

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

Thursday, 10<sup>th</sup> July 2025

09:00 – 16:00

*(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) (Chair)
Laura Bellingham (LB)	NHS England member (Data and Analytics Representative (Delegate for Michael Chapman))
Claire Delaney-Pope (CDP)	AGD independent member (Specialist Information Governance Adviser)
Dr. Arjun Dhillon (AD)	NHS England member (Caldicott Guardian Team Representative (Items 1 to part of 5.3))
Dr. Jonathan Osborn (JO)	NHS England member (Caldicott Guardian Team Representative) (Items 5.4 to 11.2)
Ellie Ward (EW)	NHS England member (Data Protection Office Representative (Delegate for Jon Moore))
Miranda Winram (MW)	AGD independent member (Lay Adviser)
<b>NHS ENGLAND STAFF IN ATTENDANCE:</b>	
<b>Name:</b>	<b>Role / Area:</b>
Damian Bowler (DB)	NHS England ( <b>Presenter:</b> item 9)
Garry Coleman (GC)	NHS England SIRO Representative
Dave Cronin (DC)	Applications Service Owner, Data Access and Partnerships, Transformation Directorate ( <b>Observer:</b> item 5.1)
Dan Goodwin (DG)	Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 5.2)
James Gray (JG)	NHS DigiTrials, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 4.1)
Lyndon Dibb (LD)	Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 5.5)

Sara Lubbock (SL)	Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 5.5)
Tiaro Micah (TM)	Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 5.6)
Humphrey Onu (HO)	Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 5.4)
Louise Smith (LS)	PTT Business Support Officer, Privacy, Transparency and Trust (PTT) Business Operations, Deputy Chief Executive Directorate ( <b>Observer:</b> items 1 to 11.2)
James Watts (JW)	Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 5.6)
Emma Whale (EW)	Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 5.3)
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Deputy Chief Executive 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)
Kirsty Irvine (KI)	AGD independent member (Chair)
Jon Moore (JM)	NHS England member (Data Protection Office Representative)
Jenny Westaway (JW)	AGD independent member (Lay Adviser)

<b>1</b>	<p><b>Welcome and Introductions:</b></p> <p>The AGD meeting Chair welcomed attendees to the meeting.</p> <p>AGD noted that, due to unforeseen circumstances, only two AGD NHS England members were in attendance for part of item 5.3.</p> <p>Noting that the <a href="#">AGD Terms of Reference</a> state that “<i>The quorum for meetings of the Group or a Sub-Group is five members, including at least three independent members, one of whom may be the Chair, Deputy Chair or Acting Chair and <b>two of the three NHSE Members</b>...</i>”, the Group agreed that, as</p>
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	there were two AGD NHS England members present, the meeting was still quorate for <b>all</b> agenda items and agreed to proceed on that basis.
<b>2</b>	<p><b>Review of previous AGD minutes:</b></p> <p>The minutes of the AGD meeting on the 3<sup>rd</sup> July 2025 were reviewed and, after several minor amendments, were agreed as an accurate record of the meeting.</p> <p>The AGD meeting chair raised a process issue with regard to the minutes (see AOB item 11.2)</p>
<b>3</b>	<p><b>Declaration of interests:</b></p> <p>There were no declarations of interest.</p>
<b>4 BRIEFING PAPER(S) / DIRECTIONS:</b>	
<b>4.1</b>	<p><b>Title:</b> GP Data for Consented Research</p> <p><b>Observer(s):</b> James Gray</p> <p>In anticipation that the Directions for GP Data for Consented Research may be approved over the coming months, work is underway with three consented studies that may request GP data collected under the Directions, to draft amendments to their existing Data Sharing Agreements (DSAs) with NHS England.</p> <p>NHS England were seeking advice on the following points:</p> <p>In relation to the drafted content for Data Sharing Agreement:</p> <ol style="list-style-type: none"> <li>1. Does AGD support the provision of access to the requested GP Data to OFH, Biobank and GEL for the stated purposes, as per the document <i>Proposed wording for DSAs to include GP Data for Consented Research July 2025</i>?</li> <li>2. Would AGD recommend any actions or points of clarification which must be resolved before the provision of access to the GP Data?</li> <li>3. Noting that the application will meet NHS England DARS standards and will use the relevant template for Section 5, do AGD think there is any reason not to proceed to a DSA, without returning to AGD?</li> </ol> <p>In relation to the drafted special conditions:</p> <ol style="list-style-type: none"> <li>4. Can AGD provide any high-level concerns relating to the current drafting (<i>Draft Special Conditions - GP Consented Research Data V 0.2 07.05.25 CLEAN</i>), noting that this is a draft that will be subject to review by Director of Privacy and Information Governance before finalising?</li> </ol> <p>In relation to the drafted transparency notice:</p> <ol style="list-style-type: none"> <li>5. Provide any high-level concerns relating to the current drafting (<i>General Practice Data for Consented Research - Transparency notice v0.3_Final</i>).</li> <li>6. Suggest where the content could be shortened / amended / removed to make the overall document less detailed and a more easily digestible for the public.</li> </ol> <p>In relation to the Directions Letter and Requirements Specification:</p>

