

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 27th March 2025

09:00 – 15:10

(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. Robert French (RF)	AGD independent member (Specialist Academic / Statistician Adviser)
Kirsty Irvine (KI)	AGD independent member (Chair)
Dr. Phil Koczan (PK)	NHS England member (Caldicott Guardian Team Representative (Delegate for Dr. Jonathan Osborn)) (Items 1 to 5.4 and 7.1 to 7.2)
Andrew Martin (AM)	NHS England member (Data Protection Office Representative (Delegate for Jon Moore))
Dr. Jonathan Osborn (JO)	NHS England member (Caldicott Guardian Team Representative) (Items 8.1 to 10.1)
Jenny Westaway (JW)	AGD independent member (Lay Adviser)
Tom Wright (TW)	NHS England member (Data and Analytics Representative (Delegate for Michael Chapman)) (not in attendance for item 8.2)
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	Role / Area:
Jack Bennett (JB)	NHS DigiTrials, Data and Analytics, Transformation Directorate (Observer: item 5.3)
Garry Coleman (GC)	NHS England SIRO Representative (not in attendance for items 8.2 to 8.4, 9.1 to 9.5 and 10.1)
Ayse Depsen (AD)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.2)

Laura Evans (LE)	NHS DigiTrials, Data and Analytics, Transformation Directorate (Observer: item 5.3)
Andrew Ireland (AI)	Information Governance Specialist, IG Risk and Assurance, Privacy, Transparency, and Trust (PTT), Delivery Directorate (Observer: items 8.1 and 8.2)
Joe Lawson (JL)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.1)
Harry Millard (HM)	Information Governance Officer, IG Risk and Assurance, Privacy, Transparency, and Trust (PTT), Delivery Directorate (Observer: items 8.1 and 8.2)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Delivery Directorate
AGD INDEPENDENT MEMBERS / NHS ENGLAND MEMBERS <u>NOT</u> IN ATTENDANCE:	
Name:	Role / Area:
Michael Chapman (MC)	NHS England member (Data and Analytics Representative)
Prof. Nicola Fear (NF)	AGD independent member (Specialist Academic Adviser)
Jon Moore (JM)	NHS England member (Data Protection Office Representative)
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 only two AGD NHS England members were in attendance for item 8.2.</p> <p>Noting that the AGD Terms of Reference state that “<i>The quorum for meetings of the Group or a Sub-Group is five members, including at least three independent members, one of whom may be the Chair, Deputy Chair or Acting Chair and two of the three NHSE Members...</i>”, the Group agreed that, as there were two AGD NHS England members present, the meeting was still quorate for all agenda items and agreed to proceed on that basis.</p>
2	<p>Review of previous AGD minutes:</p> <p>The minutes of the AGD meeting on the 20th March 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>Dr. Robert French noted a professional link to the application and applicant of NIC-672111-H3R2T (Imperial College London). It was agreed that Dr. French would not be part of the discussion for this application and left the meeting for this part of the agenda.</p> <p>Dr Robert French noted a professional link to the applicant of NIC-654590-Y0S1H (Cardiff University), but noted no specific connection with this application and it was agreed this was not a conflict of interest.</p> <p>Dr. Robert French noted a declaration of interest with NIC-184980-J5B6C and NIC-734202-N9F7P (Cardiff University), as part of his role at Cardiff University; but noted no specific connection with the applications or applicants and it was agreed that there was no conflict of interest.</p> <p>Paul Affleck noted a professional link to the University of Leeds, but noted no specific connections with the application NIC-649110-Z5S0L (University of Birmingham) or staff involved, and it was agreed that this was not a conflict of interest.</p>
4 BRIEFING PAPER(S) / DIRECTIONS:	
<i>There were no items discussed</i>	
5 EXTERNAL DATA DISSEMINATION REQUESTS:	
5.1	<p>Reference Number: NIC-776147-F5N3V-v0.4</p> <p>Applicant: Queen Mary University of London</p> <p>Data Controllers: Cambridge University Hospitals NHS Foundation Trust and University of Cambridge</p> <p>Application Title: “BEST-4 Heartburn Health Programme - Outcomes (NHS Numbers)”</p> <p>Observer: Joe Lawson</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 6th February 2025.</p> <p>Linked applications: This application is linked to NIC-753801-J5B3X.</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>

5.1.1 AGD noted and commended NHS England's Data Access Service (DAS) on seeking early advice from the Group on this application on the 6th February 2025, and noted that the application had been updated in line with the advice provided.

5.1.2 AGD noted that at the AGD BAU meeting on the 6th February 2025, the Group had suggested that it was the responsibility of the applicant to satisfy themselves that the Research Ethics Committee (REC) support covers the proposed flows and processing of data. The Group noted, in the NHS England Data Access Service (DAS) internal application assessment form, that the applicant had advised that the patient and public involvement and engagement (PPIE) representative had provided assurance that there were no ethical issues with the use of the data for this purpose. AGD noted that it was the responsibility of the applicant to satisfy themselves and **not** the PPIE representative but recognised the importance of gaining this feedback from this group to inform any decision.

5.1.3 AGD noted that at the AGD BAU meeting on the 6th February 2025, the Group had suggested that NHS England explore with the applicant the involvement of the Chief Investigators (of the BEST4 Platform/screening trial) and to seek assurance that these individuals were **not** responsible for determining the purpose and means of processing, and were therefore **not** carrying out any data controllership activities, in line with the [NHS England's DARS Standard for Data Controllers](#). Notwithstanding the discussions already held with the applicant on this point, the AGD NHS England Data Protection Office Representative and AGD suggested that either **1)** further clarity was provided in section 5(a) (Objective for Processing) that the Chief Investigators' substantive employers were **not** responsible for determining the purpose and means of processing, and were therefore **not** carrying out any data controllership activities; or **2)** to update the application to reflect the correct / factual information.

5.1.4 AGD suggest that future version of the consent materials were updated to be clear of the 'address' requirements from participants.

5.1.5 AGD suggested that the references to *"trial"* in section 5 (Purpose / Methods / Outputs), were reviewed and updated where appropriate to refer to *"programme"*.

5.1.6 AGD noted and commended the PPIE undertaken by the applicant to date; however, suggested that the information relating to PPIE in section 5(a) was amended to remove reference to processing of the data *"without explicit consent"*, noting that this was not relevant to this stage of the processing.

5.1.7 AGD suggested that the commercial aspect of the application in section 5(e) (Is the Purpose of this Application in Anyway Commercial), was replicated / expanded for transparency in (the published) section 5(a), in line with [NHS England's DAS Standard for Objective for Processing](#) and [NHS England's DAS Standard for Commercial Purpose](#).

5.1.8 AGD noted that there **was** a commercial aspect to the application.

5.2	<p>Reference Number: NIC-672111-H3R2T-v0.4</p> <p>Applicant and Data Controller: Imperial College London</p> <p>Application Title: “Follow-up of participants in the After Diagnosis Diabetes Research Support System-2 (ADDRESS-2) Cohort”</p> <p>Observer: Ayse Depsen</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 that prior to the meeting, a query had been raised by an AGD independent member, in respect of what would happen to data flowed by NHS England once a participant turns 16 years of age, noting that parental consent is only in place for those under the age of 16. AGD were advised by NHS England, in-meeting, that the applicant had confirmed that once a participant reaches the age of 16, only pseudonymised data already obtained would be processed, and that there would be no attempt to re-identify or link the data. The Group noted the verbal update provided, and acknowledged that whilst there are associated ethical issues with this, this was consistent with other research studies, where participants would turn 16 during the study. The Group also noted that it was a common approach to obtain consent from cohort members once they have turned 16 to permit the continued processing of identifiable data.</p> <p>5.2.2 AGD noted and discussed the mental health datasets had been requested for this study; and advised that there did appear to be a provision for these datasets at this time.</p> <p>5.2.3 AGD suggested that the applicant update all transparency materials, to 1) be clear / consistent as to what will happen to data if a participant withdraws from the study; and 2) to be clear on the breadth of the datasets that will be processed, for example the mental health datasets.</p> <p>5.2.4 AGD noted the information in section 5(a) (Objective for Processing) in respect of the various students at Imperial College London that would be permitted to access the data, and suggested that 1) the reference from the students being “<i>affiliated</i>” with Imperial College London was updated to state “<i>enrolled</i>” (assuming this is factually correct. If they are not enrolled students at the University, then their status should be explained further); 2) an indicative number of how many students will be accessing the data was provided; and 3) clarification / confirmation was sought as to whether the students should be limited to those undertaking a relevant course of study, under the supervision of the Chief Investigator / Study Team.</p>	
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	<p>5.2.5 The NHS England SIRO Representative noted the incorrect reference in section 5(a) to “...<i>date and cause of death, taken from the Office for National Statistics records...</i>”; and asked that this was removed.</p> <p>5.2.6 In addition, it was noted that the data field ‘cause of death’ data was referred to in section 5(a), but was not referred to in section 3(b) (Additional Data Access Requested); and suggested that this was reviewed and updated as may be necessary to reflect the factual information.</p> <p>5.2.7 The NHS England SIRO Representative noted that section 5(b) (Processing Activities) states that the NHS England data will “...<i>contain no direct identifying data items...</i>”; and noting that this did not align with section 3(b), suggested that this was reviewed and updated as may be necessary to reflect the factual information.</p> <p>5.2.8 AGD noted that funding was in place until March 2026, however the application end date was March 2028; and suggested that NHS England clarified with the applicant that there is funding in place for the duration of the data sharing agreement (DSA).</p> <p>5.2.9 AGD noted and commended the work undertaken by NHS England’s DAS on the internal application assessment form, which supported the review of the application.</p> <p>5.2.10 No AGD member noted a commercial aspect to the application.</p>	
5.3	<p>Reference Number: NIC-717299-R5H5N-v0.4</p> <p>Applicant: University of Oxford</p> <p>Data Controllers: Oxford University Hospitals NHS Foundation Trust and University of Oxford</p> <p>Application Title: “Children's Surgery Outcome Reporting (CSOR) Research Database - Case and contact details identification”</p> <p>Observers: Jack Bennett and Laura Evans</p> <p>Linked applications: This application is linked to NIC-674822-S2K9 and NIC-608743-H5X9Z.</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 majority of the Group were supportive of the application if the transparency points were adequately addressed. A minority of the Group (one member) was not supportive of the application at this time due to the transparency points raised.</p>	

	<p>The Group wished to draw to the attention of the SIRO the following substantive comments:</p> <p>5.3.1 AGD noted that prior to the meeting, a number of queries had been raised by an AGD independent adviser, in respect of the transparency materials / privacy notice; and that a response had been provided, which included a copy of the updated privacy notice that was not currently published. AGD made a number of suggestions as to how the transparency materials / privacy notice could be updated / improved, including 1) to be clearer what was happening under each aspect of the processing; 2) what the process is for withdrawing consent / opting out at each stage of the processing; and 3) to review the references to “<i>anonymised data</i>” in the updated privacy notice and updated to reflect the correct / factual information, noting that a particular standard would need to be reached for data to be described as ‘anonymised’ (guidance is due to be published on this imminently by the Information Commissioner’s Office), and that the data may be pseudonymised.</p> <p>5.3.2 The AGD independent Lay Adviser advised that they had some specific comments / suggestions on the updated privacy notice provided prior to the meeting, and that they would share these directly with NHS England colleagues for consideration following the meeting.</p> <p>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.3.3 AGD noted the reference in section 5(b) (Processing Activities) to invitations being sent to “...<i>all eligible participants who have not previously been invited to participate...</i>”; and suggested that 1) further clarification was provided as to how it would be known if families had been previously invited; and 2) if the check of whether families would be receptive would include fact checking to determine whether they had been previously invited.</p> <p>5.3.4 No AGD member noted a commercial aspect to the application.</p>	
5.4	<p>Reference Number: NIC-649110-Z5S0L-v0.5</p> <p>Applicant: University of Birmingham</p> <p>Data Controllers: Manchester University NHS Foundation Trust</p> <p>Application Title: “Colorectal Endoscopic Stenting Trial 2 (CReST2)”</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 majority of the Group were supportive of the application if the transparency points were adequately addressed. A minority of the</p>	

Group (one member) was **not** supportive of the application **at this time** due to the transparency points raised.

The Group wished to draw to the attention of the SIRO the following substantive comments:

5.4.1 AGD noted the consent materials provided and discussed whether there was a gateway for the processing outlined, and noted that the cohort had been advised that the “*best*” treatment was being considered. One AGD independent adviser thought that the overall content of the consent materials would not indicate to participants that “*best*” included cost effectiveness / best value for money and therefore there **was not** a legal gateway to process the data for this purpose. The majority of AGD members thought that it would be reasonable for the word “*best*” to include cost effectiveness / best value for money, and therefore thought there **was** a legal gateway to process the data for this purpose; however, suggested that the transparency materials were updated to make this explicitly clear to the cohort members.

5.4.2 The Group noted that in respect of point 5.4.1, that what was “*best*” for a patient, might not be “*best*” for the NHS, for example, that treatment may not be adopted due to high costs and that therefore care should be taken when describing the purposes of a trial in participant materials.

5.4.3 The AGD NHS England Data Protection Office Representative noted a number of statements in the privacy notice that were either missing or could be improved, and suggested that this was reviewed and updated in line with UK General Data Protection Regulation (UK GDPR); including, but not limited to, **1)** providing further clarity on data subjects rights; **2)** information on Data Controller / Data Processors; and **3)** who was processing what data for what purpose.

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

5.4.4 The NHS England SIRO Representative noted the inconsistent information in section 5(a) (Objective for Processing) that referred to the data being “*pseudonymised*”, and section 3(b) (Additional Data Access Requested) that referred to the data being “*identifiable*”; and asked that this was reviewed and updated to reflect the correct / factual information.

5.4.5 AGD noted in section 3(b) and section 5(a) that data would be provided for individual patients from when they joined the trial, however suggested that further information was provided as to how this would be undertaken, noting that NHS England would not have details of when patients joined the trial. The Group suggested that if the applicant was providing this information, then this should be clear in the application.

5.4.6 AGD noted the reference in section 5(b) (Processing Activities) to data being “*stored securely on University of Leeds servers*”; and suggested that this was

	<p>reviewed and amended as may be appropriate, noting that the Data Security and Protection Toolkit (DSPT) indicates that a Cloud based storage will be used.</p> <p>5.4.7 AGD noted the reference in section 5(d) (Benefits) to “<i>clients</i>”; and suggested that this was updated to refer to “<i>organisations</i>”.</p> <p>5.4.8 Those AGD members who were supportive of the application, noted that this was a one-year data sharing agreement (DSA), and advised that they would be supportive of a longer DSA in line with the necessary NHS England approvals / consent; and with the update to section 6 (Special Conditions), to include a special condition relating to the Annual Confirmation Report (ACR), in line with NHS England DAS Standard for Special Conditions.</p> <p>5.4.9 No AGD member noted a commercial aspect to the application.</p>	
6 INTERNAL DATA DISSEMINATION REQUESTS:		
<i>There were no items discussed</i>		
7 EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL		
7.1	<p>Reference Number: NIC-228903-Z0F4V-v2.7</p> <p>Applicant: Royal Free London NHS Foundation Trust</p> <p>Data Controllers: NHS England and NHS North Central London Integrated Care Board (ICB)</p> <p>Application Title: “Transforming Cancer Services Team for London access to National Cancer Waiting Times Monitoring Data Set (NCWTMDS) from the Cancer Wait Times (CWT) System”</p> <p>Previous Reviews: 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 8th July 2021, 19th December 2019, 14th November 2019 and the 14th March 2019.</p> <p>The SIRO approval was for an update to the application, to remove South London Clinical Commissioning Groups (CCG) as a Data Controller; and to add North Central London ICB as a Data Controller.</p> <p>Outcome of discussion: AGD noted that the NHS England SIRO had already provided SIRO approval and confirmed that they were supportive of this.</p> <p>AGD thanked NHS England for the written update and made the following observations on the documentation provided:</p> <p>7.1.1 AGD suggested that this data sharing agreement (DSA) and NHS England Data Access Service (DAS) internal Escalation Form, and other similar applications were reviewed and updated to ensure that the correct organisations / terminology was used at each stage of the processing, for example, ensure that legacy</p>	

	<p>organisations were noted for historical / audit purposes, but replaced with the correct organisation as may be appropriate. The NHS England SIRO Representative noted and agreed that further work would be undertaken to review the relevant DSAs.</p> <p>The NHS England SIRO representative thanked AGD for their time.</p>	
7.2	<p>Reference Number: NIC-654590-Y0S1H-v0.16</p> <p>Applicant and Data Controller: Cardiff University</p> <p>Application Title: “T3 Safety Study”</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 6th July 2023.</p> <p>The SIRO approval was for the removal of filters on the cohort.</p> <p>Outcome of discussion: AGD noted that the NHS England SIRO had already provided SIRO approval and confirmed that they were supportive of this.</p> <p>AGD thanked NHS England for the written update and made the following observations on the documentation provided:</p> <p>7.2.1 AGD noted that prior to the meeting, an AGD independent member had raised a query / comment with the NHS England SIRO Representative, in respect of the information in section 5(a) (Objective for Processing) relating to the length of follow-up; and suggested that this was reviewed and aligned with the protocol.</p> <p>The NHS England SIRO representative thanked AGD for their time.</p>	
8 OVERSIGHT AND ASSURANCE		
8.1	<p>Oversight and Assurance update (Presenter: Garry Coleman)</p> <p>The NHS England SIRO Representative advised the Group, that following the oversight and assurance review in this meeting, this programme of work would be paused until after the Easter break, to allow NHS England colleagues to review the end-to-end process for each of the four oversight and assurance workstreams.</p> <p>The Group were advised that the oversight and assurance review, would include a workshop, that AGD members were invited to join, or contribute ideas / thoughts, to support the review / workshop and this programme of work going forward.</p> <p>ACTION: AGD to arrange oversight and assurance workshop.</p> <p>The Group noted and thanked the NHS England SIRO Representative for the update.</p>	AGD Sec
8.2	<p>Oversight and Assurance Process</p> <p>Workstream 1 – Precedent approved internal and external applications</p> <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,</i></p>	

	<p><i>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) two applications (selected by the AGD Secretariat); 2) internal application assessment forms for each of the two applications; and 3) an oversight and assurance template to complete.</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 two applications.</p>	
	<p>Oversight and Assurance Conclusion / Review</p> <p>AGD and the NHS England SIRO Representative reiterated points raised at previous AGD meetings that, for applications reviewed as part of oversight and assurance, there were no documents available that provided an audit trail outlining how the decision had been reached to progress the application down the NHS England precedent route. In addition, AGD asked that all documentation, where a decision is made, is clearly dated noting information was available in the notes section of NHS England’s customer relationship management (CRM) system (which AGD Independent Members do not have access to), however the documentation should also be date stamped.</p> <p>ACTION: The AGD NHS England Data and Analytics Representative to ensure that all relevant documentation was uploaded to the CRM system as agreed previously and for audit purposes, and that any documentation uploaded contained a clearly dated audit trail of how the decision to progress the application down the NHS England precedent route had been undertaken.</p> <p>It was suggested that the O&A template was updated to provide an option where AGD members could highlight that issues had been raised that were not minor, but not serious either (middle ground).</p> <p>ACTION: The SIRO Team to update the O&A template form to reflect where an issue was not serious but not minor (middle ground).</p>	<p>D&A Rep</p> <p>SIRO Team</p>

