

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 13th November 2025

09:00 – 15:10

(Remote meeting via videoconference)

AGD INDEPENDENT / NHS ENGLAND MEMBERS IN ATTENDANCE:	
Name:	Role:
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)
Kirsty Irvine (KI)	AGD independent member (Chair)
Dr. Jonathan Osborn (JO)	NHS England member (Caldicott Guardian Team Representative)
Andy Rees (AR)	NHS England member (Data and Analytics Representative (Delegate for Michael Chapman))
Jenny Westaway (JW)	AGD independent member (Lay Adviser)
Miranda Winram (MW)	AGD independent member (Lay Adviser)
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	Role / Area:
Jack Bennett (JB)	NHS DigiTrials, Data and Analytics, Transformation Directorate (Presenter / Observer: item 4.1)
Ayse Depsen	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.3)
Dickie Langley (DL)	NHS England SIRO Representative (delegate)
Madeline Laughton	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: items 5.1 and 5.2)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Deputy Chief Executive Directorate
James Watts	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.1)
Emma Whale	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: items 5.4 and 5.5)

Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Deputy Chief Executive Directorate
INDEPENDENT ADVISER OBSERVERS IN ATTENDANCE	
Dr Jon Fistein (JF)	AGD independent adviser
AGD INDEPENDENT MEMBERS / NHS ENGLAND MEMBERS <u>NOT</u> IN ATTENDANCE:	
Name:	Role / Area:
Paul Affleck (PA)	AGD independent member (Specialist Ethics Adviser)
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 6 th November 2025 were reviewed and, after minor amendments, were agreed as an accurate record of the meeting.
3	Declaration of interests: <p>Andy Rees noted a professional link to the 'DigiTrials Recruitment Service - Invitation Letter Standards' due to his NHS England role as NHS DigiTrials and Research Products Operations Manager; it was agreed that the item would be discussed / reviewed as per usual process and that this was not a conflict of interests.</p> <p>Kirsty Irvine noted a professional link to NIC-44356-Y8N6R as part of her role at the Royal College of Obstetricians and Gynaecologists; but noted no specific connection with the application or staff involved, and it was agreed that this was not a conflict of interest.</p> <p>Dr. Jon Fistein noted a professional link to the University of Leeds but noted no specific connections with the application (NIC-766571-T4Z2L), or staff involved, and it was agreed that this was not a conflict of interest.</p> <p>Claire Delaney-Pope noted a professional link to King's Health Partners (NIC-696708-J3L1R) King's College London) 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.</p>
4 BRIEFING PAPER(S) / DIRECTIONS:	
4.1	Title: DigiTrials Recruitment Service - Invitation Letter Standards

Presenter / Observer: Jack Bennett

The NHS DigiTrials Team has been working to streamline operational processes and establish a reusable precedent for NHS DigiTrials Recruitment Service Data Sharing Agreements (DSAs). This includes developing standardised approaches that reduce complexity and ensures consistency across projects.

At the AGD meeting on the 12th June 2025, AGD supported a Precedent for NHS DigiTrials Recruitment Service DSA applications; as part of this Precedent, and to promote a standardised approach to invitation letters, AGD recommended further work be undertaken to create an invitation standard to uphold minimum information standards across recruitment invitation letters.

Under the new NHS DigiTrials Recruitment Service Directions, not all customers will require a DSA. To support these new Service Directions, invitation letters will be assessed against the new invitation standard which will form part of the NHS DigiTrials Precedent.

NHS England were seeking advice on the following points:

1. Note the development of a letter standard.
2. Provide comments and any further advice relating to the letter standard and overall approach.

Outcome of discussion: AGD welcomed the briefing paper and supporting documents, and made the following observations / comments:

In response to point 1 above:

4.1.1 AGD noted and thanked NHS England colleagues for the papers provided in advance of the meeting, including, but not limited to, the NHS DigiTrials Recruitment Service letter standard; and advised that they were supportive of the proposed approach.

