Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 30th January 2025

09:00 – 16:10

(Remote meeting via videoconference)

AGD INDEPENDENT / NHS ENGLAND MEMBERS IN ATTENDANCE:	
Name:	**Role:**
Paul Affleck (PA)	AGD independent member (Specialist Ethics Adviser)
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)
Miranda Winram (MW)	AGD independent member (Lay Adviser)
Tom Wright (TW)	NHS England member (Data and Analytics Representative (Delegate for Michael Chapman))
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	**Role / Area:**
Garry Coleman (GC)	NHS England SIRO Representative (in attendance for items 5.4 to 11.1)
Lyndon Dibb (LD)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer:** items 5.4 and 5.5)
Dan Goodwin (DG)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Presenter:** items 7.1 and 7.2)

Andrew Ireland (AI)	Information Governance Specialist, IG Risk and Assurance, Privacy, Transparency, and Trust (PTT), Delivery Directorate (**Observer**: items 9.1 and 9.2)
Matilda Koroveshi (MK)	Senior Project Manager, NHS DigiTrials and Research Products, Data and Analytics (**Observer**: item 4.1)
Dickie Langley (DL)	NHS England SIRO Representative (Delegate for Garry Coleman) (In attendance for items 1 to 5.3 and 11.2)
Katy Lindfield (KL)	Policy Advisor, Data Policy Team, Transformation Directorate (**Presenter**: item 8)
Tom Lymn (TL)	Policy Advisor, Data Policy Team, Transformation Directorate (**Presenter**: item 8)
Nicki Maher (NM)	NHS England SIRO Representative (Delegate for Garry Coleman) (In attendance for items 1 to 5.3) Information Governance Lead, IG Assurance and Risk, IG Audit Services Lead (Interim), Privacy, Transparency, and Trust (PTT), Delivery Directorate (**Observer**: items 9.1 and 9.2)
Harry Millard (HM)	Information Governance Officer, IG Risk and Assurance, Privacy, Transparency, and Trust (PTT), Delivery Directorate (**Observer**: items 9.1 and 9.2)
Tess Morely (TM)	Senior Programme Manager, NHS DigiTrials and Research Products, Data and Analytics (**Presenter**: item 4.1)
Ellie Munari (EM)	Public Engagement Design Lead, Data Policy and Digital Oversight Team, Transformation Directorate (**Presenter**: item 8)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Delivery Directorate
Jodie Taylor-Brown (JTB)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer:** items 5.3 to 5.5)
Bethan Thomas (BT)	Assistant Director of Data Access & Partnerships: Head of Data Portfolio Management and IAO for EDI (**Observer**: item 4.1)
Joanne Treddenick (JT)	Information Governance Lead, Data and Analytics, Privacy, Transparency and Trust, Delivery Directorate (**Observer**: item 4.1)

James Watts (JW)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer:** item 5.6)
Emma Whale (EW)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer:** items 5.1 and 5.2)
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Delivery Directorate
AGD INDEPENDENT MEMBERS / NHS ENGLAND MEMBERS NOT IN ATTENDANCE:	
Name:	**Role / Area:**
Michael Chapman (MC)	NHS England member (Data and Analytics Representative)
Prof. Nicola Fear (NF)	AGD independent member (Specialist Academic 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 23rd January 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 South London and Maudsley NHS Foundation Trust named in the Equality, Diversity and Inclusion (EDI) in Health and Care Research Pilot Directions 2025 (item 2.1). It was agreed this did not preclude Claire from taking part in the discussion on this item. Claire Delaney-Pope noted a professional link to NIC-729560-F2F3S as part of her role within the South London and Maudsley NHS Foundation Trust. It was agreed that Claire would not be part of the discussion for this application and left the meeting for this part of the agenda. Paul Affleck, Claire Delaney-Pope, Dr. Robert French, Kirsty Irvine, Andrew Martin, Dr. Jonathan Osborn, Jenny Westaway, Miranda Winram, Tom Wright and Dickie Langley noted a professional link to a supervisor of the PhD student named in NIC-726391-M6D4Z (University of Oxford). While the supervisor was a member of AGD (not present at the meeting) it was discussed and agreed that as no member present had discussed this application with the AGD member, and as they were not present, this was not a conflict of interest.

