QResearch Advisory Board Minutes

21 June 2018, University of Nottingham

1. **Attendees:** Jon Ford, Carol Coupland, Mike Walton, Antony Chuter, Julia Hippisley-Cox, Caroline Mitchell

2. **Apologies** Patricia Wilkie, Jonathan Meadows (JM had been due to join by Skype but there had been a mix up over the time of the meeting so JM hadn't been able to attend. JHC will meet with JM separately..

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

4. **Advisory Board Terms of Reference and Membership**
   a. Members reviewed the Terms of Reference (ToR) to ensure they were relevant and included key areas. We agreed to retain all the existing ToR and no additions were suggested
   b. It was suggested that there may be occasions where a subgroup of the Advisory Board helps with a given task and members indicated their willingness to do this where appropriate.
   c. Membership of the board was discussed. AC advised that we should consider inviting other health care professionals (eg practice manager, practice nurse) and other patient representatives (e.g. carer) to join the advisory board.
   d. *Action: JHC will consider how best to do this (post meeting note: there is an active PPI carers group in Nottingham and it might be most practical to have local carers).*

5. **Data Protection and Data Security – including General Data Protection Regulation GDPR**
   a. Following the advisory board in June 2017, JHC had asked the University Protection team to undertake a review to ensure that QResearch was GDPR compliant. This review had been completed in Dec 2017.
   b. The principal findings were that the data extracted for QResearch are anonymised to the ICO code of practice (2012). Since the data are not personal data, then the GDPR does not apply.
   c. The term 'pseudonymisation' now more clearly refers to personal data and so is not applicable to the anonymised data which is held. Therefore, the QResearch website has been updated accordingly

d. A couple of minor changes to the wording of the patient information sheet were needed. These have been approved by the Derby ethics committee and the website has been updated.
e. A GDPR privacy notice for the QResearch website was needed to cover information collected by visitors to the website. This has been added to the website.
f. JHC stated there had been no data breaches or security incidents involving QResearch.
g. JHC advised members that there are regular reviews of data protection issues along with monthly reviews of the QResearch risk register. There are also regular IT audits and ongoing information governance training for all users of the data. All these have been completed successfully.

6. **Patient information and lay summaries on the QResearch website**
    a. The group reviewed the new QResearch website which had been developed since the last meeting. Members reviewed several examples of lay summaries of projects.
    b. The group also reviewed printed copies of two new infographics relating to recently completed research. It was agreed that the lay summaries would be more accessible if they had a clearer structure and the website had a better 'search' facility. It would also to separate current research from completed studies.
    c. Members advised that it would be helpful to add the infographics to QResearch website
    d. It would be useful to add a glossary of medical terms (as emailed by CM) to the website.
    e. The patient information page should be updated to include the rubric of the term for 'opt out of QResearch' rather than the EMIS or snomed code.
    f. AC advised on ways to get QResearch to appear more readily on google search engines – eg changing content more frequently
    g. QResearch should also increase feedback of results of research to practices using the infographics and news bulletins. This could be disseminated to all EMIS practices and local CCGs (the best contact would be head of medicines management). An email could be sent to practices highlighting the relaunch of the QResearch website.
    h. *Actions: JHC to liaise with our website developer and EMIS to organize these suggestions.*

7. **British Heart Foundation (BHF) and Health Data Research (HDR)**
    a. JHC updated members on the background and progress with the request from the BHF following the Advisory Board meeting in June 2017. With the support of the board, JHC had submitted an outline bid in August 2017 and a full proposal had been invited. The full proposal had been discussed with several members during the year and a copy of the current draft was provided to members with the meeting papers.

b. The Medical Director of the BHF had asked whether a new organisation, known as Health Data Research (HDR), might be able to support the QResearch infrastructure in a co-funding arrangement. Members were not familiar with the HDR as this is a relatively new organisation which has had funding from the MRC, Wellcome, NIHR and the BHF to provide an infrastructure for health data in the UK.

c. JHC had met with the Directors of the HDR and the BHF to discuss. At the request of the Director of the HDR, JHC and CC had met with the project leads for two HDR funded Universities in two of the UK's devolved administrations. The HDR was interested to support QResearch but proposed that QResearch was hosted at one of the two HDR funded Universities which had received very substantial investment from the HDR and its predecessor organisation, the Farr institute.

d. The risks and benefits of this proposed hosting arrangement were discussed in detail. JHC highlighted that neither of the two proposed organisations had relevant experience of hosting Primary Care databases. In addition, both proposed organisations hosted substantial volumes of personal data which could result in a risk to the anonymised QResearch data should the datasets be co-located. Also, JHC was concerned that if QResearch were to be hosted in either of these two organisations, then JHC would not be able to guarantee the security of the database as the organisations concerned would own the hardware and employ the administrative staff.

e. The board was unanimous in advising that the HDR's proposal to host QResearch was unnecessary, and had very strong concerns about the database being hosted at a site other than Nottingham where JHC was able to guarantee access to and security of the database. Members also advised that such a change would require re-consenting practices and it was likely that many practices would stop contributing to QResearch. JHC thanked members for the advice and confirmed that following this discussion QResearch would continue to be hosted under the current arrangements in Nottingham.

f. JHC highlighted that increasing access to QResearch was an important priority as it was the largest GP database in the UK and there was significant potential to generate important research to help improve health and health care. Members were supportive of increasing access to QResearch data for other Universities to undertake ethical research so long as all the governance and resource requirements were met.

g. Members suggested other potential funders of infrastructure support which could be approached. Members advised that a SWOT analysis and strategic plan would be helpful to ensure that QResearch was appropriately resourced to achieve its core objectives. JHC highlighted that the QResearch management board was due to meet in the near future and would review this advice and also its current strategy as suggested.

h. Members agreed to provide further advice should there be other similar requests over the coming months.

8. **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 6 months.

Minutes prepared by JHC, 21.06.2018