4.1.2 AGD noted that to support the development of the NHS DigiTrials Recruitment Service letter standard, that a workshop had taken place on the 18th August 2025, with the NHS England SIRO Representative and the AGD NHS England Caldicott Guardian Team Representative.

In response to point 2 above:

4.1.3 AGD advised that it was difficult to identify and mitigate all of the possible risks to NHS England, given the scale of the letters that could be issued. The Group identified some possible risks, including but not limited to **1)** damaging enthusiasm for participating in research; **2)** reputational risk to NHS England; **3)** causing offence or distress; **4)** any potential founded or unfounded allegations of undue inducement or coercion.

4.1.4 AGD suggested that the NHS DigiTrials invitation letter template was updated to **1)** clearly set out the purpose of the trial / study; **2)** to add an additional question to the assessment in respect of whether the potential benefits were fairly portrayed, i.e. were not hyperbolic; **3)** to remove the reference to “financial” incentive and just refer to an “incentive” aligning with and refer to the Health Research Authority (HRA) [guidance](#) on ‘Payments and Incentives in Research’; **4)** to add further consideration into the assessment about how any commercial aspects should be highlighted (in addition to directing potential participants to a website) and **5)** that further points picked up by the AGD independent lay members advised would be shared with NHS England out of committee.

	<p>4.1.5 In addition, the Group suggested that NHS England consider what steps could be taken to enable potential participants to directly contact someone, for example, if they needed further clarity / reassurance as to why they have received a letter; or a rectification was required if an individual had received the letter in error. The Group suggested that Annex 1 of the NHS DigiTrials invitation letter template was updated with any supporting information on this point.</p> <p>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>4.1.6 AGD advised that they would support any aspect of this work coming back for a further review at a future AGD meeting as may be required, and as this work develops.</p> <p>4.1.7 AGD agreed with the proposal that the first three instances of the finalised standard being used to assess an NHS DigiTrials invitation letter would come to AGD for review.</p>	
5 EXTERNAL DATA DISSEMINATION REQUESTS:		
5.1	<p>Reference Number: NIC-44356-Y8N6R-v9.6</p> <p>Applicant: Royal College of Obstetricians and Gynaecologists (RCOG)</p> <p>Data Controllers: Healthcare Quality Improvement Partnership (HQIP) and NHS England</p> <p>Application Title: “National Maternity and Perinatal Audit (NMPA)”</p> <p>Observers: Madeline Laughton and James Watts</p> <p>Linked applications: This application is linked to NIC-752925-P6Y2W.</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 23rd May 2024.</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 18th February 2021, 20th December 2018, 26th July 2018, 5th July 2018, 11th May 2017 and the 27th April 2017.</p> <p>Application: This was an amendment application.</p> <p>NHS England were seeking advice on the following points only:</p> <ol style="list-style-type: none"> 1. The amendment to enable linkage with data from the National Neonatal Audit Programme (NNAP). <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>AGD noted that they had been provided with a curated set of documentation and noted that they would be providing observations based on these documents.</p> <p>In response to point 1 above:</p> <p>5.1.1 AGD were supportive of the amendment as outlined in the documentation provided.</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 prior to the meeting, NHS England had shared additional information, confirming that no identifiers were now flowing between the two audits under this amendment request. AGD noted the updated information, and suggested that the application was updated throughout to reflect that the status of pseudonymised data is accurately described.</p> <p>5.1.3 AGD noted the reference in section 5(c) (Specific Outputs Expected) to “<i>online interactive tables and graphs of the report’s results</i>”; and suggested that the purposes in section 5(a) (Objective for Processing) were expanded to also reflect this information.</p> <p>5.1.4 AGD noted the references section 5(b) (Processing Activities) to the data being accessed by “<i>authorised personnel</i>”; and suggested that this was updated with further clarification as to exactly who could access the data.</p> <p>5.1.5 No AGD member noted a commercial aspect to the application.</p>	
5.2	<p>Reference Number: NIC-787009-K8R3B-v0.2</p> <p>Applicant and Data Controller: Imperial College London</p> <p>Application Title: “The characterisation of patients with takotsubo cardiomyopathy from the Myocardial Ischaemia National Audit Project (MINAP)”</p> <p>Observer: Maddie Laughton</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>5.2.1 AGD noted that section 3 (Datasets Held / Requested) had not been updated to clarify how the common law duty of confidentiality had been addressed; and suggested that this was completed.</p> <p>5.2.2 In addition, AGD suggested the applicant was reminded that they were required to maintain a UK General Data Protection Regulation (UK GDPR) compliant, publicly accessible study specific 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>5.2.3 AGD welcomed the student access with the appropriate supervision, however, suggested that section 5(a) (Objective for Processing) and section 5(b) (Processing Activities) were reviewed and updated / aligned as appropriate, for example, noting that section 5(b) states that “<i>Access is restricted to employees or personnel of Imperial College London...</i>”.</p> <p>5.2.4 Separate to the application and action for NHS England SIRO Representative / AGD Secretariat: AGD advised that they would welcome a learning and development</p>	SIRO Rep /