	Jenny Westaway noted that she had undertaken some paid contract work for Templar Executives to provide training courses for Our Future Health. It was agreed this did not preclude the Jenny from taking part in the discussions about the Our Future Health application (NIC-414067-K8R6J). Jenny Westaway noted that she had some involvement with the subject matter of item 4 (opt-outs), through her National Data Guardian (NDG) role. It was agreed this did not preclude Jenny from taking part in the discussion.	
4 BRIEFING PAPER(S) / DIRECTIONS:		
4.1	**Title:** Equality, Diversity and Inclusion (EDI) in Health and Care Research Pilot Directions 2025 **Presenters:** Tess Morely **Observers:** Joanne Treddenick, Matilda Koroveshi and Bethan Thomas The purpose of the briefing paper, was to advise AGD on the EDI in Health and Care Research Pilot Directions 2025 The purpose of this data collection is to understand inclusion, representation and participation in health and care research, to ultimately improve access to good quality health and care. An EDI Pilot will enable the development and the provision of analytics and data products around equality, diversity, and inclusion in health and care research which will help funders, researchers, and the healthcare system to address these issues, and ultimately ensure their clinical trials are representative and inclusive. Initially, as part of the Pilot, data will only be made available to National Institute for Health and Care Research (NIHR) and the Department of Health and Social Care (DHSC), via aggregate small number suppressed dashboards. The Pilot will inform wider publication of research participation and diversity in the future. NHS England were seeking advice on the following points: 1. The Pilot Directions; 2. The risks identified in the Data Protection Impact Assessment (DPIA); 3. Advice on FAQs document. **Outcome of discussion:** AGD welcomed the briefing paper and made the following observations / comments: **4.1.1** AGD were supportive and noted the importance of the aims and objectives of the EDI in Health and Care Research Pilot Directions 2025. **In response to point 1 above:** **4.1.2** AGD queried what the specific benefits were of the Pilot Directions, and suggested that this was clarified within the relevant documentation, noting that this would support the overall purpose of the Pilot Directions.	

4.1.3 AGD noted that ethnicity data would **not** be collected as part of the pilot; and suggested that a brief explanation was provided as to why, within the relevant documentation (including the public-facing documentation).

4.1.4 AGD suggested that the relevant documentation was updated to make it clear as to exactly what data would be collected under the Pilot Directions, including, but not limited to, a definition / clarity on the 'administrative gender' data (it is unclear if this is a person's stated gender, biological sex at birth, or something else). It is important that consideration is given to **past** recording of 'sex' and 'gender' and prospective recording. Incorrect recording of these data points, or the misinterpretation of their intended meaning, may have an adverse effect on the clinical applicability of research findings, leading to an inaccurate assessment of the risk of developing a disease (both physical and mental) as the study may assume exposure (or lack thereof) of a person to specific risk factors (including testosterone) as a direct result of one or more of these codes. This could have direct clinical impact for an individual, or population, and therefore AGD would urge that this matter is given due consideration to prevent harm. Furthermore, if recording of 'sex' and gender' **is confused,** then work to investigate, and then address inequalities in health provision, may be based on flawed data.

4.1.5 AGD advised that the relevant documentation was updated to be clear on the requirement on the NHS Trusts taking part in the Pilot, in respect of transparency, for example, being specifically clear on their obligation to publish an updated privacy notice, in line with Caldicott Principle 8 and the UK General Data Protection Regulation (UK GDPR).

In response to point 2 above:

4.1.6 AGD noted the responsibility of the NHS Trusts taking part in the Pilot, to determine whether a Data Protection Impact Assessment (DPIA) was required, and to complete one if appropriate; and suggested that NHS England made this clear to NHS Trusts.

4.1.7 AGD queried whether all the benefits outlined in the DPIA provided as a supporting document, could be achieved at the Pilot stage; and suggested that this were reviewed and updated as may be necessary (in line with point 4.1.2).

In response to point 3 above:

4.1.8 AGD suggested that the FAQs were reviewed and updated as appropriate to ensure the points noted above were captured, including, but not limited, being clear on what data is / is not being collected, and clarifying what is meant by 'gender' data in line with point 4.1.4.

4.1.9 Separate to the briefing paper: AGD advised that they would welcome a further update / discussion on this area of work and next steps.

4.1.10 Separate to the briefing paper: the Caldicott Guardian Team Representative offered support to the team with regard to points made on gender / sex and ethnicity.

5 EXTERNAL DATA DISSEMINATION REQUESTS:		
5.1	**Reference Number:** NIC-726391-M6D4Z-v0.4 **Applicant and Data Controller:** University of Oxford **Application Title:** Long-term outcomes following traumatic brain injury: a retrospective cohort study **Observer:** Emma Whale **Application:** This was a new application. NHS England were seeking general advice on the application. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** AGD were supportive of the application and wished to draw to the attention of the SIRO the following comments: **5.1.1** AGD noted that they were unclear on the status of the archive and that they were **not** opining on the status of the archive with regard to the common law duty of confidentiality. **5.1.2** AGD queried whether the applicant's Caldicott Guardian/Data Protection Officer had supported the Public Records Act 1958 meeting the common law duty of confidentiality, and moving data to archive and this data being accessed; and suggested that NHS England explore this further with the applicant. **5.1.3** Noting this was a PhD study, AGD suggested that section 5 (Purpose / Methods / Outputs) was reviewed by the applicant, and updated to be clear on the potential / realistic benefits of this study; or that section 5 was updated to provide further information as to how the benefits outlined could be achieved, in line with NHS England DAS Standard for Expected Measurable Benefits. **5.1.4** AGD suggested that if this was an exploratory study, with further benefits that may be realised from subsequent research, that the applicant should highlight this in the application, with further information on potential next steps. **5.1.5** AGD suggested that the applicant update all documentation to be clear that the funding was for a PhD study as opposed to a wider University of Oxford initiative. **5.1.6** AGD queried if King's College London would be processing the data and suggested that NHS England discuss this further with the applicant, and the application was updated as may be necessary. **5.1.7** AGD noted that section 3 (Datasets Held / Requested) had **not** been populated to state how the common law duty of confidentiality had been addressed, and suggested that this was updated by the applicant to reflect the correct information.	

