

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

Thursday, 3<sup>rd</sup> July 2025

09:00 – 15:30

*(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)
Laura Bellingham (LB)	NHS England member (Data and Analytics Representative (Delegate for Michael Chapman)) ( <b>Presenter:</b> item 10)
Kirsty Irvine (KI)	AGD independent member (Chair)
Andrew Martin (AM)	NHS England member (Data Protection Officer Representative (Delegate for Jon Moore))
Dr. Jonathan Osborn (JO)	NHS England member (Caldicott Guardian Team Representative) (not in attendance for part of item 5.2)
Jenny Westaway (JW)	AGD independent member (Lay Adviser)
Miranda Winram (MW)	AGD independent member (Lay Adviser)
<b>NHS ENGLAND STAFF IN ATTENDANCE:</b>	
<b>Name:</b>	<b>Role / Area:</b>
Jack Bennett (JB)	Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Presenter:</b> item 9)
Ricky Brooks (RB)	Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 5.6 and 5.7)
Michael Chapman (MC)	Director of Data Access and Partnerships, Transformation Directorate ( <b>Observer:</b> item 9)
Garry Coleman (GC)	NHS England SIRO Representative
Ayse Depsen (AD)	Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 5.5)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Deputy Chief Executive Directorate
James Watts (JW)	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> items 5.3 and 5.4)
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)
Claire Delaney-Pope (CDP)	AGD independent member (Specialist Information Governance Adviser)
Dr. Robert French (RF)	AGD independent member (Specialist Academic / Statistician Adviser)
Jon Moore (JM)	NHS England member (Data Protection Officer 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 unforeseen circumstances, only two AGD NHS England members were in attendance for part of item 5.2.</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 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.</p>
<b>2</b>	<p><b>Review of previous AGD minutes:</b></p> <p>The minutes of the AGD meeting on the 26<sup>th</sup> June 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>Paul Affleck noted a previous professional link to the University of Leeds but noted no specific connections with the application (NIC-732228-T8Q0V – Leeds Institute of Health Sciences), or staff involved, and it was agreed that this was not a conflict of interest.</p>
<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-786978-Z6K4M-v0.2</p> <p><b>Applicant and Data Controller:</b> Abiomed Ltd</p>

	<p><b>Application Title:</b> ““Understanding the Use of Impella in Patients Undergoing High-Risk Protected Percutaneous Coronary Interventions in the UK (24 NAPCI 01)”</p> <p>The item was withdrawn by NHS England’s Data Access Request Service (DARS) prior to the meeting.</p>	
5.2	<p><b>Reference Number:</b> NIC-147907-MLK7R-v8.2</p> <p><b>Applicant and Data Controller:</b> Derbyshire Healthcare NHS Foundation Trust</p> <p><b>Application Title:</b> “MR1142 - Self Harm Monitoring Project - Mortality Following Self-Harm”</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 12<sup>th</sup> January 2023, 3<sup>rd</sup> February 2022 and 13<sup>th</sup> December 2018.</p> <p><b>Linked applications:</b> This application is linked to NIC-147957-4444C and NIC-147916-DPQ3Q.</p> <p><b>Application:</b> This was an amendment 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. A Reusable Decision (Precedent).</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>5.2.1</b> AGD noted that s251 had been sought / obtained from the Health Research Authority Confidentiality Advisory Group (HRA CAG); and noting the extent of the review by HRA CAG, and the conditions of support; AGD supported the position by NHS England, that <b>no</b> data will flow until the s251 conditions have been met, and appropriate confirmation had been received from HRA CAG and shared by the applicant with NHS England.</p> <p><b>5.2.2</b> AGD noted that the s251 support was for the purpose of ‘service evaluation’, however, noted the references throughout the application to “<i>research</i>”; and suggested that <b>1)</b> the UK General Data Protection Regulation (UK GDPR) Article 9(2)(j) (<i>archiving purposes in the public interest, scientific or historical research purposes or statistical purposes</i>) legal basis cited, was reviewed and updated if appropriate to ensure this aligned with the purpose of ‘service evaluation’. If this was deemed to be the correct Article 9 legal basis, then AGD suggested the specific statistical limb of this was cited; and <b>2)</b> the application was reviewed and updated throughout to ensure it aligned with the purpose of ‘service evaluation’.</p> <p><b>5.2.3</b> AGD noted that, in line with the s251 support, the National Data Opt-out (NDO) would now <b>not</b> be applied. Noting that the applicant already holds data with the NDO applied, the Group suggested that NHS England explore this further with the applicant, and made a number of suggestions, including <b>1)</b> adding a special condition to section 6 of the application stating that data held with the NDO applied must be deleted and re-supplying the data with the NDO not applied; or <b>2)</b> flow the ‘new’ data with the NDO applied, and add a special</p>	

