants and stakeholder advisers.
   3. **To model good practice** and to share, promote and occasionally provide guidance on PPIE matters, from the design and funding application stages to analysis, writing up and sharing of research findings.
   4. **To identify suitable training on PPIE and co-production** collaborating with South London ARC colleagues, andother ARCs and organisations leading on PPIE, and to look for sources of funding for PPIE training.
3. **Membership**: There will be:

* A minimum of six from service users, community networks, Maternity Voices Partnerships, relevant organisations representing diverse service user voices, (Agnes Agyepong, MVP and Best Beginnings; Emily Ahmed, Peer Research and RCM Maternity Voices; Lucy Angell John, lived experience; Kirsty Kitchen, Birth Companions; Amy Dignam, Artist and MVP co-chair; Kathryn Grant, Lived experience; Anna Horn, Maternity Transformation adviser, breastfeeding peer support and PhD student; and Aygul Ozdemir, Peer Research)
* A minimum of six ARC researcher members (Professor Jane Sandall, Professor Louise Howard, Abigail Easter, Cristina Fernandez Turienzo, Lauren Carson, Sergio A Silverio, Hannah Rayment-Jones)
* For continuity, both groups shall include 1-2 regular attenders/members of the ARC Maternity and Perinatal Mental Health Research Advisory Group,
* Two PPIE leads (Mary Newburn for Maternity and Perinatal Mental Health and Clare Dolman for the Perinatal Mental Health Advisory Group (PAG))
* Representatives from: the ARC-SL Diversity and Inclusion Working Group (Abigail Easter) King’s Health Partners Institute for Women and Children’s Health PPI/E sub-Committee (Hannah Rayment-Jones).

1. **Chairs:** Co-chairs (one PPIE member and one researcher), to be elected by all of the Group members for two years, with a second term possible, if proposed and re-elected.
2. **Minute taking:** To be arranged in advance of each meeting. Rosie Hildersley has kindly volunteered to minute the 2020 meeting.
3. **Quorum**: three PPIE members and three researchers.
4. **Schedule of meetings**: minimum of 1 per year either in person or online.
5. **Other contact**: available for email or telephone contact in between meetings for specific queries from investigators and review of documents.
6. **Responsibilities**: To work respectfully and courteously; to share insights, relevant resources and intelligence, creative ideas and concerns. To be responsive, ie to respond to requests from researchers or to let the researcher and PPIE Lead know you are not currently able to contribute.
7. **Publications**: A publication protocol will be developed setting out clear guidelines on authorship, acknowledgment and publications.
8. **Communication**: To receive minutes of the PPIE Strategy Group meetings within 21 days. Agendas, at least five days in advance of the meeting. Creative co-production work within the meetings.
9. **PPIE Payments:** Approved travel expenses and childcare costs will be paid from ARC Maternity and Perinatal Mental Health sources. PPIE payments will be made for attendance at meetings and for substantive strategy work.
10. **Reporting:** The Group will report its activities to the ARC executive, in ARC annual reports and newsletters, and to the ARC main PPIE group.

**Key Definitions**

**Meaning of Diversity:** *“When we talk about ‘diversity’, we mean making sure that we recognise, respect, value and celebrate the differences that everyone has, as well as leveraging the opportunities that different people bring to the work that we do” (Health Education England: Diversity and Inclusion Our Strategic Framework 2018-2022:8)*

**Meaning of Inclusion:** *“We define ‘inclusion’ as taking an approach to our work where we consider people, their diversity, their preferences and their abilities. It is about creating a workplace where everyone can be themselves and feel that they can contribute their views, which will be valued” (Health Education England: Diversity and Inclusion Our Strategic Framework 2018-2022:8).*

**Legislation:** D&I at King's is underpinned by the 2010 Equality Act that merged and simplified previous anti-discrimination legislation in the UK. The Equality Act requires all public bodies to eliminate discrimination, harassment and victimization, advance equal opportunity and foster good relations between employees. The Equality Act protects people from discrimination based on nine protected characteristics: These include age, disability, gender reassignment, race, religion or belief, sex, sexual orientation, marriage and civil partnership and pregnancy and maternity.

**Promoting diversity and Inclusion is now seen as central to achieving good healthcare experiences for both patients and staff:**

Aligned to discussions about diversity and inclusion in healthcare is a recognition of the principle of the inverse care law proposed by Julian Tudor in 1971, has been widely adopted. The law states that: *"The availability of good medical care tends to vary inversely with the need for it in the population served. This ... operates more completely where medical care is most exposed to market forces, and less so where such exposure is reduced."*

*“Diversity and inclusion lead to improved health and greater staff and patient experiences of the NHS” (NHS Leadership Academy).*

*“Inclusion is core to the NHS Constitution, yet it remains one of the biggest challenges that health systems face globally, nationally and systemically. In the face of a growing body of evidence, which demonstrates the critical role that inclusive leadership plays in ensuring that health and care systems operate most effectively for patients and public, it is incumbent upon us to ensure that leaders at all levels are equipped and capable of leading inclusively and effectively” (NHS Leadership Academy).*

**The NIHR South London ARC Bid notes:**

*“The aim of NIHR ARC South London is to undertake high-quality applied health and social care research which leads to improved health and social care outcomes for people in south London and beyond. To achieve this, we will conduct research and implementation activities directly informed by the needs of the local population, and the priorities of the local health and social care system. We will involve commissioners, patients and service users, carers, families, community members and practitioners at each stage, to ensure the relevance of our work, supporting implementation into practice. South London has a very diverse population with multiple social and structural inequalities. Social care and preventative public health are therefore central”.*

*“To design an ARC that is relevant to the needs of patients and the public in diverse, local communities, the health and care priorities of all relevant institutions within south London were reviewed, including CCGs and Health and Wellbeing Boards. The top five priorities were: clinical and care effectiveness, patient experience, patient safety, wider determinants of health, and mental health”.*

The above context indicates that D&I is central to the work of the NIHR ARC South London.