

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

Thursday, 15<sup>th</sup> May 2025

09:00 – 14:55

*(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)
Claire Delaney-Pope (CDP)	AGD independent member (Specialist Information Governance Adviser) (not in attendance for item 5.3)
Arjun Dhillon (AD)	NHS England member (Caldicott Guardian Team Representative (Delegate for Dr. Jonathan Osborn)) (Items 1 to 5.3 and 9.1)
Kirsty Irvine (KI)	AGD independent member (Chair) (Item 9.1 only)
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) (Items 5.4 to 8 and 9.2 to 10.2)
Jenny Westaway (JW)	AGD independent member (Lay Adviser)
Miranda Winram (MW)	AGD independent member (Lay Adviser) (not in attendance for part of 5.3)
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>
Sally Cavanagh (SC)	Project Lead & Data Quality Advisor, Senior Information Manager, National SCHIAF Business Intelligence Team, Transformation Directorate ( <b>Presenter:</b> item 4.1)
Garry Coleman (GC)	NHS England SIRO Representative
Ayse Depsen (AD)	Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 5.4)
Madeline Laughton (ML)	Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 5.5)

Joe Lawson (JL)	Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 5.1)
Jorge Marin (JM)	Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 5.3)
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> item 5.2)
Samina Shah (SS)	Information Governance Manager, IG Delivery (Data & Analytics), Privacy, Transparency and Trust (PTT), Delivery Directorate ( <b>Observer:</b> item 4.1)
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 meeting Chair welcomed attendees to the meeting.</p> <p>AGD noted that, due to the lack of availability of independent members, there was an even number of AGD independent members (three) and AGD NHS England members (three) in attendance for item 5.3 (NIC-774448-Q4C6X Beamtree UK Limited).</p> <p>The importance of the AGD independent member majority was acknowledged by those present, and it was suggested that an annual review / possible inclusion in the AGD annual report of the number of meetings where an independent majority had not been present would be useful, as this would allow consideration of whether any action needed to be taken to improve the proportion of meetings with an AGD independent member majority.</p> <p>The NHS England SIRO representative stated that should AGD members be required to vote on any issues in the meeting, then one AGD NHS England member would be asked to not participate, to ensure the appropriate balance of votes, i.e. that the majority was by AGD independent members. The Group noted and agreed with this proposal.</p>
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	Noting that the <a href="#">AGD Terms of Reference</a> state that “The <b>majority</b> of the members of the Group or Sub-Group involved in any meeting <b>should</b> be independent members...”, the Group agreed that 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 8<sup>th</sup> May 2025 were reviewed and, after several minor amendments, were agreed as an accurate record of the meeting.</p>
<b>3</b>	<p><b>Declaration of interests:</b></p> <p>Claire Delaney-Pope noted a professional link to NIC-774448-Q4C6X (Beamtree UK Limited) and would <b>not</b> be part of the discussion. It was agreed that Claire would <b>not</b> remain in the room for the discussion of this application.</p> <p>Claire Delaney-Pope noted a professional link to King's Health Partners (NIC-656860-Q5Q9Q Guy's and St Thomas' NHS Foundation Trust) as part of her role at South London and Maudsley NHS Foundation Trust (SLAM). It was agreed this did not preclude Claire from taking part in the discussion on this application.</p>
<b>4 BRIEFING PAPER(S) / DIRECTIONS / DATA PROTECTION IMPACT ASSESSMENT (DPIA):</b>	
<b>4.1</b>	<p><b>Title:</b> Collection of NHS Blood and Transplant (NHSBT) Heart and Lung Transplant Data – DPIA / Briefing Paper</p> <p><b>Presenters:</b> Sally Cavanagh</p> <p><b>Observer:</b> Samina Shah</p> <p>The purpose of the DPIA / briefing paper is to make AGD aware that NHS England has been commissioned by the Department of Health and Social Care (DHSC), to undertake a comprehensive review of cardiothoracic (transplant) services. To meet the requirements of the commission, NHS England require data from the NHS Blood and Transplant Service on patients receiving heart and lung transplants as well as limited data about the donors.</p> <p>The aim of the analysis is to better understand how services are currently being delivered and to assess whether improvements can be made to enhance patient care and experience. The aims of the transformation programme are specifically to: <b>1)</b> increase transplant rates across England's centres and consequently an improvement in waiting times and reduced deaths while waiting; <b>2)</b> result in an improvement in, and reduction in variation relating to survival post-transplant across England's centres; <b>3)</b> improve patient experience of care, including improved information to support choice of provider and better holistic support across the pathway; <b>4)</b> increase levels of and more equitable referrals and registrations for transplant – in terms of geography and socio-economic and ethnic group; <b>5)</b> provide better and more consistent clinical management of risks while waiting for transplant and after transplant (including wider long-term risks associated with transplant).</p> <p>NHS England were seeking advice on the following point:</p> <ol style="list-style-type: none"> <li>1. Do AGD foresee any issues in this processing activity and the internal transfer of data which has been de-identified in line with the requirements of the De-Identification, Analysis and Publication Directions 2023 into the secure Pseudonymised Data Environment currently the Unified Data Access Layer (UDAL)?</li> </ol>

	<p><b>Outcome of discussion:</b> AGD welcomed the DPIA / briefing paper and made the following observations / comments:</p> <p><b>In response to point 1 above:</b></p> <p><b>4.1.1</b> AGD noted that there was a clear benefit to the processing of this data; and advised that they had no specific comments to make on the processing activity outlined.</p> <p><b>4.1.2</b> The NHS England SIRO Representative suggested that for transparency / future reference, the DPIA was updated to be clear on which part of the Data Services for Commissioners Directions 2015 was being relied upon.</p> <p><b>4.1.3</b> AGD made a number of suggested updates to the privacy notice, including, but not limited to <b>1)</b> ensuring that any historical references to the Data Protection Act 1998 were updated / removed; <b>2)</b> updating the current information to reflect the Common Law Duty of Confidentiality position; <b>3)</b> ensuring that the information relating to the 'right to be informed' aligns with information elsewhere; <b>4)</b> amending the reference from "GDPR" to "UK GDPR"; <b>5)</b> adding the relevant web link to the Directions; <b>6)</b> removing reference to "interim" DPO; <b>7)</b> adding information about how complaints can be raised directly with NHS England (in addition to the other routes listed).</p> <p><b>4.1.4</b> AGD suggested that the DPIA and the privacy notice were updated to be clear that <b>only</b> postcode data would be collected on the donor.</p> <p><b>4.1.5</b> AGD noted that two Article 6 UK General Data Protection Regulation (UK GDPR) limbs had been cited; and suggested that the DPIA was updated to clarify what processing was being carried out under each Article 6 limb.</p> <p><b>4.1.6</b> AGD suggested that the response to point 4.4 in the DPIA, in respect of consultation with data subjects, was reviewed and explored further.</p> <p><b>4.1.7</b> AGD noted and commended the work undertaken by NHS England colleagues on the DPIA.</p>	
<b>5 EXTERNAL DATA DISSEMINATION REQUESTS:</b>		
5.1	<p><b>Reference Number:</b> NIC-671668-B4T0T-v1.2</p> <p><b>Applicant and Data Controller:</b> The University of Manchester</p> <p><b>Application Title:</b> "Greater Manchester Rapid Service Evaluation Team: REVAL-GM and Manchester-Leeds Collaborative National Evaluation Team: Rose-NET"</p> <p><b>Observer:</b> Joe Lawson</p> <p><b>Previous Reviews:</b> The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 25<sup>th</sup> January 2024.</p> <p><b>Application:</b> This was an amendment 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 a clear justification that the processing cannot be</p>	

<p>undertaken in an NHS secure data environment (SDE), and wished to draw to the attention of the SIRO the following substantive 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 at the AGD meeting on the 25<sup>th</sup> January 2024, the Group had reiterated previous advice, that NHS England considered having an NHS England Data Access Service (DAS) Standard for programmatic access, that addressed how any programmatic access is aligned with the DHSC <a href="#">Data Access Policy</a> (consultation) that states <i>“Secure data environments (SDEs) will become the default route for accessing NHS data for research and external uses. Instances of disseminating NHS data outside of an SDE for research and external uses will be extremely limited”</i>. The Group noted that in response to this, the NHS England DAS internal Escalation Form stated that whilst the use of the NHS England SDE was not an option when the application was first submitted in 2023, it would be appropriate to review this when all the datasets required were available in the SDE. The Group noted that the AGD NHS England Data and Analytics Representative had a meeting scheduled with the applicant on the 16<sup>th</sup> May 2025, and this point would be discussed.</p> <p><b>5.1.2 Separate to this application and for NHS England to consider:</b> AGD reiterated previous advice, that NHS England considered having an NHS England DAS Standard for programmatic access, that addressed what, if any, difference in approach would be taken for commercial programmatic access; and how any programmatic access is aligned with the DHSC <a href="#">Data Access Policy</a> (consultation) that states <i>“Secure data environments (SDEs) will become the default route for accessing NHS data for research and external uses. Instances of disseminating NHS data outside of an SDE for research and external uses will be extremely limited”</i>.</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>5.1.3</b> AGD noted that when this application had been reviewed on the 25<sup>th</sup> January 2024, the Group had deferred the application, as not all the necessary information was available to make a full assessment; and had suggested that the application be brought back to a future meeting. The Group noted that this application had then been progressed without a further review by AGD or the NHS England SIRO Representative, on the basis that the points were sufficiently addressed. The Group were advised, by the AGD NHS England Data and Analytics Representative, that the process for progressing applications following an AGD review had now changed, and sufficient measures were in place to ensure that, where an application had not been supported by AGD, it would return for a further review, or proceed via the NHS England SIRO Representative.</p> <p><b>5.1.4</b> AGD reiterated the advice from the AGD meeting on the 25<sup>th</sup> January 2024, that to ensure alignment with other programmatic applications and for the purpose for transparency, the applicant should <b>1)</b> publish minutes from their internal advisory committee; and / or <b>2)</b> a list of projects approved by the internal advisory committee should be published for transparency.</p> <p><b>5.1.5</b> In addition, AGD suggested that a special condition was added to section 6 (Special Conditions), that a list of projects approved by the internal advisory committee be made available to NHS England.</p>	<p>D&amp;A Rep</p>
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	<p><b>5.1.6</b> AGD noted that, in respect of the first amendment to the application, they were supportive of the new programme of work (Manchester-Leeds Collaborative Evaluation Team (Rose-NET)) being added to the application; however, suggested that further information was added to section 5 (Purpose / Methods / Outputs) in respect of this work.</p> <p><b>5.1.7</b> AGD noted the second amendment to the application, to increase the frequency of the Hospital Episode Statistics (HES) Admitted Patient Care and HES Outpatients datasets, from annually to quarterly; and suggested that a justification for this was provided in section 5 of the application, including, but not limited to, the expected benefits of this change in frequency.</p> <p><b>5.1.8</b> AGD noted the third amendment to the application, to enable a wider pool of individuals to minimise the data; and whilst the Group noted the controls on this outlined in section 5(b) (Processing Activities), suggested that further information could be provided to include an indication of how many individuals would be permitted to undertake the minimisation.</p> <p><b>5.1.9</b> AGD noted in section 5(b) that “<i>University of Manchester uses off-site back-up services provided by Ascendas Reit</i>”; and suggested that Ascendas Reit was added as a Data Processor to the application, in line with the <a href="#">NHS England DAS Standard for Data Processors</a>.</p> <p><b>5.1.10</b> AGD suggested that section 3(b) (Additional Data Access Requested) was updated to accurately reflect that the data is “<i>pseudonymised</i>” and not identifiable.</p> <p><b>5.1.11</b> AGD suggested that the yielded benefits in section 5(d) (Benefits) (iii) (Yielded Benefits) were reviewed and updated to <b>1)</b> ensure the yielded benefits outlined were in line with <a href="#">NHS England DAS Standard for Expected Measurable Benefits</a>; or <b>2)</b> a statement was added stating why no yielded benefits had been identified to date.</p> <p><b>5.1.12</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 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>5.1.13</b> No AGD member noted a commercial aspect to the application.</p>	
<b>5.2</b>	<p><b>Reference Number:</b> NIC-148369-8PPWK-v5.2</p> <p><b>Applicant and Data Controller:</b> University of Oxford</p> <p><b>Application Title:</b> “The Oxford Vascular Study”</p> <p><b>Observer:</b> Azeez Oladipupo</p> <p><b>Previous Reviews:</b> 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 7<sup>th</sup> July 2022, 20<sup>th</sup> January 2022, 12<sup>th</sup> December 2019, 2<sup>nd</sup> May 2019 and the 14<sup>th</sup> February 2019.</p> <p><b>Linked applications:</b> This application is linked to NIC-653950-W8D4Z.</p> <p><b>Application:</b> This was an amendment 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>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 noted in section 1(b) (Data Controller(s)), that the applicant was relying on a System Level Security Policy (SLSP) for their security assurance; and queried why the Data Security and Protection Toolkit (DSPT) was not being relied on, noting that the University of Oxford have several DSPTs in place already. The Group suggested that this was reviewed and updated as may be appropriate, and encouraged the use of DSPT where possible.</p> <p><b>5.2.2</b> In addition, if an SLSP was relied on, AGD suggested that the applicant and NHS England satisfy themselves that this aligned with the s251 support in place.</p> <p><b>5.2.3</b> AGD noted the reference to the “<i>Information Governance Toolkit standard</i>” in section 5(b) (Processing Activities); and suggested that this was reviewed and updated to reflect the correct information, noting that this would <b>not</b> align with the reliance on an SLSP.</p> <p><b>5.2.4</b> AGD noted the conflicting information in the privacy notice that stated those cohort members who consented before June 2020 were not advised of the data linkage, and s251 had been obtained for this purpose as it was not feasible to re-consent; however, section 5(a) (Objective for Processing) states that this section of the cohort were asked to re-consent. The Group suggested that both statements were reviewed and updated / aligned where appropriate to ensure the correct information was stated.</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>5.2.5</b> AGD noted in section 5(a) that the Hospital Episode Statistics (HES) data would be used to “...<i>evaluate the full cost of acute vascular events and the cost savings with the introduction of new treatments...</i>”; and suggested that <b>1)</b> the applicant satisfy themselves that this falls within the scope of the s251 support; and <b>2)</b> if this is in scope of the s251 support, that the applicant update their transparency materials to ensure this aspect of the research was clear to participants.</p> <p><b>5.2.6</b> AGD noted the statement in section 5(b) “...<i>Data will contain directly identifying data items...</i>” to enable data to be linked at record level; and suggested that this was reviewed and updated to provide further information, for example, why pseudonyms were not being used instead. AGD suggested that if direct identifiers were being used, then this could be explored further via a Data Protection Impact Assessment (DPIA).</p> <p><b>5.2.7</b> No AGD member noted a commercial aspect to the application.</p>	
5.3	<p><b>Reference Number:</b> NIC-774448-Q4C6X-v0.5</p> <p><b>Applicant and Data Controller:</b> Beamtree UK Limited</p> <p><b>Application Title:</b> “Beamtree Evolve and NHS Confederation Collaborative”</p> <p><b>Observer:</b> Jorge Marin</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 <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 once the AGD points had been sufficiently addressed (or it was clearly highlighted / justified where points were no longer applicable):</p> <p><b>5.3.1</b> AGD welcomed the application and noted the potential value of the work outlined to the wider health and care system.</p> <p><b>5.3.2</b> AGD noted the role of the NHS Confederation outlined in the application, however, suggested that NHS England explored this further, to determine whether the NHS Confederation <b>1)</b> are considered a Data Controller in line with the <a href="#">NHS England DAS Standard for Data Controllers</a>; <b>2)</b> are considered a data Processor in line with the <a href="#">NHS England DAS Standard for Data Processors</a>; <b>3)</b> may receive any commercial benefit from the work outlined, in line with <a href="#">NHS England DAS Standard for Commercial Purpose</a>. AGD suggested that the application was updated as appropriate to reflect the outcome of these points.</p> <p><b>5.3.3</b> AGD noted in section 5(a) (Objective for Processing) that Edge Health would be a 'sub processor', however, suggested that either <b>1)</b> further clarification was provided on their role / responsibilities; or <b>2)</b> they were removed from the application if they were not processing any of the data.</p> <p><b>5.3.4</b> AGD noted the content of the Legitimate Interests Assessment (LIA) that had been provided as a supporting document (SD2); however, suggested that the applicant could also address the following points <b>1)</b> the commercial interest of the applicant; and <b>2)</b> the relationship between Beamtree UK Limited and other Beamtree entities.</p> <p><b>5.3.5</b> In addition, noting that the Data Protection Officer (DPO) who reviewed the LIA appeared to be based in Australia and therefore not in the territory of use where the data will be processed, the Group suggested that the LIA was reviewed by the UK based DPO of Beamtree UK Limited.