

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 12th September

09:00 – 15:00

(Remote meeting via videoconference)

AGD INDEPENDENT / NHS ENGLAND MEMBERS IN ATTENDANCE:	
Name:	Role:
Paul Affleck (PA)	AGD independent member (Specialist Ethics Adviser) (not in attendance for items 6.6 to 11.1)
Michael Chapman (MC)	NHS England member (Data and Analytics Representative) (not in attendance for items 8.1 to 11.1)
Claire Delaney-Pope (CDP)	AGD independent member (Specialist Information Governance Adviser)
Kirsty Irvine (KI)	AGD independent member (Chair)
Dr. Phil Koczan (PK)	NHS England member (Caldicott Guardian Team Representative (Delegate for Dr. Jonathan Osborn))
Andrew Martin (AM)	NHS England member (Data Protection Office Representative (Delegate for Jon Moore))
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 (Observer: item 6.3)
Garry Coleman (GC)	NHS England SIRO Representative (not in attendance for part of items 2.3 and 2.4)
Ayse Depsen (AD)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 6.2)
Lauren Gerraghty (LG)	Governance and Assurance Officer, Data Access and Partnerships, Transformation Directorate (Observer: Item 5.1)

Tiaro Micah (TM)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: items 6.5 and 6.6)
Tess Morley (TM)	NHS DigiTrials, Data and Analytics, Transformation Directorate (Observer: item 6.3)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Delivery Directorate
Tania Palmariellodiviney (TP)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Presenter: item 5.1)
Jodie Taylor-Brown (JTB)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 6.4)
James Watts (JW)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: items 6.5 and 6.6)
AGD INDEPENDENT MEMBERS / NHS ENGLAND MEMBERS <u>NOT</u> IN ATTENDANCE:	
Name:	Role / Area:
Prof. Nicola Fear (NF)	AGD independent member (Specialist Academic Adviser)
Dr. Robert French (RF)	AGD independent member (Specialist Academic / Statistician Adviser)
Jon Moore (JM)	NHS England member (Data Protection Office Representative)
Dr. Jonathan Osborn (JO)	NHS England member (Caldicott Guardian Team 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 5 th September 2024 were reviewed and, after several minor amendments, were agreed as an accurate record of the meeting.
3	Declaration of interests: Claire Delaney-Pope noted a professional link to King's College London (NIC-753801-J5B3X-v0.2 Queen Mary University of London) as part of her role at South London and Maudsley NHS Foundation Trust. It was agreed this did not preclude Claire from taking part in the discussion on this application.

	<p>An AGD member noted a personal perspective to the study outlined in NIC-147940-WVXJF (University of Oxford). It was agreed this did not preclude the AGD member taking part in the discussion about this item and welcomed their insight.</p> <p>Jenny Westaway noted a professional link to the Royal College of Anaesthetists (NIC-63347-R8J2M). It was agreed this did not preclude Jenny from taking part in the discussion about this application.</p> <p>Subsequent to the meeting: AGD noted that at the AGD meeting on the 19th September 2024, a declaration of interest had been noted by Tania Palmariellodiviney in respect of NIC-616054-M4C8K NHS Greater Manchester Integrated Care Board (ICB). Noting Tania’s professional link to NHS ICBs, it was agreed that a declaration of interest in respect of the ‘Research for Commissioners’ Sub-Licence Precedent’ (item 5.1) should also have been made at the AGD meeting on the 12th September 2024. It was agreed this declaration would not have precluded Tania from taking part in the discussion on this briefing paper but should be made and included for transparency. The declaration added subsequent to the ratification of the minutes is as follows:</p> <p>Tania Palmariellodiviney noted a professional link to NHS ICBs (item 5.1) as part of another role outside of NHS England. It was agreed this did not preclude Tania from taking part in the discussion on this briefing paper.</p>
4	<p>AGD Action Log:</p> <p><i>The action log was not discussed.</i></p>
<p>5 BRIEFING PAPER(S) / DIRECTIONS:</p>	
5.1	<p>Title: Research for Commissioners’ Sub-Licence Precedent</p> <p>Presenter: Tania Palmariellodiviney</p> <p>Observer: Lauren Gerraghty</p> <p>Previous Reviews: The Precedent and supporting paper were previously discussed at the AGD meeting on the 11th April 2024 and the 22nd February 2024.</p> <p>The Integrated Care Boards’ (ICBs) existing data sharing agreements (DSAs) support the use of data for commissioning activities. This currently does not extend to facilitating research and therefore could inhibit health service developments through research evidence.</p> <p>The Research for Commissioners Precedent supports the additional purpose to be included in the ICB’s templated DSA (if required) through the sub-licencing of access to permissible datasets with research organisations. The research for commissioners sub-licencing arrangement is only permissible where the research is ICB led or enacted and must relate to its commissioning activities to the health and care benefit for its Integrated Care System (ICS).</p>