<p>7. Note the draft Directions and Requirements Specification to enable this recollection on provision of data to meet the consent given by research participants.</p> <p><b>Outcome of discussion:</b> AGD welcomed the briefing and relevant supporting documents, and made the following observations / 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>In response to questions 1 to 3:</b></p> <p><b>4.1.1</b> The Group acknowledged the hard work of the three pilot studies in providing the detailed information, noting that these narratives could inform revisions to section 5 of the relevant data sharing agreements (DSAs).</p> <p><b>4.1.2</b> AGD considered whether the DSAs should have any additional safeguards that were not present in a regular DSA and were of the opinion that the current DSAs were sufficiently robust and did not require any additional safeguards.</p> <p><b>4.1.3</b> AGD did suggest, however, that there was communication to the public by NHS England, separate to the DSAs, to explain this initiative using GP data.</p> <p><b>In response to question 4:</b></p> <p><b>4.1.4</b> AGD acknowledged the comprehensive list of proposed draft special conditions for the three DSAs but queried whether they were all required given the need to ensure consistency with other similar cohort applications that don't have GP data, and the robustness of the existing contractual model. If NHS England judged it necessary to include such special conditions, then NHS England would need to consider whether they should be applied to other DSAs.</p> <p><b>4.1.5</b> Whilst AGD welcomed the draft special condition with regard to patient and public involvement and engagement (PPIE), the Group noted that NHS England did not have an applicable Standard, and suggested that NHS England consider a 'PPIE Standard', as suggested by the Group previously, to underpin this special condition and introduce more broadly.</p> <p><b>4.1.6</b> AGD noted the draft special condition with regard to complying with Sections 30-33 of the Mental Capacity Act (2005), and suggested this special condition be removed, since the applicants should already be complying with the law.</p> <p><b>4.1.7</b> Noting the Group had not seen the three DSAs, AGD suggested, if not already noted in the DSA, that consideration be given to a special condition with regard to retention of data, particularly with regard to the use of parental consent and what happens when the participant becomes an adult.</p> <p><b>4.1.8 ACTION separate to the briefing:</b> The Group suggested that NHS England explore reviewing the Data Sharing Framework Contract (DSFC) and DSA templates to remove any duplication of text, and consider moving special conditions from the DSA to the DSFC. AGD would welcome being part of such a discussion.</p> <p><b>In response to questions 5 to 6:</b></p> <p><b>4.1.9</b> AGD noted that they had not proof read the document but suggested <b>1)</b> using different language to "you" to ensure that all data subjects are covered; <b>2)</b> a layered approach to transparency, noting the large volume of information; <b>3)</b> clarify what processing was being</p>	<p>D&amp;A Rep</p>
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	<p>carried out under each Article 9 condition; and <b>4)</b> be clear on geographical location and where data could be accessed from.</p> <p><b>4.1.10</b> AGD recognised the policy gap with regard to ‘consultees’, and noted AGD’s previous position that consultees cannot override a participant’s previously expressed NDO, also noting that consultee advice only applies to research into the ‘impairing condition’ or its treatment. AGD suggested that NHS England may wish to explore this latter point further with the Health Research Authority (HRA) and seek their view, noting any restrictions on research scope should come from the relevant Research Ethics Committee (REC). AGD would welcome being involved in any discussion on this matter.</p> <p><b>In response to question 7:</b></p> <p><b>4.1.11</b> The Group noted the draft Directions and Requirements Specification provided as background documentation.</p>	
<b>5 EXTERNAL DATA DISSEMINATION REQUESTS:</b>		
<b>5.1</b>	<p><b>Reference Number:</b> NIC-748215-Z7K2V-v0.7</p> <p><b>Applicant and Data Controller:</b> Leeds Teaching Hospitals Trust</p> <p><b>Application Title:</b> “The Association Between Right Bundle Branch Block and Long-term Mortality Post-TAVI – Data from the UK TAVI Registry”</p> <p><b>Observer(s):</b> Dave Cronin</p> <p><b>Previous Reviews:</b> The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 5<sup>th</sup> June 2025 (application and briefing paper).</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>5.1.1</b> AGD noted that NHS England Data Access Service (DAS) had spoken to the applicant with regard to their Article 9 legal basis, as raised at AGD on the 5<sup>th</sup> June 2025, and suggested that further improvements could be made to the NICOR <a href="#">privacy notice</a> by outlining the legal basis for all activities undertaken in relation to service evaluation.</p> <p><b>5.1.2</b> AGD reiterated the point made on the 5<sup>th</sup> June 2025 (5.1.7) that this application had been reviewed / supported by the NICOR Research Access Committee (RAC); and suggested that this was clarified in section 5(a) for transparency of the data sharing agreement (DSA).</p> <p><b>5.1.3</b> AGD reiterated the point made on the 5<sup>th</sup> June 2025 (5.1.9) that the two statements at the beginning / end of section 5(b) in the DSA, in respect of linkage be sat next to each</p>	

