



## **QResearch Advisory board Minutes**

**20 June 2016, University of Nottingham**

- 1. Board Attendees:** Mr Antony Cuter, Mr Jon Ford, , Dr Mike Walton, Dr Patricia Wilkie, Professor Julia Hippisley-Cox, Dr Jonathan Meadows, Dr Caroline Mitchell
- 2. University of Nottingham non-board attendees.** Carol Coupland (associate professor medical statistics).
- 3. Apologies** Dr Joanne Reeve
- 4. Welcome and changes to the advisory board:**
  - a. Dr Mike Walton was welcomed to the board as the representative for the EMIS National User Group
- 5. Minutes of last meeting**

The minutes were accepted shortly after the last meeting and published on the QResearch website.
- 6. 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
  - b. MW asked JHC if QResearch received data from other GP systems apart from EMIS and JHC confirmed that QResearch only receives GP data from EMIS.
  - c. We discussed membership of the advisory board and PW suggested a practice manager (Sandy Gower) who we could approach. Action JHC/PW
  - d. Members advised that QResearch should keep the current focus on supporting research projects only rather than service delivery.
- 7. Update on Practice recruitment**
  - a. We now have approximately 1200 EMIS Web practices in England and 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.
- 8. QResearch Data Linkage Project**

- a. QResearch is currently linked to mortality, cancer registration and HES data
- b. At present there are no plans to link to other data sources.

## 9. Patient participation and patient information

- a. PW highlighted the important of ensuring 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. CM highlighted a new research grant she is planning on how diabetes risk is presented to patients and how this might affect outcomes. JHC was very interested in this. **Action CM and JHC to discuss after the meeting**
- c. We also briefly discussed improvements patient information sheet which was revised after the last board meeting and approved by the ethics committee. No further changes needed at present
- d. We already have PPI involvement on the QResearch advisory board (AC & PW) at the level of the database but no formal arrangements for individual projects so JHC asked for advice on how we might approach this.
- e. We discussed a number of potential approaches to enhancing patient involvement for individual projects using the QResearch database which included
  - Continue with lay summaries for the QResearch website of recent and ongoing projects as we have recently started to do
  - Continue to involve patients with peer reviewing research proposals (AC has kindly help with this during the course of the last year)
  - Use of focus groups which could be help at the start of the project to ensure that the most important questions for patients are addressed at the planning stages (we have had recently done this for a grant proposal on mental health and technology as well as a project on drugs which might increase risk of dementia)
  - Use of focus groups towards the end of the project as the results are emerging to discuss the implications and how best to present them
  - Involvement of patients in grants where involvement could include input into the project advisory group over the lifetime of the project (AC has experience of this)
  - If disease specific groups are needed, then AC has experience of recruiting these via social media
  - NAPP has significant experience of being involved in research, grant applications and focus groups and is happy to discuss furthe. PW offered to have further discussions about how the NAPP might be able to contribute.**Action JHC/PW**

## 10. Patient opt out/opt in

- a. We discussed the current logic which is implemented to respect patient objections for QResearch. QResearch only extract data which has been pseudonymised at source. It does not include any strong identifiers or free

text (except dosage). QResearch does not extract any patient data for patients who have been marked as confidential or sensitive by the practice. JM confirmed that the QResearch opt out codes have been mapped to SNOMED CT.

- b. We discussed whether patient apps used to access records online could be used for patients to express record sharing preferences. Whilst there were some attractions to using technology in this way, four board members expressed concerns this would be complex to achieve and might be confusing (in particular it can be difficult to clearly communicate nuances) so we decided not to progress this at the present time but review again next year.
- c. JHC shared correspondence with IIGOP regarding guidance for opt outs for irreversibly pseudonymised data. IIGOP said they had no advice for patient opt outs for this type of data and that the focus of the forthcoming advice was for patient identifiable data. At the time of the meeting, no IIGOP advice had been published due to purdah restrictions.
- d. We discussed fair processing notices and how this can be made more accessible. Mike Walton suggested contacting WigglyAmps to see if this can be included on the screens in surgery waiting rooms and will work with JHC on this. **Action JHC/MW**
- e. Members agreed that QResearch should continue with the current approach for respecting patient opt outs but that we should review annually and when new written guidance is published to ensure we are compliant with best practice.

## **11. Information and benefits for practices**

- a. MW **Action JHC**
- b. MW suggested contacting accountable offices in CCGs to raise profile of QResearch and encourage practice recruitment and consider making a welcome pack for newly recruited practices (to include patient information leaflets and notices). This was agreed. **Action JHC/MW**
- c. MW said more could be done to raise visibility of the various QTools in EMIS Web, create templates, protocol and alerts and increase communication to practices. Members agreed this was a good idea and JM suggested contacting Rob Walter from EMIS about this. **Action JHC/MW**

## **12. 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. Jonathan is writing a road map for this and will share with JHC when ready.
- b. JHC/JM to discuss 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**

### **13. Examples of 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 two examples of current research projects which demonstrated research which could only be done using large scale longitudinal anonymised including
  - i. - adverse effects of antidepressants
  - ii. Association between diabetes drugs and cancer
- c. Board members felt these studies were a very good use of the QResearch database and provided valuable information for doctors and for patients. Particularly it was expressed that often patients get very little information about the drugs they are prescribed and what the risks of side effects/adverse outcomes are for different drugs. There were different views regarding the patient information supplied with medication. Some felt that it can be very useful for the side effects and risk, when to take it and what not to take but others felt it could be improved to include better bigger print with references and more detailed information designed specifically for patients to help choose between different types of medication.
- d. There was most discussion around the results of the antidepressants study and how these results could be used in consultations to help doctors and patients decide which antidepressant would be preferable. It was considered that this could vary between patients depending on particular concerns and medical history but that the information on risks of different outcomes would be very helpful. CM highlighted a guidelines document on how to choose psychiatric drugs and offered to send link after the meeting for CC to review. Action CM/CC
- e. It was acknowledged that some of the differences in risk could be due to patient characteristics and medical history, although many factors such as diabetes had been accounted for in the analysis. The varying risks for all-cause mortality were concerning.
- f. CM highlighted ongoing work as the RCGP to ask “what has research one for general practice” and commented that there are some good examples form QResearch. Action: CM to feedback minutes to RCGP

### **14. 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 agreed 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, 23.06.2016