

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 14th May 2026

09:00 – 16:00

(Remote meeting via videoconference)

AGD INDEPENDENT / NHS ENGLAND MEMBERS IN ATTENDANCE:	
Name:	Role:
Noela Almeida (NA)	NHS England member (Data Protection Office Representative (Delegate for Jon Moore))
Paul Affleck (PA)	AGD independent member (Specialist Ethics Adviser) (not in attendance for item 5.2)
Mr Christopher Barben (CB)	AGD independent member (Specialist Clinician Adviser)
Claire Delaney-Pope (CDP)	AGD independent member (Specialist Information Governance Adviser)
Dr Arjun Dhillon (AD)	NHS England member (Caldicott Guardian Team Representative)
Dr. Jon Fistein (JF)	AGD independent member (Chair)
Narissa Leyland (NL)	NHS England member (Data and Analytics Representative (Delegate for Michael Chapman))
Dr. Mark McCartney (MM)	AGD independent member (Specialist GP / Clinician Adviser)
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	Role / Area:
Jillette Brown (JB)	IG Specialist, IG Delivery (Digital & Operations), Privacy, Transparency, and Trust (PTT), Technology, Digital and Data (Observer: item 4.1)
Garry Coleman (GC)	NHS England SIRO Representative (not in attendance for part of item 5.1, part of item 5.4 and part of item 5.7)
Dave Cronin (DC)	Applications Service Owner, Data Access and Partnerships, Transformation Directorate, Transformation Directorate (Observer: item 5.1)
Ayse Depsen (AD)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.7)
Lyndon Dibb (LD)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.3)

Charlotte Elyan (CE)	Programme Manager for Early Diagnosis (Lung), NHS Cancer Programme, Planned Care Directorate (Presenter: item 4.1)
Charlie Graham (CG)	Lead Analyst – Evaluation Team, Cancer Analysis & Insights Team (CAIT), Planned Care Directorate (Observer: item 4.1)
Gavin Harrison (GH)	Senior Data Architect, Data Design, Data and Analytics, Transformation Directorate (Observer: item 4.1)
Sam Hinks (SH)	Lead for CAIT, Cancer Analysis & Insights Team (CAIT), Data and Analytics, Transformation Directorate (Presenter: item 4.1)
Joe Lawson (JL)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.1)
Sandeep Manku (SM)	Data Operations Principal Manager, Data Delivery, Data and Analytics Transformation Directorate (Observer: item 4.1)
Tiaro Micah (TM)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.6)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Technology, Digital and Data
Denise Pine (DP)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.4 to 5.5)
Emma Whale (EW)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.2)
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Technology, Digital and Data
AGD INDEPENDENT MEMBERS / NHS ENGLAND MEMBERS <u>NOT</u> IN ATTENDANCE:	
Name:	Role / Area:
Michael Chapman (MC)	NHS England member (Data and Analytics Representative)
Dr. Robert French (RF)	AGD independent member (Specialist Academic / Statistician Adviser)
Prof. Jo Knight (JK)	AGD independent member (Specialist Academic / Researcher Adviser)
Jon Moore (JM)	NHS England member (Data Protection Office Representative)
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)
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1	<p>Welcome and Introductions:</p> <p>The AGD Chair welcomed attendees to the meeting.</p> <p>AGD noted that, due to an urgent work commitment, there would not be an NHS England SIRO Representative or delegate in attendance for part of item 5.1, part of item 5.4 and part of item 5.7. Noting that the AGD Terms of Reference (ToR) state that: “...a representative of the SIRO must also be in attendance for any meetings of the Group or a Sub-Group...”, the Group were advised that, prior to the meeting, the NHS England SIRO Representative had confirmed contentment for part of item 5.1, part of item 5.4 and part of item 5.7 to be discussed in their absence.</p>
2	<p>Review of previous AGD minutes:</p> <p>The minutes of the AGD meeting on the 7th May 2026 were reviewed and, agreed as an accurate record of the meeting.</p>
3	<p>Declaration of interests:</p> <p>Paul Affleck noted a professional link to two of the study team (NIC-11809-H1Y3W - University of Leeds) and would not be part of the discussion. It was agreed that Paul would not remain in the room for the discussion of this application.</p> <p>Paul Affleck noted that he was a public contributor to the UK Longitudinal Linkage Collaboration referenced in NIC-748729-Z8B3M and NIC-420229-G9H9S (University of Bristol) 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 Oxford but noted no specific connections with the application (NIC-763031-W3L6K - The University of Manchester), and it was agreed that this was not a conflict of interest.</p> <p>Dr. Jon Fistein noted a link to team members of NIC-11809-H1Y3W (University of Leeds) through his role at the University of Leeds but noted no specific connections with the application, 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 Cambridge but noted no specific connections with the application (NIC-194629-S4F9X), or staff involved, and it was agreed that this was not a conflict of interest.</p> <p>Dr. Mark McCartney noted a potential conflict with the ‘OpenSAFELY’ application (NIC-763031-W3L6K) as part of his clinical role. It was agreed this did not preclude Dr. McCartney from taking part in the discussion about this application.</p> <p>Dr. Arjun Dhillon noted a potential conflict with the ‘OpenSAFELY’ application (NIC-763031-W3L6K) as part of his clinical role. It was agreed this did not preclude Dr. Dhillon from taking part in the discussion about this application.</p>

