

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 26th September 2024

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)
Claire Delaney-Pope (CDP)	AGD independent member (Specialist Information Governance Adviser)
Dr. Robert French (RF)	AGD independent member (Specialist Academic / Statistician Adviser)
Kirsty Irvine (KI)	AGD independent member (Chair)
Narissa Leyland (NL)	NHS England member (Data and Analytics Representative (Delegate for Michael Chapman)) (Presenter: item 9)
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)
Jenny Westaway (JW)	AGD independent member (Lay Adviser)
Miranda Winram (MW)	AGD independent member (Lay Adviser)
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	Role / Area:
Susheela Andani (SA)	Information Governance Specialist (SIRO Data Access Approvals), Information Governance Risk and Assurance, Privacy, Transparency, and Trust (PTT), Delivery Directorate (Observer: item 10.1)
Lawrence Bell (LB)	Audit Manager (IG), IG Risk and Assurance (Presenter: item 6)
Garry Coleman (GC)	NHS England SIRO Representative

Jackie Gray (JG)	Director of Privacy and Information Governance, Privacy, Transparency, and Trust (PTT), Delivery Directorate (In attendance: item 5)
Steven Hardy (SH)	NDRS Head of Genomics and Rare Disease, Data and Analytics (Presenter: item 8)
Lucy Legge (LL)	Governance and Assurance Senior Manager, Data Governance and Assurance, Data Access and Partnerships Directorate (Presenter: item 9)
Nicki Maher (NM)	Information Governance Lead, IG Assurance and Risk, IG Audit Services Lead (Interim), Privacy, Transparency, and Trust (PTT), Delivery Directorate (Observer: items 6 to 9 and 11.1 to 11.2) (Presenter: item 10.1)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Delivery Directorate
Kat Roe (KR)	NDRS Data Operations Principal Manager, Data and Analytics (Presenter: item 8)
Terry Service (TS)	Head of Data Access Service, Transformation Directorate (Presenter: item 7)
Vijay Tailor (VT)	Audit Manager (IG), IG Risk and Assurance (Presenter: item 6)
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)
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 5) of the quarterly AGD plenary meeting fulfilled clause 9.2 of the AGD Terms of Reference that states: <i>“The Chair, the</i></p>
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	<i>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>	
2	Review of previous AGD minutes: The minutes of the AGD meeting on the 19 th September 2024 were reviewed and, after several minor amendments, were agreed as an accurate record of the meeting.	
3	Declaration of interests: There were no declarations of interest.	
4	AGD Action Log: <i>The action log was not discussed.</i>	
5	AGD members feedback / reflections AGD had a discussion / provided feedback to the Director of Privacy and Information Governance, Privacy, Transparency, and Trust and the SIRO Representative, in respect of how they felt that AGD was going following the move from the ‘interim advisory group for data’ to the ‘Advisory Group for Data’ in line with the approved AGD Terms of Reference on the 1 st April 2024. AGD noted that the feedback provided in the AGD meetings is more beneficial to NHS England the earlier this is sought / received; and advised / encouraged NHS England to seek advice from the Group at the earliest opportunity. The AGD independent members advised that they were keen to ensure that there was an equal voice in the AGD meetings between the AGD independent members and the AGD NHS England members. To further support this, the Director of Privacy and Information Governance suggested that AGD NHS England members / delegates have more ‘protected time’ to review meeting documents in advance of the AGD meetings. The Group welcomed the support from the Director. AGD and the Director discussed potential different ways of working prior to the AGD meetings, for example, the Group reviewing / commenting on meeting documents in a shared space, that may reduce duplication of efforts by AGD members, in terms of issues being highlighted; and will then support the discussion in-meeting. It was also noted that this would support newer AGD members with learning and development. It was agreed that the AGD Secretariat would look at how this approach could be set up and to then set out a process for this pre-meeting document review and that this would be discussed at a future AGD meeting, before being piloted. ACTION: AGD Secretariat to develop a process for AGD members to review / comment on meeting documents in a shared space, prior to the AGD meetings.	AGD Sec

	<p>some tweaks had been made to this document by the Director; and that a copy would be shared with the Group (via the AGD Secretariat) as soon as possible.</p> <p>In addition, the Group were also advised that, in addition to the points made on the proposed quarterly report and how this information could feed into the AGD Annual Report; the Group should also give consideration as to what statistics could be added to the next AGD Annual Report.</p> <p>ACTION: The Director of Privacy and Information Governance to share a copy of the updated AGD Annual Report with the AGD Secretariat, for circulation to AGD members.</p> <p>ACTION: AGD and AGD Secretariat to consider what statistics can be collated and added to the AGD quarterly / Annual Report in future.</p>	<p>JG / AGD Sec</p> <p>AGD / AGD Sec</p>
