

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 23rd January 2025

09:00 – 16:10

(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)
Rachel Fernandez (RF)	NHS England member (Data Protection Office Representative (Delegate for Jon Moore))
Kirsty Irvine (KI)	AGD independent member (Chair)
Dr. Jonathan Osborn (JO)	NHS England member (Caldicott Guardian Team Representative)
Jenny Westaway (JW)	AGD independent member (Lay Adviser)
Miranda Winram (MW)	AGD independent member (Lay Adviser)
Tom Wright (TW)	NHS England member (Data and Analytics Representative (Delegate for Michael Chapman))
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	Role / Area:
Claire Clements (CC)	Head of Information Governance (IG) – Federated Data Platform, Data and Analytics, NHS England (Presenter: item 9)
Garry Coleman (GC)	NHS England SIRO Representative (In attendance for items 5.5 to 10.2) (Presenter: item 10.1)
Dan Goodwin (DG)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: items 5.1 and 5.2)
Andrew Ireland (AI)	Information Governance Specialist, IG Risk and Assurance, Privacy, Transparency, and Trust (PTT), Delivery Directorate (Observer: items 8.1 and 8.2)

Dickie Langley (DL)	NHS England SIRO Representative (Delegate for Garry Coleman) (In attendance for items 1 to 5.4) Assistant Director of IG (Digital Operations), Privacy, Transparency, and Trust (PTT), Delivery Directorate (Observer: item 9)
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
Jodie Taylor-Brown (JTB)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: items 5.3 and 5.4)
James Watts (JW)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.5)
Vicki Williams (VW)	AGD Secretariat Manager, 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)
Dr. Robert French (RF)	AGD independent member (Specialist Academic / Statistician Adviser)
Jon Moore (JM)	NHS England member (Data Protection Office Representative)

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 16 th January 2025 were reviewed and, after several minor amendments, were agreed as an accurate record of the meeting.
3	Declaration of interests:

