

## **Advisory Group for Data (AGD) – Meeting Minutes**

Thursday, 1<sup>st</sup> May 2025

09:00 – 16:15

*(Remote meeting via videoconference)*

<b>AGD INDEPENDENT / NHS ENGLAND MEMBERS IN ATTENDANCE:</b>	
<b>Name:</b>	<b>Role:</b>
Paul Affleck (PA)	AGD independent member (Specialist Ethics Adviser)
Claire Delaney-Pope (CDP)	AGD independent member (Specialist Information Governance Adviser)
Kirsty Irvine (KI)	AGD independent member (Chair)
Andrew Martin (AM)	NHS England member (Data Protection Office Representative (Delegate for Jon Moore))
Dr. Jonathan Osborn (JO)	NHS England member (Caldicott Guardian Team Representative)
Jenny Westaway (JW)	AGD independent member (Lay Adviser)
Miranda Winram (MW)	AGD independent member (Lay Adviser)
Tom Wright (TW)	NHS England member (Data and Analytics Representative (Delegate for Michael Chapman))
<b>NHS ENGLAND STAFF IN ATTENDANCE:</b>	
<b>Name:</b>	<b>Role / Area:</b>
Mariam Arowolo (MA)	Information Governance Apprentice, Data Protection and Trust, Privacy, Transparency and Trust (PTT), Delivery Directorate ( <b>Observer:</b> items 5.1 to 5.4)
Garry Coleman (GC)	NHS England SIRO Representative (in attendance for items 5.4 to 10.1)
James Gray (JG)	NHS DigiTrials, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 5.1)
Andrew Ireland (AI)	Information Governance Officer, IG Risk and Assurance, Privacy, Transparency, and Trust (PTT), Delivery Directorate ( <b>Observer:</b> item 8.1)
Madeline Laughton (ML)	Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 5.1)
Joe Lawson (JL)	Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 5.4)

Jorge Marin (JM)	Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 5.3)
Grace Mhora (GM)	Senior Implementation Manager & Business Change Manager, Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> items 5.1 to 5.4)
Harry Millard (HM)	Information Governance Officer, IG Risk and Assurance, Privacy, Transparency, and Trust (PTT), Delivery Directorate ( <b>Observer:</b> item 8.1)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Delivery Directorate
Azeez Oladipupo (AO)	Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> items 5.6 and 5.7)
Humphrey Onu (HO)	Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 5.5)
Jodie Taylor-Brown (JTB)	Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 5.2)
Emma Whale (EW)	Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 5.2)
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Delivery Directorate
<b>AGD INDEPENDENT MEMBERS / NHS ENGLAND MEMBERS <u>NOT</u> IN ATTENDANCE:</b>	
<b>Name:</b>	<b>Role / Area:</b>
Michael Chapman (MC)	NHS England member (Data and Analytics Representative)
Dr. Robert French (RF)	AGD independent member (Specialist Academic / Statistician Adviser)
Jon Moore (JM)	NHS England member (Data Protection Office Representative)

<b>1</b>	<p><b>Welcome and Introductions:</b></p> <p>The AGD Chair welcomed attendees to the meeting.</p> <p>AGD noted that, due to an urgent work commitment, there would not be an NHS England SIRO Representative or delegate in attendance for items 1 to 5.3.</p> <p>Noting that the <a href="#">AGD Terms of Reference</a> (ToR) state that: “...a representative of the SIRO must also be in attendance for any meetings of the Group or a Sub-Group...”, the Group were advised that, prior</p>
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	to the meeting, the NHS England SIRO Representative had confirmed contentment for items 1 to 5.3 to be discussed in his absence; and noted that he would be in attendance for item 5.4 onwards. The Group noted that the meeting was not quorate because of this, and, on this occasion, the Chair agreed to proceed in accordance with clause 7.13 of the <a href="#">AGD ToR</a> . This clause provides that: <i>“In exceptional circumstances the Chair and the representative of the SIRO may agree for the Group to still meet and conduct its business, but the minutes should note the meeting was not quorate...”</i> .
<b>2</b>	<b>Review of previous AGD minutes:</b> The minutes of the AGD meeting on the 10 <sup>th</sup> April 2025 were reviewed out of committee by the Group and, after several minor amendments, were agreed as an accurate record of the meeting by the AGD Chair on behalf of the Group.
<b>3</b>	<b>Declaration of interests:</b> There were no declarations of interest.
<b>4 BRIEFING PAPER(S) / DIRECTIONS:</b>	
<i>There were no items discussed</i>	
<b>5 EXTERNAL DATA DISSEMINATION REQUESTS:</b>	
<b>5.1</b>	<p><b>Reference Number:</b> NIC-411795-X5N2V-v2.2</p> <p><b>Applicant and Data Controller:</b> Our Future Health</p> <p><b>Application Title:</b> <i>“Our Future Health Outcomes TRE Data Linkage Application with Sublicensing”</i></p> <p><b>Observer(s):</b> Madeline Laughton, Mariam Arowolo and Grace Mhora</p> <p><b>Previous Reviews:</b> The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 10<sup>th</sup> October 2024, 13<sup>th</sup> June 2024, 7<sup>th</sup> September 2023 and the 13<sup>th</sup> July 2023.</p> <p>The application and relevant supporting documents were previously presented / discussed at the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) meeting on the 22<sup>nd</sup> September 2022.</p> <p><b>Linked applications:</b> This application is linked to NIC-414067-K8R6J.</p> <p><b>Application:</b> This was an amendment application.</p> <p>NHS England were seeking advice on the following points only:</p> <ol style="list-style-type: none"> <li>1. The amendments to <b>a)</b> add Medicines dispensed in Primary Care (NHSBSA data) data; and <b>b)</b> to expand the territories of use to include Australia and Kenya.</li> <li>2. Request for a reuseable decision</li> </ol> <p>Should an application be approved by NHS England, further details would be made available within the <a href="#">Data Uses Register</a>.</p> <p><b>Outcome of discussion:</b> AGD were <b>not</b> providing comments on the wider application as requested by NHS England; comments were limited to the specific point of advice requested. AGD were supportive of the application if the following substantive comments</p>

