

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 10th April 2025

09:00 – 16:05

(Remote meeting via videoconference)

| AGD INDEPENDENT / NHS ENGLAND MEMBERS IN ATTENDANCE: | |
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| 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) |
| Narissa Leyland (NL) | NHS England member (Data and Analytics Representative (Delegate for Michael Chapman)) |
| Dr. Jonathan Osborn (JO) | NHS England member (Caldicott Guardian Team Representative) |
| Miranda Winram (MW) | AGD independent member (Lay Adviser) |
| NHS ENGLAND STAFF IN ATTENDANCE: | |
| Name: | Role / Area: |
| Garry Coleman (GC) | NHS England SIRO Representative |
| Joe Lawson (JL) | Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.2) |
| Karen Myers (KM) | AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Delivery Directorate |
| Humphrey Onu (HO) | Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: items 5.3 and 5.4) |
| Jodie Taylor-Brown (JTB) | Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.5) |
| James Watts (JWa) | Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.1) |
| Emma Whale (EW) | Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: items 5.5 and 5.6) |

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| 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) |
| Dr. Robert French (RF) | AGD independent member (Specialist Academic / Statistician Adviser) |
| Jon Moore (JM) | NHS England member (Data Protection Office Representative) |
| Jenny Westaway (JW) | AGD independent member (Lay Adviser) |

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| 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 3 rd April 2025 were reviewed and, after several 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 College London (NIC-752595-J7L6P) as part of her role at South London and Maudsley NHS Foundation Trust. It was agreed this did not preclude Claire from taking part in the discussion on this application. |
| 4 BRIEFING PAPER(S) / DIRECTIONS: | |
| <i>There were no items discussed</i> | |
| 5 EXTERNAL DATA DISSEMINATION REQUESTS: | |
| 5.1 | <p>Reference Number: NIC-147982-J7KGV-v8.4</p> <p>Applicant and Data Controller: University of Liverpool</p> <p>Application Title: The Roy Castle Lung Cancer Research Programme, Liverpool Lung Project - University of Liverpool</p> <p>Observer: James Watts</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 19th September 2024 and the 23rd February 2023.</p> |

The application and relevant supporting documents were previously presented / discussed at the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) meetings on the 23rd July 2020, 21st June 2018, 12th April 2018 and the 20th July 2017.

Application: This was an amendment application.

NHS England were seeking advice on the following points, including general advice on any other aspect of the application:

1. The addition of National Disease Registration Service (NDRS) datasets.

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

Outcome of discussion: AGD were supportive of the application and wished to draw to the attention of the SIRO the following comments:

In response to point 1:

5.1.1 AGD raised no concerns or issues with the addition of the NDRS datasets to the application.

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

5.1.2 AGD noted that prior to the meeting, a query had been raised by an AGD independent member, in respect of the applicant's position, that once the NHS England data has been combined with other data held by the applicant, the NHS England data is then derived and is no longer subject to a data sharing agreement (DSA). The Group suggested that **1)** NHS England ensure that there is continued compliance with NHS England's policy on derived data; and **2)** the text in section 5(a) (Objective for Processing) in respect of the derived data was reviewed and simplified to be clear that once the data is derived, this data will not be part of the DSA.

5.1.3 Separate to this application and for NHS England to consider: AGD noted that at the AGD meeting on the 23rd February 2023, the Group had noted the application of the National Data Opt-out (NDO) for members of the cohort who had consented to obtaining follow up data, which raised a significant policy issue and an ethical concern (overriding a person's consent). AGD suggested that NHS England satisfies itself that they were content with the NDO being applied to a consented cohort, noting that this was not consistent with clause 6.1 of the National Data Opt-out [policy](#) that states "*The national data opt-out does not apply where explicit consent has been obtained from the patient for the specific purpose*".

5.1.4 AGD commended the applicant on the updated privacy notice; however, queried if the **options** within the opt-out form accessed via the privacy notice were correct. The Group suggested that **1)** the applicant review and update the opt-out form as may be necessary to reflect the correct / factual information / choices including with regard to commercial uses; and **2)** that the applicant update the form to ensure that it was clear what the options were for withdrawing from the research, which should contain at least **two** methods of contact for participants (post, telephone and / or e-mail).

