**NORTH WEST LONDON DATA ACCESS SUB-GROUP**

**Terms of Reference (ToR)**

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| **Version** | **Date** | **Modified by** | **Updates** |
| 0.1 | 26/11/2019 | T. Sallamuddin  | First Draft of Terms of Reference |
| 0.2 | 16/01/2020 | Data Access Sub-Group Meeting  | Review by the members of the Data Access Sub-Group  |
| 0.3 | 12/02/2019 | T.Sallamuddin  | Amended following review by the Data Access Sub-Group. Added Co-Chairs, some membership post changes.  |
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| **Title** | **North West London Data Access Sub-Group Terms of Reference** |
| 1. Date Approved and Governing Body
 | The **NW London Digital Information Governance Board** shall approve these Terms of References (ToR). The **North West London Data Access Sub-Group** (the “**Data Access Group**”)formally adopted these TORs on 16th April 2020 |
| 1. Background and Purpose
 | The Data Access Group acts as a sub-group to the NW London Digital Information Governance Board and has thus far been delegated responsibility to oversee data flows, cyber security and access to data requests (both service evaluation and research studies/projects). In relation to, data requests, the **Data Access Group** used to historically review them separately, however, since the process does not greatly differ, if at all, the **Data Access Group** will now review both these types of requests together. The purpose of the **Data Access Group** is as follows:* support the **NW London Digital Information Governance Board** by making recommendations and providing guidance to assist the development of safe and secure data flows and access to the systems used across the sector for the benefit of joined up integrated care in North West London;

 * Adhere to and encourage a culture of safe and appropriate data access whilst working within the guidelines set out in the NW London Statement of Data Sharing. Always consider the responsibility, functionality of all data controllers and their respective systems in order to deliver an Information Governance framework which is reflective of current industry best practices;
* The subgroup will review applications from data controllers to conduct clinical audit and service evaluations using the de-identified dataset within Whole Systems Integrated Care (WSIC) record;
* The Data Access Group must will ensure requests, for clinical audit and service evaluation, are supported by a service lead, clinical director, divisional director, practice lead, PCN lead or CCG lead who has the authority to support such an application, at one of the organisations who is a data controller within WSIC;
* The Data Access Group should only approve requests, for clinical audit and service evaluation, if it supports the delivery of improved direct care through quality or service improvement. This can include the improvement of both patient and staff outlook/experience;
* Oversee and manage research requests to use WSIC and Discover NOW. This will involve reviewing project applications to grant or deny access to the WSIC de-identified dataset for research purposes;
* To grants requests to use the Discover consent to contact register where appropriate;
* To assess the value of the available datasets and its suitability to what the intended research application is trying to achieve. The Data Access Group’s considerations should always align with the research purposes set out under GDPR and take into account for the strategic direction set by the Discover NOW Hub Board and the views and interests of the project stakeholders;
* In relation to research applications, the Data Access Group, may take assurances that the application has been approved by other parties involved in the research process. For example, as far as possible, the subgroup should rely on REC approval (for ethics) if applicable, any sponsor's and/or funder's confirmation (that peer review is in place and therefore the study is scientifically sound), and CRN portfolio inclusion (therefore the study reflecting the needs of the NHS, health and social care).
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| 1. Membership (Voting)
 | Membership of the **Data Access Group** will be made up of the following members:* Academic representation – from Brunel and Imperial College London;
* CCIO of the sector;
* Discover-Now Representative;
* R&D directors of the trusts;
* Information governance representation from all provider/data controller partners;
* WSIC representation;
* Lay members;
* NIHR/CRN representation.

Each member should be mindful that their appointment, to the **Data Access** Group, has been carefully considered in order to ensure there is a broad range of expertise, knowledge and experience in the overall membership to enable the committee to arrive at the best possible decision. Wherever possible, each member’s input, on the agenda items, should reflect their role in the committee. Only by way of an example to highlight the aim of this paragraph, whilst the person appointed to give ‘information governance representation’ may have an opinion on something related to how the patient/public feel about a decision, it is most likely that the perspective of the ‘Lay members’ are more relevant and must be heard, and vice versa.  |
| 1. Membership

(Non-Voting) | Members may invite individuals and teams to attend the **Data Access Group** to provide information and updates relevant to the agenda. Such attendees shall not, unless they hold a valid proxy, be eligible to vote on any matters before the group.  |
| 1. Eligibility and joining
 | To be eligible to join the **Data Access Group** the following requirements need to be met:* Your organisation needs to be in involved in the North West London Collaboration;
* A membership post must be vacant;
* You agree to act in accordance with their ethical and professional obligations set out by the group.

