



QResearch Advisory board Minutes

2 June 2015, University of Nottingham

1. **Board Attendees:** Mr Antony Cuter, Mr Jon Ford, , Dr Geoff Schrecker, Dr Joanne Reeve, Dr Patricia Wilkie, Professor Julia Hippisley-Cox
2. **University of Nottingham non-board attendees.** Carol Coupland (associate professor medical statistics), Dr Christina Brindley (research officer and PPI coordinator).
3. **Apologies** Dr Jonathan Meadows, Dr Caroline Mitchell.
4. **Welcome and changes to the advisory board:**
 - a. Mr Antony Cuter was welcomed to the meeting as one of our patient representatives.
 - b. Dr Alan Hassey has stepped down from the QResearch advisory group since he now chairs the DAAG group at the HSCIC.
 - c. Dr Coupland was also welcome as a senior statistician working with JHC on QResearch studies, interested in Public Patient Involvement (PPI) in database studies.
 - d. Christina Brindley attended in her role of research office, facilitating PPI involvement across the division of primary care including database studies.
 - e. JHC also had a telecom with Dr Jonathan Meadow from EMIS on 01.06.2015 (see appendix 1).
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
 - i. We agreed to retain all the existing ToR
 - ii. We agreed to add the following ToR “to oversee communication with and benefits back to patients”
 - iii. We agreed to add the following ToR “To ensure all research undertaken using the research database is published in accordance with the requirements for access to the database”.
 - b. We discussed membership of the advisory board to determine whether any other groups should be represented. We discussed various disease focused groups and charities. At present, however, members felt the representation was fair and there is a balance to be had between getting a broader view and keeping the membership of the group manageable. We identified that it would be useful to have a practice manager on the group (Action: JHC to

identify one). We discussed how we might benefit from liaise with specific patient groups for particular projects. For example, if we were to undertake a project looking at rare conditions, or drug safety by ethnic group, we could engage with a relevant patient organisation.

7. Update on Practice recruitment

- a. We now have approximately 1000 EMIS Web practices in England contributing to QResearch covering a historical population of 24 million and a current population of approximately 8 million currently registered patients.
- b. Practices using EMIS PCS are able to contribute to QResearch and currently two practices do this. We would like to increase coverage especially since the Scottish guidelines (SIGN) now recommend some of the QPrediction tools developed using QResearch. Better coverage would ensure the tools are more applicable to local populations.
- c. 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.
- d. One member suggested undertaking a short survey of EMIS practices to find out why some practices are not taking part.

8. Publication of research summaries on QResearch website

- a. QResearch publishes links to all research publications on published website. There are currently >140 papers/reports. There are an increasing number in high ranking journals from wide authorship from a range of universities.
- b. Members agreed that we should publish more information about ongoing and completed projects using QResearch on our website. These should include lay summaries to make it accessible to the public and have links to the research paper and other outputs such as powerpoint presentations, press releases.
- c. Should any projects fail to complete, then we should ensure there is a summary of the research question and that the researchers concerned provide an update on progress.
- d. JHC reported that the QResearch team had been disseminating research summaries of current projects via newsletters/e-shots and plan to continue with this though recognised that the penetration of this information back to practices and the public was not as high as desired.
- e. Suggestions were made about ways to improve information to patients and practices (see below).

9. Patient information and public engagement

- a. We discussed the content of the current patient information on the website; the current practice notice for the waiting room; how to improve communication and awareness of QResearch by the public and how we might improve the QResearch website.

- b. Overall, members liked the use of simple language on the patient information page and thought that the format was clear and the length was about right for a high level introduction.
- c. However there were several sections which need to be clarified or wording amended or more details provided which are listed below.
- d. We could have links to more detailed information for those who wish to drill down into the detail. This could include links to other parts of the QResearch website or other websites.
- e. We could use colourful info graphics to make some of the information more accessible.
- f. We need to capture more information about the 'mission and vision' of QResearch.
- g. We need to clarify that QResearch only covers 1000 practices of the 8,500 practices in England and that not all practices therefore contribute to the database.
- h. We need to expand what sort of projects the database is used for, what types of questions it can answer etc for example "QResearch is working to promote and monitor health in the NHS over time by undertaking research into illness and treatments and how they are used. The research helps detect side effects of medicines and also develop tools to identify patients who are at risk of various conditions so that they can receive help they need".
- i. We can make it clear that some of the risk prediction tools derived from the QResearch database have been embedded in the GP systems to assist with decisions. Also patients can also use these tools on the website using the relevant link (though with appropriate cautions since the tools are designed for use within the consultation).
- j. We can highlight that QResearch is only used to answer the most important research questions for the benefit of patients in our National Health Service.
- k. Samples of QResearch data are only shared with academic researchers based at UK universities who have a track record in undertaking and publishing research. The samples only contain specific information required to answer the research question.
- l. We can also state that the information extracted onto QResearch is de-identified coded data from the GP computer system. It doesn't include your name, address, date of birth or NHS number, phone number, email etc.
- m. PW kindly offered to make research summaries and model stories available to practices via the NAPP bulletins and conferences. Practices can then include some of these with their local PPG groups or on their websites or on their TV screens (see below).
- n. One member suggested an annual postal newsletter to practices might be more effective than e-shots as these are more likely to be read by the practices. KHC suggested there could also be a certificate for participation in QResearch which practices could use for appraisals etc.
- o. Members also suggested asking EMIS about having messages on the Egton arrivals/envisage/Numed screens about QResearch. These devices are in the waiting rooms at many surgeries and can be activated specifically for practices which contribute to the database and are the electronic equivalent

of a poster but likely to be more effective as they can combine information presented visually and verbally.

