

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 7th May 2026

09:00 – 16:05

(Remote meeting via videoconference)

AGD INDEPENDENT / NHS ENGLAND MEMBERS IN ATTENDANCE:	
Name:	Role:
Paul Affleck (PA)	AGD independent member (Specialist Ethics Adviser)
Mr Christopher Barben (CB)	AGD independent member (Specialist Clinician Adviser)
Dave Cronin (DC)	NHS England member (Data and Analytics Representative (Delegate for Michael Chapman))
Dr Arjun Dhillon (AD)	NHS England member (Caldicott Guardian Team Representative)
Dr. Jon Fistein (JF)	AGD independent member (Chair)
Prof. Jo Knight (JK)	AGD independent member (Specialist Academic / Researcher Adviser)
Jon Moore (JM)	NHS England member (Data Protection Office Representative)
Miranda Winram (MW)	AGD independent member (Lay Adviser)
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	Role / Area:
Garry Coleman (GC)	NHS England SIRO Representative
Claire Corney (CC)	Senior IG Manager (Data and Analytics), Privacy, Transparency and Trust (PTT), Technology, Digital and Data (Observer: Item 4.1)
Vanessa Kaliapermall (VK)	Information Governance Lead, Privacy, Transparency and Trust (PTT), Technology, Digital and Data (Observer: items 1 to 12.2)
Joe Lawson (JL)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.5)
Sara Lubbock (SL)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.6)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Technology, Digital and Data

Azeez Oladipupo (AO)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 1)
Humphrey Onu (HO)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.4)
Denise Pine (DP)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.4)
Jodie Taylor-Brown (JTB)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.2)
Emma Whale (EW)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: items 5.2 to 5.3)
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Technology, Digital and Data
AGD INDEPENDENT MEMBERS / NHS ENGLAND MEMBERS <u>NOT</u> IN ATTENDANCE:	
Name:	Role / Area:
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)
Dr. Mark McCartney (MM)	AGD independent member (Specialist GP / Clinician Adviser)
Dr. Jonathan Osborn (JO)	NHS England member (Caldicott Guardian Team Representative)
Jenny Westaway (JW)	AGD independent member (Lay Adviser)
NHS NORTH OF ENGLAND COMMISSIONING SUPPORT UNIT (CSU) STAFF IN ATTENDANCE (ITEMS 4.1 AND 5.3)	
Michael Ball (MB)	Data Assurance Lead / Lead Delivery Manager, North of England Commissioning support Unit (Observer: item 5.3)
Amy Soutter (AS)	Senior Consultant, FDF Virtual Wards Delivery Lead, NHS North of England Commissioning Support Unit (CSU) (Presenter: item 4.1)

1	Welcome and Introductions: The AGD Chair welcomed attendees to the meeting.
2	Review of previous AGD minutes:

	The minutes of the AGD meeting on the 30 th April 2026 were reviewed and, after minor amendments, were agreed as an accurate record of the meeting.
3	<p>Declaration of interests:</p> <p>Prof. Jo Knight noted a professional link to two of the ‘protocol contributors’ of NIC-786513-X5K6V (University of Newcastle Upon Tyne), 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>Dr. Jon Fistein noted a professional link to the University of Oxford but noted no specific connections with the application (NIC-796485-J3L4P), and it was agreed that this was not a conflict of interest.</p>
4 BRIEFING PAPER(S) / DIRECTIONS:	
4.1	<p>Title: Virtual Ward Minimum Dataset</p> <p>Presenter: Amy Soutter</p> <p>Observer: Claire Corney</p> <p>Previous Reviews: The ‘Virtual Wards Faster Data Flows Collection’ was discussed at the AGD BAU on the 3rd October 2024.</p> <p>The Ten Year Health Plan for England commits to the expansion of Hospital at Home (virtual ward) services, stating that 'systems need to better understand their virtual ward capacity'. NHS England have developed a patient-level, daily, automated virtual wards dataset to replace the aggregate SitRep and support this aim.</p> <p>In October 2024, NHS England sought advice from AGD on the pilot of the new virtual wards data collection; the pilot commenced in April 2025 and was successful, with over 80 providers submitting the new Virtual Wards Minimum Dataset (VWMDS) by April 2026, and a new operational dashboard live on the Federated Data Platform (FDP).</p> <p>The VWMDS is due to move from pilot to become a mandated national collection.</p> <p>NHS England were seeking advice on the following points:</p> <ol style="list-style-type: none"> 1. Considerations when moving from a pilot to a mandated national collection. 2. Any advice on future uses for the dataset beyond the published use cases. <p>Outcome of discussion: AGD welcomed the briefing paper and made the following observations / comments:</p> <p>In response to point 1 above:</p> <p>4.1.1 AGD welcomed the work undertaken to move from a pilot to a national virtual wards data collection; however, advised that NHS England should address a number of points as part of this ongoing programme of work.</p> <p>4.1.2 AGD noted that, when the ‘Virtual Wards Faster Data Flows Collection’ was discussed at the AGD meeting on the 3rd October 2024, the Group had advised that further patient and public involvement and engagement (PPIE) work needed to be undertaken at a wider level to gain further views / understanding of patient satisfaction. The Group expressed disappointment that work on this had not yet started, and strongly encouraged PPIE to be</p>

