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QResearch Advisory Board

Minutes

(11-1pm, 10th December 2025, Teams)

Attending: Caroline Mitchell, Antony Chuter, Paula Dhiman, Carol Coupland, Julia Hippisley-Cox

Apologies: Ian Wood, Jon Ford, Rachel Lankshear, Patricia Wilkie

Chair: Caroline Mitchell; Vice Chair Antony Chuter.

1	**Welcome and apologies** Chair welcomed the group and apologies were noted	
2	**Minutes and actions from last meeting** Minutes confirmed as a true record of the last meeting	
3	**Update on move to QMUL** JHC summarised Q Research's successful move to Queen Mary University, including strong institutional support, establishing new grants and research programs, and expanding the team. However, there were challenges in transferring existing funding from Oxford, which is still being resolved. Members asked the following questions **How will QResearch differentiate from other GP EHR databases, and what's the unique value?** • QResearch is similar to another GP database but offers longer longitudinal EMIS histories and often more complete ethnicity recording due to practice mix and continuity. • Governance is agile, enabling first-mover in novel data linkages (e.g., vaccines, chemotherapy, Maternity Services Dataset) and rapid policy changes during COVID. • Profession-led model with deep GP engagement and embedded clinical tools (e.g., QRISK in GP systems) is a distinct USP. • Cost model is cost-recovery and predictable vs TRE per-minute compute billing. • Trusted Research Environment approach has been standard at QResearch for 10+ years; Other providers only now moving from flat files.	

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- Brand identity should stress integrity, clinical relevance to practice, and equity focus, not scale alone.

Could QResearch use a university licensing model for sustainable income?

- Yes; a sub-licence template now exists to license any UK university with improved contracting speed at QMUL.
- Current approach prefers collaborative projects including at least one QMUL co-investigator; a pure "service" data-provision model is being explored for selected cases.
- Active university sublicensees were seamlessly migrated during the move; e.g. immediate back-licences to Oxford, Cambridge, Birmingham was executed to avoid gaps.

How will QResearch handle large, vague, multi-institution Machine Learning (ML) proposals asking for "all data" and "all patients"?

- Data minimisation under GDPR, NHSE Data Sharing Agreements and Section 251 requires defined questions/variables; blanket "all data" requests are non-compliant.
- Ethical transparency requires pre-specified questions/outcomes; output checking remains mandatory to prevent inadvertent disclosures.
- Capacity justice: a single 30M-record ML job cannot monopolise GPUs/TRE resources at the expense of other projects; proportionality applies.
- More efficient designs (e.g., case-cohort, stratified sampling) can answer questions without entire-population extracts.
- Decision: Board strongly supports maintaining high bar; if applicants won't specify, they should not use QResearch; refine policy language to reflect ML-era proportionality.

What's the committee's stance on sample size for ML prediction models and using it as an upper bound?

- For ML, emerging guidance (e.g., Riley framework) suggests complex simulations needing joint distributions; providers may offer summaries/simulated data to support planning.
- Minimum: justify with existing statistical guidance, uplift assumptions for ML complexity, and explicitly consider parameter count and calibration needs; transparency is key.
- Clinical Trial analogies: sample size informs both minimum and reasonable maximum sample sizes and resource allocation; in the same way, observational research studies using EHR should apply proportionality too given patient data stewardship.
- Next steps: JHC share a short position draft with PD; consider a debate/analysis paper including patient and equity perspectives.

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	Should QResearch insist on internal expertise when external teams don't include EHR specialists? • Yes; applications are reviewed for appropriate specialist expertise (including statistical sub-specialism as needed), and gaps are flagged before approval. • If academics v familiar with QResearch are not co-applicants, teams must include strong EHR methodologists to avoid substandard applications, analyses and rework.	
4	**Update on Science committee and planned recruitment** **What's the current committee status and recruitment?** • Current composition: 1 health economist, 2 statisticians (incl. prediction specialist), 1 clinician, 1 lay member, plus data manager in attendance; terms extended to July 2026. • Recruiting additional expert and lay members now (see link); open to varied career stages; interviews target late January. • Action: All to share the call; plan induction/support for new lay members.	

5	**Enhancing anonymisation and public engagement with the new IM1 data platform**
	
	Given the shift to NHS England's IM1 extraction with on-the-fly pseudonymisation, do we need new DSAs with 1,500 EMIS practices?
	
	• Proposed approach: in line with Ethics application, treat as a non-substantial amendment with opt out and practice comms—purpose, items, governance, opt-outs unchanged; only technical pathway and Section 251 basis updated.
	• Optum prefers "new agreement"; advisory view favours "amendment" with opt-out and strong comms, subject to DPO opinion from NHS England.
	• Actions:
	  ○ Seek NHS England DPO advice on amendment vs new agreement Action JHC.
	  ○ Draft practice and patient comms: infographic, plain-English explanation, privacy notice link, opt-out mechanism, showcase benefits (QRISK, patient impact), and gratitude. Action JHC
	  ○ Joint GPIT will support practice comms; Action CM to help approach RCGP Chair
	
	How to best communicate to practices and patients regarding the use of confidential data for research?
	
	• The team is engaging with various groups including a young person's advisory group, patients from diverse communities and relevant patient charities to discuss use of confidential data for research
	• This as an improvement/modernisation of pseudonymisation within NHS-	

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	supported IM1, with no expansion of data scope and continued strong safeguards. • Important to note this is not-for-profit, public benefit, and dependence on GP-record quality; invite practices to the "QResearch family" and offer patient-facing newsletter copy. • Potential to use opportunity to convene a large public online group for ongoing surveys/polls. **Should QResearch recruit TPP practices via IM1?** • Yes in principle; JGPIT supportive, initial pilot in a defined area recommended, with LMC awareness and ICB R&D leads engaged to reduce surprises. Action JHC to contact LMC • Leverage Deep End networks (Sheffield, NENC, Bristol) and contacts for inclusive practice clusters; Action CM to connect. • Engage influential GP leaders to open regional doors; Action CM to introduce. • Coordinate with NHS England on IM1 licensing mechanics and any DSA enablement support: Action JHC	
6	**Public engagement plans** **How to broaden and support lay participation, especially from underserved communities?** • Consider building a two-tier model: small inner PPI group plus a large online community (newsletter, polls, quick surveys) to diversify input. • Provide supportive practices: pre-briefs, visual cues/sign language in meetings, warm-ups, induction materials, and debriefs; focus on "support" not "training". • Recruitment and accessibility: accept narrative "story" instead of CVs; avoid academic-only norms to counter selection bias. • Action: PD to integrate support offers into Science Committee onboarding; co-develop PPI support plan post-recruitment. Action PD, AC, JHC	
7	**AOB** The group will meet again in May/June (ideally in person) with interim meetings to address actions.	