

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 12th June 2025

09:00 – 15:50

(Remote meeting via videoconference)

AGD INDEPENDENT / NHS ENGLAND MEMBERS IN ATTENDANCE:	
Name:	Role:
Paul Affleck (PA)	AGD independent member (Specialist Ethics Adviser) Chair (In attendance for items 1 to 5.3)
Claire Delaney-Pope (CDP)	AGD independent member (Specialist Information Governance Adviser)
Kirsty Irvine (KI)	AGD independent member (Chair) (In attendance for items 5.4 to 12)
Dr. Jonathan Osborn (JO)	NHS England member (Caldicott Guardian Team Representative) (not in attendance for part of item 5.1 (CCU107))
Jenny Westaway (JW)	AGD independent member (Lay Adviser)
Ellie Ward (EW)	NHS England member (Data Protection Office Representative (Delegate for Jon Moore))
Tom Wright (TW)	NHS England member (Data and Analytics Representative (Delegate for Michael Chapman)) (not in attendance for part of item 5.1 (CCU108 / CCU109 / CCU110), part of item 9 and items 10 to 12)
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	Role / Area:
Ricky Brooks (RB)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.5)
Garry Coleman (GC)	NHS England SIRO Representative (not in attendance for items 1 to 3)
Dave Cronin (DC)	Applications Service Owner, Data Access and Partnerships, Transformation Directorate (Observer: item 5.1)
Suzanne Hartley (SH)	Data Applications Service (DAS) - Senior Manager, Data Access and Partnerships, Transformation Directorate (Observer: item 5.3)
Stephen Hindle (SH)	Infectious Diseases Programme Manager, Prevention and Long-Term Conditions Team, Medical Directorate (Observer: item 5.4)
Andrew Ireland (AI)	Information Governance Specialist, IG Risk and Assurance, Deputy Chief Executive Directorate (Observer: item 5.1)

Adele Mackin (AM)	Policy Programme Delivery Manager – TB Prevention, Medical Directorate (Observer: item 5.4)
Nicki Maher (NM)	IG Assurance, Risk and Audit Services Lead, Privacy, Transparency, and Trust, Deputy Chief Executive Directorate (Observer: item 5.1)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Deputy Chief Executive Directorate
John Robinson (JR)	Senior Information Governance Manager, Privacy, Transparency, and Trust, Deputy Chief Executive Directorate (Observer: item 5.1)
Jodie Taylor-Brown (JTB)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: items 5.2, 5.4 and 9)
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Deputy Chief Executive Directorate
AGD INDEPENDENT MEMBERS / NHS ENGLAND MEMBERS <u>NOT</u> IN ATTENDANCE:	
Name:	Role / Area:
Michael Chapman (MC)	NHS England member (Data and Analytics Representative)
Dr. Robert French (RF)	AGD independent member (Specialist Academic / Statistician Adviser)
Jon Moore (JM)	NHS England member (Data Protection Office Representative)
Miranda Winram (MW)	AGD independent member (Lay Adviser)

