

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

Thursday, 15<sup>th</sup> January 2026

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) (not in attendance for item 5.4)
Eleanor Berg (EB)	NHS England member (Data Protection Office Representative (Delegate for Jon Moore))
Dr. Jon Fistein (JF)	AGD independent member (Chair)
Kirsty Irvine (KI)	AGD independent member (Lay Adviser) (In attendance for items 8.1 and 8.2)
Prof. Jo Knight (JK)	AGD independent member (Specialist Academic / Researcher Adviser)
Dr. Mark McCartney (MM)	AGD independent member (Specialist GP / Clinician Adviser)
Dr. Jonathan Osborn (JO)	NHS England member (Caldicott Guardian Team Representative)
Andy Rees (AR)	NHS England member (Data and Analytics Representative (Delegate for Michael Chapman))
Jenny Westaway (JW)	AGD independent member (Lay Adviser)
<b>NHS ENGLAND STAFF IN ATTENDANCE:</b>	
<b>Name:</b>	<b>Role / Area:</b>
Noela Almeida (NA)	Senior IG Manager, Data Protection and Trust, Privacy Transparency and Trust (PTT), Deputy Chief Executive Directorate ( <b>Observer:</b> items 1 to 10)
Laura Bellingham (LB)	Deputy Director, Data Access and Partnerships, Data and Analytics ( <b>Presenter:</b> item 4.1)
Garry Coleman (GC)	NHS England SIRO Representative (not in attendance for part of 5.3)
Dave Cronin (DC)	Applications Service Owner, Data Access and Partnerships, Transformation Directorate, Transformation Directorate ( <b>Observer:</b> item 4.2)

Dan Goodwin (DG)	Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 5.2)
James Gray (JG)	Data Operations Manager, NHS DigiTrials, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 5.2)
Maddie Laughton (ML)	Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 5.4)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Deputy Chief Executive Directorate
Sarah Petitjean (SP)	Screening Improvement Senior Manager, Pathway Business Change Team and Screening Research Office, Screening Sub-Directorate ( <b>Observer:</b> item 4.2)
Narinda (Nin) Sandhu (NS)	Head of Programme Delivery, Data Access & Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer</b> part of item 5.1 to item 10)
Jodie Taylor-Brown (JTB)	Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 5.3)
James Watts (JW)	Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> items 4.2 and 5.1)
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Deputy Chief Executive Directorate

#### **AGD INDEPENDENT MEMBERS / NHS ENGLAND MEMBERS NOT IN ATTENDANCE:**

<b>Name:</b>	<b>Role / Area:</b>
Mr Christopher Barben (CB)	AGD independent member (Specialist Clinician Adviser)
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 Office Representative)
Miranda Winram (MW)	AGD independent member (Lay Adviser)

<b>1</b>	<b>Welcome and Introductions:</b> The AGD Chair welcomed attendees to the meeting.
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2	<p><b>Review of previous AGD minutes:</b></p> <p>The minutes of the AGD meeting on the 11<sup>th</sup> December 2025 were reviewed out of committee by the Group and, after several minor amendments, were agreed as an accurate record of the meeting by the AGD Chair, on behalf of the Group.</p>
3	<p><b>Declaration of interests:</b></p> <p>Paul Affleck noted a professional link to the University of Leeds (NIC-781290-Q2Q6F) and would not be part of the discussion. It was agreed that Paul would not remain in the room for the discussion of this application.</p> <p>Dr. Jon Fistein noted a professional link to the University of Leeds but noted no specific connections with the application (NIC-781290-Q2Q6F), or staff involved, and it was agreed that this was not a conflict of interest.</p> <p>Jenny Westaway noted a professional link to the Royal College of Anaesthetists (NIC-355855-R4G6G). It was agreed that Jenny would remain in the room, but would not be part of the discussion of this application.</p>
<b>4 BRIEFING PAPER(S) / DIRECTIONS:</b>	
4.1	<p><b>Title:</b> OpenSAFELY Service Evaluation – An evaluation of the pilot</p> <p><b>Presenter:</b> Laura Bellingham</p> <p>The OpenSAFELY Service was established under the <a href="#">COVID-19 Public Health Directions 2020</a>; and NHS England became responsible for the OpenSAFELY service from the 17<sup>th</sup> November 2023. The OpenSAFELY Service was restricted to providing health data for COVID-19 related purposes only, this persists today.</p> <p>The <a href="#">NHS OpenSAFELY Data Analytics Service Pilot Directions 2025</a> were published on the 9<sup>th</sup> June 2025, this enables the service to provide health data for non-COVID-19 related purposes.</p> <p>The Group were provided with an update on the OpenSAFELY Service, including, but not limited to, the service highlights; aims and requirements; a summary of initial evaluation findings; and recommendations for next steps.</p> <p>NHS England were seeking general advice / feedback on the information provided.</p> <p><b>Outcome of discussion:</b> AGD welcomed the information provided and made the following observations / comments:</p> <p><b>4.1.1</b> AGD noted the volume of work undertaken by NHS England and the recommendations for next steps.</p> <p><b>4.1.2</b> AGD advised that they were supportive of the proposal to align OpenSAFELY with existing NHS England Data Access Request Service (DARS) best practices, including, but not limited to, data sharing arrangements; reporting processes; definitions; and communication routes to ensure consistency and efficiency.</p> <p><b>4.1.3</b> AGD discussed the proposed approach of OpenSAFELY to type one objections and the National Data Opt-out Policy; and noted that there were ongoing discussions between</p>