	5.1.8 AGD noted in section 5(a) (Objective for Processing) the statement that *"One in two people will experience a traumatic brain injury…"*; and suggested that this was reviewed by the applicant, and updated/justified as may be necessary. **5.1.9** AGD queried the references in section 5(b) (Processing Activities) 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. **5.1.10** AGD noted and commended the stakeholder engagement undertaken, including the involvement of at least one relative of a veteran; and applauded this as part of the PhD study. **5.1.11** No AGD member noted a commercial aspect to the application.	
5.2	**Reference Number:** NIC-730458-M8D6M-v0.9 **Applicant and Data Controller:** Royal Papworth Hospital NHS Foundation Trust **Application Title:** Prevalence of idiopathic ventricular fibrillation in England (PIVF) **Observer:** Emma Whale **Application:** This was a new application. NHS England were seeking general advice on the application. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **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: **5.2.1** AGD noted that the purpose of the application was for 'service evaluation', however, noted that some of the outputs in section 5(c) (Specific Outputs Expected) appeared to be for the purpose of research; and suggested the application was reviewed and updated by the applicant, for example, removing all references to 'research'. **5.2.2** AGD suggested that NHS England request evidence from the applicant that support from the Clinical Audit department has been provided, and to upload a copy to NHS England's customer relationship management (CRM) system. **5.2.3** AGD noted that the UK General Data Protection Regulation (UK GDPR) Article 9 condition cited in the application aligned with a research purpose, rather than the service evaluation purpose of the application and suggested that the applicant review this and update as necessary. **5.2.4** AGD suggested that section 7 (Ethics Approval) was updated by the applicant, to state that ethics approval was not required because the application was for service evaluation.	

	5.2.5 AGD noted the large quantum of data flowing under this application, and noted in the NHS England Data Access Service (DAS) internal application assessment form, that the applicant would be minimising the data upon receipt. It was suggested that the justification for this approach was outlined in section 5(b) (Processing Activities) for transparency.	
	5.2.6 ACTION: Separate to the application and for NHS England to consider: AGD reiterated the previous risks highlighted, in respect of excess data flowing and the reliance on the applicant to destroy data; and suggested that this could be incorporated into the NHS England consideration of the risks, checks and balances for the various modes of data access.	SIRO Rep / D&A Rep
	In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:	
	5.2.7 AGD suggested that section 2(c) (Territory of Use) was updated to reflect that the territory of use is *"England and Wales"* and not *"worldwide"*.	
	5.2.8 ACTION: For NHS England to consider: AGD noted, in the DAS internal application assessment form, that the applicant had considered accessing the data in NHS England's Secure Data Environment (SDE), however had opted for an extract instead, due to the significant difference in cost. The Group reiterated a previous suggestion that the NHS England Data and Analytics Representative discuss this with colleagues, in respect of continuing to explore all avenues to applicants accessing the SDE and how they can support this, including, but not limited to, acknowledging the transitional cost of asking users to use / pay for the SDE when they may have already invested in their own systems and infrastructure.	D&A Rep
	5.2.9 ACTION: For NHS England to consider: In addition, and in line with the Department of Health and Social Care (DHSC) Data Access Policy that states *"Secure Data Environments (SDEs) will become the primary route for accessing NHS data for research",* AGD queried at what point cost would **no longer** be a valid reason for an extract instead of using NHS England's SDE, and that NHS England should consider giving applicants a timeline; and suggested that the NHS England Data and Analytics Representative discuss this further with colleagues.	D&A Rep
	5.2.10 AGD noted that the application correctly states that the National Data Opt-out does not apply due to the data being pseudonymised; however, the supporting documents did not align and suggest they were reviewed by the applicant, and updated as may be necessary.	
	5.2.11 AGD noted that section 5(b) states that data will be accessed onsite at the premises of Royal Papworth Hospital NHS Foundation Trust only; and noting that whilst NHS England had already discussed this with the applicant, highlighted the restrictions with this arrangement.	
	5.2.12 AGD queried the statement in section 5(b) of the application *"Access is restricted to employees or **agents of**…"* 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. **5.2.13** AGD suggested that section 5(d) (Benefits) was updated by the applicant, to be clear that Royal Papworth Hospital NHS Foundation Trust is a speciality heart hospital, so the benefits may not necessarily be restricted to a small geographical area. **5.2.14** AGD suggested that there was ongoing PPIE throughout the lifecycle of the work. The HRA guidance on Public Involvement is a useful guide. **5.2.15** It was the view of AGD that there **was no** commercial aspect to the application.	
5.3	**Reference Number:** NIC-729560-F2F3S-v0.4 **Applicant and Data Controller:** King's College London **Application Title:** Twins' Early Development Study (TEDS): Medical Record Linkage **Observer:** Jodie Taylor-Brown **Application:** This was a new application. NHS England were seeking general advice on the application. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** AGD were supportive of the application and wished to draw to the attention of the SIRO the following comments: **5.3.1** AGD noted the Health Research Authority Confidentiality Advisory Group (HRA CAG) conditions of support for this application, and advised that they endorsed these, in particular condition 1, that support is provided for five-years from the date of final support, to allow the applicant time to complete the exit strategy, and gain consent from participants to undertake the proposed linkages; and condition 2, that it was reaffirmed, that the continued holding of identifiable information was clear within the annual newsletters to ensure all participants are aware of this. **5.3.2** AGD had an extensive discussion on the proposals to achieve the proposed outcomes of the study, and noted concern on the potential failure rate in matching with the proposed processing, and the risk of incorrect contact. AGD noted that the current application is for a limited cohort of 12,000 participants who do not have an updated address in the TEDS database, and, noting that it was beyond the scope of the advice requested, queried whether or not the existing HRA CAG support was expansive enough to cover the full cohort, to support a more comprehensive and robust update to the study, to be undertaken to the entire cohort. **5.3.3** AGD advised that they would be supportive of further processing and encouraged the applicant to give this further consideration, in updating the entire TEDS database as part of the study, to ensure a more robust mechanism achieving	