	<p>session at a future AGD meeting on 'National Institute for Cardiovascular Outcomes Research' (NICOR) data, to support future reviews of applications.</p> <p>5.2.5 No AGD member noted a commercial aspect to the application.</p>	AGD Sec
5.3	<p>Reference Number: NIC-785335-G6D8R-v0.2</p> <p>Applicant and Data Controller: University of Surrey</p> <p>Application Title: "The role of inequalities in cancer care experience in mediating inequalities in cancer treatment receipt and time-to-treatment."</p> <p>Observer: Ayse Depsen</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 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 7th August 2025), the Group had been asked not to review the application for this item, and had instead been provided with a new NHS England DARS internal application form that contained summary information that, once finalised, would be transferred into the usual data sharing agreement (DSA) template.</p> <p>5.3.1 AGD noted the references in section 1.6 (other organisations involved) to other organisations involved with the research; and suggested that NHS England's DAS explore this further with the applicant, to clarify that they were not determining the purpose and means of processing and were therefore not carrying out any data controllership activities in line with the NHS England DARS Standard for Data Controllers; and that the application was updated as may be required to reflect the correct / factual information.</p> <p>5.3.2 AGD noted that the data is described as pseudonymised, however advised that the information in the NHS England DARS internal application form does not provide information on 1) who is carrying out the linkage; and 2) who is holding the unique identifier. AGD noted that if NHS England were carrying out the linkage and holding the unique identifier, then the data was correctly described as pseudonymised; however, if there was any other arrangement, then this may impact on the identifiability of the data and the legal basis for processing. AGD suggested that NHS England explore this further with the applicant, and that the application was updated as may be required to reflect the correct / factual information.</p> <p>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.3.3 AGD noted the timeframe being studied which spans the COVID-19 pandemic, and suggested that the application was updated with further clarification as to how this will be addressed / accounted for in the outputs.</p>	