Requests to join the group must be made in writing to the Chair and will be considered before the group. All applications, to join, must be voted on by the whole membership of the **Data Access Group** and agreed by a simple majority.  |
| 1. Proxies
 | A member may nominate an individual to take their place as a proxy. |
| 1. Representative Change and Withdrawal
 | A member may change its appointed representative (“replacement member”) at any time by written notice to the **Data Access Group**. Details of any new member should be provided as soon as is practicably possible. The appointment of the replacement member may be vetoed by the **Data Access Group**, if the it is voted on and a simple majority agrees to veto the appointment.  Member withdrawal from **Data Access Group** should also be provided in writing to the Chair at the earliest opportunity.  |
| 1. Revocation
 | Membership to the **Data Access Group** can be revoked for:* On leaving the North West London Collaboration;
* Professional misconduct;
* Representative/Organisational leaving the collaboration;
* By a simple majority vote by the membership;
* Criminal charges.
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| 1. Chair
 | The **Data Access Group** shall appoint Co-Chairs, who must be taken from amongst its membership. This position will be held on an annual basis as defined by the group. The **Data Access Group** will record in the meeting minutes who has been appointed to be its Co-Chairs.The **Data Access Group** has appointed the Co-Chairs to deal with urgent requests that arise between scheduled meetings whilst noting that the group has not fully delegate decision-making responsibility to the chair unless it is urgent. Any urgent action taken by the Co-Chairs must be considered and can be reversed by the **Data Access Group** at the next meeting.The Co-Chairs will be responsible for agreeing the meeting agendas and priorities for each meeting. They will be responsible for ensuring that discussions are focused, and all decisions are made in a timely manner. A Deputy Chair can be appointed to undertake chairing responsibilities should the situation arise that the Co-Chairs are not available. |
| 1. Secretary
 | The **Data Access Group** has appointed Imperial College Health Partners to provide secretariat services and receive and distribute communications on its behalf (the Secretary). The Secretary will record the minutes of the meeting and attend meetings as required. He/she shall not have a vote unless the role is carried out by a member of the **Data Access Group.**  |
| 1. Quorum
 | No business shall be transacted at any meeting of the **Data Access Group** unless a quorum is present.A quorum is at least four (4) data controller representatives, including a mandatory representation from Primary Care providers, this can be both virtual and in person. A proxy shall count towards the quorum. The Co-Chairs, if relevant, shall also count towards the quorum.In the absence of the Co-Chairs being present at meeting, and if the Co-Chairs have not nominated someone else as per paragraph 9, the group shall appoint a member present to act as the “Chair” of the meeting. |
| 1. Frequency of Meetings
 | The **Data Access Group** shall meet at least every month (on the third Thursday of every calendar month) or at such other interval as the group otherwise determine if circumstances demand it. This can be carried out in person or virtually. A special meeting may be called at any time by the Chair or by two-fifths of the members of the **Data Access Group** upon not less than five (5) days' notice being given to the other members of the matters to be discussed. |
| 1. Operation of the **Data Access Group**
 | The **Data Access Group** may either regulate its own procedures subject to the provisions of these Terms of Reference or these may be amended, altered or revoked by the **NW London Digital Information Governance Board**.If necessary, the Secretary shall circulate, at least fourteen (14) days' before, notice of each meeting (other than a special meeting) stating the date, time and place of the meeting.Any member wishing to place any item on the agenda for a meeting must provide details to the Secretary at least ten (10) days before the date of the meeting.The Secretary shall circulate the agenda and necessary materials for each **Data Access Group** meeting at least seven (7) days before the meeting.The Chair may permit individuals who are not members of the **Data Access Group** to attend and participate in any meeting or part of a meeting, but non-members may not usually have vote in decision-making. However, the Chair can decide, if the input of the attendees is integral, to allow him/her a vote in the decision making of an agenda item. The Secretary shall keep minutes of the proceedings of any meeting of the **Data Access Group** and distribute minutes to all members. The **Data Access Group** may arrange for collective decision-making by exchange of emails outside of meetings as long as the Chair is satisfied that to do so is appropriate. In order to take place, the Chair must ensure the following: * All members are contacted;
* Majority of them confirm agreement with the proposal under consideration;
* Decisions that are made virtually are formally documented at the next meeting.