6	<p>Audit Services: Data Sharing Agreements (DSA) Audit Overview (Presenters: Lawrence Bell and Vijay Tailor)</p> <p>Lawrence and Vijay attended the meeting to provide an overview to the Group on the process for NHS England's audits on DSAs and the current statistics, for example, the number of published audit report from 2021 to August 2024.</p> <p>AGD queried if information was available on the percentage of live DSAs or recipient organisations which have been audited; and were advised by the NHS England SIRO Representative that this information would be shared with the Group either outside of the meeting or at a future AGD meeting.</p> <p>ACTION: The NHS England SIRO Representative to share information with the Group on the percentage of live DSAs or recipient organisations which have been audited.</p> <p>AGD noted the importance of the wording in the special conditions in section 6 of the applications / DSAs in terms of supporting audits; Lawrence and Vijay advised that the special conditions should be clear and contain as much unambiguous information as possible. AGD advised that if any examples were identified by Audit Services where the special conditions were not clear that this be fed back to AGD to support the advice provided at future AGD meetings.</p> <p>AGD thanked Lawrence and Vijay for attending the meeting, and for the helpful information provided; and requested that a further one-hour update on this area of work be provided at the next AGD plenary meeting on the 5th December 2024.</p> <p>ACTION: AGD Secretariat to add a further one-hour update from Audit Services to the AGD Forward Planner for the 5th December 2024 AGD meeting.</p>	<p>SIRO Rep</p> <p>AGD Sec</p>
7	<p>Update on expiring / expired applications and Data Sharing Framework Contract (DSFC) (Presenter: Terry Service)</p> <p>Terry Service attended the meeting to provide an overview to the Group on expiring / expired applications and the DSFC, including, but not limited to, the NHS England</p>	

	<p>Data Access Service (DAS) process / engagement with applicants prior to an application expiring and after the application has expired.</p> <p>The Group were also provided with some statistics as to how many applications were expired up to the 14th June 2024 and the progress on these up to the 29th August 2024.</p> <p>AGD noted that a programme of work was ongoing within NHS England DAS, including how NHS England DAS could provide further support to applicants to ensure applications are re-submitted in a timely manner and before they expire.</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 next AGD plenary meeting on the 5th December 2024.</p> <p>ACTION: AGD Secretariat to add a further update on the expired / expiring applications to the AGD Forward Planner for the 5th December 2024 AGD meeting.</p> <p>AGD advised that they would welcome / would be supportive of providing further advice / support on this ongoing of programme of work as may be required by NHS England.</p>	AGD Sec
8	<p>National Disease Registration Service (NDRS) (Presenters: Kat Roe and Steven Hardy)</p> <p>Kat Roe and Steven Hardy attended the meeting to provide an overview to the Group on NDRS, including, but not limited to, the history of NDRS; an overview of the datasets that the NDRS is responsible for or utilises; an explanation as to the overlap between cancer, congenital anomalies and rare diseases; and how the NDRS supports patients.</p> <p>AGD thanked Kat and Steven for attending the meeting and for the helpful information shared, that provided a really useful overview of NDRS, and built on the Group's existing knowledge of this area of work.</p>	
9	<p>Review of the NHS England Data Access Service (DAS) Standards (Presenters: Narissa Leyland and Lucy Legge)</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 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 for further consideration / discussion.</p> <p>The Group noted that the ongoing programme of work to review the NHS England DAS Standards would be done over a period of time and that appropriate engagement would be undertaken with stakeholders via workshops etc. It was also noted that the purpose of this work was to future proof the NHS England DAS Standards (or alternative) to ensure that the information was correct and suitable for</p>	

