



‘COMPLETING THE FEEDBACK CYCLE’ NEWSLETTER

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About this research

I have been to so many PPI meetings and conferences over the years where I have heard Service Users and PPI representatives remark on the lack of feedback they get from researchers (following the comments they provide). This means that PPI representatives do not know if they are providing useful comments or if their comments are even being used.

This research hopes to improve this feedback cycle between researcher and PPI representative by co-designing and testing a feedback tool.

The Story so far....

The EoE PPI RDS (Research Design Service) Working Group has been discussing this issue for some time and Doreen Tembo formed a working group (2015).

PPI CLAHRC Research Workshop discussed the Feedback project (March 2015) attended by RDS, EAHSN (Eastern Academic Health Science Network) CRN (Comprehensive Research Network), PPI leads, researchers and service users.

- Application to CLAHRC EoE for a Development Grant (Sept 2015).
- Funding Awarded: December 2016
- Grant started: April 2016

“I see more investment in PPI; this does not need to be financial, information, skills, access are often more important than money to the individual; to be valued and know that your contribution has made a difference...” (INVOLVE ‘Going the Extra Mile’ 2015)

Local NHS R&D approval

27.4.16 Cambridge and Peterborough NHS Foundation Trust and Cambridge University Hospital.

9.5.16 NHS Cambridgeshire and Peterborough CCG.

11.5.16 NHS South Norfolk CCG.

Survey distributed

During the week commencing the 9th May, the electronic and paper copies of the PPI representative and researcher surveys were distributed via six PPI group leads. We are keenly anticipating the replies! If you would like a copy of the survey, please get in touch.

Ethics approved!

The documents were all submitted to REC (Research Ethics Committee) on 17.3.16 for proportionate review.

REC granted approval on the 29.3.16 which was a very quick result with no amendments. We also had to get approval from the HRA (Health Research Authority), as some of the PPI groups are based within or attached to NHS trusts or hospitals. The HRA then asked for the consent forms and patient information leaflets to be slightly changed which has meant we had to submit a substantial amendment (6.4.16) to REC.

27.4.16 HRA approval granted!

PPI in the study PPI representatives came up with the idea, have commented on the protocol, data collection tools, information leaflet. We hope to have two members from each of the 6 PPI groups involved by attending two meetings during the 12 months. We will also have a small number of PIRg members undertaking interviews and PIRg and INSPIRE members doing data analysis.

Thank you to everyone involved so far!



PIRg members, University of Hertfordshire