

QResearch Advisory Board Minutes

28 Jan 2019, University of Nottingham

- Attendees: Jon Ford, Carol Coupland, Mike Walton, Julia Hippisley-Cox, Caroline Mitchell*, Patricia Wilkie*, Jonathan Meadows*, Derek Stewart *attended by Skype
- 2. Apologies Antony Chuter

3. Minutes of last meeting

The minutes were reviewed and accepted shortly after the last meeting in June 2018 and had been published on the QResearch website.

4. Matters arising

JHC updated members that the discussion with HDR UK and BHF relating to infrastructure funding for the QResearch Data Service were temporarily on hold until the relocation to Oxford is completed.

5. Relocation OF QResearch and QSurveillance to the University of Oxford.

- a. JHC updated members on her appointment as Professor of Clinical Epidemiology & General Practice at the University of Oxford from Feb 2019. As Founder and Principal Investigator for QResearch, Nottingham and EMIS had agreed that database would also transfer to Oxford. Oxford is offering the infrastructure support /security to secure the future of the primary care academic work undertaken by JHC and her team and other researchers in the future. In the long-term investigating options to secure the long-term future of QResearch and QSurveillance-in particular to secure the funding to support the infrastructure and work long term.
- b. Nottingham University is fully supportive of the move to Oxford and supporting the complex arrangements around agreement transfer of QSurveillance and the QResearch database and linked cancer, hospital and mortality data. The two universities will continue to work together closely; both are in the National School of Primary Care. Longer term the aim is to expand the potential of the database including widening access by other research groups and linked to other databases.
- c. JHC noted that a new Research Ethics Committee approval had been obtained to allow the linked database to be hosted in Oxford and run on a 'like-for-like' basis. Similarly, EMIS, ONS, NHS Digital and Public Health England, who supply the linked data had been very supportive of the move and had produced the relevant agreements to provide the legal basis for the QResearch linked database to be held at the University of Oxford. JHC confirmed that data sharing agreements with the GP

practice contributing to both QResearch and QSurveillance will be updated to refer to the University of Oxford instead of Nottingham.

- d. JHC noted that once the relocation had occurred, Nottingham would issue a statement confirming the transfer was complete and no data remained in Nottingham. This would ensure compliance with the various data sharing agreements and clarity regarding governance arrangements. JHC note that there will temporary period where QResearch database would be shut down and the data put beyond reach in a technical escrow whilst the final arrangements for the physical transfer were concluded.
- e. Members were supportive of the move and pleased to have the opportunity to offer advice on the plans and the considerations.
- f. The group discussed the pros and cons of various models for setting up QResearch in Oxford and the need to ensure that the right vehicle was chosen which be enable the research purposes to be most effectively in a way which continued to generate benefits for patients and command the trust of the public and the profession.
- g. The group also discussed pros and cons of broadening access to the database for research purposes (e.g. to include NHS researchers) which was potentially more feasible now the technology is in place to allow central hosting of the data and analysis without the need to download data onto locally owned computers. The group reviewed the principles of data access which are currently in operation and the rationale behind these. Overall the group were supportive of broadening access for bona fide researchers for legitimate research in line with the established principles and existing data sharing agreements with the data providers.
- h. The group also discussed the potential for hosting QResearch in the cloud as this question has been raised by stakeholders although there are no current plans to change the hosting arrangements in this way. The consensus was that the technical advances in the cloud such as Azure and AWS meant that data security is excellent and can be audited and that many public organisations, including NHS digital and the HMRC already host sensitive data in the cloud. However, there risk is regarding public perception which would require very clear communications. Also, a detailed risk assessment would need to be undertaken to identify the pros and cons.
- i. A range of new data linkages were discussed though any new linkages would require amendments to governance agreements. Hence the benefits of the linkages would need to outweigh actual or perceived risks.

6. Public engagement

The group discussed the new QResearch website and its lay summaries for new and ongoing projects. Suggestions were made about how to 'tell the story a bit stronger' to through the use of animations, blogs, social media, NAPP and EMIS newsletters etc. JHC agreed this was a priority area for development in the Oxford setting.

7. AOB

JHC thanked members of the advice. The group planned to meet again in 6 months time in Oxford.