	<p>Dr. Jonathan Osborn made a declaration of interest with NIC-757611-Y2B1J (University of Sheffield), as part of his role as Trustee of the Doctors in Distress charity; but noted no specific connections with the application or staff involved and it was agreed that this was not a conflict of interest.</p> <p>Paul Affleck noted a link to team members of NIC-743571-K7X4R (University of Oxford) through his role at the University of Leeds but noted no specific connections with the application, and it was agreed that this was not a conflict of interest.</p> <p>Claire Delaney-Pope noted a professional link to NIC-659293-T1G7M as part of her role within South London and Maudsley NHS Foundation Trust. It was agreed that Claire would remain in the room, but would not be part of the discussion of this application.</p> <p>Jenny Westaway noted a professional link to the Royal College of Anaesthetists (NIC-88623-F2H1A). It was agreed that Jenny would remain in the room, but would not be part of the discussion of this application.</p>
4 BRIEFING PAPER(S) / DIRECTIONS:	
<i>There were no items discussed</i>	
5 EXTERNAL DATA DISSEMINATION REQUESTS:	
5.1	<p>Reference Number: NIC-359692-Q4X1C-v11.7</p> <p>Applicant and Data Controller: Lightfoot Solutions UK Ltd</p> <p>Application Title: HES data through Signals From Noise (sfn) Business Intelligence Platform</p> <p>Observer: Dan Goodwin</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 17th October 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 27th August 2020, 23rd July 2020, 21st May 2020 and the 19th November 2017.</p> <p>The application and relevant supporting documents were previously presented / discussed at the Data Access Advisory Group (DAAG) meetings on the 15th September 2015 and the 1st September 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>5.1.1 AGD noted that this was a three-year data sharing agreement (DSA). The majority of AGD Members were supportive of the three-year DSA with robust Annual Compliance Reports (ACRs) as per the special condition in section 6 (Special Conditions); whilst a minority of AGD members were supportive of a one-year DSA to allow evidence to be provided of the utility of the revised processing and supply of additional data.</p> <p>5.1.2 AGD noted the detailed expected outputs in section 5(c) (Specific Outputs Expected) and the yielded benefits to date in section 5(d) (Benefits) (iii) (Yielded Benefits); but asked that NHS England satisfy itself that, in line with similar measures taken with some other commercial applicants, there is a robust forward work plan, for example, by requesting, in confidence, information on current / future users of the data that can make use of the projected outputs.</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 noted the restrictions on the commercial use of the applicant's products, and suggested NHS England discuss this aspect further with the applicant with regard to Academic Science Network (AHSN) who were included in the list of appropriate recipients, given AHSNs include industry partners with commercial interests.</p> <p>5.1.4 AGD noted the extensive work undertaken by the applicant on the privacy notice, following the comments made by the Group on the 17th October 2024; and suggested that further updates were made, including, but not limited to, 1) removing references to "<i>NHS Digital</i>" and replacing with "<i>NHS England</i>"; and 2) providing further information on the legislation reference, i.e. that use of data must be for the benefit of health and care.</p> <p>5.1.5 AGD noted the efforts undertaken by the applicant to outline the yielded benefits in section 5(d) (iii) but noted that the ACR should be clear on the benefits to health and care.</p> <p>5.1.6 AGD noted in section 5 (Purpose / Methods / Outputs) that the Lightfoot HES Group, which oversees the governance for approving and on-boarding new clients is currently not meeting due to "<i>live new data</i>" not flowing, and that the ToR suggested that the group would meet to oversee the data at all times, not just when new live data was flowing. The Group suggested that prior to the Lightfoot HES Group meetings re-starting, the applicant ensure that their Terms of Reference were updated to clarify this point, and to include 1) the position descriptions of members</p>	
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	<p>of the Group; 2) further information on quoracy and that this was in line with / reflective of the size of the Group.</p> <p>5.1.7 Noting the references in section 5 to “<i>Health Economy</i>” and “<i>Health economies</i>”, AGD suggested that the applicant review and update this to ensure there is a definition, and to provide further clarity on what this is referring to.</p> <p>5.1.8 AGD suggested that the applicant update section 5(b) (Processing Activities) to reflect that employees of Lightfoot Solutions UK Limited clients are only permitted to access “<i>pseudonymised</i>” not “<i>anonymised</i>” data.</p> <p>5.1.9 AGD suggested that the applicant update section 5(b) to reflect that full access to the data is restricted to employees of Lightfoot Solutions UK Limited who are physically located in England and Wales [or mapped to territory of use if that is UK].</p> <p>5.1.10 AGD queried the references in section 5(b) of the application to remote processing / access taking place in “<i>secure locations</i>”; and suggested that this was reviewed and updated, for example, to refer to the security of the remote connection and / or to the nature of the physical location.</p> <p>5.1.11 ACTION: Separate to the application and for NHS England to consider: AGD discussed whether NHS England should seek to recoup ongoing financial compensation for the use of citizens’ health data, as per the recent news article / report on this point. It was suggested that this was discussed further at an AGD plenary meeting.</p> <p>5.1.12 ACTION: For NHS England to consider: The AGD NHS England Caldicott Guardian Team Representative noted that the ability for 'practice level' analysis of secondary care activity, which might identify practices with different availability of appointments compared to similar, neighbouring practices, that are not otherwise explained by demographic changes. It was noted that this could be seen as a route to 'performance management' of General Practices, and therefore NHS England may wish to consult with representatives of GPs such as the British Medical Association (BMA) and Royal College of General Practitioners (RCGP)</p> <p>5.1.13 AGD noted that there was a commercial aspect to the application.</p>	<p>SIRO Rep / AGD Sec</p> <p>CG Rep</p>
5.2	<p>Reference Number: NIC-757611-Y2B1J-v0.2</p> <p>Applicant: University of Sheffield</p> <p>Data Controller(s): University College London (UCL) and University of Sheffield</p> <p>Application Title: The Target Therapies -&- SilverCloud Target Trials studies</p> <p>Observer: Dan Goodwin</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 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. The AGD Chair reiterated a point from the 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, and asked that the AGD NHS England Data and Analytics Representative check that assessments were part of the Q&A process.</p> <p>5.2.2 ACTION: The AGD NHS England Data and Analytics Representative to provide an update to the Group in January 2025 as to the process in place to ensure date of death assessments are part of the Q&A / internal process checks.</p> <p>5.2.3 AGD suggested that NHS England satisfy themselves that 1) section 2(c) (Territory of Use) reflects the correct territory of use, in line with NHS England DAS Standard for Territory of Use; and 2) that NHS England remind the applicant that the territory of use must align with the data sharing agreement (DSA).</p> <p>5.2.4 AGD noted the two-step process for sharing data between the Data Controllers, and suggested that NHS England discuss this further with the applicant to seek a clear justification for this, in line with NHS England DAS standard for data minimisation.</p> <p>5.2.5 ACTION: For NHS England to consider: AGD noted, in the internal Data Access Service (DAS) application assessment form, that the applicant had considered accessing the data in NHS England's Secure Data Environment (SDE), however had opted for an extract instead, due to the significant difference in cost. The Group suggested that the NHS England Data and Analytics Representative discuss this with colleagues, in respect of continuing to explore all avenues to applicants accessing the SDE and how they can support this, including, but not limited to, acknowledging the transitional cost of asking users to use / pay for the SDE when they may have already invested in their own internal systems and infrastructure.</p> <p>5.2.6 ACTION: For NHS England to consider: In addition, in line with the Department of Health and Social Care (DHSC) Data Access Policy that states "<i>Secure Data Environments (SDEs) will become the primary route for accessing NHS data for research</i>", AGD queried at what point cost would no longer be a valid reason for an extract instead of using NHS England's SDE, and that NHS England should consider giving applicants a timeline; and suggested that the NHS England Data and Analytics Representative discuss this further with colleagues.</p>	<p>D&A Rep</p> <p>D&A Rep</p> <p>D&A Rep</p>
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	<p>5.2.7 AGD noted the efforts by NHS England's DAS to understand the commercial aspect of the application as outlined in section 5(a) (Objective for Processing), however, suggested that additional information was added, including, but not limited to, further information outlining the coordination between the companies outlined.</p> <p>5.2.8 AGD queried the references in section 5(b) (Processing Activities) of the application to remote processing / access taking place in "<i>secure locations</i>"; and suggested that this was reviewed and updated for example, to refer to the security of the remote connection and/or to the nature of the physical location.</p> <p>5.2.9 AGD noted and commended the use of external experts to support the applicant with the patient and public involvement and engagement (PPIE).</p> <p>5.2.10 AGD noted that there was a commercial aspect to the application.</p>	
5.3	<p>Reference Number: NIC-747046-T7C5C-v0.5</p> <p>Applicant: Imperial College Healthcare NHS Trust</p> <p>Data Controller: Imperial College London</p> <p>Application Title: Indigo (Investigating Digital Outcomes) - Participant led electronic completion of PROMs and PREMs for patients living with and beyond cancer</p> <p>Observers: Jodie Taylor-Brown</p> <p>Application: This was a new application.</p> <p>NHS England were seeking general advice on the application.</p> <p>Should an application be approved by NHS England, further details would be made available within the Data Uses Register.</p> <p>Outcome of discussion: AGD were supportive of the application and wished to draw to the attention of the SIRO the following substantive comments:</p> <p>5.3.1 AGD noted that NHS England's Data Access Service (DAS) were still waiting for the applicant to send through the documentation relating to the honorary contract and were therefore unable to proffer an opinion on this aspect.</p> <p>5.3.2 AGD noted the questions raised by NHS England's DAS with regard to data controllership, however, noting colleagues, including the Chief Investigator from Imperial College Healthcare NHS Trust (Data Processor) were on honorary contracts and would be supervised by colleagues at Imperial College London (Data Controller); AGD suggested that NHS England clarify with the applicant what the supervision arrangements are for the Chief Investigator.</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 consent review provided as a supporting document (SD4), however queried if an appropriate capacity assessment had been undertaken by the applicant given that this was an online recruitment. The review confirms eligibility</p>	

	<p>checks were undertaken but it is unclear if a capacity check was also undertaken at this time.</p> <p>5.3.4 Noting that there was online recruitment, AGD suggested that the applicant also ensures that there is an online privacy notice.</p> <p>5.3.5 AGD noted the reference to “<i>approximately</i>” when referring to the cohort size, and suggested that NHS England clarify with the applicant whether this was an appropriate qualifier given the anticipated increase in cohort size.</p> <p>5.3.6 AGD suggested that to support the work outlined in the application, section 5(a) (Objective for Processing) was updated to include 1) an explanation as to where this a gap in the current landscape in terms of designing, collecting, linking and processing Patient Reported Outcome Measures (PROMs) data; 2) clarification as to why this work is not being done by a current national Registry; and 3) to explain the benefits of the effective use of accurate and relevant PROMs data.</p> <p>5.3.7 AGD queried the references in section 5(b) (Processing Activities) of the application to remote processing / access taking place in “<i>secure locations</i>”; and suggested that this was reviewed and updated, for example, to refer to the security of the remote connection and/or to the nature of the physical location.</p> <p>5.3.8 No AGD member noted a commercial aspect to the application.</p>	
5.4	<p>Reference Number: NIC-692602-Q6P4F-v4.2</p> <p>Applicant and Data Controller: Neo Health Hub Limited</p> <p>Application Title: Data modelling and analytics - Primary Care Prescribing and Primary Care Prescribing Impact on Secondary Care activity</p> <p>Observer: Jodie Taylor-Brown</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 7th November 2024, 4th July 2024, 7th December 2023, 17th August 2023 and the 25th May 2023.</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 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>5.4.1 AGD noted that the privacy notice was not easily accessible; and agreed with the suggestion made by NHS England’s Data Access Service (DAS) to the applicant, that further efforts were undertaken, to ensure that this more visible and</p>	