	<p>undertaken before the national data collection commences. The HRA guidance on Public Involvement is a useful guide.</p> <p>4.1.3 AGD observed that there was apparently conflicting information in the documents provided in respect of whether the data collection will be accessible via NHS England’s Data Access Request Service (DARS) or not. The Group advised that this was reviewed and updated to ensure the correct / consistent information is included.</p> <p>4.1.4 AGD noted that, if the data collection is going to be available via DARS, then this data would be flowing via the NHS Federated Data Platform (FDP); and noting that data in the FDP is for “...<i>direct care and population health planning purposes; it will not be used for external research</i>”, the Group advised that NHS England ensure that any use of the virtual wards data collection aligns with relevant public transparency materials.</p> <p>4.1.5 In respect of transparency on the data collection, the Group advised that:</p> <p style="padding-left: 40px;">4.1.5.1 the relevant team work with NHS England’s Data Protection Officer (DPO) Team to ensure the privacy notice: i) meets accessibility standards in line with the UK General Data Protection Regulation (UK GDPR); ii) is clear on the data being collected; and iii) reflects the relevant information, for example, details of Data Processors;</p> <p style="padding-left: 40px;">4.1.5.2 all transparency relating to the virtual wards data collection clearly outlines permitted use of the data, in line with the FDP policy; and</p> <p style="padding-left: 40px;">4.1.5.3 the number of patients reflected are correct (as currently known).</p> <p>4.1.6 AGD noted the statement in the national directors’ briefing provided as a supporting document, that there were “...<i>no media handling or communication implications</i>”; and advised that NHS England review and update this, noting for example, the organisations involved with this programme of work that may be of interest to the public.</p> <p>4.1.7 Noting the one ongoing ‘risk’ outlined in the Data Protection Impact Assessment (DPIA), AGD advised that NHS England review and update this as may be appropriate, to ensure all the relevant risks have been identified with their corresponding mitigation plans.</p> <p>In response to point 2 above:</p> <p>4.1.8 AGD queried if ‘date of death’ data was included in the data collection, and advised that NHS England:</p> <p style="padding-left: 40px;">4.1.8.1 clarify in the documentation whether this was available for the use cases; or,</p> <p style="padding-left: 40px;">4.1.8.2 clarify in the documentation if the date of death would come via another data set via linkage once collected.</p> <p>4.1.9 AGD advised that they would welcome the opportunity to advise on any future use cases as may be appropriate, for example, any that may be contentious, novel or repercussive.</p>	
5 EXTERNAL DATA DISSEMINATION REQUESTS:		
5.1	<p>Reference Number: NIC-622485-S4F5C-v0</p> <p>Applicant and Data Controller: University of Oxford</p>	

Application Title: “BHF PROTECT-TAVI (British Heart Foundation Randomised Trial of Routine Cerebral Embolic Protection in Transcatheter Aortic Valve Implantation)”

Observer: Azeez Oladipupo

Application: This was a new application.

NHS England were seeking advice on the following points:

1. There is sufficient justification for the work not being within NHS England’s secure data environment (SDE); and if so whether NHS England should seek any additional assurances as to the comparability of security controls.
2. The consent review is supported (including a view from the NHS England Caldicott Guardian and DPO Representatives).
3. The requirement for sensitive data is sufficiently justified.
4. The outputs cover all stated intentions (noting the reference to a predictive model).

Should an application be approved by NHS England, further details would be made available within the [Data Uses Register](#).

Outcome of discussion: In response to the specific points, AGD advised that the following should be addressed before further access (dissemination / release) of data proceeds:

In response to point 1:

5.1.1 AGD discussed whether the provided justification for the work not being within NHS England’s SDE was sufficient, and advised that it appeared that the cohort has consented to the data being processed in a local environment, and that this did appear to provide appropriate justification.

