Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 25th September 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)
Dave Cronin (DC)	NHS England member (Data and Analytics Representative (Delegate for Michael Chapman))
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)) (not in attendance for items 1 to 3, part of item 4 and 12.5)
Dr. Robert French (RF)	AGD independent member (Specialist Academic / Statistician Adviser)
Kirsty Irvine (KI)	AGD independent member (Chair)
Dr. Jonathan Osborn (JO)	NHS England member (Caldicott Guardian Team Representative) (**Presenter:** item 7)
Jenny Westaway (JW)	AGD independent member (Lay Adviser)
Miranda Winram (MW)	AGD independent member (Lay Adviser)
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	**Role / Area:**
Garry Coleman (GC)	NHS England SIRO Representative
Beth Crook (BC)	Senior IG Specialist, IG Policy Engagement Team, Transformation Directorate (**Observer:** items 5 to 9)
Claire Edgeworth (CE)	Head of Strategic IG – Consultancy (**Observer:** items 5 to 9)
Timir Goswami (TG)	IG Specialist, IG Policy Engagement Team, Transformation Directorate (**Observer:** items 5 to 9)

Deborah Harris (DH)	Policy Engagement Manager, Privacy, Transparency & Trust (PTT) (**Observer:** items 5 to 9)
Andrew Ireland (AI)	Information Governance Specialist, IG Risk and Assurance, Privacy, Transparency, and Trust (PTT), Deputy Chief Executive Directorate (**Observer:** items 5 to 9)
Nicki Maher (NM)	IG Assurance, Risk and Audit Services Lead, Privacy, Transparency, and Trust (PTT), Deputy Chief Executive Directorate (**Observer:** items 5 to 9)
Harry Millard (HM)	Information Governance Officer, IG Risk and Assurance, Privacy, Transparency, and Trust (PTT), Deputy Chief Executive Directorate (**Observer:** items 5 to 9)
Jon Moore (JM)	Deputy Director, Data Protection Officer (solicitor), Data Protection Office and Trust, Privacy, Transparency, and Trust (PTT), Deputy Chief Executive Directorate (**Presenter:** item 6)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Deputy Chief Executive Directorate
Dr. Jonny Pearson (JP)	Lead Data Scientist, Data Science Team (**Presenter:** item 8)
Dr Alison Tweed (AT)	Head of AI Partnership, AI Team, Joint Digital Policy and Strategy Unit, Transformation Directorate (**Presenter**: item 6)
Gemma Walker (GW)	Information Governance Specialist, IG Risk and Assurance, Privacy, Transparency, and Trust (PTT), Deputy Chief Executive Directorate (**Observer:** items 5 to 9)
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Deputy Chief Executive Directorate
INDEPENDENT ADVISER OBSERVERS IN ATTENDANCE	
Mr Christopher Barben (CB)	AGD independent adviser
Dr. Jon Fistein (JF)	AGD independent adviser
Professor Jo Knight (JK)	AGD independent adviser
Dr. Mark McCartney (MM)	AGD independent adviser
AGD INDEPENDENT MEMBERS / NHS ENGLAND MEMBERS NOT IN ATTENDANCE:	
Name:	**Role / Area:**
Jon Moore (JM)	NHS England member (Data Protection Office Representative)

