Data Access Committee (DAC) Terms of Reference

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1. **Background**

As part of a revised approval process being established with the Barts Life Science (BLS) Precision Medicine Programme, a Data Access Committee (DAC) has been established with members from Barts Health, Queen Mary University London and external public contributors. The DAC will review and make decisions on applications for large-scale or algorithmic use of patient data, including any analysis of patient data in or from the Barts Health Data Platform, see Appendix 1 DAC workflow. The DAC has the following Terms of Reference.

2. **Membership**

2.1 The membership of the DAC is composed of:

- Chief Clinical Information Officer (Chair)
- Nursing representative (e.g., CNIO)
- Clinical representative
- Academic/Research representative
- Caldicott Guardian representative
- Data Protection Officer representative (IG Office)
- Research Governance representative (JRMO)
- Data Warehouse representative (Precision Medicine Team)
- Secure Data Environment representative (Precision Medicine Team)
- 2 Data Science representatives (Barts Health & Queen Mary University of London)
- Commercial team representative (as and when required)
- Clinical Effectiveness Unit representative
- Informatics' New Initiative representative (as and when required)
- 2 Public contributors

2.2 One public contributor must attend the DAC meeting. If both public contributors send their apologies, the meeting will be cancelled.

2.3 Members of the Precision Medicine team will facilitate the meeting and provide technical expertise where required. Apart from the 2 DAC members from the Precision Medicine team named in Section 2.1, all other members of the team will be non-voting.

2.4 Observers are not members of the DAC but may be invited to observe the DAC process; observers may attend at the discretion of the Chair.

2.5 The Chair will ask members to declare any conflicts of interest before each meeting around any of the approvals being presented for discussion or decision. The conflict of interest is not restricted to financial matters – involvement in trials, previous research collaborations or intellectual investment could be relevant. The conflict will be noted in the minutes and logged on the Declaration of Interests log. Depending on the nature of the conflict the Chair may ask the member to stand down from the group for the meeting with an alternate to attend, or to recuse themselves from the discussion on when these issues are being discussed.

2.6 Members will not participate in any discussion or decision making about any access requests that they are involved with either directly or indirectly.

2.7 Members can hold their membership for 3 years. Appointments will be staggered to ensure continuity of membership where possible. Members are encouraged to not hold consecutive terms.

2.8 Members are free to resign their position with immediate effect. Where possible notice of intention to resign and 3 months' notice should be given.

2.9 Members are expected to treat the discussions that take place at the DAC and the material provided to the DAC to be kept confidential. All successful requests will be published on the website.

2.10 Membership to the DAC can be revoked for professional misconduct, breach of confidentiality and/or a breach of the conflict of interest, or any other part of the governance framework by majority decision of the BLS Precision Medicine Programme Board. Members should be active in their participation to ensure rapid review and turnover. Members who respond to less than 20% of applications within a 6-month period may be asked to reconsider their involvement in the DAC.

2.11 If members are unable to attend a meeting, they must send their feedback via email or send a representative.

3. Role

3.1 DAC will evaluate any request relating to patient data in or from the Barts Health Data Platform for data analysis and data processing, including both clinical, research, industrial and/or academic access to data to ensure it is managed in accordance with Data Protection Legislation and in the public interest, and on the principles established by the BLS Programme Board.

3.2 DAC will also provide a view on service evaluation and clinical audits referred to it where data is shared with a commercial company, or any use of patient data at scale, to ensure it is managed in accordance with Data Protection Legislation and in the public interest with the knowledge of all relevant stakeholders..

3.3 DAC may audit projects before, during and after completion as required to ensure compliance with the given approvals, and all datasets with small numbers may be audited before publication by default.

4. Quorum and decisions

4.1 At the first stage of the DAC when reviewing the feasibility of the study, a decision is carried by simple majority of the members present. However, at the second stage of approvals, the decision

must be approved by a quorum (number of members / 2 + 1), including both public representatives.

4.2 If the requester wishes to appeal the decision of the DAC then the issue will be referred to the BLS Precision Medicine Programme Board.

5. Meeting format

5.1 The DAC will meet monthly for one hour via Microsoft Teams or hybrid meeting.

5.2 Requests to be discussed including an agenda shall be sent to all member at least seven (7) days prior to the meeting. All members of the DAC shall use all reasonable endeavours to attend all meetings directly or through their recognised alternate.

5.3 Applicants will be given the opportunity to attend the DAC meeting to give a 1-slide summary of their request and provide a response to any DAC queries.

5.4 Outcomes of the meetings of the DAC shall be drafted by or on behalf of the Chair and transmitted to the members without delay and in a timely manner.

5.5 The minutes shall be considered as accepted by the members if, at the point of review, no member has objected to the Chair.

5.6 A delegated staff member will coordinate progress reports regarding the projects approved by the DAC as required by the DAC.

6. Reporting arrangements

6.1 The approved minutes of the meeting will be available to the BLS Precision Medicine Programme Board for information to discharge their operational oversight of the DAC. A summary of the DAC work will be presented to the BLS Precision Programme Board every 6 months.

6.2 A delegated staff member will provide a written response to each applicant within 14 days following the DAC meeting notifying them the outcome of the review: approved and provisionally approved – clarification required.

6.3 A representative of the DAC will provide a report including a summary of the discussions and any other issues to the BLS Precision Medicine Programme Board for information. This will normally be the Precision Medicine representative on the DAC who will also be a member of the BLS Precision Medicine Programme Board.

6.4 An annual report on the activity of the DAC will be prepared for circulation to the BLS Board and for public consumption.

7. Chairman's action

7.1 A 'chairman's action' is when the chairman is asked to take a decision on behalf of the DAC because of specific deadlines.

7.2 Chairman's action will only be taken if the DAC have previously agreed that the decision will be delegated to the chairman between meetings.

7.3 Whenever a chairman's action is called for, it will be documented and presented to the DAC for ratification at the next meeting.

7.4 Wherever possible, the use of a chairman's action will be limited.

8. Review

These Terms of Reference will be reviewed biannually by the DAC and approved by the BLS Precision Medicine Programme Board.

Appendix 1 – DAC workflow

The DAC workflow has been taken from the Precision Medicine Platform Data Access Process document: