

# NORTH WEST LONDON DATA ACCESS- Committee

## Terms of Reference (ToR)

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<b>Version History Below</b>			
<b>Version</b>	<b>Date</b>	<b>Modified</b>	<b>Updates</b>
1.0	03/01/2019	-	Base Terms of Reference created prior to version history
1.1	16/01/2019	Taj Sallamuddin (IGS)	First Draft of New Terms of Reference
1.2	18/06/2021	Data Access Sub-Group Meeting	Review by the members of the Data Access Sub-Group
1.3	12/02/2021	Taj Sallamuddin	Amended following review by the Data Access Sub-Group. Added Co-Chairs, some membership post changes.
2.0	18/04/2021	Data Access Sub-Group Meeting	Approves Form
2.1	08/02/2022	Robin Johnson (IGS)	Adding copyright statement, minor format changes.
2.2	20/01/2023	Robin Johnson (IGS)	Adding procedure for dealing with extension requests by Co-Chairs actions where the request does not materially affect the project purpose. Changed Quorum to also need 1 lay member to be present. Changing the assigned Secretary for the Data Access Group. Changing CCG references to ICB. Updating logos.
3.0	06/04/2023	IG Board	Terms of Reference approved by the North West London IG Board
3.1	20/06/2025	NWL Data Protection Office	Updates to reflect new title of this committee and amendment to the procedure for dealing with extension requests.
3.2	07/10/2025	NWL Data Protection Office	Alignment with OneLondon SDE programme

Title	North West London Data Access Committee Terms of Reference
1. Date Approved and Governing Body	<p>The NWL Data Access Committee (the “Data Access Committee”) shall develop, and the ICS-Level Governing Body (NWL Information Governance Committee), in consultation with the London Information Governance Steering Group (the “LIGSG”) shall approve these Terms of References (ToR).</p> <p>The <b>North West London Data Access Committee</b> (the “<b>Data Access Committee</b>”) formally adopted the latest version (3.1) of the ToR on 20/06/2025.</p>
2. Background and Purpose	<p>The Data Access Committee acts as a sub-group to the NW London ICS Information governance (IG) Committee 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 <b>Data Access Committee</b> used to historically review them separately, however, since the process does not greatly differ, if at all, the <b>Data Access Committee</b> will now review both these types of requests together.</p> <p>The Data Access Committee will govern data access requests for both the London SDE and WSIC.</p> <p>The purpose of the <b>Data Access Committee</b> is as follows:</p> <ul style="list-style-type: none"> <li>• Support the <b>NW London - ICS IG Committee</b> 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;</li> <li>• Adhere to and encourage a culture of safe and appropriate data access whilst working within the guidelines set out in the NW London Data Sharing Protocol and OneLondon Data Sharing Protocol. 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;</li> <li>• The <b>Data Access Committee</b> will review applications from data controllers to conduct clinical audit and service evaluations using the de-identified dataset within Whole Systems Integrated Care (WSIC) and the London SDE</li> <li>• The <b>Data Access Committee</b> will ensure requests, for clinical audit and service evaluation, are supported by a service lead, clinical director, divisional director, practice lead, PCN lead or ICB lead who has the authority to support such an application, at one of the organisations who is a data controller within WSIC or the London SDE</li> </ul>

	<ul style="list-style-type: none"> <li>• The <b>Data Access Committee</b> 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;</li> <li>• Oversee and manage research requests to use WSIC and Discover NOW and the London SDE. This will involve reviewing project applications to grant or deny access to the WSIC de-identified dataset and the London SDE for research purposes;</li> <li>• To grant requests to use the Discover consent to contact register where appropriate;</li> <li>• To assess the value of the available datasets and its suitability to what the intended research application is trying to achieve. The <b>Data Access Committee</b> considerations should always align with the research purposes set out under UK GDPR and take into account for the strategic direction set by the Discover NOW Hub Board and the OneLondon Board, and the views and interests of the project stakeholders;</li> <li>• In relation to research applications, the <b>Data Access Committee</b>, may take assurances that the application has been approved by other parties involved in the research process. For example, as far as possible, the <b>Data Access Committee</b> 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 reflects the needs of the NHS, health and social care).</li> <li>• It will also be responsible for reviewing projects where re-identification is needed for direct care purposes.</li> </ul>
<p>3. Membership (Voting)</p>	<p>Membership of the <b>Data Access Committee</b> will be made up of the following members:</p> <ul style="list-style-type: none"> <li>• Academic representation – from Brunel and Imperial College London;</li> <li>• Discover-Now representative;</li> <li>• Member of the Secretariat for Independent Information Access Group ("IIAG"), also known as the pan-London IIAG.</li> <li>• R&amp;D directors of the Trusts;</li> <li>• Information governance representation from all provider/data controller partners;</li> <li>• WSIC representation;</li> <li>• London SDE representation;</li> <li>• NWL ICB GP DPO</li> <li>• NWL ICB Corporate DPO</li> </ul>

