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QResearch Advisory Board Meeting 19.10.20

Minutes

Dial-In Remote Access

Attending: Julia Hippisley-Cox, Rafael Perera, Antony Chuter, Carol Coupland, Caroline Mitchell, Derek Stewart, Jonathan Meadows, Jonathan Ford, Rebekah Burrow, Defne Saatci, Claire Meadows (minutes)

Apologies: Patricia Wilkie

Chair: Mike Walton

	ACTION
1 Welcome and apologies	
2 Presentation by Judith Burchardt MW expressed interest in hearing about the case control aspects of the project at a later date. He also re-stated that a presentation on QResearch studies should be a regular item on the agenda for these board meetings.	
3 Minutes and actions last meeting Board agreed minutes of last meeting and approved them for public distribution. The board discussed further dissemination of minutes through the department and University channels, as well as the networks of board participants. AC said it would be a good idea to lift items from the minutes and use these in the QResearch newsletter for practice and patient engagement. CMi suggested making lay summaries of studies that can be disseminated through various different channels. With regards to the action tracker from the last meeting – PW stated that it would be helpful to have something on the Patient Access Forum on what QResearch is doing. MW will take forward, outside of meeting. **MW will pursue with Sarah Jarvis**. – JHC and MW to draft PW a piece for her NAPP newsletter. **MW and JHC will take forward**. – PW asked whether the data includes social care data. JHC confirmed not, but there is a communal establishment file that is produced by the NHS. JM will look into whether EMIS can link up with this. **MW will share GP SNOMED codes with JM**. – JM suggested that JHC take up getting more frequent data from EMIS with SoH. **JHC to pursue getting the data even quicker with EMIS.** – PW can put the e-version on her patient and practice website where it will go out to 2000 practices. She also suggested it goes to the practice manager network. PW will	

The Nuffield Department of Primary Care Health Sciences is part of the NIHR School for Primary Care Research. Head of Department: Professor Richard Hobbs FRCGP FRCP FESC FMedSci

Athena
SWAN
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give JHC the link. **CM to pursue with PW when she's back in circulation**.

- AC also suggested that we build a list of people who would be interested in QResearch in Mailchimp, like he does for Pain UK. He also suggested that we create a Virtual Patient Panel via surveymonkey to get steers on things. CM to liaise with AC to take this forward. **Keep on action tracker for now.**

4 Review of advisory board membership and appointment process

This item arose from activity within the department and wider University on making University committees more diverse.

AC thinks it's a good idea that more BAME people should be represented on the Advisory Board, as well as people whose first language isn't English. Maybe practice networks could help with this? **CM will take this forward with AC and CMi**

5 Update on newsletters, comms with patients and practices (including review of privacy notice)

CM confirmed that the second newsletter was about to go out digitally and we're about to begin the third.

JHC asked the group to review the patient information page on the qresearch website. She highlighted that she has amended the site to align with GDPR requirements of the QResearch website at the request of NHS Digital, and also included a section that states that we don't use identifiable data to make automated decisions since we only have anonymised data. She has also clarified the legal process of obtaining the data and has submitted an ethics application to link QResearch to other datasets (including the shielded patient list) be able to inform patients who is more at risk of COVID-19.

AC requested an infographic on how QResearch work with patient data. **JHC to work on this with RB and CM.**

6 Update on QResearch staffing and finances

JHC has received core funding from the University and now has a Data Manager, Data Scientist, Administrator and a Project Manager, and the team has expanded to 12 members. She is trying to recruit an IT member for the team.

JHC is in the process of working out how finances cross over at year end at the University. RP clarified that there are two cut off dates: one for funding the internal ledger which is in July and the second one is for projects that are funded outside the department in April, and it's a case of balancing between these two dates.

JHC confirmed that we are yet to put long term agreements with Nottingham in place to cover JHC's transition, not for want of trying. Members of the board discussed the possibility of them being involved in a meeting with the department to discuss the long-term future of QResearch, but raised the question of who this meeting should be with. **Discussion to carry on outside of this meeting**.

7 Review of QResearch access criteria

JHC asked that the board do its annual review of eligibility criteria for those allowed to access the database. In particular could this be extended to academics in other countries and also to

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other groups of users, noting that it is currently restricted to academics employed by UK universities. The Board are comfortable with academic organisations outside of the UK accessing the data if they are able to quality assure their work and subject to any relevant ethics requirements and data sharing agreements. AC expressed discomfort with the data becoming accessible to commercial organisations outside the UK, but is agreeable to the data being used to benefit patient welfare.

From a technical point of view, if access outside of the UK were to be agree, then the ethics agreement would need to be reviewed and potentially updated, as well as the data-sharing agreement. **JHC to draft a paper to share with the group to cover all points of the discussion for consideration at the next meeting.**

8 Update from the QResearch Scientific Committee (updated terms of reference, recruitment new members, annual report on applications and outcome, COI statements)

RP gave an overview, stating that many of the processes that were needed by the Committee have been put in place and are working well, especially those to do with the application and application feedback process.

The Committee as it stands is too small to deal with an expected influx of applications, and the expertise-base of the Committee needs diversifying. So the Committee are recruiting lay and expert members to expand the group. The response to this call was good, and those shortlisted candidates will be observing at upcoming Committee meetings in Nov and Dec.

CM and RB are currently working on figures for the Scientific Committee annual report. No applications have been rejected outright, though some applications have had to have more than one resubmission.

CC suggested that JHC formulate some training on how to use QResearch. RB is in the process of investigating this as a possible seminar. **DS can assist with training and will discuss with JHC outside this meeting**.

JHC asked the Board whether the Scientific Committee should be asking for applicants to declare conflicts of interest. JM recommended a broad statement of COI, but cautioned about this process becoming too involved. **JM will work on this with CM**.

9 Update on COVID-19 research including linkage to the SPL, Blood transfusion and Transplant

JHC confirmed that the COVID-19 test results and the care data sets are now linked to the database. First paper has been published in relation to this.

The results of JHC's work on a prediction model for COVID-19 will be published in the BMJ next week. These results will then be broken down as patient groups are keen to know the risks of going into hospital for chemotherapy during COVID-19. **AC will introduce JHC to Anne Slee at NHS Digital** to talk about the data she has which may be of use to this project.

10 AOB and Date of next meeting

DS suggested QResearch workshops would be a great way to introduce people to QResearch

in an e-conference setting. **DS and AC will submit ideas to the group on how this could potentially work in time for the next meeting**. TBC on date of next meeting	

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PW stated that it would be helpful to have something on the Patient Access Forum on what QResearch is doing. MW will take forward, outside of meeting	MW	
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JHC to draft paper on opening access to the QResearch data to universities outside the UK and share with group at the next meeting.	JHC	
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