8.3	<p>Workstream 2 - Internal and external applications that have had an independent review and been approved internally</p> <p>In advance of the meeting, the AGD independent members were provided with 1) 12 applications (selected by the AGD Secretariat); 2) internal application assessment form or DAS Escalation Form for each of the 12 applications; and 3) an oversight and assurance template to complete.</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 B for high-level points raised in-meeting on the 12 applications.</p>	
	<p>Oversight and Assurance Conclusion / Review</p> <p>AGD noted that this was the first oversight and assurance ‘workstream 2’ review undertaken; it was noted that concerns were raised with one of the applications in respect of the purpose / legal basis, and that this would be flagged with the NHS England SIRO Representative out of committee.</p> <p>The Group noted that whilst there were a number of applications that clearly communicated how the previous AGD comments had been addressed, the other applications fell into the following categories 1) previous AGD comments had not been adequately addressed; 2) it was unclear if / how the previous AGD comments had been addressed; and 3) the response to the previous AGD comments could have been clearer.</p> <p>The Group provided some feedback on potential updates to the process for future reviews, including, but not limited to, 1) more preparation time prior to the meeting, i.e. between 20 to 30 minutes per application; 2) the addition of the DSA in tracked changes to support the review; 3) selecting those AGD members to undertake the review who had been in attendance at the last AGD meeting where the application was discussed (if possible); and 4) having two AGD independent members and one NHS England AGD member per application review.</p> <p>The Group noted that the points / suggestions raised could feed into the oversight and assurance workshop (see point 8.1).</p>	
9 AGD OPERATIONS		

9.1	<p>AGD future ways of working</p> <p>AGD noted, that at the AGD plenary meeting on the 13th March 2025, it was agreed that further thought would be given by the Group, in respect of how advice was provided to NHS England, and whether any changes could be made to current processes / in-meeting discussions, whilst ensuring that the quality of the advice is not compromised.</p> <p>AGD discussed a number of potential options, including, but not limited to, the advice that could be provided both in-meeting and out of committee, and how this could work logistically; NHS England's 'risk appetite'; and how public confidence and trust is maintained following any changes.</p> <p>The NHS England SIRO Representative noted the content of the discussion, and advised that he would feed initial thoughts / suggestions back to the Director of Privacy and Information Governance, Privacy, Transparency and Trust (PTT) and provide feedback to the Group as soon as possible.</p> <p>ACTION: The NHS England SIRO Representative to feedback the content of the 'AGD future ways of working' discussion to the Director of Privacy and Information Governance, PTT.</p> <p>ACTION: The NHS England SIRO Representative to provide feedback to the Group, on 'AGD future ways of working', following discussions with the Director of Privacy and Information Governance, PTT.</p> <p>ACTION: AGD Secretariat to add 'AGD future ways of working' to the internal AGD forward planner for discussion at a future AGD meeting.</p>	<p>SIRO Rep</p> <p>SIRO Rep</p> <p>AGD Sec</p>
9.2	<p>Risk Management Framework</p> <p>AGD has been previously informed that a risk management framework is being developed by Data Access and had commented on early thinking about such a Framework. Nonetheless, presently AGD were still operating using the precedent and standard framework as an interim arrangement since February 2023 and AGD were concerned that the permanent Risk Management Framework was not in place. The Group discussed the NHS England corporate risk management framework (see minutes of 14th November 2024) and the AGD Chair subsequently formally asked via email if the NHS England corporate risk management framework could be used. The NHS England SIRO Representative updated the Group that NHS England was still considering the request, including how the NHS England corporate risk management framework could be adapted for AGD.</p> <p>ACTION: The NHS England SIRO Representative to provide a written response to AGD on the progress, and expected time frame for implementation, of the risk management framework.</p>	<p>SIRO Rep</p>
9.3	<p>AGD Stakeholder Engagement</p>	

	<i>There were no items discussed</i>
9.4	AGD Project Work <i>There were no items discussed</i>
10 Any Other Business	
10.1	Prof. Nicola Fear AGD noted that Prof. Nicola Fear was leaving the Group and wished to extend their sincere thanks for her significant contribution over the last eight years during her tenure on IGARD and AGD.
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: workstream 1 – 27th March 2025