	<ul style="list-style-type: none"> <li>• Lay members;</li> <li>• NIHR/CRN representation.</li> </ul> <p>Excluding the Member of the Secretariat for IIAG, all other listed members shall have equal voting rights. An updated log of the members shall be maintained by the Secretariat of the NWL Data Access Committee.</p> <p>Each member should be mindful that their appointment, to the <b>Data Access Committee</b>, 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.</p>
4. Membership (Non-Voting)	Members may invite individuals and teams to attend the <b>Data Access Committee</b> 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.
5. Eligibility and joining	<p>To be eligible to join the <b>Data Access Committee</b> the following requirements need to be met:</p> <ul style="list-style-type: none"> <li>• Your organisation needs to be involved in the North West London Data Sharing Framework and the OneLondon Data Sharing Framework, except for experts, lay members or elected representative roles;</li> <li>• A membership post must be vacant;</li> <li>• You agree to act in accordance with their ethical and professional obligations set out by the group.</li> </ul> <p>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 <b>Data Access Committee</b> and agreed by a simple majority.</p> <p>All efforts will be made to ensure the membership is diverse in terms of protected characteristics.</p>
6. Proxies	A member may nominate an individual to take their place as a proxy, subject to the approval of the Chairs
7. Representative Change and Withdrawal	A member may change its appointed representative ("replacement member") at any time by written notice to the <b>Data Access Committee</b> . 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 <b>Data Access Committee</b> , if it is voted on and a simple majority agrees to veto the appointment.

	Member withdrawal from <b>Data Access Committee</b> should also be provided in writing to the Chair at the earliest opportunity.
8. Revocation	<p>Membership to the <b>Data Access Committee</b> can be revoked for:</p> <ul style="list-style-type: none"> <li>• On leaving the North West London Data Sharing Framework and the OneLondon Data Sharing Framework;</li> <li>• Professional misconduct;</li> <li>• Representative/Organisational leaving the Data Sharing Framework;</li> <li>• By a simple majority vote by the membership;</li> <li>• Criminal charges brought against the member.</li> </ul>
9. Chair	<p>The <b>Data Access Committee</b> shall appoint Co-Chairs, who must be taken from amongst its membership. On an annual basis as defined by the group, this position will have a check in point for members to confirm or challenge this position.</p> <p>The <b>Data Access Committee</b> will record in the meeting minutes who has been appointed to be its Co-Chairs.</p> <p>The <b>Data Access Committee</b> 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 <b>Data Access Committee</b> at the next meeting.</p> <p>The Co-Chairs have the ability to deal with extension requests between scheduled meetings for projects that have previously been approved by the <b>Data Access Committee</b> if the nature of the extension request does not materially change the purpose or outcomes of the study. Any extension request which materially changes the purpose or outcomes of the study must be taken to the <b>Data Access Committee</b> in the usual manner.</p> <p>An extension request which does not materially change the study includes the following:</p> <ul style="list-style-type: none"> <li>• The extension request is for an extension of time only, with no change to the project purpose/ outcome or the data-items required; or</li> <li>• The extension request is concerned with adding/removing users who will have access to the de-identified dataset.</li> </ul> <p>It is expected of each sponsoring organisation to inform the admin / secretariat of the NWL Data Access Committee of the extension request (no material changes), confirming the following:</p> <ul style="list-style-type: none"> <li>• There is no material change to the project scope / outcome</li> <li>• A justification as to why the extension request is necessary</li> </ul>