were addressed with regard to Privacy, Transparency and Trust (PTT) advice, and wished to draw to the attention of the SIRO the following substantive comments:

AGD noted that they had been provided with a curated set of documentation and noted that they would be providing observations based on these documents.

**In response to point 1:**

**5.1.1** AGD were advised by NHS England colleagues in attendance that there was currently an outstanding request with NHS England's PTT, to review the request to expand the territories of use to include Australia and Kenya for this application. The Group noted that NHS England would need to be satisfied with the PTT outcome, before this amendment could progress.

**5.1.2** AGD noted and thanked the applicant for the 'risk summary' document provided as a supporting document (SD16.7) that supported the review of this amendment; however, suggested that the conclusion reached that the provision of access to researchers or other third parties located in Australia in the OFH Trusted Research Environment (TRE) is considered "low risk", may not be accurate, noting that Australia and Kenya are currently **not** on the Information Commissioner's Office (ICO) adequacy list (noting however this may change in the future).

**5.1.3** AGD noted that they were supportive of the addition of the Medicines dispensed in Primary Care (NHSBSA data) dataset to the application; however, queried the addition of the 'PRESCRIBER\_ID' data field within this dataset. The Group suggested that either **1)** a clear rationale was added to section 5 (Purpose / Methods / Outputs) for the addition of this data field and the legal basis for flowing this data field; or **2)** the data field was removed from the application.

**5.1.4** AGD suggested that the outputs in section 5(c) (Specific Outputs Expected) and the benefits in section 5(d) (Benefits) were updated to reflect the addition of the NHSBSA data, in line with the [NHS England DAS Standard for Expected Outcomes](#) and [NHS England DAS Standard for Expected Measurable Benefits](#).

**5.1.5** The Group noted the information in the 'risk summary' that stated risks relating to the expanded territories of use, could be mitigated by ensuring the terms and conditions of the research institution and the registered researcher are in place. The Group suggested that this should be expanded further to provide more granular details on the appropriate safeguards under the UK General Data Protection Regulation (UK GDPR).

**5.1.6** AGD noted that the applicant's privacy notice was clear that there would be international access to the data, but suggested that this could be updated to provide details on the specific countries involved.

**5.1.7** AGD suggested that in order to maintain ongoing support and transparency, the applicant could undertake some patient and public involvement and engagement (PPIE), including, but not limited, seeking views on the countries involved.

**5.1.8** Whilst not directly related to the amendments, AGD raised a further query on the territory of use, following a previous point raised by the Group on the 10<sup>th</sup> October 2024, in respect of a Data Processor with an address in the United States of America (USA). Whilst the Group noted the response that data will not be processed in the USA, it was suggested that section 5(a) (Objective for Processing) was updated with further information, including,