- p. CB also highlighted her role in coordinating PPI within Nottingham and will liaise with JHC regarding the forward looking plan include patients available for peer reviewing applications and commenting on research questions, press releases etc.
- q. Action: JHC to follow up on above suggestions with members and prepare a plan on how to improve the web presence and communications with patients and practices along the lines suggested.

10. QResearch Data Linkage Project

- a. QResearch is currently linked to mortality, cancer registration and HES data
- b. The HSCIC has asked whether we would like to link to Diagnostic Information Dataset (DIDS).
- c. We discussed the pros and cons of this additional linkage (would give more information on what tests have been done although some of this is already recorded in the GP or HES record). There is some concern as to the quality of the coding in the DIDS dataset and hence its utility for research. There is currently no project for which this information is critical.
- d. Overall we agreed that the benefits of this additional data linkage are not sufficient to proceed at present. If there is a specific project which requires this, then the board would discuss its relative risks and benefits at that point.

11. Patient opt out/opt in

- a. We discussed the current logic which is implemented to respect patient objections for QResearch.
- b. QResearch only extract data which has been pseudonymised at source. It does not include any strong identifiers or free text (except dosage).
- c. QResearch does not extract any patient data for patients who have been marked as confidential or sensitive by the practice.
- d. QResearch does not extract any patient data if the patient has opted out of the summary care record (code 93C1) .
- e. QResearch does not extract any patient data if the patient has opted out of QResearch (using the EMISNQOP15 code). This is an EMIS specific code introduced in May 2014.
- a. We discussed national initiatives and Read codes in relation to opt in/opt out of *identifiable* data but agreed that it is not relevant to QResearch because QResearch is not identifiable. Also there is currently no written guidance on opt outs in relation to de-identified data.
- b. JHC has contacted IIGOP (Independent Information Governance Oversight Panel) to ask for an update on guidance but no response has been received yet.
- c. Members agreed that QResearch should continue with the current approach but that we should review annually and when new written guidance is published to ensure we are compliant with best practice.

12. Examples of research projects

- a. We discussed examples of research projects eg recent paper published in the BMJ looking at risk of thrombosis associated with different type of oral contraceptives pills. The research had confirmed a smaller study undertaken in Denmark and earlier studies from 10+ years ago which had raised concerns regarding the safety of some of the newer agents. The QResearch database, because of its size and linkage to other data sources, was able to drill down to specific individual drugs to assess their comparative effects.
- b. We also discussed, as an example, a study to predict risk of patients having an existing but as yet undiagnosed cancer. The resulting Qcancer tool has been integrated back into EMIS Web so that GPs can use it within consultations with the aim of diagnosing cancers earlier. We watched a screencast provided by the EMIS National User Group which showed how this tool worked.
<http://emisnug.org.uk/article/using-cancer-symptom-checker-emis-web>
- c. Members commented that the Qcancer tool could be a nice exemplar study to use for raising awareness with the public regarding the sort of studies which are undertaken using QResearch. JHC to liaise with GS regarding progress with the tool in EMIS Web and plans regarding publicity once the latest release is available.

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. JHC thanked members for their advice and time. We plan to meet again in 12 months but will work by email and telecom on patient information as above over the next 3 months.

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Notes of telecom between JHC and Dr Jonathan Meadows (EMIS) 1st June 2015

1. **EMIS Group** – this has now expanded with various acquisitions including ASCRIBE and digital retinal screening. This may present some opportunities in future for additional data linkage for QResearch research projects subject to governance etc (eg looking at eye complications of diabetes) though we aren't actively pursuing this at present.
2. **Diagnostic information dataset** – there is an opportunity to explore linking QResearch to the results of diagnostic tests as the HSCIC has this information available in a way which could be linked to QResearch. Agreed might be useful to explore in relation to a specific project (eg evaluation of QCancer use in practices) to determine utility of the data.
3. **Patient opt out/opt in:** EMIS has now issued two EMIS codes which allow practices to opt individual patients out of QResearch (and then to opt back in). We discussed national initiatives in relation to opt in/opt out of identifiable data for caredata but agreed that not relevant to QResearch because QResearch is not identifiable and also there is no written guidance on this. We should review annually and when new written guidance is published to ensure we are compliant with best practice.
4. **Practice information:** Jonathan to contact Egton/envisage about using the screens within surgery to raise public awareness of QResearch.
5. **Newsletters:** we have been including information on QResearch research projects within EMIS newsletters. JHC to contact Matt Murphy (when back from paternity leave) to get new contact/processes within marketing to facility sharing of information about QResearch with practices and with the public more generally (also related to point 4 above)
6. **Practice recruitment:** this has gone well with now approx. 1000 EMIS web practices contributing to the database
7. **Snomed CT:** from April 2016 Read version 2 will be deprecated, EMIS will be in the process of migrating to SNOMED CT. We discussed 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.
8. **QResearch advisory board** – no obvious gaps in terms of representation on the QResearch board.