5.1.5 AGD noted that they were supportive of the demographics data flowing, however, suggested that section 5(a) was updated to clarify why this data had been requested, and

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| | <p>for what purpose it would be processed, in line with NHS England DAS Standard for Objective for Processing.</p> <p>5.1.6 AGD noted that section 5(b) (Processing Activities) states that data will be accessed onsite at the premises of the University of Liverpool only; and suggested that NHS England discuss this with the applicant, highlighted the restrictions with this arrangement.</p> <p>5.1.7 AGD noted the statement in section 5(b) of the application “<i>There will be no requirement and no attempt to reidentify individuals...</i>”; and noted that this did not align with information in section 5(a). It was suggested that this was reviewed and updated as may be necessary to reflect the correct information; or that the statement was removed.</p> <p>5.1.8 Separate to this application and for NHS England to consider: AGD suggested that the AGD NHS England Data and Analytics Representative reviewed / updated the standard wording in respect of “<i>re-identification</i>” in section 5(a), to allow for re-identification where appropriate / permitted, for example, for direct care / patient safety reasons where it is a consented cohort. An AGD independent Lay member noted that any updates to the text should be clear and understandable to a lay audience, as to what was permitted.</p> <p>5.1.9 AGD suggested that the typo in section 5(a) “<i>Biotech of Pharmaceutical companies</i>” was corrected to “<i>Biotech or Pharmaceutical companies</i>”.</p> <p>5.1.10 AGD noted and commended NHS England’s Data Access Service (DAS) on the work undertaken on the application and the NHS England DAS internal application assessment form since the last AGD review.</p> <p>5.1.11 AGD noted and commended the applicant on the updates to yielded benefits in section 5(d) (Benefits) (iii) (Yielded Benefits).</p> <p>5.1.12 AGD suggested that the commercial information in section 5(a) was updated to include a link to the research programme’s commercial collaborations.</p> <p>5.1.13 In addition, AGD noted that the published information in respect of the research programmes commercial collaborations had not been updated recently; and suggested that 1) NHS England clarify with the applicant if this information was correct / up to date; and 2) any updates were made to reflect the most recent information.</p> <p>5.1.14 AGD noted that there was a commercial aspect to the application.</p> | D&A Rep |
| 5.2 | <p>Reference Number: NIC-643421-J9T3M-v0.9</p> <p>Applicant and Data Controller: University of Oxford</p> <p>Application Title: “A long term prospective cohort study on the effects of smoking and prophylactic aspirin on all-cause mortality in male British doctors”</p> <p>Observer: Joe Lawson</p> <p>Linked applications: This application is linked to NIC-147808-3F9FR.</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> | |

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| | <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>5.2.1 AGD noted that prior to the meeting, a query had been raised by an AGD independent member, in respect of whether all the data under NIC-147808-3F9FR had been destroyed. The Group noted that the data requested under this application (NIC-643421-J9T3M) will relate to those individuals known to be alive the last time morality data was provided, which would not be possible if the mortality data (under NIC-147808-3F9FR) had been destroyed. It was suggested that NHS England explore this further with the applicant to determine 1) whether all of the data under NIC-147808-3F9FR had been destroyed; and 2) if the data had been destroyed, how those individuals known to be alive the last time morality data was provided would be identified.</p> <p>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.2.2 AGD welcomed the application and noted the importance of the study.</p> <p>5.2.3 AGD noted that this was a one-year data sharing agreement (DSA) with anticipated further processing for further years; and suggested that NHS England discussed this further with the applicant, to ensure that the DSA aligned with the appropriate time period of the processing of NHS England data.</p> <p>5.2.4 AGD queried the statement in section 5(b) (Processing Activities) “<i>Access is restricted to employees or agents of...</i>” and suggested that that either further information was provided as to who would be covered by “<i>agents</i>”; or that this word was removed as may be necessary to reflect the facts.</p> <p>5.2.5 AGD noted that section 5(b) states that data will be accessed onsite at the premises of the University of Oxford only; and suggested that NHS England discuss this with the applicant, highlighting the restrictions with this arrangement.</p> <p>5.2.6 No AGD member noted a commercial aspect to the application.</p> | |
| 5.3 | <p>Reference Number: NIC-753305-S9Y1C-v0.5</p> <p>Applicant: Cardiff University</p> <p>Applicant and Data Controller: Cardiff University and Velindre University NHS Trust</p> <p>Application Title: “SCOPE2 - A randomised Phase II/III trial to study radiotherapy dose escalation in patients with oesophageal cancer treated with definitive chemo-radiation with an embedded Phase II trial for patients with a poor early response using positron emission tomograph”</p> <p>Observer: Humphrey Onu</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> | |