The sub-licencing arrangement can support multiple ICBs as Data Controllers, working in collaboration to achieve the health and care benefits from the research across their ICS.

NHS England were seeking advice on the following points:

1. To provide advice for the SIRO to recommend accepting the Precedent allowing ICBs to sub-license the permissible datasets within their data sharing agreement (DSA) for an additional purpose of research for commissioning uses.

Outcome of discussion: AGD welcomed the updated briefing paper and made the following observations / comments:

In response to point 1 above:

5.1.1 AGD noted that an application relating to this Precedent (NIC-616054-M4C8K NHS Greater Manchester Integrated Care Board (ICB)) had been withdrawn from discussion at this meeting (see item 6.1); and would be discussed at the AGD meeting on the 19th September 2024.

5.1.2 AGD noted that they were supportive of the request from the ICBs, which was in order to help fulfil their statutory obligations; and recognised the work undertaken by NHS England to support this.

5.1.3 AGD noted that they were supportive of the proposed sub-licensing as a concept. The Group did however note that the wording, intended to constrain the scope during the initial phases, had the unintended consequence of presenting the sub-licensing arrangements as a Data Controller / Data Processor relationship.

5.1.4 In addition, it was suggested by the Group that the research undertaken by the sub-licensees should align with the individual aims of the ICBs; and suggested that this should form part of the sub-licensing arrangements.

5.1.5 AGD noted that the restriction to the geographical footprint of the ICB could create unintended consequences and queried if this was necessary if not required by the legislation.

5.1.6 In respect of the Precedent, AGD suggested that a qualifying criteria for an application to progress via the Precedent route, should be that the data is accessed in a Secure Data Environment (SDE).

5.1.7 AGD noted the importance of the governance arrangements for the oversight board, including, but not limited to, terms and conditions and compliance; and noted that this would be explored further with NIC-616054-M4C8K, at the AGD meeting on the 19th September 2024.

5.1.8 AGD suggested that the Precedent was updated to provide further information on access controls, for example, where an ICB is handling both pseudonymised and identifiable data.

