

QResearch Advisory Board Meeting 30.04.20

Minutes

Dial-In Remote Access

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

Apologies:

Chair: Mike Walton

1 Presentation by Defne Saatci	ACTION
<p>DS presented on her proposed DPhil project 'Exploring early presenting features and long term complications of child and adolescent cancers'. DS is going to be working on this with JHC using QResearch data. MW expressed interest in receiving an update on the progress of the project as time goes on.</p>	
<p>2 Minutes and actions last meeting</p>	
<p>Board agreed minutes of last meeting.</p>	
<p>3 Actions and matters arising</p>	
<p>JHC did contact research services and agreements were progressed. Nottingham now have access to the data they need. MW did speak to Shaun O'Hanlon about information going out to practices via EMIS and this had now been completed.</p>	
<p>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.</p>	MW
<p>AC suggested information could go on spare page of prescription forms. CMi highlighted that the COVID-19 circumstances has moved GP practices away from paper, and this may endure in the long-term. Her practice is contacting people largely through SMS. MW noted that there is already Standard NHSD specified requirements over how the RHS (right-hand-side) prescriptions messages are structured which means there is not leeway for a standard approach over how practices configure or word messages on the RHS of prescriptions</p>	JHC/JM
<p>JHC checked that there doesn't seem to be a SNOMED code next to the EMIS code to alert practices as to the appropriate data opt-out from QResearch secondary data use purposes. JM stated that there will be a SNOMED concept ID, and agrees that this information should be transparent to patients. JHC to discuss this with JM outside the</p>	JHC/MW

<p>meeting. Post meeting note: the SNOMED code has now been added to the website so this has been completed. NB please see my separate email re this. The Q&A needs adjusting.</p> <p>JHC and MW to draft PW a piece for her NAPP newsletter.</p> <p>JHC to look into data archiving processes, i.e. not using tapes</p> <p>PW confirmed NAPP conference is cancelled for 2020.</p>	<p>JHC</p>
<p>4 Update from the QResearch Scientific Committee</p> <p>RP confirmed that the membership has been stable, and the Scientific Committee is meeting regularly. The application process is becoming refined, and RB is taking a key role in supervising the process.</p> <p>The committee worked on a fast-track application, which took only a few days to approve.</p> <p>RP also discussed expanding the membership of the Scientific Committee, and that having representatives from different areas and departments broadens the scope of what applications can be dealt with. Also, the Committee is looking at how it can involve public and patients in the meetings. RP confirmed that the Committee is happy to take recommendations for national members from the board. CMi with put forward recommendations.</p> <p>AC is working on a similar patient participation recruitment activity within another arena, and is happy to work with RP as a member of the Scientific Committee, and in offering general advice. AC suggested a 'wish list' of potential members. RP is advocating a 'peer review' system for applications.</p> <p>JHC confirmed that the patient summary requested by PW at the last meeting has now been built into the QResearch application.</p> <p>MW drew the board's attention to the published Scientific Committee minutes on the QResearch website at https://www.qresearch.org/about/scientific-committee/</p> <p>DS will send RP a list of ten questions on PPI that he has worked on with another group, to inform the Scientific Committee's thinking on this.</p>	<p>DS</p>
<p>5 COVID-19 research including linkage to the ICNARC and PHE test results database</p> <p>JHC has linked up QResearch with ICNARC (Intensive Care National Audit and Research Centre) which links up to all 275 intensive care units around the UK. JHC also asked NHS Digital if she could access more frequent uploads of data, down from three months to one month, which has been agreed by NHS Digital but hasn't yet taken effect. COVID-19 Test data and intensive care data is coming in twice a week, but the systems could be in place to receive this data daily.</p> <p>JHC also confirmed that data transfer from EMIS is now transmitted via a live link rather than a hard drive. JHC is able to look at direct, and indirect effects of COVID-19.</p> <p>PW asked whether the data include social care data so that care homes activity can be identified. JHC confirmed not, but there is a communal establishment file that is produced</p>	<p>JM</p>

