QRESEARCH Advisory Board Meeting Minutes 01 Feb 2007, University of Nottingham.

1 Purpose of document

This document contains the minutes of the QRESEARCH advisory board held in Nottingham University on 01 Feb 2007. The meeting was structured into two sections – the first was reporting back on current activities and governance arrangements. The second section was looking forward to strategic objectives and plans for 2007 onwards.

1.1 Attendees

- Dr John Williams (JW)
- Dr Dai Evans (DE)
- Mr Jon Ford (JF)
- Dr Jonathan Meadows (JM)
- Professor John Fox (AJF)
- Professor Julia Hippisley-Cox

1.2 Apologies

- Professor Azeem Majeed (AM)
- Dr Laurence Buckman (LB)
- Mr Mike Heaps (MH)
- Professor Richard Logan (RL)

2 Section one: reporting on current activity and terms of reference

2.1 Update on membership

- There have been some changes to the membership of the advisory board and new members were welcomes
- Professor Pringle has resigned from QRESEARCH and hence the advisory board
- Professor Logan has joined the board as a University of Nottingham representative in addition to JHC.
- Professor John Fox was welcomed to the advisory board. He has recently retired from the Information Centre but continues to have a responsibility for links between the Information Centre and the Academic Community. He is also giving strategic advice to QRESEARCH with regards to its publication strategy and discrete projects.
- JHC has also contacted the MRC and the Royal College of Physicians to invite them to nominate a representative and is awaiting a reply.

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- There is a vacancy for the patient representative. JHC to contact Harry Cayton to ask for suggestions. Also consider Patricia Wilkie (action JHC)
- Board members were invited to suggest other organisations who might wish to be represented on the QRESEARCH board (action all)

2.2 Terms of reference and governance arrangements

- The board discussed the document entitled "QRESEARCH advisory board and governance arrangement.pdf" which had been circulated prior to the meeting. Overall the board approves the governance arrangements for QRESEARCH. Several issues were clarified during the meeting in response to questions from board members:
- **Financial arrangements** all finances relating to QRESEARCH are handled within a discrete cost centre within the University of Nottingham. If a new funder wishes to invest in QRESEARCH (for example ESRC) then this would be managed as a distinct contract within the QRESEARCH cost centre and the arrangements would meet the requirements of both parties.
- Scientific board Professor Azeem Majeed was appointed as chair of the QRESEARCH scientific committee and decided to run the committee as a virtual committee rather than a committee which meets a monthly basis. This is because of the unpredictable volume of applications, constraint on time, and the diversity of the reviewers needed to peer review work (the selection of reviewers depends both on methodological expertise as well a topic specific expertise). When a researcher submits an application form for a project, JHC sends these to peer review (which includes national and international experts). The committee therefore consists of a variety of academics who have reviewed proposals during the year.
- Ethical review: Trent MREC requested an amendment to the arrangements for ethical review of projects using QRESEARCH in August 2005 in order to handle the volume and nature of the requests. QRESEARCH has now agreed with Trent MREC to report annually on all uses of the data in accordance with the document entitled "mrec034021 agreement 14oct05.pdf". QRESEARCH has just reported to Trent MREC on all activity until mid Jan 2007 and has had confirmation from Trent MREC that all requirements have been met.
- Practice confidentiality. QRESEARCH were able to confirm that the identify of practices contributing to QRESEARCH remains entirely confidential and no practice level data has or will be released from QRESEARCH which could enable any third party to identify a practice. Only JHC in Nottingham and AW at EMIS have a list of consenting practices taking part in QRESEARCH. This list is encrypted and is not and cannot be linked to the QRESEARCH database. All patient level data which is supplied by QRESEARCH to third parties is truly anonymised with patient level data numbered 1 to 100 (for

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example). Each individual project is renumbered so that third parties cannot link datasets from successive projects together.

2.3 Comments on annual report

- Members commented on the annual report which was circulated prior to the meeting. The board was happy that QRESEARCH is acting within its terms of reference and that there have been a substantial number of projects conducted during QRESEARCH over the last 3 years from a range of universities and organisations.
- Members wished to circulate the annual report to the organisations they
 represent with some amendments projects which have not yet started should be
 removed from the appendix and some titles need amending(action JHC)
- In future, we hope to publish the project list on the web. This will need to be done with the consent of the investigators on each project and in a way that it does not give away research ideas before the researcher also had time to complete their project. The web reporting will also link publications to the projects (Action JHC).