	<p>5.1.9 As part of the pilot / initial phase, AGD noted that there may be ICBs that are managing Health Research Authority Confidentiality Advisory Group (HRA CAG) and HRA Research Ethics Committee (REC) conditions, and that they are complying with the DSA; and noted that there may be a limit as to how much the Precedent route can be utilised. It was noted that this would be explored further with NIC-616054-M4C8K, at the AGD meeting on the 19th September 2024.</p> <p>5.1.10 AGD looked forward to receiving the updated / finalised Precedent tabled at a future meeting. The Group advised that related notes would be shared out of committee by one of the AGD independent members.</p>	
<p>6 EXTERNAL DATA DISSEMINATION REQUESTS:</p>		
<p>6.1</p>	<p>Reference Number: NIC-616054-M4C8K-v2.2</p> <p>Applicant: NHS Greater Manchester Integrated Care Board (ICB)</p> <p>Application Title: DSfC - NHS Greater Manchester Integrated Care Board - Commissioning / Invoice Validation / Risk Stratification and Research</p> <p>The item was withdrawn by NHS England’s Data Access Service (DAS) prior to the meeting.</p>	
<p>6.2</p>	<p>Reference Number: NIC-616039-L2R9G-v1.2</p> <p>Applicant: NHS Nottingham and Nottinghamshire Integrated Care Board (ICB)</p> <p>Application Title: NHS Nottingham and Nottinghamshire Integrated Care Board - Comm/IV/RS</p> <p>Observers: Ayse Depsen and Tom Wright</p> <p>Application: This was an amendment application.</p> <p>The purpose of the application is for Invoice Validation, which is part of a process by which providers of care or services get paid for the work they do; Risk Stratification, which is a tool for identifying and predicting which patients are at high risk (of health deterioration and using multiple services) or are likely to be at high risk and prioritising the management of their care in order to prevent worse outcomes; and Commissioning, to provide intelligence to support the commissioning of health services.</p> <p>The NHS England Data will be linked to the data held by NHS Nottingham and Nottinghamshire ICB, the amendment to the application, is to reflect the changes in the data linkage method.</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 they had been provided with a curated set of documentation and noted that they would be providing observations based on these documents.</p> <p>6.2.1 AGD queried / discussed whether the Individual Funding Request (IFR) data noted in the Data Access Service (DAS) internal escalation form that would flow from local providers, was "<i>data relating to Care Items delivered under a non-contract agreement</i>" as outlined in the Data services for commissioners Directions 2015. AGD were advised by NHS England that advice on this had been sought from NHS England's Legal Team, however it was unclear if a response had been received. AGD suggested that NHS England clarify whether a response had been received on this point, and to ensure that the advice from NHS England's Legal Team was followed to determine / ensure there was a legal gateway for the IFR data to flow.</p> <p>6.2.2 AGD suggested that if the advice from NHS England's Legal Team on the IFR data was inconclusive, a further a discussion was held at a future AGD meeting to discuss / agree a way forward with this issue.</p> <p>6.2.3 AGD noted that it was not clear in the DAS internal escalation form, whether the amendment to this application would be a reusable decision for other ICB applications; and suggested that this would be determined once the legal gateway had been established for the IFR data.</p> <p>6.2.4 AGD noted the information in section 3(c) (Patient Objections) in respect of Opt-outs; however, suggested that this was updated further to outline whether the National Data Opt-out was being applied to the IFR data, and at which 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>6.2.5 AGD noted that the application had been updated to reflect the new processing, however, suggested that further clarity was provided on the purpose of processing in section 5(a) (Objective for Processing) of the application and whether the proposed amendment would come under Invoice Validation, Risk Stratification, or Commissioning as this was currently unclear.</p> <p>6.2.6 AGD noted that section 2(c) (Territory of Use) of the application stated that the territory of use was the "<i>UK</i>"; and queried why this was not "<i>England and Wales</i>"; and suggested that this was explored further, and that any updates were made to the application as may be necessary to reflect the correct / factual information.</p>	
6.3	<p>Reference Number: NIC-753801-J5B3X-v0.2</p> <p>Applicant: Queen Mary University of London</p> <p>Application Title: BEST-4 Heartburn Health Programme – Recruitment</p>	

Observers: Jack Bennett and Tess Morley

Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 18th July 2024.

Application: This was a new application.

The purpose of the application is to create a resource of participants with heartburn, indigestion or acid reflux. The Programme aims to build a community of volunteers with heartburn and allow experts to research issues such as: **1)** how to manage symptoms more effectively and reduce the need for long-term medication; and **2)** how to find more serious health problems such as severe inflammation and cancer early, when they are easier to treat.

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: The majority of the Group were supportive of the application. A minority of the Group were not supportive of the application at this time due to ongoing concerns arising from the patient and public involvement and engagement (PPIE).

The Group 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.

6.3.1 AGD noted the work undertaken by NHS England and the applicant to address the previous points raised at the AGD meeting on the 18th July 2024.

6.3.2 The AGD NHS England Data and Analytics representative provided a verbal update to the Group, in respect of how the previous points raised on the 18th July 2024 had been addressed, including, but not limited to, the wider message to the public in respect of safety of the text messages; the process for text message recipients to verify the text message inviting them to join the study; and that the sender ID was still under internal discussions, and that any use of the letters 'NHS' would require approval from the Department of Health and Social Care (DHSC).