	<p>met legal requirements, by being made available on or via a website linked to the Data Controller, in line with the NHS England DAS Standard for Transparency.</p> <p>5.4.2 AGD noted and discussed the significant quantum of data requested, however, noted that this was being accessed via NHS England's Secure Data Environment (SDE).</p> <p>5.4.3 AGD noted that in addition to the data sharing agreement (DSA), there was also a 'User Agreement' for those individuals accessing data in NHS England's SDE, that covers off key points, including, but not limited to, specific user access and restrictions on exporting data; and suggested that this was referred to in section 5(b) (Processing Activities) of the application.</p> <p>5.4.4 AGD noted in section 5(b) that the provided data will not be linked with any other external data, however, suggested that NHS England update the application to reflect that linkage with any external data is not permitted.</p> <p>5.4.5 Noting the discussion at the AGD meetings on the 28th November 2024 and the 8th August 2024, on the broader scope of the NHS Business Services Authority (NHSBSA) Medicines Data Directions 2019; it was suggested that the application was reviewed and updated throughout to reflect the broader scope.</p> <p>5.4.6 In addition, it was suggested by the Group that the NHSBSA special condition in section 6 (Special Conditions) was reviewed and updated by NHS England, to remove any restrictive wording that is no longer relevant; but suggested that the 'suppression methodology' remained.</p> <p>5.4.7 AGD queried the references in section 5(b) of the application to remote processing / access taking place in "<i>secure locations</i>"; and suggested that this was reviewed and updated for example, to refer to the security of the remote connection and/or to the nature of the physical location.</p> <p>5.4.8 AGD noted that there had been an update to the expected outcomes in section 5(c) (Specific Outputs Expected), however noted that they do not reflect the full impact of the addition of the Hospital Episode Statistics (HES) data, and suggested that the applicant provide further information, for example, will all the outcomes be in relation to linkage between HES and NHSBSA data, or will there be more substantive use of the HES data.</p> <p>5.4.9 Noting this was a two year DSA, AGD suggested that, section 6 of the application was updated to include a special condition relating to the Annual Confirmation Report (ACR), in line with NHS England DAS Standard for Special Conditions.</p> <p>5.4.10 AGD noted that there was a commercial aspect to the application.</p>	
5.5	<p>Reference Number: NIC-762279-Q6S6T-v0.7</p> <p>Applicant: University of Newcastle Upon Tyne</p>	

<p>Data Controller: Sheffield Teaching Hospitals NHS Foundation Trust and University of Aberdeen</p> <p>Application Title: Assessing the long-term effectiveness of urethroplasty and urethrotomy as treatments for recurrent urethral strictures in men: Long-term follow-up of the OPEN Trial</p> <p>Observer: James Watts</p> <p>Application: This was a new application.</p> <p>NHS England were seeking advice on the following points only:</p> <ol style="list-style-type: none"> 1. Review of consent and its compatibility with this application. <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 not providing comments on the wider application; comments were limited to the specific point of advice requested. AGD wished to draw to the attention of the SIRO the following observations in relation to the advice point:</p> <p>AGD noted that this application was a first of type review under the 'AGD first' concept.</p> <p>In response to point 1:</p> <p>5.5.1 AGD noted that there was a legal gateway in consent to make further contact with the cohort members.</p> <p>5.5.2 AGD noted that there were different views within the Group as to whether there was a legal gateway in consent to continue or whether the cohort should be asked to re-consent to move to the next phase of the study. AGD were unable to reach a consensus view on this point.</p> <p>5.5.3 AGD suggested that the applicant engaged with a small group of the cohort, to check their understanding as to what the original consent did / did not cover.</p> <p>5.5.4 In respect of the patient information sheet provided as a supporting document (SD2.1), AGD made a number of points, including 1) to be clear why individuals were receiving the information and a reference to the previous consent provided; 2) information on a new phase of the study, 3) details of any new organisations involved; and 4) options to withdraw from the study.</p> <p>5.5.5 The AGD NHS England Caldicott Guardian Team Representative queried if a further follow up trial was being considered; and if so, suggested that the application and transparency materials were clear on this.</p> <p>5.5.6 Noting AGD was only asked to advise on specific points reviewed, no AGD member noted any substantive commercial aspects.</p>	<p>6 INTERNAL DATA DISSEMINATION REQUESTS:</p>
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There were no items discussed

