



QResearch Advisory Board Meeting Minutes 14/10/2019

Present

- Dr Mike Walton (Chair) (GP, Representative of EMIS National User Group)
- Professor Julia Hippisley-Cox (Head of QResearch, Professor of Clinical Epidemiology & General Practice, Trustee of National User Group)
- Professor Carol Coupland (Statistician, University of Nottingham)
- Dr Jonathan Meadows (EMIS Health)
- Mr Jon Ford (British Medical Association)
- Professor Rafael Perera-Salazar (Statistician, Primary Health Care, Chair of Scientific Committee on QResearch)
- Dr Patricia Wilkie (Patient Representative, Social Scientist, National Association of Patient Participation)
- Ms Claire Meadows (Minutes)

1. Welcome to new members and apologies

Welcome to Rafael Perera-Salazar, and apologies from Anthony Chuter and Caroline Mitchell.

2. Minutes of the last meeting and matters arising

JHC said the minutes were agreed by email shortly after the meeting. The main outcome of last minutes was to ensure the group held the current meeting for continuity. All board members agreed to carry on publishing the meeting minutes to document decisions.

3. Appointment of the Chair of the Advisory Board – discussion of the role and process

All board members agreed that having a Chair for the meetings going forward it a good idea. Prior to the meeting two people volunteered as Chair – one for now and one to fill the role in the future. MW said he was happy to take on the role, as he felt that it was a good idea to have a Chair who was independent of the academic environment. MW added the caveat that he would take the role of Chair if no-one else wanted to do it in his stead.

PW sought clarification on whether MW was the right candidate for Chair, owing to what she perceived as a potential conflict of interest with MWs links to EMIS. MW answered this point with the correction that he was not a member of EMIS, but a representative on behalf of the general practice environment. JM stated that MW was a suitable candidate for Chair as he was a user of the EMIS system as a GP but was not a member of EMIS, so had a balanced view. MW stressed that he is also Chair of a sub-committee that watches out for where systems are not acting in the patients' interest. Vote at meeting carried the motion of MW to be Chair of Advisory Board, with role to be reviewed on annual basis going forward.

4. Review of terms of reference of the Board

JHC stated that it has been a regular process to review terms of reference to ensure that they are still fit for purpose, and that there are no gaps or things that are unclear. One of the key pieces of feedback that was missing was the process actually been fed back to the patients. JHC also stated that Oxford University is the sole data controller of the datasets that the group has, which is underpinned by agreements with NHS Digital, Public Health England, EMIS and University of Nottingham.

MW stated that the three current roles of the board – policy, operationalisation and governance – should stay in place. PW raised a question as to whether EMIS currently gets paid for participation in QResearch. JHC clarified that there is currently no financial flow back to EMIS, though there had been in the past to cover costs. JHC believes EMIS costs should be reimbursed. The University of Nottingham used to fund a part time member of staff at EMIS to cover the project. At the point of transfer to Oxford, there was a royalty-free arrangement to cover JHC settling into her role, and arranging data-transfer between organisations.

MW said that this should be an ongoing agenda item to ensure that there is clarity of purpose behind the financial flows involved in QResearch, and PW agreed this was sensible with regards to patient participation perspectives.

CC said that maybe the reference point about research type should be more general, and MW agreed that this was a consideration for the Scientific Committee. RPS agreed, and MW stressed that the strategic overview should sit with the Advisory Board. CC and JHC said that the wording of ‘types of research’ should be changed.

MW suggested that the Board reconvene on the wording of the terms of reference and review by email.

MW said that it would be valuable for someone to administratively assist the Board.

ACTION POINT – MW to contact Derek Stewart to find out whether he wants to continue on the Board.

JHC & PW discussed having more than one patient representative on the Board in case one can't attend. MW said that the Board should be allowed to bring members of organisations to future meetings who are related to a particular project, rather than broaden the list at the outset to accommodate representatives of every relevant organisation.

MW suggested that there should be a line in the terms of reference that states that members of the QResearch team reserve the right to contact the ICO, or indeed any other relevant organisation and invite them to sit at a meeting with the Board as and when appropriate.

MW raised the topic of frequency of Board meetings. Board agreed that there should be a fall-back position of one annual meeting, but to keep in touch via electronic means between meetings and on an ad-hoc basis for projects.

5. Update on transition arrangement in Oxford

JHC confirmed that the data from the University of Nottingham was moved to the University of Oxford servers on May 9th, 2019. There are Data Sharing Agreements in place between EMIS,

University of Nottingham and the University of Oxford, and there are also Agreements in place between the University of Oxford and NHS Digital and the University of Oxford and Public Health England. The mortality data is now routed through NHS Digital once a quarter.

It's to JHC's regret that it's still not been possible to solve the issue of sharing the data back to the University of Nottingham. The matter hasn't yet progressed due to delays in different departments at the University of Oxford, though JHC has now seen and commented on the relevant Data Sharing Agreement.

