

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 27th November 2025

09:00 – 15:35

(Remote meeting via videoconference)

AGD INDEPENDENT / NHS ENGLAND MEMBERS IN ATTENDANCE:	
Name:	Role:
Paul Affleck (PA)	AGD independent member (Specialist Ethics Adviser) (Chair for items 5.1 (part), 5.3 and 5.4 (part))
Claire Delaney-Pope (CDP)	AGD independent member (Specialist Information Governance Adviser)
Dr. Robert French (RF)	AGD independent member (Specialist Academic / Statistician Adviser) (In attendance for item 5.5 only)
Kirsty Irvine (KI)	AGD independent member (Chair) (Chair for items 1 to 4, 5.1 (part), 5.2, 5.4 (part), 5.5 to 10.1) (Not in attendance for item 5.1 (part), 5.3 (part) and 5.4 (part))
Professor Jo Knight (JK)	AGD independent member (Specialist Academic / Researcher Adviser)
Dr. Jonathan Osborn (JO)	NHS England member (Caldicott Guardian Team Representative)
Andy Rees (AR)	NHS England member (Data and Analytics Representative (Delegate for Michael Chapman))
Ellie Ward (EW)	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:
Jack Bennett (JB)	Senior Project Manager, NHS DigiTrials, Transformation Directorate (Observer: item 4.1)
Dave Cronin (DC)	Applications Service Owner, Data Access and Partnerships, Transformation Directorate (Observer: Item 5.5)
Lyndon Dibb (LD)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.3)
Dan Goodwin (DG)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.5)

Chris Haskins (CH)	Senior Project Manager, NHS DigiTrials, Transformation Directorate (Observer: item 4.1)
Dickie Langley (DL)	NHS England SIRO Representative (delegate) (Presenter: item 5.1(a))
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Deputy Chief Executive Directorate
Humphrey Onu (HO)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.6)
Jodie Taylor-Brown (JTB)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: items 5.1, 5.2 and 5.4)
Emma Whale (EW)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.4)
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Deputy Chief Executive Directorate
INDEPENDENT ADVISER OBSERVERS IN ATTENDANCE	
Mr Christopher Barben (CB)	AGD independent adviser
Dr Jon Fistein (JF)	AGD independent adviser
AGD INDEPENDENT MEMBERS / NHS ENGLAND MEMBERS <u>NOT</u> IN ATTENDANCE:	
Name:	Role / Area:
Michael Chapman (MC)	NHS England member (Data and Analytics Representative)
Jon Moore (JM)	NHS England member (Data Protection Office Representative)
Miranda Winram (MW)	AGD independent member (Lay Adviser)

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 20 th November 2025 were reviewed and, after minor amendments, were agreed as an accurate record of the meeting.
3	Declaration of interests: Claire Delaney-Pope noted a professional link to King's Health Partners (NIC-708913-Y2N1H-King's College Hospital NHS Foundation Trust) as part of her role at South London and Maudsley NHS

	<p>Foundation Trust (SLAM). It was noted that SLAM was not part of this application, and that there were no financial arrangements between King's Health Partners and SLAM for this application. It was agreed that that this was not a conflict of interest.</p> <p>Andy Rees noted a professional link to the 'NHS DigiTrials Recruitment Service - Non-contact Register' due to his NHS England role as NHS DigiTrials and Research Products Operations Manager; it was agreed that the items would be discussed / reviewed as per usual process and that this was not a conflict of interest.</p> <p>Dr. Jon Fistein noted a professional link to the University of Oxford but noted no specific connections with the application (NIC-148267-W26RZ), or staff involved, and it was agreed that this was not a conflict of interest.</p>
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4 BRIEFING PAPER:

4.1	<p>Title: NHS DigiTrials Recruitment Service - Non-contact Register – Briefing Paper</p> <p>Presenters: Jack Bennett and Chris Haskins</p> <p>Following the implementation of the NHS DigiTrials Recruitment Service, delivery has been dependent on trials gaining support from the Health Research Authority Confidentiality Advisory Group (HRA CAG). A standard HRA CAG condition has always been that the public must have a way to register objections, respecting the National Data Opt-out (NDO) as well as the creation of a Trial Specific Opt-out.</p> <p>As the NHS DigiTrials Recruitment Service transitions to full-service Directions (as previously discussed at the AGD meeting on the 30th October 2025), work is commencing looking into an NHS DigiTrials Non-Contact Register. This could replace Trial Specific Opt-outs and would accompany the NDO.</p> <p>NHS England were seeking advice on the following points:</p> <ol style="list-style-type: none"> 1. Provide any advice relating to the approach and specifically the considerations. <p>Outcome of discussion: AGD welcomed the briefing paper / supporting documents and made the following observations / comments:</p> <p>4.1.1 Separate to the briefing paper: AGD noted that work was ongoing within the Department of Health and Social Care (DHSC) in respect of opt-outs; and, recognising that NHS England are aware of this work, strongly suggested that NHS England engage with DHSC to explain the particular mechanism that is being proposed in respect of the NHS DigiTrials Recruitment Service - Non-contact Register, to determine whether or not it is in scope of what is being considered.</p> <p>In response to point 1 above:</p> <p>4.1.2 In respect of the 'condition specific registration' (individual disease level versus disease groups), the Group advised that they would not be supportive of this; however, suggested that there could be some granularity on the type of research, for example, non-intrusive research.</p> <p>4.1.3 In respect of the consideration outlined in respect of contact preference expiring after a time period; AGD suggested that there should be no expiry, however advised that they would be supportive of a periodic reminder, to those who had submitted a contact</p>	
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	<p>preference to remind them, and to provide guidance if they wanted to change their original preference.</p> <p>4.1.4 AGD suggested that to support those considering expressing a contact preference, NHS England should consider having a contact point for individuals to discuss the mechanics and implications of any potential choices before submission.</p> <p>4.1.5 AGD discussed the nature of the proposed service, for example, is it an 'opt-out' or a 'communication preference'; and suggested that this was discussed as part of the proposed patient and public involvement and engagement (PPIE).</p> <p>4.1.6 AGD noted that they were supportive of the approach outlined, and looked forward to receiving future updates in due course.</p>	
5 EXTERNAL DATA DISSEMINATION REQUESTS:		
5.1	<p>Reference Number: NIC-698157-B0L5B-v0.9</p> <p>Applicant and Data Controller: Certara UK</p> <p>Application Title: "Fitness for purpose of data sources relevant for real-world data (RWD) studies on CAR-T cell therapy".</p> <p>Observer: Jodie Taylor-Brown</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 11th September 2025.</p> <p>Application: This was a new application.</p> <p>NHS England were seeking general advice on the application.</p> <p>Should an application be approved by NHS England, further details would be made available within the Data Uses Register.</p> <p>Outcome of discussion: AGD were supportive of the application if the following substantive comments were addressed, and wished to draw to the attention of the SIRO the following substantive comments:</p> <p>AGD noted that as part of an NHS England Data Access Request Service (DARS) pilot (discussed at the AGD meeting on the 7th August 2025), the Group had been asked not to review the application for this item, and had instead been provided with a new NHS England DARS internal form that contained summary information that, once finalised, would be transferred into the usual data sharing agreement (DSA) template.</p> <p>5.1.1 AGD noted that at the AGD meeting on the 11th September 2025, a number of queries had been raised on the roles and responsibilities of the various limbs of Certara and noting the diligent work undertaken by NHS England to ascertain the Data Controllers, suggested that, in line with NHS England DARS Standard for Data Controllers, NHS England seek further clarity on whether 1) Certara Inc; and / or 2) the Overall Project Coordinator, who is an employee of Certara France (Data Processor), is undertaking activities that are determining the purpose and means of processing.</p> <p>5.1.2 AGD noted that the funder is not in a contractual relationship with the Data Controller, and suggested that NHS England explore this further with the applicant, since the current</p>	