	<p>other, confirming that the data will be pseudonymised and individuals cannot be reidentified, and the data will not be linked with any other data.</p> <p><b>5.1.4</b> AGD acknowledged National Data Opt Outs (NDO) were not applied when the data was collected, in line with the Section 251 support which provided an exemption for the NDO. NDO policy would be followed for any dissemination by NHS England.</p> <p><b>5.1.5</b> The Group acknowledged the hard work of both the applicant and NHS England DAS in providing responses to the advice provided by AGD on the 5<sup>th</sup> June 2025, and appreciated the way the information had been presented via a tracked change DSA.</p> <p><b>5.1.6 Separate to the application:</b> AGD noted previous requests by the Group, and the Independent Group Advising (NHS Digital) on the Release of Data (IGARD), that the provision of a tracked change DSA made the review a lot more efficient in terms of time spent reviewing what had / had not changed between DSA iterations. AGD would welcome this approach to providing a tracked change DSA to future meetings.</p> <p><b>5.1.7</b> No AGD member noted a commercial aspect to the application.</p>	
<b>5.2</b>	<p><b>Reference Number:</b> NIC-770456-K8K6H-v0.2</p> <p><b>Applicant and Data Controller:</b> Srotas Health</p> <p><b>Application Title:</b> "InsightMatch"</p> <p><b>Observer(s):</b> Dan Goodwin</p> <p><b>Previous Reviews:</b> The application and relevant supporting documents were previously presented / discussed at the AGD on the 5<sup>th</sup> June 2025 (application and briefing paper).</p> <p><b>Application:</b> This was a seeking early advice application.</p> <p>NHS England were seeking advice on the following points, including general advice on any other aspect of the application:</p> <ol style="list-style-type: none"> <li>1. Whether NHS England should be supportive,</li> <li>2. SDE or extract,</li> <li>3. Artificial Intelligence (AI) drive tool queries.</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 noted that they were specifically asked to provide advice in relation to three advice points above, and that the remainder of the application was subject to additional work. However, to assist in the development of the application, AGD provided the following advice to the SIRO (noting that the points may not be relevant once the additional detail on the application is clear):</p> <p><b>In response to point 1:</b></p> <p><b>5.2.1</b> AGD were supportive of the concept of exploring the use of large language models (LLMs) as outlined in the application, however there were many factors for NHS England to consider before that may happen, including but not limited to <b>1)</b> evidence that this proposal could add value and benefit to the health system; <b>2)</b> that any commercial benefits are proportionate; <b>3)</b> and due diligence has taken place to ensure such work can be delivered.</p>	