If relevant, then the **Data Access Group** may create and dissolve sub-committee(s) of its members and/or and shall determine the terms of reference and of any such sub-committee(s). |
| 1. Duties:

Decision Making | The **Data Access Group** may make all its decisions by consensus of the majority of those attending themeeting, if there is quoracy. Before any decisions are taken, those taking the decision shall satisfy themselves that they are authorised to do so.If consensus on any decision cannot be reached, and unless the **Data Access Group** decides otherwise, its decisions shall be taken by a simple majority and when there is a tie then the Chair (or in their absence the appointed Deputy Chair) has a casting vote.  |
| 1. Duties:

Powers and Responsibility | When considering any application to access any data, members of the **Data Access Group** must ensure that each application would comply with all data protection legislation and more specifically the following GDPR articles relating to lawfulness and security: * Article 5(1)(f) - ensures appropriate security of the data, including protection against unauthorised or unlawful processing and against accidental loss, destruction or damage, by ensuring the requester uses appropriate technical or organisational measures (‘integrity and confidentiality’);
* Article 32 – Taking into account the state of the art, the costs of implementation and the nature, scope, context and purposes of processing as well as the risk of varying likelihood and severity for the rights and freedoms of natural persons, the requester of the data shall implement appropriate technical and organisational measures to ensure a level of security appropriate to the risk;
* Article 35 - Whether the nature and the scope of the request would likely to result in high risk to the rights and freedoms of the data subjects. In these cases, a Data Protection Impact Assessment (DPIA) must be completed and submitted before a request should be approved.

The **Data Access Group** shall have the following powers and responsibilities: * Ensure that every requester has completed the ‘Data Access Form’ properly, including all the information required in order for the group to make an informed decision;
* Ensure each ‘Date Access Form’ is accompanied with a letter of support from a clinical lead/divisional manager;
* Ensure, where record level data is being requested, the requester enters into a ‘Data Processing Agreement’ (DPA) with the ‘Data Controllers’;
* Make recommendations to **NW London Digital Information Governance Board** who will inform the NWL Digital Strategy Board of any changes, reviews, and/or strategic aims, and provide assurance that the system security, data flows and access to information are in line with best practice in relation to information governance and data protection legislation;
* Determine and attach any reporting requirements that the requester, of the data, should adhere to;
* Ensure full compliance with any ‘Rights of data subject’ requests under Articles 15-22 of the GDPR and inform the **NW London Digital Information Governance Board** where appropriate;
* Review and keep up to date all “documents” that pertain to the North West London collaboration in order to ensure they reflect the latest changes to legislation or code of best practice. These “documents” could include, but not limited to; the ISS, MDPA, Privacy Notices, DPIA, ROPA, PPI material, website content and other contracts/agreements;
* Deal with any complaints relating to Discover;
* Maintain a risk register and log of mitigating controls and reporting that is periodically updated to reflect the changing risk environment.
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| 1. Accountability
 | The **Data Access Group** will be held accountable for ensuring the processing of data is in line with Interoperability Service Specification and NWL Statement of Information Sharing signed by the data controllers. It must further ensure that all processing would be in compliance with all relevant data protection legislation, common law, and ethical practices in data processing and sharing. The **Data Access Group** is accountable to the **NW London Digital Information Governance Board**.  |
| 1. Interests of **Data Access Group** members
 | All members of the **Data Access Group** shall declare any interests in any matter coming before the Group and the Co-Chairs shall consider whether such interest requires the member to withdraw from the meeting for that item of business.  |
| 1. Reporting responsibilities
 | Each member shall disseminate minutes and reports of **Data Access Group** meetings to the organisation or organisations that member represents. The **Data Access Group** will provide a report, in writing or verbal, to the **NW London Digital Information Governance Board** on activity and progress, or at a frequency as defined by the **NW London Digital Information Governance Board**.  |
| 1. Conduct of the **Data Access Group**
 | The **Data Access Group** shall keep these Terms of Reference under review.Any changes to the terms of reference should be approved by the **NW London Digital Information Governance Board**. |