Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 24th July 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)
Claire Delaney-Pope (CDP)	AGD independent member (Specialist Information Governance Adviser)
Dr. Arjun Dhillon (AD)	NHS England member (Caldicott Guardian Team Representative (in attendance for items 1 to part of 5.5, and item 6)
Dr. Robert French (RF)	AGD independent member (Specialist Academic / Statistician Adviser) (in attendance for items 1 to 4.1)
Kirsty Irvine (KI)	AGD independent member (Chair)
Narissa Leyland (NL)	NHS England member (Data and Analytics Representative (Delegate for Michael Chapman))
Andrew Martin (AM)	NHS England member (Data Protection Office Representative (Delegate for Jon Moore))
Jenny Westaway (JW)	AGD independent member (Lay Adviser)
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	**Role / Area:**
Garry Coleman (GC)	NHS England SIRO Representative
Ayse Depsen (AD)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer:** item 5.2)
Liz Gaffney (LG)	Assistant Director of Data Access & Partnerships: Head of Data Operations, Data and Analytics, Transformation Directorate (**Presenter:** item 6)
Maddie Laughton (ML)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer:** item 5.1)
Joe Lawson (JL)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer:** items 5.3 and 5.4)

Jon Moore (JM)	Data Protection Officer, Privacy, Transparency and Trust (PTT), Deputy Chief Executive Directorate (**Presenter**: item 7)
James Watts (JW)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer:** items 5.1 and 5.5)
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Deputy Chief Executive Directorate
INDEPENDENT ADVISER OBSERVERS IN ATTENDANCE	
Dr. Jon Fistein	Independent Adviser
Professor Jo Knight	Independent Adviser
Dr. Mark McCartney	Independent Adviser
AGD INDEPENDENT MEMBERS / NHS ENGLAND MEMBERS NOT 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)
Dr. Jonathan Osborn (JO)	NHS England member (Caldicott Guardian Team Representative)
Miranda Winram (MW)	AGD independent member (Lay Adviser)

1	**Welcome and Introductions:** The AGD Chair welcomed attendees to the meeting. AGD noted that only two AGD NHS England members were in attendance for part of item 5.5 and items 7 to 12.1, but 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.
2	**Review of previous AGD minutes:** The minutes of the AGD meeting on the 10th July 2025 were reviewed out of committee by the Group and, after several minor amendments, were agreed as an accurate record of the meeting by the Chair of AGD, on behalf of the Group.
3	**Declaration of interests:** Claire Delaney-Pope noted a professional link to King's Health Partners (NIC-696708-J3L1R-v0.10 King's College London) 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 on this application.
4 CONFIDENTIAL ADVICE SESSION	
4.1	AGD were provided with a verbal update regarding the context and current thinking around amended governance arrangements for applications to access NHS England data in the ONS Trust Research Environments (TREs). AGD noted the verbal update from NHS England, discussed the context and current thinking, and looked forward to a more detailed discussion of any proposed interim arrangements at a future AGD meeting.
5 EXTERNAL DATA DISSEMINATION REQUESTS:	
5.1	**Reference Number:** NIC-696708-J3L1R-v0.10 **Applicant:** King's College London **Data Controller(s):** King's College London & Guy's & St Thomas' NHS Foundation Trust **Application Title:** The South London Stroke Register: Improving the lives of stroke survivors with data **Observer(s):** Maddie Laughton, James Watts **Previous Reviews:** The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 3rd August 2023. **Linked applications:** NIC-729128-M5N1F **Application:** This was a new application. NHS England were seeking general advice on the application. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** The majority of the Group were supportive of the application; a minority of the Group (one member) were **not** supportive due to the application applying the national data opt out where there was consent. The Group wished to draw to the attention of the SIRO the following substantive comments: **5.1.1** The majority of the Group, including the AGD NHS England Caldicott Guardian Team Representative (with one member dissenting) took the view that in the circumstances, if it was not practical to determine who within the cohort has consented, and who was included under consultee advice, then the application of the national data opt out (NDO) to all cohort members was reasonable, given the different datasets and complexity of the cohort. Nonetheless, the Group thought it should first be confirmed it is impractical to determine who is under consultee advice and who had provided consent. Also, if it was impractical, it was unclear to the dissenting member why overriding consent, by applying the NDO, should be the preferred option as opposed to overriding the NDO as a result of relying on consent/consultee advice. In either situation, as a result of the conflicted position, the choices of some individuals may not be honoured.