5.1.2 The Group did however note that the applicant may have originally opted for a local environment because the NHS SDE may not have been an option at that time; and advised that:

5.1.2.1 NHS England engage with the applicant to see whether the data processing could be undertaken in NHS England’s SDE now; and if so,

5.1.2.2 NHS England / the applicant undertakes a separate consent review to determine if any existing consent was compatible with this; or,

5.1.2.3 whether some / all of the cohort would need to be re-consented.

In response to point 2:

5.1.3 AGD noted the content of the internal consent review provided, and whilst this was comprehensive, advised there still appeared to be a potential incompatibility between the various versions of the consent materials in particular regarding the organisations involved, for example, the University of York and Newcastle upon Tyne Hospitals NHS Trust. The Group advised that the applicant:

5.1.3.1 undertake some public involvement and engagement (PPIE) to determine whether cohort members would be surprised (e.g. by the involvement of the other organisations). The [HRA guidance on Public Involvement](#) is a useful guide; and

5.1.3.2 provide evidence to NHS England on the findings of any PPIE.

	<p>5.1.3.3 undertake an engagement exercise with the cohort via existing communication channels such as a regular update / newsletter, if no substantial issues were raised via the PPIE; or</p> <p>5.1.3.4 ensure that access to the data by the University of York and Newcastle upon Tyne Hospitals NHS Trust was not permitted if substantive issues were raised via the PPIE.</p> <p>In response to point 3:</p> <p>5.1.4 AGD noted that the applicant had originally asked for two sensitive data fields, but were advised by NHS England that this position had now changed, and that only ‘date of death’ was required. The Group raised no concerns on this point.</p> <p>In response to point 4:</p> <p>5.1.5 AGD noted the ‘outcomes’ in the internal form / application, and advised that these seemed to describe communication channels rather than specific outputs and so were potentially not in line with NHS England DARS Standard for Expected Outcomes The Group advised that:</p> <p>5.1.5.1 the ‘outcomes’ were reviewed throughout to ensure they presented specific outputs (for example, specific products); and</p> <p>5.1.5.2 the outcomes included detail on outputs relating to the “<i>risk model</i>” referred to covered elsewhere in the application, for example, the objective for processing.</p> <p>In addition to their advice on the specific points raised by NHS England, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.1.6 AGD noted the information on commercial involvement, and advised that further information was provided on the health economic analysis, and how this may influence the rollout of any medical devices.</p> <p>5.1.7 The Group noted the oral update from the NHS England SIRO Representative, and the NHS England Data and Analytics Representative, that NHS England would be reviewing security arrangements for local environments, including, but not limited to, processes for data access, to ensure they are as robust as the NHS SDE. AGD advised that they were supportive of this, and would welcome further information in due course.</p> <p>5.1.8 AGD urged the applicant to ensure that there has been an appropriate ethical review for the work outlined; and that appropriate evidence was provided NHS England as per the usual process.</p>	
<p>5.2</p>	<p>Reference Number: NIC-382794-T3L3M-v12.5</p> <p>Applicant and Data Controller: Queen Mary University of London (QMUL)</p> <p>Application Title: “QResearch Data Linkage Project”</p> <p>Observers: Emma Whale and Jodie Taylor-Brown</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 11th January 2024, 30th November 2023 and the 21st September 2023.</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 17th November 2022, 11th August 2022, 16th June 2022, 7th April 2022 and the 3rd March 2022.

The application and relevant supporting documents were previously presented / discussed at the IGARD COVID-19 response meetings on the 2nd March 2021, 19th January 2021 and the 12th January 2021.

Linked applications: This application is linked to NIC-656839-K5V9L.

Application: This was an amendment application requesting additional datasets.

NHS England were seeking advice on the following points:

1. The purpose provides sufficient clarity on the permitted purposes for using the data.
2. The scope of purpose and the level of delegated decision-making is appropriate
3. The governance controls give sufficient assurance that risks associated with the delegation of decision-making will be mitigated.
4. The approach to AI use is appropriate and sufficient.
5. The need to retain COVID-19 related datasets is sufficiently justified, and the approach to legal basis/common law is appropriate for those datasets ((with a view from the NHS England DPO Representative).

Should an application be approved by NHS England, further details would be made available within the [Data Uses Register](#).

Outcome of discussion: In response to the specific points, AGD advised that the following should be addressed before further access (dissemination / release) of data proceeds:

In response to point 1:

5.2.1 AGD noted that this was a complex application to discuss / review, relating to an established research environment, that has received NHS England (previously NHS Digital) data, and has a proven track record in research; however, noted that **i)** there had been some changes in organisations involved with this application; and **ii)** NHS England Data Access Request Service (DARS) [guidance / standards](#) have developed over the years, and advised that the applicant review / update the existing purpose to limit its scope, noting that as currently stated this was very broad.

5.2.2 As part of the discussion, the NHS England SIRO Representative asked for further advice on three further points

5.2.2.1 should QResearch continue to be permitted to approve projects without limiting the current scope of the purpose. The Group advised that, it would be acceptable for QResearch to continue to be permitted to approve projects prior to the purpose being reviewed / updated, however advised that a special condition was added to the internal form / application, that the purpose must be updated before a renewal.

5.2.2.2 If so, should QResearch have more of same datasets before limiting the scope of the purpose. The Group advised that it was appropriate for QResearch to have the same datasets before limiting the scope of the purpose.

5.2.2.3 Should QResearch have more COVID-19 data before limiting the scope of the purpose. The Group advised that it was appropriate for QResearch to have more data.

In response to points 2 and 3:

5.2.3 AGD noted that the arrangements in respect of access for non-substantive QMUL staff were **not** in line with current standards, for example, there appeared to be some confusion on the terminology used for honorary contracts / substantive contracts, which may be historical / legacy information left in the data sharing agreement (DSA) following the organisational changes; and advised that NHS England engage with the applicant to ensure this is reviewed and updated with the correct information.

5.2.4 AGD advised that it was unclear what the delegated decision-making process was for someone who may want access to the data via sub-licensing versus honorary contract; and advised that NHS England engage with the applicant to ensure this is reviewed and updated with the correct information.

5.2.5 AGD noted the statement in the internal form / application that “...*Requests for data are reviewed and approved by the QResearch Scientific Committee The Chief Investigator for QResearch and is responsible for ensuring that data access is provided*”; and advised that this should be reviewed, and it should be clear as to whether decision making was with the QResearch Scientific Committee **or** the Chief Investigator, noting that it was currently unclear.

5.2.6 AGD advised the QResearch Scientific Committee Terms of Reference are reviewed to ensure they capture relevant aspects of the [NHS England DARS Standard for Sub-licencing and Onward Sharing of Data](#) including, but not limited to, **1)** the revised purpose (see point 5.2.1); **2)** determining the potential benefits to health in England and Wales; and **3)** that there is a release register.

In response to point 4:

5.2.7 AGD noted no specific concerns with the approach to AI, although noted that the information provided did suggest that traditional algorithmic approaches used previously by QResearch would be undertaken, as opposed to being AI specific.

In response to point 5:

5.2.8 AGD noted that COVID-19 datasets were still requested, and advised that the applicant review the COVID-19 datasets:

5.2.8.1 to ensure they were still required; and

5.2.8.2 any work processing of these datasets was in line with the legal basis, i.e. that research should be for COVID-19 purposes.

In addition to their advice on the specific points raised by NHS England, AGD made the following observations on the application and / or supporting documentation provided as part of the review:

5.2.9 AGD noted the value of the large dataset / research under this application, however advised that NHS England should be mindful of how this may overlap with other similar initiatives to minimise duplication across the system.

	<p>5.2.10 AGD noted, throughout the review of this application, that the advice provided was based on the history of the application as outlined in 5.2.1.</p> <p>5.2.11 Noting the points made on this internal form / application, the Group advised that NHS England request that the applicant provides an update on the points raised in six-months; and suggested it be submitted to AGD for a review on progress.</p>	
<p>5.3</p>	<p>Reference Number: NIC-786513-X5K6V</p> <p>Applicant: University of Newcastle</p> <p>Data Controllers: University of Newcastle Upon Tyne and The Newcastle Upon Tyne Hospitals NHS Trust</p> <p>Application Title: “Using artificial intelligence (AI) to characterize the dynamic inter-relationships between Multiple Long-term conditions and Polypharmacy and across diverse UK populations and inform health care pathways (AI-MULTIPLY)”</p> <p>Observers: Emma Whale and Michael Ball</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 26th March 2026.</p> <p>Application: This was a new application.</p> <p>NHS England were seeking advice on the following points:</p> <ol style="list-style-type: none"> 1. The points raised previously by AGD have been sufficiently addressed. 2. There is sufficient clarity on roles and responsibilities in relation to the work <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 advised that significant concerns had been identified and advised against the proposed data access (dissemination / release). The Group advised that the following should be addressed by NHS England before any further steps are taken:</p> <p>In response to points 1 and 2:</p> <p>5.3.1 AGD noted that the majority of the points raised at the AGD meeting on the 26th March 2026 had been sufficiently addressed, however noted some significant points remained outstanding, including, but not limited to:</p> <ul style="list-style-type: none"> 5.3.1.1 clarification on the exact data flows, including, but not limited to, the management of the pseudonymisation keys; and 5.3.1.2 to be clear how the pseudonymisation keys are transferred between organisations. 5.3.1.3 to state that data flows will cease until there is a legal basis for the data flows in the special condition, noting that the s251 would need updating following the organisational changes. 5.3.1.4 to be clear that no further projects should be permitted without prior approval from NHS England. 	