1	**Welcome and Introductions:** The AGD Chair welcomed attendees to the meeting. AGD noted that, due to unforeseen circumstances, only two AGD NHS England members were in attendance for items 1 to 3, part of item 4 and 12.5. Noting that the AGD Terms of Reference state that *"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**…",* 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. 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: *"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*".	
2	**Review of previous AGD minutes:** The minutes of the AGD meeting on the 18th September 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 NIC-791166-Q7K5H (King's College London) and the applicant as part of her role within the 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	**AGD members feedback / reflections** Following on from the discussion at the AGD meeting on the 19th June 2025, 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 operating. Reassurance was given that the Director of Privacy and Information Governance, Privacy, Transparency, and Trust would be in touch shortly with an update on the contractual situation for independent members. **AGD Meetings:** AGD noted that the AGD meeting agendas were often very busy, with a large volume of supporting documents; and that further thought should be given to ensuring that the pre-meeting preparation and the in-meeting discussions / agenda is manageable for the Group, whilst still meeting the business needs of NHS England. The new AGD independent advisers suggested that further consideration could be given to how AGD members review applications, briefings etc that are submitted for review, for example, could this be done via a targeted review based on AGD member specialisms; or providing comments on documents via a collaboration area; or having early sight of research proposals, to ensure that advice is provided in a timely manner, and not at the end	

	of the process. The Group agreed that further discussions could take place over the coming months in respect of potential different ways of working. AGD sought assurance that they had sight of internal data flows that IGARD had previously seen, and as outlined within the Statutory Guidance and advised that they would welcome these as part of the review at AGD meetings. AGD noted that the AGD oversight and assurance programme of work had been paused earlier in the year, and stressed the importance of re-starting this as soon as possible. AGD noted and commended NHS England's Data Access Request Service (DARS) on the quality of the applications submitted to the Group for review. **Communications / Stakeholder Engagement:** AGD suggested that further thought could be given within NHS England, to ensure the wider organisation are aware of the work that AGD do and the support that they can offer. **NHS England AGD Members:** Acknowledgement was given to the pressure on AGD NHS England members / delegates, noting that pre-meeting preparation and attendance at the AGD meetings, was in addition to other responsibilities. The Group were advised that attendance at AGD meetings by the NHS England Data Protection Office (DPO) Representative / delegates, was now done on a rota basis, and that work was ongoing internally to ensure that points of advice were identified and discussed with the DPO in advance of the meeting, to ensure the contribution in-meeting was as thorough as possible. The NHS England SIRO Representative noted that he was involved with this pre-meeting work with the DPO and that he was happy to support the AGD NHS England Data and Analytics and AGD NHS England Caldicott Guardian Team Representatives, should they wish to follow a similar model of working. **Learning and Development:** The new AGD independent advisers suggested that it would be useful for their learning and development, to understand the application process within NHS England's Data Access Request Service (DARS) prior to an application being submitted to AGD for review / advice. The AGD NHS England Data and Analytics Representative (Delegate) advised that they would be happy to support this request, and that further information would be provided on this in due course. **ACTION:** The AGD NHS England Data and Analytics Representative, to provide further information on how support can be provided to new AGD independent members, to understand the application process within NHS England's DARS prior to an application being submitted to AGD for review / advice.	D&A Rep
5	**Introduction to the NHS Artificial Intelligence (AI) Team (Presenter: Dr Alison Tweed)** The Group were provided with a verbal update, on the work undertaken by the NHS AI Team. The Group advised that they welcome any further update as may be appropriate at a future AGD meeting. The Group noted the content of the update and thanked Dr. Tweed for attending the meeting.	

