

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

Thursday, 30<sup>th</sup> October 2025

09:00 – 12:10

*(Remote meeting 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) (Chair)
Noela Almeida (NA)	NHS England member (Data Protection Office Representative (Delegate for Jon Moore))
Laura Bellingham (LB)	NHS England member (Data and Analytics Representative (Delegate for Michael Chapman))
Claire Delaney-Pope (CDP)	AGD independent member (Specialist Information Governance Adviser)
Dr. Robert French (RF)	AGD independent member (Specialist Academic / Statistician Adviser)
Dr. Jonathan Osborn (JO)	NHS England member (Caldicott Guardian Team Representative)
<b>NHS ENGLAND STAFF IN ATTENDANCE:</b>	
<b>Name:</b>	<b>Role / Area:</b>
Jack Bennett (JB)	NHS DigiTrials, Data and Analytics, Transformation Directorate ( <b>Presenter / Observer:</b> item 4.1)
Wendy Harrison (WH)	Deputy Director of IG Delivery for Data and Analytics, Privacy, Transparency and Trust, Deputy Chief Executive Directorate ( <b>Presenter / Observer:</b> item 4.1)
Suzanne Hartley (SH)	Data Applications Service (DAS) - Senior Manager, Data Access and Partnerships, Transformation Directorate ( <b>Observer:</b> item 5.1)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Deputy Chief Executive Directorate
James Watts (JW)	Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 5.2)
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Deputy Chief Executive Directorate
<b>INDEPENDENT ADVISER OBSERVERS IN ATTENDANCE</b>	

Professor Jo Knight (JK)	AGD independent adviser
Dr. Mark McCartney (MM)	AGD independent adviser
<b>AGD INDEPENDENT MEMBERS / NHS ENGLAND MEMBERS <u>NOT</u> IN ATTENDANCE:</b>	
<b>Name:</b>	<b>Role / Area:</b>
Michael Chapman (MC)	NHS England member (Data and Analytics Representative)
Kirsty Irvine (KI)	AGD independent member (Chair)
Jon Moore (JM)	NHS England member (Data Protection Office Representative)
Jenny Westaway (JW)	AGD independent member (Lay Adviser)
Miranda Winram (MW)	AGD independent member (Lay Adviser)
<b>NHS ENGLAND STAFF NOT IN ATTENDANCE</b>	
Garry Coleman (GC)	NHS England SIRO Representative