4 BRIEFING PAPER(S) / DIRECTIONS:

4.1**Title:** Lung Cancer Screening Dataset**Presenters:** Charlotte Eylan and Sam Hinks**Observers:** Sandeep Manku, Gavin Harrison, Charlie Graham and Jillette Brown

The purpose of the NHS Vaccinations and Screening Directions 2026 is to direct NHS England to establish and operate an information system for the collection and analysis of data relating to national screening programme participants in England for purposes beyond direct care and the section 7A services. This secondary use of data will enable the delivery of those national screening programmes. It will also enable NHS England to meet its obligations in exercising the Secretary of State's public health functions, as set out in the [NHS public health functions agreement](#) established between the Department of Health and Social Care (DHSC) and NHS England by virtue of [section 7A of the National Health Service Act 2006](#).

The next collection and specification to be added to the frameworks Directions is for the Lung Cancer Screening Programme. Lung Cancer Screening has become a national screening programme following a recommendation from the UK National Screening Committee. This has followed a Cancer Programme pilot called the Targeted Lung Health Check (TLHC) programme.

NHS England were seeking advice on the following points:

1. Any feedback or relevant advice on the Lung Cancer Screening Dataset.

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

In response to point 1 above:

4.1.1 AGD noted that there was existing broad transparency information on the screening programmes, and were advised by NHS England that this is due for a review / update to ensure it is current. NHS England also advised that there would be specific transparency material for the Lung Cancer Screening Dataset. AGD advised that the following should be reflected in any planned updates:

4.1.1.1 when and what data will be used;

4.1.1.2 the legal basis for data access;

4.1.1.3 the approvals process for using the data including but not limited to who is approving and how the process works;

4.1.1.4 contact details for the Data Protection Officer (DPO);

4.1.1.5 whether Type 1 objections are applied to ensure that patients are not surprised; and

4.1.1.6 how other opt-outs are applied across the lung cancer screening and wider programme to ensure patients are not surprised.

4.1.2 AGD welcomed this important work, and commended the work undertaken by NHS England to date on this programme of work.

5 EXTERNAL DATA DISSEMINATION REQUESTS:

<p>5.1</p>	<p>Reference Number: NIC-393510-D6H1D-v11</p> <p>Applicant: University College London (UCL)</p> <p>Application Title: “Children and Families Policy Research Unit (CPRU)”</p> <p>Observers: Dave Cronin and Joe Lawson</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 12th February 2026 and the 4th May 2023.</p> <p>The application and relevant supporting documents were previously presented / discussed at the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) meetings on the 26th May 2022, 17th February 2022, 4th March 2021, 27th June 2019 and the 20th July 2017.</p> <p>Linked applications: This application is linked to NIC-419453-G3G1G, NIC-381972-Q5F0V and NIC-196263-J9Q7Z.</p> <p>Application: This was an amendment application.</p> <p>NHS England were seeking advice on the following points:</p> <ol style="list-style-type: none"> 1. That the purpose provides sufficient clarity on the permitted purposes for using the data for a) CPRU projects commissioned by the Department of Health and Social Care (DHSC); b) non-DHSC commissioned CPRU projects; and c) Great Ormond Street Hospital Biomedical Research Centre (GOSH BRC) projects, and, if not, what additional clarity is needed. 2. That the scope of purpose and the level of delegated decision-making is appropriate. 3. The described use of honorary contracts is appropriate; or should another mechanism for shared access be considered such as sublicensing or a joint controllership arrangement. 4. The governance controls give sufficient assurance that any risks associated with the delegation of decision-making will be mitigated, including the approach to project-by-project data minimisation. 5. The roles of DHSC and 'collaborators' are sufficiently defined and support the determination that UCL is the sole data controller. 6. The requirement for adult data up to age 56 has been adequately justified, and minimisation gives sufficient detail of how this occurs (i.e. is it for people under the age of 56 at 2021, or under 56 at time of release). 7. There is sufficient transparency through UCL's webpages relating to the CPRU and GOSH BRC on the scope of the programmes and the data being used. 8. The assessment of the data as pseudonymised is justified. 9. The use of COVID-19 Second Generation Surveillance System (SGSS) and COVID-19 UK Non-hospital Antigen Testing Results (Pillar 2) data continues to be justified and has an appropriate legal basis. 10. The eligibility for access is sufficiently explained and detailed. 	
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11. There is adequate justification for the inclusion of the additional programme into the purpose.

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

Outcome of discussion: AGD advised that significant concerns had been identified and advised against the proposed further data release. amendment. The Group advised that the following should be addressed by NHS England before any further steps are taken:

In response to points 1 to 11:

5.1.1 AGD noted that, as currently presented, this was a broad and complex request for data access, i.e. extended the data access from specific projects to a programmatic access model; and noted that whilst they had been asked specific questions by NHS England, the discussion was broader, and may not have covered all of the questions in detail.

5.1.2 AGD queried if the proposed approach outlined was appropriate, or whether separate data sharing agreements (DSA) would be more suitable; and advised that NHS England give this further consideration.