	<p>but not limited to, the role and function of the Data Processor, and whether they have a UK subsidiary that is responsible for the data processing.</p> <p><b>5.1.9</b> In addition, AGD noted the verbal update by NHS England in the meeting, that PTT have given permission for parties in the USA to access the data.</p> <p><b>In response to point 2:</b></p> <p><b>5.1.10</b> AGD noted that, whilst they were supportive in principle for the reusable decision, it may result in extra responsibility and significant work for NHS England’s Data Access Service (DAS) when assessing whether or not an amendment falls within the reusable decision criteria.</p> <p><b>5.1.11</b> AGD made the following suggestions in respect of the draft reusable decision ‘qualifying criteria’ (outlined in the internal DAS Escalation Form) <b>1)</b> to update point 3 on ethical approval to state <i>“the applicant confirms to NHS England that the addition of the dataset would be within its positive ethical opinion”</i> (or similar); <b>2)</b> to update point 2 to ensure that the dataset is compatible with the consent and is compatible with the Common Law Duty of Confidentiality by way of a revised and documented consent review <b>3)</b> to update point 4 on data controllership, to state that a special condition would be added to the application, obliging the Data Controller to update their privacy notice within 30 days of receiving the additional dataset; <b>and</b> for the applicant to commit to providing transparency to the cohort via their usual communication channel(s). One AGD independent member suggested that there was also a new mandatory qualifying criteria that <b>4)</b> the applicant undertake PPIE on the addition of the dataset and that the PPIE undertaken must demonstrate that there is support for the additional dataset.</p> <p><b>5.1.12</b> AGD suggested, in respect of the reusable decision ‘exclusion criteria’ (outlined in the internal DAS Escalation Form), to remove the point that states <i>“Use of the additional dataset is incompatible with the purpose”</i>, noting that this would be covered in the ‘qualifying criteria’ (point 1).</p> <p><b>5.1.13 Separate to this application and action for NHS England:</b> AGD requested that the AGD NHS England Data and Analytics Representative liaise with colleagues on the updates to the qualifying and exclusion criteria to support the reusable decision; and that a copy of the revised draft reusable decision be provided to AGD for a more detailed discussion at a future AGD meeting, and prior to finalisation and use of any reusable decision on the DAS knowledge base.</p> <p><b>5.1.14</b> AGD noted that there <b>was</b> a commercial aspect to the application.</p>	D&A Rep
5.2	<p><b>Reference Number:</b> NIC-771303-G4V1M-v0.13</p> <p><b>Applicant:</b> Pre-hospital Research and Audit Network (PRANA)</p> <p><b>Data Controller:</b> University Hospital Southampton NHS Foundation Trust</p> <p><b>Application Title:</b> “Pre-hospital Research and Audit Network (PRANA)”</p> <p><b>Observers:</b> Jodie Taylor-Brown, Emma Whale, Mariam Arowolo and Grace Mhora</p> <p><b>Previous Reviews:</b> The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 10<sup>th</sup> April 2025.</p> <p><b>Application:</b> This was a new application.</p>	

	<p>NHS England were seeking general advice on the application.</p> <p>Should an application be approved by NHS England, further details would be made available within the <a href="#">Data Uses Register</a>.</p> <p><b>Outcome of discussion:</b> AGD were supportive of the application and wished to draw to the attention of the SIRO the following comments:</p> <p>AGD noted that they had been provided with a curated set of documentation and noted that they would be providing observations based on these documents.</p> <p><b>5.2.1</b> AGD reiterated the point made on the 10<sup>th</sup> April 2025, in respect of the rationale for creating a national Registry outside of NHS England, and why this was a better approach than the previously expressed NHS England approach / policy of centralisation of Registries; and suggested, for transparency, this was clarified in section 5(a) (Objective for Processing).</p> <p><b>5.2.2</b> AGD noted the response to the previous point raised on the 10<sup>th</sup> April 2025, in respect of the role of the University of Southampton, and thanked the applicant for providing clarity on some of the queries raised; however, reiterated the query as to the Data Processor status of the University of Southampton; noting the information on the PRANA website that states the data will be under the governance of the University of Southampton. It was suggested that NHS England explore this further with the applicant and the application was updated as may be appropriate to reflect the correct / factual information.</p> <p><b>5.2.3</b> AGD advised that even though the applicant indicated that they would not accept commercial applications, it would be important for the Wessex Secure Data Environment (SDE) Data Access Committee to have a clear framework to assess if there is a commercial element to an application to access data, noting that <a href="#">NHS England DAS Standard for Commercial Purpose</a> has a broad interpretation of commercial use, which is independent of whether an organisation is in the commercial sector (for example it may be a University receiving some funding in kind from a commercial organisation).</p> <p><b>5.2.4</b> AGD noted that whilst they were supportive of Emergency Care Data Set (ECDS) flowing; queried the addition of the ‘General Medical Practitioner’ data field within this dataset. The Group suggested that either <b>1)</b> a clear rationale was added to section 5 (Purpose / Methods / Outputs) for the addition of this data field; or <b>2)</b> the data field was removed from the application.</p> <p><b>5.2.5</b> AGD suggested the applicant was reminded that they were required to maintain a UK General Data Protection Regulation (UK GDPR) compliant, <b>publicly accessible</b> transparency notice(s) for the lifetime of the agreement, in line with the contractual requirement in section 4 (Privacy Notice) of the data sharing agreement (DSA), in line with <a href="#">NHS England DAS Standard for Transparency</a>.</p> <p><b>5.2.6</b> No AGD member noted a commercial aspect to the application.</p>	
5.3	<p><b>Reference Number:</b> NIC-116883-L8W9Q-v4.2</p> <p><b>Applicant:</b> Moorfields Eye Hospital NHS Foundation Trust</p> <p><b>Data Controllers:</b> Moorfields Eye Hospital NHS Foundation Trust and University College London</p>	

**Application Title:** “Detecting Dementia in the Retina: a Big Data Machine Learning Approach”

**Observer(s):** Jorge Marin, Mariam Arowolo and Grace Mhora

**Previous Reviews:** The application and relevant supporting documents were previously presented / discussed at the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) meetings on the 1<sup>st</sup> August 2019 and the 24<sup>th</sup> January 2019.