<b>1</b>	<p><b>Welcome and Introductions:</b></p> <p>The AGD meeting Chair welcomed attendees to the meeting.</p> <p>AGD noted that, due to the lack of availability of independent members, there was an equal number of AGD independent members (three) and AGD NHS England members (three) in attendance for the meeting.</p> <p>The importance of the AGD independent member majority was acknowledged by those present, and it was suggested that an annual review / possible inclusion in the AGD annual report of the number of meetings where an independent majority had not been present would be useful, as this would allow consideration of whether any action needed to be taken to improve the proportion of meetings with an AGD independent member majority.</p> <p>In the absence of the NHS England SIRO Representative, the Group agreed that should AGD members be required to vote on any issues in the meeting, then one AGD NHS England member would be asked to not participate, to ensure the appropriate balance of votes, i.e. that the majority was by AGD independent members.</p> <p>Noting that the <a href="#">AGD Terms of Reference</a> state that “<i>The <b>majority</b> of the members of the Group or Sub-Group involved in any meeting <b>should</b> be independent members...</i>”, the Group agreed that the meeting was still quorate for <b>all</b> agenda items and agreed to proceed on that basis.</p> <p>AGD noted that, due to unforeseen circumstances, there would be no NHS England SIRO Representative or delegate in attendance for the meeting. Noting that the <a href="#">AGD Terms of Reference</a></p>
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	(ToR) state that: "...a representative of the SIRO must also be in attendance for any meetings of the Group or a Sub-Group...", the Group were advised that, prior to the meeting, the NHS England Deputy SIRO had confirmed contentment for all items to be discussed in their absence.
<b>2</b>	<b>Review of previous AGD minutes:</b> <p>The minutes of the AGD meeting on the 23<sup>rd</sup> October 2025 were reviewed and, after minor amendments, were agreed as an accurate record of the meeting, subject to the NHS England SIRO Representative providing contentment.</p>
<b>3</b>	<b>Declaration of interests:</b> <p>There were no declarations of interest.</p>
<b>4 BRIEFING PAPER(S) / DIRECTIONS:</b>	
<b>4.1</b>	<p><b>Title:</b> NHS DigiTrials Recruitment Directions 2025</p> <p><b>Presenters:</b> Jack Bennett and Wendy Harrison</p> <p>The NHS DigiTrials Recruitment Service is an innovative, direct-to-participant recruitment model designed to enhance the efficiency and effectiveness of clinical trial recruitment across the UK. Developed in collaboration with researchers and grounded in strong public and patient engagement, the service leverages routinely collected NHS health data to identify and contact potential participants for approved clinical research studies.</p> <p>The purpose of the draft Directions and supporting documents, is to make AGD aware that the NHS DigiTrials Recruitment Directions 2025 will replace the <a href="#">Pilot NHS DigiTrials Recruitment Support Services Directions 2021</a>, as the service transitions from pilot to a full service.</p> <p>NHS England were seeking advice on the following points:</p> <ol style="list-style-type: none"> <li>1. Note the draft Directions and Requirements Specification to transition to full-service directions.</li> <li>2. Provide any high-level concerns relating to the overall approach and current drafting, noting that these are drafts which will be subject to (at minimum) NHS England Privacy, Transparency and Trust (PTT) and Legal review before finalising.</li> </ol> <p><b>Outcome of discussion:</b> AGD welcomed the draft Directions and supporting documents and made the following observations / comments:</p> <p><b>In response to point 1 above:</b></p> <p><b>4.1.1</b> AGD noted the content of the draft Directions and Requirements Specification, and that these were for the purpose of transitioning from the <a href="#">Pilot NHS DigiTrials Recruitment Support Services Directions 2021</a> to full-service Directions.</p> <p><b>In response to point 2 above:</b></p> <p><b>4.1.2</b> AGD suggested that the draft Directions were reviewed and updated as may be appropriate, to ensure that the terminology was correct / aligned, for example, the reference to NHS DigiTrials being an NHS Data-Enabled Clinical Trials Service when it is providing support services not clinical trials.</p>

	<p><b>4.1.3</b> AGD noted in the 'Requirements Specification' document that there may be the possibility of organisations sending out invites themselves, as opposed to this being undertaken by the NHS DigiTrials Recruitment Service; and were provided with a verbal update by NHS England on the safeguards to support this. AGD were reassured by the safeguards NHS England had in place but would welcome such applications coming to AGD for advice.</p> <p><b>4.1.4</b> AGD noted the information in some of the supporting documents provided that e-mail invites would be issued; and suggested that this was reviewed and updated / aligned across all documentation, noting that this conflicted with information in other supporting documents provided.</p> <p><b>4.1.5</b> AGD noted the verbal update from NHS England in respect of the efforts made by the NHS DigiTrials Recruitment Service to not send invites out to deceased individuals, and noted that this process was kept under review.</p> <p><b>4.1.6</b> AGD were provided with a verbal overview from NHS England in respect of how applications for the NHS DigiTrials Recruitment Service would be prioritised; and advised that whilst they were supportive of the process outlined, there needed to be a clear and transparent process / criteria.</p> <p><b>4.1.7</b> AGD noted that patient and public involvement and engagement (PPIE) would be undertaken where any new or novel use cases arise; and suggested that there was also wider ongoing PPIE throughout the lifecycle of the work. The <a href="#">HRA guidance on Public Involvement</a> is a useful guide.</p> <p>In addition, AGD made the following observation on the documentation provided as part of the review:</p> <p><b>4.1.8</b> AGD noted that they were reviewing the documentation ahead of NHS England's Privacy, Transparency and Trust (PTT) and Legal services.</p> <p><b>4.1.9</b> AGD noted and commended NHS England on the quality of the information provided in the Directions / supporting documents, including, but not limited to the recruitment service evaluation, which supported the review.</p>	
<b>5 EXTERNAL DATA DISSEMINATION REQUESTS:</b>		
<b>5.1</b>	<p><b>Reference Number:</b> NIC-688223-X1W4R-v0.12</p> <p><b>Applicant:</b> University of Nottingham</p> <p><b>Data Controller:</b> University Hospitals of Derby and Burton NHS Foundation Trust</p> <p><b>Application Title:</b> "POSNOG - POSitive Sentinel NOde: adjuvant therapy alone versus adjuvant therapy plus Clearance or axillary radiotherapy. A randomised controlled trial of axillary treatment in women with early-stage breast cancer who have metastases in one or two sentinel nodes"</p> <p><b>Observer:</b> Suzanne Hartley</p> <p><b>Previous Reviews:</b> The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 6<sup>th</sup> March 2025.</p> <p><b>Application:</b> This was a new application.</p>	