	<p>arrangement of the funder having a contractual arrangement with the Data Processor is counterintuitive.</p> <p>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.1.3 AGD advised that they were supportive of the purpose / aims of the study outlined in the documentation provided.</p> <p>5.1.4 AGD noted and commended the work undertaken by NHS England's Data Access Request Service (DARS) on the engagement with the applicant, and the work undertaken on this application following the review on the 11th September 2025.</p> <p>5.1.5 AGD noted that as suggested at the AGD meeting on the 11th September 2025, the data processing would now be undertaken in NHS England's Secure Data Environment (SDE), and advised that they were supportive of this.</p> <p>5.1.6 AGD suggested that in line with the NHS England DARS Standard for Expected Measurable Benefits, section 5(d) (Benefits) of the application be updated to say this study would be a benefit to patients in England and Wales, due to the expected utility of the research.</p> <p>5.1.7 In respect of the commercial aspect of the application, AGD suggested that 1) the commercial information in section 4.9 (Commercial Benefit Evaluation) is also in section 5(a) (Objective for Processing) and section 5(e) (Is the Purpose of this Application in Anyway Commercial) of the final application; and 2) there is a clear statement in the application that Certara is a commercial company and as such will be carrying out the work under this application to generate income.</p> <p>5.1.8 AGD noted that there was a commercial aspect to the application.</p>	
5.2	<p>Reference Number: NIC-351722-W7D4N-v17.3</p> <p>Applicant and Data Controller: *L2S2 Ltd <i>(*the applicant was previously "CRAB Clinical Informatics"*)</i></p> <p>Application Title: "Commercial work by L2S2 Ltd to support NHS England, CQC, ICBs and NHS Trusts"</p> <p>Observer: Jodie Taylor-Brown</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 23rd 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 5th May 2022, 27th February 2020, 14th March 2019, 11th October 2018, 4th October 2018, 5th July 2018 and the 13th July 2017.</p> <p>The application and relevant supporting documents were previously presented / discussed at the Data Access Advisory Group (DAAG) 22nd September 2015 and the 25th August 2015.</p> <p>Application: This was an amendment application.</p> <p>NHS England were seeking general advice on the application.</p>	

