

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 3rd April 2025

09:00 – 12:15

(Remote meeting via videoconference)

AGD INDEPENDENT / NHS ENGLAND MEMBERS IN ATTENDANCE:	
Name:	Role:
Paul Affleck (PA)	AGD independent member (Specialist Ethics Adviser)
Eleanor Berg (EB)	NHS England member (Data Protection Office Representative (Delegate for Jon Moore))
Claire Delaney-Pope (CDP)	AGD independent member (Specialist Information Governance Adviser)
Arjun Dhillon (AD)	NHS England member (Caldicott Guardian Team Representative (Delegate for Dr. Jonathan Osborn)) (Items 1 to 5.1 and 7.1 to 10.1)
Kirsty Irvine (KI)	AGD independent member (Chair)
Narissa Leyland (NL)	NHS England member (Data and Analytics Representative (Delegate for Michael Chapman))
Dr. Jonathan Osborn (JO)	NHS England member (Caldicott Guardian Team Representative) (Items 1 to 5.4)
Jenny Westaway (JW)	AGD independent member (Lay Adviser)
Miranda Winram (MW)	AGD independent member (Lay Adviser)
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	Role / Area:
Ricky Brooks (RB)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.2)
Garry Coleman (GC)	NHS England SIRO Representative
Laura Evans (LE)	NHS DigiTrials, Data and Analytics, Transformation Directorate (Observer: item 5.1)
Joe Lawson (JL)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.3)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Delivery Directorate

Suzanne Shallcross	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.4)
Ross Thornton (RT)	Chief of Staff, Business Operations, Privacy, Transparency, and Trust (PTT), Delivery Directorate (Observer: items 1 to 10.2)
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)
Dr. Robert French (RF)	AGD independent member (Specialist Academic / Statistician Adviser)
Jon Moore (JM)	NHS England member (Data Protection Office Representative)

1	Welcome and Introductions: The AGD Chair welcomed attendees to the meeting.
2	Review of previous AGD minutes: The minutes of the AGD meeting on the 27 th March 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 King's College London (NIC-746522-Y4R7L University of Glasgow) as part of her role at South London and Maudsley NHS Foundation Trust. It was agreed this did not preclude Claire from taking part in the discussion on this application. Claire Delaney-Pope noted a professional link to King's Health Partners (NIC-765257-H7B7S University of Cambridge) as part of her role at South London and Maudsley NHS Foundation Trust (SLAM). It was agreed this did not preclude Claire from taking part in the discussion on this application. Paul Affleck noted a professional link to the University of Leeds but noted no specific connections with the application NIC-750163-K6F7T (University College London Hospitals NHS Foundation Trust) or staff involved, and it was agreed that this was not a conflict of interest.
4 BRIEFING PAPER(S) / DIRECTIONS:	
<i>There were no items discussed.</i>	
5 EXTERNAL DATA DISSEMINATION REQUESTS:	
5.1	Reference Number: NIC-614954-G8P7P-v0.4

