

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

Thursday, 20<sup>th</sup> June 2024

09:00 – 15:10

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

<b>AGD INDEPENDENT / NHS ENGLAND MEMBERS IN ATTENDANCE:</b>	
<b>Name:</b>	<b>Role:</b>
Paul Affleck (PA)	AGD independent member (Specialist Ethics Adviser)
Michael Chapman (MC)	NHS England member (Data and Analytics Representative) (not in attendance for items 9.1, 13 to 16)
Dave Cronin (DC)	NHS England member (Data and Analytics Representative (Delegate for Michael Chapman) ( <b>Presenter:</b> items 13 to 15)
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)
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)
<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 ( <b>Presenter:</b> item 9.1)
Angeliki Antonarou (AA)	Senior Data Scientist, Data Wrangler - SDE Service, Data Access and Partnerships Directorate ( <b>Observer:</b> item 12)

Laura Bellingham (LB)	Deputy Director, Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Presenter:</b> item 10)
Helen Buckels (HB)	SDE Service Lead, Data Access and Partnerships Directorate <b>Observer:</b> item 12)
Garry Coleman (GC)	NHS England SIRO Representative
Liz Gaffney (LG)	SDE Service Owner, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 12) ( <b>Presenter:</b> item 11)
Nicki Maher (NM)	IG Risk and Assurance, Privacy, Transparency and Trust (PTT), Delivery Directorate ( <b>Presenter:</b> item 9.1) ( <b>In attendance</b> for items 1 to 8 and 1- to 18)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Delivery Directorate
Bethan Thomas (BT)	Assistant Director of Data Access and Partnerships, Head of Data Portfolio Management, Data and Analytics, Transformation Directorate ( <b>Presenter:</b> item 11) ( <b>Observer:</b> item 12)
James Watts (JW)	Data Access and Partnerships, Data and Analytics ( <b>Observer:</b> item 6.1)
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Delivery Directorate
<b>AGD INDEPENDENT MEMBERS / NHS ENGLAND MEMBERS <u>NOT</u> IN ATTENDANCE:</b>	
<b>Name:</b>	<b>Role / Area:</b>
Prof. Nicola Fear (NF)	AGD independent member (Specialist Academic Adviser)
Jon Moore (JM)	NHS England member (Data Protection Office Representative)
Miranda Winram (MW)	AGD independent member (Lay Adviser)

<b>1</b>	<b>Welcome and Introductions:</b> The AGD meeting Chair welcomed attendees to the meeting.
<b>2</b>	<b>Review of previous AGD minutes:</b>

	The minutes of the AGD meeting on the 13 <sup>th</sup> June 2024 were reviewed and, after several minor amendments, were agreed as an accurate record of the meeting.
3	<b>Declaration of interests:</b> There were no declarations of interest.
4	<b>AGD Action Log:</b> <i>The action log was not discussed.</i>
<b>5 BRIEFING PAPER(S) / DIRECTIONS:</b>	
<i>There were no items discussed</i>	
<b>6 EXTERNAL DATA DISSEMINATION REQUESTS:</b>	
6.1	<p><b>Reference Number:</b> NIC-727610-S2V3N-v0.5</p> <p><b>Applicant:</b> University College London (UCL)</p> <p><b>Application Title:</b> The impact of reimbursement schemes on healthcare providers' operational performance</p> <p><b>Observer:</b> James Watts</p> <p><b>Application:</b> This was a new application.</p> <p>The purpose of the application is for a research project with the aim of <b>1)</b> examining how different reimbursement schemes proposed by the NHS to reimburse healthcare providers affect providers' operational efficiency, costs, and quality of care; and <b>2)</b> to understand why the same reimbursement scheme leads to different behaviours among healthcare providers depending on their characteristics and patient types.</p> <p>Should an application be approved by NHS England, further details would be made available within the <a href="#">Data Uses Register</a>.</p> <p><b>Outcome of discussion:</b> AGD were <b>not</b> supportive of the application <b>at this time</b> and wished to draw to the attention of the SIRO the following significant comments, and suggested that the application be brought back to a future meeting:</p> <p><b>6.1.1</b> AGD noted in the internal application assessment form that there had been some discussions as to whether the data under this application could be accessed within NHS England's Secure Data Environment (SDE), however, AGD noted that no update had been provided on this point within the documentation provided. NHS England advised the Group that as the data sharing agreement (DSA) would be for a period of three years, this did not align with the current SDE criteria which only allowed for one-year DSAs, and so this application would <b>not</b> be suitable for SDE access. The AGD NHS England Data and Analytics Representative advised that prior to the meeting contact had been made with NHS England's SDE Team, to seek further clarification on this point. The Group advised that they were supportive of NHS</p>