<p>by the NHS. JM will look into whether EMIS can link up with this.</p> <p>JHC will liaise with JM at EMIS over how Residential Institute data can be included in future data extractions from EMIS</p> <p>CMi flagged up frailty measures as being important, as well as data on those individuals with learning disabilities</p> <p>JM suggested that JHC take up getting more frequent data from EMIS with SoH. All in agreement on this.</p>	<p>MW</p> <p>JHC/JM</p>
<p>6 Practice recruitment</p> <p>JHC confirmed that 1200 practices had previously been feeding data into QResearch but after recruitment via Twitter and other platforms, for more practices, there are now 2500 feeding data.</p> <p>JHC also informed the board that 200 GP surgeries in Northern Ireland have now signed up for QResearch. The technology to facilitate this is still under development. The board confirmed that they want to see all four nations of the United Kingdom represented on QResearch.</p>	
<p>7 Update on move to Oxford and advice on next steps</p> <p>JHC confirmed that QResearch has been successful in received sizeable grant funding in the past few months, including institutional bids from the Wellcome Trust, Cancer Centre and the John Fell Fund. As a result JHC and colleagues are recruiting staff and will have a team of 12 staff by October.</p>	
<p>8 AOB</p> <p><u>Newsletter</u></p> <p>JHC asked the board for suggestions on how and where to distribute the newsletter. MW suggested that he can take the e-version to the NUG and suggest that they distribute it.</p> <p>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 give JHC the link.</p> <p>AC suggested that it be sent to practices to go on their websites and practice newsletters, with a small sample article with a link to the QResearch website.</p> <p>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. CMe to liaise with AC to take this forward.</p> <p>JHC suggested to RP that a virtual panel be taken forward for the Scientific Committee. RP expressed interest, but needs to think more about where this fits. AC suggested that the board put together a patient and public engagement strategy in place, and look at it from a comms point of view.</p> <p>CMi stated that the Clinical Innovation and Search Centre (CIRC) will be happy to promote the newsletter. See https://www.rcgp.org.uk/clinical-and-research/about/about-</p>	<p>PW</p> <p>CM</p>

<p>circ.aspx. Has newsletter already been sent out via CIRC? CMi to confirm</p> <p>JF suggested that he investigate whether the BMA General Practitioner Committee (GPC) would be happy to share the newsletter via their network of Local medical Committees (LMCs) and report back.</p>	<p>CMi</p>
<p>9 Date of next meeting</p> <p>The board decided that, in the current circumstances, we should reconvene in three months, rather than six. CMe to send around doodle poll for dates at the end of July 2020</p>	<p>CM</p>

Action point	Owner	Notes
<p>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.</p>	<p>MW</p>	<p>CM chased 8.7.20</p>
<p>JHC checked that there doesn't seem to be a SNOMED code next to the EMIS code. JM stated that there will be a concept ID, and agrees that this information should be transparent to patients. JHC to discuss this with JM outside the meeting</p>	<p>JHC/JM</p>	<p>Completed 30.04.2020</p>
<p>JHC and MW to draft PW a piece for her NAPP newsletter.</p>	<p>JHC/MW</p>	<p>CM to liaise with PW by end of week 10th July.</p>
<p>JHC to look into data archiving date as per last meeting's minutes.</p>	<p>JHC</p>	<p>COMPLETE – DATA NOW ARCHIVED ON SERVER VAULT AS WELL AS TAPE</p>
<p>DS will send RP a list of ten questions on PPI that he has worked on with another group, to inform the science committee's thinking on this.</p>	<p>DS</p>	<p>COMPLETE</p>
<p>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.</p>	<p>JM</p>	<p>CM chased JM 8/720</p>
<p>MW will also look into other ways of obtaining this information, via the NHS.</p>	<p>MW</p>	
<p>JM suggested that JHC take up</p>	<p>JHC</p>	<p>COMPLETE. Oxford now has a live</p>

getting more frequent data from EMIS with SoH. All in agreement on this.		connection with EMIS which enables more frequent data transfer.
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 give JHC the link.	PW	Contacted PW 8/7/20
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.	AC/CMe	CM took forward with AC 8/7/20
The board decided that, in the current circumstances, we should reconvene in three months, rather than six. CM to send around doodle poll for dates at the end of July 2020	CMe	COMPLETE. Meeting organised for July 2020.
CMi to confirm whether the CIRC newsletter has already been sent	CMi	