<p>Applicant: University of Edinburgh</p> <p>Data Controllers: NHS Lothian and University of Edinburgh</p> <p>Application Title: "ASPIRING - Antiplatelet Secondary Prevention International Randomised Study After Intracerebral Haemorrhage - Recruitment Agreement"</p> <p>Observer: Laura Evans</p> <p>Application: This was a new application.</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 Data Uses Register.</p> <p>Outcome of discussion: AGD were supportive of the flow of data to send out the invitations only.</p> <p>AGD were not supportive of the flow of data to support the performance uptake report at this time due to the limited information provided around the legal basis and wished to draw to the attention of the SIRO the following substantive comment:</p> <p>5.1.1 In respect of the performance uptake report, AGD discussed and noted that identifiers would need to flow to NHS England for linkage, to identify which type of letter had been sent to the participant and were advised by NHS England that the legal basis for this was consent. AGD suggested that 1) NHS England satisfy themselves that the consent materials provide a legal basis for this flow of data; and 2) if the consent materials are not clear, that the consent / patient information is updated as may be necessary.</p> <p>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.1.2 AGD noted that the s251 support outlined in the letter dated the 12th August 2024 (SD4.0) was for <i>"approximately 50,000 patients..."</i> to be identified and contacted; however, noted that section 5(a) (Objective for Processing) states <i>"NHS England may identify further eligible individuals to be contacted...should the recruitment target not be met"</i>. The Group suggested that section 5(a) was reviewed and updated to accurately align with the s251 support, noting that if the number of invites significantly exceeds 50,000, then this would require a further review by the Health Research Authority Confidentiality Advisory Group (HRA CAG).</p> <p>5.1.3 AGD queried if the recruitment target was met, whether the processing of the data would stop; and suggested that NHS England seek clarification from the applicant, and update the application as appropriate.</p> <p>5.1.4 AGD noted the HRA CAG conditions of support outlined in the letter dated the 12th August 2024 (SD4.0), and noting that two of the conditions were time specific (to be addressed within one-month), the Group suggested that the applicant provide NHS England with evidence that these conditions had been satisfactorily addressed, and that the documentation be uploaded to NHS England's customer relationship management (CRM) system.</p> <p>5.1.5 AGD noted that the sign-up letters provided as supporting documents (SD6.1a and SD6.1b) state that individuals would not be contacted about the study again if they did not respond to the initial letter. Notwithstanding the relevant support already in place for sending</p>	
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<p>the letters, the Group advised that this restrictive text would not currently permit reminder letters to be issued, and suggested that NHS England bring this to the attention of the applicant.</p> <p>5.1.6 In addition, AGD noted that the sign-up letters (SD6.1a and SD6.1b) incorrectly state that <i>“NHS England received legal permission to invite people from the Health Research Authority”</i>; and suggested that this was updated to correctly state that the applicant / Study Team had received legal permission.</p> <p>5.1.7 AGD noted the statement in section 5(a) of the application <i>“ASPIRING is performing a Study Within a Trial (SWAT) to evaluate the uptake of participants to the study, based on the invitation letter received”</i>; and advised that notwithstanding previous comments made on this type of arrangement, the sign-up letters (SD6.1a and SD6.1b) which referred to the research as <i>“life changing”</i>, may warrant a review. One AGD independent Specialist Adviser suggested that the reference to the research being <i>“life changing”</i> was inappropriate and pre-judging the results of the study.</p> <p>5.1.8 In addition, AGD suggested that further ‘criteria for success’ are included when reviewing versions of the invitation letter, that could include 1) assessing the comprehension as to the purpose of the study; and 2) understanding the motivation of participants when joining the study.</p> <p>5.1.9 AGD suggested that the applicant update the patient information sheet to ensure that it was clear what the options were for withdrawing from the study, which should contain at least two methods of contact for participants (post, telephone and / or e-mail).</p> <p>5.1.10 AGD suggested that if there was scope for the applicant to review how the levels of identifiability are described in the participant materials, that it may be useful to refer to the recently published Information Commissioner’s Office (ICO) guidance on anonymisation.</p> <p>5.1.11 AGD noted the statement in section 5(a) <i>“Where the number of potential invitees is less than the population available, invoking a system to choose invitees at random”</i>; and asked that this was clarified, for example, if more people meet the criteria than the number of intended invitations, individuals will be selected at random to receive an invitation.</p> <p>5.1.12 AGD suggested that the application was updated throughout, to accurately reflect that ‘PSL Print Management Ltd’ and ‘Datagraphic Ltd’ are sub-Data Processors.</p> <p>5.1.13 Separate to this application and for NHS England to consider: the NHS England SIRO Representative highlighted (and AGD agreed) that statements within Data Sharing Agreements regarding sub-processing arrangements may constrain future changes between NHS England and companies providing printing and invitation services.</p> <p>5.1.14 AGD noted the statement in section 5(b) (Processing Activities) that <i>“Access is restricted to substantive employees of NHS England and Datagraphic Ltd only”</i>; and suggested that if it was intended that only substantive employees could carry out the various actions then this would also need to be reflected in the existing data processing agreements; or if this was incorrect, then section 5(b) should be updated to reflect the correct / factual information.</p> <p>5.1.15 AGD suggested that for the purpose of transparency, the study website was updated to include a link to the NHS England DigiTrials webpage.</p>	<p>SIRO Rep</p>
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	<p>5.1.16 AGD suggested that section 2(c) (Territory of Use) was updated to align with the flows of data outlined in the application, to reflect that the territory of use is “UK” and not “England and Wales”.</p> <p>5.1.17 AGD noted and commended the PPIE undertaken by the applicant to date, including the work undertaken by the Patient Advisory Group.</p> <p>5.1.18 No AGD member noted a commercial aspect to the application.</p>	
5.2	<p>Reference Number: NIC-746522-Y4R7L-v0.13</p> <p>Applicant and Data Controller: University of Glasgow</p> <p>Application Title: “Follow-up of clinical outcomes, healthcare episodes and prescriptions in individuals with microvascular angina: The PRIZE Registry”</p> <p>Observer: Ricky Brooks</p> <p>Application: This was a new application.</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 Data Uses Register.</p> <p>Outcome of discussion: AGD were supportive of the application if the following substantive comments were addressed, and wished to draw to the attention of the SIRO the following substantive comment:</p> <p>5.2.1 AGD suggested that the application and the NHS England Data Access Service (DAS) internal application assessment form were reviewed and updated / aligned to be clear that there will be no data flowing for a participant who has withdrawn their consent.</p> <p>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.2.2 AGD suggested that section 3(b) (Additional Data Access Requested) was reviewed and updated as may be necessary to ensure the ‘identifiability’ fields were correct.</p> <p>5.2.3 AGD noted the references to “English” individuals / participants in section 5(a) (Objective for Processing); and suggested that these were updated to refer to refer to “people who reside in England” or similar.</p> <p>5.2.4 AGD suggested that section 5(a) was updated to be clear that ‘The Precision Medicine With Zibotentan in Microvascular Angina’ (PRIZE) Registry, is not a subset of another Registry and is ‘the registry’ referred to in the application.</p> <p>5.2.5 AGD noted the statement in section 5(b) (Processing Activities) of the application “There will be no requirement and no attempt to reidentify individuals...”; and suggested that there may be instances where it would be beneficial to re-identify individuals, for example in respect of patient safety. It was suggested that this was reviewed and updated as may be necessary to reflect the correct information; or that the statement was removed.</p> <p>5.2.6 AGD queried the references in section 5(b) to remote access taking place in “secure locations”; and suggested that this was reviewed and updated, for example, to refer to the security of the remote connection and/or to the nature of the physical location.</p>	