7 EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL

7.1	<p>Reference Number: NIC-762920-X1J6C-v0.5</p> <p>Applicant and Data Controller: Cardiff University</p> <p>Application Title: Acute Myeloid Leukaemia Treatment (AML) treatment rates in the UK</p> <p>The SIRO approval was for a two-year data sharing agreement.</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 queried why the application had gone down the SIRO approval route, since there had not been any previous AGD, interim AGD, IGARD or DAAG review, and advised that this point was unclear in the papers provided.</p> <p>The NHS England SIRO representative thanked AGD for their time.</p>
7.2	<p>Reference Number: NIC-769062-G5F1K-v0.3</p> <p>Applicant: University College London (UCL)</p> <p>Data Controllers: Care England, The Outstanding Society Community Interest Company and UCL</p> <p>Application Title: Vivaldi Social Care</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 21st November 2024.</p> <p>The SIRO approval was for a one-year data sharing agreement.</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 their previous concerns had been addressed.</p> <p>7.2.2 AGD noted that, prior to the meeting, a query had been raised by an AGD independent member with the NHS England SIRO Representative, in respect of, the information provided explaining the Department for Health and Social Care (DHSC) data policy, that allows for resources to be hosted elsewhere where it is not feasible to use NHS infrastructure; and queried whether the Vivaldi Social Care study were</p>

	<p>judged a permanent or a temporary exception to using an NHS Secure Data Environment (SDE); and if it is a temporary exception, what is the transition plan.</p> <p>The NHS England SIRO representative thanked AGD for their time.</p>	
7.3	<p>Reference Number: NIC-743571-K7X4R-v0.2</p> <p>Applicant and Data Controller: University of Oxford</p> <p>Application Title: MyMelanoma Study - NHS DigiTrials Recruitment Service</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 10th October 2024.</p> <p>The SIRO approval was for the inclusion of 'Study Within a Trial' (SWAT), which is to evaluate the uptake of participants to the study, based on the invitation letter received.</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>7.3.1 AGD noted that prior to the meeting, a query had been raised by an AGD independent member with the NHS England SIRO Representative, in respect of the response to a point raised by AGD on the 10th October 2024, in relation to the patient information sheet (PIS), that states the data would not include information "<i>such as the hospital you were treated at</i>"; and had queried whether this would be included in the HES data. If this data was captured in the HES data, the Group had suggested that this was discussed with the applicant, and that the PIS and any other supporting information was updated to reflect the correct / factual information. The Group noted that this information had been shared with the applicant, who had advised that when an application to request HES data was submitted, the PIS and supporting information would be updated accordingly. The point was raised that if the applicant would want to later apply for HES data including hospital code, the PIS and supporting information should be updated before members of the cohort are consented. It was agreed that this point would be passed to relevant colleague within NHS England's Data Access Service (DAS) to discuss further with the applicant.</p> <p>The NHS England SIRO representative thanked AGD for their time.</p>	
8 OVERSIGHT AND ASSURANCE		
8.1	<p>Oversight and Assurance Process</p> <p>Workstream 3 - Annual Compliance Report (ACR)</p> <p>Following on from the initial ACR review on the 22nd August 2024 (published in the AGD minutes from the 5th September 2024), and as requested by the NHS England</p>	

	<p>SIRO Representative, AGD undertook a second ACR review, as part of the AGD oversight and assurance programme of work.</p> <p>In advance of the meeting, the AGD independent members were provided with 1) 15 applications (selected by the AGD Secretariat); 2) internal application assessment forms for each of the 14 applications; 3) the ACR document; 4) other supporting documents as may be required; and 5) an ACR review 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 colleagues in NHS England's Data Access Service and relevant NHS England colleagues as may be appropriate.</p> <p>Please see appendix A for high-level points raised in-meeting on the 14 applications.</p>	
8.2	<p>Oversight and Assurance Conclusion / Review</p> <p>AGD noted that the AGD NHS England Data and Analytics Representative in attendance, was in the process of reviewing the ACR end to end process, and made a number of suggestions for consideration, including 1) to ask the applicant to include a link to their published privacy notice in the ACR; 2) to ask the applicant to include a link to the Health Research Authority Confidentiality Advisory Group (HRA CAG) register where relevant in the ACR; 3) to include the date the ACR is due and the date the ACR is received by NHS England.</p> <p>AGD reiterated points discussed at the 5th September 2024 meeting, including but not limited to, amending the signatory box on the ACR form to be clear they have to have a suitable level of authority or provide written evidence of delegation of authority; splitting the s251 into two parts – “<i>is it in place</i>” and if “<i>yes</i>” then “<i>provide the CAG reference number</i>”; splitting the sub licensing questions into two parts – “<i>is it in place</i>” and if “<i>yes</i>” then “<i>are you complying with the special conditions in section 10</i>”.</p> <p>In addition, AGD suggested the ACR form be updated to require applicants to put the link to the privacy notice, rather than to tick a box that there is one; to add the data the ACR form was received in order to check whether the form was received on time or late; for NHS England to consider using docu-sign or other software for the ACR form, rather than MS Word; to be clear in the abstract of the DSA or SDA what documents were reviewed to make the decision so that they could be downloaded for the oversight and assurance review by AGD.</p>	