<p>Should an application be approved by NHS England, further details would be made available within the Data Uses Register.</p> <p>Outcome of discussion: AGD were supportive of the application and wished to draw to the attention of the SIRO the following substantive comments:</p> <p>AGD noted that they had been provided with a curated set of documentation and noted that they would be providing observations based on these documents.</p> <p>5.2.1 AGD noted that this application had an amendment to add a new applicant / Data Controller (L2S2 Ltd) and to remove the previous applicant / Data Controller (CRAB Clinical Informatics); and suggested that NHS England engage with the new applicant / Data Controller to 1) establish what their precise programme of work is; and 2) what their contractual arrangements are with those had previously engaged with the previous applicant / Data Controller, including, but not limited to, arrangements with the Care Quality Commission (CQC).</p> <p>5.2.2 AGD suggested that a special condition was added to section 6 (Special Conditions) that until the appropriate contracts were in place between L2S2 with the relevant organisations, that the new applicant / Data Controller will hold but otherwise not process the data.</p> <p>5.2.3 AGD queried the data destruction arrangements for the data held by the previous Data Controller (CRAB Clinical Informatics); and suggested that NHS England satisfy itself that the appropriate data destruction had been undertaken, for any data not covered by the revised agreement, and appropriate evidence of this had been received.</p> <p>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.2.4 AGD suggested that NHS England engage with the applicant, to determine if the dashboard products could work with Secure Data Environment (SDE) access, and therefore whether the data could be held in the National NHS England SDE.</p> <p>5.2.5 AGD discussed Artificial Intelligence (AI) and suggested that 1) NHS England make the applicant aware that a separate amendment to the data sharing agreement (DSA) would be required if they wished to further develop the existing product using AI or to develop new products, noting the responses to the AI questions referred to further iterations of the tools and future plans; 2) NHS England to establish with the applicant whether the tools would require Medicines and Healthcare products Regulatory Agency (MHRA) approval; and 3) whether the tools complied with the UK General Data Protection Regulation (UK GDPR) (for example, Article 22 (<i>Automated individual decision-making, including profiling</i>)).</p> <p>5.2.6 AGD noted the use of the consultant ID code and suggested that section 5(a) (Objective for Processing) was updated to 1) remove any reference to “untoward harm”; 2) remove any reference to identifying harm from the data; and 3) clarify the reports are designed to provide a granular local dashboard to help the CQC and NHS Trusts / Independent Sector Providers offering NHS services, to interpret and understand safety in relation to potentially avoidable harm, morbidity and areas for improvement.</p> <p>5.2.7 AGD noted that a privacy notice had been provided as a supporting document, however suggested that the applicant review this for errors and update it as required. Also,</p>	
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	<p>AGD suggested including the details of a specific Data Protection Office (DPO) contact for example a named DPO.</p> <p>5.2.8 AGD suggested that NHS England make it explicitly clear with the new applicant / Data Controller, that the processing is restricted to specifically what is set out in section 5 (Purpose / Methods / Outputs) of the data sharing agreement (DSA), and that any other work they wish to undertake using the data would require an amendment.</p> <p>5.2.9 AGD noted that there was a commercial aspect to the application.</p>	
5.3	<p>Reference Number: NIC-709746-N2T6T-V0.5</p> <p>Applicant and Data Controller: Cardiff University</p> <p>Application Title: “Clinical and cost-effectiveness of a maternity quality improvement programme to reduce excess bleeding and need for transfusion after childbirth: the Obstetric Bleeding Study UK (OBS UK)”</p> <p>Observer: Lyndon Dibb</p> <p>Application: This was a new application.</p> <p>NHS England were seeking general advice on the application.</p> <p>Should an application be approved by NHS England, further details would be made available within the Data Uses Register.</p> <p>Outcome of discussion: AGD were supportive of the application if the following substantive comments were addressed, and wished to draw to the attention of the SIRO the following substantive comments:</p> <p>5.3.1 AGD noted in the Health Research Authority Confidentiality Advisory Group (HRA CAG) documentation provided, that Cardiff and Vale Health Board were named as a Data Controller; and suggested that NHS England explored their role further, to determine if they had any data controllership responsibilities in line with NHS England DARS Standard for Data Controllers.</p> <p>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.3.2 AGD queried if the specification for the data was modelled on a “standard pregnancy”, and may therefore capture too much or too little information for those who do not have a “standard pregnancy”, for example, those who have a premature birth or those who have a late hospital discharge; and suggested that NHS England explore this further with the applicant.</p> <p>5.3.3 AGD queried why the request for data under this application did not include all of the individuals included in the study; and were advised by NHS England that data was only being requested for those individuals who had suffered with postpartum haemorrhage.</p> <p>5.3.4 AGD suggested that for those taking part in the sub-studies that do require consent, that there may have been an opportunity to take consent for access to their data.</p> <p>5.3.5 Separate to the application and action for the AGD Chair and AGD NHS England Data and Analytics Representative: AGD suggested this would be another example of a cluster trial for NHS England to work through with the Health Research Authority (HRA) and</p>	AGD Chair /