	<p>NHS England and stakeholders, and noted that the outcome of these discussions may impact on future Directions for the full service.</p> <p><b>4.1.4</b> AGD noted the challenges in respect of OpenSAFELY encompassing such a large number of GP practices, and queried whether GP practice participation should be optional or mandatory, to ensure there is an appropriate and pragmatic balance of maximising the amount of GP communication and recruitment.</p> <p><b>4.1.5</b> AGD discussed how users of OpenSAFELY should be accredited, whilst ensuring that any requirements were not viewed as a retrograde step by researchers; and advised that there should be appropriate scrutiny of users of the service, without posing undue burden or delays to them.</p> <p><b>4.1.6</b> AGD looked forward to further updates on this work.</p>	
<b>4.2</b>	<p><b>Title:</b> Proposed use of the Data Access Request Service (DARS) to manage access to NHS Screening Data – Briefing Paper</p> <p><b>Observers:</b> James Watts, Sarah Petitjean and Dave Cronin</p> <p>Researcher requests for NHS England screening data are currently managed by the legacy process from NHS England’s Screening Directorate, which is a process that existed prior to the NHS Digital merger with NHS England. The NHS England Screening Directorate have been working towards sharing data via the same route as all other NHS England data; and are there therefore proposing that the NHS England Screening Directorate access the NHS England Data Access Request Service (DARS) Customer Relationship Management (CRM) system, so that applicants for data are not forced to apply through two different processes to request screening and other data. This will assure legal compliance, simplify the experience of data customers and improve the timeliness of data sharing requests.</p> <p>NHS England were seeking advice on the following points:</p> <ol style="list-style-type: none"> <li>1. The proposal to utilise NHS England’s Data Access Request Service (DARS) to support screening data sharing for secondary use.</li> <li>2. Any actions or points of clarification which must be resolved before the provision of access to the data via DARS.</li> </ol> <p><b>Outcome of discussion:</b> AGD welcomed the briefing paper and made the following observations / comments:</p> <p><b>In response to points 1 and 2 above:</b></p> <p><b>4.2.1</b> AGD noted that they were supportive of the proposal outlined, to utilise NHS England’s DARS to support screening data sharing for secondary use; noting that this provided the opportunity to improve transparency and the timeliness of the applications being processed.</p> <p><b>4.2.2</b> AGD noted that the proposal outlined was for a proposed “pilot”, and advised that they would welcome further information on this, including, but not limited to, <b>1)</b> the criteria for success; and <b>2)</b> the timeline for the “pilot”.</p> <p><b>4.2.3</b> AGD suggested that NHS England satisfy itself that the proposal outlined was streamlining the process, and engaging with AGD at all appropriate points throughout the process, not just at the end and asked that any review requested would be in line with the AGD <a href="#">Terms of Reference</a>.</p>	