<p>NHS England were seeking advice on the following points, including general advice on any other aspect of the application:</p> <ol style="list-style-type: none"> <li>1. Whether AGD would be supportive of the flow of data beyond five years for <u>all cohort members</u> and not restricted to those cohort members consented on version four onwards only.</li> </ol> <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 supportive of the flow of data for the five years after recruitment for the whole cohort; <b>and</b> were supportive of the flow of data beyond five years after their recruitment for those cohort members consented on version four onwards <b>only</b>, and wished to draw to the attention of the SIRO the following substantive comments:</p> <p>AGD noted that a briefing paper had been provided to the Group for this agenda item, in addition to the application / supporting documents.</p> <p><b>5.1.1</b> AGD noted the content of the briefing paper, which outlined the applicant's response in respect of whether the flow of data beyond five years after their recruitment applied to the whole cohort, or just for those cohort members consented on version four onwards only. The Group maintained their original position and reiterated their point raised on the 6<sup>th</sup> March 2025 minutes (5.2.1 / 5.2.2), that this applied to those cohort members consented on version four onwards only; and that it was unclear whether those cohort members consented on versions one to three, permitted the flow of data beyond five years.</p> <p><b>5.1.2</b> AGD suggested that the applicant might consider the following options <b>1)</b> seek s251 support from Health Research Authority Confidentiality Advisory Group (HRA CAG) for the flow of data beyond five years for those cohort members consented on versions one to three; <b>2)</b> reiterated their point raised on the 6<sup>th</sup> March 2025 minutes (5.2.3) to engage with a small group of cohort members (more than 5 but less than 10) consented on versions one to three, to test whether they would be surprised by the longer term follow-up; and establish that processing was still within the reasonable expectations of those cohort members based on the consent materials they saw at the time; or <b>3)</b> if option 2 is not possible, to engage with a mixed focus group of participants, to test whether they would be surprised by the longer term follow-up based on the consent documents.</p> <p><b>5.1.3</b> AGD suggested that <b>1)</b> as part of any patient and public involvement and engagement (PPIE), the applicant could determine what time limit on the follow-up data would align with the consent taken; and <b>2)</b> following any PPIE undertaken on the time limit for the follow-up data, that the applicant ensure that the privacy notice and any transparency materials were updated accordingly.</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>5.1.4</b> AGD noted and commended NHS England's Data Access Request Service (DARS) on the work undertaken on the responses to the previous AGD advice provided on the 6<sup>th</sup> March 2025.</p> <p><b>5.1.5</b> AGD advised that they would welcome a further review of this application as may be required by NHS England.</p>	
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	<p><b>5.1.6</b> No AGD member noted a commercial aspect to the application.</p>	
<b>5.2</b>	<p><b>Reference Number:</b> NIC-787193-Y8W6D-v0.5</p> <p><b>Applicant and Data Controller:</b> University of York</p> <p><b>Application Title:</b> “Health Educational Attainment and Research on Treatment Outcomes in Percutaneous Coronary Interventions (HEART-OP)”</p> <p><b>Observer:</b> James Watts</p> <p><b>Previous Reviews:</b> The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 31<sup>st</sup> July 2025.</p> <p>NHS England were seeking general advice on the application.</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 supportive of the application <b>if</b> the following substantive comments were addressed, and wished to draw to the attention of the SIRO the following substantive comments:</p> <p>AGD noted that as part of an NHS England Data Access Request Service (DARS) pilot (discussed at the AGD meeting on the 7<sup>th</sup> August 2025), the Group had been asked <b>not</b> to review the application for this item, and had instead been provided with a new NHS England DARS internal form that contained summary information that, once finalised, would be transferred into the usual data sharing agreement (DSA) template.</p> <p><b>5.2.1</b> AGD noted the complexity of the data linkage, and suggested that NHS England seek evidence that all relevant permissions were in place, including, but not limited to, the onward linkage of the component datasets of the UKMED such as the Higher Education Statistics Agency (HESA) data.</p> <p><b>5.2.2</b> AGD reiterated the point raised on the 31<sup>st</sup> July 2025 (5.2.6), in respect of UK General Data Protection Regulation (UK GDPR) transparency requirements for the UK Medical Education Database (UKMED); and noted that a privacy notice would be added to their website. AGD suggested the applicant was reminded that they were required to maintain a UK GDPR compliant, publicly accessible <b>study specific</b> transparency notice for the lifetime of the agreement, in line with the contractual requirement in section 4 (Privacy Notice) of the data sharing agreement (DSA).</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>5.2.3</b> AGD noted the response to the point raised on the 31<sup>st</sup> July 2025 (5.2.4), in respect of key stakeholder groups and engagement; and suggested that there was ongoing engagement with a wide range of stakeholder groups; and this may support the analysis in terms of accounting for variables.</p> <p><b>5.2.4</b> AGD noted in section 4.6 (comments of processing activities) reference to ‘Universities and Colleges Admissions Service’ (UCAS) data; and suggested that the stakeholders should also include those who were born or qualified overseas.</p>	