	<p>5.3.1.5 to ensure it is clear that any linkage to other NHS Trusts would be in the North East and North Cumbria region (or clarify which geographical region if this is incorrect).</p> <p>5.3.1.6 to include the commercial aspect / benefits in line with NHS England DARS Standard for Commercial Purpose.</p> <p>5.3.2 AGD advised that as further information on the organisational changes are known over the coming months, they would encourage a further review of this internal form / application, with further details as outlined above at a future AGD meeting.</p>	
<p>5.4</p>	<p>Reference Number: NIC-243790-Y8K8C-v9</p> <p>Applicant and Data Controller: Carnall Farrar Limited</p> <p>Application Title: “Carnall Farrar’s request for NHS England data permitting detailed insights into population needs and challenges facing the system when shaping sustainable health and social care services”</p> <p>Observers: Denise Pine and Humphrey Onu</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 12th June 2025 and the 18th January 2024.</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 19th January 2023, 3rd February 2022, 4th November 2021, 10th December 2020, 27th February 2020, 10th October 2019 and the 26th September 2019.</p> <p>Application: This was an amendment application requesting additional datasets.</p> <p>NHS England were seeking advice on the following points:</p> <ol style="list-style-type: none"> 1. Whether the application sufficiently justifies the need for each of the additional datasets being requested. 2. Whether the provision of the additional datasets creates additional risk factors for NHS England that are not mitigated within the application. 3. The autonomy given to the commercial company to consider a) its own specific projects; and b) where commissioned by third parties should be strengthened, and if so how. 4. The Purpose section of the data sharing agreement (DSA) provides sufficient clarity on a) the purposes; and b) the process and criteria used by the applicant to decide what research purposes to conduct for specific types of clients and, if not, what additional clarity is needed. 5. Given the breadth of the data being provided as an extract, additional safeguards need to be put in place. <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 advised that significant concerns had been identified and advised against the proposed data access (dissemination / release). The Group advised that the following should be addressed by NHS England before any further steps are taken:</p>	

	<p>In response to points 1 to 5:</p> <p>5.4.1 AGD noted that the purpose, as currently stated, was very broad, and it was therefore difficult to provide NHS England with advice on the appropriateness of the request; noting that without further detail of the purpose, they were unable to determine if what was being requested was reasonable / justified.</p> <p>5.4.2 In addition, AGD noted that the documents provided did not provide any further information / clarification on any recent projects / benefits, and that the latest information on this was from 2023/24. The Group advised that NHS England clarify with the applicant as to whether more up to date information was available, noting that, as it currently stands, the outcomes and benefits to date did not appear to justify the amendment request and noted that this was a risk to NHS England.</p> <p>5.4.3 AGD advised that, in line with other similar applications, they would expect to see further details of any decision making body for approving access to the data, including, but not limited to, Terms of Reference that include 1) quoracy; 2) stakeholder involvement; 3) patient and public engagement; 4) ethics; 5) commercial organisation access; and 6) determining the potential benefits to the healthcare system in England and Wales. AGD advised that NHS England engage with the applicant on this.</p> <p>5.4.4 AGD noted information in the internal form / application that the data would be stored on the applicant’s servers; and advised that NHS England clarify if this is correct with the applicant. It was the understanding of the Group that the data would be stored on the Cloud, and the supplier would need to be named.</p> <p>In addition to their advice on the specific points raised by NHS England, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.4.5 AGD noted that applicant’s published privacy notice was out of date, and advised that the applicant should review and update this as soon as possible.</p> <p>5.4.6 AGD queried why this data could not be accessed in NHS England’s secure data environment (SDE), particularly given the broad purpose outlined; and advised that NHS England explore this further with the applicant.</p>	
<p>5.5</p>	<p>Reference Number: NIC-786702-B8R5P</p> <p>Applicant and Data Controller: Sanius Health</p> <p>Application Title: “Sickle Cell Disease (SCD) Unmet Patient Needs, Standards of Care & National Clinically-Established Treatment Costing Project”</p> <p>Observer: Joe Lawson</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 13th November 2025, 10th July 2025 and the 26th June 2025.</p> <p>Application: This was an amendment application to significantly broaden the purpose for data access from a single defined project to a broad programme of research and other activities.</p> <p>NHS England were seeking advice on the following points:</p>	