	<p><b>4.2.4</b> AGD suggested that NHS England ensure that there were no duplications / contradiction of existing processes as part of the proposal, for example, noting the role / involvement of NHS England's Research Innovation Development Advisory Committee.</p> <p><b>4.2.5</b> AGD suggested that NHS England ensure that any interim arrangements were clear to applicants of data, noting the potential confusion that may be caused by having two separate processes for screening data and other NHS England data.</p> <p><b>4.2.6</b> AGD noted that a number of screening applications would be processed via the proposed new process, and suggested that it would be helpful to have further details on this in respect of any AGD support.</p> <p><b>4.2.7</b> AGD suggested that any new screening datasets that may be included in future applications, should be flagged to the Group prior to any applications being submitted for review, as per the usual AGD process, i.e. a briefing paper in advance of an application.</p> <p><b>4.2.8</b> AGD looked forward to further information / engagement on this work as may be required.</p>	
<b>5 EXTERNAL DATA DISSEMINATION REQUESTS:</b>		
<p><b>5.1</b></p>	<p><b>Reference Number:</b> NIC-786978-Z6K4M</p> <p><b>Applicant and Data Controller:</b> Abiomed INC</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><b>Observer:</b> James Watts</p> <p><b>Previous Reviews:</b> The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 24<sup>th</sup> July 2025 and the 3<sup>rd</sup> July 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>AGD noted that as part of an NHS England Data Access Request Service (DARS) pilot (discussed at the AGD meeting on the 7<sup>th</sup> August 2025), the Group had been asked <b>not</b> to review the application for this item, and had instead been provided with a new NHS England DARS internal form that contained summary information that, once finalised, would be transferred into the usual data sharing agreement (DSA) template.</p> <p><b>5.1.1</b> The Group noted that at the AGD meeting on the 24<sup>th</sup> July 2025, that it had been suggested that the applicant clearly demonstrate there is a benefit to health and social care in England and Wales; and that further information was provided in respect of the balance between public and commercial benefit, in line with the National Data Guardian (NDG) <a href="#">guidance on benefits</a>. AGD noted that whilst some information had been provided to address these points, further clarity should be provided to explain <b>1)</b> whether outcomes will</p>	

	<p>be measured and, if so, how; and <b>2)</b> that both ‘positive’ and ‘negative’ findings from the study will be published.</p> <p><b>5.1.2</b> AGD noted that information was in the public domain in respect of Impella devices, for example <a href="#">Abiomed Impella ‘Instruction for Use’ Recall Linked to 49 Deaths</a> and <a href="#">FDA flags Abiomed’s latest recall as Impella pump woes continue - Medical Device Network</a>; and queried whether this had any impact on the potential benefits of the study compared to any potential harm to patients; and suggested that NHS England explore this further with the applicant.</p> <p><b>5.1.3</b> AGD noted that the stated purpose of the application was for ‘service evaluation’, and suggested the application was clarified to explain how it was distinguished from research.</p> <p><b>5.1.4</b> AGD noted that the date of birth had been referred to in some of the supporting documents provided, however noted that this was not referred to in the application form provided, and that the data was described as pseudonymised. The Group suggested that NHS England explore this further with the applicant, and amend the application / relevant supporting documents as appropriate to ensure that the correct / factual information was reflected.</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>5.1.5</b> Given the points raised by the Group, the NHS England SIRO representative noted this application could <b>not</b> progress via delegated authority until such time as the NHS England SIRO Representative had reviewed the updated application.</p> <p><b>5.1.6</b> AGD noted and commended the work undertaken by NHS England’s Data Access Request Service (DARS) and the applicant on the work undertaken on this application and the responses to the previous advice provided by the Group.</p> <p><b>5.1.7</b> AGD noted that there <b>was</b> a commercial aspect to the application.</p>	
<b>5.2</b>	<p><b>Reference Number:</b> NIC-793230-S7H9P</p> <p><b>Applicant:</b> University of Edinburgh</p> <p><b>Data Controllers:</b> University of Edinburgh and NHS Lothian</p> <p><b>Application Title:</b> “Antiplatelet Secondary Prevention International Randomised study after INtracerebral haemorrhage (ASPIRING) - DigiTrials Outcome Service”</p> <p><b>Observers:</b> Dan Goodwin and James Gray</p> <p><b>Previous Reviews:</b> The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 3<sup>rd</sup> April 2025.</p> <p><b>Linked applications:</b> This application is linked to NIC-614954-G8P7P.</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 (five independent members and the AGD NHS England Data Protection Office Representative) were supportive of the</p>	

application **if** the National Data Opt-out was applied to any data flowing under consultee advice. A minority of the Group (AGD NHS England Data and Analytics Representative and the AGD NHS England Caldicott Guardian Team Representative) were supportive of the application as it is in line with the NHS England current agreed position. The Group wished to draw to the attention of the SIRO the following substantive comments:

AGD noted that as part of an NHS England Data Access Request Service (DARS) pilot (discussed at the AGD meeting on the 7<sup>th</sup> August 2025), the Group had been asked **not** to review the application for this item, and had instead been provided with a new NHS England DARS internal form that contained summary information that, once finalised, would be transferred into the usual data sharing agreement (DSA) template.

**5.2.1** The NHS England SIRO Representative advised the Group that, separate to this application, the University of Edinburgh is in the process of deleting data held under a separate data sharing agreement given that the Department that held the data no longer exists, and does not therefore have a Data Security and Protection Toolkit (DSPT). NHS England continues to monitor and take action should organisations who have access to data not maintain their DSPT. The Group noted and thanked the NHS England SIRO Representative for the update.