	<p>5.3.4 AGD noted the references section 4.5 (processing activities) to the data being accessed by “<i>authorised personnel</i>”; and suggested that this was updated with further clarification as to exactly who could access the data.</p> <p>5.3.5 AGD noted that section 5.6 (transparency) referred to a generic privacy notice for the University of Surrey; and suggested the applicant was reminded that they were required to maintain a UK General Data Protection Regulation (UK GDPR) compliant, publicly accessible study specific 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>5.3.6 No AGD member noted a commercial aspect to the application.</p>	
5.4	<p>Reference Number: NIC-745296-R1J2M-v0.7</p> <p>Applicant and Data Controller: University of Liverpool</p> <p>Application Title: “Liverpool-Heart and bRain Project (L-HARP)”</p> <p>Observer: Emma Whale</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 research but were not supportive of the current application, requiring clarification with regard to whether or not the consent was compatible with the creation of artificial intelligence (AI) tools, and wished to draw to the attention of the SIRO the following substantive comments:</p> <p>5.4.1 Some of the AGD members felt that it was ambiguous as to whether or not the consent was compatible with the creation of AI tools; and suggested that 1) the applicant provide additional transparency to participants; and 2) the applicant undertake some patient and public involvement and engagement (PPIE) with a selection of the cohort (more than 5 but fewer than 10) to determine if they would be surprised on the AI aspects of the research.</p> <p>5.4.2 AGD also suggested that the consent / transparency materials were updated to be clear on the planned creation of the AI tools, including, but not limited to 1) what AI tools are being created; 2) who owns the intellectual property generated; and 3) the involvement of any other organisation(s).</p> <p>5.4.3 AGD noted the references in the consent materials to participants being able to withdraw from the research, and advised that the consent / transparency materials should contain at least two methods of contact for participants (post, telephone and / or e-mail).</p> <p>5.4.4 AGD also noted references in the consent materials to “<i>NHS Digital</i>”, and suggested that this, along with any transparency materials was reviewed and updated to ensure that “<i>NHS England</i>” was correctly referred to.</p> <p>5.4.5 AGD noted the information in the application in respect of Bristol-Myers Squibb, however suggested that 1) further information was provided in section 5(e) (Is the Purpose of this Application in Anyway Commercial) to be clear that they will not directly monetise the results of the study; and 2) to update section 5(a) (Objective for Processing) to be clear that</p>	

	<p>Bristol-Myers Squibb develops treatments for stroke prevention, and there may aspects of the research outcomes that they may have an interest in, either now or in the future.</p> <p>5.4.6 AGD noted that the volume of funding from each funder was not clear in the NHS England Data Access Request (DARS) internal application assessment form; and suggested that further information was provided as this helps clarify potential influence on the project.</p> <p>5.4.7 Separate to the application: AGD noted that they had not been provided with a copy of the legal advice that supported NHS England's position that the National Data Opt-out (NDO) would not apply for those recruited via consultee advice; and reiterated a point previously made at the AGD meeting on the 25th September 2025 (see AOB item 10.1).</p> <p>5.4.8 AGD noted and thanked NHS England's Data Access Request Service (DARS) on the quality of the information / documentation provided in advance of the meeting, including, but not limited to, 1) the internal consent review; and 2) the questions posed to the applicant in respect of the use of AI.</p> <p>5.4.9 Separate to the application and for NHS England to consider: AGD suggested that the AGD NHS England Data and Analytics Representative discuss the source of the excellent AI questions asked by NHS England's DARS to the applicant on NIC-745296-R1J2M; and determine whether they could be included in the NHS England DARS internal application assessment form template.</p> <p>5.4.10 Given the points raised by the Group, the NHS England SIRO representative noted this application could not progress via delegated authority until such time that AGD had provided a further review on the updated application.</p> <p>5.4.11 AGD noted that there was a commercial aspect to the application.</p>	D&A Rep
5.5	<p>Reference Number: NIC-766571-T4Z2L-v0.8</p> <p>Applicant and Data Controller: University of Leeds</p> <p>Application Title: "Impact of an Intervention on Inequalities in Overprescribing - the 3i-o study"</p> <p>Observer: Emma Whale</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>5.5.1 AGD welcomed the application and noted that study was interesting and potentially impactful.</p> <p>5.5.2 AGD suggested that NHS England satisfies itself that all necessary honorary contracts are in place, and comply with the NHS England's DARS Standard for Honorary Contracts.</p>	