	<p>all data access models and for the right audience(s). In addition, it was noted that any updates made to the NHS England DAS Standards (or alternative) should be easily accessible for applicants of data and for the general public.</p> <p>The Group reviewed the proposals put forward for each of the NHS England DAS Standards and noted the following:</p> <p><u>Standard 1</u> – Term of Data Sharing Agreement</p> <p>AGD noted that the proposal is to retire this Standard, and advised that they were supportive of this approach; however, suggested that the information within the current Standard was reviewed and updated as may be appropriate, and that the information contained was re-branded as ‘guidance’.</p> <p>It was suggested that the updated guidance was available both in NHS England’s customer relationships management (CRM) system and published on NHS England’s website, to ensure that there is transparency to the public.</p> <p>It was also noted that the NHS England Data Sharing Framework Contract (DSFC) would need to be reviewed to confirm exactly where information in relation to this Standard was already covered in the DSFC (or if not, if it would need to be captured elsewhere, or require a contractual amendment in either the DSFC or data sharing agreement (DSA)).</p> <p><u>Standard 1b</u> – Data Controllers</p> <p>AGD noted that the proposal is to retire this Standard, and advised that they were supportive of this approach; however, suggested that the information within the current Standard was reviewed and updated as may be appropriate, and that the information contained was re-branded as ‘guidance’.</p> <p>AGD noted and supported the proposal to include a reference within the ‘guidance’ to the relevant Information Commissioner’s Office (ICO) guidance on Data Controllers.</p> <p>AGD suggested that it would be helpful to have some worked examples within the ‘guidance’ of where an organisation may / may not be a Data Controller; and advised that they would support NHS England DAS with this, noting that this was an issue that had been discussed at AGD meetings on numerous occasions.</p> <p>It was suggested that the updated guidance was available both in NHS England’s customer relationships management (CRM) system and published on NHS England’s website, to ensure that there is transparency to the public.</p> <p>ACTION: AGD to provide some worked examples to NHS England DAS to feed into the ‘guidance’ document.</p> <p><u>Standard 1c</u> – Data Processors</p> <p>AGD noted that the proposal is to retire this Standard, and advised that they were supportive of this approach; however, suggested that the information within the</p>	<p>AGD</p>
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	<p>current Standard was reviewed and updated as may be appropriate, and that the information contained was re-branded as 'guidance'.</p> <p>AGD noted and supported the proposal to include a reference within the 'guidance' to the relevant Information Commissioner's Office (ICO) guidance on Data Processors.</p> <p>AGD suggested that it would be helpful to have some worked examples within the 'guidance' of where an organisation may / may not be a Data Processor; and advised that they would support NHS England DAS with this, noting that this was an issue that had been discussed at AGD meetings on numerous occasions.</p> <p>It was suggested that the updated guidance was available both in NHS England's customer relationships management (CRM) system and published on NHS England's website, to ensure that there is transparency to the public.</p> <p>ACTION: AGD to provide some worked examples to NHS England DAS to feed into the guidance document.</p> <p><u>Standard 2a</u> – Security Assurance</p> <p>AGD noted that the proposal is to retire this Standard, however it was noted that there were ongoing discussions within NHS England, including, but not limited to, colleagues in Cyber Security.</p> <p>It was agreed that a workshop would be held to discuss this area further and to agree as to whether the current Standard should be retired, or updated and remain as a Standard, or whether this should be re-branded as 'guidance'.</p> <p>ACTION: NHS England DAS to set up a workshop to discuss further.</p> <p><u>Standard 2b</u> – Data Protection Act Registration</p> <p>AGD noted that the proposal is to retire this Standard, and advised that they were supportive of this approach; however, suggested that the information within the current Standard was reviewed and updated as may be appropriate, and that the information contained was re-branded as 'guidance'.</p> <p>It was suggested that the updated 'guidance' was available both in NHS England's customer relationships management (CRM) system and published on NHS England's website, to ensure that there is transparency to the public.</p> <p><u>Standard 3</u> – Data Minimisation</p> <p>AGD noted that the proposal is to retire this Standard, and advised that they were supportive of this approach; however, suggested that the information within the current Standard was reviewed and updated as may be appropriate, and that the information contained was re-branded as 'guidance'.</p> <p>It was suggested that the updated 'guidance' was available both in NHS England's customer relationships management (CRM) system and published on NHS England's website, to ensure that there is transparency to the public.</p>	<p>AGD</p> <p>DAS</p>
