

## **Advisory Group for Data (AGD) – Meeting Minutes**

Thursday, 7<sup>th</sup> March 2024

09:30 – 15:00

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

<b>INDEPENDENT ADVISERS IN ATTENDANCE:</b>	
<b>Name:</b>	<b>Role:</b>
Paul Affleck (PA)	Specialist Ethics Adviser
Claire Delaney-Pope (CDP)	Specialist Information Governance Adviser
Dr. Robert French (RF)	Specialist Academic / Statistician Adviser
Kirsty Irvine (KI)	Chair
Dr. Imran Khan (IK)	Specialist GP Adviser
Dr. Geoffrey Schrecker (GS)	Specialist GP Adviser
Dr. Maurice Smith (MS)	Specialist GP Adviser
Jenny Westaway (JW)	Lay Adviser
Miranda Winram (MW)	Lay Adviser (not in attendance for item 14)
<b>NHS ENGLAND STAFF IN ATTENDANCE:</b>	
<b>Name:</b>	<b>Role / Area:</b>
Susheela Andani (SA)	Information Governance Specialist (SIRO Data Access Approvals), Privacy, Transparency, and Trust, Delivery Directorate (not in attendance for items 1,2,4 and 12)
Michael Chapman (MC)	NHS England Data and Analytics Representative (not in attendance for items 5 and 12)
Garry Coleman (GC)	NHS England SIRO Representative ( <b>Presenter:</b> items 11 and 13)
Shavaun Glen (SG)	Senior Communications Business Partner, Transformation Directorate ( <b>Observer:</b> item 6)
Vicki Hartley (VH)	Data Access Business and Operational Delivery Manager, Data Access Service, Data and Analytics ( <b>Presenter:</b> item 5)

Dickie Langley (DL)	Assistant Director of Information Governance (Digital Operations), Privacy, Transparency and Trust (PTT) Delivery Directorate ( <b>Presenter:</b> item 7) ( <b>Observer:</b> item 6)
Andrew Martin (AM)	NHS England Data Protection Office Representative (Delegate for Jon Moore)
Ellie Munari (EM)	Communications and Engagement Manager, Transformation Directorate ( <b>Presenter:</b> item 6)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Delivery Directorate ( <b>Presenter:</b> item 12)
Jonathan Osborn (JO)	NHS England Caldicott Guardian Team Representative
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Delivery Directorate ( <b>Presenter:</b> item 3)
<b>INDEPENDENT ADVISERS NOT IN ATTENDANCE:</b>	
Prof. Nicola Fear (NF)	Specialist Academic Adviser
<b>NHS ENGLAND STAFF NOT IN ATTENDANCE:</b>	
Jon Moore (JM)	NHS England Data Protection Office Representative