	<p>AGD and the NHS England SIRO representative agreed that the ACR oversight and assurance would continue as a quarterly item.</p> <p>ACTION: AGD Secretariat to add the ACR review on the AGD forward planner as a quarterly item (January / April / July / October).</p>	AGD Sec
9	<p>Federated Data Platform (FDP) update (Presenter: Claire Clements)</p> <p>The Group were provided with a verbal update on the FDP programme of work to date, including, background, the number of organisations using FDP to date, and communications / engagement undertaken to date on FDP.</p> <p>The Group noted the verbal update provided, and thanked Claire for attending the meeting.</p>	
10 AGD OPERATIONS		
10.1	<p>AGD Terms of Reference (ToR) Annual Review (Presenter: Garry Coleman)</p> <p>In line with paragraph 9.9 of the AGD ToR that states the “...<i>Terms of Reference will be reviewed by the Group, the SIRO Representative and the Deputy SIRO annually</i>”, the Group were advised by the NHS England SIRO Representative that work would commence over the coming weeks to allow AGD members to review and add suggested / relevant high-level edits to the AGD ToR.</p> <p>It was noted that the AGD ToR review would need further discussion with regard to the process / actions.</p> <p>ACTION: AGD Secretariat to add ‘AGD ToR review’ to the internal AGD forward planner for a future AGD discussion(s).</p>	AGD Sec
10.2	<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>	SIRO Rep
10.3	Standard Operating Procedures (SOPs) (Update from Vicki Williams)	

	<p>The ongoing forward plan of work for creating the AGD Standard Operating Procedures was discussed.</p> <p>The Group noted that the 'AGD member Declaration of Interest' was in the process of being finalised, and a further update on this would be provided in due course, and published on the AGD webpage.</p>	
10.4	<p>AGD Stakeholder Engagement</p> <p>The AGD Chair noted that she had met with Jackie Gray, Director of Privacy and Information Governance, Privacy, Transparency, and Trust on the 21st January 2025; this was in line with clause 9.2 of the AGD Terms of Reference that states: <i>"The Chair and the Deputy SIRO shall meet at least every six months to review the operation of the Group"</i>.</p>	
10.5	<p>AGD Project Work</p> <p>Consent review for consented cohorts</p> <p>The NHS England SIRO Representative advised that NHS England would be seeking advice from the AGD and asking them to review the consent materials for consented cohorts for a small number of organisations.</p> <p>The Group noted the verbal update provided, and advised they were happy to support this area of work, but that NHS England should provide further detail around the draft Direction, what the proposed processing is, what AGD is reviewing against (NHS England Standards or other), what PPIE has been undertaken with the cohorts, and how the outputs would be collated / presented.</p> <p>ACTION for the NHS England SIRO Representative: Noting the extensive work that this project work would entail, AGD suggested that NHS England consider utilising a Thursday in February for a workshop. The NHS England SIRO Representative to consider this request and confirm the date with the NHS England DARS and AGD.</p>	SIRO Rep
11 Any Other Business		
11.1	<p>'Study Within a Trial' (SWAT)</p> <p>AGD noted that the use of a 'SWAT' had been presented / discussed in a number of recent AGD meetings and requested that a briefing was provided / presented to the Group at a future AGD meeting.</p> <p>ACTION: AGD Secretariat to add 'SWAT briefing / presentation' to the internal AGD forward planner for a future AGD discussion.</p>	AGD Sec
10.1	<p>How NHS England consider the legislation and apply it to Directions</p> <p>An AGD independent member noted that following the discussion on <i>'Directions including how NHS England consider the legislation and apply it to Directions'</i> at the AGD plenary meeting on the 5th December 2024, they had met with Kevin Willis and Joanne Tredennick as part of their learning and development to discuss this in more</p>	