	correct matching as a basis for contact, in line with the HRA CAG support provided, and with the appropriate justifications. **5.3.4** AGD noted the efforts made and distinction in respect of engaging with *"active and less active"* participants but highlighted to the applicant, that even the *"less active"* participants would presumably have their details in the TEDS database, and therefore may be biased in favour of the acceptability of contact details being accessed. They would not be representing the views of those who have chosen to be inactive, and their views should not be presented in this way to establish the acceptability of the proposed processing. **5.3.5** AGD noted that this study is part of the UK Longitudinal Linkage Collaboration (LLC), and advised that further transparency to cohort members may be required. **5.3.6** The NHS England SIRO Representative (delegate) noted that the Personal Demographic Service (PDS) may not hold more up to date information for some individuals. **5.3.7** AGD encouraged the use of NHS numbers as a first line of matching, however, noted the verbal update from NHS England's Data Access Service (DAS) that this information is not available. **5.3.8** AGD noted and commended the work undertaken by NHS England's DAS, which supported the review of the application. **5.3.9** No AGD member noted a commercial aspect to the application.	
5.4	**Reference Number:** NIC-644891-N5T3S-v0.11 **Applicant and Data Controller:** University College London (UCL) **Application Title:** AspECT EXceL- Aspirin Esomeprazole Chemoprevention Trial-Consenting Subset of the Cohort **Observers:** Jodie Taylor-Brown and Lyndon Dibb **Linked applications:** This application is linked to NIC-776114-J7Q9J (item 5.5). **Application:** This was a new application. NHS England were seeking general advice on the application. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** AGD were supportive of the application and wished to draw to the attention of the SIRO the following comments: **5.4.1** AGD noted reference in the patient information sheet provided as a supporting document (SD3.0) to the data being retained and disposed of securely ten years after the trial has finished, and noted that there may be some ambiguity with this statement; and in line with the advice from NHS England's Data Access Service (DAS), the	