	<p>5.5.3 AGD noted the references to “<i>consenting GP practices</i>” in section 5(a) (Objective for Processing), and suggested that this was updated to remove the word “<i>consenting</i>”, and / or replace with “<i>supporting</i>” or “<i>participating</i>”.</p> <p>5.5.4 AGD noted the references in the application to “<i>North of England Care Support System (NECS)</i>”; and queried whether this should be amended to refer to ‘Data Services for Commissioners Regional Offices (DSCRO)’. AGD suggested that NHS England review and amend this as may be appropriate.</p> <p>5.5.5 AGD noted and supported the transparency being undertaken by the applicant above and beyond the posters in the GP Practices, including, but not limited to, the using the GP Practice websites and the innovative process of adding information to repeat prescription slips.</p> <p>5.5.6 AGD noted and commended the applicant on the excellent patient and public involvement and engagement (PPIE) undertaken to date.</p> <p>5.5.7 No AGD member noted a commercial aspect to the application.</p> <p>Subsequent to the meeting: The NHS England SIRO Representative noted that following the meeting, it had been noted that the dataflow diagram provided to the Group was inaccurate. It was noted that NHS England’s Data Access Request Service (DARS) are seeking clarification on this and will take the update to the NHS England SIRO Representative to determine whether the application should return to AGD for review, or can be approved directly.</p>	
6 INTERNAL DATA DISSEMINATION REQUESTS:		
<i>There were no items discussed</i>		
7 EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL		
<i>There were no items discussed</i>		
8 OVERSIGHT AND ASSURANCE		
8.1	<p>Oversight and Assurance Process (Workstream 2: Internal and external applications that have had an independent review in the last 6 months and been approved internally)</p> <p>The Statutory Guidance 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 AGD independent members were provided with 1) 12 applications (selected by the AGD Secretariat); 2) internal application assessment forms for each of the 12 applications; and 3) an oversight and assurance template to complete.</p> <p>Following review of the applications by the AGD independent members out of committee, the completed oversight and assurance templates were sent to the AGD Secretariat prior to the meeting.</p> <p>It was noted that only high-level points would be discussed in meeting (and noted in the minutes); however, the full suite of comments and feedback from AGD independent</p>	

	<p>members on the oversight and assurance templates would be collated by the AGD Secretariat and shared with the NHS England SIRO representative and relevant NHS England colleagues as may be appropriate.</p> <p>Please see appendix A for high-level points raised in-meeting on the 12 applications.</p>	
8.2	<p>Oversight and Assurance Conclusion / Review</p> <p>AGD noted this was the second oversight and assurance ‘workstream 2’ review undertaken (the first being 27th March 2025).</p> <p>The Group noted that whilst there were a number of applications that clearly communicated how the previous AGD comments had been addressed, the other applications fell into the following categories 1) previous AGD comments had not been adequately addressed; 2) it was unclear if / how previous AGD comments had been addressed; and 3) the response to the previous AGD comments could have been clearer.</p> <p>The Group provided some feedback for future reviews including, but not limited to 1) the preparation time of 10 minutes per application was sufficient if it was clear how AGD comments had been addressed; 2) having two independents and one AGD NHS England representative per application review would be sufficient; and 3) reviewing fewer applications per independent members could be more effective.</p> <p>The Group noted their disappointment that the process had not moved on since the initial review undertaken on 27th March 2025, those reiterated points including but not limited to 1) a lack of understanding amongst some NHS England colleagues that the AGD NHS England Data and Analytics representative is a part of AGD and agreed with the points of advice raised and recorded in the minutes; 2) NHS England colleagues are seemingly writing the responses to the AGD advice as though AGD will see those comments, (but they do not unless the application is picked for oversight and assurance); and 3) that if NHS England colleagues do not agree with the advice given by AGD to the NHS England SIRO, that they raise with the AGD NHS England Data and Analytics Representative and return to AGD under an AOB item. The Group asked that the AGD NHS England Data and Analytics Representative reiterate these points with colleagues in NHS England as a matter of urgency.</p> <p>The NHS England SIRO Representative noted that it was important for NHS England Data Access Request Service (DARS) to clearly articulate how the AGD advice had been considered across all points. The NHS England SIRO Representative noted that there was still room for improvement and thanked AGD and NHS England colleagues for the work undertaken to date, and asked that the advice on oversight and assurance was separated into feedback on the application and feedback on process (this is outlined in appendix A).</p>	
9 AGD OPERATIONS		
9.1	<p>Risk Management Framework</p> <p>The Group noted that the NHS England SIRO Representative had engaged with the Group out of committee following the AGD meeting on the 30th October 2025 in respect of the Risk Management Framework; and that a further update on this outstanding action would be provided as soon as possible.</p>	