**5.2.2** AGD noted that, for this study as presented, consultee advice would override previous National Data Opt-outs (NDO) submitted by research participants; a position that the majority of the Group could **not** support, noting that this did **not** align with the Section 33(2)(b)(ii) safeguard in the Mental Capacity Act 2005. As discussed at the AGD meeting on the 25<sup>th</sup> September 2025 and the 31<sup>st</sup> July 2025, the Group noted that NHS England's current position is that consultee advice that an individual should take part in a research project can override an NDO, as a consultee considers that it would be in accordance with the individual's wishes and feelings for them to participate in the research, the view of the consultee should take precedence. The AGD NHS England Caldicott Guardian Team Representative confirmed that NHS England would reflect further on the advice from AGD, and would provide a further update / engagement on this (see point 5.2.8 below).

**5.2.3** AGD suggested that further clarity was provided on **1)** the data flows between the various parties, including but not limited to, the University of Edinburgh and Arrow Business Services Ltd; and **2)** the correct Data Processor(s), in line with [NHS England DAS Standard for processing activities](#) and the information provided in the privacy notice.

**5.2.4** AGD noted that international data would be "combined" with NHS England datasets, and suggested that further clarity was provided on this, including, but not limited to, confirmation that the combining of data would **not** increase the information risk relating to any NHS England datasets in the shared environment.

**5.2.5** AGD also suggested that further clarity was provided as to **1)** who would be able to access the data; and **2)** that this was restricted to UK personnel and **not** international collaborators.

In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:

**5.2.6** AGD noted and commended the work undertaken by NHS England's Data Access Request Service (DARS) and the applicant on the work undertaken on this application and the responses to the previous advice provided by the Group.



	<p><b>5.2.7</b> No AGD member noted a commercial aspect to the application.</p> <p>In addition, <b>AGD made the following observations separate to the application:</b></p> <p><b>5.2.8 Separate to the application:</b> AGD noted that they had <b>not</b> been provided with a copy of the legal advice that supported NHS England's position that the National Data Opt-out (NDO) would not apply for those recruited via consultee advice; and reiterated a point previously made at the AGD meeting on the 25<sup>th</sup> September 2025 (see AOB item 10) (see point 5.2.2 above).</p>	
<b>5.3</b>	<p><b>Reference Number:</b> NIC-792386-W7W1M</p> <p><b>Applicant and Data Controller:</b> NHS Norfolk and Waveney Integrated Care Board (ICB)</p> <p><b>Application Title:</b> "The Norfolk &amp; Waveney Data Hub"</p> <p><b>Observer:</b> Jodie Taylor-Brown</p> <p><b>Application:</b> This was a new 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. Noting the concerns raised by the AGD independent member regarding patient and public involvement and engagement (PPIE), do AGD have any concerns about the PPIE undertaken, the outcome of the PPIE and whether further PPIE is required on any areas?</li> <li>2. Any concerns or advice about the proposed purpose and use of the data hub.</li> <li>3. Any concerns or advice around re-identification for direct care purposes.</li> <li>4. Has the advice from the AGD independent member been adequately addressed?</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 the four points raised 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>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>AGD noted that as part of an NHS England Data Access Request Service (DARS) pilot (discussed at the AGD meeting on the 7<sup>th</sup> August 2025), the Group had been asked <b>not</b> to review the application for this item, and had instead been provided with a new NHS England DARS internal form that contained summary information that, once finalised, would be transferred into the usual data sharing agreement (DSA) template.</p> <p><b>5.3.1</b> AGD noted that s251 support was <b>not</b> in place from the Health Research Authority Confidentiality Advisory Group (HRA CAG), however the Group agreed to provide advice based on the current position, noting that the advice provided may change as the application evolves and HRA CAG have reviewed. The Group also noted that any future iterations of the application, should be submitted with the relevant updates made in line with AGD and HRA CAG advice; and with the relevant documentation provided, as per the usual process.</p>	