<b>1</b>	<p><b>Welcome and Introductions</b></p> <p>The NHS England Senior Information Risk Owner (SIRO) Representative, noting the Advisory Group for Data (AGD) Terms of Reference (ToR) had not yet been agreed, proposed that:</p> <ul style="list-style-type: none"> <li>• Kirsty Irvine (as an independent adviser) will be asked to Chair the AGD meetings;</li> <li>• The meeting will be minuted, with advice and minutes published;</li> <li>• Attendees will include both independent advisers from outside NHS England and representatives from within NHS England. Attendees from NHS England include representatives covering the offices of the Data Protection Officer (DPO); the Caldicott Guardian; Data and Analytics; and the SIRO.</li> <li>• Attendees would not be listed as “members” in minutes during the transitional period;</li> <li>• NHS England representatives would not, during the transitional period, be formally part of any consensus that is reached, but would be active participants in the meeting;</li> <li>• It was agreed to use the Data Access Service (DAS) Standards / Precedents in relation to applications for external data sharing.</li> </ul>
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	<p>The attendees present at the meeting considered the proposal put forward by the NHS England SIRO Representative and, as no objections were raised, it was agreed that the meeting would proceed on this basis.</p> <p>Kirsty Irvine noted and accepted the request from the NHS England SIRO Representative to chair; and welcomed attendees to the meeting.</p>	
<b>2</b>	<p><b>Review of previous AGD minutes:</b></p> <p>The minutes of the 29<sup>th</sup> February 2024 AGD meeting were reviewed and subject to a number of minor amendments were agreed as an accurate record of the meeting.</p>	
<b>3</b>	<p><b>AGD Action Log</b></p> <p>The group undertook a 'deep dive' of the AGD action log.</p> <p>A number of open actions were agreed as 'closed' and could be moved to the 'non-live actions' list, and a number of action responses were unclear and further information was requested.</p>	
<b>4</b>	<p><b>Declaration of interests:</b></p> <p>There were no declarations of interest.</p>	
<b>5</b>	<p><b>Data Access Request Service (DARS) Online (Presenter: Vicki Hartley)</b></p> <p>The group noted that at the AGD meeting on the 18<sup>th</sup> January 2024, Michael Chapman had advised the group that the new DARS online service had gone live on the 15<sup>th</sup> January 2024.</p> <p>As per the request from the group on the 18<sup>th</sup> January 2024, Vicki Hartley attended the meeting to present an overview of the new DARS online, to further support the group's knowledge in this area.</p> <p>The group made a number of suggestions and observations in-meeting, which were noted by Vicki for further discussion internally with NHS England colleagues.</p> <p>The group thanked Vicki for attending the meeting and for providing an overview of DARS online to the group.</p>	
<b>6</b>	<p><b>Public attitudes to data (Presenter: Ellie Munari)</b></p> <p>Ellie presented 'public attitudes to data'. The group were advised that a programme of research had been undertaken to develop insight into public and NHS staff audiences, and how these audiences segment, in order to: <b>1)</b> develop a proactive communications plan, with messages that are targeted, timely and impactful; <b>2)</b> meet NHS England's duty of transparency; <b>3)</b> understand how to support people in making informed decisions around data sharing and/or opting out; and <b>4)</b> support policy and programme development.</p>	

	<p>The group were advised that the outcomes following the programme of research would made publicly available within the coming weeks and published on the NHS England website.</p> <p>The independent advisers noted the findings of the research and made a number of observations to Ellie and Shavaun.</p> <p>The group were advised that ‘phase 2’ of the research would be starting soon and that Ellie and Shavaun would welcome any feedback on the proposed draft questions and / or suggestions for additional questions, which would be circulated for information.</p> <p><b>ACTION:</b> Ellie and Shavaun to share the draft questions with the group (via AGD Secretariat); and AGD Secretariat to add to the AGD forward planner for a discussion at a future AGD meeting.</p> <p>The group thanked Ellie and Shavaun for attending the meeting and advised that they would be supportive of further updates / engagement as required.</p>	EM / SG / AGD Sec
7	<p><b>Federated Data Platform (FDP) and Privacy Enhancing Technology (PET) Data Protection Impact Assessments (DPIA) (Presenter: Dickie Langley)</b></p> <p>The group noted that prior to the meeting, they were provided with a copy of the draft FDP DPIA and PET DPIA documents, for information.</p> <p>The group briefly discussed a number of points linked to the DPIA documents provided, including, but not limited to, public engagement, transparency, public trust and timings.</p> <p>The group were advised by Dickie that further work was ongoing within NHS England and their stakeholders on both the FDP and PET, and that a further update would be provided in due course.</p> <p>In addition, the group noted that as part of stakeholder engagement, an AGD independent adviser (TBC) has been invited to join the FDP Data Governance Group.</p> <p>The group thanked Dickie and looked forward to a further update on both the FDP and PET in due course.</p>	
<b>AGD Operations</b>		
8	<p><b>Statutory Guidance</b></p> <p>The independent advisers again noted the reference to reviewing materials in accordance with “<i>a clearly understood risk management framework</i>” within the published <a href="#">Statutory Guidance</a> and advised that they were not aware of an agreed risk management framework, and requested that NHS England provide further information/ clarity on this, noting this topic had been raised by Lord Hunt in the House of Lords on the 26<sup>th</sup> June 2023, and was answered by Lord Markham on the 5<sup>th</sup> July 2023: <a href="#">Written questions, answers and statements – UK Parliament</a>.</p>	

