



QResearch Advisory Board Minutes

8 June 2017, University of Nottingham

1. **Attendees:** Jon Ford, Carol Coupland, Mike Walton, Patricia Wilkie, Julia Hippisley-Cox, Jonathan Meadows, Caroline Mitchell
2. **Apologies** Antony Chuter
3. **Minutes of last meeting**

The minutes were accepted shortly after the last meeting and published on the QResearch website.
4. **Advisory Board Terms of Reference and Membership**
 - a. Members reviewed the Terms of Reference (ToR) to ensure they were relevant and included key areas. We agreed to retain all the existing ToR and no additions were suggested
5. **Update on Practice recruitment**
 - a. We now have approximately 1500 EMIS Web practices in England (1200 current and 300 historical practices) plus 3 in Scotland contributing to QResearch covering a historical population of 27 million and a current population of approximately 10 million currently registered patients.
 - b. There are 20 or so practices in Wales and Northern Ireland who have previously contributed to QResearch but who aren't currently due to changes in technology and data items. We are hoping to facilitate practices to contribute from both Wales and Northern Ireland over the coming years.
 - c. We would like to increase to 2000 practices to ensure we have sufficient patients so we can undertake research to assess drug safety of new and less commonly prescribed medicines
 - d. JM and MW asked how the EMIS Health and the EMIS National User Group could help facilitate recruitment, noting that there were over 4,000 practices contributing to the QSurveillance database. MW/JM offered to work with JHC to raise awareness and recruitment to the database. **Action: JHC/MW/JM to liaise about this.**
6. **Patient information**
 - a. PW highlighted the important of continuing to ensure that we consider how best to communicate benefits of research project back to patients and how QResearch can work with the NAPP to achieve this.
 - b. We already have PPI involvement on the QResearch advisory board (AC & PW) at the level of the database and have patient representatives who

review individual research proposals. There are also lay summaries of the research projects on the QResearch website

- c. CC described how she has engaged with patients at each stage of a current project looking at risk of dementia in relation to some prescribed medicines.
- d. JHC described how the team have increased patient engagement at the start of the new NIHR Biomedical Research Centre theme on decision aids for mental health, giving some examples of how input at this stage had helped focus the research questions on issues which were v important for patients (for example, patients highlighted the important of looking at drug interactions in the work we are planning on safety of antidepressants).
- e. We discussed whether there is potential for making results of research more accessible for patients by including links to press releases on the www.patient.info website. **Action: JM offered to investigate/put JHC in touch with the relevant staff at Patient.info.**

7. Data protection and Data security

- a. JHC stated there had been no data breaches or security incidents involving QResearch.
- b. JHC also updated the board on data security measures. This includes
 - i. regular internal and external risk assessments
 - ii. external penetration tests (no vulnerabilities identified)
 - iii. storage of data on dedicated secure encrypted servers based at the University of Nottingham which can only be accessed by approved researchers with strong authentication from known IP addresses using computers which have been “locked down” by IT services; disability of utilities which prevent copying of data onto or off the servers. No data is stored on local computers, laptops, flash drives etc.
 - iv. regular IT audits against our QResearch and University policies contractual requirements from data providers
 - v. policies on data destruction including degaussing hard drives and certificated destruction
 - vi. regular training of all staff with data access.
- c. Members said they were reassured by the measures taken to ensure ongoing security and confidentiality of the data and that they seemed appropriate to the level of data collected.
- d. MW highlighted changes in EU regulations on data protection due in 2018 including information on the ICO website which JHC agreed to investigate.
- e. JHC also described how she had worked with the Data Protection Officer from the Registrar’s office at the University of Nottingham to undertake an assessment of QResearch + linked datasets to ensure compliance with the ICO code on anonymization, which it is.

8. QResearch Data Linkage Project – retinal screening data

- a. QResearch is currently linked to mortality, cancer registration and HES data

- b. We discussed the opportunity to link QResearch to EMIS Health retinal screening data to undertake research to personalise the screening schedule for people with type 2 diabetes.
- c. Currently all patients with diabetes are invited to attend for retinal screening every year. For some patients who are at low risk of retinopathy this may be too often. For other patients at high risk of retinopathy, the interval of a year may be too long (some patients may go blind between the annual screening visits).
- d. There is the potential to link GP data from the QResearch database to coded retinal screening data (but not retinal images since these may be personally identifiable). This could then be used to develop risk assessment tools to stratify patients according to their risk of serious retinopathy and hence inform the frequency of screening. It could also help improve shared decision making between patients and doctors. The results could also be shared with patients via the online web portal/patient access apps.
- e. The board advised there was likely to be a significant benefit for patients from this research and that the data linkage was likely to be in the public interest. Since only coded data would be used and this could be linked without the need to share patient identifiable data, the risk to confidentiality was low. **Action: JHC to progress with the ethical and governance approval to allow the data linkage to take place**