	<p><b>5.2.2</b> The Group also recognised the need for policy in the area of LLMs and other similar approaches and would support the evaluation of the use of LLMs, recognising the benefit in assessing and evaluating such tools.</p> <p><b>In response to point 2:</b></p> <p><b>5.2.3</b> AGD reiterated their view, which supported the NHS England view, that the use of the secure data environment (SDE) should be by default, rather than providing an extract. If the SDE cannot be used, then a clear and robust justification should be provided in section 5 of the application.</p> <p><b>5.2.4</b> AGD queried whether the applicant could undertake work with synthetic data, or a smaller volume of data / sub-set of data as part of a proof-of-concept phase, noting that this is an approach previously recommended by NHS England; and suggested that this is explored further with the applicant.</p> <p><b>In response to point 3:</b></p> <p><b>5.2.5</b> The Group recognised the potential of AI software as a tool, but also cautioned that there are public concerns regarding its use and there is a need to proceed with care.</p> <p><b>5.2.6</b> AGD queried if the clinical safety implications of the device had been considered and what human governance was in place, and suggested that NHS England explore this further with the applicant.</p> <p><b>5.2.7</b> It was also unclear whether this was a medical device (as defined by legislation), as there was not enough information to ascertain. The Group noted that if it was a medical device, that it should comply with, for example, the relevant law(s) and legislation(s).</p> <p><b>5.2.8</b> In addition, the Group suggested that a clear potential clinical benefit be outlined within the documentation, since as currently presented it was unclear what the proposal would add to the existing ways of identifying potential trial participants.</p> <p><b>5.2.9</b> AGD suggested that the applicant may wish to undertake involvement and engagement with patients and companies / NHS body stakeholders in order to garner evidence of demand for, and value in developing, such an AI tool.</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>5.2.10 ACTION for the NHS England SIRO Representative:</b> AGD recognised the challenge for the NHS England Data Access Service (DAS) and the limited resources in the team fielding requests such as this, alongside upholding the NHS England Standards and being fair to all applicants. The Group suggested the NHS England formalise its current approach to requests for such innovation and develop some model questions for applicants at the pre-application stage with regard to developing such tools.</p> <p><b>5.2.11</b> Noting AGD was only asked to advise on specific points reviewed, members noted that there <b>was</b> a commercial aspect to the application.</p>	SIRO Rep
<b>5.3</b>	<p><b>Reference Number:</b> NIC-786702-B8R5P-v0.2</p> <p><b>Applicant and Data Controller:</b> Sanius Health</p>	