1	<p>Welcome and Introductions:</p> <p>The AGD meeting Chair welcomed attendees to the meeting.</p> <p>AGD noted that, due to the lack of availability of independent members, there was an even number of AGD independent members (three) and AGD NHS England members (three) in attendance for the meeting.</p> <p>The importance of the AGD independent member majority was acknowledged by those present, and it was suggested that an annual review / possible inclusion in the AGD annual report of the number of meetings where an independent majority had not been present would be useful, as this would allow consideration of whether any action needed to be taken to improve the proportion of meetings with an AGD independent member majority.</p> <p>In line with existing practice, should AGD members be required to vote on any issues in the meeting, then one AGD NHS England member would be asked to not participate, to ensure the appropriate balance of votes.</p>
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	<p>Noting that the AGD Terms of Reference state that “<i>The majority of the members of the Group or Sub-Group involved in any meeting should be independent members...</i>”, the Group agreed that the meeting was still quorate for all agenda items and agreed to proceed on that basis.</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 items 1 to 3.</p> <p>Noting that the AGD Terms of Reference (ToR) state that: “...<i>a representative of the SIRO must also be in attendance for any meetings of the Group or a Sub-Group...</i>”, the Group were advised that, prior to the meeting, the NHS England SIRO Representative had confirmed contentment for items 1 to 3 to be discussed in his absence; and noted that he would be in attendance for item 5.1 onwards. The Group noted that the meeting was not quorate because of this, and, on this occasion, the Chair agreed to proceed in accordance with clause 7.13 of the AGD ToR. This clause provides that: “<i>In exceptional circumstances the Chair and the representative of the SIRO may agree for the Group to still meet and conduct its business, but the minutes should note the meeting was not quorate...</i>”.</p>
2	<p>Review of previous AGD minutes:</p> <p>The minutes of the AGD meeting on the 5th June 2025 were reviewed and, after several minor amendments, were agreed as an accurate record of the meeting.</p>
3	<p>Declaration of interests:</p> <p>Claire Delaney-Pope noted a professional link to King's College London (NIC-381078-Y9C5K) 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>
4 BRIEFING PAPER(S) / DIRECTIONS:	
<i>There were no items discussed</i>	
5 EXTERNAL DATA DISSEMINATION REQUESTS:	
5.1	<p>Reference Number: NIC-381078-Y9C5K-v11.3</p> <p>Applicant: Health Data Research UK (British Heart Foundation (BHF) Data Science Centre)</p> <p>Data Controllers: Imperial College London, Kings' College London, London School of Hygiene and Tropical Medicine, Swansea University, The University of Manchester, University College London (UCL), University of Bristol, University of Cambridge, University of Dundee, University of Glasgow, University of Leicester, University of Liverpool, University of Nottingham, University of Oxford, University of Sheffield, and the University of Southampton</p> <p>Application Title: “R14.2 - COVID-IMPACT-UK. Health conditions and COVID19: using UK-wide linked routine healthcare data to address the impact of health conditions on COVID-19 and the impact of COVID-19 on health conditions”</p> <p>Observers: Dave Cronin, Nicki Maher, Andrew Ireland and John Robinson</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 22nd February 2024.</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 24th November 2022, 5th May 2022, 29th July 2021, 25th February 2021, 6th August 2020, 3rd December 2020, 22nd October 2020, 15th October 2020, 20th August 2020, 23rd July 2020 and the 25th June 2020.

The application and relevant supporting documents were previously presented / discussed at the IGARD COVID-19 response meetings on the 29th June 2021, 19th January 2021, 24th November 2020, 16th June 2020, 9th June 2020, 2nd June 2020 and the 26th May 2020.

The application and relevant supporting documents were previously presented / discussed at the General Practice Extraction Service (GPES) Data for Pandemic Planning and Research (GDPPR) – Profession Advisory Group (PAG) meetings on the 28th July 2021 and the 24th June 2020.

Application: This was a seeking advice application.

NHS England were seeking advice on the following points **only**:

1. Whether or not each of the eight final projects should be supported and allowed to proceed (in the context of the agreed DSA).

Outcome of discussion: AGD noted NHS England were **not** seeking support of the application itself, and made the following observations on the eight final projects as part of the review:

AGD noted that they had been provided with a curated set of documentation and would be providing observations based on these documents.

Project 1 (CCU099: Cardiovascular disease and cancer screening, diagnosis and mortality in people with severe or complex mental illness: the impact of the COVID-19 pandemic)

5.1.1 The Group noted that the project sought to access GPES data for pandemic planning and research (COVID 19) (GDPPR) data which is for COVID-19 related purposes only. AGD discussed whether COVID-19 was central to this project, noting that it could be interpreted that this was a secondary aim; however, AGD agreed that it did fall within scope, and they were therefore **supportive** of the project.

5.1.2 AGD noted that the document provided on this project was not clear on the specific datasets that would be processed; and suggested that the document was updated with further clarity.