5.1.3 AGD noted that there were a number of significant risks in the proposed amendment to the application, and advised that the applicant should provide further clarification in the internal form / application on:

5.1.3.1 the overarching purpose, clearly reflect any sub-projects; and

5.1.3.2 the appropriate safeguards in place to ensure that **only** the data required for each sub-project was processed, and there was no over processing / misuse of data.

5.1.4 It was AGD's opinion that the use cases proposed (and purposes) were not clearly defined, and advised that the applicant review and update the internal form / application with further information / clarity, including, but not limited to:

5.1.4.1 a clear justification;

5.1.4.2 a clear purpose for the requirement of the data; and

5.1.4.3 clarification whether it's the same or different data;

5.1.5 It was the Group's view that the arrangements for delegated decision-making, the use of honorary contracts and the associated governance controls were not clear. AGD advised that, in line with other similar applications, they would expect to see further details of any decision making body for approving access to the data, including, but not limited to, Terms of Reference that include **1)** quoracy; **2)** stakeholder involvement; **3)** patient and public engagement; **4)** ethics; **5)** commercial organisation access; and **6)** determining the potential benefits to the healthcare system in England and Wales; and **7)** that there is a public project register. AGD advised that NHS England engage with the applicant on this.

5.1.6 AGD noted that the approach outlined looked like a secure data environment (SDE) and advised that this would require scrutiny to ensure that the processes were in line with NHS England's SDE.

5.1.7 AGD's opinion was that the reasons for data being required up to the age of 56 were not clear / sufficient. The Group advised that further clarification should be provided by the applicant on the projects undertaken to date, to support the justification for adult data up to

	<p>the age 56, a list of projects that have used this data, and the benefits that have been identified from this.</p> <p>5.1.8 AGD noted in the internal form / application the reference to ‘collaborators’ and advised that the applicant:</p> <ul style="list-style-type: none"> 5.1.8.1 clarify who the collaborators are; and 5.1.8.2 the contractual arrangements for the collaborators. <p>5.1.9 AGD noted in the internal form / application that students would potentially have honorary contracts, and noting that this would not include students from UCL, advised that the applicant clarify which students, and from which organisation, would be working under an honorary contract.</p> <p>5.1.10 AGD noted they had been asked to consider whether the assessment of the data as pseudonymised is justified. The group discussed whether there was a re-identification risk for the data held by UCL, given date of death is flowing to UCL, advised that more information was needed from the applicant on this matter, in particular:</p> <ul style="list-style-type: none"> 5.1.10.1 what has been done to assess the data as pseudonymous rather than confidential and what the risk of re-identification is; and 5.1.10.2 what will be done to mitigate the risk of re-identification. <p>5.1.11 AGD advised 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), noting that the transparency materials were not clear and out of date.</p> <p>5.1.12 Noting the substantial points made on this internal form / application, the Group advised that NHS England request that the applicant provides an update on the points raised in six-months; and advised it be submitted to AGD for a review on progress.</p> <p>In addition to their advice on the specific points raised by NHS England, AGD made the following observations separate to the application:</p> <p>5.1.13 The NHS England SIRO Representative requested that the AGD NHS England Data and Analytics Representative provide the Group with an update at a future AGD meeting on the following:</p> <ul style="list-style-type: none"> 5.1.13.1 the process for ensuring new applicants of data are accessing data in NHS England’s SDE; 5.1.13.2 the process for transitioning existing applicants into NHS England’s SDE; and 5.1.13.3 the latest information on the datasets that still need to migrate into NHS England’s SDE. 	<p>D&A Rep</p>
<p>5.2</p>	<p>Reference Number: NIC-11809-H1Y3W-v8</p> <p>Applicant and Data Controller: University of Leeds</p> <p>Application Title: “Yorkshire Specialist Register of Cancer in Children and Young People”</p> <p>Observer: Emma Whale</p>	

Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 20th November 2025.

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 29th September 2022, 23rd July 2020 and the 13th April 2017.

Linked applications: This application is linked to NIC-656761-R6H7W and NIC-155843-0MQMK.

Application: This was an amendment application.

NHS England were seeking advice on the following points:

1. That the breach issue is now addressed.
2. That the additional dataset is sufficiently justified and minimised.
3. The s251 covers the totality of purpose and datasets now being used.

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

Outcome of discussion: AGD advised that significant concerns had been identified and advised against the proposed data access (dissemination / release). The Group advised that the following should be addressed by NHS England before any further steps are taken:

In response to point 1:

5.2.1 AGD noted that the applicant had breached their data sharing agreement (DSA) by not publishing their Data Security and Protection Toolkit (DSPT), noting a missing publication for 2024/25. AGD advised that as this was a significant breach of the DSA and that:

5.2.1.1 NHS England should undertake an audit to ensure that the entirety of the DSA had been complied with; and,

5.2.1.2 that no further data should flow until this audit had been carried out, and no additional breaches had been identified.

5.2.2 In addition, AGD advised that the breach may also invalidate the s251 support from Health Research Authority Confidentiality Advisory Group (HRA CAG); and advised that NHS England satisfy itself that the applicant has informed HRA CAG of the breach.

In response to points 2 and 3:

5.2.3 AGD noted that the Maternity Services Data Set (MSDS) had been requested, in addition to a renewal of existing data; and that one of the purposes for requesting this MSDS data was for the purpose of understanding how cancer treatments affect fertility outcomes in adolescent and young adult survivors aged 15 -39 years at cancer diagnosis. The Group advised that as the MSDS data would **not** provide direct information on fertility, the applicant should provide further clarification in the internal form / application on the methods for achieving this purpose, to ensure that this is an appropriate release of data.