1. Whether the purpose provides sufficient clarity on the permitted purposes for using the data.
2. Whether the scope of purpose and the level of delegated decision-making is appropriate.
3. Whether the governance controls give sufficient assurance that risks associated with the delegation of decision-making will be mitigated.
4. Whether the approach to AI use is appropriate and sufficient

Should an application be approved by NHS England, further details would be made available within the [Data Uses Register](#).

Outcome of discussion: AGD advised that significant concerns had been identified and advised against the proposed data access (dissemination / release). The Group advised that the following should be addressed by NHS England before any further steps are taken:

In response to points 1 to 4:

5.5.1 AGD advised that, given the scale of what is being requested by the applicant, i.e. to significantly expand the scope to allow research into other haematology conditions, that it was not appropriate to submit this as an amendment to the existing data sharing agreement (DSA), which was for the purpose of research for one health condition (sickle cell).

5.5.2 AGD noted that the proposed amendment was for a large volume of data to be used across a broad range purposes, for a potentially wide range of clients; and advised that this should be submitted as a new application; and which could include further details, including, but not limited to:

5.5.2.1 a clear justification as to why there was a need / demand from the NHS for the data / research;

5.5.2.2 further information on the expected benefits in line with the [NHS England DARS Standard for Expected Measurable Benefits](#) and a timeline for the benefits;

5.5.2.3 expected outputs in line with the [NHS England DARS Standard for Expected Outcomes](#);

5.5.2.4 clarification of the commercial aspect / benefits in line with [NHS England DARS Standard for Commercial Purpose](#); and

5.5.2.5 clarification as to the independent oversight of any delegated decision-making.

5.5.3 AGD also advised that, as part of a new application, the applicant should consider focussing on specific projects, rather than making the application too broad.

5.5.4 AGD advised that any references to the applicant providing “*research services*” were clearly articulated, including, the types of clients they work with / want to work with.

5.5.5 In addition, if the term “*research*” was used, AGD advised that they should be clearly demonstrating the usual governance was being adhered to for research.

5.5.6 AGD advised that the applicant should review and update any transparency information relating the current / any future work undertaken by the applicant using NHS data, in line with [NHS England DARS Standard for Commercial Purpose](#).

	<p>5.5.7 AGD noted that data under this current DSA was provided in 2025; and advised that the applicant may want to wait to identify the benefits from this research, before submitting a new application for the separate purpose, noting the volume of work that was required by the applicant on any new application.</p> <p>5.5.8 In addition, AGD advised that the applicant should review the Data Uses Register so they are aware of the information in the public domain.</p>	
<p>5.6</p>	<p>Reference Number: NIC-12828-M0K2D-v11</p> <p>Applicant and Data Controller: Imperial College London</p> <p>Application Title: “Imperial College London Dr Foster Unit (ICL DFU) - Research to identify measures of quality and safety of healthcare”</p> <p>Observer: Sara Lubbock</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 21st March 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 24th February 2022, 20th August 2020, 25th June 2019, 11th July 2019, 20th June 2019 and the 13th December 2018.</p> <p>The application and relevant supporting documents were previously presented / discussed at the Data Access Advisory Group (DAAG) meetings on the 2nd August 2016 and the 19th July 2016.</p> <p>Application: This was an amendment application.</p> <p>NHS England were seeking advice on the following points:</p> <ol style="list-style-type: none"> 1. Whether the purpose provides sufficient clarity on the permitted purposes for using the data. 2. The scope of purpose and the level of delegated decision-making is appropriate. 3. The described use of honorary contracts is appropriate or should another mechanism for shared access be considered such as sublicensing or a joint data controllership arrangement. 4. The governance controls give sufficient assurance that risks associated with the delegation of decision-making will be mitigated. 5. The approach to AI use is appropriate and sufficient. 6. The precedent for renewals should be amended to include consideration of whether SDE provision is available <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: In response to the specific points, AGD advised that the following should be addressed before further access (dissemination / release) of data proceeds:</p> <p>In response to point 1:</p> <p>5.6.1 AGD discussed the purpose outlined in the internal form / application, and advised that it is broadly clear on the permitted purposes for using the data; however, noted that further</p>	