	5.1.2 Separate to the application and for NHS England to consider: to document clearly how to manage the differing scenarios involving the NDO in the event of consultee advice. In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review: **5.1.3** AGD suggested that access arrangements for substantive employees be clarified to ensure consistency across both the data sharing agreement (DSA) and applicant's governance documentation and that **1)** section 5(a) was updated to clarify only substantive employees would access the data; **2)** section 5(a) be updated to clarify how the data would be accessed; **3)** SD9.1 '*NIHR202339 Data Access TOR'* be updated to refer to only substantive employees accessing the data; **4)** further information was provided as to who would be covered by "agents" or this word was removed, as may be necessary to reflect the facts. **5.1.4** AGD noted reference in section 5(a) (Objective for Processing) and SD9.1 '*Data Access Terms of Reference (TOR)*' that membership of the stakeholder engagement group did not appear to include lay members / independent members and suggested the applicant may wish to consider lay / independent members on the group. **5.1.5** In addition, the Group noted reference in section 5(d) (Benefits) to the stakeholder engagement group, but that the website has **not** been updated regarding the group since 2023; and suggested the website and/or application are updated as appropriate. **5.1.6** AGD suggested that the narrative in section 5(a) "*limited to a study cohort of 7,500 stroke patients who consented to participate*" be updated to reflect the different ways the cohort had been formed, by including reference to s251 support and consultee advice. **5.1.7** AGD noted that that linkage was not available for a certain section of the cohort because the NHS number had not been collected by the research team, and were supportive of using other identifiers to link, if there was a legal basis do so. **5.1.8** AGD noted reference in SD8.1 '*22CAG0021 HRA Amendment'* to King's College Hospital; NHS Foundation Trust DSPT, and, noting they are **not** party to the DSA as a Data Controller / Data Processor, suggested that NHS England follow this up with the applicant. **5.1.9** AGD noted that funding was in place until December 2026, however the application end date was 31st July 2028 and suggested that **1)** NHS England clarify with the applicant that there is funding in place for the duration of the DSA, for example to ensure there is sufficient funds to sustain the project through to possible archiving and destruction; and **2)** the NHS England Data Access Service (DAS) internal application assessment form was updated to reflect any discussions on this point with the applicant. **5.1.11 Separate to this application and for NHS England to consider:** AGD reiterated previous advice from the 15th May 2025 and 25th January 2024, that NHS England considered having an NHS England DAS Standard for programmatic access in order to support a consistent policy approach; and how any programmatic access is aligned with the DHSC Data Access Policy (consultation) that states *"Secure data environments (SDEs) will become the default route for accessing NHS data for research and external uses. Instances of disseminating NHS data outside of an SDE for research and external uses will be extremely limited"*. **5.1.12** No AGD member noted a commercial aspect to the application.	SIRO Rep SIRO Rep

5.2	**Reference Number:** NIC-715080-X0J9J-v0.4 **Applicant:** The University of Manchester **Data Controller:** The Christie NHS Foundation Trust **Application Title:** Understanding causal relationships between socio-economic inequalities, multi-morbidity, and cancer treatment and outcomes **Observer:** Ayse Depsen **Application:** This was a new application. NHS England were seeking general advice on the application. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** AGD were supportive of the application **if** the following substantive comments were addressed, and wished to draw to the attention of the SIRO the following substantive comments:0 **5.2.1** AGD noted in the NHS England Data Access Service (DAS) internal application assessment form, that the Chief Investigator (CI) and Co-Chief Investigator (Co-CI) held honorary contracts with the Christie NHS Foundation Trust (FT). Noting the University of Manchester are **not** named in the application as a Data Controller / Data Processor, and notwithstanding the discussions already held with the applicant on this point, the Group suggested that in line with NHS England's DAS Standard for Honorary Contracts and NHS England DAS Standard for Data Controllers, NHS England clarify with the applicant that **1)** what the supervision arrangements are for the CI / Co-CI; **2)** who at the Christie NHS FT is determining the purpose and means; **3)** the CI / Co-CI's substantive employer are **not** responsible for determining the purpose and means of processing and therefore **not** carrying out any data controllership activities; **4)** the University of Manchester would **not** be credited on any academic outputs and **5)** to update the application to reflect the correct / factual information. **5.2.2** AGD also suggested that NHS England clarify with the applicant the arrangement whereby the CI / Co-CI providing authorisation / decisions around access to systems is workable, given the CI / Co-CI are under honorary contracts. In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review: **5.2.3** AGD noted that date of death was flowing and suggested that this was reviewed / assessed to determine whether this would in fact make the data identifiable and would therefore be confidential patient data; and suggested section 5a (Objective for Processing) was updated with a statement regarding the determination. **5.2.4 Separate to the application and for NHS England to consider:** The AGD Chair reiterated a point from the 23rd January 2025, 12th December 2024 and the 10th October 2024, that NHS Digital had reached a position with the National Data Guardian in that NHS Digital / England should be carrying out an assessment about the risk of identification. AGD noted that this was not being always completed, NHS England agreed that this should be part of the Q&A. NHS England Data and Analytics Representative offered to follow this up.	D&A Rep / SIRO Rep