5.2.4 Noting the sensitive nature of this aspect of the research, the Group advised that the applicant should ensure that appropriate ethical consideration has been undertaken, noting that in line with the [Equality Act 2010](#), pregnancy is a protected characteristic.

	<p>5.2.5 AGD noted that the current s251 support does not cover the updated purpose outlined, and were advised by NHS England that the latest protocol (version 16) had not yet been presented to HRA CAG; however, version 15 of the protocol had been shared with HRA CAG, and this did include the amendment to include the MSDS dataset, and the updated purpose in respect of looking at fertility outcomes. AGD noted and thanked NHS England for the oral update, and advised that as part of the review of version 16 of the protocol, the applicant ensure that HRA CAG confirm that they are content with the proposed updates.</p> <p>In addition to their advice on the specific points raised by NHS England, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.2.6 AGD noted that there was previous linkage to data under NIC-155843-0MQMK, and advised that NHS England satisfy itself, that this linkage is within expectations, and that the two DSA's align.</p>	
<p>5.3</p>	<p>Reference Number: NIC-791211-T1X4G</p> <p>Applicant: University of Surrey</p> <p>Data Controller: University of Hull</p> <p>Application Title: "Improving Bowel Cancer Screening Uptake Among South Asian Adults in Bradford"</p> <p>Observer: Lyndon Dibb</p> <p>Application: This was a new application.</p> <p>NHS England were seeking advice on the following points:</p> <ol style="list-style-type: none"> 1. The flows of data, and the roles of organisations in that flow, are clear. 2. Whether an alternate flow of data direct to University of Hull of pseudonymised data (using a study ID) where it could be combined with other data from the Hub, would be more appropriate. 3. It is clear what data minimisation is occurring. 4. The justification for not using the NHS England secure data environment (SDE) is sufficient (noting the potential for a very limited quantity of data to be provided). <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: In response to the specific points, AGD advised that the following should be addressed before access (dissemination / release) of data proceeds:</p> <p>In response to point 1:</p> <p>5.3.1 AGD queried the role of the University of Surrey, and were advised by NHS England, that they initially supported the set-up of the study, however had no further involvement / influence. The Group advised that NHS England should satisfy itself that they are not acting in any way as a Data Controller, and if this was confirmed, that they were removed from the internal form / application.</p> <p>In response to point 2 and 4:</p>	

	<p>5.3.2 AGD discussed the data flows under this internal form / application, and noted that study was being run from the University of Hull and is dependent on linkage by The North East Bowel Cancer Screening Programme Hub (hosted by the Gateshead Health NHS Foundation Trust). The Group noted that the role and necessity of the ‘Hub’ is currently unclear, and advised that NHS England engage with the applicant on other models which may be more appropriate, for example:</p> <p style="padding-left: 40px;">5.3.2.1 NHS England to directly supply the ethnicity data via a linkage identifier to the University of Hull; or</p> <p style="padding-left: 40px;">5.3.2.2 NHS England to host the study, with a ‘bring your own data’ model in NHS England’s secure data environment (SDE).</p> <p>In response to point 3:</p> <p>5.3.3 AGD noted that the Hospital Episode Statistics (HES) data is restricted to the cohort, and advised that the internal form / application was updated to be clear on which data field are being requested.</p> <p>In addition to their advice on the specific points raised by NHS England, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.3.4 AGD welcomed the application and noted the importance of the study.</p> <p>5.3.5 AGD noted in the internal form / application, that there is ambiguity that could suggest that the ‘Hub’ will generate a separate database, including linked ethnicity data, for wider use. AGD advised NHS England that, if this was the case, it should be covered under a separate data sharing agreement (DSA), which should be considered in its own merit, including, but not limited to, the benefits that may flow from this database.</p> <p>5.3.6 AGD advised that 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). The Group advised that this should include information on opt-out arrangements, and how this works for both the participant group and the control group.</p> <p>5.3.7 AGD advised that the applicant ensure that the internal form / application reflect both potential positive and negative outcomes, in line with NHS England DARS Standard for Expected Outcomes.</p> <p>5.3.8 AGD noted that the potential benefits currently outlined may not fully reflect the broad range of national benefits that may be achieved from this study; and advised that the applicant review and update these in line with NHS England DARS Standard for Expected Measurable Benefits.</p>	
<p>5.4</p>	<p>Reference Number: NIC-226261-M2T0Q-v8</p> <p>Applicant and Data Controller: The Nuffield Trust for Research and Policy Studies in Health Services</p> <p>Application Title: “Nuffield Trust Primary DSA”</p> <p>Observer: Denise Pine</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) meetings on the 13th October 2022, 28th April 2022, 9th September 2021, 29th July 2021 and the 23rd May 2019.

Linked applications: This application is linked to NIC-384572-J7P6Y and NIC-194629-S4F9X (item 5.5).

Application: This was an amendment application.