<p><b>Application Title:</b> “Sickle Cell Disease (SCD) Unmet Patient Needs, Standards of Care &amp; National Clinically-Established Treatment Costing Project”</p> <p><b>Observer(s):</b> Emma Whale</p> <p><b>Previous Reviews:</b> The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 26<sup>th</sup> June 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 <b>if</b> the following substantive comments were addressed, and wished to draw to the attention of the SIRO the following substantive comments.</p> <p><b>5.3.1</b> AGD noted that the application had returned to AGD prior to the draft minutes being ratified, and whilst the Group were concerned that the draft minutes may have been shared with the applicant (see AOB 11.2), the Group agreed to review the application. The Group acknowledged the hard work of both the applicant and NHS England DAS in providing responses to the draft minutes.</p> <p><b>5.3.2</b> AGD noted the response from NHS England / the applicant with regard to the point made on the 26<sup>th</sup> June 2026 (5.2.3) with regard to establishing a costing index to support the NHS and wider system, however AGD noted that the robust justification for the volume of data / datasets had not been clearly set out in section 5 of the application. The Group suggested that more reassurance and thought was given to the proportionality of data versus what they were doing with the data, including any data minimisation, in line with the NHS England DARS Standard for Data Minimisation, and less emphasis on the costing index.</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>5.3.3 Separate to the application for AGD Secretariat to add to the AGD Forward Plan:</b> AGD noted they were to receive an update from NHS England with regard to the secure data environment (SDE), including the data minimisation options and the role of applicants in minimising data.</p> <p><b>5.3.4</b> AGD noted the applicant’s close links with patients and suggested that the applicant may wish to seek patient and public involvement and engagement (PPIE) with regard to the volume of data / the datasets requested / the data minimisation, to help formulate a robust justification for section 5 of the application. The Group noted that NHS England did not have a PPIE Standard, and suggested that NHS England consider a ‘PPIE Standard’ as suggested by the Group previously.</p> <p><b>5.3.5</b> AGD reiterated the point made on the 26<sup>th</sup> June (5.2.8) and <b>separate to this application and for NHS England to consider:</b> AGD queried what the due diligence process was for new applicants of data; and were advised by the NHS England SIRO Representative that further information would be shared with the Group on the regional SDE process at a future AGD meeting.</p>	<p>AGD Sec</p> <p>SIRO Rep</p>
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	<p><b>5.3.6</b> AGD noted that section 1(b) referred to “<i>NHS England (Quarry House)</i>”, and suggested that this was updated to reflect the most recent / up to date information.</p> <p><b>5.3.7</b> AGD noted that there <b>was</b> a commercial aspect to the application.</p>	
<b>5.4</b>	<p><b>Reference Number:</b> NIC-765457-R1Z0N-v0.4</p> <p><b>Applicant and Data Controller:</b> University of Bristol</p> <p><b>Application Title:</b> “Effectiveness of intensive care for patients undergoing vascular surgery in the United Kingdom”</p> <p><b>Observer(s):</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 <b>if</b> the data being flowed was pseudonymous, and wished to draw to the attention of the SIRO the following substantive comments.</p> <p><b>5.4.1</b> AGD noted within the SDA that the applicant had committed to destroying the Date of Death (DOD) data when the survival data was generated, however, noting this was not described in the application, suggested that NHS England may wish to discuss this further with the applicant.</p> <p><b>5.4.2</b> AGD reiterated a point from the 23<sup>rd</sup> January 2025, 12th December 2024 and the 10th October 2024, that NHS Digital had reached a position with the National Data Guardian in that NHS Digital / England should be carrying out an assessment about the risk of identification, and noted that NHS England Data Access Service (DAS) had undertaken such a review and concluded that the data was identifiable. Noting that this was now <b>not</b> in line with the Patient Information Leaflet or the Health Research Authority Confidential Advisory Group (HRA CAG) s251 support. The Group suggested that NHS England reexamine if the data was identifiable, since there was no legal basis to flow identifiable data.</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>5.4.3</b> AGD suggested the applicant was reminded that they were required to maintain a UK General Data Protection Regulation (UK GDPR) compliant, publicly accessible <b>project specific</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>5.4.4</b> AGD noted in section 5 of the application that two conditions were noted under Article 9, and asked for clarification with regard to what processing was being carried out under each Article 9 limb.</p> <p><b>5.5.5</b> No AGD member noted a commercial aspect to the application.</p>	
<b>5.5</b>	<p><b>Reference Number:</b> NIC-746266-S8M6T-v0.4</p>	