6	**Artificial Intelligence (AI) and Legal (Presenter: Jon Moore)** The Group were provided with a verbal update, on AI from a legal perspective. The Group advised that they welcome any further update as may be appropriate at a future AGD meeting. The Group noted the content of the update and thanked Jon for attending the meeting.	
7	**Artificial Intelligence (AI) and Ethics (Presenter: Dr. Jonathan Osborn)** The Group were provided with a verbal update, on AI from an ethical perspective. The Group advised that they welcome any further update as may be appropriate at a future AGD meeting. The Group noted the content of the update and thanked Dr. Osborn.	
8	**Artificial Intelligence (AI) and Monitoring (Presenter: Dr. Jonny Pearson)** The Group were provided with a verbal update, on the monitoring of AI usage. The Group advised that they welcome any further update as may be appropriate at a future AGD meeting. The Group noted the content of the update and thanked Dr. Pearson for attending the meeting.	
9	**Artificial Intelligence (AI) - Reflections and Advice to NHS England** The NHS England SIRO Representative noted that there were an increased number of applications referring to AI, and that it is an area that is subject to considerable public interest and guidance; and noted that NHS England needed to establish a position which appropriately supports requests for data access that involve AI. The Group were asked to provide advice on the following points: **1. Do requests for access to NHS England data that refer to the use of AI require any specific consideration?** AGD noted that, to support this question, it would be helpful for the Group to understand the process within NHS England's Data Access Request Service (DARS) currently, when requests for data are data received that refer to the use of AI. Also, applicants need to be prompted to understand if their work has any AI component. AGD suggested that NHS England should **1)** specify what the definition of AI is; and what is / is not in scope as part of this definition, and **2)** determine what NHS England's legal obligations are in respect of AI. **2. If so, what are the particular risks that NHS England are looking to mitigate?** AGD discussed a number of possible risks to NHS England, including, but not limited to, **1)** the risk of magnified bias; **2)** the risk of non-compliance; **3)** interruption of operations; **4)** data minimisation; **5)** safety; **6)** public trust linked to lack of understanding of how conclusions have been reached; and **7)** reputation. AGD also requested that NHS England provide a clear steer on applications that are for the purpose of automated decision making and profiling.	

	3. What questions might NHS England ask in order to inform appropriate controls within the data sharing agreement (DSA)? AGD suggested that a Q&A list could be produced of key points / questions to clarify, with applicants of data, and these could be piloted against applications, to determine what is / is not necessary to clarify. AGD suggested that NHS England's DARS produce a draft Q&A document in line with the Data Protection Principles as set out in Article 5 of UK GDPR, as they relate to AI (as detailed in Jon Moore's presentation referred to above). It was suggested that a separate session is held with AGD to discuss this in more detail. **ACTION:** AGD Secretariat to add 'AI Q&A document' to the internal AGD forward planner. **4. What might the "standard" look like, in order for NHS England to agree access for such purposes?** Any new standard, or uplift of existing NHS England DARS Standards, needed to reflect the Data Protection Principles, as they relate to AI as a basic starting point; the extent to which further ethical aspects were incorporated would be a matter of NHS England policy. AGD noted that further discussions should be held to determine whether **1)** a new AI standard was appropriate; **2)** whether existing NHS England DARS Standards could be updated to encompass AI; or **3)** whether both were needed (a new Standard and the updating of existing Standards). The NHS England SIRO Representative noted the feedback provided by the Group, and advised that NHS England and AGD needed to jointly advance this programme of work; and that a further update would be provided on this as soon as possible.	AGD Sec
10	**Consultee / National Data Opt-Out (NDO)** AGD noted that at the AGD meeting on the 31st July 2025, the NHS England SIRO Representative had advised the Group that it has been agreed with NHS England Legal and Policy colleagues that consultee advice that an individual should take part in a research project **can** override an NDO, as an NDO is **not** specific to the research project and therefore if a consultee considers that it would be in accordance with the individual's wishes and feelings for them to participate in the research, the view of the consultee should take preference. AGD members noted that this was not aligned with previous requests for data, and its compatibility with the Section 33(2)(b)(ii) safeguard in the Mental Capacity Act 2005, with regard to nothing being done to, or in relation to, the individual in the course of the research which would be contrary to any prior statement of the research participant of which the consultee is aware. AGD noted that they had requested sight of the legal advice (under privilege) received on this matter, and that this was still outstanding. The NHS England SIRO Representative advised that this request was in progress, and that a further update would be provided at a future AGD meeting. **ACTION:** AGD Secretariat to add 'Consultee / National Data Opt-Out (NDO) legal advice' to the AGD internal forward planner.	AGD Sec