ACTION POINT RPS suggested that the Board write a letter to Head of Research Services at the University of Oxford, expressing that the Board hopes the difficulties that have caused delays at this stage do not continue in the future and affect future projects

ACTION POINT JHC and RPS to find out who the letter should go to in Research Services.

ACTION POINT JHC and RPS to meet with Research Services to address this issue.

6. Communication with practices and patients

This section makes reference to proposed email from Shaun O'Hanlon to practices in meeting pack.

MW sees this agenda item as having two 'arms': 1) one that addresses the points raised in the previous section about process and legal requirements 2) thoughts and ideas circulating about communication between patients and practices as to what QResearch is doing and how it improves the patient experience.

Shaun O'Hanlon – SOH (Medical Director at EMIS) SOH email is a proposed communication to about 1300 general practices. JHC confirms that QResearch is only receiving GP information from EMIS systems, not from any other GP systems.

ACTION POINT: MW to chase SOH to find out the status of the proposed email to practices, which SOH intended to send on 9/10/19. (has it gone, what was the channel of communication?)

Board approved text of the email in the event that it hasn't already gone out. JHC interested what the response to the email has been, if it hasn't gone out already. JHC pointed out that information pertaining to QResearch involvement with GP practices has been on website for months, even if direct communication has not yet been had.

ACTION POINT: JHC to ensure that SNOMED code is on website alongside EMIS code.

MW expressed need for GPs to have better awareness of the visibility of the QResearch system, as emails could be overlooked by busy GPs. JHC suggested that it could be sent for inclusion in a newsletter by the EMIS National User Group.

PW suggested that NAPP puts the information on the NAPP e-bulletin and website, which will go to 2000 GP practices.

ACTION POINT: For JHC and MW to draft a piece for PW to include in the NAPP literature.

MW flagged up that the Board hadn't yet had a conversation about DPIA (Data Privacy Impact Assessment) requirements under GDPR. Should this be referenced?

MW stated that the more channels of communication in getting this message out to practices the better.

PW raised two questions: 1) who anonymises the QResearch data, and 2) how do patients know what the outcomes are of a particular study?

With reference to point 1) JHC confirmed that the system anonymises the data, and it's no way traceable back to a particular practice or patient. The data can't be used for upgrading patient care because of the anonymisation.

With regards to point 2) MW said CPRD have a regular newsletter process, which goes out to practices, which is useful for practices and patients: a similar newsletter could be implemented for QResearch.

There is also an existing section on the QResearch website around outcomes, but newsletter would perhaps be more effective. JHC and CM are currently working on newsletter template and meeting the communications team in Oxford for advice on the process and further tips. JHC hoping to get newsletter out after Christmas.

ACTION POINT: CM to circulate drafts of newsletters as the process goes along.

MW raised the idea that what Jez McCole has done with his patient interface could be of some use to the QResearch group. JM suggested EMIS could help by utilising their marketing department to publicise what QResearch are doing. MW and PW said this has to be considered from all sides to avoid potential conflict of interest arguments.

PW said that she thinks that it's important that patients are able to opt-out of the QResearch process. MW answered that by working with JM we'll be shoring up information on opt-outs, and that it needs to be clear to patients what they need to do to opt-out.

7. Update on the QResearch Scientific Committee

RPS has taken on the Chairmanship of the Committee, with the view to getting more researchers on board. He's taken the recommendations of the Advisory Board to decide which applications should be used for research, and that there is now an updated form in place so the Scientific Committee can gather the information they need to make this decision. The review of applications happens once monthly, but this may increase if traffic of applications increases.

CC asked whether the applications will have already gone through assessment for funding before it reached the Scientific Committee. RPS noted that that a specific point had not been made on this being part of the process.

JHC wondered whether it should be specified as part of the process that the applications should have already been subject to patient review. PW suggested that a patient representative should be part of the Committee.

MW summarised that the ultimate decision on whether an application is successful, and passes acceptance criteria, lies with the Scientific Committee. MW also suggested that there be a specific question on the form which specifies whether the applicant has tried to engage patients in their study, and if not, why not. JHC confirmed that question is already on there, but MW suggested that it become a mandatory point in the evaluation process.

JF asked RPS in what circumstances would he envisage an application being referred back to the Advisory Board. RPS clarified that there could be issues with the way a research question is phrased, whether it's ambiguous.

ACTION POINT: MW to attend Scientific Committee meetings. RPS to keep MW informed of dates these are going to take place.

JHC suggested that, once the process is completely up and running that RPS report back to the Board on metrics i.e. how many applications have we received and how many have been approved.

PW confirmed she would be able to facilitate patient participation in cases where an application is missing patient involvement.

8. Review of access arrangements

JHC is concerned that the current access restrictions as they stand could deter applicants from QResearch and asked Board to review. Data storage has become centralised so JHC feels there may not need to be such strict rules surrounding participants handling it.