	<p>detail on the specific projects should be included in the internal form / application; and advised that NHS England engage with the applicant on this.</p> <p>In response to point 2:</p> <p>5.6.2 AGD discussed the purpose and the level of delegated decision-making and whether this was appropriate; and advised that, for consistency and in line with other delegated decision making type models, that NHS England engaged with the applicant to ensure that further information on this, including, but not limited to requesting further information on the governance arrangements for the delegated decision making.</p> <p>In response to point 3 and 4:</p> <p>5.6.3 AGD advised that a significant amount of information was still required in respect of 1) the process for deciding on which projects are supported; and 2) the signing of the honorary contracts; noting that if, for example an individual was working under an honorary contract but were making decisions on projects, then in line with NHS England DARS Standard for Data Controller(s), then they may be considered a joint Data Controller; and advised that an honorary contract should not be used in any instance where there were clear data controller responsibilities.</p> <p>5.6.4 AGD queried how many individuals would be on honorary contracts, and advised that NHS England engage with the applicant to clarify this information.</p> <p>5.6.5 AGD also advised that the internal form / application was updated to be clear which staff from which organisations were eligible for an honorary contract, noting that other published information advised that the applicant was offering wider research access. The Group advised that NHS England engage with the applicant on this to ensure that what was being offered was in line with what is permitted in the data sharing agreement (DSA).</p> <p>In response to point 5:</p> <p>5.6.6 AGD advised that they had no major concerns with the approach to AI, based on the information provided.</p> <p>In response to point 6:</p> <p>5.6.7 AGD queried why this data could not be accessed in NHS England’s secure data environment (SDE), particularly given the broad purpose outlined; and advised that NHS England explore this further with the applicant, including, but not limited to, a clear time bound plan to transition to NHS England’s SDE.</p>	
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		
8.1	Oversight and Assurance Process	

	<p>The Statutory Guidance 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 1) four applications (selected by the AGD Secretariat); 2) internal application assessment forms for each of the four applications (where available); and 3) an oversight and assurance template to complete for each of the applications that each individual member had been asked to review.</p> <p>Following review of the applications by the AGD independent members out of committee, the completed oversight and assurance templates were sent to the AGD Secretariat prior to the meeting.</p> <p>It was noted that only high-level points 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 appendix A for high-level points raised in-meeting on the four applications.</p>
<p>8.2</p>	<p>Oversight and Assurance Conclusion / Review</p> <p>AGD noted that the last oversight and assurance for workstream 1 review had taken place on the 5th March 2026.</p> <p>The Group noted that in all cases the appropriate precedent / reuseable decision had been used.</p> <p>The Group noted that for some applications, 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.</p> <p>The Group noted the diligence of DARS to update the abstract with the Knowledgebase reference and where the SDA / Escalation form was not available that the abstract contained enough information for the review.</p> <p>The Group thanked the NHS England Risk & Assurance Team for providing the outputs from the review timely.</p> <p>The Group thanked the AGD Secretariat for the background information provided in the agenda pack, which was invaluable to an effective review including clear labelling and relevant screenshots.</p> <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.</p>
<p>9 AGD OPERATIONS</p>	
<p>9.1</p>	<p>AGD ways of working</p> <p>The Group were advised that the AGD Chair was still in the process of having 1-2-1 discussions with AGD members / delegates, to discuss / seek views on the proposed AGD new ways of working.</p>

	The Group noted a half day AGD plenary meeting would take place on the 21 st May 2026, to discuss the AGD ways of working, including the proposed updated AGD Terms of Reference, which were currently with the NHS England SIRO Representative and the AGD Secretariat for initial comments.
9.2	<p>AGD Stakeholder Engagement</p> <p>Federated Data Platform</p> <p>The Group's representative on the Federated Data Platform Data Governance Group provided a brief update.</p>
9.3	<p>AGD Project Work</p> <p><i>There were no items discussed</i></p>
10 Any Other Business	
10.1	<p>NHS England Data Access Request Service (DARS) internal form / application form</p> <p>AGD noted that following the presentation to the Group on the 26th February 2026 to discuss the NHS England DARS internal form / application form, the Group had now started to receive revised forms for discussion in-meeting. The Group noted that some feedback had been provided to NHS England over recent weeks, and that a more in-depth discussion would take place at the AGD Plenary meeting on the 18th June 2026.</p>
10.2	<p>UK Biobank</p> <p>An AGD independent member noted that there have been various public statements from organisations in respect of the recent UK Biobank data incident, and queried whether NHS England would be releasing a statement. The NHS England SIRO Representative advised that NHS England had not issued a statement, but may do so in the future if appropriate.</p>
Meeting Closure	
As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.	