6.3.3 AGD reiterated the previous point / concern raised on the 18th July 2024, in respect of the results of the patient and PPIE survey, which indicated that 9% of those eligible for an invite to the study would **not** want their personal details to be used in this way, which would equate to approximately 400,000 recipients. It was noted however, that some of these individuals may have submitted an NDO and would not therefore receive an invite. On this basis, the majority of the AGD members felt it was reasonable to proceed with this approach, whilst a minority did not.

6.3.4 The AGD NHS England Data and Analytics representative advised the Group that further information in respect of the PPIE undertaken and any pilot outcomes, would be provided to the Group. The Group were supportive of this and advised that they would be particularly interested in the benefit analysis and any findings from the pilot.

6.3.5 AGD noted that they would be supportive of a phased approach to the dissemination of the data, with an ongoing assessment on uptake and any potential unintended consequences.

In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:

6.3.6 AGD noted the extensive discussions between NHS England including the NHS England SIRO representative and the applicant on data controllership, including, the assurances received from the various parties Data Protection Officers (DPO). It was suggested by the Group that given the significant utilisation of the NHS England data, and that this was an early adopter, that NHS England should consider an early audit on this application.

6.3.7 AGD suggested that section 5(a) (Objective for Processing) of the application was updated, to be clear on the system for the dissemination of data, i.e. as a phased approach to the recipient.

6.3.8 In addition, noting that it was currently unclear, it was suggested by the Group, that NHS England clarify with the Health Research Authority Confidentiality Advisory Group (HRA CAG), whether the quantum of data supported, related to criteria (with an estimated total) or a firm ceiling (representing a selection resulting from the criteria); and that once confirmation had been received from HRA CAG, the application should be updated throughout with the correct information.

6.3.9 AGD queried whether the NHS App could be utilised in addition to / instead of text messages; however, were advised by NHS England that this was currently not possible due to legal restrictions in relation to NHS Notify.

6.3.10 Separate to this application: AGD discussed the use of NHS branding by applications including a commercial element; and noted that this was last discussed at the AGD meeting on the 18th January 2024 (as part of NIC-414067-K8R6J Our Future Health); and asked the SIRO Representative to clarify NHS England's policy with the group, outlining the process for seeking permission to use the NHS logo or name on a project and what criteria are used to decide whether such requests should be granted; and to keep the Group updated with any decisions / outcomes on this point.

6.3.11 In addition, AGD advised that they would be supportive of feeding into any discussions on the criteria for projects to use of the NHS logo or state that they are working with the NHS, should NHS England require this input.

SIRO
Rep

	<p>ACTION: The SIRO representative to clarify NHS England’s policy with the Group, and outline the process and criteria for projects to gain permission to use the NHS logo or state that they are working with NHS (and to keep the Group updated with any decisions / outcomes on this point).</p> <p>6.3.12 AGD noted in the DAS internal application assessment form, that the consent materials, including the consent materials provided / discussed previously, would be discussed at a future AGD meeting.</p>	
<p>6.4</p>	<p>Reference Number: NIC-147940-WVXJF-v6.6</p> <p>Applicant: University of Oxford</p> <p>Application Title: Audit of the effect of age at the first invitation for Breast Screening in the NHSBSP</p> <p>Observer: Jodie Taylor-Brown</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) meeting on the 18th February 2021.</p> <p>Application: This was an amendment application.</p> <p>The amendments are to 1) permit the applicant to start processing the data again, Section 5(a) (Objective for Processing) of the application has been uplifted accordingly; 2) to receive the latest available pseudonymised Demographics, Cancer Registration and Deaths data; 3) to destroy all identifiable data found in the MRIS products that was disseminated by NHS England; and 4) To update section 5(c) (Specific Outputs Expected) of the application with the expected outputs.</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 they had been provided with a curated set of documentation and noted that they would be providing observations based on these documents.</p> <p>6.4.1 AGD noted that prior to the meeting, an AGD member had raised a query with NHS England’s Data Access Service (DAS), in respect of conflicting information in the letter from Health Research Authority Confidentiality Advisory Group (HRA CAG) dated the 10th August 2021 provided as a supporting document (SD3.4) that states “...Name, NHS number, date of birth, postcode will be deleted before linkage takes place...” and section 5(b) (Processing Activities) of the application that states “The identifying details will be stored in a separate database to the linked dataset used for analysis”. It was suggested that NHS England advise the applicant to discuss this further with the HRA CAG to clarify when the identifiers will be deleted; and that any</p>	

updates were made to the application as may be necessary to reflect the correct / factual information.