**Application:** This was an amendment application.

NHS England were seeking general advice on the application.

Should an application be approved by NHS England, further details would be made available within the [Data Uses Register](#).

**Outcome of discussion:** AGD were supportive of the application if the following substantive comments were addressed, and wished to draw to the attention of the SIRO the following substantive comments:

AGD noted that they had been provided with a curated set of documentation and noted that they would be providing observations based on these documents.

**5.3.1** AGD noted that there were a number of amendments to this version of the application, including, but not limited to, a significant increase of the data; and the removal of filtering carried out by NHS England prior to the data being disseminated. The Group noted that the applicant was unaware that filtering was being carried out, and that they had noted concerns on the potential bias on the study outcomes as a result of this.

**5.3.2** AGD noted they were supportive of the additional data flowing if necessary to support the research aims; however, suggested that **1)** a clear justification was added to section 5(a) (Objective for Processing) for the additional data and the legal basis for flowing this data in line with [NHS England DAS Standard for Objective for Processing](#); **2)** that the flow of the additional data aligns with [NHS England DAS standard for data minimisation](#) to ensure data is not being over processed; **3)** to update section 5(b) (Processing Activities) to clarify the need for all of the data requested; and **4)** that the outputs in section 5(c) (Specific Outputs Expected) and the benefits in section 5(d) (Benefits) were updated to reflect the additional data, in line with [NHS England DAS Standard for Expected Outcomes](#) and [NHS England DAS Standard for Expected Measurable Benefits](#).

**5.3.3** AGD also queried whether the s251 and / or ethical support would align with the additional data flowing; and suggested that NHS England explore this further with the applicant.

**5.3.4** Noting the applicants concerns over potential bias on the study outcomes as a result of the filtering (see point 5.3.1), AGD suggested that NHS England explore the following points with the applicant, **1)** whether any of the previous research would need to be carried out again; **2)** whether any of the research outcomes would need to be reconsidered, and **3)** if the response to either of these points was “no”, then to determine why not.

**5.3.5** Notwithstanding previous points made by IGARD on the 1<sup>st</sup> August 2019 in respect of privacy notices; AGD advised that they were unable to locate published privacy notices, and suggested the applicant was reminded that they were required to maintain a UK General Data Protection Regulation (UK GDPR) compliant, **publicly accessible** transparency

	<p>notice(s) for the lifetime of the agreement, in line with the contractual requirement in section 4 (Privacy Notice) of the data sharing agreement (DSA).</p> <p><b>5.3.6</b> AGD noted the statements on Moorfields Eye Hospital NHS Foundation Trust ‘general’ research <a href="#">privacy notice</a>, that “<i>We might invite you to take part in research, but we will never use your personally identifiable data in research without your permission</i>” and “<i>Specific consent will be sought when researchers wish to use any information that would identify you, collect data with the intention to reuse this data in further research, or when data will be share outside Moorfields Eye Hospital</i>”. The Group suggested that this privacy notice was updated to <b>1)</b> provide clarification that there may be circumstances where s251 may be relied on for the flow of data; and <b>2)</b> provide details of this specific study.</p> <p>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p><b>5.3.7</b> AGD noted that prior to the meeting, a query had been raised by an AGD independent member, in respect of whether the applicant envisaged any future extension to the cohort beyond the 1<sup>st</sup> April 2024. The Group noted that the Chief Investigator had advised that they would not be requesting a further extension to the cohort beyond the 1<sup>st</sup> April 2024; and that s251 was in place to get a refresh of data from NHS England in 2026, however this will use the same cohort. The Group suggested that if it was determined that an extension to the cohort was required, then obtaining prospective consent may be the appropriate legal basis instead of s251.</p> <p><b>5.3.8</b> AGD queried if the research under this application was connected to other work ongoing by Moorfields Eye Hospital NHS Foundation Trust, and whether there were duplication of data flowing; and suggested that NHS England explore this further with the applicant, in line with <a href="#">NHS England DAS standard for data minimisation</a>.</p> <p><b>5.3.9</b> AGD queried the statement in section 5(b) “<i>Access is restricted to employees or agents of...</i>” and suggested that that either further information was provided as to who would be covered by “<i>agents</i>”; or that this word was removed as may be necessary to reflect the facts.</p> <p><b>5.3.10</b> AGD suggested that NHS England make the applicant aware of the Information Commissioner’s Office <a href="#">guidance</a> on Artificial Intelligence (AI) and data protection, in particular the recommendations within this guidance on having a Data Protection Impact Assessment (DPIA).</p> <p><b>5.3.11</b> No AGD member noted a commercial aspect to the application.</p>	
<p><b>5.4</b></p>	<p><b>Reference Number:</b> NIC-764229-C0C7B-v0.7</p> <p><b>Applicant and Data Controller:</b> University of Birmingham</p> <p><b>Application Title:</b> “Long-term clinical outcomes for the Rate Control Therapy Evaluation in Permanent Atrial Fibrillation (RATE-AF) trial”</p> <p><b>Observers:</b> Joe Lawson, Mariam Arowolo and Grace Mhora</p> <p><b>Previous Reviews:</b> The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 27<sup>th</sup> February 2025.</p> <p><b>Application:</b> This was a new application.</p>	