	<p>Where any decisions are made by Co-Chairs actions in between each <b>Data Access Committee</b> meeting, the <b>Data Access Committee</b> shall be informed of any actions or decisions made at the next available meeting. An extension request of the above nature can be approved by one co-chair and does not require the approval from both co-chairs.</p> <p>If there is a significant gap (6 months onwards) between the time at which the original request was approved by the committee or an extension request was approved outside of the committee, the sponsoring organisation is to inform the admin / secretariat of the NWL Data Access Committee of a clear justification as to why there may have been a gap.</p> <p>In addition, if an extension request is made 3 times, and a 4<sup>th</sup> extension request is put forward, then the sponsoring organisation must present the project to the NWL Data Access Committee confirming the justification as to why the 4<sup>th</sup> extension request is necessary.</p> <p>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.</p> <p>A Deputy Chair can be appointed to undertake chairing responsibilities should the situation arise that the Co-Chairs are not available.</p>
10. Secretary	<p>The <b>Data Access Committee</b> has appointed NWL Data Protection Office (ICHNT and NWL ICB) to provide secretariat services and receive and distribute communications on its behalf (the Secretary).</p> <p>The Secretary will record the minutes of the meeting and attend meetings as required. The Secretary shall send the agenda out to all members of the <b>Data Access Committee</b> and any users who are invited to the <b>Data Access Committee</b> for that particular month. He/she shall not have a vote unless the role is carried out by a member of the <b>Data Access Committee</b>.</p>
11. Quorum	<p>No business shall be transacted at any meeting of the <b>Data Access Committee</b> unless a quorum is present.</p> <p>To be quorate at least 50% of Members must be in attendance including a nominated NHS clinician, a NWL ICB GP DPO, a member of the public, a qualified IG lead/representative. The attendance for the NWL Data Access Committee can be both virtual and in person. A proxy shall count towards the quorum. The Chair(s) if relevant, shall also count towards the quorum.</p> <p>In the absence of the Co-Chairs being present at meeting, and if the Co-Chairs have not nominated someone else as per</p>

	<p>paragraph 9, the group shall appoint a member present to act as the “Chair” of the meeting.</p>
<p>12. Frequency of Meetings</p>	<p>The <b>Data Access Committee</b> 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.</p> <p>A special meeting may be called at any time by the Chair or by two-fifths of the members of the <b>Data Access Committee</b> upon not less than five (5) days' notice being given to the other members of the matters to be discussed.</p>
<p>13. Operation of the <b>Data Access Committee</b></p>	<p>The <b>Data Access Committee</b> 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 <b>NW London ICS IG Committee</b>.</p> <p>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.</p> <p>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.</p> <p>The Secretary shall circulate the agenda and necessary materials for each <b>Data Access Committee</b> meeting at least seven (7) days before the meeting.</p> <p>The Chair may permit individuals who are not members of the <b>Data Access Committee</b> 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.</p> <p>The Secretary shall keep minutes of the proceedings of any meeting of the <b>Data Access Committee</b> and distribute minutes to all members.</p> <p>The <b>Data Access Committee</b> 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:</p> <ul style="list-style-type: none"> <li>• All members are contacted;</li> <li>• Majority of them confirm agreement with the proposal under consideration;</li> <li>• Decisions that are made virtually are formally documented at the next meeting.</li> </ul> <p>If relevant, then the <b>Data Access Committee</b> may create and dissolve sub-committee(s) of its members and/or and shall</p>