Ref:	NIC Number:	Organisation:	Areas to consider:
250327a	NIC-148100-6RFK9-v7.2	University College London	<ul style="list-style-type: none"> The Group noted that the application had last been seen by IGARD on the 3rd August 2017, where IGARD had recommended for approval subject to conditions and amendments; and that the conditions had been signed off by the IGARD Chair. No assessment provided advising why this was suitable for the precedent route, therefore unclear if the precedent was applied correctly. <ul style="list-style-type: none"> Process point: Action for D&A Representative to ensure that it is clear in s1 of the DSA or in the SDa what documents were reviewed to make the decision with regard to the precedent route. It was suggested that the O&A template was updated to provide an option where AGD members could highlight that issues had been raised that were not minor, but not serious either (middle ground). <ul style="list-style-type: none"> Process point: Action for AGD Secretariat to update the O&A template to

			reflect where an issue was not serious but not minor (middle ground).
250327b	NIC-758242-X1X1K-v0.7	Royal Borough of Windsor and Maidenhead Council	<ul style="list-style-type: none"> The Group noted that the application had not had a previous DAAG / IGARD / AGD review. No assessment provided advising why this was suitable for the precedent route, therefore unclear if the correct precedent was applied correctly. <ul style="list-style-type: none"> Process point: Action for D&A Representative to ensure that it is clear in s1 of the DSA or in the SDa what documents were reviewed to make the decision with regard to the precedent route. A query was raised as to whether the consent materials should have been reviewed.

Appendix B

Oversight and Assurance Review: workstream 2 – 27th March 2025

Ref:	NIC Number:	Organisation:	Areas to consider:
250327(1)	NIC-726177-R0H8V-v0.8	University of Newcastle Upon Tyne	<ul style="list-style-type: none"> The application was last seen by AGD on the 6th June 2024, where the Group were supportive, however flagged a substantive comment and several additional comments. It was felt that the previous comments made by AGD had not been adequately considered.
250327(2)	NIC-617755-B4F1L-v0.7	East Sussex County Council	<ul style="list-style-type: none"> The application was last seen by AGD on the 13th June 2024, where the Group were supportive of the standalone application, however flagged a number of substantive comments / several additional comments. It was unclear if / how the previous AGD points had been considered / addressed. Specific concern was raised on the previous points raised in respect of Regulation 3 of COPI; and it was noted that DAS colleagues would have required support from wider NHS England colleagues to be able to progress this point. Key concern noted that here may be processing under this DSA without a legal

			basis, for example, outputs of cancer. It was suggested that this is discussed with the applicant as soon as possible.
250327(3)	NIC-334745-L4J6P-v2.2	University Hospital Southampton NHS Foundation Trust	<ul style="list-style-type: none"> • The application was last seen by AGD on the 13th June 2024, where the Group (with one AGD independent member dissenting) were supportive of the application, however flagged a substantive comment / several additional comments. • It was unclear to some of the reviewers if / how some of the previous AGD points had been considered / addressed; whilst others felt that most of the previous points had been addressed.
250327(4)	NIC-184980-J5B6C-v9.5	Cardiff University	<ul style="list-style-type: none"> • The application was last seen by AGD on the 18th July 2024, where half of the Group (two AGD independent members and one AGD NHS England member) were supportive of the archiving outlined but not supportive of the application. Half of the Group (two AGD independent members and one AGD NHS England member) were supportive of the archiving application, however flagged a number of substantive comments / several additional comments.

			<ul style="list-style-type: none"> It was noted that further detail could have been provided as to how / why the previous AGD points had / had not been considered / addressed.
250327(5)	NIC-707682-B4H2R-v0.5	University of York	<ul style="list-style-type: none"> The application was last seen by AGD on the 18th July 2024, where AGD were supportive of the purpose but were not supportive of the current application, because of the uncertain status of the data that would flow; and flagged a number of substantive comments / several additional comments. DAS were commended on the clear and concise responses to the previous AGD points.
250327(6)	NIC-755472-Y7C7F-v0.6	Care Quality Commission (CQC)	<ul style="list-style-type: none"> The application was last seen by AGD on the 1st August 2024, where AGD were supportive of the purpose but were not supportive of the current application, requiring clarification with regard to the legal basis and the identifiability of the data; and flagged a number of substantive comments. No concerns were raised on how the previous AGD points had been addressed.
250327(7)	NIC-147852-RV70L-v8.2	University of Newcastle Upon Tyne	<ul style="list-style-type: none"> The application was last seen by AGD on the 1st August 2024, where AGD were supportive of the application on the presumption that the