	<p>NHS England were seeking general advice on the application.</p> <p>Should an application be approved by NHS England, further details would be made available within the <a href="#">Data Uses Register</a>.</p> <p><b>Outcome of discussion:</b> AGD were supportive of the application and wished to draw to the attention of the SIRO the following comments:</p> <p><b>5.4.1</b> AGD suggested that section 5(b) (Processing Activities) was updated to <b>1)</b> clarify who is processing the data; <b>2)</b> who is retaining the data and for what purpose; and <b>3)</b> to make clear that the controls listed are going to apply to all parts of the processing.</p> <p><b>5.4.2</b> AGD noted that in respect of security assurances, the Data Processor was relying on ISO 27001, however, suggested that NHS England follow this up to ensure there are no outstanding issues prior to the data flowing, noting that the organisation were ‘approaching standards’ with the Data Security and Protection Toolkit (DSPT).</p> <p><b>5.4.3</b> AGD noted that section 2(c) (Territory of Use) had not been completed, and suggested that the this was populated with the territory of use in line with <a href="#">NHS England DAS Standard for Territory of Use</a>.</p> <p><b>5.4.4 Separate to this application and for NHS England to consider / action:</b> AGD had a wider discussion about the identifiability of the data, i.e. whether it was ‘pseudonymised’ or ‘identifiable’; and noted that the NHS England Data Protection Office Representative’s advice that an update on this would be provided at a future AGD meeting, in line with the Information Commissioner’s Office (ICO) guidance, to support future discussions.</p> <p><b>5.4.5</b> AGD queried the statement in section 5(b) “<i>Access is restricted to employees or agents of...</i>” and suggested that that either further information was provided as to who would be covered by “<i>agents</i>”; or that this word was removed as may be necessary to reflect the facts.</p> <p><b>5.4.6</b> AGD noted that the previous point raised at the AGD meeting on the 27<sup>th</sup> February 2025, in respect of there being further transparency to the cohort members, on the benefits of flowing the NHS number, had not been addressed in the documentation provided to the Group; and that a response had not been provided on how / if this had been considered. The Group suggested that patient and public involvement and engagement (PPIE) could be undertaken on this point to help progress this.</p> <p><b>5.4.7</b> AGD noted and commended the applicant on <b>1)</b> the establishment of the patient and public involvement and engagement (PPIE) Team; and <b>2)</b> the PPIE work undertaken by the PPIE Team as outlined in the letter from the PPIE Team to NHS England’s Data Access Service on the 21<sup>st</sup> January 2025.</p> <p><b>5.4.8</b> AGD noted and commended NHS England’s Data Access Service on the internal consent review provided as a supporting document (SD6), which supported the review of the application.</p> <p><b>5.4.9</b> No AGD member noted a commercial aspect to the application.</p>	DPO Rep
5.5	<p><b>Reference Number:</b> NIC-775504-H4Z5Q-v0.5</p> <p><b>Applicant and Data Controller:</b> University of Oxford</p> <p><b>Application Title:</b> “PARADISE Study: Longer-term outcomes”</p>	