<p><b>Applicant and Data Controller:</b> University College London (UCL)</p> <p><b>Application Title:</b> “Investigating the association between prenatal exposure to air pollution and maternal and child health outcomes”</p> <p><b>Observer(s):</b> Lyndon Dibb, Sara Lubbock</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 <b>if</b> the following substantive comment was addressed, and wished to draw to the attention of the SIRO the following substantive comments.</p> <p><b>5.5.1</b> AGD noted the COVID-19 dataset requested and suggested that section 5(a) of the application was updated to clarify and reflect that all processing of the COVID-19 dataset, must be done within the scope of the <a href="#">COVID-19 Public Health Directions 2020</a>. Depending on the discussion with the applicant, NHS England may wish to add a special condition in section 6, that all processing of this dataset is restricted to COVID-19 purposes. The AGD NHS England Caldicott Guardian Representative offered to help with the judgment as to COVID-19 purposes for this particular application.</p> <p><b>5.2.2. Separate to the application:</b> the NHS England SIRO Representative asked if AGD would be supportive of NHS England making the decision as to whether something is a COVID-19 purpose or not. AGD suggested that advice be sought from the Group on a case by case basis for future applications, recognising the value in AGD’s role.</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>5.5.3</b> AGD suggested the applicant was reminded that they were required to maintain a UK General Data Protection Regulation (UK GDPR) compliant, <b>easily found and publicly accessible</b> study specific 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>5.5.4</b> AGD noted that funding was in place until August 2025, however the application end date was July 2028; and suggested that <b>1)</b> NHS England clarify with the applicant that there is funding in place for the duration of the data sharing agreement (DSA), for example to ensure there is sufficient funds to sustain the project through to possible archiving and destruction; and <b>2)</b> the NHS England Data Access Service (DAS) internal application assessment form was updated to reflect any discussions on this point with the applicant.</p> <p><b>5.5.5</b> AGD noted that NHS England DAS has spoken to the applicant regarding what would happen when participants became adults, and that the applicant had responded it was a long way in the future. AGD recommended NHS England DAS advised the applicant to plan ahead since some of participants were 8 or 9 years old and a plan for when they turn 16 would be needed well in advance.</p> <p><b>5.5.6</b> AGD noted and commended the work undertaken by NHS England’s DAS on the questions asked of the applicant, which enabled AGD to reach its consensus view.</p>	
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	<p><b>5.5.7</b> No AGD member noted a commercial aspect to the application.</p>	
5.6	<p><b>Reference Number:</b> NIC-392669-T1F8B-v6.5</p> <p><b>Applicant and Data Controller:</b> University of Oxford</p> <p><b>Application Title:</b> “The Oxford Heart Vessels and Fat (ox-HVF) Cohort”</p> <p><b>Observer(s):</b> Tiaro Micah, James Watts</p> <p><b>Previous Reviews:</b> The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 8<sup>th</sup> August 2024.</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) meetings on the 30<sup>th</sup> January 2020 and 27<sup>th</sup> June 2019.</p> <p>The application was previous presented / discussed at the Data Access Advisory Group (DAAG) meetings on the 7<sup>th</sup> December 2017, 16<sup>th</sup> November 2017 and 25<sup>th</sup> May 2027.</p> <p><b>Application:</b> This was a renewal application.</p> <p>NHS England were seeking advice on the following point, including general advice on any other aspect of the application:</p> <ol style="list-style-type: none"> <li>1. to ensure the duration of the consent covers the years of data requested.</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 <b>deferred</b> the application as not all the necessary information was available to make a full assessment. AGD wished to draw to the attention of the SIRO the following substantive points; and suggested that the application be brought back to a future meeting:</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>5.6.1</b> AGD noted that when this application had been discussed on the 8<sup>th</sup> August 2024, they had recommended holding but not further processing data, until aspects of the consent were resolved.</p> <p><b>In response to point 1:</b></p> <p><b>5.6.2</b> The Group noted the efforts undertaken to address all the previous points raised by AGD at the 8<sup>th</sup> August 2024 meeting, however concerns remained around the study end date and whether the earliest consent documents cover the requesting of data from NHS England, since those earlier forms only refer to “medical records”.</p> <p><b>5.6.3</b> The Group were unclear as to what a participant understood to be the end of the study date and how long data could be retained for; and suggested that NHS England seek clarity from the applicant, and update section 5 of the application accordingly.</p> <p><b>5.6.4</b> AGD suggested, in order for NHS England to satisfy itself that consent was in place for all cohort members, that as part of the consent review process, NHS England Data Access Service (DAS) look at each version of consent form and the patient information sheets / leaflets in turn, and note how many of the cohort consented under each version.</p>	

