

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

Thursday, 20<sup>th</sup> November 2025

09:00 – 15:10

*(Remote meeting via videoconference)*

<b>AGD INDEPENDENT / NHS ENGLAND MEMBERS IN ATTENDANCE:</b>	
<b>Name:</b>	<b>Role:</b>
Claire Delaney-Pope (CDP)	AGD independent member (Specialist Information Governance Adviser)
Rachel Fernandez (RF)	NHS England member (Data Protection Office Representative (Delegate for Jon Moore))
Kirsty Irvine (KI)	AGD independent member (Chair)
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))
Miranda Winram (MW)	AGD independent member (Lay Adviser) (Not in attendance for part of item 3.1 and part of item 3.2)
<b>NHS ENGLAND STAFF IN ATTENDANCE:</b>	
<b>Name:</b>	<b>Role / Area:</b>
Jack Bennett (JB)	Senior Project Manager, NHS DigiTrials, Transformation Directorate ( <b>Observer:</b> items 4.2 and 5.1)
Helen Buckels (HB)	Data Operations Manager, Data and Analytics, Transformation Directorate ( <b>Presenter:</b> item 4.3)
Laura Evans (LE)	NHS DigiTrials, Transformation Directorate ( <b>Observer</b> item 3.1)
Liz Gaffney (LG)	Assistant Director of Data Access & Partnerships: Head of Data Operations, SDE Service Owner, Data and Analytics, Transformation Directorate ( <b>Presenter:</b> item 4.3)
Michael Goodson (MG)	IG Lead, IG Delivery (Data and Analytics), Privacy, Transparency, and Trust (PTT), Deputy Chief Executive Directorate ( <b>Observer:</b> item 4.1)
Dan Goodwin (DG)	Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> items 5.1 and 5.2)
Suzanne Hartley (SH)	Data Applications Service, Senior Manager, Data Access and Partnerships, Transformation Directorate ( <b>Observer:</b> item 4.3)

Chris Haskins (CH)	Senior Project Manager, NHS DigiTrials, Transformation Directorate ( <b>Observer:</b> item 4.2)
Dickie Langley (DL)	NHS England SIRO Representative (delegate) ( <b>Presenter:</b> item 5.1(a))
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Deputy Chief Executive Directorate
Debbie Porter (DP)	Deputy Director, Genomics Service Transformation, Genomics Unit, Specialised Commissioning ( <b>Presenter:</b> item 4.1)
Jodie-Taylor-Brown (JTB)	Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 4.3)
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Deputy Chief Executive Directorate
<b>INDEPENDENT ADVISER OBSERVERS IN ATTENDANCE</b>	
Dr Jon Fistein (JF)	AGD independent adviser
<b>AGD INDEPENDENT MEMBERS / NHS ENGLAND MEMBERS <u>NOT</u> IN ATTENDANCE:</b>	
<b>Name:</b>	<b>Role / Area:</b>
Paul Affleck (PA)	AGD independent member (Specialist Ethics Adviser)
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)
Jenny Westaway (JW)	AGD independent member (Lay Adviser)