<p>England exploring this further and suggested that this could be done as a 12-month DSA, with a renewal at each 12-month point as appropriate.</p> <p><b>6.1.2 Separate to this application:</b> Noting that some processes are already in place within NHS England, AGD suggested that NHS England should consider seeking advice from the NHS England SDE Team at an earlier stage in the application process, to determine whether applications would be suitable to access data in the SDE, or not.</p> <p><b>ACTION:</b> the AGD NHS England Data and Analytics Representative should consider seeking advice from the SDE Team at an earlier stage in the application process, to determine whether applications would be suitable for data access in the SDE, or not.</p> <p><b>6.1.3</b> AGD noted that accessing the data within the SDE would support the applicant with the contractual transparency obligations; however, suggested that NHS England give further consideration as to how and where transparency information undertaken within the SDE is located / accessed.</p> <p><b>6.1.4</b> Noting the large volume of data requested under this application, AGD suggested that either a clear justification was provided in the application and the internal application assessment form as to why the quantum of data was required, for example, was the quantum of data requested based on a similar study; or, that data minimisation was explored further, in line with <a href="#">NHS England DAS standard for data minimisation</a>.</p> <p><b>6.1.5</b> In addition, the Group suggested that in addition to any potential data minimisation explored with the applicant, NHS England also determine whether the applicant could use less data, or fewer data fields, or a shorter time period; and if not, to provide a clear justification of this within the in the application and the internal application assessment form.</p> <p>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p><b>6.1.6</b> AGD noted that section 2.4 (commercial benefit evaluation) of the internal application assessment form and section 5(e) (Is the Purpose of this Application in Anyway Commercial) of the application, stated that there were “no” commercial benefits; however, suggested that this was explored further with the applicant in line with <a href="#">NHS England DAS Standard for Commercial Purpose</a>, noting the funder (UCL Faculty of Engineering Research Capital Investment Fund) and any potential conflict of interest with the PhD student or supervisors etc, and the nature of the outputs and benefits; and that the application and internal application assessment form was updated as may be appropriate.</p> <p><b>6.1.7</b> In addition, AGD suggested that NHS England explore the experience of the PhD student, their supervisor and their use of health data; and whether / how the stated outputs and benefits link to health and social care, in line with <a href="#">NHS England DAS Standard for Expected Outcomes</a> and <a href="#">NHS England DAS Standard for Expected</a></p>	<p>D&amp;A Rep</p>
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<p><a href="#">Measurable Benefits</a>, and beyond, for example, the publication of outputs in management journals as outlined in the application.</p> <p><b>6.1.8</b> AGD noted the expected benefits in section 5(d) (Benefits) of the application; and suggested that these were reviewed and updated as may be necessary in line with <a href="#">NHS England DAS Standard for Expected Measurable Benefits</a>, to reflect the scale of the study by a PhD student; and to also ensure that the inclusion of the templated wording in its entirety in this section was correct and appropriate (because any Annual Confirmation Report or revised DSA would need to update progress in yielded benefits against <b>all</b> of the expected benefits currently outlined).</p> <p><b>6.1.9</b> AGD queried whether all of the stated outcomes in section 5(c) (Specific Outputs Expected) could be achieved with the data requested, and suggested that NHS England explore this further with the applicant; and that the application and internal application assessment form was updated as may be appropriate.</p> <p><b>6.1.10</b> AGD noted in section 5(a) (Objective for Processing) that there had been <b>no</b> patient and public involvement and engagement (PPIE); however, suggested that that the applicant should consider undertaking some PPIE, to seek views on a number of points, including, but not limited to, the proposed research and the expected benefits. The <a href="#">HRA guidance on Public Involvement</a> is a useful guide.</p> <p><b>6.1.11</b> AGD noted that institutional ethical support had been sought and obtained, however, suggested that the applicant re-submit the form to the UCL School of Management Research Ethics Committee (REC), to reflect any revised scope and clarify that personal data is being processed, and to clarify whether the ‘low risk’ application used previously was correct, noting the quantum of special category personal data requested.</p> <p><b>6.1.12</b> In addition, AGD noted the references in the UCL School of Management REC application form, that referred to data being “<i>purchased</i>” from NHS Digital; and noting that this was incorrect / misleading suggested that this was removed because NHS England <b>do not</b> sell data.</p> <p><b>6.1.13</b> In addition, it was suggested that the UCL School of Management REC may also wish to consider any potential misuse of outcomes of the work by taking them out of context, for example to promote particular funding models.</p> <p><b>6.1.14</b> AGD queried the statement in section 5(b) (Processing Activities) “<i>Access is restricted to employees or <b>agents</b> of UCL...</i>”; and suggested that either further information was provided as to who would be covered by “<i>agents</i>”, or that this was removed.</p> <p><b>6.1.15</b> AGD noted the reference in section 1.8 of the internal application assessment form that referred to students signing honorary contracts; and suggested that this was reviewed given that if an individual is a student of a university they are already accountable to that institution.</p>	
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## 7 INTERNAL DATA DISSEMINATION REQUESTS:

*There were no items discussed*

## 8 EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL

*There were no items discussed*

## 9 OVERSIGHT AND ASSURANCE

9.1	<p><b>Oversight and Assurance (O&amp;A) Overview (Presenters: Nicki Maher and Susheela Andani)</b></p> <p>AGD were provided with an overview of the O&amp;A undertaken by AGD independent members from 21<sup>st</sup> March 2024 to 6<sup>th</sup> June 2024, including, the headline statistics and findings, what has gone well, challenges and next steps.</p> <p>AGD were advised that as a result of the O&amp;A, there had been 130 points raised across the applications, which Nicki and Susheela were looking into further on behalf of / with the NHS England SIRO Representative; and in collaboration with relevant stakeholders, including, but not limited to, colleagues within Data and Analytics and the AGD Secretariat.</p> <p>It was noted that the next round of O&amp;A would commence on a monthly basis from September 2024, and that work was ongoing to determine what / how AGD could support with a 'light touch' review of a selection of some of the Application Compliance Reports (ACR) in August 2024.</p> <p>AGD were advised that work would be undertaken to determine how technology could better support the O&amp;A process.</p> <p>AGD noted and thanked Nicki and Susheela for the update, and the volume of work that has gone into addressing the points raised as part of the O&amp;A process; and were supportive of the monthly review from September 2024, and the ACR 'light touch' O&amp;A in August 2024.</p> <p><b>ACTION:</b> Nicki / Susheela to provide a copy of the presentation to the Group for information.</p>	NM / SA
10	<p><b>Data Services for Commissioners Regional Offices (DSCRO) / Unified DSCRO update (Presenter: Laura Bellingham)</b></p> <p>AGD were provided with an overview of the background / history of DSCROs, the current status of DSCROs following the merger of NHS England and NHS Digital; and the ongoing programme of work within NHS England, including the challenges involved.</p> <p>As part of this work programme, AGD were advised that NHS England would be engaging with them at future AGD meetings over the coming weeks / months, to seek</p>	