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| | <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 and agreed that Cardiff University and Velindre University NHS Trust were joint Data Controllers; however, suggested that the application was reviewed and updated throughout, to be clear on 1) which organisation was handling and transferring data at each stage; 2) which organisation was handling the identifiers; and 3) how the Chief Investigator, who was a substantive employee of Velindre University NHS Trust would be directing staff / processes at Cardiff University.</p> <p>5.3.2 The NHS England SIRO Representative asked that section 3 (Datasets Held / Requested) and section 5 (Purpose / Methods / Outputs) were reviewed and aligned to ensure that 1) the identifiability of the data was correctly referenced; and 2) the correct data fields were referenced.</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 and commended NHS England’s Data Access Service (DAS) for the consent review undertaken; which supported the review of the application / the conclusion that there was a legal gateway in consent to address the common law duty of confidentiality.</p> <p>5.3.4 Notwithstanding the legal gateway in consent, AGD suggested that for those participants consented on versions one to four of the consent form, a further update could be provided, for example via a newsletter, to outline / clarify the linkage of their data, in line with UK General Data Protection Regulation (UK GDPR). The Group noted that the consent forms from version five onwards were clearer on this point.</p> <p>5.3.5 AGD noted that the description of the processing in section 5(a) (Objective for Processing) was quite technical, and suggested that this was reviewed and updated as may be necessary to ensure this was clearer, for example, replacing the reference to “RT” with “radiotherapy”; and describing the radiation dose as “high” or “low” and removing any technical language.</p> <p>5.3.6 AGD suggested that section 5(a) and section 5(b) (Processing Activities) were updated to remove any statements that there will be no requirement / no attempt to reidentify individuals, noting that this was a consented cohort and identifiable data would be flowing.</p> <p>5.3.7 No AGD member noted a commercial aspect to the application.</p> | |
| 5.4 | <p>Reference Number: NIC-752595-J7L6P-v0.4</p> <p>Applicant and Data Controller: University of Birmingham</p> <p>Application Title: “PET-CT guided, symptom-based, patient-driven surveillance versus clinical follow-up in advanced head neck cancer (PETNECK 2)”</p> <p>Observer: Humphrey Onu</p> <p>Application: This was a new application.</p> <p>NHS England were seeking advice on the following points only:</p> | |

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| | <p>1. The provision of mortality and Hospital Episode Statistics (HES) data for the purposes detailed in this 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>In response to point 1:</p> <p>5.4.1 AGD noted and commended NHS England’s Data Access Service (DAS) on seeking advice from the Group on the provision of mortality and HES data at this stage.</p> <p>5.4.2 AGD noted that they were supportive of the provision of mortality and HES data for the purposes outlined in this application; however, suggested that this was progressed via the relevant NHS England DAS Precedent route, noting that this would then be eligible for AGD’s oversight and assurance process.</p> <p>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.4.3 The NHS England SIRO Representative suggested that section 5(a) (Objective for Processing) was reviewed and updated to ensure that the outputs are possible with the data that would be flowing, for example, data of death data would not provide details on the cause of death.</p> <p>5.4.4 AGD noted that section 3 (Datasets Held / Requested) and section 5 (Purpose / Methods / Outputs) stated that the identifiability of the data was “<i>pseudonymised</i>”, however suggested that this was reviewed and updated as may be necessary, noting that data would be linked to participants study ID and would therefore be identifiable.</p> <p>5.4.5 AGD noted that section 2(c) (Territory of Use) had not been populated, and suggested that the applicant update this with the territory of use, in line with NHS England DAS Standard for Territory of Use.</p> <p>5.4.6 No AGD member noted a commercial aspect to the application.</p> | |
| 5.5 | <p>Reference Number: NIC-771303-G4V1M-v0.13</p> <p>Applicant and Data Controller: University Hospital Southampton NHS Foundation Trust</p> <p>Application Title: “Pre-hospital Research and Audit Network (PRANA)”</p> <p>Observers: Jodie Taylor-Brown and Emma Whale</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 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> | |

5.5.1 AGD have previously expressed strong support for the expanded use of Secure Data Environments (SDEs), and recognised in particular the excellent patient and public involvement and engagement (PPIE) undertaken by the applicant. The Group recognised that the SDE network is at an early stage in development, and wished to encourage that work. However, potentially because of the early stage of the work, the evidence was **not** yet available at AGD to describe how it met the current NHS England Data Access Service (DAS) standards for sharing of data, which are the ‘bar’ against which AGD currently advise. Some AGD members strongly supported the intent of NHS England to continue to work closely with the applicant in developing the application and ensuring that points raised are applied across the wider regional SDE network. AGD outlined a number of specific points of advice aimed to help focus future work on the application.