	<p><b>In response to point 1:</b></p> <p><b>5.3.2</b> AGD noted and commended the applicant on the patient and public involvement and engagement (PPIE) undertaken, including but not limited to, the work on the use of data for health purposes; however, noted that the PPIE was not overwhelmingly supportive of the proposal outlined. The Group suggested that <b>1)</b> the applicant engage with the public to address the concerns raised by the PPIE; and <b>2)</b> that there was also wider ongoing PPIE throughout the lifecycle of the work. The <a href="#">HRA guidance on Public Involvement</a> is a useful guide.</p> <p><b>In response to point 2:</b></p> <p><b>5.3.3</b> AGD noted that the proposed work outlined in this application, was to support NHS Norfolk and Waveney ICB to fulfil their statutory functions; and whilst the Group were supportive of this in principle, a number of concerns were raised, including, but not limited to overlaps or duplication with other systems in place, for example, regional Secure Data Environments (SDE) and / or the Federated Data Platform (FDP); and suggested that NHS England explore this further.</p> <p><b>5.3.4</b> AGD discussed the boundaries between NHS England data being processed for health and care purposes (i.e. those connected with the provision of health care or adult social care, or the promotion of health) versus non-health and care purposes; and how these are being defined. The Group suggested that NHS England discuss this with the applicant to ensure that there is a clear boundary in line with <b>1)</b> legal definitions; and <b>2)</b> public and patient expectations.</p> <p><b>5.3.5</b> AGD suggested that the application was updated to be clearer <b>1)</b> where data is being used for non-health and care purposes; and <b>2)</b> that any data used for non-health and care purposes would <b>not</b> be identifiable or pseudonymised.</p> <p><b>5.3.6</b> AGD suggested that NHS England satisfy themselves that no other parties required access to the data, other than those permitted in the data sharing agreement.</p> <p><b>In response to point 3:</b></p> <p><b>5.3.7</b> AGD noted and agreed that any re-identification should be for the purpose of direct care <b>only</b>.</p> <p><b>5.3.8</b> AGD suggested that NHS England should satisfy itself that any definition of “direct care” should be in line with NHS England definitions.</p> <p><b>5.3.9</b> AGD suggested that NHS England should satisfy itself that <b>1)</b> there is an appropriate decision-making body locally, and <b>2)</b> the local Caldicott Guardian was central to all of the decision making in respect of re-identification for direct care.</p> <p><b>In response to point 4:</b></p> <p><b>5.3.10</b> NHS England noted and passed on their thanks for the support provided on this application by the AGD independent Specialist Information Governance Adviser out of committee (and not in attendance for this discussion).</p> <p><b>5.3.11</b> The Group advised that they had no additional comments to make in addition to the comments made by the AGD member out of committee.</p>	
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	<p>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p><b>5.3.12</b> No AGD member noted a commercial aspect to the application.</p> <p>In addition, <b>AGD made the following observations separate to the application:</b></p> <p><b>5.3.13</b> AGD suggested that some of the PPIE work undertaken for this application, could feed into the work being undertaken by the Department of Health and Social Care, looking at the linkage of health data and non-health data.</p> <p><b>5.3.14</b> AGD suggested that there was a separate discussion in respect of the boundaries for health and care purposes versus non-health and care purposes.</p>	
<b>5.4</b>	<p><b>Reference Number:</b> NIC-781290-Q2Q6F</p> <p><b>Applicant and Data Controller:</b> University of Leeds</p> <p><b>Application Title:</b> “BLISS - Blood cancer clinical trials Long-term follow-up using Integrated healthcare SystemS data”</p> <p><b>Observers:</b> Maddie 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>AGD noted that as part of an NHS England Data Access Request Service (DARS) pilot (discussed at the AGD meeting on the 7<sup>th</sup> August 2025), the Group had been asked <b>not</b> to review the application for this item, and had instead been provided with a new NHS England DARS internal application form that contained summary information that, once finalised, would be transferred into the usual data sharing agreement (DSA) template.</p> <p><b>5.4.1</b> AGD were advised by NHS England that the applicant was in the process of developing a website where the transparency information would be made available, and that this was expected to be completed in the near future. AGD noted and thanked NHS England for the updated.</p> <p><b>5.4.2</b> AGD noted and commended the applicant on the patient and public involvement and engagement (PPIE) undertaken via the Project Management Group.</p> <p><b>5.4.3</b> AGD noted and commended the work undertaken by NHS England’s Data Access Request Service (DARS) and the applicant on the work undertaken on this application, including, but not limited to, the clarification of the commercial aspects.</p> <p><b>5.4.4</b> AGD noted that they would welcome a further update on the outcome of this study, to help both the Group and NHS England understand whether the data was useful in supporting the objective for processing.</p> <p><b>5.4.5</b> AGD noted that there <b>was</b> a commercial aspect to the application.</p>	