11 EXTERNAL DATA DISSEMINATION REQUESTS:		
11.1	**Reference Number:** NIC-791166-Q7K5H **Applicant:** King's College London (KCL) **Application Title:** "Evaluating the implementation of NICE gout guidance within the NHS" **Presenter:** Dave Cronin **Application:** This was a seeking early advice application. NHS England were seeking advice on the following points only: 1. Advice, comments or questions on this first-of-type application that may inform development of the process for handling OpenSAFELY applications and which identify any further information which would be expected before this application returns to AGD seeking general support. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** AGD noted that they were specifically asked to provide advice in relation to this first-of-type application, and that the remainder of the application was subject to additional work. However, to assist in the development of the application, AGD provided the following advice to the SIRO (noting that the points may not be relevant once the additional detail on the application is clear): 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. **11.1.1** AGD noted that this application had been submitted for early advice, following the meeting on the 18th September 2025, where the OpenSAFELY Draft Application Process had been discussed. The Group also noted and supported the approach of having a briefer summary of information in the OpenSAFELY applications. **11.1.2** AGD noted that in line with the 'Profession Advisory Group' (PAG) Terms of Reference (ToR), provided as a supporting document at the AGD meeting on the 18th September 2025, PAG advice on this application should be provided to AGD when it returns for a further review or following the AGD review, which will then be appended to the AGD meeting minutes. **11.1.3** AGD queried whether UK General Data Protection Regulation (UK GDPR) requirements had been captured, noting that whilst the applicant was not receiving or processing personal data, they may be a data controller, and suggested that UK GDPR aspects were reviewed and updated as may be appropriate. **11.1.4** AGD also suggested that the application was updated to be clear who had the legal basis for what activity. **11.1.5** AGD noted that section 3.5 (Data Level) stated that the data was *"aggregated – with small numbers suppressed"*; and noting that the analysis data would not fall under this description, suggested that this was reviewed and updated as appropriate.	

	11.1.6 AGD noted the information in section 3.9 (National Data Opt-outs) in respect of the National Data Opt-out, and suggested that this was reviewed and updated in line with NHS England's National Data Opt-out policy and other documentation. **11.1.7** AGD suggested that the application was updated with further information on Type 1 objections, in line with NHS OpenSAFELY Data Analytics Service Pilot Directions 2025. **11.1.8** AGD noted that the stated purpose of the application was for 'service evaluation', and suggested how it was distinguished from research was clarified. **11.1.9** AGD noted that in line with AGD's Terms of Reference, they usually provide advice on personal data; and here applicants do not receive access to personal data, however, it was noted that NHS England were able to seek advice from the Group as may be appropriate, and advised that they would welcome providing advice on this type of application as may be required by NHS England. **11.1.10** AGD noted that section 4.9 (Commercial Benefit Evaluation) had not been completed, and suggested that if access to OpenSAFELY could produce commercial benefits, then this should be completed. **11.1.11** Noting AGD was only asked to advise on specific points reviewed, no AGD member noted any substantive commercial aspects.	
11.2	**Reference Number:** NIC-791168-N2D1Z **Applicant:** London School of Hygiene and Tropical Medicine **Application Title:** "Harmonised Assessment of Risk Groups for Vaccine Prioritisation" **Presenter:** Dave Cronin **Application:** This was a seeking early advice application. NHS England were seeking advice on the following points only: 1. Advice, comments or questions on this first-of-type application that may inform development of the process for handling OpenSAFELY applications and which identify any further information which would be expected before this application returns to AGD seeking general support. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** AGD noted that they were specifically asked to provide advice in relation to this first-of-type application, and that the remainder of the application was subject to additional work. However, to assist in the development of the application, AGD provided the following advice to the SIRO (noting that the points may not be relevant once the additional detail on the application is clear): 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. **11.2.1** AGD noted that this application had been submitted for early advice, following the meeting on the 18th September 2025, where the OpenSAFELY Draft Application Process had been discussed. The Group also noted and supported the approach of having a briefer summary of information in the OpenSAFELY applications.	