NHS England were seeking advice on the following points:

1. If the purpose is covered within the scope of the programme of work; and if so,
2. Whether the new dataset is sufficiently justified and minimised.
3. The extract should be permitted given the on-going discussions around a move to using the NHS England secure data environment (SDE).
4. There is sufficient detail on what data minimisation occurs in relation to access for each project.
5. There are sufficient controls in place around downloading of record level data from Nuffield servers.

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

Outcome of discussion: AGD advised that significant concerns had been identified and advised against the proposed further release of data. The Group advised that the following should be addressed by NHS England before any further data release:

In response to point 1:

5.4.1 AGD noted that the purposes as currently stated were very broad, and advised that the internal form / application should be updated, to:

5.4.1.1 explain how the outputs stated relate to the overall purpose, in line with [NHS England DARS Standard for Objective for Processing](#); and

5.4.1.2 clarify how the governance in place for the data aligns with the overall purpose.

5.4.2 AGD noted that there was a governance process in place for access to the data, and commended the involvement of the senior leadership team in this process; however advised that it was unclear if this was in line with what is outlined in the data sharing agreement (DSA) and other similar applications; and noted that they would expect to see further details of any decision making body for approving access to the data, including, but not limited to, Terms of Reference that include **1)** quoracy; **2)** stakeholder involvement; **3)** patient and public engagement; **4)** ethics; **5)** commercial organisation access; and **6)** determining the potential benefits to the healthcare system in England and Wales; and **7)** that there is a public project register. AGD advised that NHS England engage with the applicant on this.

In response to point 2:

	<p>5.4.3 AGD advised that NHS England carefully consider the data requested under this iteration of the internal form / application, including, but not limited to, the justification for the time periods requested, noting that this appears to be open ended.</p> <p>In response to point 3:</p> <p>5.4.4 AGD noted that approved users would access the data via an established secure environment; however, advised that this appears to be a good candidate for transitioning into the NHS England secure data environment (SDE), noting they are only using NHS England data; and noted that this would help mitigate any risks noting the breadth of the datasets requested.</p> <p>In response to point 4:</p> <p>5.4.5 AGD advised that the data minimisation for each project links to the point raised under 5.4.1; and advised that NHS England engage with the applicant on this further in line with NHS England DARS standard for Data Minimisation once the purposes had been reviewed / updated.</p> <p>5.4.6 AGD advised that NHS England confirm with the applicant, how they ensure they only hold data that is relevant to its ongoing list of projects.</p> <p>In response to point 5:</p> <p>5.4.7 AGD advised that there did not appear to be any intention of downloading record level data from Nuffield servers; however, advised that this was clarified with the applicant, to ensure there were appropriate organisational and technical controls in the internal form / application in respect of this.</p> <p>In addition to their advice on the specific points raised by NHS England, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.4.8 AGD noted an inconsistency between the internal form / application that states only substantive employees of Nuffield Trust will be able to access the data; and the Data Protection Impact Assessment (DPIA), that refers to third parties. The Group advised that they were working on the assumption that the internal form / application was correct, noting that any third-party access would be a breach of the DSA, however, advised that NHS England should explore this further with the applicant.</p> <p>5.4.9 AGD noted that some patient and public involvement and engagement (PPIE) had been referred to in the internal form / application, however this was at a broad / generic level, with a reference to this being tailored by project; and advised that NHS England engage with the applicant to ensure this is undertaken at a project level.</p>	
<p>5.5</p>	<p>Reference Number: NIC-194629-S4F9X-v7.1</p> <p>Applicant: The Nuffield Trust for Research and Policy Studies in Health Services</p> <p>Data Controllers: The Nuffield Trust for Research and Policy Studies in Health Services, University College London and University of Cambridge</p> <p>Application Title: “Nuffield RSET”</p> <p>Observer: Denise Pine</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) meetings on the 28th April 2022, 19th August 2021, 18th February 2021, 14th February 2019, 22nd November 2018 and the 30th August 2018.

Linked applications: This application is linked to NIC-226261-M2T0Q (item 5.4) (formerly NIC-384572-J7P6Y).

Application: This was an amendment application.

NHS England were seeking advice on the following points:

1. The purpose is covered within the scope of the programme of work; and if so,
2. Whether the new dataset is sufficiently justified and minimised.
3. The extract should be permitted given the on-going discussions around a move to using the NHS England secure data environment (SDE).
4. There is sufficient detail on what data minimisation occurs in relation to access for each project.
5. There are sufficient controls in place around downloading of record level data from Nuffield servers.

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

Outcome of discussion: AGD advised that significant concerns had been identified and advised against the proposed further release of data. The Group advised that the following should be addressed by NHS England before any further data release:

In response to points 1:

5.5.1 AGD advised the internal form / application was clear on the purpose.

In response to point 2:

5.5.2 AGD noted that the applicant was requesting the Adult Social Care Client Level dataset, and advised that the internal form / application was updated with a clearer justification of why this additional dataset was required.

5.5.3 Noting that the data would be flowing / was accessed under NIC-226261-M2T0Q, the Group queried whether the data was being minimised at the appropriate point, or if it could be minimised at all; and advised that NHS England engage with the applicant to seek further clarification on this, in line with the [NHS England DARS standard for Data Minimisation](#).

5.5.4 AGD advised that NHS England carefully consider the data requested under this iteration of the internal form / application, including, but not limited to, the justification for the time periods requested, noting that this appears to be open ended.