	<p>the HRA Confidentiality Advisory Group (CAG), to explore whether study consent is required, and, more specifically, whether it would be practical for the sub-studies to obtain consent for access to medical records.</p> <p>5.3.6 AGD noted the references in the application to an opt-out, and suggested that the applicant ensure the consent / transparency materials contain at least two methods of contact for participants (post, telephone and / or e-mail).</p> <p>5.3.7 AGD noted the contradictory information in section 5(b) (Processing Activities) as to who can access the data, and suggested that these were reviewed and updated to reflect the correct / factual information, for example, substantive employees of Cardiff University and one individual on an honorary contract.</p> <p>5.3.8 No AGD member noted a commercial aspect to the application.</p>	D&A Rep
5.4	<p>Reference Number: NIC-152414-W3P6Q-v5.5</p> <p>Applicant and Data Controller: University of Bristol</p> <p>Application Title: "Continuation of AVON LONGITUDINAL STUDY OF PARENTS AND CHILDREN (ALSPAC): consent"</p> <p>Observers: Jodie Taylor-Brown and Emma Whale</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 16th October 2025 and the 14th March 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 April 2018, 15th February 2018 and the 25th January 2018.</p> <p>Linked applications: This application is linked to NIC-789772-N6S1N.</p> <p>Application: This was an amendment application.</p> <p>NHS England were seeking advice on the following points, including general advice on any other aspect of the application:</p> <ol style="list-style-type: none"> 1. Sub-licencing; and, 2. Other substantive changes including additional datasets, additional linkages and commercial involvement <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 (seven) were supportive of the application; a minority of the Group (one AGD independent member) was not supportive of the application at this time due to the query raised on the process for effectively determining whether research is for commercial gain / profit or not.</p> <p>The Group wished to draw to the attention of the SIRO the following substantive comments:</p> <p>AGD noted that they had been provided with a curated set of documentation and noted that they would be providing observations based on these documents.</p> <p>AGD noted that as part of an NHS England Data Access Request Service (DARS) pilot (discussed at the AGD meeting on the 7th August 2025), the Group had been asked not to</p>	