	<p><b>Observer:</b> Humphrey Onu</p> <p><b>Application:</b> This was a new application.</p> <p>NHS England were seeking general advice on the application.</p> <p>Should an application be approved by NHS England, further details would be made available within the <a href="#">Data Uses Register</a>.</p> <p><b>Outcome of discussion:</b> AGD were supportive of the application and wished to draw to the attention of the SIRO the following comments:</p> <p><b>5.5.1</b> AGD noted the patient notification document (SD2) provided, had Health Research Authority Confidentiality Advisory Group (HRA CAG) and HRA Research Ethics Committee (REC) support, however, made the following suggestions for the benefit of those individuals covered by the s251 support, <b>1)</b> that the study specific / local opt out was noted <b>before</b> the National Data Opt-out (NDO); and <b>2)</b> noting that once the data had been pseudonymised, there would be no opportunity for individuals to withdraw from the study, it was suggested that the applicant gave further consideration to a robust and effective communication campaign, to ensure participants have the opportunity to learn about the research and opt out should they wish to.</p> <p><b>5.5.2 Separate to this application and for NHS England to consider / action:</b> AGD suggested that the comments made in point 5.5.1 were fed back to HRA CAG for information, via the usual NHS England Data Access Service (DAS) / HRA CAG communication channels.</p> <p><b>5.5.3</b> AGD noted that standard wording in section 5(b) (Processing Activities) in respect of data not being linked, however, suggested that this was updated to be clear that there would be no additional data linkage, other than what was already outlined in the application.</p> <p><b>5.5.4 Separate to this application and for NHS England to consider / action:</b> AGD noted that this application had a reference in section 5(b) to remote access taking place in “<i>secure locations</i>”. The NHS England SIRO Representative advised the Group that he would take an action to clearly articulate what was meant by “secure locations”, and that this would be used internally and to support applicants, so they are aware of what they were committing to in their data sharing agreement (DSA).</p> <p><b>5.5.5</b> No AGD member noted a commercial aspect to the application.</p>	<p>D&amp;A Rep</p> <p>SIRO Rep</p>
<p><b>5.6</b></p>	<p><b>Reference Number:</b> NIC-747507-C5G6T-v0.7</p> <p><b>Applicant:</b> University of Oxford</p> <p><b>Data Controllers:</b> National Perinatal Epidemiology Unit and University of Leicester</p> <p><b>Application Title:</b> “SurfON: Multicentre, open-label, randomised controlled trial of early surfactant therapy versus expectant management in late preterm and early term infants with respiratory distress”</p> <p><b>Observer:</b> Azeez Oladipupo</p> <p><b>Application:</b> This was a new application.</p> <p>NHS England were seeking general advice on the application.</p>	

	<p>Should an application be approved by NHS England, further details would be made available within the <a href="#">Data Uses Register</a>.</p> <p><b>Outcome of discussion:</b> AGD were supportive of the application and wished to draw to the attention of the SIRO the following comments:</p> <p><b>5.6.1</b> AGD noted that they were supportive of the flow of data for one year, as outlined in the application, however, suggested that this could be increased to one year <b>plus</b> the additional weeks of prematurity, for example, for a baby born at 34 weeks, this would be one year and six weeks. It was discussed and agreed that there would be a legal gateway for this, noting the way in which age is adjusted for premature babies, and that it should not be a surprise to the parents if more than one year’s supply of data (from date of birth) would be flowing. The Group suggested the application was updated as may be necessary to reflect the agreed position on this.</p> <p><b>5.6.2</b> Noting that this was a time limited study, AGD noted the reference in the benefits in section 5(d) (Benefits), to improving long-term health; and suggested that if the researchers were considering continued long-term follow-up, then they should consider engaging with the cohort now.</p> <p><b>5.6.3</b> AGD suggested that the application was updated to reflect the information in the NHS England Data Access Service (DAS) internal application assessment form, in respect of data controllership, i.e. to note that the University of Oxford is the Data Controller and not the National Perinatal Epidemiology Unit.</p> <p><b>5.6.4</b> AGD noted and agreed with NHS England’s DAS, as outlined in the consent review, that there was a legal gateway in consent for those participants consented on versions three and four of the consent forms. The Group understood that none of the cohort were consented on earlier versions of the consent forms.</p> <p><b>5.6.5</b> AGD suggested that the applicant updated their published transparency materials, to ensure that it was clear / factually correct, on the options for withdrawing from the research, which should contain at least <b>two</b> methods of contact for participants (post, telephone and / or e-mail).</p> <p><b>5.6.6</b> AGD suggested that the reference in section 5(b) (Processing Activities) to the participant ID being “<i>anonymised</i>” should be updated to correctly refer to this as being “<i>pseudonymised</i>”.</p> <p><b>5.6.7</b> AGD noted the statement in section 5(b) “<i>Access is restricted to employees or <b>agents</b> of...</i>” and suggested that this was removed, noting the statement in section 5(a) (Objective for Processing) that “<i>Only University of Oxford <b>substantive employees</b>... will be allowed access to data</i>”.</p> <p><b>5.6.8</b> AGD noted and commended NHS England’s Data Access Service on the internal consent review provided as a supporting document (SD10), which supported the review of the application.</p> <p><b>5.6.9</b> No AGD member noted a commercial aspect to the application.</p>	
5.7	<p><b>Reference Number:</b> NIC-772615-N4N1V-v0.10</p> <p><b>Applicant and Data Controller:</b> Liverpool University Hospitals NHS Foundation Trust</p>	

