

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 7th August 2025

09:00 – 16:00

(Remote meeting via videoconference)

AGD INDEPENDENT / NHS ENGLAND MEMBERS IN ATTENDANCE:	
Name:	Role:
Paul Affleck (PA)	AGD independent member (Specialist Ethics Adviser)
Laura Bellingham (LB)	NHS England member (Data and Analytics Representative (Delegate for Michael Chapman))
Eleanor Berg (EB)	NHS England member (Data Protection Office Representative (Delegate for Jon Moore))
Claire Delaney-Pope (CDP)	AGD independent member (Specialist Information Governance Adviser)
Dr. Robert French (RF)	AGD independent member (Specialist Academic / Statistician Adviser) (Observer: Items 4.1 to 4.2, 9 and 10)
Kirsty Irvine (KI)	AGD independent member (Chair)
Dr. Jonathan Osborn (JO)	NHS England member (Caldicott Guardian Team Representative)
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	Role / Area:
Kathryn Anderson-Nicholls (KAN)	Senior Project Manager, PTT Business Operations, Privacy Transparency and Trust (PTT), Deputy Chief Executive Directorate (Observer: items 1 to 3, and 4.2)
Garry Coleman (GC)	NHS England SIRO Representative
Dave Cronin (DC)	Applications Service Owner, Data Access and Partnerships, Transformation Directorate (Observer: items 4.2) (Presenter: item 9)
Lyndon Dibb (LD)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.4)
Lucy Elliss-Brookes (LEB)	Deputy Director, Data Collection and Delivery, Data and Analytics, Transformation Directorate (Presenter: item 10)
James Gray (JG)	NHS DigiTrials, Data and Analytics, Transformation Directorate (Observer: items 4.2)

Maddie Laughton (ML)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: items 5.1 and 5.2)
Tiaro Micah (TM)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.3)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Deputy Chief Executive Directorate
Jodie Taylor-Brown (JTB)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: items 4.2)
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Deputy Chief Executive Directorate
INDEPENDENT ADVISER OBSERVERS IN ATTENDANCE	
Mr Christopher Barben (CB)	AGD independent adviser
Professor Jo Knight (JK)	AGD independent adviser
Dr. Mark McCartney (MM)	AGD independent adviser
AGD INDEPENDENT MEMBERS / NHS ENGLAND MEMBERS <u>NOT</u> IN ATTENDANCE:	
Name:	Role / Area:
Michael Chapman (MC)	NHS England member (Data and Analytics Representative)
Jon Moore (JM)	NHS England member (Data Protection Office Representative)
Jenny Westaway (JW)	AGD independent member (Lay Adviser)
Miranda Winram (MW)	AGD independent member (Lay Adviser)