	<p>review the application for this item, and had instead been provided with a new NHS England DARS internal form that contained summary information that, once finalised, would be transferred into the usual data sharing agreement (DSA) template.</p> <p>In response to point 1:</p> <p>5.4.1 AGD noted that the sub-licensing agreement provided as a supporting document, referred to The Avon Longitudinal Study of Parents And Children (ALSPAC) as being the Data Controller, however, since they are not a legal entity, suggested this should be the University of Bristol.</p> <p>5.4.2 AGD noted that due to the explicit restrictions in the consent on research projects being 'not for profit', there would need to be a clear mechanism, in the access review process, that will ensure the reviewers can screen out applications that are for profit. It was noted that there was currently no clear process that could effectively determine whether research is for profit or not.</p> <p>5.4.3 AGD reiterated the point from the AGD meeting on the 16th October 2025, in respect of the references to data being "<i>effectively anonymous</i>" in the form, and suggested that this was reviewed and updated as appropriate, noting that NHS England were not necessarily of the view that the data would be effectively anonymous and that the 'whose hands' test would not apply to the data controller or their processor.</p> <p>5.4.4 Separate to the application and for NHS England to consider: The NHS England SIRO Representative noted that the point raised on data being "<i>effectively anonymous</i>" had a very broad reach, noting the potential impacts / ramifications across not just NHS England data sharing agreements (DSA), but also across the Secure Data Environment (SDE) network and, in future, the Health Data Research Service (HDRS) (and therefore the entire UK); and suggested that NHS England should satisfy itself both internally (consulting the Data for Research and Development programme, and Information Governance colleagues) and establishing common ground with other UK SDEs.</p> <p>5.4.5 AGD advised the Data Access 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) quoracy; 2) stakeholder involvement; 3) patient and public engagement; 4) ethics; and 5) determining the potential benefits to health in England and Wales.</p> <p>5.4.6 AGD suggested that the sub-licensing agreement aligns with the exact territory of use restrictions in the application.</p> <p>In response to point 2:</p> <p>5.4.7 AGD suggested that the application was updated to include the standard honorary contract special condition in section 6 (Special Conditions).</p> <p>5.4.8 AGD noted the importance of transparency on such a large and significant study; and suggested that NHS England discuss a transparency plan with the applicant.</p> <p>5.4.9 AGD noted the processing outlined in terms of linkage with non-health related datasets, and suggested that the applicant monitor the ongoing public dialogue on this issue, which is being led by the Department of Health and Social Care and NHS England.</p>	<p>SIRO Rep</p>
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	<p>5.4.10 AGD queried whether the withdrawal mechanism is in operation (deleting all active research data within a week of receiving the withdrawal of consent request) and suggested that the applicant ensures that what happens is in line with the consent materials which state participants are free to withdraw at any time without giving a reason.</p> <p>5.4.11 AGD noted and commended NHS England's DARS and the applicant on the work undertaken on the application following the last review on the 16th October 2025.</p> <p>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.4.12 AGD noted there was a commercial aspect to the application.</p>	
5.5	<p>Reference Number: NIC-708913-Y2N1H-v0.11</p> <p>Applicant and Data Controller: King's College Hospital NHS Foundation Trust</p> <p>Application Title: "King's College London Cardiovascular Diseases Database"</p> <p>Observer: Dan Goodwin and Dave Cronin</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 6th March 2025.</p> <p>Application: This was an advice application.</p> <p>NHS England were seeking advice on the following points only:</p> <ol style="list-style-type: none"> 1. Do AGD feel the actions taken in response to their original advice is adequate and in line with their expectations. 2. In light of the additional information and updated supporting documentation, do AGD consider the controls as documented through section 4 (Purpose) of the form sufficient to ensure appropriate use of the data. 3. In light of the additional information and updated supporting documentation, are AGD supportive of the application in its current state; or, 4. Would AGD wish to give any additional advice on how the application might be improved to ultimately generate a DSA with appropriate and adequate controls to ensure the data is only used in ways that are appropriate and supported by AGD. <p>Should an application be approved by NHS England, further details would be made available within the Data Uses Register.</p> <p>Outcome of discussion: The Group were broadly supportive of the purpose outlined in the application, but were not supportive of the application at this time and wished to draw to the attention of the SIRO the following significant comments, and suggested that the application be brought back to a future meeting:</p> <p>AGD noted that they had been provided with a curated set of documentation and noted that they would be providing observations based on these documents.</p> <p>AGD noted that as part of an NHS England Data Access Request Service (DARS) pilot (discussed at the AGD meeting on the 7th August 2025), the Group had been asked not to review the application for this item, and had instead been provided with a new NHS England DARS internal form that contained summary information that, once finalised, would be transferred into the usual data sharing agreement (DSA) template.</p>	

In response to points 1 and 2:

5.5.1 AGD noted that at the AGD meeting on the 6th March 2025, concern was raised that a database was being created using the King's College London (KCL) name, when KCL were not a Data Controller or Data Processor. Notwithstanding the change to the name of the database (see point 5.5.2), the Group, which included the AGD independent Specialist Information Governance Adviser and the AGD NHS England Data Protection Office Representative, suggested that **1)** the applicant seeks the views of the KCL **and** the Guy's and St Thomas' NHS Foundation Trust Data Protection Officers (DPOs); and **2)** the applicant clarifies that KCL and / or Guy's and St Thomas' NHS Foundation Trust will **not** be named in any publications resulting from the work outlined in this application.

5.5.2 AGD noted that at the AGD meeting on the 6th March 2025, a query had been raised in respect of the name of the 'King's College London (KCL) Cardiovascular Diseases Database' (KCL-CVD), when they are **not** listed as a Data Controller or as a Data Processor in the application. The Group noted that the applicant had since renamed this to the 'South London Registry of Cardiovascular Diseases' however, advised that the updated name did **not** accurately reflect the cohort / hospitals involved.