	<p>condition to section 6 stating no attempt will be made to analyse the data that may identify who has applied an NDO or the characteristics of people who have applied the NDO.</p> <p><b>5.2.4</b> AGD noted that the applicant had updated their <a href="#">website</a> to make reference to the changed s251 support, however suggested that <b>1)</b> the website was updated to ensure that it was clear that the purpose of processing was for service evaluation and not research; and <b>2)</b> it was made explicitly clearer that even if individuals have applied an NDO, that data will still flow to support this service evaluation.</p> <p><b>In response to point 1:</b></p> <p><b>5.2.5</b> AGD discussed whether a Reusable Decision (Precedent) for a change in approach with the National Data Opt-out (NDO) could be used for other, similar applications. AGD noted and discussed the request in-line with the advice provided on this point; and suggested that whilst some AGD members were broadly supportive of this, they would welcome a more focussed discussion on the content of the Reusable Decision (Precedent), to ensure that the inclusion / exclusion etc was captured correctly. One AGD member thought that a change in NDO status within an existing application was an unusual circumstance and, given it has implications for what happens to data that has already flowed, it may <b>not</b> be suitable for a reusable decision.</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>5.2.6</b> AGD welcomed the application and noted the importance of the work outlined.</p> <p><b>5.2.7</b> AGD noted the statement in section 7 (Ethics Approval) that ethical approval “...<i>is required and in place</i>”, and suggested that <b>1)</b> this was updated by the applicant, to state that ethics approval was <b>not</b> required because the application was for service evaluation; or <b>2)</b> further clarification was provided as to whether there were any activities taking place that did require ethical approval.</p> <p><b>5.2.8</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>study 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>5.2.9</b> No AGD member noted a commercial aspect to the application.</p>	
<b>5.3</b>	<p><b>Reference Number:</b> NIC-720122-Y6Q0Y-v0.10</p> <p><b>Applicant and Data Controller:</b> University of Essex</p> <p><b>Application Title:</b> “Examining intersectional inequalities in effective stroke care and stroke outcomes across England”</p> <p><b>Observer:</b> Emma Whale</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> The majority of the Group were supportive of the application; a minority of the Group (one member) were <b>not</b> supportive of the application <b>at this time</b> due</p>	

	<p>to the nature of the research and there not being enough information available on the data minimisation.</p> <p>The Group wished to draw to the attention of the SIRO the following substantive comment:</p> <p><b>5.3.1</b> AGD noted that the data processing would be within NHS England's Secure Data Environment (SDE), and queried <b>1)</b> the degree of data minimisation being undertaken; and <b>2)</b> that it was unclear who would be undertaking the data minimisation. NHS England advised the Group, that a further general discussion on this subject would be held at the AGD meeting on the 24<sup>th</sup> July 2025, where more information would be provided. AGD noted and thanked NHS England for the update, however noted that the queries raised could not be sufficiently addressed as part of the discussion on this application.</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>5.3.2</b> AGD noted the technical aspects of the application, however, noted that they were content, if NHS England were satisfied that there was sufficient specialist statistical support for the research team: to ensure that any outcomes are attributable to true intersectional inequalities, rather than random variation.</p> <p><b>5.3.3</b> AGD noted that in respect of security assurances, the University of Essex was relying on ISO 27001, and that this was due to expire in May 2025; and suggested that section 1(b) was updated with the latest / up to date information.</p> <p><b>5.3.4</b> No AGD member noted a commercial aspect to the application.</p>	
<b>5.4</b>	<p><b>Reference Number:</b> NIC-564296-L7V1M-v0.22</p> <p><b>Applicant:</b> Renal Registry</p> <p><b>Data Controller(s):</b> The Renal Association</p> <p><b>Application Title:</b> "Linking the National Registry of Rare Kidney Diseases with Hospital Episode Statistics for Research (Consent DSA)"</p> <p><b>Observer:</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 1<sup>st</sup> August 2024.</p> <p><b>Linked applications:</b> This application is linked to NIC-787477-W3G5Z.</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 for all cohort members <b>except</b> those recruited with the 2014 and 2016 consent materials, and wished to draw to the attention of the SIRO the following substantive comments:</p> <p><b>5.4.1</b> AGD advised that there was appropriate consent in place from all of the cohort members, apart from those consented on the documents from 2014 and 2016; and noted that this view aligned with the information provided in NHS England's Data Access Service Request (DARS) internal consent review form, provided as a supporting document.</p>	