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	<p><u>Standard 3c</u> – Patient Objections</p> <p>AGD noted that the proposal is to retire this Standard, and advised that they were supportive of this approach; however, suggested that the information within the current Standard was reviewed and updated as may be appropriate, and that the information contained was re-branded as ‘guidance’.</p> <p>It was suggested that the updated ‘guidance’ was available both in NHS England’s customer relationships management (CRM) system and published on NHS England’s website, to ensure that there is transparency to the public.</p> <p>AGD suggested that it would be helpful to have some worked examples within the ‘guidance’ of the different types of opt-outs and where they may / may not apply.</p> <p>ACTION: AGD to provide some worked examples to NHS England DAS to feed into the guidance document.</p> <p><u>Standard 6</u> – Special Conditions</p> <p>AGD noted that the proposal is to retire this Standard, and update the DSFC with relevant new or amended clauses. The NHS England SIRO Representative noted the complexities / lengthy timescales with making updates to the DSFC.</p> <p>It was suggested that a workshop could be held to discuss this area further and to agree as to whether the current Standard should be updated and remain as a Standard, or whether this should be re-branded as ‘guidance’; and determine whether the DSFC should be updated.</p> <p>ACTION: NHS England DAS to set up a workshop to discuss further.</p> <p><u>Section 5a</u> – Objective for Processing / <u>Section 5b</u> – Processing Activities / <u>Section 5c</u> – Expected Outcomes / <u>Section 5d</u> – Expected Measurable Benefits</p> <p>AGD noted a standard / bar was required for each of the sections in order that applicants understand what is expected and NHS England has a transparent framework for applying clear and consistent criteria across applications.</p> <p>It was suggested that the information within the current Standard was reviewed and updated as may be appropriate, it was noted however that ‘guidance’ may not be the correct term for this information and that further thought should be given on this.</p> <p>It was suggested that the updated information was available both in NHS England’s customer relationships management (CRM) system and published on NHS England’s website, to ensure that there is transparency to the public.</p> <p><u>Standard 5e</u> – Commercial Purpose</p> <p>AGD noted that the proposal is to maintain this as a more simplified Standard, and it was agreed that a workshop would be held to discuss this area further.</p> <p>AGD requested that in advance of a Workshop, that NHS England DAS give further consideration as to what needs addressing in this Standard and what the Standard</p>	<p>AGD</p> <p>DAS</p>
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	<p>is currently not addressing and / or where it is not meeting a need by way of worked examples.</p> <p>ACTION: NHS England DAS to provide some worked examples to AGD to feed into the workshop.</p> <p>ACTION: NHS England DAS to set up a workshop to discuss further.</p> <p><u>Standard 7a</u> – Ethical Approval</p> <p>AGD noted that the proposal is to retain this as a Standard and to consult relevant stakeholders on whether updates are required; AGD advised that they were supportive of this approach.</p> <p><u>Standard 7b</u> – Duty of Confidentiality</p> <p>AGD noted that the proposal is to retain this as a Standard; and advised that they were supportive of this approach.</p> <p>The AGD Chair noted that Health Research Authority Confidentiality Advisory Group (HRA CAG) have advised that they were happy to be involved on producing any updates / guidance to this Standard (see item 11.3).</p> <p><u>Standard 8</u> – GDPR Consent</p> <p>AGD noted that the proposal is to retire this Standard, and advised that they were supportive of this approach; however, suggested that the information within the current Standard was reviewed and updated as may be appropriate, and that the information contained was re-branded as ‘guidance’ or a ‘process’.</p> <p>It was suggested that the updated ‘guidance’ was available both in NHS England’s customer relationships management (CRM) system and published on NHS England’s website, to ensure that there is transparency to the public.</p> <p><u>Standard 10</u> – Sub-Licencing and Onward Sharing</p> <p>AGD noted that a further discussion was required on this Standard; and advised that they were supportive of this being retired as a Standard. It was suggested that the information within the current Standard was reviewed and updated as may be appropriate, and that the information contained was re-branded as ‘guidance’.</p> <p>It was suggested that the updated ‘guidance’ was available both in NHS England’s customer relationships management (CRM) system and published on NHS England’s website, to ensure that there is transparency to the public.</p> <p><u>Standard 11</u> – Territory of Use</p> <p>AGD noted that the proposal is to retire this Standard, and advised that they were supportive of this approach; however, suggested that the information within the current Standard was reviewed and updated as may be appropriate, and that the information contained was re-branded as ‘guidance’ or a ‘process’.</p>	<p>DAS</p> <p>DAS</p>