6.4.2 AGD queried what Opt-outs would be applied, noting the inconsistent information within the application, protocol, HRA CAG support and the transparency materials; and suggested that these was reviewed and updated / aligned where may be necessary to ensure that the information provided is factually correct, and aligns with what HRA CAG have been advised and subsequently supported. If the information provided to HRA CAG was incorrect, then the Group suggested that HRA CAG were updated as may be necessary.

In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:

6.4.3 AGD queried whether the data requested could be minimised to ensure that **only** data was flowing on breast cancer in line with [NHS England DAS standard for data minimisation](#); or, if data was required on other types of cancer, the Group suggested the application was updated with further information / a justification.

6.4.4 AGD members noted that the data had been sitting unused for a significant period of time, meaning that the considerable potential benefits of the project had yet to be achieved. It was however noted by the Group that the Annual Confirmation Report (ACR), introduced by NHS England in 2023, would now ensure more timely reporting on progress made by projects on achieving public benefit from processing the data.

6.4.5 It was suggested by the Group, that section 5(d) (Benefits) (iii) (Yielded Benefits) of the application was updated with a brief explanation as to why data had been held but there had been no analysis carried out.

6.4.6 AGD queried why earlier data had not been requested; and advised that they would be supportive of the applicant requesting earlier data not contained within the Medical Research Information Service (MRIS) data if this aligned with the purpose outlined in the protocol, application etc.

6.4.7 AGD queried the reference in section 5(a) of the application to “*cancelled cipher*”, and asked that a further explanation was provided on what this was referring to.

6.4.8 AGD noted the patient and public involvement and engagement (PPIE) undertaken to date, and the planned PPIE at the end of the study; however, suggested that there was ongoing PPIE throughout the lifecycle of the project. The [HRA guidance on Public Involvement](#) is a useful guide.

6.4.9 AGD queried the statement in section 5(b) “*The Data will be accessed onsite at the premises of the University of Oxford*”; and noting that this was quite restrictive, suggested that NHS England discuss this further with the applicant, and that the application was updated as may be necessary, for example, to reflect any remote access arrangements.

	<p>6.4.10 AGD noted the reference in section 5(d) of the application to “<i>clients</i>”; and suggested that this was updated to refer to “<i>organisations</i>”.</p>	
<p>6.5</p>	<p>Reference Number: NIC-678273-F2S0V-v0.7</p> <p>Applicant: University College London (UCL)</p> <p>Application Title: Investigating the utility of machine learning methods to predict prognosis and guide treatment decisions for people with lung cancer (Lung-ORACLE)</p> <p>Observer: James Watts</p> <p>Application: This was a new application.</p> <p>The purpose of the application is for a research project, to derive and validate multiple prognostic models for lung cancer patients, using a variety of statistical approaches to identify the most accurate modelling approach, with a view to improve treatment decisions for lung cancer patients.</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>6.5.1 AGD queried what consideration had been given to the transparency to the Lung Cancer Audit data subjects; and suggested that this was given further consideration, including, but not limited to, updating the Lung Cancer Audit privacy notice.</p> <p>6.5.2 In addition, it was noted that the Lung Cancer Audit data subjects have been advised that the Healthcare Quality Improvement Partnership (HQIP) Data Access Group will be involved in the uses of patient data for research and suggested that NHS England investigate this further, and that the outcome of any discussions are documented and uploaded to NHS England’s customer relationships management (CRM) system for future reference.</p> <p>6.5.3 AGD discussed Article 5(1)(a) of the UK General Data Protection Regulation (UK GDPR) that personal data shall be “<i>processed lawfully, fairly and in a transparent manner in relation to the data subject (‘lawfulness, fairness and transparency’)</i>” and it was noted that there may be a risk that this was not being complied with in respect of the Lung Cancer Audit data subjects.</p> <p>6.5.4 Separate to this application: AGD suggested that NHS England ascertain what steps need to be taken in respect of this dataset and other NDRS audit datasets, to ensure that the appropriate procedures are being respected.</p>	