	<p>The NHS England SIRO Representative had provided further clarity on the risk management framework via email to the group, which confirmed that NHS England were asking the interim data advisory group to use the NHS England DAS Standards and Precedents model to assess the risk factors in relation to items presented to the interim data advisory group for advice; however the independent advisers noted that the wording in the statutory guidance “...using a clearly understood risk management framework, precedent approaches and standards that requests must meet...”, suggested that the risk management framework is separate to the DAS Standards and Precedents, and asked that this be clarified by NHS England. The group noted that the Deputy Director, Data Access and Partnerships, Data and Analytics attended the meeting on the 23<sup>rd</sup> November 2023, and noted that plans for this work were in train.</p> <p>It had been noted previously that an Oversight and Assurance Programme of applications that had not be subject to AGD review could form part of this Risk Management Framework.</p> <p>The AGD Chair referred to the requirement within the published <a href="#">Statutory Guidance</a> for an annual review; and that further thought / consideration was needed, on how the annual report would be presented, for example, on an NHS England standard template or other means.</p> <p><b>ACTION:</b> The group to give further thought / consideration as needed, on how the annual report would be presented, for example, on an NHS England standard template or other means.</p> <p>The 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>AGD</p> <p>SIRO Rep</p>
9	<p><b>AGD Terms of Reference (ToR)</b></p> <p>The independent advisers noted that over nine months had passed since the <a href="#">Statutory Guidance</a> had been published, requiring a ToR to be agreed and published.</p> <p>The AGD Chair noted that on the 23<sup>rd</sup> February 2024, Jackie Gray had shared with the group, a <b>final</b> draft version 0.16 of the ToR and had advised that this document was being sent to Steve Russell, NHS England’s Chief Delivery Officer, National Director for Vaccinations and Screening and Senior Information Risk Owner (SIRO) for final approval, ahead of seeking approval from the Data, Digital and Technology Committee (DDAT) of the NHS England Board. It was noted that Jackie has also advised that as per the previous commitment made to the group, if there are any changes to this version of the ToR following review by Steve Russell and / or DDAT, an updated version would be shared with the group prior to publication.</p> <p>The group noted that clarification had been provided with the final draft ToR, showing updates made to the document reviewed at the workshop on the 27<sup>th</sup></p>	

	<p>November 2023 and further updates / clarifications made by the AGD Chair in early February 2024. The group looked forward to being notified of the formal approval of the ToR by NHS England.</p> <p><b>ACTION:</b> The SIRO representative to advise AGD when the ToR have been formally approved by NHS England.</p>	SIRO Rep
10	<p><b>Standard Operating Procedures Workshop (SOPs)</b></p> <p>As part of the ongoing programme of work to draft AGD SOPs, the group had been provided with three draft SOPs: <b>1)</b> the Chair and Deputy Chair SOP; <b>2)</b> the Members and Conduct at AGD SOP; and <b>3)</b> the Meeting Operations SOP.</p> <p>It was noted that high level feedback on the three draft SOPs provided in-meeting would feed into further updates / progression of the draft SOPs in line with the progression of the AGD ToR.</p> <p>The group were asked that all comments / notes on the draft SOPs provided and reviewed as part of their pre-meeting preparation and comments / notes on draft SOPs discussed in the workshop should be sent to the AGD Secretariat by the 8<sup>th</sup> March 2024.</p> <p><b>ACTION:</b> The group to ensure that all their comments / notes on the draft SOPs are sent to the AGD Secretariat by the 8<sup>th</sup> March 2024.</p>	AGD
11	<p><b>Oversight and Assurance (Presenters: Garry Coleman / Kirsty Irvine / Jenny Westaway)</b></p> <p>The <a href="#">Statutory Guidance</a> states that the data advisory group (AGD) should be able to provide NHS England with advice on: <i>“Precedents for internal and external access, including advising in accordance with an agreed audit framework whether processes for the use of precedents are operating appropriately, to provide ongoing assurance of access processes”</i>.</p> <p>In advance of the meeting, the group were provided with a draft oversight and assurance template that will be used to support reviews. It was proposed that these will be undertaken by AGD independent advisers, as set out in the (draft) AGD Terms of Reference. The non-use of NHS England members to carry out oversight and assurance may be reviewed in the light of experience.</p> <p>The group discussed the proposed draft oversight and assurance template; and feedback a number of points / suggestions to the presenters. It was also agreed that the summary of the review / advice would be included in the AGD published minutes for transparency.</p> <p>The group thanked those involved for the work undertaken to date on the proposed oversight and assurance remit of work, and noted that a further discussion would take place on this subject at the AGD meeting on the 14<sup>th</sup> March 2024.</p>	