1	<p>Welcome and Introductions:</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 the meeting. Should AGD members be required to vote on any issues in the meeting, then one AGD NHS England member would be asked to not participate, to ensure the appropriate balance of votes, i.e. that the majority was by AGD independent members. The Group noted and agreed with this proposal, and in line with the paragraph 7.13 of the AGD Terms of Reference, the meeting was still quorate for all agenda items and the Group agreed to proceed on that basis.</p>
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2	<p>Review of previous AGD minutes:</p> <p>The minutes of the AGD meeting on the 31st July 2025 were reviewed and, after several minor amendments, were agreed as an accurate record of the meeting.</p>
3	<p>Declaration of interests:</p> <p>Kirsty Irvine noted a professional link to NIC-12784-R8W7V (Genomics England) and NIC-776828-L9R1G (University Hospitals Birmingham NHS Foundation Trust) as part of her roles at Genomics England; but noted no specific connection with the application or staff involved, and it was agreed that this was not a conflict of interest.</p> <p>Professor Jo Knight noted a professional link to the applicant of NIC-745735-D8M0S (Lancaster University) but noted no specific connection with the application or other staff involved, and it was agreed that this was not a conflict of interest.</p> <p>Claire Delaney-Pope noted that she had some involvement with the subject matter of item 4.1 (Foresight AI Project), as part of her role at South London and Maudsley NHS Foundation Trust (SLAM). It was agreed this did not preclude Claire from taking part in the discussion.</p>
4 CONFIDENTIAL ADVICE SESSION	
4.1	<p>Foresight AI Project (Update from Garry Coleman)</p> <p>Following the update at the AGD meetings on the 5th June 2025 and the 15th May 2025, the NHS England SIRO Representative provided a verbal update on the Foresight AI Project, and agreed to come back to a future AGD BAU meeting with any further updates.</p>
4.2	<p>GP Data for Consented Research</p> <p>Observers: Dave Cronin, Jodie Taylor-Brown and James Gray</p> <p>Following the discussion at the AGD meeting on the 10th July 2025, the Group were provided with a further update on GP Data for Consented Research, and they provided confidential advice.</p>
5 EXTERNAL DATA DISSEMINATION REQUESTS:	
5.1	<p>Reference Number: NIC-749150-S0M7G-v0.5</p> <p>Applicant: Evidera Ltd</p> <p>Data Controller: Takeda Development Center Americas, Inc.</p> <p>Application Title: “Characteristics, Treatment Patterns and Outcomes of patients with Refractory Metastatic Colorectal Cancer”</p> <p>Observers: Maddie Laughton</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 7th November 2024.</p> <p>Application: 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 Data Uses Register.</p> <p>Outcome of discussion: AGD were supportive of the application and wished to draw to the attention of the SIRO the following substantive comments:</p> <p>5.1.1 AGD noted that when this application had been submitted to the Group for early advice on the 7th November 2024, the data was going to be accessed via NHS England's Secure Data Environment (SDE). The Group noted that, in this iteration of the application, the data would be disseminated via a data extract, due to the National Disease Registration Service (NDRS) data not being currently available in the SDE. AGD advised that they were supportive of this approach at the current time, however suggested that this was kept under review, and that a special condition was added to ensure that, at the appropriate time, the data is migrated from a data extract to the SDE.</p> <p>5.1.2 Separate to this application and for NHS England to consider: AGD suggested that NHS England Data Access Request Service (DARS) ensure that there are appropriate internal mechanism to monitor the status of the NDRS data to support the migration of the data access for this (and any other) applications to the SDE.</p> <p>5.1.3 AGD noted in the Data Protection Impact Assessment (DPIA) a statement that data subjects can request deletion of their personal information via NHS England; and suggested that this is updated to add clarity between the NDRS opt-out and what is / isn't possible for NHS England to delete, and to avoid any misunderstanding with the National Data Opt-out. In addition, AGD noted that data will not be able to be deleted once the data has flowed as a pseudonymous extract.</p> <p>5.1.4 In addition, AGD suggested that the points raised above (5.1.3) are also made clear in the applicant's privacy notice.</p> <p>5.1.5 AGD suggested the applicant was reminded that they were required to maintain a UK General Data Protection Regulation (UK GDPR) compliant, publicly accessible study specific transparency notice for the lifetime of the agreement, in line with the contractual requirement in section 4 (Privacy Notice) of the data sharing agreement (DSA).</p> <p>5.1.6 AGD suggested that section 5(a) (Objective for Processing) was updated to reflect that 1) Takeda required Evidera Ltd to have access to the data; 2) employees of Takeda are only permitted to access or receive aggregated anonymous data, adhering to the relevant small number suppression rules, to minimise the risk of individuals being identified.</p> <p>5.1.7 AGD suggested that section 5(a) and section 5(e) (Is the Purpose of this Application in anyway Commercial) were updated to be clear that Takeda make the drug being studied.</p> <p>5.1.8 AGD noted the 'Fruquintinib for previously treated metastatic colorectal cancer, technology appraisal guidance' published on the 23rd July 2025; and suggested that the specific outcomes accruing to Takeda (and not just the processor Evidera) were added to section 5(a) and section 5(e), in line with the NHS England DAS Standard for Commercial Purpose.</p> <p>5.1.9 AGD noted that the results of the study would be published on the Takeda website in the USA, however, suggested that further consideration was given by the applicant as to how this could be more visible to the public in England and Wales.</p>	<p>SIRO Rep</p>
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5.2	<p>Reference Number: NIC-748004-M6G9X-v0.5</p> <p>Applicant: Evidera Ltd</p> <p>Data Controller: Takeda Development Center Americas, Inc.</p> <p>Application Title: “A retrospective observational study to evaluate demographic/clinical characteristics, treatments, patterns of therapy, and outcomes of patients with advanced non-small cell lung cancer (aNSCLC) in England”</p> <p>Observers Maddie Laughton</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 7th November 2025.</p> <p>Application: 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 Data Uses Register.</p> <p>Outcome of discussion: AGD were supportive of the application and wished to draw to the attention of the SIRO the following comments:</p> <p>5.2.1 AGD noted in the Data Protection Impact Assessment (DPIA) that data subjects can request deletion of their personal information via NHS England; and suggested that this is updated to add clarity between the NDRS opt-out and what is / isn’t possible for NHS England to delete, and to avoid any misunderstanding with the National Data Opt-out (NDO). In addition, AGD noted that data will not be able to be deleted once the data has flowed as a pseudonymous extract.</p> <p>5.2.2 In addition, AGD suggested that the points raised above (5.2.1) are also made clear in the applicant’s privacy notice.</p> <p>5.2.3 AGD suggested the applicant was reminded that they were required to maintain a UK General Data Protection Regulation (UK GDPR) compliant, publicly accessible study specific transparency notice for the lifetime of the agreement, in line with the contractual requirement in section 4 (Privacy Notice) of the data sharing agreement (DSA).</p> <p>5.2.4 AGD suggested that section 5(a) (Objective for Processing) was updated to reflect that 1) Takeda required Evidera Ltd to have access to the data; 2) employees of Takeda are</p>	