	<p>6.5.10 AGD noted that section 7 (Ethics Approval) of the application referred to an ethics review by Health Research Authority Research Ethics Committee (HRA REC); however, suggested that this was updated to also refer to the institutional ethical review that had also been sought.</p>	
<p>6.6</p>	<p>Reference Number: NIC-727610-S2V3N-v0.9</p> <p>Applicant: University College London (UCL)</p> <p>Application Title: The impact of reimbursement schemes on healthcare providers' operational performance</p> <p>Observer: James Watts</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 20th June 2024.</p> <p>Application: This was a new application.</p> <p>The purpose of the application is for a research project with the aim of 1) examining how different reimbursement schemes proposed by the NHS to reimburse healthcare providers affect providers' operational efficiency, costs, and quality of care; and 2) to understand why the same reimbursement scheme leads to different behaviours among healthcare providers depending on their characteristics and patient types.</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: The Group were broadly supportive of the purpose outlined in the application, but were not supportive of the application at this time and wished to draw to the attention of the SIRO the following significant comments:</p> <p>6.6.1 AGD noted the work undertaken by NHS England and the applicant, to address the previous points raised at the AGD meeting on the 20th June 2024.</p> <p>6.6.2 The Group advised that they were supportive of the proposed objective for processing; and were satisfied on some the responses provided on the points raised on the 20th June 2024, including the response in respect of the experience of the PhD student and their supervisor.</p> <p>6.6.3 As noted at the AGD meeting on the 20th June 2024, the Group remained concerned about the large volume of data requested under this application, and reiterated their previous advice that this should be accessed within NHS England's Secure Data Environment (SDE).</p> <p>6.6.4 In addition, it was noted that the data minimisation proposal outlined in the Data Access Service (DAS) internal application assessment form, did not address</p>	

	<p>the previous concerns raised and supported the view that the data should be access within NHS England’s Secure Data Environment (SDE).</p> <p>6.6.5 The Group noted that NHS England would need to clarify internally whether the proposed data under this application could be accessed with NHS England’s SDE.</p> <p>6.6.6 Separate to this application: As discussed at the AGD meeting on the 13th June 2024, the Group suggested that NHS England continue to explore all avenues / barriers to applicants accessing the SDE, for example timing of payments, and how they can support this.</p> <p>ACTION: NHS England Data and Analytics representative explore all avenues / barriers to applicants accessing the SDE and how they can support this.</p> <p>6.6.7 AGD noted the applicant’s response in the DAS internal application assessment form, on the previous point made on the 20th June 2024, in respect of the applicant re-submitting the form to the UCL School of Management Research Ethics Committee (REC), to reflect any revised scope and clarify that special category personal data is being processed. It was noted that there appeared to be some misunderstanding as to what was considered ‘personal data’; and suggested that NHS England explore this further with the applicant, in line with UK General Data Protection Regulation (UK GDPR).</p> <p>6.6.8 AGD noted the applicant’s response in the DAS internal application assessment form, in respect of the previous point made on the 20th June 2024, in respect of the suggestion that that the applicant should consider undertaking some PPIE, to seek views on a number of points, including, but not limited to, the proposed research and the expected benefits; and that this could not be undertaken due to time / resource issues. The Group noted that this was not a reasonable justification for not undertaking PPIE.</p>	D&A Rep
7 INTERNAL DATA DISSEMINATION REQUESTS:		
<i>There were no items discussed</i>		
8 EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL		
8.1	<p>Reference Number: NIC-147811-YTH88-v4.5</p> <p>Applicant: The University of Manchester</p> <p>Application Title: MR559 - The Norfolk Arthritis Register (NOAR)</p> <p>Previous Reviews: The application and relevant supporting documents had previously been presented / discussed at the AGD meeting on the 1st August 2024.</p>	