5.1.3 AGD suggested that NHS England and the applicant ensure that appropriate data minimisation is undertaken, in line with the [NHS England DAS standard for data minimisation](#).

5.1.4 AGD noted the importance of the research outlined.

Project 2 (CCU102: The effects of COVID-19 on rate of A&E attendances for dental reasons in the general, learning disability, and at-risk-of-infective-endocarditis populations)

5.1.5 The Group noted that the project sought to access GDPPR data which is for COVID-19 related purposes only. A minority of AGD members (two) were **supportive** of the project outlined. The majority of AGD members were **not supportive** of the project outlined, noting

<p>that some of the elements of the project were out of scope and COVID-19 was not sufficiently central. It was suggested that if the project was reviewed and updated, then it may fall within scope.</p> <p>5.1.6 AGD noted that the document provided on this project, was not clear on the specific datasets that would be processed; and suggested that the document was updated with further clarity.</p> <p>5.1.7 AGD suggested that NHS England and the applicant ensure that appropriate data minimisation is undertaken, in line with NHS England DAS standard for data minimisation.</p> <p>Project 3 (CCU103: Healthcare utilisation of patients with atrial fibrillation in England pre and post COVID-19 pandemic)</p> <p>5.1.8 The Group noted that the project sought to access GPPR data which is for COVID-19 related purposes only. AGD agreed that the project did fall within the scope of having a COVID-19 purpose, and had the potential to inform relevant national policy, and were therefore supportive of the project.</p> <p>5.1.9 AGD noted that the document provided on this project, was not clear on the specific datasets that would be processed; and suggested that the document was updated with further clarity.</p> <p>5.1.10 AGD suggested that NHS England and the applicant ensure that appropriate data minimisation is undertaken, in line with NHS England DAS standard for data minimisation.</p> <p>Project 4 (CCU104: Neurological consequences of COVID-19: impact of the COVID-19 pandemic on stroke and dementia in England)</p> <p>5.1.11 The Group noted that the project sought to access GPPR data which is for COVID-19 related purposes only. AGD noted that the project did fall within the scope of having a COVID-19 purpose, and they were therefore supportive of the project.</p> <p>5.1.12 AGD did however discuss aim three of the project in respect of the <i>“to enhance clinical risk prediction models for the susceptibility and prognosis of stroke and dementia, as well as the impact of COVID-19 on these risks, aiming to enable earlier interventions and better targeted treatments”</i>, and agreed that whilst this was in scope, focus should be given to the COVID-19 aspects.</p> <p>5.1.13 AGD also queried if the prediction project / model had any commercial aspects, and suggested that NHS England discussed this further with the applicant in line with NHS England DAS Standard for Commercial Purpose. The Group advised that if there was a commercial aspect, this may not be compatible with the agreed DSA.</p> <p>5.1.14 AGD noted that the document provided on this project, was not clear on the specific datasets that would be processed; and suggested that the document was updated with further clarity.</p> <p>5.1.15 AGD suggested that NHS England and the applicant ensure that appropriate data minimisation is undertaken, in line with NHS England DAS standard for data minimisation.</p> <p>5.1.16 AGD noted the potential importance of the project outlined.</p>	
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	<p>Project 5 (CCU107: An intersectionality approach to evaluate the variation of statins and anticoagulants prescriptions among stroke survivors before and during COVID-19)</p> <p>5.1.17 The Group noted that the project sought to access GDPR data which is for COVID-19 related purposes only. A minority of AGD members (two) were supportive of the project outlined if the relevance of COVID-19 to the sub-group was clarified / justified. The majority of AGD members were not supportive of the project outlined, noting that some of the elements of the project were out of scope and COVID-19 was not sufficiently central.</p> <p>5.1.18 AGD noted that the document provided on this project, was not clear on the specific datasets that would be processed; and suggested that the document was updated with further clarity.</p> <p>5.1.19 AGD suggested that NHS England and the applicant ensure that appropriate data minimisation is undertaken, in line with NHS England DAS standard for data minimisation.