In response to point 3:

5.5.5 AGD noted that approved users would access the data via an established secure environment; however, advised that this appears to be a good candidate for transitioning into the NHS England secure data environment (SDE), noting they are only using NHS England data; and noted that this would help mitigate any risks noting the breadth of the datasets requested.

	<p>In response to point 4:</p> <p>5.5.6 AGD noted the UCL Population Health Sciences webpage references to ‘Birmingham, RAND and Cambridge Evaluation (‘BRACE’) Centre’; and advised that NHS England clarify with the applicant that there is a separation between that project, and the work outlined under this application and the use of this data will be for the purposes outlined in this internal form / application only.</p> <p>In response to point 5:</p> <p>5.5.7 AGD advised that there did not appear to be an intention of downloading record level data from Nuffield servers; however, advised that this was clarified with the applicant, to ensure there were appropriate controls in the internal form / application in respect of this.</p> <p>In addition to their advice on the specific points raised by NHS England, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.5.8 AGD noted that the internal form / application states data access will be for “<i>Substantive employees of the Nuffield Trust NIHR RSET team</i>”; and advised that this was updated to remove the reference to “<i>...NIHR RSET team</i>”.</p> <p>5.5.9 AGD queried if the applicant had submitted a recent annual compliance report (ACR), and were advised by NHS England, that the latest ACR received was from 2024. The Group advised that the applicant ensure that the most recent ACR was submitted to NHS England as per process; and advised that data should not flow until this has been received.</p>	
<p>5.6</p>	<p>Reference Number: NIC-795997-H9N1D-v0.1</p> <p>Applicant and Data Controller: The Royal Marsden Hospital</p> <p>Application Title: “Outcomes in Ano-Uro-Genital Mucosal Melanoma in England”</p> <p>Observer: Tiaro Micah</p> <p>Application: This was a new application.</p> <p>NHS England were seeking advice on the following points:</p> <ol style="list-style-type: none"> 1. That the application is correctly categorised as ‘service evaluation’. 2. Separate to the application: Point 1 accepted, whether this application could have been considered for approval under a new Precedent and if so, what criteria might apply. <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: In response to the specific points, AGD advised that the following should be addressed before access (dissemination / release) of data proceeds:</p> <p>In response to point 1:</p> <p>5.6.1 AGD noted that the form / application referred to the work being undertaken as “<i>service evaluation</i>”, however queried whether the work was in fact “<i>research</i>”, noting the ‘research’ themed outputs; or had elements of both. The Group advised that:</p>	

	<p>5.6.1.1 NHS England clarify with the applicant organisation whether the work was “<i>service evaluation</i>” and / or “<i>research</i>”, for example, via the Health Research Authority (HRA) decision tool;</p> <p>5.6.1.2 the form / application is updated to reflect the correct / factual information, in line with NHS England’s DARS Standards;</p> <p>5.6.1.3 the expected outcomes are reviewed / updated in line with NHS England DARS Standard for Expected Outcomes; and</p> <p>5.6.1.4 the expected benefits are reviewed / updated in line with NHS England DARS Standard for Expected Measurable Benefits</p> <p>5.6.2 AGD advised that if any of the work outlined was considered to be ‘research’, then further consideration should be given to:</p> <p>5.6.2.1 seeking / obtaining the view / support of a research ethics committee; and</p> <p>5.6.2.2 undertake some patient and public involvement and engagement (PPIE).</p> <p>In response to point 2:</p> <p>5.6.3 AGD noted that notwithstanding the points made in 5.6.1 in respect of the purpose of the application, this appeared to be relatively low risk, and did appear to be a candidate for approval under a new Precedent.</p> <p>5.6.4 AGD advised that some of the criteria that might apply to a new Precedent:</p> <p>5.6.4.1 whether the project is time limited;</p> <p>5.6.4.2 whether the project is restricted to a narrowly defined set of health conditions;</p> <p>5.6.4.3 that data is accessed via the NHS England secure data environment (SDE);</p> <p>5.6.4.4 the territory of use is in the UK,</p> <p>5.6.4.5 there is a single Data Controller; and</p> <p>5.6.4.6 that relevant exclusion criteria are identified.</p> <p>5.6.5 AGD looked forward to further information / engagement on this work as may be required.</p> <p>In addition to their advice on the specific points raised by NHS England, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.6.6 AGD noted in the internal form / application, that one of the Investigators was a Research Fellow who was substantively employed at The Royal Marsden Hospital and a PhD Candidate at the Institute of Cancer Research (ICR). The Group noted that it was unclear if this information was noted for background information; or if this project was informing / part of PhD or other research at the ICR; and advised that NHS England satisfy itself that ICR do not have data controllership responsibilities in line with NHS England DARS Standard for Data Controller(s).</p>	
<p>5.7</p>	<p>Reference Number: NIC-763031-W3L6K</p> <p>Applicant and Data Controller: The University of Manchester</p>	