	5.2.5 Noting the assertion by the applicant that the University of Manchester were **not** part of the data sharing agreement (DSA), the applicant had approached the University's ethics committee rather than followed the Christie NHS FT's research sponsorship process; the Group suggested that the NHS England DARS Standard for Ethical Approval had not been followed and that NHS England discuss further with the applicant. **5.2.6** AGD noted that to initiate the project the study team would organise a patient and public involvement and engagement (PPIE) workshop to shape the design of the study, but suggested that there was PPIE throughout the lifecycle of the work. The HRA guidance on Public Involvement is a useful guide. **5.2.7 Separate to the application and for NHS England to consider:** The Group noted that NHS England did not have an applicable PPIE Standard, and suggested that NHS England consider a 'PPIE Standard', as suggested by the Group previously. **5.2.8** AGD noted that funding was in place until 31st July 2025, however the application end date was 31st July 2028 and suggested that **1)** NHS England clarify with the applicant that there is funding in place for the duration of the DSA, for example to ensure there is sufficient funds to sustain the project through to possible archiving/ data destruction; and **2)** the NHS England Data Access Service (DAS) internal application assessment form was updated to reflect any discussions on this point with the applicant. **5.2.9** AGD suggested that section 2(c) (Territory of Use) was updated to align with the flows of data outlined in the application, to reflect that the territory of use is *"England and Wales"* and not *"UK",* unless a justification can be provided for "*UK*". **5.2.10** AGD suggested that section 3(c) (Patient Objections) was updated from "*yes*" patient objections applied to "*no*". **5.2.11** No AGD member noted a commercial aspect to the application.	SIRO Rep
5.3	**Reference Number:** NIC-694476-T3R6K-v0.10 **Applicant and Data Controller:** University of Aberdeen **Application Title:** HEALTH: a randomised comparison of laparoscopic supracervical hysterectomy with endometrial ablation for women with heavy menstrual bleeding – medium-term follow-up at a minimum of five years **Observer:** Joe Lawson **Application:** This was a new application. NHS England were seeking general advice on the application. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** AGD were supportive of the application **if** the following substantive comments were addressed, and wished to draw to the attention of the SIRO the following substantive comments: **5.3.1** There was a lengthy discussion with regard to the gateway in consent to flow the data for the cohort of 387. The Group suggested that NHS England explore with the applicant the level of engagement the applicant had with cohort members since the original consent had	

	been sought, for example, which cohort members had actively engaged with the follow up questionnaire, which cohort members had not responded to the follow up questionnaire, **5.3.2** Pending the outcome of the engagement, a number of options were available to NHS England to receive assurance that there was a legal gateway in consent and in line with the Caldicott Principles, for example **1)** to consult with a small representative sample of the cohort to check their expectation of the time period during which their medical records would be accessed; **2)** to provide additional transparency materials to the cohort setting out how their data was being processed and how a cohort member could withdraw from the study. In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review: **5.3.4** AGD welcomed the application and noted that this was valuable research. **5.3.5** The AGD NHS England Caldicott Guardian Team Representative noted their support for the application, and that the Caldicott Guardian Team would be available to support NHS England Data Access Request Service (DARS) with any further conversations with the applicant. **5.3.6** The Group suggested that the tables in 3(b) (Additional Data Access Requested) be updated to be clear the data was "*identifiable*", not "*pseudo/anonymised*". **5.3.7** No AGD member noted a commercial aspect to the application.	
5.4	**Reference Number:** NIC-761685-K1C1Z-v0.5 **Applicant and Data Controller:** University of Aberdeen **Application Title:** Female Urgency, Trial of Urodynamics as Routine Evaluation (FUTURE study); a superiority randomised clinical trial to evaluate the effectiveness and cost effectiveness of invasive urodynamic investigations in management of women with refractory overactive bladder symptoms **Observer:** Joe Lawson **Application:** This was a new application. NHS England were seeking general advice on the application. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** AGD were supportive of the application and wished to draw to the attention of the SIRO the following comments. **5.4.1** AGD has queried in advance of the meeting why the data would be onwardly shared by the University of Aberdeen (UoA) with the University of Sheffield (UoS). The applicant had responded that the health economist based at the UoS was unable to use the UoA's existing remote access solutions. The Group suggested that NHS England have sight of the relevant processing agreement between the UoA and UoS and that a copy be uploaded to NHS England's customer relationship management system (CRM) for future reference. **5.4.2** In addition, AGD suggested that section 5(b) (Processing Activities) of the application be updated with a clear and robust rationale for the UoA onwardly sharing data with the UoS, and why the UoA cannot provide the necessary UoA equipment for the health	