5.5.3 AGD noted that at the AGD meeting on the 6th March 2025, a query had been raised in respect of where the data would be stored, and that the applicant had since confirmed that this would be King's College Hospital (KCH) and that de-identified datasets will be made available to researchers via remote access via a Secure Data Environment (SDE). The Group suggested that NHS England clarify with the applicant that KCH had an SDE as this was unclear.

5.5.4 AGD noted that at the AGD meeting on the 6th March 2025, the Group had noted that it was **not** clear whether was a commercial aspect to the application; and that the applicant has confirmed that it is expected that the majority of applications will have **no** commercial element; however, there could be some circumstances where there **may be** a benefit to a commercial organisation. AGD supported the update to section 5(a) (Objective for Processing) and section 5(e) (Is the Purpose of this Application in Anyway Commercial) to reflect this, in line with [NHS England DARS Standard for Commercial Purpose](#).

In response to point 3:

5.5.5 The Group were broadly supportive of the purpose outlined in the application, but were **not** supportive of the application at this time, due to the lack of clarity around data controllership.

In response to point 4:

5.5.6 AGD suggested that the applicant ensures that the objectives outlined are reviewed and updated as may be required, to ensure that they are not too restrictive, in line with [NHS England DARS Standard for Objective for Processing](#).

5.5.7 AGD noted the South London Registry of Cardiovascular Diseases – Oversight Committee Terms of Reference (ToR) and the evaluation criteria, and advised that they were supportive of the scoring matrix, and that this brought a measure of objectivity to the assessment; however, they made a number of observations / points in respect of the ToR, including, but not limited to **1)** currently Guy's and St Thomas' NHS Foundation Trust are part of the membership, it is unusual to see a Data Processor on such a group and feeding in to such decision making; **2)** the quoracy seems unusual, i.e. only one Chair, one member

	<p>and one lay member; in such a big group, when it would be expected to have a half the group plus one process in place for quoracy; and 3) professional members advise lay members which could be seen to dilute independent feedback. If lay members require advisors, then it was suggested this could be provided by independent, non-voting members.</p> <p>5.5.8 AGD advised that the honorary contract arrangements outlined do not align with the NHS England's DARS Standard for Honorary Contracts, and suggested that NHS England discuss this further with the applicant.</p> <p>In addition, AGD made the following observation on the application and / or supporting documentation provided as part of the review:</p> <p>5.5.9 No AGD member noted a commercial aspect to the application.</p>	
5.6	<p>Reference Number: NIC-148267-W26RZ-v8.3</p> <p>Applicant and Data Controller: University of Oxford</p> <p>Application Title: "Study of Cancer in Vegetarians"</p> <p>Observer: Humphrey Onu</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 6th March 2025 and the 2nd May 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 13th May 202 and the 1st June 2017.</p> <p>Application: This was an extension application.</p> <p>NHS England were seeking general advice on the application.</p> <p>Should an application be approved by NHS England, further details would be made available within the Data Uses Register.</p> <p>Outcome of discussion: AGD were supportive of the application and wished to draw to the attention of the SIRO the following substantive comments:</p> <p>AGD noted that they had been provided with a curated set of documentation and noted that they would be providing observations based on these documents.</p> <p>5.6.1 AGD noted that prior to the meeting, a query had been raised with NHS England, in respect of information in the privacy notice, that suggests participant identifiers such as names, addresses and dates of birth are still held; and if this was correct, whether it is technically possible to link them to data supplied by NHS England. The Group noted that NHS England had advised that the privacy notice would need updating to confirm that the identifiers have been destroyed. The Group thanked NHS England for the update and noted the response, however suggested that NHS England satisfy itself that 1) all direct identifiers have been deleted, including, but not limited to, those collected at the start of the study; and 2) if any form of identifying data was still being held, then the legal basis would need to be clarified.</p> <p>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p>	