	<p><b>5.4.2</b> AGD suggested that in respect of the 2014 and 2016 cohort members, data could flow with those cohort members removed; and that, the applicant could consult with a small group of cohort members recruited in 2014 and 2016, to determine whether they judge that their previously given consent covered their data being obtained from NHS England, and to be guided by the outcome of this participant involvement.</p> <p><b>5.4.3</b> Alternatively, AGD discussed whether there was a legal gateway for demographic data to flow, to support a 'list clean' / further contact with the 2014 and 2016 cohort; however, noted that the cohort may be surprised if their data was used for this purpose, noting the specific statements in the consent material in respect of contact being made in limited circumstances. It was therefore the view of the Group that they would <b>not</b> be supportive of the data being processed for this purpose.</p> <p><b>5.4.4</b> AGD suggested that NHS England satisfy themselves that there is an appropriate legal basis to flow data for those cohort members recruited via consultee advice.</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 noted that the applicant did have a plan in place for those young people turning 16 during the course of the registry, in respect of obtaining consent, however, queried whether their data would still flow to NHS England and what would happen to their data if consent was not provided, and suggested that this was made clear in section 5(a) of the application.</p> <p><b>5.4.6</b> AGD noted the description of the UK Renal Registry (UKRR) in the NHS England Data Access Request Service (DARS) internal application assessment form, in that it is a separate registry with separate governance and permissions; and suggested that this was added to section 5(a) for transparency.</p> <p><b>5.4.7</b> AGD suggested that the applicant update their transparency materials, including, but not limited to, the distinction / relation between the UKRR and the UK Kidney Association, for example the trading name and legal entity.</p> <p><b>5.4.8</b> AGD suggested that NHS England should consider auditing this application due to the complex nature of the registry and the possible commercial use.</p> <p><b>5.4.9</b> AGD noted and commended NHS England DAS on their diligence and the considerable amount of work undertaken on the application and with the applicant.</p> <p><b>5.4.10</b> AGD also noted and commended the work undertaken by NHS England's DAS on the NHS England internal consent review.</p> <p><b>5.4.11</b> AGD noted that there <b>was</b> a commercial aspect to the application.</p>	
<b>5.5</b>	<p><b>Reference Number:</b> NIC-747531-J2Q0W-v0.2</p> <p><b>Applicant:</b> London School of Hygiene and Tropical Medicine</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> "Controlled trial of High-risk coronary Intervention with Percutaneous left ventricular unloading (CHIP-BCIS3)"</p> <p><b>Observer:</b> Ayse Depsen</p> <p><b>Application:</b> This was a new application.</p>	

	<p>NHS England were seeking advice on the following point, including general advice on any other aspect of the application:</p> <p>1. Legal basis: the consent / s251.</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>In response to point 1:</b></p> <p><b>5.5.1</b> AGD noted that based on the application / supporting documents provided, there was a legal gateway in consent for the flow of data for the purposes outlined.</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>5.5.2</b> AGD suggested that the applicant update the Health Research Authority Confidentiality Advisory Group (HRA CAG) on the status of the legal basis relied on, i.e. s251 or consent.</p> <p><b>5.5.3</b> AGD noted the conflicting statement in section 5(a) that “<i>Data will be accessed by substantive employees of LSHTM only</i>”; and section 5(b) “Access is restricted to employees or agents of LSHTM who have authorisation from the Chief Investigator”. AGD suggested that <b>1)</b> this was reviewed and updated as necessary to reflect the correct / factual information; and <b>2)</b> 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>5.5.4</b> AGD noted and commended the applicant on the information provided on their website.</p> <p><b>5.5.5</b> No AGD member noted a commercial aspect to the application.</p>	
5.6	<p><b>Reference Number:</b> NIC-732228-T8Q0V-v0.7</p> <p><b>Applicant:</b> Leeds Institute of Health Sciences</p> <p><b>Data Controller(s):</b> Leeds Teaching Hospitals NHS Trust and University of Leeds</p> <p><b>Application Title:</b> “Yorkshire Lung Screening Trial”</p> <p><b>Observer:</b> Ricky Brooks</p> <p><b>Previous Reviews:</b> The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 12<sup>th</sup> June 2025.</p> <p><b>Application:</b> This was a new application.</p> <p>NHS England were seeking advice on the following point, including general advice on any other aspect of the application:</p> <p>1. s251 legal gateway.</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>In response to point 1:</b></p>	