5.5.2 AGD noted that they had reviewed the Wessex SDE Data Access Committee Terms of Reference (ToR), and advised that they could not see that an assessment of the balance between public and commercial benefits would be undertaken, in line with [NHS England DAS Standard for Commercial Purpose](#) and / or the NDG [guidance on benefits](#).

5.5.3 Separate to this application and for NHS England to consider: AGD suggested that the AGD NHS England Data and Analytics Representative provides feedback to the SDE network that, as currently drafted, the draft Data Access Committee ToR do **not** appear to align with the [NHS England DAS Standard for Commercial Purpose](#) and / or the NDG [guidance on benefits](#).

5.5.4 AGD queried the rationale for creating a national Registry outside of NHS England, and why this was a better approach than the previously expressed NHS England approach / policy of centralisation of Registries; and suggested, for transparency, this was clarified in section 5(a) (Objective for Processing).

5.5.5 AGD noted that the University of Southampton were listed as a Data Processor; however queried if this was correct, noting **1**) the information on the PRANA website that states the data will be under the governance of the University of Southampton, and **2**) the information in section 3(b) (Additional Data Access Requested) that refers to a “...*cohort identified by the University of Southampton*”. The Group suggested that NHS England’s Data Access Service (DAS) explore this further with the applicant, to clarify that they were not determining the purpose and means of processing and were therefore not carrying out any data controllership activities in line with the [NHS England DAS Standard for Data Controllers](#); and that the application was updated as may be required to reflect the correct / factual information.

5.5.6 AGD noted that three Article 9 UK General Data Protection Regulation (UK GDPR) limbs had been cited, Article 9(2)(h) (*Health or social care (with a basis in law)*), Article 9(2)(i) (*Public health (with a basis in law)*) and 9(2)(j) (*processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purpose*); and suggested that section 5(a) of the application was updated to **1**) clarify what processing was being carried out under each Article 9 limb; and **2**) provide additional information on the processing under Article 9(2)(i) noting the high bar required to use this particular Article 9 limb.

5.5.7 AGD noted the statement in section 5(a) “...*a team of researchers from across the country have collaborated...within the governance of the Wessex NHS Secure Data*”

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| | <p><i>Environment...</i>"; and suggested that this was updated or removed noting that this was not reflected in the data controllership arrangements.</p> <p>5.5.8 AGD noted and commended the PPIE undertaken by the applicant to date, however, suggested that section 5(a) was updated to also include information on the outcome(s) of the PPIE.</p> <p>5.5.9 AGD suggested that section 5(e) (Is the Purpose of this Application in Anyway Commercial) was updated to reflect that there are potential commercial aspects to the application, in line with NHS England DAS Standard for Commercial Purpose, noting that there may be commercial sub-licencing.</p> <p>5.5.10 Separate to this application and for NHS England to consider: AGD noted that NHS England's DAS had created and submitted a new internal 'Sublicense Assessment Form' with the papers for this application, and advised the Group that they would welcome feedback on this form. The Group welcomed the introduction of this form that supported the review of the application, and made the following comments / suggested updates: 1) the Group noted that the form aligned with NHS England DAS standard for sub-licencing and onward sharing; 2) the Group suggested that a question was added to the form asking DAS to note how the sub-licensor addressed the NHS England DAS Standard for Commercial Purpose, for example, does the Access Review Committee undertake an assessment of the balance between public and commercial benefit, in line with the National Data Guardian (NDG) guidance on benefits. AGD noted that they would be supportive of the wider use of this form.</p> <p>5.5.11 AGD noted there were commercial aspects to the application including the potential for commercial sub-licencing.</p> | D&A Rep |
| 5.6 | <p>Reference Number: NIC-765236-C7C1B-v0.9</p> <p>Applicant and Data Controller: University of Oxford</p> <p>Application Title: "RECOVERY – Pneumonia"</p> <p>Observer: Emma Whale</p> <p>Linked applications: This application is linked to NIC-365354-R3M0Q.</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>5.6.1 AGD noted that the applicant's privacy notice had been updated, and suggested that members of the cohort were provided with a link to the privacy notice for information.</p> <p>5.6.2 AGD noted that section 2(c) (Territory of Use) had not been populated, and suggested that the applicant update this with the territory of use, in line with NHS England DAS Standard for Territory of Use.</p> | |

