

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 13th March 2025

08:30 – 15:00

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

AGD INDEPENDENT / NHS ENGLAND MEMBERS IN ATTENDANCE:	
Name:	Role:
Paul Affleck (PA)	AGD independent member (Specialist Ethics Adviser)
Michael Chapman (MC)	NHS England member (Data and Analytics Representative) (item 5)
Claire Delaney-Pope (CDP)	AGD independent member (Specialist Information Governance Adviser)
Dr. Robert French (RF)	AGD independent member (Specialist Academic / Statistician Adviser) (not in attendance for items 1 and 13.1)
Kirsty Irvine (KI)	AGD independent member (Chair)
Andrew Martin (AM)	NHS England member (Data Protection Office Representative (Delegate for Jon Moore))
Dr. Jonathan Osborn (JO)	NHS England member (Caldicott Guardian Team Representative) (not in attendance for items 2, 10, 11, 14.1, 14.2 and 15.2))
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:
Laura Bellingham (LB)	Deputy Director, Data Access and Partnerships, Data and Analytics, Transformation Directorate (Presenter: items 7 to 11)
Michael Chapman (MC)	Director of Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: items 11 and 15.2)
Garry Coleman (GC)	NHS England SIRO Representative

Andrew Ireland (AI)	Information Governance Specialist, IG Risk and Assurance, Privacy, Transparency, and Trust (PTT), Delivery Directorate (Presenter: item 13.1)
Harry Millard (HM)	Information Governance Officer, IG Risk and Assurance, Privacy, Transparency, and Trust (PTT), Delivery Directorate (Presenter: item 13.1)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Delivery Directorate
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:
Prof. Nicola Fear (NF)	AGD independent member (Specialist Academic Adviser)
Jon Moore (JM)	NHS England member (Data Protection Office Representative)

1	<p>Welcome and Introductions:</p> <p>The AGD Chair welcomed attendees to the meeting.</p> <p>The AGD Chair noted that the Group discussion session (item 4) of the quarterly AGD plenary meeting fulfilled clause 9.2 of the AGD Terms of Reference that states: <i>“The Chair, the Secretariat, the SIRO Representative and at least one of the NHSE members of the Group will meet at least once every three months to review the operation of the Group”</i>.</p>
2	<p>Review of previous AGD minutes:</p> <p>The minutes of the AGD meeting on the 6th March 2025 were reviewed and, after several minor amendments, were agreed as an accurate record of the meeting.</p>
3	<p>Declaration of interests:</p> <p>There were no declarations of interest.</p>
4	<p>NHS England Update (Presenter: Jackie Gray)</p> <p>The Group welcomed Jackie Gray, Director of Privacy and Information Governance, Privacy, Transparency, and Trust (PTT) to the meeting, who attended to provide a verbal update to the Group in respect of the announcement made on the 10th March 2025. The Group were</p>

7	<p>Annual Compliance Reports (ACRs) update (Presenter: Laura Bellingham)</p> <p>Following on from the update provided under item 6, Laura attended the meeting, to provide an additional verbal update on the ACR programme of work, including the work ongoing to look at this programme through a wider lens in terms of governance whilst ensuring that potential risks are reviewed / addressed.</p> <p>The Group noted and thanked Laura for providing the update, and noted that further updates would be provided in due course.</p>
8	<p>Standardising the data sharing process across NHS England (Presenter: Laura Bellingham)</p> <p>AGD were provided with a verbal update on the ongoing programme of work in standardising the data sharing process across NHS England, including increased use of NHS England's Secure Data Environment (SDE).</p> <p>AGD noted the content of the verbal update provided, including the increased use of NHS England's SDE, however, noted some practical concerns about the implementation process, and advised that they would welcome a further update as this area of work progresses, including some worked examples if possible. An AGD independent member did express surprise that not all of NHS England's data falls within AGD's remit, potentially leading to a lack of public transparency.</p> <p>It was noted that AGD's Terms of Reference (ToR) have not been updated to reflect the broader data sharing activities of NHS England, and as they stand the Group's ToR only pertain to assurance on internal and external data in relation to the exercise of NHS England's functions transferred to it from NHS Digital under the Health and Social Care Information Centre (Transfer of Functions, Abolition and Transitional Provisions) Regulations 2023.</p> <p>NHS England confirmed to the Group that a process of mapping what data was released from where at present across the organisation had not been undertaken, but that the largest by volume are the Federated Data Platform (FDP); NHS England Unified Data Access Layer (UDAL) and the Outcomes Registry. OpenSAFELY is also a volume data sharing mechanism, but is viewed as already en-route to being included in DARS processes.</p> <p>The Group noted and thanked Laura for providing the verbal update, and looked forward to a further update in due course.</p>
9	<p>Onboarding of 'National Institute for Cardiovascular Outcomes Research' (NICOR) data (Presenter: Laura Bellingham)</p> <p>AGD were provided with a verbal update on the ongoing programme of work in respect of the onboarding of NICOR data.</p> <p>AGD noted the content of the verbal update provided, and advised that they were supportive of the onboarding of the NICOR data. The Group also noted the bespoke arrangements for utilising subject matter experts. It was suggested that use of such arrangements could be part of a precedent approach to data requests, once the NICOR data had been onboarded,</p>