	<p>advice as appropriate on topics including, but not limited to, aligning and standardising data outputs across legacy data systems, standardising access to data processes across NHS England and wider, improving transparency on NHS England data flows, and improving data quality and assurance.</p> <p>AGD welcomed the update provided and looked forward to further engagement at future AGD meetings.</p> <p><b>ACTION:</b> Laura to provide a copy of the presentation to the Group for information.</p>	LB
11	<p><b>Data Portfolio Management and Access Methodologies (Presenter: Bethan Thomas)</b></p> <p>AGD were provided with an overview of the Data Portfolio Management and Access Methodologies programme of work, including the key issues and priorities driving the programme, the proposals for consistency with data access, data minimisation, forward planning and progress, internal and external transparency, access methodologies and the roles of internal stakeholders.</p> <p>The NHS England SIRO Representative queried how AGD would be able to see the latest / most up to date information on the datasets and how they would be notified where a change had occurred and was informed that the team were currently looking at how additional tabs could be added to the current report in order to generate a 'data set level metadata summary' which could be used to notify AGD of changes, including a change log so that advice provided by AGD could be tracked against changes to the metadata summary.</p> <p>As part of this work programme, AGD were advised that NHS England would welcome feedback at any point on this programme of work, noting that there would be further engagement at future AGD meetings over the coming months, to seek advice as appropriate; but that outputs would be shared with AGD by the end of the current financial year.</p> <p>AGD thanked Bethan for the update provided and looked forward to further engagement at future AGD meetings.</p> <p><b>ACTION:</b> Bethan to provide a copy of the presentation to the Group for information.</p>	BT
12	<p><b>NHS England Secure Data Environment (SDE) update (Presenter: Liz Gaffney)</b></p> <p>AGD were provided with an overview of NHS England's SDE, which is part of the NHS Research Secure Data Environment network, including the features and benefits of the SDE, progress to date, the application process and requirements prior to accessing the SDE, current and future datasets within the SDE, data provisioning and Data Wrangler support, technical controls and user responsibilities.</p> <p>NHS England advised the Group that there was an ongoing programme of work to allow some new applicants of data to access data in the SDE, if they fit the specific criteria.</p>	



	<p>In addition, and noting the limited datasets within the current SDE, work was ongoing to migrate further datasets into the SDE.</p> <p>AGD raised a number of points, including, but not limited to, how data access was audited, the cost to applicants using the SDE versus the cost of a data extract, and how this is being managed; the length of SDE agreements; and patient and public involvement and engagement (PPIE).</p> <p>As part of this work programme, AGD were advised that NHS England would provide a further update at future AGD meetings over the coming weeks / months, including responses to their questions raised.</p> <p>AGD thanked Liz for the update provided and looked forward to further engagement at future AGD meetings.</p>	
13	<p><b>Quarterly review of Standard Wording and Special Conditions (Presenter: Dave Cronin)</b></p> <p>The Group noted that as part of the meeting pack circulated to the group in advance of the meeting, version 1.3 of the special conditions and standard wording document had been included for review / discussion in-meeting.</p> <p>The group provided verbal feedback as part of this review to support the development / progression of this document / area of work.</p> <p>It was noted by Dave that an updated version of this document would be shared with the group in due course.</p> <p><b>ACTION:</b> Dave Cronin to provide an updated version of the special conditions and standard wording document to be shared with the Group.</p> <p>It was agreed by the Group that should any further special conditions be discussed at future AGD meetings, they should be noted in the special conditions and standard wording document; that these would be noted in the AGD minutes with an action for colleagues in DAS.</p> <p>Separate to the review of the standard wording and special conditions: AGD queried whether the section of the application form which asks if ethics approval is required and, if so, in place, could be used more broadly to indicate if institutional ethical support was obtained (where appropriate) in line with the <a href="#">NHS England DAS Standard for Ethical Approval</a>; and it was agreed that NHS England would take this point away for further consideration and update the internal application assessment form as may be appropriate.</p> <p><b>ACTION:</b> the AGD NHS England Data and Analytics Representative to further consider how the application form could reflect, whether the applicant had obtained institutional ethical support (where appropriate) in line with the <a href="#">NHS England DAS Standard for Ethical Approval</a>.</p>	<p>DC</p> <p>D&amp;A Rep</p>