	11.2.2 AGD noted that in line with the 'Profession Advisory Group' (PAG) Terms of Reference (ToR), provided as a supporting document at the AGD meeting on the 18th September 2025, PAG advice on this application should be provided to AGD when it returns for a further review or following the AGD review, which will then be appended to the AGD meeting minutes. **11.2.3** AGD queried whether UK General Data Protection Regulation (UK GDPR) requirements had been captured, noting that whilst the applicant was not receiving or processing personal data, they may be a data controller, and suggested that UK GDPR aspects were reviewed and updated as may be appropriate. **11.2.4** AGD also suggested that the application was updated to be clear who had the legal basis for what activity. **11.2.5** AGD noted that section 3.5 (Data Level) stated that the data was *"aggregated – with small numbers suppressed"*; and noting that the analysis data would not fall under this description, suggested that this was reviewed and updated as appropriate. **11.2.6** AGD noted in section 4.2 (Purpose for Processing), that the project would be focussed on selected vaccine-preventable diseases, including COVID-19; and suggested that this was reviewed to ensure that it aligned with the (because COVID-19 activities are excluded under the Pilot Directions). **11.2.7** AGD noted the information in section 3.9 (National Data Opt-outs) in respect of the National Data Opt-out, and suggested that this was reviewed and updated in line with NHS England's National Data Opt-out and other documentation. **11.2.8** AGD suggested that the application was updated with further information on Type 1 objections, in line with. **11.2.9** AGD noted that the stated purpose of the application was for 'service evaluation', and suggested how it was distinguished from research was clarified. **11.2.10** AGD noted that in line with AGD's Terms of Reference, they usually provide advice on personal data; and here applicants do not receive access to personal data, however, it was noted that NHS England were able to seek advice from the Group as may be appropriate, and advised that they would welcome providing advice on this type of application as may be required by NHS England. **11.2.11** AGD noted that section 4.9 (Commercial Benefit Evaluation) had not been completed, and suggested that if access to OpenSAFELY could produce commercial benefits, then this should be noted. **11.2.12** Noting AGD was only asked to advise on specific points reviewed, no AGD member noted any substantive commercial aspects.	
12 AGD OPERATIONS		
12.1	**AGD Management Information (Presenter: Vicki Williams)** AGD were provided with a verbal update on the management information collated to date by the AGD Secretariat, on the AGD meetings / outputs, for example, the number of applications reviewed by AGD, and the outcomes of the discussions.	

	The Group noted and thanked Vicki for providing the verbal update, and looked forward to a further update in due course.	
12.2	**AGD Action Log (Presenter: Vicki Williams)** AGD were advised that there was ongoing work on the AGD action log, and that further information would be provided on this at a future AGD meeting. **ACTION:** AGD Secretariat to add 'AGD action log' to the AGD internal forward planner. The Group noted and thanked Vicki for providing the verbal update, and looked forward to a further update in due course.	AGD Sec
12.3	**Risk Management Framework** The AGD Chair asked for an update on the risk management framework referred to in the Group's Terms of Reference. The NHS England SIRO Representative updated the Group that there was ongoing work with this outstanding action, and that a further update would be provided in the coming weeks. **ACTION:** The NHS England SIRO Representative to provide a written response to AGD on the progress by the end of in September 2025, of the risk management framework.	SIRO Rep
12.4	**AGD Stakeholder Engagement** The AGD Chair and Dr Jon Fistein noted to the Group that they had met with Jackie Gray, Director of Privacy and Information Governance, Privacy, Transparency, and Trust on the 24th September 2025; this was in line with clause 9.2 of the AGD Terms of Reference that states: *"The Chair and the Deputy SIRO shall meet at least every six months to review the operation of the Group"*.	
12.5	**AGD Project Work** *There were no items discussed*	
13 Any Other Business		
There were no items discussed		
Meeting Closure As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.		