	<p>without the requirement of an AGD review for each data request; but where the applications for this dataset would be subject to the usual AGD oversight and assurance; and suggested that NHS England gave this further consideration.</p> <p>The Group noted and thanked Laura for providing the update, and looked forward to a further update in due course.</p>
10	<p>Sharing of aggregated data with small number suppression by Commissioning Support Units (CSUs) (Presenter: Laura Bellingham)</p> <p>AGD were provided with a verbal update on the ongoing programme of work in respect of the sharing of aggregated data with small number suppression by CSUs.</p> <p>AGD noted the content of the verbal update provided, and advised that they were supportive of the proposal outlined.</p> <p>The Group noted and thanked Laura for providing the update.</p>
11	<p>NHS England Procedure for Pseudonymisation and internal transfer of Directly Identifiable Personal Data to an NHS England De-identified Secure Data Environment (SDE) (Presenter: Laura Bellingham)</p> <p>AGD were provided with a verbal update on the NHS England Procedure for Pseudonymisation and internal transfer of Directly Identifiable Personal Data to an NHS England De-identified SDE.</p> <p>AGD noted the content of the verbal update provided, and advised that they were supportive of the processes outlined, however raised some specific points in respect of the practicalities, and ensuring that AGD advice was received / responded to. The Group recognised the challenges in respect of this ongoing programme of work, and commended NHS England for addressing this issue.</p> <p>The Group noted and thanked Laura for providing the update, and looked forward to a further update in due course.</p>
12	<p>Data Minimisation</p> <p>Due to the meeting agenda overrunning, AGD noted that an update would be provided to the Group out of committee.</p>
13 OVERSIGHT AND ASSURANCE	
13.1	<p>Oversight and Assurance Process</p> <p>Workstream 1 (Precedent approved internal and external applications) (Presenter: Tom Wright)</p> <p>AGD noted that a verbal update was provided to the Group under item 6.</p>
	<p>Update on Workstream 1 (Precedent approved internal and external applications) and Workstream 2 (Internal and external applications that have</p>