	<p>The application and relevant supporting documents had previously been 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.</p> <p>Linked applications: This application is linked to NIC-333021-B6W2C (item 8.2).</p> <p>The SIRO approval was for a six-month extension with the University of East Anglia as a joint Data Controller.</p> <p>Outcome of discussion: AGD noted that the NHS England SIRO had already provided SIRO approval and confirmed that they were supportive of this.</p> <p>AGD thanked NHS England for the written update and advised that they had no further comments to make on the documentation provided.</p> <p>The NHS England SIRO representative thanked AGD for their time.</p>	
<p>8.2</p>	<p>Reference Number: NIC-333021-B6W2C-v3.3</p> <p>Applicant: The University of Manchester</p> <p>Application Title: The Norfolk Arthritis Register (NOAR) a longitudinal observational study</p> <p>Previous Reviews: The application and relevant supporting documents had previously been presented / discussed at the AGD meeting on the 1st August 2024.</p> <p>The application and relevant supporting documents had previously been presented / discussed at the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) meetings on the 2nd March 2017.</p> <p>The application and relevant supporting documents had previously been presented / discussed at the Data Access Advisory Group (DAAG) meeting on the 31st January 2017.</p> <p>Linked applications: This application is linked to NIC-147811-YTH88 (item 8.1).</p> <p>The SIRO approval was for a six-month extension with the University of East Anglia as a joint Data Controller.</p> <p>Outcome of discussion: AGD noted that the NHS England SIRO had already provided SIRO approval and confirmed that they were supportive of this.</p> <p>AGD thanked NHS England for the written update and advised that they had no further comments to make on the documentation provided.</p> <p>The NHS England SIRO representative thanked AGD for their time.</p>	
<p>8.3</p>	<p>Reference Number: NIC-63347-R8J2M-v6.2</p> <p>Applicant: Royal College of Anaesthetists</p> <p>Application Title: Perioperative Quality Improvement Programme (PQIP)</p>	

	<p>Previous Reviews: The application and relevant supporting documents had previously been presented / discussed at the AGD meetings on the 30th November 2023.</p> <p>The application and relevant supporting documents had previously been presented / discussed at the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) meetings on the 17th February 2022, 12th October 2017, 28th September 2017 and the 14th September 2017.</p> <p>The SIRO approval was for a six-month extension to hold, but not process the data. The application will be returning to AGD in the coming weeks.</p> <p>Outcome of discussion: AGD noted that the NHS England SIRO had already provided SIRO approval and confirmed that they were supportive of this.</p> <p>AGD thanked NHS England for the written update and advised that they had no further comments to make on the documentation provided.</p> <p>The NHS England SIRO representative thanked AGD for their time.</p>	
--	--	--

9 OVERSIGHT AND ASSURANCE

There were no items discussed

10 AGD OPERATIONS

<p>10.1</p>	<p>Risk Management Framework</p> <p>The NHS England SIRO Representative confirmed that a risk management framework was continuing to be developed by Data Access, and in the meantime asked that AGD use the agreed NHS England DAS Standards and Precedents model as a proxy in assessing the risk factors in relation to items presented to AGD for advice.</p> <p>It had been noted previously by the interim data advisory group that the Oversight and Assurance Programme of applications that were not subject to AGD review would form part of this Risk Management Framework.</p> <p>The NHS England SIRO representative noted an outstanding action in respect of providing a written response to AGD on the risk management framework; and noted that this was progressing under the NHS England Precedents and Standards work.</p> <p>ACTION: The NHS England SIRO Representative to provide a written response to AGD on the risk management framework</p>	<p>SIRO Rep</p>
--------------------	---	-----------------

<p>10.2</p>	<p>Standard Operating Procedures (SOPs)</p> <p>The ongoing forward plan of work for creating the AGD Standard Operating Procedures was discussed; and noting that the AGD Terms of Reference (ToR) had now been approved, it was noted that work was progressing in order to finalise relevant AGD SOPs in line with the approved AGD ToR.</p>
--------------------	---

10.3	<p>AGD Stakeholder Engagement</p> <p><i>There were no items discussed</i></p>
10.4	<p>AGD Project Work</p> <p>It was noted that Kirsty Irvine, Paul Affleck and Claire Delaney-Pope attended an NHS England Data Access Service (DAS) Standards Working Group on the 10th September 2024.</p>
<p>11 Any Other Business</p>	
11.1	<p><i>There were no items discussed</i></p>
<p>Meeting Closure</p> <p>As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.</p>	