## 6 INTERNAL DATA DISSEMINATION REQUESTS:

*There were no items discussed*

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

7.1	<p><b>Reference Number:</b> NIC-368233-L2N0W-v11.5</p> <p><b>Applicant and Data Controller:</b> McKinsey &amp; Company, Inc. United Kingdom</p> <p><b>Application Title:</b> “Standard Extract Subscription”</p> <p><b>Previous Reviews:</b> The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 20<sup>th</sup> April 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) meetings on the 30<sup>th</sup> April 2020, 23<sup>rd</sup> April 2020, 29<sup>th</sup> August 2019, 4<sup>th</sup> July 2019, 28<sup>th</sup> March 2019, 13<sup>th</sup> December 2018 and the 22<sup>nd</sup> March 2018.</p> <p>The application and relevant supporting documents were previously presented / discussed at the Data Access Advisory Group (DAAG) meeting on the 13<sup>th</sup> October 2015.</p> <p>The SIRO approval was for the extended Retention of 2019/20 data as a pre-COVID-19 baseline for analysis.</p> <p><b>Outcome of discussion:</b> AGD noted that the NHS England SIRO had already provided SIRO approval and confirmed that they were supportive of this.</p> <p><b>7.1.1</b> The Group discussed the wording of the new special condition and endorsed the NHS England SIRO Representative suggestion that the retention period was clarified with the applicant to ensure a shared understanding. Also, the Group noted that it would be sensible to give specific retention dates (month and year) in such special conditions to aid clarity.</p> <p>AGD thanked NHS England for the written update and advised that they had no further comments to make on the documentation provided.</p> <p>The NHS England SIRO representative thanked AGD for their time.</p>
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## 8 OVERSIGHT AND ASSURANCE

8.1	<p><b>Oversight and Assurance Process (Workstream 1:</b> Precedent approved internal and external applications (not had an independent review in the last 6 months / or not had an independent review at all)</p> <p>The <a href="#">Statutory Guidance</a> states that the data advisory group (AGD) should be able to provide NHS England with advice on: “<i>Precedents for internal and external access, including advising in accordance with an agreed audit framework whether processes for the use of precedents are operating appropriately, to provide ongoing assurance of access processes</i>”.</p> <p>In advance of the meeting, the AGD independent members were provided with <b>1)</b> 8 applications (selected by the AGD Secretariat); <b>2)</b> internal application assessment forms for each of the 8 applications; and <b>3)</b> an oversight and assurance template to complete for each of the applications that each individual member had been asked to review.</p>
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	<p>Following review of the applications by the AGD independent members <b>out of committee</b>, the completed oversight and assurance templates were sent to the AGD Secretariat prior to the meeting.</p> <p>It was noted that only <b>high-level points</b> would be discussed in meeting (and noted in the minutes); however, the full suite of comments and feedback from AGD independent members on the oversight and assurance templates would be collated by the AGD Secretariat and shared with the NHS England SIRO representative and relevant NHS England colleagues as may be appropriate.</p> <p>Please see <b>appendix A</b> for high-level points raised in-meeting on the 8 applications.</p>	
<b>8.2</b>	<p><b>Oversight and Assurance Conclusion / Review</b></p> <p>AGD noted that the last oversight and assurance for workstream 1 review had taken place on the 20<sup>th</sup> November 2025, and that as agreed, workstream 1 would be a monthly agenda item.</p> <p>The Group noted that some applications fell into the following categories <b>1)</b> previous AGD/IGARD comments had not been adequately addressed or it was unclear if / how previous AGD/IGARD comments had been addressed; <b>2)</b> the annual compliance report (ACR) was not available to be selected from the NHS England Customer Relationship Management (CRM) system because it was either not named correctly or had not been provided by the applicant in line with due agreed process; and <b>3)</b> where HRA CAG support was given, it did not appear that the s251 support had been checked to ensure it still aligned with the application.</p> <p>The Group provided some feedback for future reviews including, but not limited to <b>1)</b> the preparation time per application minutes should be reviewed by the AGD Secretariat Team; <b>2)</b> reviewers for applications should be limited to 3 independents and 1 NHS England member per application (noting the increase in reviewers this month plus February and March was to aid learning and development); and <b>3)</b> no more than 3 applications should be reviewed per independent member / NHS England member.</p> <p>Whilst the MS Form used for workstream 1 was working well, the Group agreed that a number of updates were required including, but not limited to <b>1)</b> updating the precedents in the drop down menu to the four currently available including the “risk assessed amendment” which is currently absent from the list; <b>2)</b> to be clear that although the four precedents note “SIRO” they are undertaken by DA&amp;P via delegated authority; and <b>3)</b> to remove from the spreadsheet provided to the Group the background data if not required by the team for management information statistics: “start time”, “completion time”, “email”, “name” and “last time modified”.</p> <p>The Group were supportive of the ongoing learning and development which was being undertaken across the Data and Analytics and welcomed the teams to review the documentation provided to AGD to review the oversight and assurance documentation provided for this workstream and any subsequent workstreams and feed back in real time, min-meeting aligning to the deadlines of AGD.</p> <p>In addition, the Group suggested that “archiving precedent / review of archiving reuseable decision” be added to the internal AGD forward planner for a future discussion with the DARS Team.</p>	<p>DARS</p> <p>AGD Sec</p> <p>SIRO Rep</p> <p>AGD Sec</p>