<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 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 items 1 to 4.1 and 5.2 to item 10.2; but for item 5.1 only, two AGD independent members and three AGD NHS England members were in attendance at the meeting.</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</p>
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	<p>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 (items 1 to 4.1 and 5.2 to 10.2), 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> <p>The NHS England SIRO representative stated that for item 5.1, it would not be possible to ask one AGD NHS England member to not participate, without affecting the NHS England member quoracy. Accordingly, a balance of votes was <b>not</b> available for those items. The Group noted and agreed with this proposal.</p> <p>Noting that the <a href="#">AGD Terms of Reference</a> state at clause 7.13: “<i>The quorum for meetings of the Group or a Sub-Group is <b>five members, including at least three independent members</b>, one of whom may be the Chair, Deputy Chair or Acting Chair and two of the three NHSE Members. In addition, a representative of the SIRO must also be in attendance for any meetings of the Group or a Sub-Group. <b>In exceptional circumstances the Chair and the representative of the SIRO may agree for the Group to still meet and conduct its business, but the minutes should note the meeting was not quorate and provide details of the number of NHSE members and independent members who were in attendance and provided advice on any matters</b>”</i>; the Group agreed that the meeting was quorate for items 1 to 4.1 and 5.2 to 10.2 but was <b>not</b> quorate for agenda item 5.1. The Chair and the SIRO representative agreed to proceed in “exceptional circumstances” in accordance with clause 7.13. The members in attendance for each item are noted in the table above.</p>
2	<p><b>Review of previous AGD minutes:</b></p> <p>The minutes of the AGD meeting on the 13<sup>th</sup> November 2025 were reviewed and, after minor amendments, were agreed as an accurate record of the meeting.</p>
3	<p><b>Declaration of interests:</b></p> <p>Kirsty Irvine noted a professional link to the ‘Framework Direction for Genomic Medicine Service 2025’ due to her roles at Genomics England; it was agreed that this was not a conflict of interest.</p> <p>Andy Rees noted a professional link to the ‘DigiTrials Recruitment Service - Reminders Service’ and NIC-791694-D2J8T (Akrivia Health) due to his NHS England role as NHS DigiTrials and Research Products Operations Manager; it was agreed that the items would be discussed / reviewed as per usual process and that this was not a conflict of interests.</p> <p>Claire Delaney-Pope noted a professional link to King’s College London (NIC-147955-M8D2Q) as part of her role at South London and Maudsley NHS Foundation Trust. It was agreed this did not preclude Claire from taking part in the discussion on this application.</p> <p>Claire Delaney-Pope noted a professional link to NIC-785339-D9Q2D (The Newcastle Upon Tyne Hospitals NHS Foundation Trust) as part of her role at South London and Maudsley NHS Foundation Trust. It was agreed this did not preclude Claire from taking part in the discussion on this application.</p>
4 BRIEFING PAPER(S) / DIRECTIONS:	
4.1	<p><b>Title:</b> Framework Directions for Genomic Medicine Service 2025</p> <p><b>Presenter:</b> Debbie Porter</p>

	<p><b>Observer:</b> Michael Goodson</p> <p>NHS England is seeking a unified legal framework via Direction to support the delivery of genomics services for the NHS in England in line with the <a href="#">NHS England Accelerating genomic medicine in the NHS Strategy</a> and the recently published 10 Year Health Plan. The framework Direction will be accommodating of multiple data and informatics initiatives that will collect, link and analyse data in connection with genomics information in England. The new infrastructure and operational changes will occur over a phased period, subject to NHS England information governance advice and governance processes.</p> <p>The first collection service to be established under the new Directions is the Genomics Order Management Service.</p> <p>NHS England were seeking advice on the following points:</p> <ol style="list-style-type: none"> <li>1. Note the draft Direction and related Order Management IG products.</li> <li>2. Provide any high-level concerns relating to the overall approach and current drafting.</li> </ol> <p><b>Outcome of discussion:</b> AGD welcomed the briefing paper and draft Direction and made the following observations / comments:</p> <p><b>In response to point 1 above:</b></p> <p><b>4.1.1</b> AGD were provided with an overview of the Framework Directions for Genomic Medicine Service 2025. AGD noted the content of the Framework Directions for Genomic Medicine Service 2025 and related Order Management IG products and noted no high-level concerns.</p> <p><b>In response to point 2 above:</b></p> <p><b>4.1.2</b> AGD noted the reference in paragraph 9 of the draft Directions to the “...<i>prohibition on publication set out in paragraph 7...</i>”, however, suggested that the internal cross reference was updated to correctly refer to “<i>paragraph 8</i>”.</p> <p><b>4.1.3</b> AGD noted that they were supportive of the approach outlined, and looked forward to receiving future updates in due course with regard to future steps and, in particular, data controllership.</p>	
<p><b>4.2</b></p>	<p><b>Title:</b> NHS DigiTrials Recruitment Service - Reminders Service – Briefing Paper</p> <p><b>Observers:</b> Jack Bennett and Chris Haskins</p> <p>The NHS DigiTrials Recruitment Service is an innovative, direct-to-participant recruitment model designed to enhance the efficiency and effectiveness of clinical trial recruitment across the UK. Developed in collaboration with researchers and grounded in strong public and patient engagement, the service leverages routinely collected NHS health data to identify and contact potential participants for approved clinical research studies.</p> <p>As part of the commitment to continuous improvement, the NHS DigiTrials Team has been working to create a Participant Engagement Strategy that brings together all participant-facing enhancements into a single program of work that explores efficiency in the system, optimise recruitment conversion rates and build trust and transparency with the public.</p> <p>NHS England were seeking advice on the following points:</p> <ol style="list-style-type: none"> <li>1. Note the development of the NHS DigiTrials Recruitment – Reminder Service.</li> </ol>	