</p> <p><b>5.3.6 Separate to this application and for NHS England to consider / action:</b> Noting some commercial organisations were not always clearly articulating their commercial interest and the potential benefits to them within their LIA, AGD suggested that the AGD NHS England Data and Analytics Representative discuss this further with colleagues, to ensure that LIAs submitted to NHS England are reviewed and clear on these points.</p> <p><b>5.3.7</b> AGD queried whether the applicant could undertake work with synthetic data, or a smaller volume of data as part of their development phase, noting that is an approach previously recommended by NHS England; and suggested that this is explored further with the applicant.</p> <p><b>5.3.8</b> AGD noted that, prior to the meeting, a query had been raised by an AGD independent member in respect of the territory of use which is England and Wales, noting that the Data Protection Act (DPA) registration entry was an Amazon Web Services Luxembourg entity.</p>	<p>D&amp;A Rep</p>
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	<p>AGD noted that NHS England Data Access Service (DAS) had advised that all data was processed and stored in England and Wales, and that the application had been updated accordingly.</p> <p><b>5.3.9</b> AGD noted the statement in section 5(a) <i>“This processing is in the public interest because it adheres to the UK Policy Framework for Health and Social Care Research”</i>; and suggested this statement was clarified with the applicant, and updated / removed as may be appropriate.</p> <p><b>5.3.10</b> AGD noted the statement in section 5(c) (Specific Outputs Expected) that <i>“The product allows clinicians to drill down to episode level which is not aggregated in any way”</i>; and noting that this may enable clinicians to identify individuals, the Group suggested that the statement was revised and any necessary updates made to the data sharing agreement (DSA) which also states that individuals would not be reidentified.</p> <p><b>5.3.11</b> AGD noted the statement in section 5(b) (Processing Activities) <i>“The Data will not be linked with any other data”</i>; and suggested that this was reviewed and updated as may be necessary, to reflect the correct / factual information, and in line with information elsewhere.</p> <p><b>5.3.12</b> AGD noted that the applicant does not yet have access to NHS England data, but suggested the applicant was advised that <b>1)</b> they were required to maintain a UK General Data Protection Regulation (UK GDPR) compliant, publicly accessible 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); and <b>2)</b> the privacy notice should be clear on the processing being undertaken / territory of use under this application.</p> <p><b>5.3.13</b> AGD noted and commended NHS England’s DAS on the NHS England internal application assessment form, in particular the assessment of whether the data could be processed in NHS England’s Secure Data Environment (SDE) or not.</p> <p><b>5.3.14</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-656860-Q5Q9Q-v5.2</p> <p><b>Applicant:</b> Guy’s and St Thomas’ NHS Foundation Trust</p> <p><b>Data Controllers:</b> Guy’s and St Thomas’ NHS Foundation Trust and King’s College London</p> <p><b>Application Title:</b> “A follow-up of GLACIER (a study to investigate the Genetics of LobulAr Carcinoma In situ in EuRope) and ICICLE (A study to Investigate the genetiCs of In situ Carcinoma of the ductaLsubtypE). (ODR1920_145)”</p> <p><b>Observer:</b> Ayse Depsen</p> <p><b>Previous Reviews:</b> The application and relevant supporting documents were previously discussed at the AGD meeting on the 15<sup>th</sup> June 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 19<sup>th</sup> January 2023.</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 addition of the National Disease Registration Service (NDRS) Cancer Pathway dataset.</li> <li>2. The change in legal basis from consent to s251.</li> <li>3. Subject to the resolution of the identified issues, do AGD support / not support the request.</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 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>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 point 1:</b></p> <p><b>5.4.1</b> AGD noted that they were supportive of the addition of the NDRS Cancer Pathway dataset.</p> <p><b>In response to point 2:</b></p> <p><b>5.4.2</b> In respect of the change in legal basis from consent to s251, AGD suggested that <b>1)</b> section 5 (Purpose / Methods / Outputs) was updated to be clear on what opt outs are applied; when they are applied and how they are applied; <b>2)</b> a special condition was added to section 6 (Special Conditions), stating that no analysis will be attempted in relation to those who applied an opt out, including the re-identification of any individuals.</p> <p><b>5.4.3 Separate to this application and for NHS England to consider / action:</b> The AGD NHS England Data and Analytics Representative to discuss adding a standard special condition to relevant applications, that there no analysis will be attempted in relation to those who applied an opt out, including the re-identification of any individuals.