	applicant should produce and publish a privacy notice in line with NHS England DAS Standard for Transparency. **5.4.2** AGD noted that NHS England's DAS were still waiting for the applicant to send through a copy of the honorary contract for the Chief Investigator. The Group queried **1)** with regard to data controllership, whether the Chief Investigator who was on an honorary contract (with UCL) would be supervised by colleagues at UCL, and suggested that NHS England clarify with the applicant what the supervision arrangements are for the Chief Investigator; and **2)** given the Chief Investigator's Non-Executive Director role with the body who would be countersigning the honorary contract, suggested that it may not be possible for them to countersign the honorary contract, and suggested that NHS England DAS review the NHS England's DAS Standard for Honorary Contracts and determine whether a special provision may need to be made in this instance. **5.4.3** AGD noted that section 3(b) (Additional Data Access Requested) referred to the Medicines dispensed in Primary Care (NHSBSA) data as being *"non sensitive"*; and suggested that this was reviewed and updated to reflect the correct information. **5.4.4** AGD suggested that the *"exclusion criteria"* in section 5(a) (Objective for Processing) was reviewed and updated to refer to the s251 support, as outlined in the DAS internal application assessment form. **5.4.5** AGD suggested that section 5(b) (Processing Activities) was updated to reflect that the data will not *"leave"* England or Wales at any time. **5.4.6** AGD queried the references in section 5(b) of the application 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. **5.4.7** No AGD member noted a commercial aspect to the application.	
5.5	**Reference Number:** NIC-776114-J7Q9J-v0.3 **Applicant and Data Controller:** University College London (UCL) **Application Title:** AspECT EXceL- Aspirin Esomeprazole ChemopreventionTrial-Section 251 Subset of the Cohort **Observer:** Jodie Taylor-Brown and Lyndon Dibb **Linked applications:** This application is linked to NIC-644891-N5T3S (item 5.4). **Application:** This was a new application. NHS England were seeking general advice on the application. Should an application be approved by NHS England, further details would be made available within the Data Uses Register.	

	Outcome of discussion: AGD were supportive of the application and wished to draw to the attention of the SIRO the following comments: **5.5.2** AGD noted that NHS England's DAS were still waiting for the applicant to send through a copy of the honorary contract for the Chief Investigator. The Group queried **1)** with regard to data controllership, whether the Chief Investigator who was on an honorary contract (with UCL) would practically be able to be supervised by colleagues at UCL, and suggested that NHS England clarify with the applicant what the supervision arrangements are for the Chief Investigator; and **2)** given the Chief Investigators Non-Executive role with the body who would be countersigning the honorary contract, suggested that it may not be possible for them to countersign the honorary contract, and suggested that NHS England DAS review the NHS England's DAS Standard for Honorary Contracts and determine whether a special provision may need to be made in this instance. **5.5.3** AGD noted that section 3 (Datasets Held / Requested) had not been populated to state how the common law duty of confidentiality had been addressed, and suggested that this was updated to reflect the correct information. **5.4.4** AGD suggested that section 5(b) (Processing Activities) was updated to reflect that the data will not *"leave"* England or Wales at any time. **5.4.5** AGD queried the references in section 5(b) of the application 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. **5.4.6** No AGD member noted a commercial aspect to the application.	
5.6	**Reference Number:** NIC-414067-K8R6J-v7.2 **Applicant and Data Controller:** Our Future Health **Application Title:** Our Future Health Recruitment Programme **Observer:** James Watts **Previous Reviews:** The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 11th April 2024, 14th March 2024, 18th January 2024, 2nd November 2023, 28th September 2023, 10th August 2023, 13th July 2023, 29th June 2023, 11th May 2023, 30th March 2023 and the 2nd March 2023. 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 1st December 2022, 17th November 2022, 26th May 2022 and the 5th May 2022. **Linked applications:** This application is linked to 411795-X5N2V. **Application:** This was an amendment application.	

NHS England were seeking general advice on the application.

Should an application be approved by NHS England, further details would be made available within the Data Uses Register.

Outcome of discussion: AGD were supportive of a six-month amendment application and wished to draw to the attention of the SIRO the following substantive comments:

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.

5.6.1 The Group noted the request had been for a two-year data sharing agreement (DSA), and advised that they were **not** supportive.

5.6.2 AGD noted the extensive and detailed Health Research Authority Confidentiality Advisory Group (HRA CAG) conditions for this application which they endorsed; and suggested that, should NHS England progress this version of the application with the proposed amendments, that the data sharing agreement (DSA) duration should align with the HRA CAG support period.

5.6.3 AGD noted condition 3 of the HRA CAG support, that the applicant should continue to explore the possibility of sending personalised **reminder** letters via NHS England's DigiTrials; and asked that NHS England provide an update on what steps had been taken to address this apparent functionality problem in an effort to reduce the amount of new confidential data flowing.

5.6.4 AGD noted that whilst there were a number HRA CAG conditions that would address some of the points raised when AGD last reviewed this application on the 18th January 2024, AGD reiterated a number of outstanding points:

5.6.4.1 The AGD independent members noted that they had previously suggested that further work should be undertaken by OFH, to ensure the commercial involvement was made explicitly clear to the cohort; however, there was no update to the Group on what work had taken place.

5.6.4.2 In addition, the Group also reiterated previous advice, that the applicant should amend the cohort letters to include **all** of the partners' logos, and not just the NHS partnership logo.

5.6.4.3 The independent advisers noted that they had previously queried the worldwide use of data for those who had consented, and queried whether the public understand that once they participate in the Programme that their data will be used worldwide; and noted that the response from OFH was that transparency had been updated, but it was not clear to the Group how.

5.6.5 AGD suggested that NHS England should satisfy itself that at the current rate of recruitment, the applicant was confident that they would still be able to reap the benefits of the use of confidential data, to meet their recruitment target.