	<p>5.6.2 AGD noted the change to the nature of the data during the lifecycle of the study; and suggested that 1) section 5(a) (Objective for Processing) and section 5(b) (Processing Activities) were updated to be clear on how the status of the data had changed from ‘identifiable’ to ‘pseudonymised’; and 2) clarify that the National Data Opt-out was originally applied.</p> <p>5.6.3 AGD suggested that the historical statement in section 5(c) (Specific Outputs Expected) “<i>Identifiable data will be retained until the end of 2024...</i>” was deleted.</p> <p>5.6.4 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-147957-4444C-v6.2</p> <p>Applicant and Data Controller: University of Oxford</p> <p>Application Title: “MR1134 - The Oxford Monitoring System for Attempted Suicide: Mortality following Deliberate Self-harm”</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 13th December 2018, 22nd November 2018 and the 1st November 2018.</p> <p>Linked applications: This application is linked to NIC-147907-MLK7R and NIC-147916-DPQ3Q.</p> <p>The SIRO approval was for a simple amendment to bring the expired data sharing agreement back under agreement until October 2028 and to apply an exemption to the application of the National Data Opt-out (NDO) in line with revised s251 support.</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 noted and commended the work being undertaken by NHS England’s Data Access Request Service (DARS) on the work undertaken on the application.</p> <p>The NHS England SIRO representative thanked AGD for their time.</p>	
7.2	<p>Reference Number: NIC-234656-C3J1D-v4.2</p> <p>Applicant: University College London (UCL)</p> <p>Data Controllers: City St George’s University of London and UCL</p> <p>Application Title: “Family, household and environmental risk factors for hospital admissions in childhood”</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) / Data Access Advisory Group (DAAG) meetings on the 4th February 2021 and the 4th April 2019.</p> <p>The SIRO approval was for an amendment to the data sharing agreement, to reflect the merger of City, University of London and St George's, University of London merged on the 1st August 2024; and that the updated Data Controller is now 'City St George's, University of London'.</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 advised that they had no further comments to make on the documentation provided.</p> <p>The NHS England SIRO representative thanked AGD for their time.</p>	
8 OVERSIGHT AND ASSURANCE		
<i>There were no items discussed</i>		
9 AGD OPERATIONS		
9.1	<p>Risk Management Framework</p> <p>The Group noted that the NHS England SIRO Representative had engaged with the Group out of committee following the AGD meeting on the 30th October 2025 in respect of the Risk Management Framework; and that a further update on this outstanding action would be discussed at the AGD plenary meeting on the 4th December 2025.</p>	SIRO Rep
9.2	<p>AGD Stakeholder Engagement</p> <p><i>There were no items discussed</i></p>	
9.3	<p>AGD Project Work</p> <p>Federated Data Platform</p> <p>A brief update was given by the Group's representative on the Federated Data Platform Data Governance Group.</p>	
10 Any Other Business		
10.1	<p>New Application Assessment Form Pilot</p> <p>AGD noted that as part of an NHS England Data Access Request Service (DARS) pilot (discussed at the AGD meeting on the 7th August 2025), that instead of the Group being provided with an application form, they were being provided with a new NHS England DARS internal form, that contained both the application text and explanatory notes made by the team.</p> <p>Noting that this pilot had been in progress since September 2025, a number of AGD members including the AGD NHS England Data Protection Office Representative, noted some feedback, specifically in respect of the issues faced by members, with not having an</p>	

	<p>application to review, noting that it was difficult to review the new NHS England DARS internal application form as a 'silo' document, when it is unclear what text will be added to the final application and into what section of the data sharing agreement (DSA), since it was a mixture of internal notes and actual text for the application form (particularly for complex applications that have required a lot of questions and answers and therefore detailed internal notes reflecting an evolving picture).</p> <p>AGD also suggested that possible updates to the new NHS England DARS internal form, could include highlighting text that will be added to the final application; or which text is internal to the team, to help aid the AGD review / discussion.</p> <p>The AGD NHS England Data and Analytics Representative agreed to take the feedback back to the team.</p>	D&A Rep
<p>Meeting Closure</p> <p>As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.</p>		