	economist to access the data remotely (which would reduce the risk arising from additional copies of data). **5.4.3** AGD queried in advance of the meeting the study end date since it determines when the ten-year data retention period begins. The Group thanked the applicant for the additional information but suggested that further consideration be given to when the 10-year period starts and it is clearly communicated in relevant transparency materials such as the privacy notice. **5.4.4** No AGD member noted a commercial aspect to the application.	
5.5	**Reference Number:** NIC-786978-Z6K4M-v0.4 **Applicant and Data Controller:** Abiomed Ltd **Application Title:** Understanding the Use of Impella in Patients Undergoing High-Risk Protected Percutaneous Coronary Interventions in the UK (24 NAPCI 01). **Observer(s):** James Watts **Previous Reviews:** The application and relevant supporting documents were previously presented at the AGD meeting on the 3rd July 2025 where the item was withdrawn by NHS England prior to the meeting. **Application:** This was a new application. NHS England were seeking advice on the following points, including general advice on any other aspect of the application: 1. the parties; 2. the purpose; 3. the territory of use Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** AGD were **not** supportive of the application **at this time** and wished to draw to the attention of the SIRO the following substantive comments, and suggested that any further application be brought back to a future meeting: 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. **In response to point 1:** **5.5.1** In line with the NHS England DARS Standard for Data Controllers, AGD suggested that given the small number of staff employed by Abiomed Limited and the justification given for Abiomed Inc accessing the data, Abiomed Limited were **not** in a position to determine the purpose and means of the processing of the data, and therefore could **not** be the Data Controller. AGD were therefore **not** supportive of a data sharing agreement (DSA) with Abiomed Ltd as the sole data controller. **5.5.2** AGD noted that the 'Chief Investigator' was based in Boston, United States of America (USA) and noted the discrepancy between the SDA which stated the 'chief investigator' was employed by Abiomed Ltd, but section 5(b) (Processing Activities) noted the 'Principal	

	Investigator' was an employee of Johnson & Johnson Medical Ltd, and suggested this was further explored by NHS England to ensure the correct parties were cited in any DSA. **5.5.3** AGD suggested that the application was updated to reflect the true facts with regard to who was a data controller(s) / data processor(s) in line with NHS England's DARS Standard for Data Controllers / NHS England DARS Standard for Data Processors, and noted that being a commercial organisation based in the USA was not a bar to submitting an application to NHS England, nor receiving data from NHS England. **5.5.4** AGD also suggested that the commercial aspect of the application in section 5e (Is the Purpose of this Application in Anyway Commercial), was replicated / expanded for transparency in (the published) section 5(a) (Objective for Processing), in line with NHS England's DAS Standard for Objective for Processing and NHS England's DAS Standard for Commercial Purpose. **In response to point 2:** **5.5.5** In addition, and subject to the data controllership queries raised, AGD suggested that the applicant clearly demonstrate there is a benefit to health and social care in England and Wales in order for NHS England to be confident it is meeting the requirements under the Health & Social Care Act 2012, as amended by the Care Act 2014 and in line with the NHS England DARS Standard for Commercial Purpose, and that section 5(a) and section 5(e) were updated with an assessment of the balance between public and commercial benefit, in line with the National Data Guardian (NDG) guidance on benefits. **5.5.6** Noting the applicant stated "*yes*" in answer to the question "*is your study research*" on the HRA REC tool, provided as SD2, AGD suggested the further clarity was sought from the applicant as to whether this is in fact service evaluation as stated in the data sharing agreement (DSA); and to update section 5 of the application to reflect the correct / factual information. **In response to point 3:** **5.5.7** AGD noted that NHS England's due process with regard territory of use and remote access from the USA is through the Privacy, Transparency and Trust (PTT) assessment, and noted that it was essential to ensure the correct data controller(s) / data processor(s) were named on the DSA, and before that assessment was undertaken by PTT. In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review: **5.5.8** The Group noted the project was reviewed and supported by the NICOR Research Access Committee (RAC) in October 2024, and would **not** have expected RAC to assess the application from an NHS England perspective nor in line with NHS England's DARS Standards, for example the NHS England DARS Standard for Data Controllers. **5.5.9** AGD noted that there **was** a commercial aspect to the application.	
6	**Secure Data Environment (SDE) Briefing (Presenter: Liz Gaffney)** AGD were provided with a comprehensive verbal update of NHS England's SDE. Noting discussions with NHS England when providing advice on applications, AGD queried how data was minimised. Liz confirmed that data was minimised in line with section 3(a) (Data Access Already Given) and 3(b) (Additional Data Access Requested) of the data	

