



QRESEARCH ADVISORY BOARD MEETING

Room 1302, 13th Floor, Tower Building
Division of Primary Care
University of Nottingham

Monday 10th June 2013

Minutes

1. **Attendees:** Mr Terry Wiseman (Patient rep), Mr Jon Ford (BMA), Dr Mark Caulfield (EMIS National User Group), Dr Alan Hassey (GP), Dr Joanne Reeve (GP and SAPC), Dr Jonathan Meadows (EMIS), Professor Julia Hippisley-Cox (UoN and QResearch)
2. **Apologies:** Dr Peter Holden, Dr Patricia Wilkie, Dr Caroline Mitchell.
3. **Welcome:** Dr Joanne Reeve and Dr Alan Hassey were welcomed to the board. Mark Caulfield was welcomed as a deputy for Dr Chris Frith (EMISNUG).
4. **Minutes:** The minutes of the last meeting were accepted and published shortly after the last meeting.
5. **PowerPoint QResearch Research database**

JHC did a PowerPoint presentation to update members on progress and priorities which form part of the minutes for the meeting and will be posted on the website once the minutes have been confirmed. Members are invited to circulate the finalised minutes and PowerPoint presentation to their respective organisations.

We agreed to continue with the current terms of reference for the group and also to add an additional one which is to ensure review of any changes to the content of the data extracted by QResearch or its terms of use.

Action: JHC to update TOR on QResearch website

6. Practice recruitment

- ✚ There are currently around 680 practices contributing to the QResearch database (730 have contributed at some stage but some have moved to a different system or EMIS Web).
- ✚ We are planning to expand to include as many EMIS practices as possible in order to:
 - a) Increase the number of practices with longitudinal data, tracking back over a decade to enable us to develop new risk prediction algorithms such as QRISK, QDScore and QFracture. This data can then be integrated back into the clinical system.
 - b) Enhance our ability to undertake research on rare diseases.
 - c) Enable the rapid evaluation of the safety and effectiveness of newly introduced medication
- ✚ Bulk extraction software has now been written which allows EMIS Web practices to contribute to QResearch database.
- ✚ Work is in progress to automate this extraction on a daily basis.
- ✚ A new agreement will shortly be made available within the EMIS Web data sharing manager. We plan to email all practices once this is available to increase recruitment.

We discussed methods for raising awareness of the database with practices and increasing recruitment and agreed the following

1. Continue to do annual presentation at NUG committee and write for the EMIS user magazine
2. Liaise with JM about EMIS doing an email shot to sites with updated information on QResearch and its outputs (including electronic link to a revised notice to display in the waiting room).
3. Asking EMIS to add a link to www.qresearch.org on the home page of EMIS Web and www.patient.co.uk (action JHC/JM)

7. Qinnovation competition.

- ✚ JHC updated members on the new Qinnovation competition which had been launched in 2012/2013.
- ✚ Applications were invited for research projects which were likely to have a measurable benefit for patient care.
- ✚ The prize was 10K+ some research data + some academic support. Two projects were awarded the prize. The panel included some members of the QResearch

Advisory Board, the CEO and clinical director of EMIS. Members were thanked for their contribution

- ✚ There are plans to re-run the competition in 2014. Members advised that it might be worth thinking about offering benefits in kind instead of the 10K of funding (e.g. statistical/data analysis support) but as well as the data. There were also suggestions about having focused topics e.g. mental health or cancer which QResearch will now consider.

Information about the competition and the prize winners can be found at <http://www.qresearch.org/SitePages/QInnovation.aspx>

8. Research governance and access criteria

- a. All proposals reviewed in accordance with Derby REC procedures. MREC approval process working well with no security breaches or complaints. There is an online application form and set of tools for researcher to use to define their queries.
- b. All requests for data have been logged and processed according to our published criteria and none from the UK have been turned down (although not all enquiries progress since some fail to get funding or the researcher doesn't complete the application process).
- c. We had a discussion regarding the implications of the recently published Caldicott review of information sharing ("Caldicott2"). The main action point agreed is for QResearch to explore getting accreditation as an 'Accredited Safe Haven' once the criteria and procedure for accreditation is available.

9. QResearch Access criteria

- ✚ Over the last few months, the QResearch management board (EMIS and UoN) had been considering broadening access criteria in order to increase usage of the QResearch database and hence the public benefit.
- ✚ Members were invited to revisit the access published criteria for QResearch data which had been drawn up in 2002/3 when QResearch was founded and which had remained relatively unchanged. These are available at www.qresearch.org
- ✚ Members agreed that increasing usage of existing sources of data such as QResearch is likely be preferable to proliferation of new databases from an information governance perspective and were keen to see this explored in more detail.

- ✚ The benefits of broadening access criteria would need to be balanced against the advantages of the current tight governance controls which are aimed at minimising the risk of inadvertent misuse of the data, inadvertent re-identification of patients or practices whilst ensuring high quality research questions from capable research teams.

The following suggestions were supported by members and will now be explored with a view to updating the published access criteria for QResearch

- a. Allow access for researchers from EU countries rather than just UK as at present. This should be supported by MREC in the view of the members.
- b. Change the requirement for each research team to have a medical professional to take responsibility for governance to a health care professional with a similar duty of care, duty of confidence and professional regulatory body. Examples include pharmacists, dentists, nurses, occupational therapists (this list is not exhaustive).
- c. Broaden requirement for projects to generate research papers as a primary goal to allow projects which plan to publish reports as well as or instead of research papers.
- d. Amend the requirement for the data only to be hosted at a UK university to allow the data to be hosted in organisations which are able to demonstrate good levels of information governance and security. This could include, for example, NHS organisation with good levels of achievement on the Information Governance Tool Kit or an accredited safe haven.
- e. Members advised though that all projects must still include meet MREC requirements and include at least one academic with a relevant track record and experience to ensure quality. The scientific review process would continue and help ensure a good scientific standard for research projects.
- f. Develop a more explicit procedure for re-use of data supplied for previous projects. Applicants should obtain data direct from QResearch not from the third party in order to guarantee that all uses of the data comply with Derby REC requirements which include having a research protocol which is subject to satisfactory peer review.
- g. Members also warned against including QResearch data in national data banks since this would make it extremely difficult to guarantee the appropriate onward use and security of the data. Options to be explored which could increase accessibility whilst maintaining strong governance controls could include making datasets available on University of Nottingham servers which third parties can access (QResearch already undertakes some collaborative work on this basis).
- h. QResearch should explore on site access options and IG requirements particularly for larger datasets and also linked datasets since QResearch has now been linked to HES, cancer and mortality data, subject to license restrictions of the linked data.

10. Research outputs – public and practice benefits

- ✚ Links to all research publications on published website with >130 papers/reports. There are an increasing number in high ranking journals from wide authorship from a range of universities.
- ✚ Not all research who have been provided with QResearch data have completed and published their projects as peer reviewed papers (though most have written up the findings as reports for funding bodies). JHC is chasing researchers up to encourage publication in peer reviewed journals. Not all teams find time to complete their work however so this is proving to be difficult.
- ✚ JHC did a presentation on two different types of research projects to give members more idea on how the data are used. This included a drug safety project and also the new Qadmissions research project (this is a tool to identify patients at high risk of an emergency admission who may be suitable for intervention).
- ✚ Following on from last year's discussion, we considered ways of ensuring the research tools which have been developed using the database are made available to practices in a useful way e.g. comparisons of patient's risk of a disease against the age/sex average so the GP can advise the patient on how high or low their relative risk compared to other patients of the same age and sex. Action: JM to follow up progress with this
- ✚ We discussed how these tools could be made more available as apps (some tools have already been developed as apps e.g. QDiabetes and QFracture).
- ✚ JHC also demonstrated the QFeedback tool which allows practices to compare incidence and prevalence rates with other local and national practices. This tool is currently linked to the QSurveillance database (rather than QResearch). Members saw a good opportunity for an enhanced version of QFeedback to be made available to QResearch practices in exchange for practices contributing pseudonymised patient level data to the database.

11. Funding

Research grants have been awarded from the following bodies for individual projects:

- a) MRC
- b) HTA
- c) NIHR
- d) Dept Health

- e) National primary care school
- f) European Union

- ✚ Joanne Reeve mentioned a possible opportunity for QResearch to work with SAPC. We agreed this would be good to explore in principle subject to agreement with SAPC.
- ✚ Whilst infrastructure funding would be ideal, it remains unlikely that this will be obtained. QResearch is managing to recover costs from inclusion of costs within grant applications which won in open competition.

12. QResearch data linkage project

- ✚ In 2011, the board agreed that we should explore linkage of the database hospital episode statistics and the cancer registry. Since then, we have successfully obtained all approvals from ethics committee, national information governance board and data custodians.
- ✚ We have also developed a new method of data linkage based on pseudonymised data which means that no strong identifiers (such as NHS number) need to leave the source systems. The 'open pseudonymiser approach' has now been published and adopted by a number of organisations. Members discussed the approach and were supportive of it since it minimised the need for identifiable information.
- ✚ The QResearch database has now been linked to mortality, cancer registry and HES data. The linkage was completed in the first quarter of 2013 and the data is now being used for initial research projects to test the validity and utility of the data for research. Currently the linked data are only analysed on site at the University of Nottingham (see above).

13. Raising public awareness

- ✚ JHC said that all research is press released and that opportunities to do radio interviews etc. are taken to help disseminate the results. Patient representatives are included in discussions on research questions and interpretation of results wherever possible.
- ✚ However members recognised that public awareness of databases and research such as this is generally quite low. We discussed other ways to raise public awareness including twitter, blogs, podcasts etc.
- ✚ We discussed the patient information sheet which Terry Wiseman had written and agreed it was useful to make this available to practices possibly as a PILS (patient information leaflet)
- ✚ Patricia Wilkie from the National Association Patient Participation (<http://www.napp.org.uk>) had sent her apologies to the meeting but emailed

to suggest including a column in the NAPP newsletter and coverage at the next national conference which we will do.

Action: JHC to liaise with JM on PILS and see if patient.co.uk could include more information about QResearch on their website.

JHC also to discuss dissemination of research with Joanne Reeve to see how we can co-ordinate with SAPC.

14. Priorities

Members supported the current activities and also the priorities for QResearch which are to continue to focus on research and the data linkage project.

In summary, the board is happy with the progress being made with QResearch and that it is operating within its scope and according to its principles. There were no concerns raised.

The next meeting will be in June 2014.