</p> <p>Project 6 (CCU108: Simulation modelling of aortic disease detection and management: implications for post-COVID policy)</p> <p>5.1.20 The Group noted that the project sought to access GDPR data which is for COVID-19 related purposes only. A minority of AGD members (two) were supportive of the project outlined. The majority of AGD members were not supportive of the project outlined, noting that some of the elements of the project were out of scope and COVID-19 was included in addition to a wider project / scope.</p> <p>5.1.21 AGD noted that the document provided on this project, was not clear on the specific datasets that would be processed; and suggested that the document was updated with further clarity.</p> <p>5.1.22 AGD suggested that NHS England and the applicant ensure that appropriate data minimisation is undertaken, in line with NHS England DAS standard for data minimisation.</p> <p>5.1.23 AGD noted the potential importance of the project outlined.</p> <p>Project 7 (CCU109: Inequalities in non-ST elevation myocardial infarction care during the COVID-19 pandemic for people living with chronic kidney disease and frailty)</p> <p>5.1.24 The Group noted that the project sought to access GDPR data which is for COVID-19 related purposes only. AGD noted that the project outlined did fall within the scope of having a COVID-19 purpose, and they were therefore supportive of the project.</p> <p>5.1.25 AGD noted the references to future research need to be removed, noting that this would be out of scope.</p> <p>5.1.26 AGD noted that the document provided on this project, was not clear on the specific datasets that would be processed; and suggested that the document was updated with further clarity.</p> <p>5.1.27 AGD suggested that NHS England and the applicant ensure that appropriate data minimisation is undertaken, in line with NHS England DAS standard for data minimisation.</p> <p>5.1.28 AGD noted the potential importance of the project outlined</p> <p>Project 8 (CCU110: Unplanned hospital use and ambulance conveyances for people in the last year of life, and the impact of the COVID-19 pandemic))</p>	
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	<p>5.1.29 The Group noted that the project sought to access GDPR data which is for COVID-19 related purposes only. A majority of AGD members (four) were not supportive of the project outlined, noting that the purpose of the project was too broad and was therefore out of scope. One AGD member was unsure if the project was in or out of scope.</p> <p>5.1.30 AGD noted that the document provided on this project, was not clear on the specific datasets that would be processed; and suggested that the document was updated with further clarity.</p> <p>5.1.31 AGD suggested that NHS England and the applicant ensure that appropriate data minimisation is undertaken, in line with NHS England DAS standard for data minimisation.</p> <p>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.1.32 AGD queried if any of the eight projects would involve the use of Artificial Intelligence (AI); and suggested that NHS England explored this further with the applicant.</p> <p>5.1.33 AGD noted that, regarding all of the projects discussed, that any eventual published outputs would need to flow from COVID-19 purposes.</p> <p>5.1.34 Separate to this application and for NHS England to consider: AGD noted that several of the submitted projects include the development of data models as part of their proposed outcomes. The Group advised that the Data Controller should assure themselves that any creation of data models is transparent within the project specific applications and that any potential commercial aspects are considered. The Data Controller should be assured that they are aware of what the outputs from these models are used for after the project end. It should also be considered that the data used to train these models will not be readily available after the end of this programme ends and this needs to be considered if replication is required.</p> <p>5.1.35 AGD members noted the possibility of commercial aspects.</p>	D&A Rep
5.2	<p>Reference Number: NIC-780525-J4L3S-v0.3</p> <p>Applicant: NHS England</p> <p>Data Controller: Department of Health and Social Care (DHSC)</p> <p>Application Title: “NHSE / DHSC – Enabling Policy Analysis – UDAL”</p> <p>Observer: Jodie Taylor-Brown</p> <p>Application: This was a new application.</p> <p>NHS England were seeking general advice on the application.</p> <p>Should an application be approved by NHS England, further details would be made available within the Data Uses Register.</p> <p>Outcome of discussion: AGD deferred the application as not all the necessary information was available to make a full assessment. AGD wished to draw to the attention of the SIRO the following substantive points; and suggested that the application be brought back to a future meeting once AGD points had been sufficiently addressed:</p>	