9. British Heart Foundation

- a. BHF is a registered charity whose charitable objects focus on cardiovascular research. The Director of the British Heart Foundation initiated a meeting with JHC at his offices in May 2017. This was to discuss whether the BHF may be able to provide infrastructure support for QResearch to increase access to QResearch + linked datasets for BHF supported academics with substantive contracts of employments at universities and BHF funded research proposals. BHF is currently having problems ensuring access for data to support research that it wishes to fund and is aware of how useful QResearch might be for this purpose.
- b. JHC reminded members that currently academics from other universities can apply to QResearch using the standard application process for data of up to 100,000 records to be held securely at their university to undertake research which has been approved by the QResearch peer reviewed process. Data subsets are limited to the variables needed to answer the specific research question in the approved scientific protocol.
- c. External academics, however, are not able to physically access any of the data linked to the QResearch database (e.g. cancer, HES, mortality) as the third-party dataset are only licensed to the university of Nottingham. External academic are able to collaborate with UoN academics on join projects using the linked data but only UoN can physically handle the data.
- d. JHC has agreed to explore whether it might be possible to extend access to QResearch + linked database bearing in mind that the benefits would be

increased utilisation of the linked data for research purposes leading to potential improvements in health care for patients.

- e. So far, JHC has had discussions with NHS Digital (who supply HES); UoN IT services and legal services and the Dean of the Medical School. JHC is due to meet with the QResearch Management Board on 20.06.2017 where this proposal will also be considered.
- f. Members discussed two potential IT models for providing data access (subject to relevant legal and governance considerations)
 - Model A - this is where the linked data are made available to external researchers in a similar way to internal researchers as described above. i.e. data is held at the UoN on its secure servers and approved external researchers with substantive contracts from UK universities are given secure access using known IP addresses from computers with the UoN security settings which are certificated and audited to an agreed protocol.
 - Model B – linked data are physically supplied to the external researcher to download onto their own computers.
- g. We discussed the risks and benefits of both models, noting that there is a legal requirement to carry through all the assurances and obligations of the primary data sharing agreements for each dataset.
- h. The Board advised that that it was very difficult to see how Model B could guarantee those assurances so that Model A would be preferred though members expressed some anxiety about how this would work and whether it could have any detrimental effects for QResearch.
- i. Members advised the following
 - Access and scientific review criteria- we must ensure continue to apply the criteria including independent review and requirement to publish results
 - Training – we must ensure all researchers with data access had the necessary training and skills to analyse the data bearing in mind that some researchers may only have lab experience and could be early career researchers
 - Resources – we must that it is properly resourced including administrative and support costs.
 - Oversight – we must ensure there is an oversight committee to provide to ensure above and also that the BHF resource was being used effectively.
 - Pilot – We must have a pilot where the legal, governance and practical aspects could be considered in detail
 - The board would like to see an outline proposal for further comments once it is ready. **Action JHC to consider advice and prepare outline and share with the board.**

10. Examples of current research projects

- a. JHC highlighted the publication of the new patient lay summaries for ongoing and recently completed research projects which are now on the QResearch website following advice from the QResearch advisory board last years. Members agreed this was an improvement.
- b. Professor Coupland presented and examples of current research projects looking at risk of dementia among patients prescribed different anticholinergic drugs which demonstrated research which could only be done using large scale longitudinal anonymized data.
- c. JHC outlined the changes which have recently been made to the QRISK3 algorithm in addition to the annual updates which have occurred every year since QRISK was first published in 2007. QRISK3 now includes additional factors such as migraine, severe mental illness, corticosteroids, variable blood pressure, erectile dysfunction and atypical antipsychotic drugs so will provide more accurate estimates for people who have these conditions.
- d. JHC highlighted a new research project which is being commissioned by Sean Riddell (Sean Riddell was CEO of EMIS Group and a director of QResearch until 2013 and now lives in Bermuda). The project is to compare the natural history of type 2 diabetes (investigations, complications and treatments) of a cohort of patients in Bermuda with a UK cohort from QResearch. Diabetes is a major problem in Bermuda as it has very high levels of obesity. The group discussed how the proposed research posed various challenges because of how health care is delivered and data are collected in Bermuda. However, it is hoped that the project will provide a baseline comparison to help highlight potential improvements in the delivery of health care or patients in Bermuda.

11. Snomed CT:

- a. JM updated members on progress which is being made on the plans for EMIS to migrate to SNOMED CT and the potential implications for the QResearch database and also implementation of utilities such as QRISK2 back into the system.
- b. JHC/JM are discussing a potential project to look at the NHS assured mapping between Read2 and SNOMED CT to see how QResearch could help with this nationally. Action JHC/JM

12. Cascade screening –

- a. we discussed the potential utility of the anonymized ‘household key’ for cascade screening to identify patients with inherited disorders. There are important aspects of this for patients (benefits are increased chances that they will be offered appropriate testing) but also considerable confidentiality issues (relating to the use of information about one person being used to help another).
- b. This was the subject of PW research in 1972 and she offered to send me this and discuss the issues further should the research project proceed. **Action PW top send JHC information on previous research project**

13. Any other business

- a. Members were asked if they had any concerns or other suggestions and replied they were happy and had no further suggestions at this point.
- b. Members to feedback minutes from the meeting to their respective organisations. **Action all**
- c. JHC thanked members for their advice and time. We plan to meet again in 12 months.

Minutes prepared by JHC, 19.06.2016