5.6.6 AGD noted the process outlined in section 5(a) (Objective for Processing) for the letters / envelopes that are returned to NHS England, to support the Personal

	Demographic Service (PDS); and suggested that NHS England assure itself that there is a legal basis for this data to be used in this way. **5.6.7** AGD suggested that section 5 (Purpose / Methods / Outputs) was reviewed and updated as appropriate to ensure that the current information and dates stated were correct. **5.6.8** AGD suggested that NHS England undertake some analysis to determine **1)** how many OFH specific opt out requests had been received; **2)** why opt outs had been submitted based on the seven categories / options provided; and **3)** how many complaints had been received. The Group suggested that the analysis was summarised by number and percentages based on the number of invites sent out. **5.6.9** The Group reiterated previous advice from the 18th January 2024, that, if there were further amendments to this application, NHS England should consider bringing an updated progress report back to the Group, with updates on how all the points are being addressed, prior to submitting an amended application. **5.6.10** AGD strongly suggested that following the submission of a progress report (see point 5.6.9), any future iterations of this application were brought back to AGD for review. The NHS England SIRO Representative agreed that this application would be submitted to AGD for a further review. **5.6.11** AGD noted that there **was** a commercial aspect to the application.	
6 INTERNAL DATA DISSEMINATION REQUESTS:		
There were no items discussed		
7 EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL		
7.1	**Reference Number:** NIC-147811-YTH88-v4.5 **Applicant:** The University of Manchester **Data Controllers:** The University of Manchester and the University of East Anglia **Application Title:** MR559 - The Norfolk Arthritis Register (NOAR) **Presenter:** Dan Goodwin **Previous Reviews:** The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 12th December 2024 and the 1st August 2024. 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 3rd February 2022 and the 15th April 2021. **Linked applications:** This application is linked to NIC-333021-B6W2C (item 7.2). The SIRO approval was for the applicant to retain but not otherwise process the data.	

	Outcome of discussion: AGD noted that the NHS England SIRO had **not** yet provided SIRO approval. AGD thanked NHS England for the written / verbal update and made the following observations on the documentation provided: **7.1.1** The majority of the Group were supportive of the application proceeding via the NHS England SIRO approval route as outlined for the applicant to hold but not process the data, a minority of the Group (one independent member) was **not** supportive of the application **at this time** due to the ongoing history of the applicant not complying with deadlines. **7.1.2** AGD noted that failure by the applicant to meet deadlines had resulted in a number of data breaches, by not having an active data sharing agreement (DSA). **7.1.3** AGD noted the ongoing work within NHS England in respect of whether the National Data Opt-out (NDO) should be applied. It was also noted that if there was uncertainty as to whether there was consent this needed to be resolved, since the NDO Operational Policy Guidance is clear that the NDO does not apply where explicit consent has been obtained for a specific purpose. To apply the NDO because there is uncertainty as to whether a purpose is covered by consent or s251 support risks acting contrary to what the individual has chosen (by consenting to the study or by taking out an NDO). **7.1.4** AGD noted the impact on the NOAR if the applicant was asked to destroy the data, however suggested that NHS England review other possible sanctions to the applicant, should they continue to not comply, for example, by stopping the processing of data on all applications that have involvement by The University of Manchester. The NHS England SIRO representative thanked AGD for their time.	
7.2	**Reference Number:** NIC-333021-B6W2C-v3.5 **Applicant:** The University of Manchester **Data Controllers:** The University of Manchester and the University of East Anglia **Application Title:** The Norfolk Arthritis Register (NOAR) a longitudinal observational study **Presenter:** Dan Goodwin **Previous Reviews:** The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 12th December 2024 and the 1st August 2024. The application and relevant supporting documents were previously presented / discussed at the Data Access Advisory Group meeting on the 2nd March 2017. **Linked applications:** This application is linked to NIC-147811-YTH88 (item 7.1).	