<p>5.2.1 AGD suggested that clarity was provided on the relationship between DHSC and NHS England, and whether they are jointly controlling a single project, or whether there is a different arrangement, noting that this was currently unclear.</p> <p>5.2.2 AGD noted that section 5(a) (Objective for Processing) outlined the broad scope of processing to support public sector bodies in policy development; however, suggested that it was made clear what the relevant statutory powers were for the Data Controllers (DHSC and NHS England), noting that this would impact on the scope of what could / could not be done.</p> <p>5.2.3 AGD noted that Article 9(2)(j) (<i>processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes</i>) of the UK General Data Protection Regulation (UK GDPR) had been cited; however, suggested that this was reviewed and amended as may be necessary, noting that an alternate or more than one Article 9 legal basis may be appropriate in this instance.</p> <p>5.2.4 AGD noted the references throughout the application to “<i>research</i>”; and noted that this did not align with the statement in section 7 (Ethics Approval) that “<i>Ethics approval is not required because the data will be used exclusively for non-research purposes</i>”. AGD suggested that NHS England explore this further with the application to ensure the correct information was reflected in the application.</p> <p>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.2.5 AGD welcomed the application and noted they were supportive of the work outlined.</p> <p>5.2.6 AGD noted that, prior to the meeting, a query had been raised by an AGD independent member in respect of 1) the information in the application, that describes the data as both identifiable and pseudonymised; and 2) the information within the data specification provided as a supporting document (SD1) that included local patient identifiers and consultant codes, and why these fields, which were not pseudonymised, were needed for supporting policy development. The Group were advised by NHS England that the data would be pseudonymised and that the consultant code would be removed as it was not necessary / required. The Group noted the update and suggested that 1) the application was updated throughout to reflect this update; and 2) a clear justification was provided in the application for the processing of local patient identifiers.</p> <p>5.2.7 Separate to this application and for NHS England to consider: AGD noted that in light of the forthcoming NHS England / DHSC organisational changes, data may currently be pseudonymised in the hands of DHSC, however this may change in the future; and that these risks should be given further consideration via the relevant Data Protection Impact Assessment (DPIA).</p> <p>5.2.8 AGD noted that section 1(b) (Data Controller(s)) referred to DHSC’s Data Security and Protection Toolkit (DSPT); and noting that DHSC do not rely on DSPT for their security assurance, suggested that this was updated with the correct information.</p> <p>5.2.9 AGD noted that section 1(b) referred to “<i>NHS England (Quarry House)</i>”, and noted a Quarry House address; and suggested that this was updated to reflect the most recent / up to date information.</p>	<p>SIRO Rep / D&A Rep</p>
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	<p>5.2.10 AGD noted the reference in section 5(b) (Processing Activities) to aggregated data flowing to DHSC’s “<i>DAC platform</i>”; and suggested that further clarity was provided as to what else was stored on this platform, and how this aligned with the application.</p> <p>5.2.11 AGD noted the reference in section 5(c) (Specific Outputs Expected) to the “<i>creation of software tools</i>”; and suggested that, if this is correct, that this was also added to the purposes outlined in section 5(a).</p> <p>5.2.12 AGD suggested that the application was updated to reflect the standard NHS England citation special condition in section 6 (Special Conditions).</p> <p>5.2.13 AGD suggested that the application was reviewed and updated to ensure that the specific Secretary of State / title was referred to consistently throughout the application.</p> <p>5.2.14 No AGD member noted a commercial aspect to the application.</p>	
5.3	<p>Reference Number: NIC-484452-H8S1L-v9.6</p> <p>Applicant and Data Controller: Department of Health and Social Care (DHSC)</p> <p>Application Title: “Department of Health and Social Care (DHSC) SDE access - Enabling Policy Analysis”</p> <p>Observer: Suzanne Hartley</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 27th February 2025, 3rd October 2024, 11th July 2024, 25th January 2024 and the 14th December 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 8th September 2022, 19th May 2022, 7th April 2022, 21st October 2021 and the 16th September 2021.</p> <p>The application and relevant supporting documents were previously presented / discussed at the General Practice Extraction Service (GPES) Data for Pandemic Planning and Research (GDPPR) – Profession Advisory Group (PAG) meetings on the 24th November 2021, 3rd November 2021, 15th September 2021 and the 25th August 2021.</p> <p>Application: This was an amendment application.</p> <p>NHS England were seeking advice on the following points only:</p> <ol style="list-style-type: none"> 1. To allow DHSC secondees to access NHS England Data. <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 not providing comments on the wider application as requested by NHS England; comments were limited to the specific point of advice requested. AGD wished to draw the attention of the SIRO to the following observations in relation to the advice point:</p> <p>AGD noted that they had been provided with a curated set of documentation and that they would be providing observations based on these documents.</p>	

