Data Access Committee (DAC) Terms of Reference

V1.4 21.06.23

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) is being established with members from Barts Health, Queen Mary University London and external public contributors. The DAC will review and make decisions on applications to use patient data for any purpose other than direct patient care, including analysis of patient data in or from the Barts Health Secure Data Environment. The DAC is being established with 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)
- PMP Data warehouse representative (Precision Medicine Team)
- Data Science representative
- Commercial team representative
- Clinical audit team representative
- 2 Public contributors

2.2 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.

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

2.4 Members can hold their membership for 3 years. Appointments will be staggered to ensure continuity of membership where possible.

2.5 Members are free to resign their position with immediate effect. Where possible, 3 months' notice should be given.

2.6 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.

2.7 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 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.

3. **Role**

3.1. DAC will evaluate any request relating to patient data for data analysis and data processing, including both industrial and/or academic access to data to ensure it is managed in accordance with Data Protection Legislation and in the public interest.

3.2. The 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. 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.

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

5.5. 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 circulated to the BLS Precision Medicine Programme Board for information to discharge their operational oversight of the DAC.

6.2. A representative of the DAC will provide a report including a summary of decisions (approvals/rejections) and any other issues to the Barts Life Science (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.

6.3. An annual report on the activity of the DAC will be prepared for circulation to the Barts Life Science board and for public consumption.

7. **Review**

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