QRESEARCH ADVISORY BOARD MEETING MINUTES

Thursday 8 November 2007, London

1. Welcome, introductions and apologies

Julia Hippisley-Cox (JHC) welcome to all and new members.

1.1 Present

- Jonathan Meadows (EMIS)
- Patricia Wilkie (Patient representative)
- Manpreet Pujara (deputising for Dai Evans, EMIS NUG)
- Jon Ford (British Medical Association)
- John Fox (Strategic advisor)
- Julia Hippisley-Cox (chair)

1.2 Apologies
- John Williams (RCGP)
- Richard Logan (University of Nottingham)
- Azeem Majeed (Chair Scientific Committee)
- Laurence Buckman (GPC)

2. Update on Membership and Review of Terms of Reference

- JHC welcomed Patricia Wilkie to the Board as the new patient representative and Manpreet Pujara (Deputising for Dai Evans, NUG)
- The Wellcome Trust, RCP, MRC, UKCRC have all been contacted to invite them to nominate a member for the advisory board. No responses have been received to follow up emails. The board did not identify any further groups who should be represented at this stage.
- The advisory board reviewed and agreed the current terms of reference.
- In addition, the board agreed to a new TOR suggested by Manpreet Pujara 'to oversee communication and benefits back to contributing practices' **(action JHC to update the TOR on the website)**

3. Update on membership of the QRESEARCH Management Board

- The management board has been expanded to include two additional directors. It now consists of
  - two directors from UoN (Julia Hippisley-Cox, Bruce Venning)
  - two from EMIS (David Stables, Sean Riddell).

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- Manpreet Pujara asked whether NUG should be represented on the management board as well as the advisory board. **Action: JHC to discuss with QR management board and MP with EMIS NUG**.

4. Report on plans for 2007:

JHC presented an update on progress against priorities agreed in early 2007. The annual report for 2006 was presented and approved by the board in Feb 2007. JHC is preparing the 2007 annual report which will be presented to the next meeting.

4.1 Qweb and researcher access

- QWeb a set of web tools to help improve researcher access. This is a high priority for development. The utilities include a
  a) query authoring tool
  b) summary databases to present aggregated results back to the end-user
- Phase one of the website is now live and users can use the utilities to set up projects and Read Code definitions for research projects. It also includes a summary database of public health indicators.
- Phase two will include further utilities (building on EMISWeb) to enable researchers to define other parameters needed for their searches which can then be run against the off line QRESEARCH repository.

4.2 Benefits back to practices

- There was a good discussion on potential benefits of feeding back to practices that contribute data freely to QRESEARCH and how this needs to improve. This has now previously been designated high priority for development and resource has now been allocated to this.
- Practices were promised 'feedback' and initially QRESEARCH provided some Excel spreadsheets containing normative data on GP contract indicators prior to the publication of the first year of QOF results, sent by email. This was appreciated by practices. However, it has been difficult to automate 'practice feedback' as the data on the QR database are anonymised so individual patients are not identified. Instead, a software system is needed to run searches locally in the practice system and then provide a background distribution for comparison. The technology could now be built into EMIS-web. A practice feedback service has now been specified and development resource has now been allocated to work on this in the New Year with the intention of this being operational during 2008.
- Practices have asked QR/EMIS to provide an automated service to submit monthly and annual data on flu vaccine and pneumococcal vaccine data to the Dept of Health. This has been in place for the last 3 seasons and has saved many practices time. This has been appreciated.
- QR/EMIS also devised a search to identify patients with high glucose who had not been followed up.

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- QR/EMIS also devised a search to identify patients with diabetes who had fallen off the QOF register with the change in code definition.

4.3 QSurveillance

- Since the last meeting on 01 Feb 07, three existing services (QFLU, QVTP and QPN) have been rolled into one system (QSurveillance). This is a real time system which extracts aggregated data for infectious diseases, flu and pneumococcal vaccine from over 3,000 practices spread throughout the UK. The consent from practices now includes a facility to extend the dataset in the event of an urgent public health problem (eg drug safety, bioterrorism, flooding eg in Avon this summer). An infectious diseases bulletin is published every week by the Health protection Agency and can be found at the following link

  http://www.hpa.org.uk/infections/topics_az/primary_care_surveillance/Qresearch.htm

- Some practices are already on the distribution list for the bulletin. MP suggested we should raise awareness of this output among EMIS practices in general.
- PW also suggested we need to communicate with patient groups more effectively for this and for Qresearch in general.
  Action: JHC agreed to work on a communication strategy with PW, MP and John Fox.

4.4 QRISK CVD algorithm

- The paper describing the QRISK CVD algorithm was published. It has now been developed and validated and is under consideration by NICE as a replacement for Framingham. A web calculator has been developed http://www.qrisk.org
- The board asked about IP issues relating to QRISK CVD algorithm. JHC informed the board there is a free web calculator available but there have been a number requests from commercial companies wishing to exploit it. The QRESEARCH management board will be discussing this issue at the next meeting. The Advisory Board's view was that academic/research and individual patient use and use of QRISK software within EMIS should be free but that it would be appropriate for commercial companies to pay a fee that would go to improvements in patient care. The income could be used for further developments of QRISK algorithms and for developing the clinical software for practices. The overall goal is to help develop risk prediction utilities and then translate the research into clinical benefits for patients.
- There has been a request from an insurance company for some development work to QRISK and ways of presenting it back to clients for commercial use

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eg for the company to offer financial incentives for patients to reduce their risk factors. Whilst the idea of patient financial incentives was novel and interesting, the Advisory Committee identified a number of risks to QRESEARCH from this proposal. The Advisory Committee saw no real benefits since the current web calculator meets GP and patient needs and there were potential risks of being linked to a commercial company it was agreed that this request should not be pursued. **(action JHC to feedback to the company concerned).**

5. New developments and grant applications.

5.1 HTA grant

- JHC informed the Advisory Board of a successful grant application to the Health Technology Assessment for research into the Safety & Harms of antidepressants. This research grant is for 15 months starting on 01 April 2008 and is lead by Dr Carol Coupland (associate professor of statistics).