Appendix A

Oversight and Assurance Review – 7th May 2026

Ref:	NIC Number:	Organisation:	Areas to consider:
260507a	NIC-134719-D5W2Y-v1.2	University Hospitals Bristol and Weston NHS Foundation Trust	<p>The application had last been seen by IGARD on the 10th November 2022</p> <p>Feedback on the application:</p> <ul style="list-style-type: none"> • The Group noted that it appeared the DSPT status had slipped. • The Group welcomed the provision of the ACR but queried if the signatory had authority to sign on behalf of the organisation <p>Feedback on process:</p> <ul style="list-style-type: none"> • Process point: Action for D&A Representative to ensure its clear in the documentation if the DSPT status has slipped, what actions have been undertaken, for example an improvement plan • Process point: Action for SIRO Representative to consider whether scheduled audit outcomes should be visible at the next O&A review
260507b	NIC-168879-K2N8Q-v1.5	University College London	<p>The application had last been seen by IGARD on the 10th November 2022</p> <p>Feedback on application:</p>

			<ul style="list-style-type: none"> • Without provision of the SDA / escalation form, it was unclear what had happened to the DSA during its lifetime, and would be difficult therefore to audit. • The Group queried whether a new special condition creating a fresh positive compliance obligation on the applicant should progress under the Simple Extension precedent. • It did not appear that the application had been updated in line with the NHSE DARS Standards, and it was therefore unclear how the application had progressed under precedent / reusable decision • It appeared from the documentation provided, that no annual ACR had been completed by the applicant since January 2025. <p>Feedback on process:</p> <ul style="list-style-type: none"> • Process point: Action for D&A Representative to ensure that all relevant documentation, for example the SDA / escalation form, is uploaded to CRM and easily findable – the Group noted section 1 of the application was completed. • Process point: Action for D&A Representative to ensure annual ACRs are completed timely. • Process point: Action for D&A Representative to ensure that all relevant documentation, for example the latest ACR, is uploaded to CRM and easily findable
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			<ul style="list-style-type: none"> • Process point: Action for SIRO Representative to consider whether no provision of an ACR should be an exclusion criterion
260507c	NIC-682587-K5N5K-v1.3	UK Health Security Agency	<p>The application had last been seen by AGD on the 25th May 2023</p> <p>Feedback on application:</p> <ul style="list-style-type: none"> • It appeared from the documentation provided, that no annual ACR had been completed by the applicant since May 2024. • Whether an application relying on s251 support as the common law duty of confidentiality route, note the approval / expiry date so that reviewers can confirm cover runs until the new DSA end date <p>Feedback on process:</p> <ul style="list-style-type: none"> • Process point: Action for D&A Representative to ensure annual ACRs are completed timely. • Process point: Action for D&A Representative to ensure that all relevant documentation, for example the latest ACR, is uploaded to CRM and easily findable • Process point: Action for SIRO Representative to consider whether no provision of an ACR should be an exclusion criterion
260507d	NIC-75079-V7Y7L-v2.3	Bangor University	<p>The application had last been seen by IGARD on the 5th March 2020</p> <p>Feedback on application:</p>

			<ul style="list-style-type: none"> • Without provision of the SDA / escalation form, it was unclear what had happened to the DSA during its lifetime, and would be difficult therefore to audit • It appeared from the documentation provided, that no annual ACR had been completed by the applicant <p>Feedback on process:</p> <ul style="list-style-type: none"> • Process point: Action for D&A Representative to ensure that all relevant documentation, for example the SDA / escalation form, is uploaded to CRM and easily findable – the Group noted section 1 of the application was completed. • Process point: Action for D&A Representative to ensure annual ACRs are completed timely. • Process point: Action for D&A Representative to ensure that all relevant documentation, for example the latest ACR, is uploaded to CRM and easily findable • Process point: Action for SIRO Representative to consider whether no provision of an ACR should be an exclusion criterion
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