	<p>5.2.7 AGD queried the statement in section 5(b) “<i>Access is restricted to employees or agents of...</i>” and suggested that that either further information was provided as to who would be covered by “<i>agents</i>”; or that this word was removed as may be necessary to reflect the facts, noting that this did not align with section 5(a) that referred to “<i>substantive employees</i>” of the University of Glasgow reviewing the data.</p> <p>5.2.8 AGD noted and commended the work undertaken by NHS England’s Data Access Service (DAS) on the review of the commercial aspects of the application in line with NHS England DAS Standard for Commercial Purpose, which supported the review of the application.</p> <p>5.2.9 AGD suggested that section 5(e) (Is the Purpose of this Application in Anyway Commercial) was updated to reflect that there are commercial aspects to the application, in line with NHS England DAS Standard for Commercial Purpose.</p> <p>5.2.10 AGD noted that there was a commercial aspect to the application.</p>	
5.3	<p>Reference Number: NIC-750163-K6F7T-v0.4</p> <p>Applicant and Data Controller: University College London Hospitals NHS FT</p> <p>Application Title: “What clinical outcomes are associated with the 'joint care' proposed by NHS England for Teenagers and Young Adults with cancer (BRIGHTLIGHT-2021)”</p> <p>Observer: Joe Lawson</p> <p>Application: This was a new application.</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 Data Uses Register.</p> <p>Outcome of discussion: AGD were supportive of the application and wished to draw to the attention of the SIRO the following comments:</p> <p>5.3.1 AGD suggested that section 5(a) (Objective for Processing) was updated for transparency, to refer to the s251 support / legal basis.</p> <p>5.3.2 AGD suggested that section 3 (Datasets Held / Requested) was updated to clarify how the common law duty of confidentiality is addressed.</p> <p>5.3.3 AGD noted the incorrect reference in section 3(b) (Additional Data Access Requested) to “<i>UK General Data Protection Regulation (UK GDPR) consent</i>”, and suggested that this was removed.</p> <p>5.3.4 AGD suggested that a special condition was added to section 6 (Special Conditions) to reflect the Health Research Authority Confidentiality Advisory Group (HRA CAG) condition of support in relation to data deletion.</p> <p>5.3.5 AGD noted that section 5(a) contained a list of organisations involved with the study; and noting the duplication, suggested that one of the two references to the University of Leeds was removed.</p> <p>5.3.6 AGD queried the references in section 5(b) (Processing Activities) to remote access taking place in “<i>secure locations</i>”; and suggested that this was reviewed and updated, for</p>	