	<p>2. Provide any advice relating to the overall approach and specifically the implementation criteria.</p> <p><b>Outcome of discussion:</b> AGD welcomed the briefing paper and made the following observations / comments:</p> <p><b>In response to point 1 above:</b></p> <p><b>4.2.1</b> AGD were provided with an overview of the NHS DigiTrials Recruitment Service - Reminders Service. AGD noted the content of the NHS DigiTrials Recruitment Service - Reminders Service Briefing Paper / supporting documents and noted no high-level concerns.</p> <p><b>In response to point 2 above:</b></p> <p><b>4.2.2</b> AGD had a discussion on the overall approach and specifically the implementation criteria; however, advised that they had no specific comments / advice for the team to address.</p> <p><b>4.2.3</b> AGD noted that they were supportive of the approach outlined, and looked forward to receiving future updates in due course.</p>	
<b>4.3</b>	<p><b>Title:</b> Secure Data Environment (SDE) Bring your own Data</p> <p><b>Presenters:</b> Liz Gaffney and Helen Buckels</p> <p><b>Observers:</b> Suzanne Hartley and Jodie-Taylor-Brown</p> <p>As part of the Department for Health and Social Care and NHS England commitment in <a href="#">Data saves lives: reshaping health and social care with data</a> to move to a system of 'data access as default' for the secondary uses of NHS health and social care data ('NHS data'); AGD were provided with an overview of the 'SDE Bring your own Data' programme of work.</p> <p>NHS England were seeking advice on the following points:</p> <ol style="list-style-type: none"> <li>1. To inform AGD about SDE service developments, and</li> <li>2. To ask for AGD advice on what they feel it might be helpful to see/understand when considering any specific application for BYOD on the SDE</li> </ol> <p><b>Outcome of discussion:</b> AGD welcomed the briefing and made the following observations / comments:</p> <p><b>In response to point 1 above:</b></p> <p><b>4.3.1</b> AGD were provided with an overview of the SDE Bring your own Data programme of work, and the Group noted that demand for this service was increasing.</p> <p><b>In response to point 2 above:</b></p> <p><b>4.3.2</b> AGD advised that applications that include applicants bringing their own data into the SDE, should ensure that <b>1)</b> the legal basis for all data flow should be clearly stated; and <b>2)</b> it was clear how the common law duty of confidentiality had been addressed.</p> <p><b>4.3.3</b> AGD noted that whilst the data would be accessed in the SDE, data minimisation and the relevant checks and balances undertaken should be clearly articulated.</p> <p><b>4.3.4</b> AGD noted that the first application with an applicant bringing their own data into the SDE, should be submitted to the Group for review within the coming weeks.</p>	

