QResearch Advisory board Minutes

12 June 2014, University of Nottingham

1. **Attendees:** Mr Jon Ford, Dr Caroline Mitchell, Dr Geoff Schrecker, Professor Julia Hippisley-Cox
2. **Apologies** Dr Hasib Ur Rub, Dr Alan Hassey, Dr Jonathan Meadows, Dr Joanne Reeve, Mr Terry Wiseman.

3. **Welcome:** Dr Geoff Schrecker was welcomed to the meeting as the new co-chair of EMIS NUG. Mr Terry Wiseman has very recently stepped down from the board to failing health. Terry was thanked for his contribution over the last 3 years.

4. **Minutes of last meeting**
   The minutes were accepted shortly after the last meeting and published on the QResearch website.

5. **PowerPoint & terms of reference**
   a. 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.
   b. Members are invited to circulate the finalized minutes and PowerPoint presentation to their respective organisations.
   c. We agreed to continue with the current terms of reference for the group.
   d. We also agreed to continue with face to face meetings annually for as many who can make it, with email and telephone discussions during the year as relevant topics arise.
   e. JHC said she had a telecom booked with Dr Joanne Reeve on 16.06.2014 (see minutes for meeting in appendix) and had spoken with Dr Jonathan Meadows recently patient opt outs for emis and had requested the relevant clinical codes (see below)

6. **QResearch 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
   c. We discussed the possible changes to QResearch access criteria at the last board meeting.
   d. We agreed to 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.

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e. QResearch now provides a new facility for researchers to be able to agreed subsets of the data by logging into a secure dedicated server at the university of Nottingham to undertake analysis rather than download it their own computers. This is used for large datasets or where access to linked data is required. This is working well and is likely to be expanded. The advantage is that the data doesn't leave Nottingham and can be archived, offering an additional level of security.
f. Due to all the upset and confusion around NHS England's recent caredata project, we decided not to change any other access criteria at present but to review it annually.
g. Should any of the access criteria or usage of QResearch change, then practices would need to informed and permission obtained.

7. Research agreement

a. In response to some questions from Alan Hassey, we discussed the application form and Agreement which is published on the QResearch website. This has been drawn up by the university of Nottingham and EMIS and discussed with the ethics committee and advisory board at the time. It is similar to agreements used by other similar research databases but is written in plain English to assist with understanding .
b. Members thought the agreement was fine.
c. Caroline suggested we should make it clearer how to make an initial enquiry at the grant application stage when a fully completed form is not needed but where a letter of support might be requested. JHC agreed to review the website and to highlight this.

8. Research publication s

a. Links to all research publications on published website with >135 papers/reports. There are an increasing number in high ranking journals from wide authorship from a range of universities.
b. 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.
c. Members suggested that if researchers fail to publish within a year of their stated end date, then a summary/report could be published on the QResearch website.
d. Members also suggested that it would be good to publish research summaries of ongoing projects on the QResearch website where possible.
e. JHC reported that the QResearch team had been disseminating research summaries of current projects via newsletters/e-shots and plan to continue with this.

9. Patient information & patient engagement

a. With Terry Wiseman stepping down just before the meeting, we had a discussion on how best to engage with patient groups. Members suggested that JHC write a short role profile and then share it with various patient organisations. Patient organisations could then either send a representative or contribute to discussions by phone or email. Organisations include Patient Opinion, Health Watch in addition to the Patient Participation Association where we already have a contact (Patricia Wilkie). **Action JHC**
b. Alan Hassey had suggested that the patient information page on the QResearch website should be reviewed and updated so we discussed this. The current page had been written by our patient representative, Terry Wiseman, and was very clear but quite short.
c. Members suggested a number of changes to the Patient Information which JHC will amend and then circulate to members but also liaise with patient organisations. In particular, the information should include the following

    i. *"QResearch is working to promote and monitor health in the NHS over time by undertaking research into illness and various treatments and how they are used.*
    ii. *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.*
    iii. *QResearch is only used to answer the most important research questions for the benefit of patients in our National Health Service.*
    iv. *QResearch data is only shared with academic researchers based at UK universities who have a track record in undertaking and publishing research*
    v. *The information extracted onto QResearch is unrecognizable coded data from the GP computer system. It doesn't include your name, address, date of birth or NHS number, phone number, email etc*

d. Members also suggested asking EMIS about having messages on the Egton arrivals/envisage 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**. Action: JHC to follow up with Jonathan Meadows from EMIS**

10. Respecting Patient objections.

a. We discussed the current logic which is implemented to respect patient objections
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 has been introduced in May 2014 in response to requests from practices. A national read code has been requested which will then replace this.
f. QResearch extract will extract data for patients who have opted out of extraction of identifiable data for secondary purposes (9Nu0) unless they have one of the above criteria which will prevent extraction.
g. Members agreed that the current rule set for QResearch remains appropriate.