	<p>detail, suggesting that a further verbal update be provided at a future AGD plenary meeting.</p> <p>ACTION: AGD Secretariat to add 'Directions including how NHS England consider the legislation and apply it to Directions' to the internal AGD forward planner for a future AGD plenary discussion.</p>	AGD Sec
10.2	<p>AGD collaboration on in-meeting documentation proposal</p> <p>AGD noted, that as discussed at the AGD meetings on the 16th January 2025, 12th December 2024 and the 26th September 2024, the application for item 5.1 on this week's AGD meeting agenda had been reviewed by AGD members in an internal shared space prior to the in-meeting discussion.</p> <p>As this process was running as a pilot throughout January 2025, the Group discussed how this had worked and whether it had supported the discussion in the meeting.</p> <p>The Group agreed that prior to the AGD meeting on the 30th January 2025, one application would be uploaded to the internal shared space for the Group to undertake another review prior to the meeting; and that this would be reviewed under 'AOB' at the end of the meeting.</p> <p>ACTION: AGD Secretariat to select an application from the AGD meeting agenda on the 30th January 2025, and upload to the AGD internal SharePoint site for review, prior to the meeting.</p>	AGD Sec
<p>Meeting Closure</p> <p>As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.</p>		

Appendix A

Oversight and Assurance Review – 23rd January 2025

Workstream 3 (quarterly) - Annual Compliance Report (ACR)

Ref:	NIC Number:	Organisation:	Areas to consider:
250123a	NIC-656752-G2L2P	University of Oxford	No issues raised
250123b	NIC-384504-N2V5B	University College London	<ul style="list-style-type: none"> Four DSAs had been included on the one ACR form which was not in line with due NHS England process. Three linked DSAs had not been provided as part of the review, since the ACR should only apply to one DSA. The ACR provided noted that transparency was publicly available, however AGD were unable to find an easily accessible published privacy notice. <ul style="list-style-type: none"> Process point: Action for the D&A Representative to consider the request that the ACR form be updated to require applicants to put the link to the privacy notice, rather than to tick a box that there is one. Noting the special condition in section 6 of the DSA, AGD were unable to locate the sub licence release register.

			<ul style="list-style-type: none"> ○ Action for the SIRO Team to check that the applicant had a sub licence register in line with the special condition
250123c	NIC-657422-S1K1C	University of York	<ul style="list-style-type: none"> • It was not clear if the ACR form had been submitted on time in line with the special condition, and suggested that NHS England review their internal processes. <ul style="list-style-type: none"> ○ Process point: Action point for the D&A Representative to review the ACR form and internal processes in order to add the date the ACR form received and a marker as to whether this was on time or late.
250123d	NIC-291981-Y7J2F	Imperial College London	<ul style="list-style-type: none"> • Query if “X” was a suitable signature for an ACR document • Query if the Information Governance Lead had the delegated authority to sign on behalf of the Data Controller and in line with the DSA’s special condition. <ul style="list-style-type: none"> ○ Process point: Action for D&A Representative to ensure that the team are checking that the Data Controller has confirmed that the signatory has the relevant delegated authority and that the relevant evidence of delegation is provided.

			<ul style="list-style-type: none"> ○ Action for the SIRO Team to check if the signatory has the relevant delegated authority to sign on behalf of the Data Controller • Query if Word documents were the right conduit for the ACR and suggested the NHS England explore docu-sign or other software <ul style="list-style-type: none"> ○ Process point: Action for the D&A Representative to review whether docu-sign or other software could be used for the ACR rather than Word.
250123e	NIC-12629-B4N5K	Queen Mary University London	<ul style="list-style-type: none"> • A number of ACR boxes had been ticked as having been complied with, that when reviewing the DSA were not relevant to the ACR for example, ticking the box in reference to having a contract between the Controller and Processors listed with regard to processing, when the processor listed was QMUL OR ticking the box for both consent and s251, when only s251 applied • s251 documentation had not been provided (noting they would only be provided with the documentation that the reviewer had reviewed when making a decision around the ACR). <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 s1 of the SDA what

			documents were reviewed to make the decision with regard to the ACR.
250123f	NIC-727537-C3V4G	Royal College of Physicians	<ul style="list-style-type: none"> The Data Processor had signed the ACR and queried if they had the delegated authority to sign on behalf of the Data Controller and in line with the DSA's special condition <ul style="list-style-type: none"> Process point: Action for D&A Representative to ensure that the team are checking where the signatory is not the Data Controller that the relevant evidence of delegation is provided. Action for the SIRO Team to check if the Data Processor has the relevant delegated authority to sign on behalf of the Data Controller.
250123g	NIC-727954-G5X8B	Royal College of Physicians	<ul style="list-style-type: none"> The Data Processor had signed the ACR and queried if they had the delegated authority to sign on behalf of the Data Controller and in line with the DSA's special condition <ul style="list-style-type: none"> Process point: Action for D&A Representative to ensure that the team are checking where the signatory is not the Data Controller that the relevant evidence of delegation is provided. Action for the SIRO Team to check if the Data Processor has the relevant