	<p><b>Application Title:</b> “Evaluating risk stratification tools that assess the risk of bleeding whilst using antiplatelet therapy following myocardial infarction”</p> <p><b>Observer:</b> Azeez Oladipupo</p> <p><b>Application:</b> This was a new application.</p> <p>NHS England were seeking general advice on the application.</p> <p>Should an application be approved by NHS England, further details would be made available within the <a href="#">Data Uses Register</a>.</p> <p><b>Outcome of discussion:</b> AGD were supportive of the application and wished to draw to the attention of the SIRO the following comments:</p> <p><b>5.7.1</b> AGD suggested that <b>1)</b> section 3(b) (Additional Data Access Requested) was updated to accurately reflect that the data is “<i>identifiable</i>” and not pseudonymised; and <b>2)</b> section 5 (Purpose / Methods / Outputs) was updated to clarify that the data is treat as identifiable as the applicant has the mean to re-identify.</p> <p><b>5.7.2</b> AGD noted that there is s251 support in place, and that the Health Research Authority Confidentiality Advisory Group (HRA CAG) annual review is due in May 2025; and suggested that NHS England note this to the applicant.</p> <p><b>5.7.3</b> AGD advised that they were unable to locate a published privacy notice, and suggested the applicant was reminded that they were required to maintain a UK General Data Protection Regulation (UK GDPR) compliant, <b>publicly accessible</b> transparency notice for the lifetime of the agreement, in line with the contractual requirement in section 4 (Privacy Notice) of the data sharing agreement (DSA).</p> <p><b>5.7.4</b> AGD noted that, from information in the public domain, it would appear Menarini Group are active in this healthcare sector.</p> <p><b>5.7.5</b> AGD noted that whilst the research grant from Menarini Group is modest, it is within the remit of the <a href="#">NHS England DAS Standard for Commercial Purpose</a>; and therefore suggested that section 5(e) (Is the Purpose of this Application in Anyway Commercial) was updated to reflect that there is a commercial purpose to the application.</p> <p><b>5.7.6</b> AGD noted that there <b>was</b> a commercial aspect to the application.</p>	
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**6 INTERNAL DATA DISSEMINATION REQUESTS:**

*There were no items discussed*

**7 EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL**

*There were no items discussed*

**8 OVERSIGHT AND ASSURANCE**

8.1	<p><b>Outputs from meeting held on 24<sup>th</sup> April 2025 / next steps</b></p> <p>AGD noted that a meeting had been held on the 24<sup>th</sup> April 2025, with the AGD Chair, AGD Deputy Chair, AGD Secretariat and colleagues from NHS England’s SIRO Team; to discuss the current oversight and assurance workstreams and processes.</p>	
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	<p>The four oversight and assurance workstreams / current frequency of reviews are as follows:</p> <ul style="list-style-type: none"> <li>• <b>Workstream 1</b> - Precedent approved internal and external applications – weekly.</li> <li>• <b>Workstream 2</b> - Internal and external applications that have had an independent review in the last six months and been approved internally – monthly.</li> <li>• <b>Workstream 3</b> - Annual Compliance Report (ACR) oversight and assurance – quarterly.</li> <li>• <b>Workstream 4</b> - SIRO Approval of internal and external applications – added to next available agenda.</li> </ul> <p>AGD noted that there were a number of actions from the meeting / discussion that are in the process of being progressed, including, but not limited, setting up relevant meetings to discuss the individual workstreams, with the relevant stakeholders; agreeing the frequency of the different workstream reviews moving forward; and how outcomes/ feedback from the review are recorded, shared and addressed.</p> <p>The Group discussed and agreed that oversight and assurance for Workstream 2, which is deemed to be the current highest priority, would re-start over the coming weeks.</p> <p>The Group were advised that a further updated on all workstreams would be provided in due course at a future AGD meeting.</p> <p><b>ACTION:</b> AGD Secretariat to set up a meeting with Michael Chapman / Tom Wright to discuss workstream 1 and next steps.</p> <p><b>ACTION:</b> AGD Secretariat to add ‘AGD oversight and assurance – workstream 2’ to the AGD internal forward planner.</p> <p><b>ACTION:</b> AGD Secretariat to set up a meeting with Tom Wright to discuss workstream 3 and next steps.</p> <p><b>ACTION:</b> AGD Secretariat to add ‘AGD oversight and assurance – overview / update’ to the AGD internal forward planner.</p>	<p>AGD Sec</p> <p>AGD Sec</p> <p>AGD Sec</p> <p>AGD Sec</p>
<b>9 AGD OPERATIONS</b>		
<p>9.1</p>	<p><b>AGD Annual Report 2023/24</b></p> <p>AGD noted that at the AGD meeting on the 10<sup>th</sup> April 2025, the Director of Privacy and Information Governance, PTT had advised (via the AGD Chair) that the AGD Annual Report 2023/24 had been submitted to the relevant colleagues / groups within NHS England for review / approval; and that this would be submitted for final sign-off around the end of April 2025.</p> <p>The NHS England SIRO Representative advised that there was no further update on this, and a further update would be provided in due course.</p> <p><b>ACTION:</b> The NHS England SIRO Representative to provide an update on the AGD Annual Report 2023/24 at a future AGD meeting.</p>	<p>SIRO Rep</p>
<p>9.2</p>	<p><b>AGD Annual Report 2024/25</b></p>	

