![QRESEARCH logo]

QRESEARCH ADVISORY BOARD MEETING

Room 1313, 3ᵗʰ Floor, Tower Building
Division of Primary Care
University of Nottingham

Friday 2ⁿᵈ March 2012

Minutes

1. **Attendees**: Mr Terry Wiseman (Patient rep), Mr Jon Ford (BMA), Dr Chris Frith (EMIS National User Group), Dr Caroline Mitchell (RCGP), Dr Jonathan Meadows (EMIS) Professor Julia Hippisley-Cox (UoN and QResearch)

2. **Apologies**: Dr Azeem Majeed, Dr Peter Holden, Dr Patricia Wilkie, Edward O'Neill (Northern Ireland)

3. **Welcome:** Chris Firth and Terry Wiseman were welcomed to the board.

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 will 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 public benefits arising from research using the database.

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

Actions: 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. Target Scottish practices as 50% of practices will soon be using EMIS. JHC to contact Keith Burns and John Duke who are NUG committee members for Scotland and also find out about the SCIMP conference later this year.
3. 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).
4. Consider an annual certificate to state that practices are contributing to QResearch – this could be used by GPs as evidence for their appraisal and also act as a reminder of participation.
5. Asking EMIS to add a link to www.qresearch.org on the home page of EMIS Web (**Action:** JHC/JM)

7. Research governance:

All proposals reviewed in accordance with Trent MREC procedures. MREC approval process working well with no security breaches or complaints. There is now an online application form and set of tools for researcher to use to define their queries (JHC gave a demonstration).

All requests for data have been logged and processed according to our published criteria and none have been turned down (some teams have failed to get funding). The only exception is the request from the Department of Health for consultations analyses in May 2010. The University of Nottingham had previously agreed with EMIS that this particular project was a service rather than research and that QResearch would not be used to provide this information since the

contract ended in 2009. The Department of Health had therefore been referred to EMIS to discuss obtaining these analyses.

8. **Research outputs – public and practice benefits**

    Links to all research publications on published website with >120 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 project – one on safety of antidepressants which was published in the BMJ and was able to drill down to look at individual drugs and side effect and one on risk prediction tools (e.g. www.qrisk.org). This was to demonstrate some examples of projects using QResearch and their benefits to patients and also to practices.

    We discussed 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: CF, JHC and JM to discuss with EMIS how best to maximise the practices benefits from the research arising from QResearch

9. **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

    Whilst infrastructure funding would be ideal, it is unlikely that this will be obtained. QResearch is managing to recover costs from inclusion of costs within grant applications which won in open competition.

10. QResearch data linkage project

At its last meeting 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. We agreed some changes to the wording of the notice which practices are invited to display in their waiting room to inform patients of QResearch project.

Action: JHC to attend a NUG committee meeting to discuss the data linkage project in more detail and how best to communicate with practices about it (in addition to the presentation which is planned for the 2012 NUG conference). **CF to organise suitable dates.**

11. Raising public awareness Practice notice

We discussed ways to raise public awareness and agreed some changes to the practice notice – removed one unnecessary sentence and also to add a statement that no free text is removed.

We also reviewed the patient information sheet which Terry Wiseman had written and agreed it was useful to make this available to practices as well as an alternative format to the conventional practice notice as the question and answer format is more accessible

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 national conference which we will do.

JHC informed members 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.

Action: JHC to revise practice notice and work with (a) patient.co.uk to include some of the information in their website and with (b) EMIS marketing to ensure practices have access to an updated notice to print out for their waiting rooms

12. Migration to EMIS Web

The QResearch database will be migrated to EMIS web in the next few months – this will also give an opportunity for practices which have previously been PCS to contribute.

Action: JHC to ensure that the current tools for opting patients out of the extract and for practices to opt in/opt out of contributing to the database are clearly visible in the system and have links to further information **(Action JHC)**

13. Update on the practice feedback system

The QFeedback system has now been released to all 3300 EMIS LV practices who contribute to QSurveillance. This includes all the QResearch practices. The system is available for practices who contribute data for free. It is currently being used by around 1000 practices per month.

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.

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.

15. AOB

- **Open data policy.** We discussed the coalition government's plans to publish individual patient level data online. The need to publish data may apply to public bodies. The board members agreed that this would not be applicable or appropriate for the QResearch database to be made available online in this way, given its legal and ethical framework and its confidentiality agreements and security arrangements**.**
- **Access criteria:** JHC asked the board whether the current access criteria (which include an academic and a doctor) are too restrictive. The Board's view was that these current criteria and requirements are fine and will help ensure good scientific quality to the research and help avoid misunderstanding of the data and so should remain unchanged.

16. Date of next meeting
We agreed to continue with an annual meeting since this gives enough time for a reasonable amount of progress to be made. The next meeting will therefore be in spring 2013.