5.2 EU grant – ALERT project

- JHC also informed the Advisory Board of a successful grant application to the European Commission for the ALERT project. This project is to develop a new system for measuring and monitoring drugs safety especially of new drugs. It involves an academic network of 17 European partners and most of the major electronic health databases in the Europe. QRESEARCH is the largest database to agree to take part and the only database to agree to take part from the UK. The project will start on 01 Feb 2008 and run for 3 years.

5.3. Access to QR/EMIS data for Industry (need for third party)

- As discussed with the Advisory Board by email during the summer, QRESEARCH has now amended it access arrangement and practice consents to enable a mechanism for industry to commission independent analyses of drug safety where this is in the public interest. Research must be undertaken independently and be published. Following approval by MREC and the Advisory Board and the advice of NUG, a third party is now needed to broker this arrangement. So far, JHC had approached the Wellcome Trust, MHRA and GPRD without success. PW suggested the Academy of Medical Science and the Royal Colleges. **Action: MP agreed to ask NUG for comments on these suggestions.**

6. New proposals

6.1 Wellcome Trust

- JHC informed the Advisory Board that The Wellcome Trust had issued a call for proposals for research into E-Health. QRESEARCH has submitted a proposal which has been short listed for a 5-year programme of research which includes drug safety and risk prediction. The proposal also included a request for infrastructure support to help improve researcher access as this is a high priority. The Advisory Board agreed that this research council was an appropriate body to request support to build up QRESEARCH as a communal research resource. **Action: JHC to continue discussions with the Trust and feedback to the advisory board.**

- QRESEARCH was asked and is supporting a wide range of competing bids lead by other institutions. Among those also shortlisted include a bids led by three separate universities. Some of the proposals require data linkage - for example one proposal involves linkage of other database to primary care records via the clinical system with extraction of fully anonymised data onto the research database. The Advisory Board agreed that it and NUG would like to discuss any formal proposal from the relevant academic to assure itself that there were no implications that might undermine QRESEARCH. The Advisory Board requires clarity regarding the intended governance arrangements and how would be proposed to control access to any combined dataset for research. **Action: JHC to discuss with the requesting party regarding the need to engage with the Advisory Board and NUG.**

7. Measuring Data Quality in GP databases

- JHC is organising a meeting with custodians of other primary care research database in the newyear to discuss definitions and measurement of data quality with a view to developing some standard measures. The board welcomes this development. **(action JHC to organise and feedback to the board the results).**

8. Database Request from a University

- Another university have requested a download of data for 14 practices contributing to their NHS R&D research network on an ongoing annual basis. EMIS have asked QR to enable this and also provide the governance framework. QR has agreed subject to governance and costs being covered.
- The QR proposal is that the NHS R&D practices would contribute to the QR database and that this would be the mechanism by which data are extracted into a separate database. In order to protect confidentiality of patients which is

at risk in a very small network with a high degree of local knowledge from the researcher, the BMA require that the resulting database will not include practice GUIDs. The university concerned has agreed to this. This proposed solution would help QR to increase its size and it would also minimise additional development/infrastructure support.

- The other university, however, have asked that their NHS R&D practices should have the option of choosing whether to be included in the QR database. This would mean some practices contribute to only to the new database whilst others would be in both databases. This is technically more complex to deliver. The Advisory Board's view is that practices should also contribute to the QRESEARCH database and that this is a realistic expectation since it will be using QRESEARCH infrastructure and technology. The Advisory Board also advised that costs and governance requirements should be met. The Advisory Board also recognised that meeting this request is likely to generate further requests from larger networks and so a clear framework is needed. The solution should support not undermine QRESEARCH.

- Alternatively the other University could request a database direct from EMIS without using QR infrastructure or technology or governance framework and the oversight of the Advisory Board. QR would have no involvement or responsibility for this and the database would not include data which is specifically developed by or licensed to QRESEARCH (eg deprivation data, ONS cause of deaths data). MP expressed concern about multiple databases not involving the QR governance framework. MP asked for a short note about this request for him to discuss with NUG. (**Action: JHC to prepare a short note; and MP to discuss the options with NUG and feedback to JHC).**

10. AOB & date of next meeting.

- The board said it was happy with the scope and progress of QRESEARCH and agreed with the top priorities of improving the infrastructure for researcher access and increasing the visibility and benefits of QRESEARCH back to practices.
- The Advisory Board commented on the need for members to actively feedback and discuss issues with the organisations they represent.
- Jon Ford agreed to check with Laurence Buckman about GPC representation now that LB is chair of the GPC.**(action Jon Ford)**
- JHC to check with John Williams w.r.t. representation of the RCGP **(action JHC)**
- PW agreed to work with JHC to improve the patient notice about QRESEARCH which practices are asked to display in their waiting room to ensure it is accessible **(action JHC and PW)**
- The next meeting will be in March/April 2008 as there are a significant number of issues to feed back on.

Minutes by Julia Hippisley-Cox, 09 Nov 2007