<p>Application Title: “OpenPREGnosis-Longitudinal: Expanding and Validating Pregnancy Identification Algorithms”</p> <p>Observer: Ayse Depsen</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 26th March 2026.</p> <p>The application and relevant supporting documents were previously presented / discussed at the Profession Advisory Group (PAG) meetings on the 20th March 2026.</p> <p>Application: This was a new application.</p> <p>NHS England were seeking advice on the following points:</p> <ol style="list-style-type: none"> 1. Whether the points previously raised by AGD have been sufficiently addressed. 2. Separate to the application: clarification as to whether it would be helpful to have details of the specific datasets accessed within OpenSAFELY in the internal form / application. <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: In response to the specific points, AGD advised that the following should be addressed before access (dissemination / release) of data proceeds:</p> <p>In response to point 1:</p> <p>5.7.1 AGD noted the responses to the points made by the Group on the 26th March 2026, and advised that they had been addressed satisfactorily with the exception of the previous point (5.2.4) made in respect of pregnancy being a protected characteristic, and any further assessment that may be required, noting that this is a protected characteristic as outlined in the Equality Act 2010. The Group advise that NHS England strongly encourages the applicant to demonstrate how they have taken equality into consideration with the design of their algorithm and how it might be used, for example, by completing an Equality Impact Assessment (EqIA), that should cover the lifecycle of the study, noting that the algorithm they are potentially producing, may be used to select individuals with a protected characteristic.</p> <p>In response to point 2:</p> <p>5.7.2 AGD advised that, at the current time, given the limited access via OpenSAFELY it would not be necessary to detail the specific datasets accessed within OpenSAFELY in the internal form / application; however, noted that this position may change as things progress in this area.</p>	
<p>6 INTERNAL DATA DISSEMINATION REQUESTS:</p>	
<p><i>There were no items discussed</i></p>	
<p>7 EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL</p>	
<p>7.1</p>	<p>Reference Number: NIC-748729-Z8B3M-v1.3</p> <p>Applicant and Data Controller: University of Bristol</p> <p>Application Title: “UK Longitudinal Linkage Collaboration (UK LLC) – Consent”</p>

	<p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 21st November 2024.</p> <p>The application and relevant supporting documents were previously presented / discussed at the IGARD COVID-19 response meetings on the...</p> <p>Linked applications: This application is linked to NIC-420229-G9H9S (item 7.2).</p> <p>The SIRO approval was for a number of amendments to the data sharing agreement (DSA). It was noted that all of the amendments were progressing via the SIRO approval route, due to non-compliance with the DSA.</p> <p>Outcome of discussion: AGD noted that the NHS England SIRO had already provided SIRO approval on the 17th March 2026 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>
7.2	<p>Reference Number: NIC-420229-G9H9S-v1.3</p> <p>Applicant and Data Controller: University of Bristol</p> <p>Application Title: “University of Bristol - Longitudinal Linkage Collaboration - s251 cohort”</p> <p>Linked applications: This application is linked to NIC-748729-Z8B3M (item 7.1).</p> <p>The SIRO approval was for an additional Longitudinal Population Study in scope of the data sharing agreement (DSA), namely, the Caerphilly Heart Disease Study, also known as the Caerphilly Prospective Study (CaPS).</p> <p>Outcome of discussion: AGD noted that the NHS England SIRO had already provided SIRO approval on the 17th March 2026 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>
8 OVERSIGHT AND ASSURANCE	
8.1	<p>Oversight and Assurance Process</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) six applications (selected by the AGD Secretariat); 2) internal application assessment forms for each of the six applications; and 3) an oversight and assurance template to complete for each of the applications that each individual member had been asked to review.</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 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 six applications.</p>	
<p>8.2</p>	<p>Oversight and Assurance Conclusion / Review</p> <p>AGD noted that the last oversight and assurance for workstream 2 review had taken place on the 12th March 2026.</p> <p>The Group noted that whilst the majority of applications clearly communicated how the previous AGD comments had been addressed, a few 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; 3) the response to the previous AGD comments could have been clearer; and 4) AGD minutes should be dated within the SDA.</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) reviewing fewer applications per independent member was more effective; and 3) two independent members per review was sufficient.</p> <p>The Group acknowledged that some of the points highlighted above may be in part due to ongoing issues in the NHS England Customer Relationship Management (CRM) system, in that the documentation was not always visible. AGD and the NHS England SIRO Representative suggested work to rectify this issue be prioritised as a matter of urgency, since the lack of visibility of documents did not just affect the small number of applications picked each month for oversight and assurance, but more importantly impacted on all other applications where a clear document audit trail of the decision making, may not be visible to NHS England staff.</p> <p>The AGD Chair noted that O&A was a key topic for discussion at the next plenary meeting on the 18th June 2026 and would welcome the Group's thoughts and feedback on how the process and feedback can be improved to support NHS England.</p>	<p>TO NOTE</p>
<p>9 AGD OPERATIONS</p>		
<p>9.1</p>	<p>AGD ways of working</p> <p><i>There were no items discussed</i></p>	
<p>9.2</p>	<p>AGD Stakeholder Engagement</p> <p><i>There were no items discussed</i></p>	
<p>9.3</p>	<p>AGD Project Work</p> <p><i>There were no items discussed</i></p>	
<p>10 Any Other Business</p>		