	ACTION: The NHS England SIRO Representative to provide a written response to AGD on the progress at a future AGD meeting.	SIRO Rep
9.2	AGD Stakeholder Engagement <i>There were no items discussed</i>	
9.3	AGD Project Work <i>There were no items discussed</i>	
10 Any Other Business		
10.1	<p>Consultee / National Data Opt-Out (NDO)</p> <p>AGD noted that at the AGD meeting on the 31st July 2025, the NHS England SIRO Representative had advised the Group that it has been agreed with NHS England Legal and Policy colleagues that consultee advice that an individual should take part in a research project can override an NDO, as an NDO is not specific to the research project and therefore if a consultee considers that it would be in accordance with the individual's wishes and feelings for them to participate in the research, the view of the consultee should take preference.</p> <p>AGD members noted at the AGD meeting on the 25th September 2025, that this was not aligned with previous requests for data, and queried its compatibility with the Section 33(2)(b)(ii) safeguard in the Mental Capacity Act 2005, with regard to nothing being done to, or in relation to, the individual in the course of the research which would be contrary to any prior statement of the research participant of which the consultee is aware.</p> <p>AGD reiterated the point made on the 25th September 2025, that they had requested sight of the legal advice received on this matter, and that this was still outstanding. The NHS England SIRO Representative advised that this request was in progress, and that a further update would be provided at a future AGD meeting.</p> <p>ACTION: The NHS England SIRO Representative to provide an update on Consultee / National Data Opt-Out (NDO).</p>	SIRO Rep
10.2	<p>NHS England Patient & Public Involvement & Engagement (PPIE) Standard</p> <p>The Group queried the consideration by NHS England of a PPIE Standard, following discussion at AGD on the 24th July 2025 (see item 5.2.7) and asked for the NHS England SIRO Representative to provide an update at a future AGD meeting.</p>	SIRO Rep
10.3	<p>AGD Future Ways of Working</p> <p>The NHS England SIRO Representative noted that work was ongoing with regard to the AGD future ways of working and that further updates would be provided at the next plenary session of AGD on the 4th December 2025.</p>	SIRO Rep
<p>Meeting Closure</p> <p>As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.</p>		

Appendix A

Oversight and Assurance Review – 13th November 2025 (Workstream 2)

Ref:	NIC Number:	Organisation:	Areas to consider:
251113a	NIC-680303-Y3X4W-v0.6	University of Oxford	<p>The application had been seen by AGD on the 8th May 2025 where the Group had been supported if a number of substantive comments had been addressed.</p> <p>Feedback on application</p> <ul style="list-style-type: none"> Overall, the Group noted that there was little analysis of the responses made by the applicant and it was felt that the previous comments made by AGD had not been adequately considered, for example: <ul style="list-style-type: none"> Point 5.3.4 had been communicated to the applicant but it was unclear what changes had been made or followed up. Point 5.3.5 as above, it was unclear what changes had been made or follow up. Point 5.3.7 noted that the case officer did not agree with the removal of the word 'agent' however it was unclear if this was a department decision, noting the AGD NHS England D&A Representative agreed with the inclusion of the point. <p>Feedback on process</p>

			<ul style="list-style-type: none"> • Process point: Action for D&A Representative to ensure that it is clear in s1 of the DSA or in the SDa what documents were reviewed to make the decision with regard to the precedent route. • Process point: Action for AGD to be more explicit in how it gives its advice
251113b	NIC-671668-B4T0T-v1.2	The University of Manchester	<p>The application had been seen by AGD on the 15th May 2025 where the Group had been supported if a number of substantive comments had been addressed.</p> <p>Feedback on application</p> <ul style="list-style-type: none"> • Overall, the Group felt that the previous comments made by AGD had not been adequately considered, for example: <ul style="list-style-type: none"> ○ Point 5.1.1 noted that the AGD NHS England D&A Representative was to meet with the applicant, however there was no follow up as to whether this had happened or not. ○ Point 5.1.2 The response suggested that AGD had conflated programmatic standard with SDE access, however the point was that given there was still no programmatic standard (first raised by IGARD), the next best approach was via the SDE, rather than an extract. ○ Point 5.1.6 advice had been declined. ○ Point 5.1.7 advice had been declined.

