

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 5th December 2024

09:00 – 15:30

(In-person at Wellington Place, Leeds & via videoconference)

| AGD INDEPENDENT / NHS ENGLAND MEMBERS IN ATTENDANCE: | |
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| Name: | Role: |
| Paul Affleck (PA) | AGD independent member (Specialist Ethics Adviser) (Meeting Chair) |
| Claire Delaney-Pope (CDP) | AGD independent member (Specialist Information Governance Adviser) |
| Dr. Robert French (RF) | AGD independent member (Specialist Academic / Statistician Adviser) |
| Dr. Phil Koczan (PK) | NHS England member (Caldicott Guardian Team Representative (Delegate for Dr. Jonathan Osborn)) (not in attendance for items 11, 12, 13, 16.1 and 16.2) |
| Andrew Martin (AM) | NHS England member (Data Protection Office Representative (Delegate for Jon Moore)) |
| 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: |
| Lawrence Bell (LB) | Audit Manager (IG), IG Risk and Assurance (Presenter: item 10) |
| Garry Coleman (GC) | NHS England SIRO Representative (not in attendance for items 10 and 11) |
| Lauren Gerraghty (LG) | Governance and Assurance Officer, Governance and Assurance Team, Data Access and Partnerships, Data and Analytics, Transformation Directorate (Presenter: item 7) |

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| Andrew Ireland (AI) | Information Governance Specialist, IG Risk and Assurance, Privacy, Transparency, and Trust (PTT), Delivery Directorate (Observer: item 11) |
| Lucy Legge (LL) | Governance and Assurance Senior Manager, Data Governance and Assurance, Data Access and Partnerships Directorate (Presenter: item 7) |
| Narissa Leyland (NL) | Head of Data Governance and Assurance, Data Access and Partnerships, Data and Analytics, Transformation Directorate (Presenter: item 6) |
| Nicki Maher (NM) | Information Governance Lead, IG Assurance and Risk, IG Audit Services Lead (Interim), Privacy, Transparency, and Trust (PTT), Delivery Directorate (Observer: item 9) (Presenter: items 10 and 11) |
| Nichola Makin (NM) | Audit Manager (IG), IG Risk and Assurance, Privacy, Transparency, and Trust (PTT), Delivery Directorate (Presenter: item 9) |
| Harry Millard (HM) | Information Governance Officer, IG Risk and Assurance, Privacy, Transparency, and Trust (PTT), Delivery Directorate (Observer: item 11) |
| Karen Myers (KM) | AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Delivery Directorate (Presenter: item 16.1) |
| Terry Service (TS) | Head of Data Access Service, Transformation Directorate (Presenter: item 8) |
| Vijay Tailor (VT) | Audit Manager (IG), IG Risk and Assurance (Presenter: items 9 and 10) |
| Joanne Treddenick (JT) | Information Governance Lead, Data and Analytics, Privacy, Transparency and Trust, Delivery Directorate (Presenter: item 5) |
| Vicki Williams (VW) | AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Delivery Directorate (Presenter: item 12) |
| Kevin Willis (KW) | Head of Information Law, NHS England Legal Team, Chief Delivery Officer Directorate (Presenter: item 5) |
| AGD INDEPENDENT MEMBERS / NHS ENGLAND MEMBERS <u>NOT</u> IN ATTENDANCE: | |

| Name: | Role / Area: |
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| Michael Chapman (MC) | NHS England member (Data and Analytics Representative) |
| Prof. Nicola Fear (NF) | AGD independent member (Specialist Academic Adviser) |
| Kirsty Irvine (KI) | AGD independent member (Chair) |
| Jon Moore (JM) | NHS England member (Data Protection Office Representative) |
| Dr. Jonathan Osborn (JO) | NHS England member (Caldicott Guardian Team Representative) |

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| 1 | <p>Welcome and Introductions:</p> <p>The AGD meeting Chair welcomed attendees to the meeting.</p> <p>AGD noted that, due to unforeseen circumstances, only two AGD NHS England members were in attendance for items 11, 12, 13 and 16.1.</p> <p>Noting that the AGD Terms of Reference state, “<i>The quorum for meetings of the Group or a Sub-Group is five members, including at least three independent members, one of whom may be the Chair, Deputy Chair or Acting Chair and two of the three NHSE Members...</i>”, the Group agreed that, as there were two AGD NHS England members present, the meeting was still quorate for all agenda items and agreed to proceed on that basis.</p> |
| 2 | <p>Review of previous AGD minutes:</p> <p>The minutes of the AGD meeting on the 28th November 2024 were reviewed and, after several minor amendments, were agreed as an accurate record of the meeting.</p> |
| 3 | <p>Declaration of interests:</p> <p>There were no declarations of interest.</p> |
| 4 | <p>AGD members feedback / reflections</p> <p>Following on from the discussion at the AGD meeting on the 26th September 2024, and in line with paragraph 9.1 of the AGD Terms of Reference, the Group discussed and provided feedback to the NHS England SIRO Representative, in respect of how they felt that AGD was going.</p> <p>AGD suggested that it would be helpful to receive information in advance of it going into the public domain, for example, in relation to a new use of patient data; and that this was shared with the Group either for information only, or for AGD to provide advice as may be required by NHS England.</p> |

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| 5 | <p>General update / overview of Directions including how NHS England consider the legislation and apply it to Directions (Presenters: Joanne Treddenick and Kevin Willis)</p> <p>Joanne and Kevin attended the meeting to provide an update / overview to the Group on Directions including how NHS England consider legislation and apply it to Directions.</p> <p>The Group were provided with an overview of the Statutory Guidance and relevant sections of the Health and Social Care Act 2012.</p> <p>In addition, The Group were provided with an overview of the purpose and use of Directions in line with UK General Data Protection Regulation (UK GDPR).</p> <p>The Group were advised that dissemination of data obtained (collected or created through analysis of data) under the Directions is not limited to the purposes described in the 'Purposes' section of the Direction. This is because Directions under s254 are concerned with the collection and analysis of information, not dissemination. The 'Purpose' in a Direction is a justification for that collection and analysis and sets out the parameters for such collection and analysis. It is not a limitation on the purposes for which the data obtained under the Directions can be disseminated. This is because Parliament expressly provided NHS England with powers to disseminate data obtained under Directions under s261 and it is the provisions in s261 which set the parameters for dissemination of the data obtained under the s254 Directions.</p> <p>The Group were advised that NHS England were not limited in their dissemination of data under s261 by the purpose limitation principle in Ar5 (1) b of UK GDPR that indicates that further processing of data must be for purposes compatible with the purposes of the collection. This is because, as explained in Recital 50 of UK GDPR, the compatibility consideration does not apply where the further processing (in this case, dissemination) is based on a law which constitutes a necessary and proportionate measure to safeguard important objectives of general public interest. It is considered that s261 meets this test given the important objectives of enabling dissemination of data obtained under s254 and s255 for many noble purposes satisfying the public interest.</p> <p>The Group were advised that supporting information e.g. the Data Protection Impact Assessment should be clear and transparent to the public that the Purpose statement in Directions did not limit the dissemination of the data obtained under the Directions as this was subject to separate requirements in s261.</p> <p>The Group noted the information provided and thanked Joanne and Kevin for attending the meeting.</p> |
| 6 | <p>NHS England Unified Data Access Layer (UDAL) Access for External Organisations (Presenter: Narissa Leyland)</p> <p>Narissa attended the meeting to provide an update to the Group on the NHS England UDAL access for external organisations.</p> |