	The NHS England SIRO Representative noted there was still room for improvement, noting the ongoing learning and development within Data and Analytics and thanked AGD for the work undertaken to date.	
9 AGD OPERATIONS		
9.1	<p><b>Risk Management Framework</b></p> <p>The NHS England SIRO Representative noted the recent discussions at the AGD plenary meeting on the 4<sup>th</sup> December 2025, on a number of different scenarios that may influence the content of a Risk Management Framework; and it was noted that further work / discussions on this will take place out of committee with some of the AGD members; and that further information would be provided / discussed with the Group at a future AGD meeting.</p> <p><b>ACTION:</b> The NHS England SIRO Representative, AGD Chair and AGD Secretariat to discuss out of committee work on the Risk Management Framework.</p>	SIRO Rep
9.2	<p><b>AGD Stakeholder Engagement</b></p> <p>The AGD Chair noted to the Group that they had met with Jackie Gray, Director of Privacy and Information Governance, within Privacy, Transparency, and Trust following the last update at the AGD plenary meeting on the 14<sup>th</sup> January 2026; this was in line with clause 9.2 of the <a href="#">AGD Terms of Reference</a> that states: “<i>The Chair and the Deputy SIRO shall meet at least every six months to review the operation of the Group</i>”.</p>	
9.3	<p><b>AGD Project Work</b></p> <p><b>Federated Data Platform</b></p> <p>A brief update was given by the Group’s representative on the Federated Data Platform Data Governance Group.</p>	
10 Any Other Business		
10.1	<p><b>AGD Ways of Working</b></p> <p>It was noted that there would be a substantive discussion around the new ways of working at AGD on the 22<sup>nd</sup> January 2026 and that all independent members / AGD NHS England members and delegates had been invited to attend.</p>	
<p><b>Meeting Closure</b></p> <p>As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.</p>		

## Appendix A

### Oversight and Assurance Review – 15<sup>th</sup> January 2026

Ref:	NIC Number:	Organisation:	Areas to consider:
260115a	NIC-401935-N9W7P-v2	East Anglian Air Ambulance	<p>The application had last been seen by AGD on the 20<sup>th</sup> July 2023 where the Group were supportive with substantive comments.</p> <p><b>Feedback on application:</b></p> <ul style="list-style-type: none"> <li>There was <b>no</b> evidence that the s251 had been checked to ensure that the s251 supported the planned activities outlined in the application.</li> </ul> <p><b>Feedback on process:</b></p> <ul style="list-style-type: none"> <li><b>Process point: Action for D&amp;A Representative</b> to ensure, for audit purposes, that all narrative is dated.</li> </ul>
260115b	NIC-190996-C4P8G-v5.2	The Royal Marsden NHS Foundation Trust	<p>The application had last been seen by IGARD via oversight and assurance with points raised on the 16<sup>th</sup> July 2020</p> <p><b>Feedback on application:</b></p> <ul style="list-style-type: none"> <li>It appeared from the documentation provided, that <b>no</b> annual ACR had been completed by the applicant</li> <li>It appeared that the DARS Standard for Expected Measurable Benefits had <b>not</b> been met, despite it progressing down a reuseable decision route.</li> </ul> <p><b>Feedback on process:</b></p>



			<ul style="list-style-type: none"> <li>• <b>Process point: Action for D&amp;A Representative</b> to ensure that it is clear in s1 abstract / SDA / escalation form, as audit trail, which NHSE Standards have been applied in line with the precedent / reuseable decision.</li> <li>• <b>Process point: Action for D&amp;A Representative</b> to ensure annual ACRs are completed timely.</li> <li>• <b>Process point: Action for D&amp;A Representative</b> to ensure that all relevant documentation, for example the latest ACR, is uploaded to CRM and easily findable.</li> </ul>
260115c	NIC-355855-R4G6G-v11.5	Royal College of Anaesthetists	<p>The application had last been seen by IGARD on the 17<sup>th</sup> November 2022 and recommended for approvals subject to amendments and advice.</p> <p><b>Feedback on application:</b></p> <ul style="list-style-type: none"> <li>• It appeared from the documentation provided, that <b>no</b> annual ACR had been completed by the applicant 18<sup>th</sup> January 2024</li> <li>• In addition, it appeared that the 2024 ACR had been signed by the Data Processor, in lieu of the Data Controller</li> </ul> <p><b>Feedback on process:</b></p> <ul style="list-style-type: none"> <li>• <b>Process point: Action for D&amp;A Representative</b> to ensure annual ACRs are completed timely.</li> <li>• <b>Process point: Action for D&amp;A Representative</b> to ensure that the correct signatory is signing the ACR.</li> <li>• <b>Process point: Action for D&amp;A Representative</b> to ensure that all relevant documentation, for example the latest ACR, is uploaded to CRM and easily findable.</li> </ul>