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| | <p>5.6.3 AGD noted that funding was in place until June 2026, however the application end date was March 2028; and suggested that 1) NHS England clarify with the applicant that there is funding in place for the duration of the data sharing agreement (DSA); and 2) the NHS England Data Access Service (DAS) internal application assessment form was updated to reflect any discussions on this point with the applicant.</p> <p>5.6.4 AGD suggested that all of the key points from the commercial aspect of the application outlined in section 5(e) (Is the Purpose of this Application in Anyway Commercial), were replicated / expanded for transparency in (the published) section 5(a) (Objective for Processing), in line with NHS England's DAS Standard for Objective for Processing and NHS England's DAS Standard for Commercial Purpose.</p> <p>5.6.5 AGD noted that there was a commercial aspect to the application.</p> | |
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6 INTERNAL DATA DISSEMINATION REQUESTS:

There were no items discussed

7 EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL

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| <p>7.1</p> | <p>Reference Number: NIC-147858-KGYSS-v5.3</p> <p>Applicant and Data Controller: Saving Faces - The Facial Surgery Research Foundation</p> <p>Application Title: “The Role of Selective Neck Dissection Used Electively in Patients”</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 17th February 2022.</p> <p>The SIRO approval was for an extension; to replace Medical Research Information Service (MRIS) data with Cancer Registration Data in replace to retrieve cancer occurrence and date of occurrence.</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 that the ongoing issue with the applicant’s System Level Security Policy (SLSP) had now been resolved; and noted that whilst this had caused additional work for the small Study Team within the charity, the size of a charity / Study Team was irrelevant when it came to handling data and ensuring that the correct security measures were in place.</p> <p>The NHS England SIRO representative thanked AGD for their time.</p> | |
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8 OVERSIGHT AND ASSURANCE

There were no items discussed

9 AGD OPERATIONS

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| <p>9.1</p> | <p>AGD future ways of working</p> | |
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| | <p>AGD noted that at the AGD plenary meeting on the 13th March 2025, following a request from the Director of Privacy and Information Governance, Privacy, Transparency, and Trust (PTT), 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 to give greater efficiency could be made to current processes / in-meeting discussions, whilst ensuring that the quality of the advice is not compromised.</p> <p>AGD noted that a discussion on AGD future ways of working had been held at the AGD meeting on the 27th March 2025, where it had been agreed that the NHS England SIRO Representative would feedback the content of the ‘AGD future ways of working’ discussion to the Director of Privacy and Information Governance, PTT.</p> <p>The NHS England SIRO Representative provided a verbal update to the Group on the outcome of discussions held with the Director of Privacy and Information Governance, PTT, in respect of potential future ways of working for AGD, including, but not limited to, a move away from quality assurance of applications for data; more focus on the AGD oversight and assurance programme of work; more in depth discussions on advice sought on specific key areas; more work undertaken out of committee as opposed to in-meeting with fewer and shorter Thursday meetings; that better use of technology would be explored to support AGD / transparency to the public; and that there would be a move away from review by all members which may in turn lead to a risk that somethings may be missed, the value of the discussion is lost but with a focus on focusing member expertise and potential to sample some application for full review.</p> <p>AGD and the NHS England SIRO Representative noted that any new ways of working would result in new ways of working for both NHS England colleagues / teams, AGD Secretariat and AGD members / delegates.</p> <p>The NHS England SIRO Representative noted that there would be further discussions on this at future AGD meeting to discuss further and agree how changes could start to be implemented in the work of AGD, noting a number of next steps including, but not limited to. working with NHS England DARS colleagues on new precedents; for AGD / AGD Secretariat to trial ‘MS Copilot’; to repeat the collaboration pilot undertaken by AGD on applications; and to test an alternative approach to reviewing applications for example by way of a smaller group of reviewers with comments captured out of committee.</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>9.2</p> | <p>AGD Annual Report 2023/24</p> <p>The AGD Chair noted that prior to the meeting, the Director of Privacy and Information Governance, PTT had advised that the AGD Annual Report 2023/24 had been submitted to the relevant colleagues / groups within NHS England for review / approval; and that this would be submitted for final sign-off around the end of April 2025. AGD asked that a further update was provided on this by the NHS England SIRO Representative at the AGD meeting on the 1st May 2025.</p> <p>ACTION: The NHS England SIRO Representative to provide an update on the AGD Annual Report 2023/24 at the AGD meeting on the 1st May 2025.</p> | <p>SIRO Rep</p> |