	<p><b>4.3.5</b> AGD noted the update and advised that they would welcome a further update on this programme of work, which NHS England noted would be provided in due course.</p>	
<b>5 EXTERNAL DATA DISSEMINATION REQUESTS:</b>		
<b>5.1</b>	<p><b>Reference Number:</b> NIC-791694-D2J8T-v0.1</p> <p><b>Applicant:</b> Akrivia Health</p> <p><b>Data Controller:</b> Cristal Health Ltd t/a Akrivia Health</p> <p><b>Application Title:</b> “GlobalMinds - Recruitment Agreement”</p> <p><b>Observer:</b> Dan Goodwin, Jack Bennett and Laura Evans</p> <p><b>Application:</b> This was a new / seeking early advice application.</p> <p>NHS England were seeking advice on the following points only:</p> <ol style="list-style-type: none"> <li>1. Do AGD members have any comments on the invitation letters.</li> <li>2. Do AGD members wish to raise any other points of concern or advice on what should be addressed in the application?</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 acknowledged that they would <b>not</b> be quorate for the discussion of application / invitation letters noting only two independent members and three AGD NHS England members were available; noting that the <a href="#">AGD Terms of Reference</a> states that “<i><b>In exceptional circumstances the Chair and the representative of the SIRO may agree for the Group to still meet and conduct its business...</b></i>” the Group agreed to discuss the application / invitation letters (see Section 1 above).</p> <p>AGD were <b>not</b> providing comments on the wider application as requested by NHS England; comments were limited to the specific point of advice requested. AGD wished to draw to the attention of the SIRO the following observations in relation to the advice point:</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>5.1.1</b> AGD noted the invitation letters provided, and advised that the rigour undertaken by NHS England in respect of reviewing the letters was appropriate.</p> <p><b>5.1.2</b> AGD queried whether an ethical review had been undertaken on the incentive for those providing consultee advice; and suggested that NHS England explore this further with the applicant, in line with <a href="#">NHS England DARS Standard for Ethical Approval</a>.</p> <p><b>5.1.3</b> AGD suggested that further information could be added to the consultee letter in respect of what the consultee should consider before / as part of providing consultee advice.</p> <p><b>5.1.4</b> AGD suggested that the applicant consider splitting the signposting for mental health support into two categories for example, mental health crisis support and mental health routine support.</p> <p><b>In response to point 2:</b></p>	