<p>10.1</p>	<p>AGD Service Improvements (Presenter: Karen Myers)</p> <p>An update was provided to the group, in respect of the service improvement programme of work, where a number of 'observations' and 'actions' were highlighted following initial feedback from the AGD members and NHS England colleagues.</p> <p>AGD thanked Karen for the work she was doing on this programme of work and looked forward to future service improvement discussions.</p>
<p>10.2</p>	<p>NHS England Patient & Public Involvement and Engagement (PPIE) Standard</p> <p>The Group queried the consideration by NHS England of a PPIE Standard, following discussion at AGD on the 13th November 2025 (see item 10.2), 6th November 2025 (see item 10.1) and 24th July 2025 (see item 5.2.7).</p> <p>The NHS England SIRO Representative advised that there was an ongoing / wider programme of work in respect of PPIE, and that work in respect of developing a PPIE Standard had been linked into this work; and advised that an update would be provided to the Group at the 4th June 2026 AGD meeting.</p> <p>The Group noted and thanked the NHS England SIRO Representative for the update, and looked forward to a further update on the 4th June 2026.</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>	

Appendix A

Oversight and Assurance Review – 14th May 2026

Ref:	NIC Number:	Organisation:	Areas to consider:
260514a	NIC-152414-W3P6Q-v5.5	University of Bristol	<p>The application has last been seen by AGD on the 27th November 2025 where the majority of the Group (seven) were supportive of the application and a minority of the Group (one AGD independent member) was not supportive of the application at the time due to the query raised on the process for effectively determining whether research is for commercial gain / profit or not</p> <p>Feedback on the application:</p> <ul style="list-style-type: none"> • Notwithstanding the technical issues with CRM, the Group suggested that the guidance in the SOP, in response to 5.4.2 could be clearer. • Notwithstanding the technical issues with CRM, the Group noted DAS had provided a position and would welcome an update from the NHSE SIRO Representative in response to item 5.4.3 – it was agreed the response should be updated to “noted”, since the position was not agreed by NHSE. • Notwithstanding the technical issues with CRM, the Group noted that in response to 5.4.5 there was no indication the ToRs had been checked by DAS nor evidence that a special condition had been added prior to the DSA becoming active.

			<p>Feedback on the process:</p> <ul style="list-style-type: none"> • Notwithstanding the technical issues with CRM – Process point: Action for D&A Representative to ensure that all relevant documentation, for example the SDA / escalation form, clearly indicate the actions taken by DAS in response to the AGD minutes.
260514b	NIC-778927-P3D9Z-v0.2	Imperial College London	<p>The application had last been seen by AGD on the 4th December 2025 when the Group had been supportive IF the substantive comments had been addressed.</p> <p>Feedback on application:</p> <ul style="list-style-type: none"> • Notwithstanding the technical issues with CRM, the Group noted that a special condition seemed necessary to align with the response to point 5.5.1. <p>Feedback on the process:</p> <ul style="list-style-type: none"> • Notwithstanding the technical issues with CRM – Process point: Action for D&A Representative to ensure that any special conditions are updated to the DSA prior to it becoming active.
260514c	NIC-791694-D2J8T-v0.3	Cristal Health Ltd t/a Akrivia Health	<p>The application had last been seen by AGD on the 4th December 2025 when the Group had been supportive IF the substantive comments had been addressed.</p> <p>Feedback on the application:</p> <ul style="list-style-type: none"> • No issues raised on the application. <p>Feedback on the process:</p>

			<ul style="list-style-type: none"> No issues raised on the process.
260514d	NIC-338864-B3Z3J-v6.2	Barts and the London School of Medicine and Dentistry	<p>The application had last been seen by AGD on the 22nd January 2026 when the Group had been supportive IF the substantive comments had been addressed and were providing advice in response to NHSE’s request for advice on specific points only.</p> <p>Feedback on the application:</p> <ul style="list-style-type: none"> Notwithstanding the technical issues with CRM, the Group noted that it was not clear how the points raised by AGD would be picked up at renewals, extension or amendment, since the most recent AGD minutes were not findable in the SDA document provided. <p>Feedback on the process:</p> <ul style="list-style-type: none"> Notwithstanding the technical issues with CRM – Process point: Action for D&A Representative to ensure that all relevant documentation, for example the SDA / escalation form, are easily findable in the document holder(s) on CRM.
260514e	NIC-791168-N2D1Z-v0.2	London School of Hygiene and Tropical Medicine	<p>The application had last been seen by AGD on the 22nd January 2026 when the Group had been supportive IF the substantive comments had been addressed.</p> <p>Feedback on the application:</p> <ul style="list-style-type: none"> Notwithstanding the technical issues with CRM, the Group noted that it was not clear how the points raised by AGD would be picked up at renewal,

			<p>extension or amendment, since the most recent AGD minutes were not findable in the SDA document provided.</p> <p>Feedback on the process:</p> <ul style="list-style-type: none"> • Notwithstanding the technical issues with CRM – Process point: Action for D&A Representative to ensure that all relevant documentation, for example the SDA / escalation form, are up to date and the most recent AGD minutes are dated.
260514f	NIC-144057-G4S0Q-v5.11	University of Oxford	<p>The application had last been seen by AGD on the 22nd January 2026 when the Group had been supportive IF the substantive comments had been addressed and were providing advice in response to NHSE’s request for advice on specific points only.</p> <p>Feedback on the application:</p> <ul style="list-style-type: none"> • No issues raised on the application. <p>Feedback on the process:</p> <ul style="list-style-type: none"> • No issues raised on the process.