			<ul style="list-style-type: none"> ○ Point 5.1.8 response did not detail what analysis had been undertaken in response. <p>Feedback on process</p> <ul style="list-style-type: none"> • Process point: Action for D&A Representative to ensure that it is clear in s1 of the DSA or in the SDa what documents were reviewed to make the decision with regard to the precedent route. • Process point: Action for D&A Representative to ensure that there is a clear narrative as to how each point of advice is being addressed
251113c	NIC-736873-X9F8V-v0.7	Imperial College London	<p>The application had been seen by AGD on the 5th June 2025 where the Group had been supported if a number of substantive comments had been addressed.</p> <p>Feedback on application</p> <ul style="list-style-type: none"> • The Group noted a risk that a decision had been made to flow data on draft minutes. <p>Feedback on process</p> <ul style="list-style-type: none"> • Process point: Action for D&A Representative to ensure that it is clear in s1 of the DSA or in the SDa what documents were reviewed to make the decision with regard to the precedent route. • Process point: Action for D&A Representative to ensure that if NHS England use the draft AGD minutes due to the urgency of the application, that the ratified minutes are subsequently added to the SDa, since

			there is no evidence the ratified minutes were responded to.
251113d	NIC-484452-H8S1L-v9.6	Department of Health and Social Care	<p>The application had been seen by AGD on the 12th June 2025 where the Group had not been providing advice on the wider application as requested and comments were limited to a specific point of advice.</p> <p>Feedback on application</p> <ul style="list-style-type: none"> No concerns were raised on how the previous AGD points had been addressed. <p>Feedback on process</p> <ul style="list-style-type: none"> Process point: Action for D&A Representative to ensure that it is clear in s1 of the DSA or in the SDa what documents were reviewed to make the decision with regard to the precedent route.
251113e	NIC-331142-P5K6M-v5.6	University of Bristol	<p>The application had been seen by AGD on the 26th June 2025 where the Group had not been providing advice on the wider application as requested and comments were limited to a specific point of advice.</p> <p>Feedback on application</p> <ul style="list-style-type: none"> No concerns were raised on how the previous AGD points had been addressed. <p>Feedback on process</p> <ul style="list-style-type: none"> Process point: Action for D&A Representative to ensure that it is clear in s1 of the DSA or in the SDa

			what documents were reviewed to make the decision with regard to the precedent route.
251113f	NIC-720122-Y6Q0Y-v0.10	University of Essex	<p>The application had been seen by AGD on the 3rd July 2025 where the majority of the Group had been supportive and a minority of the Group (one member) has not been supportive of the application at the time.</p> <p>Feedback on application</p> <ul style="list-style-type: none"> No concerns were raised on how the previous AGD points had been addressed. <p>Feedback on process</p> <ul style="list-style-type: none"> Process point: Action for D&A Representative to ensure that it is clear in s1 of the DSA or in the SDa what documents were reviewed to make the decision with regard to the precedent route.
251113g	NIC-564296-L7V1M-v0.22	Renal Registry	<p>The application had been seen by AGD on the 3rd July 2025 where the Group had been supportive for all cohort members except those recruited with the 2014 and 2016 consent materials, with substantive comments.</p> <p>Feedback on application</p> <ul style="list-style-type: none"> No concerns were raised on how the previous AGD points had been addressed. <p>Feedback on process</p> <ul style="list-style-type: none"> Process point: Action for D&A Representative to ensure that it is clear in s1 of the DSA or in the SDa