	determine the terms of reference and of any such sub-committee(s).
14. Duties: Decision Making	<p>The <b>Data Access Committee</b> may make all its decisions by consensus of the majority of those attending the meeting, if there is quoracy. Before any decision is taken, those taking the decision shall satisfy themselves that they are authorised to do so.</p> <p>If consensus on any decision cannot be reached, and unless the <b>Data Access Committee</b> 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.</p>
15. Duties: Powers and Responsibility	<p>When considering any application to access any data, members of the <b>Data Access Committee</b> must ensure that each application would comply with all data protection legislation and more specifically the following UK GDPR Articles relating to lawfulness and security:</p> <ul style="list-style-type: none"> <li>• <b>Article 5(1)(f)</b> - 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');</li> <li>• <b>Article 32</b> – 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;</li> <li>• <b>Article 35</b> - 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.</li> </ul> <p>The <b>Data Access Committee</b> shall have the following powers and responsibilities:</p> <ul style="list-style-type: none"> <li>• Ensure that every applicant has completed the 'Data Access Request Form', capturing project information, and signed an Acceptable Use Policy, which sets out how each User must conduct themselves. Notably, the application form must confirm that the project is sponsored/supported by one of the organisations acting as a data controller under the NWL Data Sharing Framework and the OneLondon Data Sharing Framework;</li> </ul>

	<ul style="list-style-type: none"> <li>• Oversee regular updates pertaining to the development, results, outcomes, and patient benefits from Users who have commenced their projects utilising the patient confidential data held in pan-London information sharing initiatives subject to the NWL Data Sharing Framework and the OneLondon Data Sharing Framework;</li> <li>• Review and determine the approval or rejection of new Interoperability Projects, in consultation with NWL ICS IG Committee and LIGSG;</li> <li>• Review proposed amendments to existing Interoperability Projects, in consultation with ICS-level Governing Bodies and LIGSG;</li> <li>• Ensure, where record-level data is being requested, the requester enters into a 'Data Processing Agreement' (DPA) or 'Data Sharing Agreement' (DSA) as appropriate, with the relevant data controllers, as required under the NWL and OneLondon Data Sharing Protocol;</li> <li>• Make recommendations to <b>NWL ICS IG Committee</b> 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;</li> <li>• Receive recommendations from the Independent Information Access Group ("IIAG"), which will undertake a preliminary review of data access requests at regional level. Independently review and make a final decision on the outcome of the access request made by a member of the OneLondon Data Sharing Framework or a third-party applicant for any pan-London information sharing initiatives;</li> <li>• Oversee requests for extensions to the duration of access granted to Users;</li> <li>• Determine and attach any reporting requirements that the requester, of the data, should adhere to;</li> <li>• Ensure full compliance with any 'Rights of data subject' requests under Articles 15-22 of the UK GDPR and inform the <b>NWL ICS IG Committee</b> where appropriate;</li> <li>• 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</li> </ul>
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	<p>to; the DSS, DPA, Privacy Notices, DPIA, ROPA, PPI material, website content and other contracts/agreements;</p> <ul style="list-style-type: none"> <li>• Act as a point of contact for any pan-London information sharing initiatives under the NWL and OneLondon Data Sharing Framework using controller data from the area, and communicate decisions to any data processors as appropriate and under the strict instructions of the data controllers;</li> <li>• To either investigate or to commission an investigation of any breaches of access controls and agreements and decide on the appropriate actions that need to be undertaken.</li> <li>• Maintain a risk register and log of mitigating controls and reporting that is periodically updated to reflect the changing risk environment.</li> </ul>
16. Accountability	<p>The <b>Data Access Committee</b> will be held accountable for ensuring the processing of data is in line with NWL Data Sharing Framework and the OneLondon Data Sharing Framework) 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.</p> <p>The <b>Data Access Committee</b> is accountable to the <b>NWLICS IG Committee</b>.</p>
17. Interests of <b>Data Access Committee</b> members	<p>All members of the <b>Data Access Committee</b> 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.</p>
18. Reporting responsibilities	<p>Each member shall disseminate minutes and reports of <b>Data Access Committee</b> meetings to the organisation or organisations that member represents.</p> <p>The <b>Data Access Committee</b> will provide a report, in writing or verbal, to the <b>NWL ICS IG Committee</b> and the London Information Governance Steering Group on activity and progress, or at a frequency as defined by the <b>NWL ICS IG Committee and the London Information Governance Steering Group</b>.</p>
19. Conduct of the <b>Data Access Committee</b>	<p>The <b>Data Access Committee</b> shall keep these Terms of Reference under review.</p> <p>Any changes to the terms of reference should be approved by the <b>NWL ICS IG Committee</b> and the London Information Governance Steering Group.</p>