260115d	NIC-474674-R3F7S-v1.2	University of Oxford	<p>The application had last been seen by IGARD on the 3<sup>rd</sup> November 2022 and recommended for approval subject to amendments</p> <p><b>Feedback on application:</b></p> <ul style="list-style-type: none"> <li>• There was <b>no</b> evidence that the s251 support had been checked to ensure it still supported the application.</li> <li>• There was <b>no</b> evidence as to why the extension had been approved by DARS, noting that previously the DARS team had been clear that <b>no</b> extension would be provided beyond May 2025 without a robust justification</li> </ul> <p><b>Feedback on process:</b></p> <ul style="list-style-type: none"> <li>• <b>Process point: Action for D&amp;A Representative</b> to ensure that there is a clear narrative of checks undertaken within s1 abstract / SDA / escalation form</li> </ul>
260115e	NIC-656836-T2J0T-v3.5	Manchester University NHS Foundation Trust	<p>The application had last been seen by AGD on the 21st September 2023 via SIRO Approval for a 12-month extension</p> <p><b>Feedback on application:</b></p> <ul style="list-style-type: none"> <li>• It appeared, from the documentation provided, that <b>no</b> annual ACR had been completed by the applicant.</li> <li>• Although breast cancer may lead to lymphoedema, the publications all related to breast cancer, not lymphoedema which was the title of, and narrative as outlined in section 5(a)</li> </ul> <p><b>Feedback on process:</b></p>

			<ul style="list-style-type: none"> <li>• <b>Process point: Action for D&amp;A Representative</b> to ensure annual ACRs are completed timely.</li> <li>• <b>Process point: Action for D&amp;A Representative</b> to ensure that all relevant documentation, for example the latest ACR, is uploaded to CRM and easily findable.</li> <li>• <b>Process point: Action for D&amp;A Representative</b> to ensure, for audit purposes, that all narrative is dated.</li> </ul>
260115f	NIC-788212-W2D4D-v0.2	King's College Hospital NHS Foundation Trust	<p>The application had had no previous DAAG / IGARD / AGD review.</p> <p><b>Feedback on application:</b></p> <ul style="list-style-type: none"> <li>• The application had been noted as an “extension”, however new data had been requested</li> <li>• It appeared from the documentation provided, that <b>no</b> annual ACR had been completed by the applicant.</li> </ul> <p><b>Feedback on process:</b></p> <ul style="list-style-type: none"> <li>• <b>Process point: Action for D&amp;A Representative</b> to ensure the team are aware of the difference between “extensions” and “renewals” and ensure they are applying correctly.</li> <li>• <b>Process point: Action for D&amp;A Representative</b> to ensure annual ACRs are completed timely.</li> <li>• <b>Process point: Action for D&amp;A Representative</b> to ensure that all relevant documentation, for example the latest ACR, is uploaded to CRM and easily findable.</li> </ul>

260115g	NIC-329869-Q9Z2Z-v2.2	London School of Hygiene and Tropical Medicine	<p>The application had last been seen by IGARD on the 20<sup>th</sup> October 2022 and recommended for approval subject to amendments and advice.</p> <p><b>Feedback on application:</b></p> <ul style="list-style-type: none"> <li>• No issues were raised on the application</li> </ul> <p><b>Feedback on process:</b></p> <ul style="list-style-type: none"> <li>• No issues were raised on the process</li> </ul>
260115h	NIC-13906-G0F3F-v15.2	Private Healthcare Information Network (PHIN)	<p>The application had last been seen by IGARD on the 23<sup>rd</sup> June 2023 and recommended for approval subject to amendments and advice</p> <p><b>Feedback on application:</b></p> <ul style="list-style-type: none"> <li>• It appeared from the documentation provided, that <b>no</b> annual ACR had been completed by the applicant.</li> </ul> <p><b>Feedback on process:</b></p> <ul style="list-style-type: none"> <li>• <b>Process point: Action for D&amp;A Representative</b> to ensure annual ACRs are completed timely.</li> <li>• <b>Process point: Action for D&amp;A Representative</b> to ensure that all relevant documentation, for example the latest ACR, is uploaded to CRM and easily findable.</li> </ul>