	<b>ACTION:</b> AGD Secretariat to include 'oversight and assurance' on the 14 <sup>th</sup> March 2024 meeting agenda.	AGD Sec
<b>Any Other Business</b>		
<b>12</b>	<p><b>AGD Webpage update (Presenter: Karen Myers)</b></p> <p>Following the update at the AGD meeting on the 22<sup>nd</sup> February 2024; the group were provided with a presentation outlining the draft AGD webpage; and were advised what further work was required before this could be published in early April 2024.</p> <p>The group noted, and thanked Karen, for the update and looked forward to a further update by the end of March 2024.</p> <p><b>ACTION:</b> AGD Secretariat to provide a further update on the final updated draft AGD webpage at the 21<sup>st</sup> March 2024 AGD meeting.</p>	AGD Sec
<b>13</b>	<p><b>AGD future ways of working (Presenter: Garry Coleman)</b></p> <p>Following the brief update at the AGD meeting on the 29<sup>th</sup> February 2024, the NHS England SIRO representative provided a further update to the group about AGD future ways of working and proposed changes (in line with the current draft v0.16 Terms of Reference); including, but not limited to, the start and end time of AGD meetings, the frequency of AGD meetings from April 2024 onwards, and in-meeting quoracy of the independent advisers.</p> <p>The group noted the verbal update from the NHS England SIRO representative, noted that further discussions were required, and looked forward to a further discussion at a future AGD meeting.</p> <p><b>ACTION:</b> the SIRO representative to provide further information on future ways of working from April onwards at a future AGD meeting.</p>	SIRO Rep
<b>14</b>	<p><b>Dr. Maurice Smith</b></p> <p>Both independent advisers and NHS England noted that this was Dr. Maurice Smith's final meeting and wished to extend their sincere thanks for his significant contribution over the last five years during his tenure on IGARD and the interim AGD.</p>	
<b>15</b>	<p><b>AGD GP independent advisers</b></p> <p>The independent advisers noted the departure of Dr. Maurice Smith and the imminent departure of Dr. Geoffrey Schrecker and Dr. Imran Khan over the coming weeks, meaning that from the end of March 2024 there would be <b>no</b> independent GP advisors on AGD. Whilst it was noted that NHS England was prioritising the recruitment of clinicians (including GP representation) to join AGD, without interim arrangements there was a risk to NHS England that AGD may not be seen as representative and that not all relevant views were available in providing AGD advice.</p>	

	<p>The group reiterated the point made at the AGD meeting on the 22nd February 2024 (item 11.4), that the current draft AGD Terms of Reference do not preclude the General Practice Extraction Service (GPES) Data for Pandemic Planning &amp; Research (COVID-19) (GDPPR) Profession Advisory Group (PAG) meeting in common with AGD; however noted that an independent GP adviser on AGD would provide NHS England with a more holistic view of applications and engage with the wider work of the group.</p>
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### **Meeting Closure**

As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.