	<p>example, to refer to the security of the remote connection and/or to the nature of the physical location.</p> <p>5.3.7 AGD queried the statement in section 5(b) “<i>Access is restricted to employees or agents of...</i>” and suggested that either further information was provided as to who would be covered by “agents”; or that this word was removed as may be necessary to reflect the facts, noting that this did not align with section 5(a) that referred to “researcher <i>substantively employed...</i>” by University College London.</p> <p>5.3.8 AGD noted that there was a commercial aspect to the application.</p>	
5.4	<p>Reference Number: NIC-765257-H7B7S-v0.10</p> <p>Applicant: University of Cambridge</p> <p>Applicant and Data Controller: Cambridge University Hospitals NHS FT and University of Cambridge</p> <p>Application Title: “Barrett’s oESophagus Trial 3 (BEST3): oesophagus: A Randomized Controlled Trial Comparing the Cytosponge:TFF3 test with usual care to facilitate the diagnosis of Oesophageal pre cancer in primary care”</p> <p>Observer: Suzanne Shallcross</p> <p>Application: This was a new application.</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 Data Uses Register.</p> <p>Outcome of discussion: AGD were supportive of the application if the following substantive comments were addressed, and wished to draw to the attention of the SIRO the following substantive comments:</p> <p>5.4.1 AGD suggested that section 5(a) (Objective for Processing) was updated, to 1) be clear on the historical involvement of Medtronic Limited, including, but not limited to, the support provided in kind for the current study; 2) any wider involvement of Medtronic Limited; and 3) the potential commercial benefits of the study to the applicant, Medtronic Limited and / or any other relevant companies or Intellectual Property (IP) holders, in line with NHS England DAS Standard for Commercial Purpose.</p> <p>5.4.2 AGD suggested that section 5(e) (Is the Purpose of this Application in Anyway Commercial) was updated to reflect that there are potential commercial aspects, in line with NHS England DAS Standard for Commercial Purpose.</p> <p>5.4.3 AGD suggested that section 5(a) and section 5(e) were updated with an assessment of the balance between public and commercial benefit, in line with the National Data Guardian (NDG) guidance on benefits</p> <p>5.4.4 AGD noted the 10-year follow-up of participants, and discussed whether the consent taken provided a legal basis for this; and agreed that it would be reasonable for the data to flow. Notwithstanding the information already available, AGD suggested that transparency materials were reviewed and updated as may be necessary, to be clear on 1) the breadth of data being processed; and 2) the length of the follow-up.</p>	

	<p>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.4.5 AGD noted and commended the work undertaken by NHS England's Data Access Service (DAS) on the potential commercial aspects of the application in line with NHS England DAS Standard for Commercial Purpose.</p> <p>5.4.6 AGD noted the statement in section 5(b) of the application "<i>There will be no requirement and no attempt to reidentify individuals...</i>"; and suggested that there may be instances where it would be beneficial to re-identify individuals, for example in respect of patient safety. It was suggested that this was reviewed and updated as may be necessary to reflect the correct information; or that the statement was removed.</p> <p>5.4.7 AGD noted the three committees referenced at the end of section 5(a), and suggested that further information was added to be clear that the three committees have now disbanded, and are not part of the ongoing governance process.</p> <p>5.4.8 AGD noted that there was a commercial aspect to the application.</p>	
6 INTERNAL DATA DISSEMINATION REQUESTS:		
<i>There were no items discussed</i>		
7 EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL		
7.1	<p>Reference Number: NIC-338864-B3Z3J-v5.4</p> <p>Applicant: Barts and the London School of Medicine and Dentistry</p> <p>Data Controller: Queen Mary University of London</p> <p>Application Title: "Genes and Health"</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 18th May 2023.</p> <p>The application and relevant supporting documents were previously presented / discussed at the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) meetings on the 15th July 2021, 6th May 2021 and the 29th October 2020.</p> <p>The SIRO approval was for the continued territory of use to include the European Economic Area (EEA), with a request for the application to be brought back to a future AGD meeting.</p> <p>Outcome of discussion: AGD noted that the NHS England SIRO had already provided SIRO approval and confirmed that they were supportive of this.</p> <p>AGD thanked NHS England for the written update and made the following observations on the documentation provided:</p> <p>7.1.1 AGD noted that whilst they supported the SIRO approval for the continued territory of use to include the EEA, concern was raised on 1) the three-year term of this iteration of the data sharing agreement (DSA); 2) that this had not been submitted for an AGD review prior to progressing, noting the number of previous comments / issues raised by AGD and IGARD previously; and 3) it was unclear how the previous points raised had been addressed.</p>	