			<p>delegated authority to sign on behalf of the Data Controller.</p> <ul style="list-style-type: none"> • Four DSAs had been included on the one ACR form which was not in line with due NHS England process. • Three linked DSAs had not been provided as part of the review, since the ACR should only apply to one DSA.
250123h	NIC-659293-T1G7M	South London and Maudsley NHS Foundation Trust	<ul style="list-style-type: none"> • The majority of members of AGD did not support the decision made to give continued access to the data because it was not clear whether NHS England is confident about the status of the data in terms of CLDoC and the status of the data needs to be clarified (pseudonymised or identifiable). • AGD acknowledged that the applicant had sought advice from HRA CAG and been informed that CAG support was no longer required.
250123i	NIC-682048-S9P4H	Laser Europe Ltd	<ul style="list-style-type: none"> • S251 documentation had not been provided (noting they would only be provided with the documentation that the reviewer had reviewed when making a decision around the ACR). <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 s1 of the SDA what documents were reviewed to make the decision with regard to the ACR.

250123j	NIC-663093-K1B0K	Ipsos MORI UK Ltd	<ul style="list-style-type: none"> • S251 documentation had not been provided (noting they would only be provided with the documentation that the reviewer had reviewed when making a decision around the ACR). <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 s1 of the SDA what documents were reviewed to make the decision with regard to the ACR. • It was not clear if the ACR form had been submitted on time in line with the special condition or late, and suggested that NHS England review their internal processes. <ul style="list-style-type: none"> ○ Process point: Action point for the D&A Representative to review the ACR form and internal processes in order to add the date the ACR form received and a marker as to whether this was on time or late.
250123k	NIC-685917-H4X8G	NHS Blood and Transplant	No issues raised
250123l	NIC-682583-Z3V2H	Adelphi Real World	<ul style="list-style-type: none"> • A signatory from Adelphi Real World had signed the ACR – query if they had the delegated authority to sign on behalf of the Data Controller and in line with the DSA's special condition <ul style="list-style-type: none"> ○ Process point: Action for D&A Representative to ensure that the team

			<p>are checking where the signatory is not the Data Controller that the relevant evidence of delegation is provided.</p> <ul style="list-style-type: none"> ○ Action for the SIRO Team to check if the signatory from Adelphi Real World has the relevant delegated authority to sign on behalf of the Data Controller. • AGD commended the applicant on the transparency and why the benefits had not been advanced as envisage, as outlined in the ACR.
250123m	NIC-655446-P9K9Q	Adelphi Group Ltd	<ul style="list-style-type: none"> • A signatory from Adelphi Real World had signed the ACR – query if they had the delegated authority to sign on behalf of the Data Controller and in line with the DSA's special condition <ul style="list-style-type: none"> ○ Process point: Action for D&A Representative to ensure that the team are checking where the signatory is not the Data Controller that the relevant evidence of delegation is provided. ○ Action for the SIRO Team to check if the signatory from Adelphi Real World has the relevant delegated authority to sign on behalf of the Data Controller. • Query if Word documents were the right conduit for the ACR and suggested the NHS England explore docu-sign or other software

			<ul style="list-style-type: none"> ○ Process point: Action for the D&A Representative to review whether docu-sign or other software could be used for the ACR rather than Word.
250123n	NIC-88623-F2H1A	Royal College of Anaesthetists	<ul style="list-style-type: none"> • Query if the Chief investigator had the delegated authority to sign on behalf of the Data Controller and in line with the DSA's special condition. <ul style="list-style-type: none"> ○ Process point: Action for D&A Representative to ensure that the team are checking that the Data Controller has confirmed that signatory has the relevant delegated authority and that the relevant evidence of delegation is provided. ○ Action for the SIRO Team to check if the signatory has the relevant delegated authority to sign on behalf of the Data Controller • It was not clear what progress towards the benefits had been, since the text appeared to be a repetition of what was in the DSA.
250123o	NIC-604847-S4B5L	Grail Gio UK Limited	<ul style="list-style-type: none"> • The NIC number on the ACR form did not match the NIC number on the DSA and asked that NHS England confirm that the right documentation had been uploaded to CRM.

			<ul style="list-style-type: none"> • Query if the signatory had the delegated authority to sign on behalf of the Data Controller and in line with the DSA's special condition. <ul style="list-style-type: none"> ○ Process point: Action for D&A Representative to ensure that the team are checking that the Data Controller has confirmed that the signatory has the relevant delegated authority and that the relevant evidence of delegation is provided. ○ Action for the SIRO Team to check if the signatory has the relevant delegated authority to sign on behalf of the Data Controller
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