JHC confirmed for MW that the data is held in a 'data warehouse' in Oxford, and that access is tightly monitored. MW asked JHC how the stored data can be re-analysed after the researchers are finished with it. JHC confirmed that data is stored on cassette tapes and they are logged and available to analyse. JF pointed out that tapes are not the best means of storage as they deteriorate.

JHC was keeping a risk register at Nottingham re risks of Qresearch and how to ensure these are mitigated.

MW suggested that the Advisory Board have access to risk register, which is to be considered by Board.

ACTION POINT: JHC to look into alternative means of storage of archived data.

Board reviewed access points on QResearch website with the view to whether they should remain or be deleted going forward. (cross-reference with Restriction spreadsheet attached to these minutes as Appendix 1).

- Q1 to be deleted.
- Q2 to stay with no amendments
- Q3 to be amended to clarify the point
- Q4 through Q7 to stay with no amendments
- Q8 to contain note stating that if it's a new project the researcher will need a study amendment, and a link to FAQs

- Q9 amended to 'three months' from 'one month'
- Q10 to be deleted
- Q11 to stay with no amendments
- Q12 to be deferred for future meeting
- Q13 to stay
- Q14 to stay
- Q15c to be removed.
- Q15d should be amended to 'non-adherence to fundamental principles by underpinning QResearch'

MW suggested patient engagement should be featured in restrictions of use list. This was agreed.

9. Future plans

JHC wants group to consider whether QResearch should become a legal entity as this has been raised. MW said this would need a strategic conversation.

MW suggested that once arrangement with Nottingham and Oxford is complete, the Board should think about holding a one-day conference around QResearch and its benefits, to pitch to potential clients.

PW wants to know whether patients could set research questions. JHC said that an 'ideas generator' could be part of the conference suggested by MW.

PW mentioned the NAPP conference in June 2020 which the Board seemed to agree was a great opportunity for the QResearch team.

ACTION POINT: PW will explore including QResearch in the NAPP conference with her colleagues and revert back to the team

PW wants recently completed projects featured in agenda and website. This was agreed.

JF wants to feature data-hosting in the cloud on the ongoing meeting agenda. This was agreed.

10. AOB

PW raised a point about access to QResearch by insurance companies. JHC confirmed that ethics ensured that there is a ban on insurance companies having access to QResearch. Board would like to keep this on the agenda to discuss in future meeting.

11. Date of next meeting

Next meeting to be held in six months from the date of this meeting. Doodle to be circulated to find date.

ACTION POINTS

DATE	ACTION	OWNER	COMPLETED	NOTES

			(Y/N)	
14/10/19	Contact Derek Stewart to find out whether he wants to continue on the Board.	MW		
14/10/19	Write a letter to Head of Research Services at the University of Oxford, expressing that the Board hopes the difficulties that have caused delays at this stage do not continue in the future and affect future projects	MW		
14/10/19	Find out who the letter should go to in Research Services before above task can be completed	JHC/RPS		
14/10/19	Arrange in- person meeting with Research Services and RPS to address ongoing issues	JHC		
14/10/19	Chase Shaun O'Hanlon to find out the status of the proposed email to practices, which SOH intended to send on 9/10/19. (has it gone, what was the channel of communication?)	MW	yes	09/10/2019
14/10/19	Ensure that SNOMED code is on website alongside EMIS code.	JHC	yes	06/12/2019
14/10/19	Draft a piece for PW to include in the NAPP literature	JHC		
14/10/19	Circulate drafts of newsletters as the process goes along.	CM		
14/10/19	Attend Scientific Committee meetings.	MW		RPS to keep MW informed of dates these are going to take place.
14/10/19	Look into alternative means of storage of archived data.	JHC		
14/10/19	Explore opportunities for QResearch at NAPP conference and revert back to the Board	PW		

APPENDIX 1

ID	RESTRICTION DESCRIPTION
1	Did you have the original idea for this research project?
2	To your knowledge is this work original and capable of publication as original research in a peer-reviewed journal?
3	Are you free to undertake this study and publish its findings without needing to clear it with the funding source or any other organisation?
4	Do you agree to acknowledge the source of QResearch data in any publication, paper, report or software/tool?
5	Do you agree NOT to attempt to identify patient(s) or practice(s)?
6	Do you undertake to provide a copy of the final report of the project and copies of any publications within one year of the project completion?
7	Do you agree NOT to release the data to any third party including the funder, sponsor or other such body?
8	Do you agree not to use the data for any other project except that which is expressly described in your protocol?
9	Do you undertake to check the data you are given within a month of receipt and report back any problems within that time?
10	Do you have a statistician on the project team who has contributed to the design of the study and will advise on the analysis?
11	Do you agree to have a project summary on the QResearch website once the project starts?
12	Are you an academic employed by a UK university?
13	Has the proposal been approved by the QResearch Scientific Committee?
14	Does the researcher have funds to cover cost of access?
15	Studies which can't be done using QResearch
	a. Any intervention on patients or practices
	b. Need to contact patients or practices
	c. Requirement for data not already held by QResearch
	d. Any changes to fundamental principles underpinning QResearch