	The SIRO approval was for the applicant to retain but not otherwise process the data. **Outcome of discussion:** AGD noted that the NHS England SIRO had **not** yet provided SIRO approval. AGD thanked NHS England for the written / verbal update and made the following observations on the documentation provided: **7.2.1** The majority of the Group were supportive of the application proceeding via the NHS England SIRO approval route as outlined for the applicant to hold but not process the data, a minority of the Group (one independent member) was **not** supportive of the application **at this time** due to the ongoing history of the applicant not complying with deadlines. **7.2.2** AGD noted that failure by the applicant to meet deadlines, had resulted in a number of data breaches, by not having an active data sharing agreement (DSA). **7.2.3** AGD noted the ongoing work within NHS England in respect of whether the National Data Opt-out (NDO) should be applied. It was also noted that if there was uncertainty as to whether there was consent this needed to be resolved, since the NDO Operational Policy Guidance is clear that the NDO does not apply where explicit consent has been obtained for a specific purpose. To apply the NDO because there is uncertainty as to whether a purpose is covered by consent or s251 support risks acting contrary to what the individual has chosen (by consenting to the study or by taking out an NDO). **7.2.4** AGD noted the impact on the NOAR if the applicant was asked to destroy the data, however suggested that NHS England review other possible sanctions to the applicant, should they continue to not comply, for example, by stopping the processing of data on all applications that have involvement by The University of Manchester. The NHS England SIRO representative thanked AGD for their time.	
8	**Opt-out public deliberation (Presenters: Ellie Munari, Tom Lymn and Katy Lindfield)** AGD were provided with a verbal update on why there is a public deliberation on opt outs; issues with the current opt out options; how the public were being engaged and when; and the draft questions that would feed into the public engagement exercises. AGD noted the verbal update provided, and made a number of suggestions to support this area of work, including, but not limited to, tweaks to the draft questions and further information that could be provided as part of the engagement process, for example, how other countries manage opt outs and being clear as to what each opt out will / won't do; not presuming that what everyone wants a national opt out system; explaining more about the different opt outs available to the public; and looking at how secure data environments can provide reassurance to the public.	

	The Group thanked Ellie, Tom and Katy for attending the meeting, and it was agreed that a further update on this work would be provided at a future AGD meeting in April / May 2025. **ACTION:** AGD Secretariat to add 'opt out public deliberation outcomes / next steps' to the internal AGD forward planner for April / May 2025.	AGD Sec
9 OVERSIGHT AND ASSURANCE		
9.1	**Oversight and Assurance Process** **Workstream 1 - Precedent approved internal and external applications** The Statutory Guidance states that the data advisory group (AGD) should be able to provide NHS England with advice on: *"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"*. In advance of the meeting, the AGD independent members were provided with **1)** two applications (selected by the AGD Secretariat); **2)** relevant supporting documents; and **3)** an oversight and assurance template to complete. Following review of the applications by the AGD independent members **out of committee**, the completed oversight and assurance templates were sent to the NHS England SIRO Representative Team and the AGD Secretariat prior to the meeting. 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 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. Please see **appendix A** for high-level points raised in-meeting on the two applications.	
9.2	**Oversight and Assurance Conclusion / Review** The Group suggested that there should be further discussions to clearly define how AGD members decide whether they are supportive, not supportive or undecided of an application proceeding via the Precedent route in order to support AGD members reaching a conclusion when reviewing applications for oversight and assurance. AGD and the NHS England SIRO Representative reiterated the point raised at the 21st November 2024 AGD meeting (see point 8.2) that for both applications that were reviewed as part of oversight and assurance, there were no documents available that provided an audit trail that outlined how the decision had been reached to progress the application down the NHS England precedent route.	

	ACTION: The NHS England SIRO Representative asked that AGD NHS England Data and Analytics Representative ensure that all relevant documentation was uploaded to the customer relationship management (CRM) system as agreed previously and for audit purposes. AGD reiterated previous concerns raised in oversight and assurance, that one of the applications had progressed down the NHS England precedent route, when a further independent review had been suggested by IGARD, and queried the process / justification as to why the advice would / would not be followed. The Group thanked Nicki Maher and the SIRO Team for their diligent work in refining the MS Form which was enabling better feedback / results of the oversight and assurance process.	D&A Rep To Note
10 AGD OPERATIONS		
10.1	**Risk Management Framework** 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. **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.	SIRO Rep
10.2	**Standard Operating Procedures (SOPs) (Update from Vicki Williams)** The ongoing forward plan of work for creating the AGD Standard Operating Procedures was discussed. 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.	
10.3	**AGD Stakeholder Engagement** *There were no items discussed*	
10.4	**AGD Project Work**	