	sharing agreement (DSA). Liz also confirmed that the data minimisation within the SDE worked akin to an extract, in that if an applicant had a DSA specifying only a certain number of data fields within a dataset, then the view provided within the SDE would be restricted to the data fields listed in the DSA. The Group noted that, during a number of discussions around data minimisation linked to applications presented, NHS England colleagues had advised that the applicant would be asked to undertake some data minimisation rather than the NHS England data wranglers. Liz confirmed that this was **not** the approach taken by NHS England and that the NHS England data wranglers minimised the data in alignment with section 3(a) and 3(b) of the application and prior to the applicant accessing the data in the SDE, therefore the data is minimised per DSA not per project(s) within a DSA. The Group queried whether output checking included checking proposed outputs from the SDE for their alignment with the purpose of the DSA. Liz confirmed that this was not the case, as per wider SDE Policy, noting that it is an organisation's responsibility to ensure that it complies with its DSA. The Group noted that recent public engagement had strongly advocated for output checking and suggested that NHS England may wish to consider its transparency and ensure that it is not giving more reassurance to the public, than what is actually happening. The Group noted the NHS England output checking guidance was clear on disclosure controls. The AGD NHS England Caldicott Guardian Team Representative queried how the data minimisation was undertaken: by package or via data field. Liz confirmed that dependent on the dataset, the data minimisation would be undertaken either by package or via data field, this is included on NHS England's public website. The Group suggested a further discussion at a future AGD. **ACTION:** AGD Secretariat to invite NHS England Data Portfolio Management to a future meeting of AGD, to discuss to the technicalities of data minimisation within the SDE. The Group queried the auditing capability of the SDE and the dashboards it created. Liz confirmed that all user interaction is recoded and audit logs were available, but would welcome any case studies or worked examples around users accessing data, from AGD for the SDE Team to explore. AGD suggested that as part of any audit checks, NHS England may wish to consider capturing IP addresses/locations to ensure they aligned with the DSA. **ACTION:** AGD to provide Liz Gaffney with case studies / examples with regard to users accessing data. AGD queried what would happen when a DSA ends and Liz confirmed that prior to the DSA ending, applicants receive a number of emails, before the SDE access was terminated on the same date the application ends. Liz did confirm that that NHS England have a retention period once access is removed, and that the SDE Team were looking to automate this process. AGD thanked Liz for the informative and comprehensive update provided, and looked forward to further engagement at future AGD meetings.	AGD Sec AGD
7	**Data (Use and Access) Act 2025 (Presenter: Jon Moore)**	

	AGD were provided with a verbal update with regard to the Data (Use and Access) Act 2025, and in particular an update with regard to the background to the Act; research; new lawful basis; purpose limitation; automated decision making; internal data transfers; complaints; information standards; Information Commissioner. AGD thanked Jon for the update provided and noting that a number of provisions will come into force over the coming 12 months, looked forward to updates / briefings at a future AGD meeting, and as appropriate.	
8 INTERNAL DATA DISSEMINATION REQUESTS:		
There were no items discussed		
9 EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL		
There were no items discussed		
10 OVERSIGHT AND ASSURANCE		
There were no items discussed		
11 AGD OPERATIONS		
11.1	**Standard Operating Procedures (SOPs)** *Due to time constraints this item was not discussed.*	
11.2	**AGD Stakeholder Engagement** *Due to time constraints this item was not discussed.*	
11.3	**AGD Project Work** *Due to time constraints this item was not discussed.*	
12 Any Other Business		
12.1	*Due to time constraints this item was not discussed.*	
Meeting Closure As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.		