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QResearch Vision for 2021 - Advisory Board Workshop

Minutes

Dial-In Remote Access

Attending: Mike Walton, Patricia Wilkie, Antony Chuter, Carol Coupland, Caroline Mitchell, Derek Stewart, Jonathan Meadows, Jonathan Ford, Rebekah Burrow, Katja Pfafferot, Paul Aveyard, Alex Eavis, Claire Meadows (minutes)

Apologies: Rafael Perera,

Chair: Julia Hippisley-Cox

1 Welcome and apologies	ACTION
<p>Presentation/ SWOT analysis</p> <p>The team noted the biggest strength of QResearch is the core of where it originated – the GP health record. They feel that there is an enormous amount of ‘buy-in’. The phraseology of QResearch is embodied in frontline lexicon of GPs. We should take an opportunity to increase understanding around the various outputs.</p> <p>One team member said you can’t help but compare with CPRD. There isn’t a compelling to use one above the other. QResearch is efficient.</p> <p>CPRD is quite costly. QResearch has higher coverage of London, and more ethnicity data than CPRD. There are more data linkages. Science Committee reviewers take into account if access has already been gained from CPRD for a new application. Some members of the team thought the main difference is that CPRD research outputs aren't embedded in clinical practice in the way QResearch eg through the research with impact.</p> <p>The PPI member confirmed that we have not yet got to a place where the public understand what their data is being used for. A campaign that says that data is being used responsibly like donor card or giving blood could be a good idea to take forward. We need more information circulating on good news stories of what QResearch has achieved. Case studies to work towards informing patients, especially around COVID projects, and helping the national COVID effort.</p> <p>As a weakness, there are geographical holes in data. There is an opportunity to expand the number of contributing practices. 99% of all practices currently take part in QCOVID. We should consider possible opportunities for greater practice engagement. Maybe we could also set up a lay panel and look at reach? Lay members of group could advise on this.</p> <p>The team suggested a COVID special newsletter and noted that with twice the number of practises could achieve results twice as quickly.</p>	

It was noted that the Chief Medical Officer for England likes to look beyond the 'golden towns' to deprived communities and coastal towns. Maybe EMIS could flag these up? There is currently not good coverage on North East but North West very good with similar levels of deprivation.

From a GP perspective, it could be considered that there is a plethora of data sharing agreements and any barrage of information is 'overwhelming'. Practices think they've been contributing but haven't clicked the option to use so we need to raise awareness of this. Working together with EMIS we can take an opportunity to instruct on how to use QResearch. We can work through different networks to push the practices into working on research efforts.

It was suggested we make the costing model simpler so researchers know how to cost this into their projects to increase access in a sustainable way. The figures that we have already worked out come in at a fraction of the cost of CPRD. How do we make the data available to those without the budget to use it? RP suggested that there is a data service where people can apply for data sets that we can provide instead of being involved in the research. The money that comes back from this could be used for DPhil students. AE wants us to tread carefully in terms of what GPs and patients have signed up to so we stay on the right side of ethics.

From a patient perspective, patients do not know what is done with their medical record. Individuals do but as a collective. There is an issue about the difference between patients and members of the public as to where the data is coming from.

Patient Access 11 million registered users via app and web presence. QResearch could feature on this if the research is peer reviewed and has a lay summary. Agree a publication strategy for the year with general information and if it's published on the website the publication could be automatically pulled into Patient Access. EMIS will help us take this forward.

It was confirmed that people worldwide can use the data, but it stays in the UK. There are criteria as to who can access it. Where people are tends not to be as much of an issue. EMIS want to double-check that GPs, and the central authorities are comfortable with data being accessed from abroad offline.

Threats were identified – one of the biggest threats is the media and social media as we have seen with vaccine and anti-vaxxers on social media. Need to have a plan if members of the public attempt to attack and criticise.

It was noted that there is a changing attitude amongst patients about the way that they get information. Patient Access has not asked the users what they think about their service. Some board members find it uninformative, but it can be used efficiently to disseminate the message. We also need to carry out risk analysis and due diligence on our partners, so involvement doesn't backfire on QResearch. Data breaches can also do damage. We need to have a good handle on the research outcomes in case there is controversy in the results.

GDPR has caused a lot of concern in the patient population and we need to mitigate against any confusion.

We need to make sure we look at non-COVID conditions and make sure there is a plan for continuing QResearch administration in case any of the QResearch team come down with COVID.

The team raised the issue of bringing on other suppliers outside of the link with EMIS. The more EMIS sites that are lost to TPP is a threat to QResearch. We also need to explore different streams of data from clinical systems feeding into QResearch. Major partners should have a voice in governance, whether on the Advisory Board or elsewhere. The team discussed that thinks it could be worthwhile having an external chair and recruiting a more diverse board.

'Patients as partners' should be the line to take going forward. Perhaps we need to advertise for more practices as it is a good time to get the public on board and perhaps practiced can be wooed by the feeling that patients would support them signing up their data at this time. There was a comment about patients seeing anonymised data sharing as another way they are doing their bit, and we could capitalise on the huge increase in research participation in patient facing studies re CVOVID

The team stressed that we need to focus on and build on the strengths of the system. We also need an action plan. It was suggested we extrapolate slides from the points in the meeting notes as a presentation to feed back to the board in due course.

The team are also aware that we have to think very carefully about international and commercial uses to make sure we remain in line with GP and public understanding of how data is used

Further strengths identified

- QResearch is well established and longstanding primary care database- well connected with it's constituents- patients and practitioners-strong engagement. Excellent governance structures. 'Branding' in the linked software impacting on pt care from our desktops everyday- QRisk, QFracture etc etc
- Good reputation and history of generating actionable intelligence in terms of integration with clinical system (e.g. QRisk)
- Excellent internationally renowned publication outputs
- Patients actively involved with Q Research and members of Advisory Board
- High level of patient data security. Very important in the current climate

There in opportunity to use the NIHR CRCNs to target these underserved communities and capitalise on research enthusiasm - a targeted mailout to those practices which are already research active by IMD/ ethnicity data etc

Summary:

- We need to do more about patient engagement.
- Making sure governance strategy is strong.
- More diversity in data sources and involved in governance
- We should think about not-for-profit ideas.
- The team will discuss how we use all allocated funds

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