	<p><b>5.6.5</b> In addition, the Group suggested that the applicant undertake some patient and public involvement and engagement (PPIE) and consult with a small group of the cohort, consented on the earlier consent forms / information sheets / leaflets as to what they understood to be the study end date and what the cohort understood by the term “<i>medical records</i>”.</p> <p><b>5.6.6</b> AGD suggested that the applicant determine the specific end date for the study, and, when agreed, to be transparent about that end date with the cohort.</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>5.6.7</b> AGD suggested that section 5(a) be updated to clarify that the Article 9(2)(j) description goes beyond archiving.</p> <p><b>5.6.8</b> No AGD member noted a commercial aspect to the application.</p>	
<b>6 INTERNAL DATA DISSEMINATION REQUESTS:</b>		
<i>There were no items discussed</i>		
<b>7 EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL</b>		
<i>There were no items discussed</i>		
<b>8 OVERSIGHT AND ASSURANCE</b>		
<i>There were no items discussed</i>		
<b>9</b>	<p><b>Commercial Financial Modelling (Presenter: Damian Bowler)</b></p> <p>AGD were presented with a verbal update with regard to the commercial financial modelling. The Group welcomed the update, and suggested Damian may wish to come back to a future AGD to update the Group further.</p>	
<b>10 AGD OPERATIONS</b>		
<b>10.1</b>	<p><b>Risk Management Framework</b></p> <p>AGD Chair asked for an update on the risk management framework. The NHS England SIRO Representative updated the Group that NHS England was developing an interim approach, and he would bring thoughts back to AGD in the timeline previously outlined.</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>10.2</b>	<p><b>Standard Operating Procedures (SOPs)</b></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>	

	<b>ACTION:</b> NHS England SIRO Representative to update the Group at a future AGD Meeting.	SIRO Rep
<b>10.3</b>	<b>AGD Stakeholder Engagement</b>	
<b>a)</b>	<b>Federated Data Platform</b> A brief update was given by the Group’s Representative on the Federated Data Platform Data Governance Group.	
<b>b)</b>	<b>NHS England Data Access Request Service Webinar for the Research Community</b> Some members of the Group noted they had attended the webinar and congratulated the NHS England team on the positive and informative presentation to the research community.	
<b>10.4</b>	<b>AGD Project Work</b> <i>There were no items discussed</i>	
<b>11 Any Other Business</b>		
<b>11.1</b>	<b>AGD Recruitment (update from Garry Coleman)</b>  The NHS England SIRO Representative advised the Group that the four new independent members of AGD were reaching the end of the onboarding process with NHS England and are due to start attending AGD as observers from the 24 <sup>th</sup> July 2025. Garry confirmed that the new independent members were in the roles of Chair, clinician (x 2) and research / academic.  Garry thanked Kirsty Irvine and Paul Affleck for their support throughout the AGD recruitment process including the assessment centres and interviews.  Garry thanked the AGD Secretariat Team for their support in the end-to-end process of recruitment, alongside the ‘business as usual’ activities of AGD.	
<b>11.2</b>	<b>AGD draft minutes / AGD ratified minutes</b>  It was recognised that NHS England staff may have a need, in exceptional circumstances, to access AGD draft minutes to assist with an application, and the process for this was re-confirmed: specifically, any request to access the AGD draft minutes, prior to review and ratification by AGD, <b>must</b> go via the AGD Secretariat Team.	
<b>Meeting Closure</b>  As there was no further business raised, the Chair of the meeting thanked attendees for their time and closed the meeting.		