	<p><b>5.2.5</b> AGD noted the patient and public involvement and engagement (PPIE) undertaken in section 7 (PPIE), however suggested that, given the scope and scale of the project, further PPIE was undertaken, including, but not limited to, the project cohort.</p> <p><b>5.2.6</b> AGD noted the response to the point raised on the 31<sup>st</sup> July 2025 (5.2.5), that a Data Protection Impact Assessment (DPIA) had been produced / provided as a supporting document; however, suggested that the applicant ensure that the data subject rights outlined in this document were also reflected in the privacy notice.</p> <p><b>5.2.7</b> AGD noted that reference was made in the DPIA to opt-outs, and suggested that NHS England seek further clarification on <b>1)</b> who the opt-outs might be for, i.e. patients, Clinicians or both; and <b>2)</b> what, if any, the arrangements are for individuals wanting to opt-out.</p> <p><b>5.2.8</b> AGD suggested that section 4.5 (Processing Activities) was updated with a clear statement that the General Medical Council (GMC) would <b>not</b> be asked to re-identify any clinicians.</p> <p><b>5.2.9</b> AGD noted and commended NHS England's DARS and the applicant on the work undertaken on the responses to the previous AGD advice provided on the 31<sup>st</sup> July 2025.</p> <p><b>5.2.10</b> No AGD member noted a commercial aspect to the application.</p>	
<b>6 INTERNAL DATA DISSEMINATION REQUESTS:</b>		
<i>There were no items discussed</i>		
<b>7 EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL</b>		
<i>There were no items discussed</i>		
<b>8 OVERSIGHT AND ASSURANCE</b>		
<i>There were no items discussed</i>		
<b>9 AGD OPERATIONS</b>		
<b>9.1</b>	<p><b>Risk Management Framework</b></p> <p><i>This item was not discussed.</i></p>	
<b>9.2</b>	<p><b>AGD Stakeholder Engagement</b></p> <p><i>There were no items discussed.</i></p>	
<b>9.3</b>	<p><b>AGD Project Work</b></p> <p><i>There were no items discussed.</i></p>	
<b>10 Any Other Business</b>		
<b>10.1</b>	<i>There were no items discussed.</i>	

**Meeting Closure**

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