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| | <p>The Group were advised that a working group had been established to assess the use cases and ensure the appropriate governance arrangements are in place.</p> <p>The Group noted that NHS England and stakeholders are undertaking work to consider the range of options for data access and how each of them should best be used and how they fit together.</p> <p>The Group noted the information provided and thanked Narissa for attending the meeting; and requested that a further update on this area of work be provided at the AGD plenary meeting on the 12th June 2025.</p> <p>ACTION: AGD Secretariat to add a further update on UDAL to the AGD Forward Planner for the 12th June 2025 AGD plenary meeting.</p> | AGD Sec |
| 7 | <p>Review of the NHS England Data Access Service (DAS) Standards (Presenters: Lucy Legge and Lauren Gerraghty)</p> <p>The Group noted that some of the AGD independent advisers were part of the NHS England Data Access Service (DAS) Standards Working Group (as noted in the AGD minutes from the 21st November 2024, 24th October 2024, 17th October 2024, 26th September 2024, 19th September 2024 and the 12th September 2024).</p> <p>Following discussions at the NHS England DAS Standards Working Group meetings, and in advance of this meeting, the Group were provided with a summary of the proposals for the existing NHS England DAS Standards and work undertaken to date.</p> <p>The Group were provided with an overview of the stakeholder engagement, including who was responsible, accountable, consulted and informed as part of the ongoing programme of work.</p> <p>The NHS England SIRO Representative noted that whilst three AGD independent members had attended the NHS England DAS Standards Working Group meetings; as part of the ongoing stakeholder engagement, NHS England DAS should ensure they are engaging with AGD as a Group at the relevant point in the process in order for NHS England to receive formal advice from the Group, which is documented and transparent in published minutes.</p> <p>ACTION: NHS England DAS to ensure that AGD are engaged in the review and approval of the NHS England DAS Standards; in addition to the engagement with individual AGD independent members.</p> <p>The NHS England SIRO Representative asked that there was an audit trail of the historical information on the NHS England DAS Standards, to ensure it is clear how they were drafted previously, the updates made and the justification for the update / amendment.</p> <p>ACTION: NHS England DAS to ensure that there is a clear audit trail of the historical information on the NHS England DAS Standards, to ensure it is clear how they were</p> | <p>DAS</p> <p>DAS</p> |

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| | <p>drafted previously, the updates made and the justification for the update / amendment.</p> <p>AGD thanked Lucy and Lauren for the work they were doing on this important programme of work, and looked forward to further discussions in due course.</p> | |
| 8 | <p>Update on expiring / expired applications and Data Sharing Framework Contract (DSFC) (Presenter: Terry Service)</p> <p>Following on from the discussion at the AGD meeting on the 26th September 2024, Terry attended the meeting to provide a further update to the Group on expiring / expired applications/DSFCs.</p> <p>The Group were also provided with statistics as to how many applications were in the system, awaiting signature, expired etc. up to the 18th November 2024 and the progress on these up to the 24th November 2024.</p> <p>In addition, the Group were also provided with DSFC statistics up to the 21st November 2024.</p> <p>Terry advised the Group that there was internal discussion / ongoing work in respect of an automated process for DSFCs and how NHS England engage with contract holders, for example, via an annual meeting.</p> <p>Terry noted that there were currently 804 'live' data sharing agreements (DSA) in the system and 173 DSFCs linked to 'live applications'.</p> <p>AGD advised that they would welcome / be supportive of providing further advice / support on this ongoing of programme of work as may be required by NHS England.</p> <p>AGD thanked Terry for attending the meeting, and for the helpful information provided; and requested that a further update on this area of work be provided at the AGD plenary meeting on the 12th June 2025.</p> <p>ACTION: AGD Secretariat to add a further update on the expired / expiring applications to the AGD Forward Planner for the 12th June 2025 AGD plenary meeting.</p> | AGD Sec |
| 9 | <p>Audit Services: Secure Data Environment (SDE) Audit Overview (Presenters: Vijay Tailor and Nichola Makin)</p> <p>Vijay and Nichola attended the meeting to provide the Group with an overview of the audit process for SDEs, including, but not limited to, how an SDE audit differed from a data dissemination audit; the audit cycle; the SDE audit scope; data access control; operational management and control, and lessons learnt.</p> <p>The Group were advised that the NHS England Audit Team had carried out the first SDE audit in November 2024.</p> <p>The Group thanked Vijay and Nichola for attending the meeting and for the information provided.</p> | |

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| 10 | <p>Audit Services: Data Sharing Agreements (DSA) Audit Overview (Presenters: Lawrence Bell, Vijay Tailor and Nicki Maher)</p> <p>As agreed at the AGD meeting on the 26th September 2024, Lawrence, Nicki and Vijay attended the meeting to provide a further overview to the Group on the process for NHS England's audits on DSAs.</p> <p>The Group were provided with a verbal update of a recent 'full' audit undertaken and the end-to-end process, including, but not limited to, the audit process, the engagement with the applicant / Data Controller(s) and the governance prior to the final audit report being published.</p> <p>AGD noted that at the AGD meeting on the 26th September 2024, an action had been raised with the NHS England SIRO Representative, to share information with the Group on the percentage of live DSAs or recipient organisations which have been audited. The Group were advised by Nicki, that although a percentage could not be provided, NHS England would be aiming to undertake approximately 30 audits per year on 'live' DSAs.</p> <p>The Group thanked Lawrence, Vijay and Nicki for providing a further update to the Group, and noted the importance of the work undertaken by the NHS England Audit Team, in maintaining public trust and confidence.</p> |
| 11 | <p>Oversight and Assurance (O&A) (Presenter: Nicki Maher)</p> <p>Nicki attended the meeting to provide a further update to the Group on the O&A programme of work, including an update on the recent oversight and assurance review (as noted in the 21st November 2024 AGD minutes) including the headline points from this review and what went well, challenges and next steps.</p> <p>Nicki advised the Group that there would be ongoing O&A reviews from January to March 2025, following the same process as outlined on the 21st November 2024.</p> <p>In addition, Vicki Williams advised the Group that she was writing a proposal for consideration by the NHS England SIRO Representative and SIRO Team, to look at those applications that had been to AGD but had not been supported, minority / majority not supported, deferred etc in order to understand whether they had progressed via a Precedent route, rather than come back to AGD as happened in IGARD, with the appropriate checks and audit trail of decisions made.</p> <p>The Group advised that they welcome any feedback from Nicki and colleagues on how they are undertaking the O&A reviews, including where improvements can be made by individuals / the Group to support NHS England.</p> <p>AGD thanked Nicki and colleagues for the work they were doing on this programme of work and looked forward to further discussions in due course.</p> |
| 12 | <p>AGD Action Log (Presenter: Vicki Williams)</p> <p>Vicki advised the Group that the AGD action log had been updated by action owners to reflect the current status of 'live' actions; or where an action had been resolved,</p> |

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| | <p>there was a request to close this item, since the action log had been last discussed at AGD.</p> <p>The Group noted that they were content to 'close' all relevant actions outlined in the document, but noted that the AGD Chair would be given the opportunity to review these actions out of committee, ahead of them being formally closed, or if necessary, further information would be sought / noted on the action log for audit purposes.</p> <p>The Group noted that due to the volume of actions delegated to the AGD NHS England Data and Analytics Representative and / or the Data Access Service (DAS), future AGD meeting agendas would have a slot for updates to be provided to the Group in a timely manner.</p> <p>ACTION: The AGD Secretariat to add an 'action log and DAS updates' slot on AGD meeting agendas for the AGD NHS England Data and Analytics Representative to provide updates to the Group on any ongoing actions.</p> <p>AGD thanked Vicki for the work she was doing on this programme of work and looked forward to further action log discussions.</p> | AGD Sec |
| 13 | <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; and noted that there would be a further update in January 2025.</p> <p>ACTION: The NHS England SIRO Representative to provide a written response to AGD on the progress, and expected time frame for implementation, of the risk management framework.</p> <p>The Group noted the NHS England SIRO Representative's response and asked for an update in January 2025.</p> | SIRO Rep |
| 14 | <p>AGD Stakeholder Engagement</p> <p><i>There were no items discussed</i></p> | |
| 15 | <p>AGD Project Work</p> | |

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| | <p>Kirsty Irvine, Claire Delaney-Pope and Paul Affleck attended the NHS England Data Access Service (DAS) Standards Working Group on the 3rd December 2024 with regard to the NHS England DAS Standard for Sub-licencing and Onward Sharing of Data.</p> <p>A brief update was given by the Group's Representative on the Federated Data Platform Data Governance Group.</p> |
| 16 Any Other Business | |
| 16.1 | <p>AGD Service Improvements (Presenter: Karen Myers)</p> <p>An update was provided to the group, in respect of the service improvement programme of work, where a number of 'observations' and 'actions' were highlighted following initial feedback from the AGD members and NHS England colleagues.</p> <p>AGD thanked Karen for the work she was doing on this programme of work and looked forward to future service improvement discussions.</p> |
| 16.2 | <p>Health Research Authority (HRA) Consultation</p> <p>A member flagged a Health Research Authority (HRA) consultation, on a proposal to simplify the way that informed consent is sought and recorded in 'low risk' clinical trials, which may have implications for future applications to NHS England for data. It was suggested members may wish to complete the linked HRA survey.</p> |
| <p>Meeting Closure</p> <p>As there was no further business raised, the Chair of the meeting thanked attendees for their time and closed the meeting.</p> | |