	AGD thanked Dave for the update provided and looked forward to further engagement at future AGD meetings.	
14	<p><b>NHS England Data Access Service (DAS) application backlog (Presenter: Dave Cronin)</b></p> <p>AGD were advised that as of 25<sup>th</sup> March 2024, there were 365 applications waiting to be processed, and that as of the 20<sup>th</sup> June 2024, this had been reduced to 183 applications.</p> <p>NHS England also advised AGD, that since March 2024, there had been 145 new applications received by DAS.</p> <p>NHS England provided a brief update advising how applications since March 2024 were being processed, and the ongoing work to ensure different parts of the system work more efficiently / collaboratively.</p> <p>AGD noted and thanked NHS England for the information provided; and acknowledged and applauded the work undertaken by Data and Analytics in reducing the backlog of applications, noting the internal pressures / challenges, in terms of resources and skills.</p> <p>AGD advised that to support the progression of any applications in the system, they welcome NHS England submitting applications for review at an earlier stage, to seek advice as may be required.</p> <p>AGD thanked Dave for the update provided and looked forward to further engagement at future AGD meetings.</p>	To Note
15	<p><b>Overview of Governance Pathways to inform Q&amp;A (Presenter: Dave Cronin)</b></p> <p>AGD were provided with an overview of the Governance pathways and Precedents, including what governance pathways were used, how to understand the governance pathway used from the application form, and what legacy Precedents are no longer in use, and what they have been superseded by.</p> <p>AGD were advised by Dave, that the internal Question and Answer (Q&amp;A) document that supports colleagues within the Data Access Service when engaging with applicants, would be brought to a future AGD meeting for a review / update as may be required.</p> <p><b>ACTION:</b> AGD Secretariat to add the internal Q&amp;A document review to the internal AGD meeting forward planner.</p> <p><b>ACTION:</b> Dave Cronin to provide a copy of the internal Q&amp;A document to AGD secretariat to include on a future AGD agenda.</p> <p>AGD thanked Dave for the update provided and looked forward to further engagement at future AGD meetings.</p> <p><b>ACTION:</b> Dave to provide a copy of the presentation to the Group for information.</p>	<p>AGD Sec DC</p> <p>DC</p>

16	Confidential Advice Session
17 AGD OPERATIONS	
17.1	<p><b>Risk Management Framework</b></p> <p>As last noted in the AGD minutes from the 21<sup>st</sup> March 2024, the independent members 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 reiterated a previous request that NHS England provide further information/ clarity on this to the Group, 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 AGD (and previously 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 AGD for advice; however the independent members noted that the wording in the statutory guidance “...<i>using a clearly understood risk management framework, precedent approaches and standards that requests must meet...</i>”, 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 plans for this work were in train.</p> <p>It had been noted previously by the interim data advisory group that the 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 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><b>ACTION:</b> The NHS England SIRO Representative to provide a written response to AGD on the risk management framework</p>
17.2	<p><b>AGD Standard Operating Procedures (SOPs)</b></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 the AGD SOPs in line with the approved AGD ToR.</p> <p>It was noted that a further update would be provided to the Group in due course.</p>
17.3	<p><b>AGD Stakeholder Engagement</b></p> <p><i>There were no items discussed</i></p>

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<b>17.4</b>	<b>AGD Project Work</b> <i>There were no items discussed</i>	
<b>17.5</b>	<b>AGD Annual Report</b> <p>Following on from the submission of the final draft AGD Annual Review v0.6 to Jackie Gray following the 18<sup>th</sup> April 2024 AGD meeting, the NHS England SIRO Representative had asked AGD to provide further narrative based on what AGD had been seeing in terms of requests for advice to date, in support of the drafting of the NHS England annual report: ‘what themes/areas could we improve on?’ and ‘what themes/areas are we doing well and should build on?’.</p> <p>AGD noted that the request had been received yesterday, with a deadline for a response early next week. Garry Coleman agreed to draft some initial text based on the in-meeting discussion and emails already received and circulate to AGD via the AGD Secretariat.</p> <p><b>ACTION:</b> the NHS England SIRO Representative to circulate some initial narrative in response to the two questions posed by NHS England, via the AGD Secretariat, for consideration by AGD by close of play on the 20<sup>th</sup> June 2024.</p> <p><b>ACTION:</b> AGD members to consider the two questions posed by NHS England and to provide draft narrative for the NHS England report, prior to the next meeting of AGD.</p>	SIRO Rep  AGD
<b>18 Any Other Business</b>		
<b>18.1</b>	<i>There were no items discussed</i>	
<b>Meeting Closure</b> As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.		