</p> <p><b>5.4.4</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 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>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p><b>5.4.5</b> AGD suggested that NHS England satisfy itself that the applicant is on course to meet the s251 condition of support in respect of undertaking patient and public involvement and engagement (PPIE) by the first annual review.</p> <p><b>5.4.6</b> AGD noted that it was unclear how the data will flow, and suggested that <b>1)</b> section 5(a) (Objective for Processing) and section 5(b) (Processing Activities) were reviewed and updated to be clear on this point, including, but not limited to, which organisation's server will be used to flow the data; and <b>2)</b> to update section 5 to be clear how the data will be shared between the Data Controllers.</p> <p><b>5.4.7</b> AGD noted the reference to section 5(b) to "<i>open access databases</i>"; and suggested that this was updated with further clarification as to what, if any, NHS England data would be in these databases.</p>	<p>D&amp;A Rep</p>
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	<p><b>5.4.8</b> Noting the PhD student is a substantive employee of King's College London, AGD suggested that section 5(a) and section 5(b) were reviewed and updated to remove any unnecessary text on what access they will have to the data, noting that they will be covered under the 'substantive employees' reference.</p> <p><b>5.4.9</b> AGD noted that whilst the website had been updated, the applicant should review the current information and update where appropriate to ensure that the information was lay friendly.</p> <p><b>5.4.10</b> AGD suggested that section 3(b) (Additional Data Access Requested) was updated to accurately reflect that the data is "<i>identifiable</i>" and not pseudonymised.</p> <p><b>5.4.11</b> AGD suggested that section 3(c) (Patient Objections) was updated to correctly state that patient objections are applied.</p> <p><b>5.4.12</b> AGD noted the yielded benefits in section 5(d) (Benefits) (iii) (Yielded Benefits), but suggested that these were updated with more information, in line with <a href="#">NHS England DAS Standard for Expected Measurable Benefits</a>; including, but not limited to, further information on the yielded benefit in respect of the novel associations that have been discovered with further disease occurrence.</p> <p><b>5.4.13</b> AGD noted the citation special condition had been added to section 6 (Special Conditions), however, suggested that the reference to "<i>NHS England Data Access Request Service</i>" was amended to correctly refer to NHS England Data Access Service".</p> <p><b>5.4.14</b> AGD noted that section 1 (Abstract) of the application incorrectly stated that this application was a SIRO approval; and suggested that this was updated with the correct information.</p> <p><b>5.4.15</b> No AGD member noted a commercial aspect to the application.</p>	
<b>5.5</b>	<p><b>Reference Number:</b> NIC-260281-Y6X5N-v0.4</p> <p><b>Applicant and Data Controller:</b> Barts Health NHS Trust</p> <p><b>Application Title:</b> "Mechanisms of Excess Risk in Aortic STEnosis after Aortic Valve Replacement (MASTER)"</p> <p><b>Observer:</b> Madeline Laughton</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 that the Data Security and Protection Toolkit (DSPT) status for University College London (UCL) was 'baseline'; and suggested that NHS England explore this further to ensure that standards have been met.</p> <p><b>5.5.2</b> AGD noted the diligent work undertaken by NHS England's Data Access Service (DAS) to establish who has data controllership responsibilities; however, noting the references to Barts Health NHS Trust in the consent materials, it was suggested that <b>1)</b> the</p>	

	<p>applicant seek the views of the Barts Health NHS Trust Data Protection Officer (DPO); and <b>2)</b> the applicant clarifies that Barts Health NHS Trust will <b>not</b> be named (in respect of authorship) in any publications resulting from the work outlined in this application.</p> <p><b>5.5.3</b> AGD noted that funding was in place until July 2025, however the application end date was March 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); 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>5.5.4</b> In addition to the transparency materials shared with the cohort, 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 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>5.5.5</b> AGD noted and commended NHS England's Data Access Service (DAS) and the applicant on the work undertaken on the application.</p> <p><b>5.5.6</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 AGD OPERATIONS</b>		