			<p>what documents were reviewed to make the decision with regard to the precedent route.</p> <ul style="list-style-type: none"> • Process point: Action for D&A Representative to ensure that where a point is not for DARS to respond to, that the team may wish to use “noted, but not for DARS to response to” or similar
251113h	NIC-366913-C2V5F-v4.4	National Institute for Health Research	<p>The application had been seen by AGD on the 3rd July 2025 where the majority of the Group had been supportive and a minority of the Group (one member) has not been supportive of the application.</p> <p>Feedback on application</p> <ul style="list-style-type: none"> • No concerns were raised on how the previous AGD points had been addressed. <p>Feedback on process</p> <ul style="list-style-type: none"> • Process point: Action for D&A Representative to ensure that it is clear in s1 of the DSA or in the SDa what documents were reviewed to make the decision with regard to the precedent route.
251113i	NIC-786702-B8R5P-v0.2	Sanius Health	<p>The application had been seen by AGD on the 10th July 2025 where the Group had been supportive with substantive comments.</p> <p>Feedback on application</p> <ul style="list-style-type: none"> • No concerns were raised on how the previous AGD points had been addressed. <p>Feedback on process</p>

			<ul style="list-style-type: none"> • Process point: Action for D&A Representative to ensure that it is clear in s1 of the DSA or in the SDa what documents were reviewed to make the decision with regard to the precedent route.
251113j	NIC-765457-R1Z0N-v0.4	University of Bristol	<p>The application had been seen by AGD on the 15th May 2025 where the Group had been supported if a number of substantive comments had been addressed.</p> <p>Feedback on application</p> <ul style="list-style-type: none"> • Overall the Group felt that the previous comments made by AGD had not been adequately considered, for example: <ul style="list-style-type: none"> ○ Point 5.4.2 response by DARS was raised in advance with the NHSE SIRO Representative, since it appeared the team had put in place a special condition to cover the disclosure of identifiable data rather than legal basis. ○ Point 5.4.4 there was no follow up within the SDa as to whether this had happened or not <p>Feedback on process</p> <ul style="list-style-type: none"> • Process point: Action for D&A Representative to ensure that it is clear in s1 of the DSA or in the SDa what documents were reviewed to make the decision with regard to the precedent route.
251113k	NIC-696708-J3L1R-v0.12	King's College London	<p>The application had been seen by AGD on the 24th July 2025 where the majority of the Group had been supportive</p>

			<p>and a minority of the Group (one member) has not been supportive of the application.</p> <p>Feedback on application</p> <ul style="list-style-type: none"> No concerns were raised on how the previous AGD points had been addressed. <p>Feedback on process</p> <ul style="list-style-type: none"> Process point: Action for D&A Representative to ensure that it is clear in s1 of the DSA or in the SDa what documents were reviewed to make the decision with regard to the precedent route.
251113I	NIC-773953-N5L3H-v0.2	Tolley Ltd	<p>The application had been seen by AGD on the 31st July 2025 where the majority of the Group had been supportive if the substantive points were addressed and a minority of the Group (one member) had not been supportive of the application.</p> <p>Feedback on application</p> <ul style="list-style-type: none"> Overall the Group felt that the previous comments made by AGD had not been adequately considered, for example: <ul style="list-style-type: none"> Point 5.1.1 response did not detail what analysis had been undertaken to assess, and instead the application summary had been copied into the SDa. In addition, the response to add narrative from section 5(e) to section 5(a) had been rejected, despite the fact that section 5(e) is not published on the data use register, but noted by

			<p>DARS that in future that section may be published.</p> <ul style="list-style-type: none"> ○ Point 5.1.9 response noted the advice to be of little significance in relation to transparency, however the Group suggested that the views of a diverse group of people on transparency were of value, and that the reason given for declining the advice was not adequate. <p>Feedback on process</p> <ul style="list-style-type: none"> • Process point: Action for D&A Representative to ensure that it is clear in s1 of the DSA or in the SDa what documents were reviewed to make the decision with regard to the precedent route.
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