	<p><b>5.1.5</b> AGD noted that the application was seeking early advice and that further work would be undertaken before this was submitted to AGD for a full review; and made a number of suggestions as to what they would expect to see, including but not limited to an update on the commercial aspects in line with <a href="#">NHS England DAS Standard for Commercial Purpose</a>.</p> <p><b>5.1.6</b> AGD noted that Health Research Authority Confidentiality Advisory Group (HRA CAG) were due to review the application on the 27<sup>th</sup> November 2025; and the Group advised that they expect to see the HRA CAG feedback as part of the meeting pack for this application, in line with the usual process.</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>5.1.7</b> AGD noted that at the AGD meeting on the 13<sup>th</sup> November 2025, as part of the 'DigiTrials Recruitment Service - Invitation Letter Standards' review / discussion, AGD had agreed that the first three instances of the finalised standard (which will form part of the NHS DigiTrials Precedent) used to assess an NHS DigiTrials invitation letter would come to AGD for review. AGD noted that this application was the <b>first</b> instance of where the finalised standard had been used to assess an NHS DigiTrials invitation letter. The Group discussed how the standard had been applied to the invitation letters and advised that the exclusion criteria was correct and that AGD should review life science / commercial applications.</p> <p><b>5.1.8</b> AGD noted that there <b>was</b> a commercial aspect to the application.</p>	
5.2	<p><b>Reference Number:</b> NIC-785339-D9Q2D-v0.1</p> <p><b>Applicant:</b> The Newcastle Upon Tyne Hospitals NHS Foundation Trust</p> <p><b>Data Controllers:</b> Cambridge University Hospitals NHS Foundation Trust, NIHR Bioresource and The Newcastle Upon Tyne Hospitals NHS Foundation Trust</p> <p><b>Application Title:</b> "Inflammatory bowel disease-associated lymphoma"</p> <p><b>Observer:</b> Dan Goodwin</p> <p><b>Application:</b> This was a new / seeking early advice application.</p> <p>NHS England were seeking advice on the following points only:</p> <ol style="list-style-type: none"> <li>1. To establish whether the consent is compatible with this request for those recruited under all versions of consent.</li> <li>2. Where there are concerns with the consent, whether there is anything that NIHR Bioresource can do to uplift the level of consent required without reconsenting the whole cohort.</li> <li>3. Whether NHS England would be supportive of this methodology where the Data Controller can rely on a legal basis to meet the common law duty of confidentiality, that is owned by another organisation.</li> </ol> <p>Should an application be approved by NHS England, further details would be made available within the <a href="#">Data Uses Register</a>.</p> <p><b>Outcome of discussion:</b> AGD were <b>not</b> providing comments on the wider application as requested by NHS England; comments were limited to the specific points of advice requested. AGD wished to draw to the attention of the SIRO the following observations in relation to the advice points:</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>5.2.1</b> AGD noted and commended the work undertaken by NHS England’s Data Access Request Service (DARS) on the NHS England internal consent review; and agreed that there were some potential shortcomings in respect of the processing outlined in versions one to six of the consent materials. It was noted that version seven onwards of the consent materials adequately outlined the proposed processing.</p> <p><b>In response to point 2:</b></p> <p><b>5.2.2</b> AGD suggested that as a priority, the applicant updated their website with the information / proposed processing as outlined in version seven onwards of the consent materials, including, but not limited to <b>1)</b> the retention period; and <b>2)</b> the role of The Newcastle Upon Tyne Hospitals NHS Foundation Trust.</p> <p><b>5.2.3</b> AGD suggested that in line with the <a href="#">Caldicott Principles</a>, specifically Principle 8 that “A range of steps should be taken to ensure no surprises for patients and service users...”, the applicant should undertake some patient and public involvement and engagement (PPIE) with a selection of the cohort (more than 5 but fewer than 10) consented on version one to six of the consent materials, to <b>1)</b> determine if they would be surprised at the proposed processing and whether this was within their reasonable expectations; and <b>2)</b> to seek views as to any further updates that could be made to the website (in addition to the suggestion in point 5.2.2).</p> <p><b>5.2.4</b> AGD suggested that a special condition was added to section 6 (Special Conditions) that <b>before</b> data flows, the applicant should <b>1)</b> update their website with the latest information for transparency; and <b>2)</b> provide NHS England with evidence that all reasonable measures had been taken to update the cohort, for example, via existing communication channels such as a regular update / newsletter.</p> <p><b>In response to point 3:</b></p> <p><b>5.2.5</b> AGD discussed whether NHS England should be supportive of the methodology whereby the Data Controller can rely on a legal basis to meet the common law duty of confidentiality, that had been obtained by another organisation; and whilst it may be an approach, NHS England should satisfy itself of this via NHS England’s Privacy, Transparency and Trust (PTT).</p> <p><b>5.2.6</b> No AGD member noted a commercial aspect to the application.</p>	
<b>5.3</b>	<p><b>Reference Number:</b> NIC-790533-Z1B6W-v0.6</p> <p><b>Applicant and Data Controller:</b> Global Data Support B.V.</p> <p><b>Application Title:</b> “Health Insight Analytics Environment”</p> <p><b>Application:</b> This was a new / seeking early advice application.</p> <p>NHS England were seeking advice on the following points only:</p> <ol style="list-style-type: none"> <li>1. Do AGD members support the decision to reject the application for the reasons outlined.</li> </ol>	