	<p>had an independent review in the last six months and been approved internally) (Presenters: Andrew Ireland and Harry Millard)</p> <p>AGD were provided with a verbal update on the latest information / statistics in relation to workstream 1, including a summary of AGD reviews and issues that had been highlighted (as addressed in previous AGD meeting minutes).</p> <p>AGD were advised that there was ongoing work within NHS England's Data Access Service (DAS), to update section 1 of the applications, to be clear what evidence had been looked at when an application proceeds down the NHS England Precedent route and why the Precedent had been deemed to apply. AGD noted the verbal update provided, and asked that this is presented to the Group at a future AGD meeting.</p> <p>ACTION: AGD Secretariat to add 'update to section 1 of applications to highlight evidence for NHS England Precedent route' to the AGD internal forward planner.</p> <p>The Group noted and thanked Andrew and Harry for providing the update, and noted that further updates would be provided in due course.</p>	AGD Sec
14 AGD OPERATIONS		
14.1	<p>AGD Terms of Reference (ToR) Annual Review</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>”.</p> <p>AGD noted that as agreed at the AGD meeting on the 27th February 2025, the AGD ToR had been shared with the Group for review / comment prior to the meeting. The Group discussed in-meeting which suggested amendments were 'minor' and which were 'substantive'.</p> <p>AGD noted that the AGD chair and AGD Secretariat would update the draft document and send to the Director of Privacy and Information Governance, Privacy, Transparency, and Trust (PTT) for consideration.</p> <p>ACTION: AGD Chair and AGD Secretariat to finalise comments / suggested updates to the AGD ToR and send to the Director of Privacy and Information Governance, PTT for consideration.</p>	AGD Chair / AGD Sec
14.2	<p>AGD Annual Report Template 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>AGD noted that following the discussion at the AGD meeting on the 27th February 2025, a draft template had been produced by the AGD Secretariat, and shared with</p>	

	<p>the Group prior to the meeting. The Group discussed the draft template and made some suggested updates.</p> <p>AGD noted that the draft template would be updated with the suggestions made in-meeting, and shared with the Group for discussion as a future AGD meeting, including the possible content of the AGD Annual Report 2024/25.</p> <p>ACTION: AGD Secretariat to update the AGD Annual Report 2024/25 template, and share with the Group for further discussion.</p> <p>ACTION: AGD Secretariat to add 'AGD Annual Report 2024/25' to the AGD internal forward planner.</p> <p>AGD noted, that following discussions at the 27th February 2025 meeting, they were yet to receive confirmation from NHS England that the AGD 2023/24 Annual Report was in agreed final form.</p> <p>ACTION: The NHS England SIRO Representative to provide AGD with confirmation that the final 2023/2024 Annual Report is in final agreed form, to support further discussions around content / format.</p>	<p>AGD Sec</p> <p>AGD Sec</p> <p>SIRO Rep</p>
14.3	<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 NHS England corporate risk management framework (see minutes of 14th November 2024) and the AGD Chair subsequently formally asked via email if the NHS England corporate risk management framework could be used. The NHS England SIRO Representative updated the Group that NHS England was still considering the request, including how the NHS England corporate risk management framework could be adapted for AGD.</p> <p>ACTION: The NHS England SIRO Representative to provide a written response to AGD on the progress, and expected time frame for implementation, of the risk management framework.</p>	<p>SIRO Rep</p>
14.4	<p>Standard Operating Procedures (SOPs)</p> <p>The ongoing forward plan of work for creating the AGD Standard Operating Procedures was discussed; and noting that the AGD Terms of Reference (ToR) had now been approved, it was noted that work was progressing in order to finalise relevant AGD SOPs in line with the approved AGD ToR.</p>	
15 Any Other Business		

15.1	<p>NIC-15625-T8K6Lv14 Clinical Practice Research Datalink (CPRD) (Presenter: Garry Coleman)</p> <p>The NHS England SIRO Representative provided the Group with a verbal update on NIC-15625-T8K6Lv14 Clinical Practice Research Datalink (CPRD) that is due to be discussed at the AGD meeting on the 20th March 2025.</p> <p>The Group noted and thanked the NHS England SIRO Representative on the verbal update provided.</p>	
15.2	<p>AGD independent member reviews</p> <p>The AGD independent members discussed whether having a regular review with NHS England would be beneficial in terms of feedback, and training and development needs etc.</p> <p>The Group noted that feedback on the performance of AGD as a group from stakeholders is received via the AGD service improvement programme of work; and that any individual reviews / discussions would be done in addition to this. The Group noted that individual feedback, in an informal meeting, may be beneficial in particular to new AGD members as part of their ongoing development and to support them in their role on AGD.</p> <p>AGD noted that the next round of AGD service improvement feedback would be sought at the end of March 2025, and that a further discussion would be held at an AGD meeting at the end of April 2025.</p> <p>ACTION: AGD Secretariat to add 'AGD service improvement feedback review' to the AGD internal forward planner.</p>	<p>.</p> <p>AGD Sec</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>		