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| | <p>ACTION: AGD Secretariat to add 'AGD Annual Report 2023/24' to the AGD internal forward planner for the 1st May 2025 AGD meeting.</p> | AGD Sec |
| | <p>AGD Annual Report 2024/25</p> <p>The Group discussed the 2024/25 AGD Annual Report draft template, in line with paragraph 8.1 of the AGD Terms of Reference that state that <i>“The Group will produce an annual report on its work...for the SIRO following the end of the financial year...”</i>.</p> <p>The Group noted that following discussions at the AGD meetings on the 13th March 2025 and the 27th February 2025, the updated AGD Annual Report 2024/25 template had been updated by the AGD Secretariat and uploaded to AGD’s internal collaboration area for AGD members / delegates to review and make further comments / suggested updates.</p> <p>The Group discussed the comments / suggested updates made to the draft template and made further amendments as necessary to reflect the discussion in-meeting. AGD noted that the AGD Annual Report 2024/25 template would be updated by the AGD Secretariat following the meeting, and the next version of the report uploaded to AGD’s internal collaboration area for AGD members / delegates and the AGD Secretariat to start populating over the coming weeks.</p> <p>ACTION: AGD Secretariat to update the AGD Annual Report 2024/25 template, and upload to AGD’s internal collaboration area.</p> <p>ACTION: AGD to start populating the AGD Annual Report 2024/25 template once uploaded to AGD’s internal collaboration area.</p> <p>The Group also discussed the management information (MI) that would be included in the AGD Annual Report 2024/25, and noted several actions for the AGD NHS England’s Data and Analytics Representative and the AGD Secretariat in respect of the collation / production of the MI.</p> <p>ACTION: The AGD NHS England’s Data and Analytics Representative to discuss / collate the MI for the AGD Annual Report 2024/25 with colleagues and ensure this is populated in the AGD Annual Report 2024/25 template.</p> <p>ACTION: The AGD Secretariat to collate the MI for the AGD Annual Report 2024/25 with colleagues and ensure this is populated in the AGD Annual Report 2024/25 template.</p> <p>The Group noted that this would be a standing item on all AGD agenda’s up until the first draft of the AGD Annual Report 2024/25 was produced by mid-May 2025, and the second draft which would be produced by the end of June 2025. The Group noted that the deadlines were in line with a request from the Director of Privacy and Information Governance, PTT.</p> <p>ACTION: The AGD Secretariat to add 'AGD Annual Report 2024/25' to the AGD internal forward planner for every AGD meeting in May and June 2025.</p> | <p>AGD Sec</p> <p>AGD</p> <p>D&A Rep</p> <p>AGD Sec</p> <p>AGD Sec</p> |
| 9.3 | <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</p> | |

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| | <p>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 |
| 9.4 | <p>Standard Operating Procedures (SOPs)</p> <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> <p>AGD queried if the review of the AGD Terms of Reference, forwarded to the Director of Privacy and Information Governance on the 14th March 2025 had been considered and asked that an update be provided as to next steps.</p> <p>ACTION: NHS England SIRO Representative to update the Group at a future AGD Meeting.</p> | SIRO Rep |
| 9.5 | <p>AGD Stakeholder Engagement</p> <p><i>There were no items discussed</i></p> | |
| 9.6 | <p>AGD Project Work</p> <p><i>There were no items discussed</i></p> | |
| 10 Any Other Business | | |
| 10.1 | <p>Data Access Developments (Presenter: Garry Coleman)</p> <p>The NHS England SIRO Representative advised the Group on the announcement made by the Prime Minister on the 7th April 2025, in respect of the government and the Wellcome Trust investing up to £600 million to create a new Health Data Research Service.</p> <p>The Group were advised that further information would be shared on this when available.</p> | |
| <p>Meeting Closure</p> <p>As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.</p> | | |