	<p>2. Do AGD members wish to raise any other points of concern or advice on what should be addressed in the application prior to resubmission in the future.</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 <b>not</b> providing comments on the wider application as requested by NHS England; comments were limited to the specific points of advice requested. AGD wished to draw to the attention of the SIRO the following observations in relation to the advice points:</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 application form that contained summary information that, once finalised, would be transferred into the usual data sharing agreement (DSA) template.</p> <p><b>In response to point 1:</b></p> <p><b>5.3.1</b> AGD noted the number of substantive points raised on this application, both by NHS England and the Group; and were therefore supportive of NHS England's view that this application should be <b>rejected</b> and that no further NHS England time or resources were invested until the fundamentals / basics were in place by the applicant.</p> <p><b>In response to point 2:</b></p> <p><b>5.3.2</b> AGD noted and expressed concern that the applicant's website does <b>not</b> provide any information / references to the processing / activity outlined in the application, in particular, the work undertaken with NHS organisations / data as referred to in the application.</p> <p><b>5.3.3</b> AGD suggested that should this application progress at any point, then NHS England should seek further information on the applicant, including, but not limited to the applicant's reputation, financial situation, and the experience of the applicant with handling data.</p> <p><b>5.3.4</b> AGD noted that they could <b>not</b> see any evidence that the applicant had undertaken any stakeholder engagement or that there was a demand for the proposed service.</p> <p><b>5.3.5</b> AGD noted that there did <b>not</b> appear to be a project proposal, and they were unclear on <b>1)</b> what the objective for processing was in line with <a href="#">NHS England DAS Standard for Objective for Processing</a>; and <b>2)</b> what processing would take place in line with <a href="#">NHS England DAS Standard for processing activities</a>.</p> <p><b>5.3.6</b> AGD noted that the applicant was a commercial organisation, and that the applicant had asserted that <b>no</b> commercial gain would be obtained from the work undertaken in this application; however, advised that this would need reviewing to ensure that <b>1)</b> any potential commercial benefit was outlined in line with <a href="#">NHS England DARS Standard for Commercial Purpose</a>; <b>2)</b> how the balance between public and commercial benefits was assessed and was proportionate, in line the NDG <a href="#">guidance on benefits</a>; and <b>3)</b> there is a clear benefit to health and care in <b>in the UK</b> in line with <a href="#">NHS England DARS Standard for Expected Measurable Benefits</a>.</p>	
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	<p><b>5.3.7</b> AGD noted that <b>one</b> Lead Analyst would be reviewing requests for access to the data; and suggested that one reviewer would <b>not</b> be sufficient or appropriate for the use of this data.</p> <p><b>5.3.8</b> AGD noted that there <b>was</b> 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>		
<b>8.1</b>	<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> 6 applications (selected by the AGD Secretariat); <b>2)</b> internal application assessment forms for each of the 6 applications; and <b>3)</b> an oversight and assurance template to complete.</p> <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 6 applications.</p>	
<b>8.2</b>	<p><b>Oversight and Assurance Conclusion / Review</b></p> <p>AGD noted that the last oversight and assurance workstream 1 review had taken place on the 25<sup>th</sup> March 2025.</p> <p>The Group agreed that workstream 1 should be a monthly agenda item and that the next review would be December 2025 and monthly thereafter.</p> <p>The Group noted that whilst the majority of applications clearly communicated how the previous AGD / IGARD comments had been addressed, some applications fell into the following categories <b>1)</b> previous AGD/IGARD comments had not been adequately addressed; and <b>2)</b> it was unclear if / how previous AGD/IGARD comments had been addressed.</p> <p>The Group provided some feedback for future reviews including, but not limited to <b>1)</b> the preparation time of 30 minutes per application was sufficient; <b>2)</b> there was no requirement for the IG Risk and</p>	