	<p><b>5.6.1</b> AGD advised there was an appropriate s251 legal gateway.</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>5.6.2</b> AGD suggested that the end of the paragraph in section 5(a) that starts “<i>The usual care group were not invited to take part...</i>” was removed, noting the point was covered elsewhere in the application.</p> <p><b>5.6.3</b> AGD noted and commended NHS England’s Data Access Request Service (DARS) on the work undertaken on this complex application.</p> <p><b>5.6.4</b> No AGD member noted a commercial aspect to the application.</p>	
<b>5.7</b>	<p><b>Reference Number:</b> NIC-366913-C2V5F-v4.4</p> <p><b>Applicant:</b> National Institute for Health Research</p> <p><b>Data Controller:</b> Department of Health and Social Care (DHSC)</p> <p><b>Application Title:</b> “MR1393 - Join Dementia Research”</p> <p><b>Observer:</b> Ricky Brooks</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, 10<sup>th</sup> October 2019 and the 11<sup>th</sup> July 2019.</p> <p>The application and relevant supporting documents were previously presented / discussed at the Data Access Advisory Group (DAAG) meeting on the 19<sup>th</sup> January 2016.</p> <p><b>Application:</b> This was an amendment 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. Reusable 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> The majority of the Group were supportive of the application; a minority of the Group (one member) were <b>not</b> supportive due to the application implying the consultee could override a national data opt out.</p> <p>The Group wished to draw to the attention of the SIRO the following substantive comments:</p> <p><b>5.7.1</b> AGD noted that the National Data Opt out (NDO) should be applied in accordance with the NDO policy and any Privacy, Transparency and Trust advice given, to ensure consistency.</p> <p><b>5.7.2</b> AGD suggested that a careful review of the language be undertaken by the applicant to ensure that that where the application refers to the consultees giving “<i>consent</i>” that this accurately reflects the nature of consultee advice.</p> <p><b>In response to point 1:</b></p> <p><b>5.7.3</b> The majority of the Group (with one member dissenting) were supportive of the reusable decision, where the data sharing agreement is already in place and the consent / consultee advice has already been assessed by NHS England.</p>	



	<p><b>5.7.4</b> AGD suggested that the beginning of the wording of the reusable decision be clearer to read: “<i>Application of the National Data Opt-Out may be amended from 'Yes' or 'Mixed' to 'No' when an individual/ individuals was/were recruited under MCA05 for the purpose of carrying out a list cleaning exercise using mortality status (Fact of Death and/or Date of Death).</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>5.7.5</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>Precedent (reusable decision) for NHS DigiTrials Recruitment Service (Presenter: Jack Bennett)</b></p> <p>Following on from the AGD meeting on the <a href="#">12<sup>th</sup> June 2025</a>, the Group confirmed that they were <b>not</b> supportive of this approach.</p> <p>AGD had a lengthy discussion and noted that though a number of amendments had been made to the invitation letters template, the Group still had concerns and it was agreed that NHS England colleagues would have a further discussion outside of the AGD meeting and agree a way forward, for example how the template letter or review of letters could work in practice, noting that AGD had supported the underlying templated application <b>only</b> being precededented at the <a href="#">12<sup>th</sup> June 2025</a> AGD meeting.</p> <p>AGD also recognised the role of this work in supporting ‘<a href="#">the 10 year health plan for England</a>’ that had been published on the 3<sup>rd</sup> July 2025.</p> <p>AGD thanked NHS England for the further work done on this, and advised that they would welcome a further update / discussion on this item at a future AGD meeting.</p>	
<b>10</b>	<p><b>Data and Analytics Process update (Presenter: Laura Bellingham)</b></p> <p>AGD were provided with an update on a number of areas, including, but not limited to, the data access process; the complexity and timelines for assessing applications; how AGD support the process; and an update on a number of areas that have been discussed by AGD on a number of occasions, for example, data controllership, the use of the word “agents”, and research versus service evaluation, and the NHS England position on these; and some stakeholder engagement feedback from NHS England’s Data and Analytics on AGD.</p> <p>AGD noted the information provided and advised that they would welcome a further update at AGD on the 31<sup>st</sup> July 2025</p>	

	<b>ACTION:</b> AGD Secretariat to add "Data and Analytics Process" on the internal AGD forward planner.	AGD Sec
<b>11 AGD OPERATIONS</b>		
<b>11.1</b>	<b>Risk Management Framework</b>  The SIRO representative confirmed work continues as per the previous update to AGD, and that the paper from Laura Bellingham at this meeting gives an indication of the approach to risk assessment (see item 10).  <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.	SIRO Rep
<b>11.2</b>	<b>Standard Operating Procedures (SOPs)</b>  <i>Due to time constraints this item was not discussed.</i>	
<b>11.3</b>	<b>AGD Stakeholder Engagement</b>  <i>Due to time constraints this item was not discussed.</i>	
<b>11.4</b>	<b>AGD Project Work</b>  <i>Due to time constraints this item was not discussed.</i>	
<b>12 Any Other Business</b>		
<b>12.1</b>	<i>Due to time constraints this item was not discussed.</i>	
<b>Meeting Closure</b>  As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.		