	<p>only permitted to access or receive aggregated anonymous data, adhering to the relevant small number suppression rules, to minimise the risk of individuals being identified.</p> <p>5.2.5 The NHS England SIRO Representative noted that the NDRS Systemic Anti-Cancer Therapy Dataset (SACT) dataset referred to in section 3(b) (Additional Data Access Requested) was “<i>identifiable</i>”; and suggested that this was reviewed and updated to correctly state that this data is pseudonymised.</p> <p>5.2.6 AGD suggested that in line with step 3 of the NHS England DAS Standard for Ethical Approval, the applicant outline in section 5(a) what they had done to address any ethical issues.</p> <p>5.2.7 AGD suggested there was ongoing PPIE throughout the lifecycle of the work. The HRA guidance on Public Involvement is a useful guide.</p> <p>5.2.8 AGD noted and commended NHS England’s Data Access Request Service (DARS) on the work undertaken on the application.</p> <p>5.2.9 AGD noted that there was a commercial aspect to the application.</p>	
5.3	<p>Reference Number: NIC-776828-L9R1G-v0.10</p> <p>Applicant: University Hospitals Birmingham NHS Foundation Trust</p> <p>Data Controller: The University of Manchester</p> <p>Application Title: “Routinely collected treatment data to evaluate the uptake and utility of UK paediatric early phase trial infrastructure”</p> <p>Observer: Tiaro Micah</p> <p>Application: 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 Data Uses Register.</p> <p>Outcome of discussion: The Group were broadly supportive of the purpose outlined in the application, but were not supportive of the application at this time and wished to draw to the attention of the SIRO the following significant comments, and suggested that the application be brought back to a future meeting:</p> <p>5.3.1 AGD noted that there was an appropriate s251 legal gateway for the processing of confidential information; however, noting that a substantial part of the project is linking data with *SMPaeds and Genomics England Whole Genome Sequencing (GE-WGS). The Group noted that the s251 support provided as a supporting document, did not cover this, and noted that it was unclear what the legal basis was for the linkage, noting that this was not direct care; and suggested that NHS England explore this further with the applicant and satisfy themselves that there is a legal basis for this linkage.</p> <p><i>*Stratified Medicine Paediatrics</i></p> <p>5.3.2 AGD noted that if consent is being relied upon for the linkage of data (outlined in 5.3.1 above), NHS England satisfy itself that the consent expressly covers such linkage for research purposes using identifying data.</p>	

	<p>5.3.3 AGD noted and commended the work undertaken by NHS England's Data Access Request Service (DARS) with the applicant with regard to Data Controllership, identifying the University of Manchester as a Data Controller, however suggested that the status of the University of Manchester needed to flow through to the s251 support.</p> <p>5.3.4 Separate to this application and for NHS England to consider: AGD suggested that NHS England discuss with the Health Research Authority Confidentiality Advisory Group (HRA CAG) 1) the appropriate transparency measures for sub-regional Secure Data Environment (SDE), where they are being used for processing such as this; in order for individuals to exercise their right to opt-out of processing; and 2) how individuals would know they had been included in such processing.</p> <p>5.3.5 Separate to this application and for NHS England to consider: AGD suggested that NHS England discuss with HRA and HRA CAG, how best to formulate approvals for specific studies within overarching SDE support.</p> <p>5.3.6 AGD queried how the transparency obligations were being met, and suggested that the applicant give this further consideration.</p> <p>5.3.7 AGD queried who will access the data, at what stage, and in what form; and suggested that section 5(a) (Objective for Processing) was updated with clarification, in line with NHS England DAS Standard for Objective for Processing.</p> <p>5.3.8 AGD queried whether researchers from the Institute for Cancer Research (ICR) will have access to the data in the West Midlands Secure Data Environment (WMSDE); and suggested that this was clarified. If ICR researchers do have access to the data in the WMSDE, then the Group suggested that NHS England explore this further with the applicant, to determine whether they also need adding to the application as a Data Controller / Data Processor in line with the NHS England DAS Standard for Data Controllers / NHS England DAS Standard for Data Processors.</p> <p>5.3.9 AGD noted that title of the study and suggested that the applicant review and update to ensure this is reflective of how the study has evolved; and that the application was updated as may be necessary, including, but not limited to, section 1 (General) and section 5(a).</p> <p>5.3.10 AGD suggested that the application was updated to reflect that the reference to "anonymised" data was reviewed and updated, to reflect that the analysis would presumably be carried out on pseudonymised data to produce aggregated outputs.</p> <p>5.3.11 AGD queried the statement in section 5(b) that "<i>The identifying details will be securely destroyed...</i>"; and suggested that NHS England ensure that there are appropriate contractual controls to support this.</p> <p>5.3.12 No AGD member noted a commercial aspect to the application.</p>	<p>SIRO Rep / D&A Rep</p> <p>SIRO Rep</p>
<p>5.4</p>	<p>Reference Number: NIC-745735-D8M0S-v0.2</p> <p>Applicant and Data Controller: Lancaster University</p> <p>Application Title: "Understanding the epidemiology of cancer within the Northwest of England"</p> <p>Observer: Lyndon Dibb</p>	