	<p>Assurance Team to be in attendance since their pre-meeting documentation was excellent and provided all the narrative on reviews in one clear place; <b>3)</b> that the pre-meeting documentation from the IG Risk and Assurance Team was provided to all AGD members in attendance at AGD, not just the AGD Chair and SIRO Representative; <b>4)</b> reviewers per applications should be no more than 4 (2 to 3 independents and 1 NHSE member per application; and <b>5)</b> there should be no more than 6 to 8 applications for workstream 1 per session.</p> <p>The Group noted that the MS Form used for workstream 1 was working very well and thanked the IG Risk and Assurance Team for maintaining the outputs. The Group agreed that no further updates were required on the MS Form at present, including but not limited to extra questions required to be asked or answered.</p> <p>The Group noted their disappointment that the process had not appeared to move on since March 2025, however, were very supportive of the ongoing learning and development which was being undertaken across the Data and Analytics directorate, which would feed into clearer narrative within applications for clear audit of actions taken by the team. The Group also noted that as part of the learning and development members of the Data and Analytics Team had also undertaken a review of oversight and assurance applications that AGD also reviewed, and Andy Rees provided in-meeting verbal feedback, where it was concluded that the Team had done an excellent review, with both reviews raising similar points as outlined in Appendix A.</p> <p>The NHS England SIRO Representative noted that there were still room for improvement, noting the ongoing learning and development within Data and Analytics, and thanked both AGD and NHS England colleagues for the work undertaken to date. The NHS England SIRO Representative asked that advice on oversight and assurance was separated into feedback on the application and feedback on the process (this is outlined in Appendix A)</p>	
9 AGD OPERATIONS		
9.1	<p><b>Risk Management Framework</b></p> <p>The Group noted that the NHS England SIRO Representative had engaged with the Group out of committee following the AGD meeting on the 30<sup>th</sup> October 2025 in respect of the Risk Management Framework; and that a further update on this outstanding action would be provided as soon as possible.</p> <p><b>ACTION:</b> The NHS England SIRO Representative to provide a written response to AGD on the progress at a future AGD meeting.</p>	SIRO Rep
9.2	<p><b>AGD Stakeholder Engagement</b></p> <p><i>There were no items discussed</i></p>	
9.3	<p><b>AGD Project Work</b></p> <p><i>There were no items discussed</i></p>	
10 Any Other Business		
10.1	<p><b>NHS England Patient &amp; Public Involvement and Engagement (PPIE) Standard</b></p> <p>The Group queried the consideration by NHS England of a PPIE Standard, following discussion at AGD on the 24<sup>th</sup> July 2025 (see item 5.2.7).</p>	

	<p>The NHS England SIRO Representative advised that colleagues within NHS England had advised that there was an ongoing / wider programme of work commencing in early 2026 in respect of PPIE, and that work in respect of developing a PPIE Standard would link on with this work.</p> <p>The Group noted and thanked the NHS England SIRO Representative for the update, and looked forward to a further update in early 2026.</p>
<b>10.2</b>	<p><b>AGD Service Improvements</b></p> <p>An update was provided to the group by Karen Myers, in respect of the service improvement programme of work, where a number of 'observations' and 'actions' were highlighted following initial feedback from the AGD members and NHS England colleagues.</p> <p>AGD thanked Karen for the work she was doing on this programme of work and looked forward to future service improvement discussions.</p>
<p><b>Meeting Closure</b></p> <p>As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.</p>	

## Appendix A

### Oversight and Assurance Review – 20<sup>th</sup> November 2025 (Workstream 1)

Ref:	NIC Number:	Organisation:	Areas to consider:
251120a	NIC-11809-H1Y3W-v7.2	University of Leeds	<p>The application had last been seen by IGARD on the 29<sup>th</sup> September 2022 when it had been recommended for approval subject to amendments and advice</p> <p><b>Feedback on application:</b></p> <ul style="list-style-type: none"> <li>• There was no evidence that the s251 had been checked to ensure that the s251 supported the extended timeframe outlined in the application.</li> <li>• No SDA / escalation form provided (noting document not available in CRM for AGD Secretariat to download)</li> <li>• It appeared from the documentation provided, that no annual ACR had been completed by the applicant since February 2024.</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> <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 / SDA / escalation form, is uploaded to CRM and easily findable.</li> </ul>