	<p>5.3.1 AGD reviewed the responses to the previous points made at the AGD meeting on the 3rd October 2024, and advised that they had no comments.</p> <p>In response to point 1:</p> <p>5.3.2 In respect to the amendment to allow DHSC secondees to access NHS England Data, AGD advised that this was a sensible approach. AGD suggested that it should be restricted to secondees from public bodies, however if it was expanded beyond this, then this would require further consideration by NHS England.</p> <p>5.3.3 AGD discussed the training and governance arrangements for the secondees, and suggested that the special conditions in section 6 (Special Conditions) were amended: 1) point 4 of special condition 7.0 was updated to clearly define the seniority of those giving access to the data within DHSC; and 2) an additional point 6 was added to special condition 7.0 to state that up to date information governance training was required and appropriate evidence of this was retained for each secondee.</p> <p>In addition, AGD made the following observation on the application and / or supporting documentation provided as part of the review:</p> <p>5.3.4 No AGD member noted a commercial aspect to the application.</p>	
<p>5.4</p>	<p>Reference Number: NIC-780518-Q7K4W-v0.2</p> <p>Applicant: UK Health Security Agency</p> <p>Data Controller(s): Department for Health and Social Care (DHSC)</p> <p>Application Title: “Flag 4 - Latent TB Screening Portal and Database (LTBI)”</p> <p>Observers: Jodie Taylor-Brown, Adele Mackin and Stephen Hindle</p> <p>Application: This was a new application.</p> <p>NHS England were seeking general advice on the application.</p> <p>Should an application be approved by NHS England, further details would be made available within the Data Uses Register.</p> <p>Outcome of discussion: AGD were supportive of the application and wished to draw to the attention of the SIRO the following substantive comments:</p> <p>5.4.1 AGD noted that the Data Protection Impact Assessment (DPIA) provided as a supporting document (SD1) stated that the processing did not involve any automated decision making; and advised that they did not agree with this position. The AGD Chair wished the minutes to reflect that the AGD NHS England DPO representative, NHS England’s Deputy DPO, expressly noted this. AGD suggested that this was reviewed and updated as appropriate, noting that invitation or non-invitation to testing would be based on the AI determination of place of birth without further human intervention and that being invited / not being invited could have significant effects on individuals in terms of their health. If it was determined that there was automated decision making, then it was noted that UK General Data Protection Regulation (UK GDPR) would apply.</p> <p>5.4.2 AGD noted the statement in the DPIA “...AI will disproportionately improve the accuracy of processing for people from these countries, and so avoids bias”; and advised that there may be a risk of bias, including, but not limited to, if the model did not read place</p>	