			<p>SIRO would not approve this application until such time as the issues relating to the previous breach had been resolved to the SIRO's satisfaction; and flagged a number of substantive comments / several additional comments.</p> <ul style="list-style-type: none"> • It was unclear if / how some of the previous AGD points had been considered / addressed. • It was noted that further detail could have been provided as to how / why the previous AGD points had / had not been considered / addressed. • Specific queries were raised on the response / comments relating to restrictions to IARC. • Specific queries were raised on the response / comments relating to onward sharing of data to the USA.
250327(8)	NIC-753801-J5B3X-v0.2	Queen Mary University of London	<ul style="list-style-type: none"> • The application was last seen by AGD on the 12th September 2024, where the majority of the Group were supportive of the application. A minority of the Group were not supportive of the application at this time due to ongoing concerns arising from the patient and public involvement and engagement (PPIE). A number of substantive comments / several additional comments were flagged.

			<ul style="list-style-type: none"> • It was unclear to some of the reviewers if / how some of the previous AGD points had been considered / addressed; whilst others felt that most of the previous points had been addressed. • Specific queries were raised on the response relating to invitation numbers and whether consideration had been given to the target not being met. • Specific queries were raised on the extent of the PPIE and concern over the text messages.
250327(9)	NIC-727610-S2V3N-v0.9	University College London (UCL)	<ul style="list-style-type: none"> • The application was last seen by AGD on the 20th June 2024, where AGD were not supportive of the application at this time, and suggested that the application be brought back to a future meeting. • No concerns were raised on how the previous AGD points had been addressed. • It was unclear where changes had been made in the DSA following the last AGD review. <ul style="list-style-type: none"> ○ Action for the D&A Representative: to clarify whether it is possible for AGD to be provided with a tracked changes version of DSAs to support O&A reviews.

			<ul style="list-style-type: none"> • Specific point raised that the quantum of data point was addressed in the SDA but not the application. • To determine whether there should be a process in place for applications that are not supported by AGD, for example, a re-review. <ul style="list-style-type: none"> ○ Action for the SIRO Representative and D&A Representative: to determine if a process should be in place for applications not supported by AGD.
250327(10)	NIC-764470-N9W3S-v0.4	Office for National Statistics	<ul style="list-style-type: none"> • The application was last seen by AGD on the 3rd October 2024, where AGD were only supportive of the ‘The Health and Labour Market Project’ and the NHS England analysts working in the ONS TRE environment. AGD were not supportive of any other aspect of this application; and flagged a number of substantive comments / several additional comments. • No concerns were raised on how the previous AGD points had been addressed. • DAS were commended on the clear and concise responses to the previous AGD points.

			<ul style="list-style-type: none"> It was noted that the legal advice referred to could have been provided to support the review.
250327(11)	NIC-734202-N9F7P-v0.5	Cardiff University	<ul style="list-style-type: none"> The application was last seen by AGD on the 17th October 2024, where the majority of the Group were supportive of the application, and a minority (one member) of the Group were not supportive of the application at this time due to the outstanding query on the follow-up and whether there had been patient and public involvement and engagement (PPIE). A number of substantive comments / several additional comments were flagged. No concerns were raised on how the previous AGD points had been addressed.
250327(12)	NIC-147922-T7W2F-v1.21	University College London (UCL)	<ul style="list-style-type: none"> The application was last seen by AGD on the 21st November 2024, where AGD were supportive of the templated application for the four linked applications but were providing comments in response to NHS England's request for advice on specific points rather than all aspects of the templated application for the four linked applications. AGD drew to the attention of the SIRO observations in relation to the advice points.

			<ul style="list-style-type: none"> • Most of the previous points had been addressed. • DAS were commended on the clear and concise responses to some of the previous AGD points. • Unclear how the points for the DPO / SIRO Representative have been addressed. • Having a date in the SDa / DAS Escalation Form would be helpful. <ul style="list-style-type: none"> ○ Action for the SIRO Representative and D&A Representative: to clarify whether the SDa / DAS Escalation template can be updated to include a date.
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