251120b	NIC-29822-N0N7W-v2.2	London School of Economics and Political Science (LSE)	<p>The application had last been seen by IGARD on the 2<sup>nd</sup> December 2021 when it had been recommended for approval subject to amendments, advice and a significant risk area.</p> <p>No issues raised on the application or process</p>
251120c	NIC-147955-M8D2Q-v4.2	King's College London	<p>The application had last been seen by IGARD on the 2<sup>nd</sup> December 2021 when it had been recommended for approval subject to amendments and advice. IGARD had specifically advised that they would wish to see the application again when it comes up for renewal because the legal basis was in a state of transition as cohort members move from s251 to consent.</p> <p><b>Feedback on application</b></p> <ul style="list-style-type: none"> <li>There was no assessment provided as to why the application had progressed down the NHSE precedent route when IGARD had been clear that they would wish to see the application again when it comes up for renewal.</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 NHSE colleagues that IGARD / interim AGD points do not fall away and that their advice is still valid.</li> </ul>
251120d	NIC-148030-Q5N4D-v5.4	UK Haemophilia Centre Doctors' Organisation	<p>The application had last been seen by IGARD on the 27<sup>th</sup> October 2022 when it had been recommended for approval for those cohort members covered by s251 support only subject to amendments and advice. IGARD had noted that the application would not be suitable for precedent route, including SIRO precedent due to the uncertainty as to the</p>

			<p>future model to address the Duty of Confidentiality for recruits to the registry.</p> <p><b>Feedback on application</b></p> <ul style="list-style-type: none"> <li>• There was no assessment provided as to why the application had progressed down the NHSE precedent route when IGARD had been clear that the application was not suitable for precedent route.</li> <li>• The Group noted that as IGARD, interim AGD and AGD had requested, all narrative should be date stamped, to ensure a clear audit trail.</li> <li>• It appeared from the documentation provided, that no annual ACR had been completed by the applicant.</li> <li>• No SDA / escalation form provided (noting document not available in CRM for AGD Secretariat to download)</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 NHSE colleagues that IGARD / interim AGD points do not fall away and that their advice is still valid.</li> <li>• <b>Process point: Action for D&amp;A Representative</b> to ensure, for audit purposes, that all narrative is dated.</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</li> </ul>
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			latest ACR / SDA / escalation form, is uploaded to CRM and easily findable.
251120e	NIC-351522-Y6W3L-v8.2	Health and Safety Executive	<p>The application had last been seen by IGARD on the 4<sup>th</sup> November 2021 via oversight and assurance where the Group had noted the application had progressed via SIRO precedent but had not been notified to the Group as per usual process.</p> <p><b>Feedback on application</b></p> <ul style="list-style-type: none"> <li>• There was no written narrative of what amendments had been applied to the application other than a reference to a verbal discussion around amendments with the applicant; therefore, it was unclear if the precedent had been applied correctly or not.</li> <li>• Noting no SDA / escalation form had been provided, it appeared the application had not been updated in line with NHSE standards, for example there were no updated benefits / yielded benefits after 5 years of the applicant processing data.</li> <li>• It appeared from the documentation provided, that no annual ACR had been completed by the applicant since February 2024.</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 as to how the amendments had been applied to the application summary.</li> <li>• <b>Process point: Action for D&amp;A Representative</b> to ensure that is it clear in s1 abstract / SDA / escalation form, as audit trail, which NHSE Standards have been applied.</li> </ul>

			<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 / SDA / escalation document, is uploaded to CRM and easily findable.</li> </ul>
251120f	NIC-616081-Z8H5D-v4.2	ICB - Integrated Care Board	<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 Group were surprised that the applicant had not submitted an ACR as per the agreed NHS England process.</li> <li>• No SDA / escalation form provided (noting document not available in CRM for AGD Secretariat to download), however, the Group commended the team on the good use of the s1 abstract.</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 or SDA, is uploaded to CRM and easily findable.</li> </ul>