	<p>The Group discussed the 2024/25 AGD Annual Report draft template, in line with paragraph 8.1 of the AGD Terms of Reference that state that <i>“The Group will produce an annual report on its work...for the SIRO following the end of the financial year...”</i>.</p> <p>The Group noted that following discussions at the AGD meetings on the 10<sup>th</sup> April 20205, 13<sup>th</sup> March 2025 and the 27<sup>th</sup> February 2025, the updated AGD Annual Report 2024/25 template had been uploaded to AGD’s internal collaboration area for AGD members / delegates to review and make further comments / suggested updates.</p> <p>The Group discussed the comments / suggested updates made to the draft template and made further amendments as necessary to reflect the discussion in-meeting. AGD noted that the AGD Annual Report 2024/25 template would be updated by the AGD Secretariat following the meeting, and the next version of the report uploaded to AGD’s internal collaboration area for AGD members / delegates and the AGD Secretariat to continue populating over the coming weeks.</p> <p><b>ACTION:</b> AGD Secretariat to update the AGD Annual Report 2024/25 template, and upload to AGD’s internal collaboration area.</p> <p><b>ACTION:</b> AGD to continue populating the AGD Annual Report 2024/25 template once uploaded to AGD’s internal collaboration area.</p> <p>The Group also discussed the management information (MI) that would be included in the AGD Annual Report 2024/25, and noted several actions for the AGD NHS England’s Data and Analytics Representative, and the AGD Secretariat in respect of the collation / production of the MI.</p> <p><b>ACTION:</b> The AGD NHS England’s Data and Analytics Representative / NHS England SIRO Team to discuss / collate the MI for the AGD Annual Report 2024/25 with colleagues and ensure this is populated in the AGD Annual Report 2024/25 template.</p> <p><b>ACTION:</b> The AGD Secretariat to collate the MI for the AGD Annual Report 2024/25 with colleagues and ensure this is populated in the AGD Annual Report 2024/25 template.</p> <p>The Group noted that a number of meetings would be set-up by the AGD Secretariat over the coming weeks, separate to the AGD meetings, to discuss / finalise the first draft of the AGD Annual Report 2024/25.</p> <p><b>ACTION:</b> The AGD Secretariat to set-up the relevant meetings to discuss / finalise the first draft of the AGD Annual Report 2024/25.</p>	<p>AGD Sec</p> <p>AGD</p> <p>D&amp;A Rep / SIRO Team</p> <p>AGD Sec</p> <p>AGD Sec</p>
<p><b>9.3</b></p>	<p><b>Risk Management Framework</b></p> <p>AGD has been previously informed that a risk management framework is being developed by Data Access and had commented on early thinking about such a Framework. Nonetheless, presently AGD were still operating using the precedent and standard framework as an interim arrangement since February 2023 and AGD were concerned that the permanent Risk Management Framework was not in place. The Group discussed the NHS England corporate risk management framework (see minutes of 14<sup>th</sup> November 2024) and the AGD Chair subsequently formally asked via email if the NHS England corporate risk management framework could be used. The NHS England SIRO Representative updated</p>	

	<p>the Group that NHS England was still considering the request, including how the NHS England corporate risk management framework could be adapted for AGD.</p> <p><b>ACTION:</b> The NHS England SIRO Representative to provide a written response to AGD on the progress, and expected time frame for implementation, of the risk management framework.</p>	SIRO Rep
<b>9.4</b>	<p><b>Standard Operating Procedures (SOPs)</b></p> <p>The ongoing forward plan of work for creating the AGD Standard Operating Procedures was discussed.</p> <p>The Group noted that the ‘AGD member Declaration of Interest’ SOP was in the process of being finalised, and a further update on this would be provided in due course, and published on the AGD webpage.</p> <p>AGD queried if the review of the AGD Terms of Reference, forwarded to the Director of Privacy and Information Governance on the 14<sup>th</sup> March 2025 had been considered and asked that an update be provided as to next steps.</p> <p><b>ACTION:</b> NHS England SIRO Representative to update the Group at a future AGD Meeting.</p>	SIRO Rep
<b>9.5</b>	<p><b>AGD Stakeholder Engagement</b></p> <p><i>There were no items discussed</i></p>	
<b>9.6</b>	<p><b>AGD Project Work</b></p> <p><i>There were no items discussed</i></p>	
<b>10 Any Other Business</b>		
<b>10.1</b>	<p><b>AGD Service Improvements</b></p> <p>An update was provided to the group, in respect of the service improvement programme of work, where a number of ‘observations’ and ‘actions’ were highlighted following initial feedback from the AGD members and NHS England colleagues.</p> <p>AGD thanked Karen for the work she was doing on this programme of work and looked forward to future service improvement discussions.</p>	
<p><b>Meeting Closure</b></p> <p>As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.</p>		