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QResearch Advisory Board

Minutes

(24.11.22 12.00am – 13.00pm, dial-in)

Attending: Paula Dhiman, Antony Chuter, Carol Coupland, Jonathan Meadows, Jonathan Ford, Rebekah Burrow, Patricia Wilkie, Vanessa Young, Claire Meadows (minutes)

Apologies: Allison Hirst, Derek Stewart

Chair: Caroline Mitchell

1	<p>Welcome and introductions and apologies</p> <p>Chair welcomed group and apologies were noted.</p> <p>Member informed the group that another member of the board is leaving the Board owing to personal reasons. Members were grateful for the contribution this member has made over the years</p>	
2	<p>Minutes and actions from last meeting</p> <p>Minutes approved as a true record of the last meeting</p>	
3	<p>PPI update - data flows diagram and progress on patient facing page.</p> <p>A member met with PHC PPI advisor and Comms team – Comms are pulling together a plan to make the patient page more user friendly in the next few months. This member hopes to update members before the next Advisory board meeting for those interested in this.</p> <p>The group commented on the data flows diagram – general consensus of the group was that the diagram still needs to be made more user-friendly. It's a great document for researchers, but we need more information of the role of the SC in the approval process for the public, and how patient-level data is used and an animation might be useful</p> <p>A member confirmed that we have the budget for a video but we need a stronger focus on what we want to say before we go ahead with the video. One of the other members will link her up with the EMIS patient network to take this further.</p>	
4	<p>Update from Scientific Committee</p>	

	<p>Chair of the SC informed the group that the SC is working very well, and that we're recruiting new members to start in the new year to refresh and diversify the Committee.</p>	
5	<p>Update on QResearch EXA and recruitment</p> <p>A member confirmed that the EXA platform is waiting to go live. There are currently 1430 practices involved, with 40 million patient records. This member also noted that the breakdown of data on the QResearch website needs refreshing which the team hope to do in 2023.</p>	
7	<p>Data linkage including new pregnancy project and request from NIHR re access model</p> <p>A member discussed the new project which is under consideration by NIHR. NIHR have requested the team gets advice from CPRD, MHRA and UK Biobank how to ensure maximum value from the grant if funded and that data can be accessed by researchers in a similar way to the successful UK Biobank model.</p> <p>Access paper JIM July19.pdf</p> <p>The UKB model has a simplified access structure for three tiers – (a) EHR data; (b) lab data; (c) genetic data and researchers can access all of the data for broad programs of work with a light scientific review process</p> <p>Chair of the SC expressed that she had a concern about losing the quality control and 'value added' of the QResearch Scientific Committee if this link-up were to go ahead. The other member commented that the QR science committee offered excellent formative feedback especially for junior researchers and how valuable the feedback was at the planning stages of the project (rather than when the paper is submitted for publication, by which time it is too late). Another member also expressed that we should be protecting the science as any risk from poor quality research with wrong conclusions could have a detrimental effect on QResearch and practices willingness to share data. The group did consider though that the processes could be streamlined perhaps where the applicants had already got a peer reviewed research grant or an accepted application for the same study from another database e.g. CPRD and this would be kept under review. Chair of the SC will consider options.</p>	
8	<p>Newsletter & comms</p> <p>Secretary has already emailed the group the recent newsletters so the Chair moved on from this item in the interests of time.</p>	
9	<p>AOB & date of next meeting</p> <p>A member informed group that EMIS had announced that QScores (widely used prediction tools developed using the QResearch database) would be removed from GP practice following a decision by the EMIS Clinical Governance Board. There will need</p>	

to be another mechanism to ensure benefit back for the practices who share data with QResearch and for patients in the NHS whose data is used.	
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Secretary to poll for next meeting in six months.	
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