<p>names in some jurisdictions as well as others. AGD suggested that the applicant explored this further and update the DPIA as appropriate.</p> <p>5.4.3 In respect of transparency, AGD noted that they could only locate a generic UKHSA privacy notice, which did not cover the processing outlined in this application; and suggested that this was updated with any additional information, including, but not limited automated decision making if appropriate, and in line with the contractual requirement in section 4 (Privacy Notice) of the data sharing agreement (DSA). .</p> <p>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.4.4 AGD welcomed the application and supported the purpose / proposed processing outlined.</p> <p>5.4.5 AGD noted and supported the use of Regulation 3 of The Health Service (Control of Patient Information) (COPI) Regulations 2002, and that this had been appropriately documented by the UKHSA Caldicott Guardian.</p> <p>5.4.6 AGD noted several references in the application to “<i>research</i>” in the application, including in planned outputs; and noted that Article 9(2)(j) (<i>processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes</i>) of the UK General Data Protection Regulation (UK GDPR) had been cited. AGD suggested that 1) references to “<i>research</i>” were removed from the application noting that this did not align with the Regulation 3 legal basis; 2) the Article 9 UK GDPR legal basis was reviewed and updated as appropriate; and 3) NHS England make the applicant aware that any processing of the data for the purpose of research, would need s251 support.</p> <p>5.4.7 AGD noted the references to “<i>MOU</i>” in section 5(a) (Objective for Processing), and suggested that 1) the acronym was expanded to refer to “<i>Memorandum of Understanding</i>”; and 2) noting the epidemiological analysis that may take place under the MOU, AGD suggested that NHS England seek further clarity on what this might be, and that this is within the Regulation 3 legal basis, for example, that this would not be research.</p> <p>5.4.8 AGD noted that the application stated that the AI had been developed “<i>with UKHSA</i>” which implies that a third party was also involved; and suggested that NHS England satisfies itself that 1) the third party will not have access to NHS England; and 2) all the appropriate contractual controls are in place.</p> <p>5.4.9 AGD noted that there is no legal requirement for an ethical review, however suggested that the UKHSA Equalities, Ethics and Communities Committee or similar review the project to identify any ethical / equality issues that may arise, including, but not limited to, the data being processed might not be reflective of where someone has lived in a relevant timeframe; and whether or the processing may impact on a individuals’ willingness to seeking healthcare if they think their health data will be shared with immigration services / organisations.</p> <p>5.4.10 AGD noted the helpful leaflet provided to patients at the GP practice during their consultation; however, suggested that this could be updated, with reassurance (which is currently on the website) that being tested will not affect visa status or right to stay in the UK.</p>	
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	<p>5.4.11 AGD noted that UKHSA will process flag 4 data for a number of uses, including, but not limited to, producing quarterly, timely personal demographics service (PDS) patient data to providers; and suggested that further information was provided as to why PDS data would be provided to providers.</p> <p>5.4.12 AGD noted the reference in section 5(b) (Processing Activities) to linking the data to data already held by UKHSA; and suggested that this was updated to clarify which data this will be.</p> <p>5.4.13 AGD noted that the surveillance would be a long running programme of work, and suggested that NHS England satisfy itself that the relevant bodies, including the British Medical Association (BMA) and the Royal College of General Practitioners (RCGP) have been consulted with as may be appropriate, if it emerges that there is a change in workload / expectations.</p> <p>5.4.14 No AGD member noted a commercial aspect to the application.</p>	
5.5	<p>Reference Number: NIC-732228-T8Q0V-v0.4</p> <p>Applicant: University of Leeds</p> <p>Application Title: "Yorkshire Lung Screening Trial"</p> <p>Observer: Ricky Brooks</p> <p>Application: This was a new application.</p> <p>NHS England were seeking advice on the following points only:</p> <ol style="list-style-type: none"> 1. Do the consent and transparency materials provide a legal gateway to support the provision of access to the requested data for the stated purpose? 2. Would AGD recommend any actions or points of clarification relating to consent, which must be resolved before an application is progressed? 3. If AGD are supportive that there is an appropriate legal gateway, the DAS team will work with the applicant to prepare an application. Noting that any future application will meet NHS England DARS standards and will use the relevant template for Section 5, do AGD think there is any reason not to proceed to a DSA, without returning to AGD? <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 not providing comments on the wider application as requested by NHS England; comments were limited to the specific point of advice requested. AGD wished to draw to the attention of the SIRO the following observations in relation to the advice point:</p> <p>AGD noted that they had been provided with a curated set of documentation, and that no application had been provided, and noted that they would be providing observations based on these documents.</p> <p>In response to point 1:</p>	