3 Section 2: QRESEARCH plans for 2007

JHC did a power point presentation which updated members on staffing and plans for 2007. A copy of the presentation is included with these minutes.

3.1 Expansion of QRESEARCH and Q related project

JHC reported that 3,800 practices were taking part in one of more Q related projects covering just under half of the population.

525 practices contribute to QRESEARCH; 3,300 contribute to QFLU; 3,100 contribute to QPN (pneumococcal vaccine) and 3,400 to QVTP (flu vaccine).

Apart from QRESEARCH, the other projects involve the extraction and reporting of aggregate rather than patient level data. QFLU had been set up in response to concerns about a flu pandemic and is now the UK surveillance system. QPN and QVTP had been set up in response to demand from practices for centrally authored queries to help with vaccine submission for the Dept Health.

We plan to increase the size of QRESEARCH to 900-1000 practices to enable better coverage of data from the mid 1990's for studies requiring time series over ten years (for example). Also a larger population will enable us to undertake research into safety and effectiveness of new drugs within 4 months after the launch of a new drug into clinical practice (this requires adequate numbers of patients taking the drug in

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order for the data to be ready for analysis). We also plan to develop other Q related projects as needs arise.

3.2 QRISK and Drug safety research

JHC discussed her own academic interest in risk factor modelling and developing algorithms to estimate individual risk of diseases and to balance up the risks and benefits of treatments (which is also of interest to David Stables). This work stream has been badged as 'QRISK' and is unfunded. The first project is looking at the development of a new CHD risk scoring algorithm which can be applied to general practice patients.

One component of QRISK is drug safety assessment. JHC highlighted an international gap in the independent analysis of drug safety both for new and commonly used drug. Since QRESEARCH is probably the single best and biggest source of drug safety data internationally, we need to consider how to make a contribution to enhance patient safety in this area. The board discussed terms under which QRESEARCH might engage in analyses of drug safety given concerns of QRESEARCH, EMIS NUG and the RCGP relating to the pharmaceutical industry.

JHC agreed to draft and circulate a position statement/proposal for consideration by the board which would incorporate the basic requirements of any research using QRESEARCH. ie the need for academic independence in the design and execution of any analyses and the freedom to publish the results.

3.3 QWeb and EMIS Web and practice feedback

The board heard about the plans to develop research utilities which can be used within EMIS Web. The plans are at an early stage but it is likely that QR will migrate to EMIS web data structures at some point in the next two years. In this event, QR would ensure that the resulting database had the same high level of confidentiality for practices and patients as the current QR database. JW offered to give advice on this in more detail and this offer was accepted (Action JHC and JW)

QRESEARCH is developing a practice feedback module which will work within EMIS web. Practice feedback was one of the things which practices were offered at recruitment and until now, the technology has not been available to meet this requirement. The board discussed the role which QR has in the development of new clinical indicators and how these might be used to give practices feedback on disease specific areas (eg osteoporosis). QR intends to focus on projects which it can see might have a direct benefit for patient care. It is possible that some of the indicators developed during a project would also be proposed for QOF indicators. The board's view was that QR should help in the development of new clinical indicators and that these could be fed back to practices with the aim of improving patient care. However, in order to ensure that patients registered with non EMIS practices are not

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disadvantaged, then QR needs to consider a mechanism for making the indicators and reference data generally available (action JHC and DS)

3.4 Access to QRESEARCH for non-EMIS practices

The RCGP said how strongly the profession endorsed and supported the 'QRESEARCH' solution especially with respect the strong processes which are in place to protect the confidentiality of practices and the patients they serve. JW asked JHC to clarify whether QRESEARCH would be willing to accept data from non-EMIS practices so that all practices could have a chance to contribute should they wish (action JHC).

Post meeting note: This issue was discussed in more detail by JHC and David Stables after the meeting. QRESEARCH is pleased to confirm that it is willing to receive data from non EMIS practices and EMIS has confirmed that it would help enable this as required. There are significant considerable technical and resource issues to consider and such a development would require careful thought and planning but the principle of equitable access for clinicians (and hence the populations they serve) is one which we would strongly uphold.

3.5 Security check

DE conducted the onsite security check for QRESEARCH and confirmed that arrangements meet requirements

Minutes prepared by Julia Hippisley-Cox, 06 Feb 2007