<b>9.1</b>	<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 8<sup>th</sup> May 2025, 1<sup>st</sup> May 2025, 10<sup>th</sup> April 2025, 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 document and made further amendments as necessary to reflect the discussion in-meeting, including, but not limited to, any quotes resulting from the positive feedback received by AGD. 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</p>	

	<p>collaboration area for AGD members / delegates and the AGD Secretariat to continue populating.</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 to discuss / collate the MI for the AGD Annual Report 2024/25 with colleagues and ensure this is populated in the draft Report.</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 draft Report.</p>	D&A Rep AGD Sec
9.2	<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 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
9.3	<p><b>Standard Operating Procedures (SOPs)</b></p> <p>The Group noted that the 'AGD member Declaration of Interest' SOP was in the process of being finalised 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
9.4	<p><b>AGD Stakeholder Engagement</b></p> <p><i>There were no items discussed</i></p>	
9.5	<p><b>AGD Project Work</b></p> <p><b>NIC-402963-P0Y5D – University of Liverpool</b></p> <p>The NHS England SIRO Representative noted, that NIC-402963-P0Y5D was discussed at the AGD meeting on the 6<sup>th</sup> March 2025, where the Group had not been supportive of the application, and a number of points had been raised, including, but not limited to, transparency; the complex explanation</p>	

	<p>of Regulation 3 and Regulation 5 of The Health Service (Control of Patient Information) (COPI) Regulations 2002; the National Data Opt-out etc.</p> <p>The Group were advised that following this meeting, two of the AGD members, Jenny Westaway and Dr. Jonathan Osborn, had met, at the request of NHS England, with NHS England's Data Access Service (DAS) colleagues and the applicant, to discuss their transparency information. The meeting was productive and involved a 'deep dive' into each section of the transparency notice and other areas of the website, and a number of suggested actions were discussed.</p> <p>On behalf of NHS England's DAS and the study team, the NHS England SIRO Representative thanked Jenny and Jonathan for taking the time to reviewing the existing transparency materials, attending the meeting, and providing their expertise; and that their feedback and suggested edits have been invaluable.</p> <p>The Group were advised that the study team are actively working through the suggestions and making changes to the transparency information; and once the updated information is available, an updated web link will be shared with members.</p> <p>The Group noted and thanked the NHS England SIRO Representative for the verbal update.</p>	
<b>10 Any Other Business</b>		
<b>10.1</b>	<p><b>Foresight AI case study (Update from Jonathan Osborn)</b></p> <p>AGD were provided with an update on the <a href="#">Foresight AI case study</a>, which is using de-identified NHS data from approximately 57 million people in England; researchers at University College London (UCL) and King's College London (KCL) are developing an innovative system to help clinicians, planners and policymakers predict health outcomes following the COVID-19 pandemic more effectively.</p> <p>Foresight is a generative AI model, predicting what happens next based on previous medical events. Predictions are validated against real-world data. The NHS England Secure Data Environment (SDE) provided secure access to extensive de-identified records to train the Foresight AI.</p> <p>The Group were advised that the use of data for such a project is novel, and that other researchers may be interested in developing such approaches. Noting the importance of NHS England's transparency and governance, the Group were advised that work is being undertaken within NHS England on the data that has been used and the broader governance for such projects in place under this data sharing agreement. This internal work will support other similar programmatic access, and use of data within SDEs. The Group were advised that further information would be shared at a future AGD meeting.</p> <p><b>ACTION:</b> The AGD Secretariat to add 'Foresight AI case study – data and governance' to the internal AGD forward planner.</p>	AGD Sec
<b>10.2</b>	<p><b>AGD Recruitment (update from Garry Coleman)</b></p> <p>The NHS England SIRO Representative advised the Group that interviews for the Researcher / Academic and Clinician posts had been completed and that candidates would be advised of the outcome of those interviews in due course.</p>	



	<p>The Group were also advised that interviews for the Chair role were taking place this week / next week.</p> <p>The NHS England SIRO Representative advised that further information would be shared with the Group at a future AGD meeting.</p>
<p><b>Meeting Closure</b></p> <p>As there was no further business raised, the Chair of meeting thanked attendees for their time and closed the meeting.</p>	