	Consent review for consented cohorts As discussed at the AGD business as usual (BAU) meeting on the 23rd January 2025, the NHS England SIRO Representative advised the Group, that the request from NHS England for AGD to review and provide advice on the consent materials for consented cohorts for a small number of organisations, would take place on the 13th February 2025, instead of the usual AGD BAU meeting. The Group reiterated the request from the previous discussion, that prior to the 13th February 2025 workshop meeting, NHS England should provide further detail around the draft Direction, what the proposed processing is, what AGD is reviewing against (NHS England Standards or other), what PPIE has been undertaken with the cohorts, and how the outputs would be collated / presented. The Group noted that the relevant supporting papers for the discussion on the 13th February 2025 would be circulated by the 5th February 2025. In addition, the Group noted that there would be a meeting held on the 3rd February 2025 between the AGD Chair / Deputy Chair, the NHS England SIRO Team and the AGD Secretariat to discuss the logistics for the 13th February 2025 workshop meeting. The Group also noted that there was a further discussion on this work, scheduled at the AGD BAU meeting on the 6th February 2025.	
11 Any Other Business		
11.1	**AGD recruitment (Update from Garry Coleman)** The NHS England SIRO Representative advised the Group that as per the update at the AGD meeting on the 16th January 2025, discussions had taken place with all AGD independent members to discuss contracts and / or pay; and that recruitment to AGD independent member roles would proceed partly based on the outcome of these discussions. The Group were also advised that work was ongoing within NHS England to support the recruitment of AGD independent members, in line with current policies; and a further update would be provided in due course.	
11.2	**AGD collaboration on in-meeting documentation proposal** AGD noted, that as discussed at the AGD meetings on the 23rd January 2025, 16th January 2025, 12th December 2024 and the 26th September 2024, the Group discussed the pilot that had taken place in January 2025, on the collaboration on in-meeting documentation. The Group noted that whilst this had been a worthwhile exercise to determine whether this supported the AGD meeting discussions, the pilot had increased the pre-meeting preparation time for AGD members and AGD Secretariat without any clear benefit. The Group did however agree that the pilot had demonstrated there may be value to the AGD meeting discussions and to NHS England colleagues, if the Group were to	

	collaborate on documents such as briefing papers, Directions, DPIAs etc. The Group agreed that they would pilot / review this going forward. **ACTION:** AGD Secretariat to select a briefing paper, Direction, DPIA etc (where available) and upload to the AGD internal SharePoint site for AGD to review / collaborate on, prior to the meeting.	AGD Sec

Meeting Closure

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

Appendix A

Oversight and Assurance Review – 30th January 2025

Ref:	NIC Number:	Organisation:	Areas to consider:

250130a	NIC-90126-D4Z2W-v1.2	Keele University	• No assessment provided advising why this was suitable for the precedent route, therefore unclear if the precedent was applied correctly.
			  ○ **Process point: Action for D&A Representative** to ensure that it is clear in s1 of the DSA or s1 of the SDa what documents were reviewed to make the decision with regard to the precedent route.
			• No SDa / escalation form provided (noting the document was not available in CRM for Secretariat to download).
			  ○ **Process point: Action for D&A Representative** to ensure that all applications have the latest version of the requisite SDa / escalation form on CRM, since it is that form that is cited as the "working document" for NHSE.
			• All the supporting documents labelled "SD" had been provided by Secretariat because it was unclear what documents had been used to show how the decision had been made by NHSE to progress down the precedent route.
			  ○ **Process point: Action for D&A Representative** to ensure that it is clear in s1 of the DSA or s1 of the SDa what documents were reviewed to make the decision with regard to the precedent route
			• AGD noted that this application had been reviewed by IGARD on the 29th July 2019 and recommended for approval subject to conditions and amendments – the conditions had never come back to IGARD for review out of committee as was the process at that time.

			• Minutes of the previous independent review or how points addressed were not included, including who had signed off the IGARD conditions. ○ **Process point: Action for D&A Representative** to ensure that previous minutes / oversight & assurance reviews / SIRO decisions etc. are documented within the SDa, including how each point has been addressed.

250130b	NIC-659282-H1F7C-V1.2	Royal Marsden NHS Foundation Trust	• No assessment provided advising why this was suitable for the precedent route, therefore unclear if the precedent was applied correctly.
			  ○ **Process point: Action for D&A Representative** to ensure that it is clear in s1 of the DSA or s1 of the SDA what documents were reviewed to make the decision with regard to the precedent route
			• No SDa / escalation form provided (noting the document was not available in CRM for Secretariat to download).
			  ○ **Process point: Action for D&A Representative** to ensure that all applications have the latest version of the requisite SDa / escalation form on CRM, since it is that form that is cited as the “working document” for NHSE.
			• All the supporting documents labelled “SD” had been provided by Secretariat because it was unclear what documents had been used to show how the decision had been made by NHSE to progress down the precedent route.
			  ○ **Process point: Action for D&A Representative** to ensure that it is clear in s1 of the DSA or s1 of the SDa what documents were reviewed to make the decision with regard to the precedent route
			• To provide a copy of the knowledge base or the text relating to the reusable decision in the abstract / SDa.

			○ **Action for the D&A Representative:** to provide a copy of the knowledge base referenced, or for the wording of the knowledge base cited to be included in the SDa. • AGD asked the NHSE SIRO Representative to consider whether all applications should have an independent review after a certain number of years. ○ **Action for the SIRO Rep**: to consider whether all applications should have an independent review. • AGD noted this application had never had a previous independent review by DAAG / IGARD / AGD, however had been noted under SIRO approvals via IGARD minutes on the 15th December 2022, when IGARD had requested that on the next iteration the application be brought back for a full independent review. ○ **Process point: Action for D&A Representative** to ensure that previous minutes / oversight & assurance reviews / SIRO decisions etc. are documented within the SDa, including how each point has been addressed.