11. Practice recruitment

a. Many practices had moved from LV to EMIS web over the last year
b. The QResearch management board had agreed that on migration, practices should be requested to activate the sharing agreement (rather than this to be migrated from LV). This would ensure that there was a clear audit trail on EMIS Web agreements manager as to when the practice activated the agreement and by whom.
c. EMIS NUG had kindly produced a screencast on how to activate the sharing agreement which had been very helpful for practices.
d. As a result, we now have 753 practices which activated sharing agreements on either LV or Web. The remaining LV practices are expected to migrate to Web by April 2015.
e. We are actively recruiting practices to contribute to QResearch, with the aim of getting a maximum of 1000 practices. EMIS have included information about QResearch on their websites and in the RSS feeds and via e-shots. EMIS NUG have included information in the quarterly magazine.

12. Benefits for practices.

a. We discussed what additional benefits practices would like for contributing to QResearch as practices are not paid.
b. A number of tools have been implemented into the system over the years including searches & risk algorithms such as QRISK, QFracture, QStroke, QDiabetes. Geoff asked whether practices contributing to QResearch might get a discount on QAdmissions which has been implemented as a chargeable item. Geoff agreed to follow this up with EMIS. (post meeting note – Geoff has emailed Paul Davis at EMIS).
c. We discussed whether practices would value an enhanced practice feedback tool similar to the one which is available for practices contributing to QSurveillance. Members thought it might be very useful for a minority of practices but many would not have time to use it. What might be more useful is provision of templates in the system. JHC to discuss further with Geoff.

13. Qinnovation

a. The first round of Qinnovation had two winners - Dr Tim Walter who had been undertaking work on diabetes risk stratification in his CCG

(www.predm.co.uk) and Dr Daniel Kotz for s study looking at safety of smoking cessation treatments. Both studies are still in progress

b. The QResearch management board decided not to appoint to the second round as each of the applications has significant shortcomings highlighted on the external scientific peer review.
c. We discussed potential changes to how the Qinnovation initiative might be managed in future - including not having a competition at a fixed point in the year but keeping an eye out for suitable projects throughout the year.
d. CM suggested looking at the RCGP scientific board initiative & CIRC and which JHC will follow up on.

14. GP consultations project

a. We discussed requests which fall outside the research scope of QResearch
b. For example, there had been a request from the HSCIC, NHS England, BMA RCGP and some CCGs to update the time series analysis for GP consultation rates which was last done in 2009. The project had been ended by the HSCIC in 2009.
c. Also, in 2009 subsequent to this, EMIS and Nottingham had redrawn its boundaries around permitted use of QResearch data usage to focus solely on academic research projects rather than service deliver.
d. Members as agreed that should this project go ahead, then it should be a new data collection, specifically for this purpose with an opt-in patient consent. The data would be pseudonymised and would be handled with the same security and IG standards as QResearch although it would be separate to it.

15. 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 moths

Appendix 1. Notes of meeting between Joanne reeve and JHC 16.06.2014

From: Reeve, Joanne [mailto:Joanne.Reeve@liverpool.ac.uk]
Sent: 17 June 2014 09:00
To: 'Julia Hippisley-Cox'
Subject: RE: notes from today

Looks great to me thanks Julia

Great to speak with you too.

Until soon.

Best wishes

Joanne

From: Julia Hippisley-Cox [mailto:Julia.Hippisley-Cox@nottingham.ac.uk]
Sent: 16 June 2014 18:11
To: Reeve, Joanne
Subject: notes from today

Joanne

it was so good to speak to you on the phone just now – thank you for your time to discuss QResearch.

As promised, here are some notes from our discussion. Once agreed, I would then like to add them as an appendix to the notes from the face-to-face meeting we had last week.

1. **patient participation**: We discussed the need to have more patient participation in QResearch especially now that Terry Wiseman has stepped down due to ill health. I will be writing a role specification which makes it clear what it involves and that we cover expenses and a small honorarium of £175. I am also planning to update the patient info page with suggestions from last week's meeting. When I have both of these two documents, I will send to you for discussion with Ben Brown to see if we can link into PPI that way.
2. **Qinnovation reviews**: We plan to change the award to be more of a fund for which applications can be made during the year rather than a competition with a deadline. You kindly offered to continue to be involved in reviewing applications for us and also to speak to Imran Rafi about potential links with CIRC and the RCGP Sowerby scheme (if, for example, an innovative application needed some data). I will also follow up on the suggestion of looking at the Terms and conditions for the RCGP scientific board to get some ideas on how to make the conditions a bit more robust.
3. **access criteria**: we agreed it was wise to keep the status quo broadly for access criteria, given the recent problems with caredata except that we would now accept (c) ie outputs could include a report or a paper. If we change at a future point to accept (d) relating to hosting data, then we should ensure that alternative hosts are 'clinically equivalent' in a measurable way. Similarly, the lead academic should be "GPC" approved or equivalent.
4. **respecting patient objections:** currently QResearch does not upload patient records where the patient is marked as confidential or sensitive; where the patient has opted out of the summary care record; where the patient has opted out of QResearch (there is a new code for this). We are happy with this approach – best to keep it simple.

5. **impact**: we discussed communication with practices about how the data is used. this is currently done via the NUG conference, press releases and news items. We also talked about focusing on projects which have a measurable impact and also advantages of trying to link with other organisations which might help us paint more of a picture about the importance of primary care research.

Does this sounds about right - please add anything which is missing or amend anything which I have misunderstood.

thank you once again for your time – very much appreciated.

best wishes

Julia