**Patient and Public Involvement Funding Report**

Layla Lavallee

Thank you very much for the Patient and Public Involvement (PPI) funding award. The funding went towards the development of my DPhil study proposal – a qualitative study exploring under-served women’s experiences of postnatal care following a hypertensive pregnancy. Whilst I had a fairly good idea of the type of research I wanted to undertake it was important to hear from women who had experienced Hypertensive Disease in Pregnancy (HDP), particularly those who tend to be under-represented in research and who are more likely to experience poor outcomes because of their ethnicity or socio-economic status. Namely I wanted to explore with the PPI representatives:

* Their experiences of HDP care, particularly in the postnatal period
* Their knowledge about the relationship between HDP and longer term cardiovascular disease risks
* Whether they thought the objectives of the study were relevant and worthwhile, and if not, why
* What they felt the key priorities for research were
* If they felt the study design was suited to the objectives and how it might be improved
* What they felt would be the best way to reach and engage under-served women and to disseminate the findings

Consequently, in addition to two PPI contributors from the Gypsy and Traveller community I had spoken to previously (outside of this funding scheme), I met with three women who had experience of HDP:

* A Pakistani/British woman, with 3 children, living in an area of high deprivation in the north of England.
* A White Irish woman, with 1 child who recently moved to Northern Ireland from London and who works as a social worker with under-served women.
* A White British woman living in Essex who had one child that she became pregnant with at the age of 18.

All of the women reported that they knew little about HDP prior to developing the disorder and none had been aware of the associated long-term cardiovascular risks until I approached them. Consequently the lay summary (which they provided feedback on) was revised to provide a more thorough explanation of HDP.

Some of the women said their care-givers had been kind, however all felt their concerns had been trivialised or dismissed. The younger woman felt judged because of her age and said that if weight management strategies been suggested to her she would have felt like she was being judged further. This reinforced the importance of exploring the invisible barriers/harms women can face within the health system, which much of the study will be devoted to, and of the need for maximum variation within the sample to explore diverse perspectives.

The women also provided suggestions on how to maximise recruitment and engagement and discussed where they turned to for health information. All were positive about the online resource that I intend to develop with my study, particularly as they felt that it was a reliable source of information. There was a consensus that social media (e.g. WhatsApp groups) were the best way to reach under-served women and to disseminate information.

All of the PPI contributors were keen to share their insights and to address the gaps in care and evidence they felt was lacking. They have agreed to contribute further to the study when it commences as members of an advisory panel.

I also met with an independent, organisational ethics specialist who has expertise in using power analysis within organisational governance to address the harms that can arise from institutional biases and power imbalances. She provided design input where she encouraged me to evaluate and address my own “power” and to seek diversity within the advisory panel which she will also be member of.

Immediately following the interviews I sent each PPI contributor a brief email to thank them for meeting with me and for indicating that they’d like to contribute further. I also said that I would keep them updated on the progress of my funding applications and in September I sent the following update:

*Dear (insert name)*

*Thank you so much for meeting with me previously to share your experiences of high blood pressure in pregnancy. Your input made a valuable contribution to my study proposal and I wanted to give you an update on its progress.*

*I am currently applying for funding and your input has provided crucial support for my study. Your experiences illustrate why this research is needed and you have shared important insights that have helped shape the design of my study.*

*I submitted my first funding application to the National Institute of Health Research (NIHR) in July and am waiting to hear whether I have been selected for an interview. I am also applying to several other schemes. In the meantime I have been successful in securing a smaller award which will cover some of my tuition costs.*

*The funding process is very competitive, and while I am confident that I have a strong application (thanks in large part to your contribution) I am aware that it can take some time to be successful. However, I will continue to update you on my progress, especially as you have indicated that you would be interested in contributing to the study as an advisory panel member once it begins.*

*Thank you very much again for all you help and I look forward to hopefully working with you soon.*

*Best wishes*

*Layla*

\*The wording was altered accordingly for the non-profit sector PPI contributor.