	The NHS England SIRO representative thanked AGD for their time and asked that this application be included in the relevant workstream of AGD's forthcoming oversight and assurance cycle.	AGD Sec
7.2	<p>Reference Number: NIC-748653-S9J4H-v0.5</p> <p>Applicant and Data Controller: Office for National Statistics (ONS)</p> <p>Application Title: "Waiting List Minimum Data Set (WLMDs) - for the purposes of Statistics and Statistical Research, under section 45 of the Statistics and Registration Services Act 2007 as amended by the Digital Economy Act 2017"</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 16th January 2025, 24th October 2024 and the 9th May 2024.</p> <p>Linked Application: This application is linked to NIC-748645-R5G3D.</p> <p>The SIRO approval was for the Waiting List Minimum Datasets.</p> <p>Outcome of discussion: AGD noted that the NHS England SIRO had already provided SIRO approval and confirmed that they were supportive of this.</p> <p>AGD thanked NHS England for the written update and made the following observations on the documentation provided:</p> <p>7.2.1 AGD noted that, as per previous AGD advice, a patient and public involvement and engagement (PPIE) plan / report had been provided to NHS England by ONS. AGD noted the PPIE work undertaken and planned to support future work by ONS.</p> <p>The NHS England SIRO representative thanked AGD for their time.</p>	
8 OVERSIGHT AND ASSURANCE		
<i>There were no items discussed</i>		
9 AGD OPERATIONS		
9.1	<p>Risk Management Framework</p> <p>AGD has been previously informed that a risk management framework is being developed by Data Access and had commented on early thinking about such a Framework. Nonetheless, presently AGD were still operating using the precedent and standard framework as an interim arrangement since February 2023 and AGD were concerned that the permanent Risk Management Framework was not in place. The Group discussed the NHS England corporate risk management framework (see minutes of 14th November 2024) and the AGD Chair subsequently formally asked via email if the NHS England corporate risk management framework could be used. The NHS England SIRO Representative updated the Group that NHS England was still considering the request, including how the NHS England corporate risk management framework could be adapted for AGD.</p> <p>ACTION: The NHS England SIRO Representative to provide a written response to AGD on the progress, and expected time frame for implementation, of the risk management framework.</p>	SIRO Rep

9.2	<p>Standard Operating Procedures (SOPs)</p> <p>The ongoing forward plan of work for creating the AGD Standard Operating Procedures was discussed.</p> <p>The Group noted that the ‘AGD member Declaration of Interest’ was in the process of being finalised, and a further update on this would be provided in due course, and published on the AGD webpage.</p> <p>AGD queried if the review of the AGD Terms of Reference, forwarded to the Director of Privacy and Information Governance on the 14th March 2025 had been considered and asked that an update be provided as to next steps.</p> <p>ACTION: NHS England SIRO Representative to update the Group at a future AGD Meeting.</p>
9.3	<p>AGD Stakeholder Engagement</p> <p>Federated Data Platform</p> <p>A brief update was given by the Group’s Representative on the Federated Data Platform Data Governance Group.</p>
9.4	<p>AGD Project Work</p> <p><i>There were no items discussed.</i></p>
<p>10 Any Other Business</p>	
10.1	<p>AGD Recruitment (update from Garry Coleman)</p> <p>The SIRO Representative advised the Group that recruitment to roles had closed on the 23rd March 2025 and that shortlisting had been completed across the roles of Chair, Clinician, Researchers and Adult Social Care.</p> <p>Garry noted that due to recent NHS England announcements and operational reasons, the vacancy for Lay Adviser and Adult Social Care Specialist Adviser positions have been removed from the recruitment.</p> <p>Garry noted that interviews for the Research/Academic and Clinician roles would take place on the 14th and 15th April 2025 and that the Chair interview dates were still to be confirmed.</p>
10.2	<p>NHS Notify Service Directions 2025 and National Proxy Service Directions 2025</p> <p>AGD noted that they had been advised by NHS England’s Privacy, Transparency and Trust (PTT) colleagues that the NHS Notify Service Directions 2025 and National Proxy Service Directions 2025 had been published on the 27th March 2025.</p> <p>AGD thanked PTT colleagues for sharing this information.</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>	