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	<p>It was suggested that the updated 'guidance' / 'process' was available both in NHS England's customer relationships management (CRM) system and published on NHS England's website, to ensure that there is transparency to the public.</p> <p>NHS England DAS advised the Group that a policy decision was being sought on those wanting to process or access data from outside of the European Economic Area (EEA); and that further discussions on this Standard would take place once this information had been received.</p> <p>ACTION: NHS England DAS to update AGD on the policy decision those wanting to process or remotely access data from outside of the European Economic Area (EEA); and to arrange a workshop to discuss the NHS England DAS Standard for Territory of Use.</p> <p><u>Standard 12</u> – Honorary Contracts</p> <p>AGD noted that this Standard had recently been subject to some updates; however, noted that further discussions would be required to ensure that this Standard was relevant for all data access models.</p> <p>It was suggested that this could be re-branded as 'requirements' with supporting 'guidance' to sit alongside this.</p> <p>AGD thanked Narissa and Lucy for the work they were doing on this programme of work, and looked forward to further discussions in due course.</p>	DAS
10 OVERSIGHT AND ASSURANCE		
10.1	<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 progress made with the 130 points raised across the applications reviewed by AGD independent members from 21st March 2024 to 6th June 2024; and, an update on the 11 applications where AGD independent members were not supportive, had mixed views or were unsure as to whether the Precedent had been applied correctly.</p> <p>AGD were advised that a number of steps / actions were required before the O&A process / reviews could re-start by AGD independent members, including, a review of the updated O&A form and whether better use of technology could be used to support this process.</p> <p>Nicki advised AGD that the updated O&A form had been received prior to the meeting following suggested updates by NHS England's Data Access Service (DAS), and that this would be shared with AGD (via the AGD Secretariat) as soon as possible for review / discussion at a future AGD meeting.</p> <p>ACTION: Nicki to share the updated O&A form with the AGD Secretariat.</p>	NM

	<p>ACTION: AGD Secretariat to add the review of the O&A form to the AGD Forward Planner.</p> <p>AGD were also advised that the proposal is to re-commence O&A reviews from November 2024 and that it was expected that this would proceed on a monthly basis.</p> <p>ACTION: AGD Secretariat to add a O&A to the AGD Forward Plan from November 2024.</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>	<p>AGD Sec</p> <p>AGD Sec</p>
11 AGD OPERATIONS		
11.1	<p>Risk Management Framework</p> <p>The NHS England SIRO Representative confirmed that a risk management framework was continuing to be developed by Data Access, and in the meantime asked that AGD use the agreed NHS England DAS Standards and Precedents model as a proxy in assessing the risk factors in relation to items presented to AGD for advice.</p> <p>It had been noted previously by the interim data advisory group that the Oversight and Assurance Programme of applications that were not subject to AGD review would form part of this Risk Management Framework.</p> <p>The NHS England SIRO representative noted an outstanding action in respect of providing a written response to AGD on the risk management framework; and noted that this was progressing under the NHS England Precedents and Standards work.</p> <p>ACTION: The NHS England SIRO Representative to provide a written response to AGD on the risk management framework</p>	<p>SIRO Rep</p>
11.2	<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>	
11.3	<p>AGD Stakeholder Engagement</p> <p>The AGD Chair noted to the Group that she had met with Jackie Gray, Director of Privacy and Information Governance, Privacy, Transparency, and Trust on the 25th September 2024; this was in line with clause 9.2 of the AGD Terms of Reference that states: <i>“The Chair and the Deputy SIRO shall meet at least every six months to review the operation of the Group”</i>.</p> <p>The AGD Chair noted to the Group that she had met with Dr. Tony Calland, the Chair of the Health Research Authority Confidentiality Advisory Group (HRA CAG) and Dr. Nicola Byrne,</p>	

	<p>the National Data Guardian for health and adult social care in England, on Tuesday 24th September 2024, as part of their regular engagement.</p> <p>The Group were advised that as part of the catch-up, reference was made to the NHS England Standard 7b – Duty of Confidentiality (see item 9); and noted that Dr. Tony Calland had advised that HRA CAG were happy to support with the review of this; and that Dr. Nicola Byrne had also advised that the NDG were happy to be engaged at the relevant point.</p>
11.4	<p>AGD Project Work</p> <p><i>There were no items discussed</i></p>
12 Any Other Business	
12.1	<p><i>There were no items discussed</i></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>	