	<p>Application: 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 Data Uses Register.</p> <p>Outcome of discussion: AGD were supportive of the application and wished to draw to the attention of the SIRO the following comments:</p> <p>5.4.1 AGD noted the references in the data minimisation table in section 3(b) to a “<i>data dictionary</i>”; and advised that although AGD do not have access to this, agreed that on balance, the quantum of data was appropriate for the nature of the processing and research aims.</p> <p>5.4.2 AGD were assured by NHS England this was a tabulation of data with small number unsuppressed and had come through the appropriate route; however, suggested that section 5 (Purpose / Methods / Outputs) was updated with further information on the nature of the tabulation.</p> <p>5.4.3 Separate to this application and for NHS England to consider: The AGD NHS England Caldicott Guardian Team Representative to discuss with NHS England colleagues, if the useful exercise outlined in this application could be undertaken for the whole country and facilitated by NHS England.</p> <p>5.4.4 AGD suggested the standard NHS England citation wording in the special condition in section 6 (Special Conditions), was updated to reflect the National Disease Registration Service (NDRS) wording.</p> <p>5.4.5 AGD suggested that the audit fees noted in section 11 (Chargers) were updated to reflect the correct amount that would be charged.</p> <p>5.4.6 No AGD member noted a commercial aspect to the application.</p>	CG Rep
6 INTERNAL DATA DISSEMINATION REQUESTS:		
<i>There were no items discussed</i>		
7 EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL		
<i>There were no items discussed</i>		
8 OVERSIGHT AND ASSURANCE		
<i>There were no items discussed</i>		
9	<p>New Application Assessment Form Pilot (Presenter: Dave Cronin)</p> <p>The Group were provided with a verbal update on a pilot by NHS England’s Data Access Request Service (DARS), testing a new version of the internal application assessment form, for a six-week period, and that will be submitted to AGD meetings from September 2025.</p> <p>The aims of the new application assessment form is to improve clarity on the data sharing agreements (DSA); improve transparency / auditability of changes to applications following AGD reviews; improve</p>	

	<p>efficiency; mitigate risks identified within current ways of working; and determine user requirements ahead of potential system development to automate process.</p> <p>NHS England would welcome any feedback on the pilot and new application assessment forms.</p> <p>The Group noted and thanked Dave for the update, and looked forward to receiving the new application assessment forms; and further discussion during / following the pilot.</p>	
10	<p>Data Flows Transformation (DFT) and the National Data Integration Tenant (NDIT) (Presenter: Lucy Elliss-Brookes)</p> <p>AGD were provided with a verbal update on the DFT and NDIT, including, but not limited to, data transformation vision, priorities and key milestones; programme objectives and benefits; the NDIT platform; benefits of developing NDIT; and the roadmap ahead.</p> <p>AGD noted and thanked Lucy for providing the update, and looked forward to further information / engagement in due course.</p>	
11 AGD OPERATIONS		
11.1	<p>Risk Management Framework</p> <p>AGD Chair asked for an update on the risk management framework referred to in the Group’s Terms of Reference. The NHS England SIRO Representative updated the Group that NHS England was developing an interim approach, and he would bring thoughts back to AGD in the timeline previously outlined: September 2025.</p> <p>ACTION: The NHS England SIRO Representative to provide a written response to AGD on the progress in September 2025, of the risk management framework.</p>	SIRO Rep
12.2	<p>AGD Stakeholder Engagement</p> <p>Federated Data Platform</p> <p>A brief update was given by the Group’s Representative on the Federated Data Platform Data Governance Group.</p>	
12.3	<p>AGD Project Work</p> <p><i>There were no items discussed</i></p>	
13 Any Other Business		
13.1	<i>There were no items discussed</i>	
<p>Meeting Closure</p> <p>As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.</p>		