	<p>5.5.1 AGD noted and supported the assessment by NHS England that there is a legal gateway in consent, to support the provision of access to the requested data for the stated purpose.</p> <p>5.5.2 AGD noted that in line with the information provided in the consent materials, the University of Leeds would not be able to process identifiers other than date of birth and NHS number.</p> <p>5.5.3 AGD noted and commended the work undertaken by NHS England's DAS on the NHS England internal consent review.</p> <p>In response to point 2:</p> <p>5.5.4 AGD suggested that the applicant update their published privacy notice to 1) clearly delineate between the rights of the consented cohort and the s251 cohort; 2) ensure that it is clear / factually correct, on the options / process for withdrawing consent for the research, which should contain at least two methods of contact for participants (post, telephone and / or e-mail); and 3) to be clear on what they are doing with the different data they are receiving.</p> <p>In response to point 3:</p> <p>5.5.5 AGD and the NHS England SIRO Representative advised that this application should come back to AGD for a review once this is available / ready.</p> <p>5.5.6 AGD noted that both the consented cohort and the s251 cohort would be under separate data sharing agreements, and advised that they were supportive of this, as this would ensure the opt-outs were applied as appropriate.</p> <p>5.5.7 AGD noted that they had not reviewed the s251 support as part of this review.</p> <p>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.5.8 Noting AGD was only asked to advise on specific points reviewed, no AGD member noted any substantive commercial aspects.</p>	
6 INTERNAL DATA DISSEMINATION REQUESTS:		
<i>There were no items discussed</i>		
7 EXTERNAL DATA DISSEMINATION – SIRO APPROVED / SEEKING SIRO APPROVAL		
7.1	<p>Reference Number: NIC-243790-Y8K8C-v8.2</p> <p>Applicant and Data Controller: Carnall Farrar Limited</p> <p>Application Title: “Carnall Farrar’s request for NHS England data permitting detailed insights into population needs and challenges facing the system when shaping sustainable health and social care services”</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 18th January 2024.</p> <p>The application and relevant supporting documents were previously presented / discussed at the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) meetings</p>	

	<p>on the 19th January 2023, 3rd February 2022, 4th November 2021, 10th December 2020, 27th February 2020, 10th October 2019 and the 26th September 2019.</p> <p>The SIRO approval was for an extension to the data retention period within the existing agreement (which runs until 2027) from five-years to six-years to allow for COVID related analysis.</p> <p>Outcome of discussion: AGD noted that the NHS England SIRO had already provided SIRO approval. Whilst AGD did not disagree with the precise SIRO decision, AGD expressed concerns that a number of previously raised points were outstanding, and asked NHS England to follow up on these urgently and before any renewal / extension.</p> <p>AGD thanked NHS England for the written update and made the following observations on the documentation provided:</p> <p>7.1.1 AGD noted that the application had been reviewed by IGARD on the 19th January 2023, where a significant number of points had been raised, including, advice to NHS Digital (now NHS England) that the application should be reviewed by its successor group (AGD) when it comes up for renewal, extension or amendment; and that it would not be suitable for the Precedent route, including the SIRO Precedent, due to the commercial aspect of the application. The Group noted that at the AGD meeting on the 18th January 2024, this application was discussed as part of the 'SIRO approved applications. At this time AGD independent advisors had suggested that NHS England should consider submitting this for a review at a future AGD meeting, noting that this was a commercial organisation. Subsequently the application had received a further renewal. AGD noted that this application had not had a full independent review since the 18th January 2023.</p> <p>7.1.2 AGD noted that there were a number of points from the IGARD review on the 19th January 2023, that had still not been addressed, including, but not limited to, updates to the privacy notice / transparency materials. AGD noted that the IGARD conditions of support had not been reviewed out of committee by IGARD or its successor following the meeting, and as per due process.</p> <p>7.1.3 AGD suggested that NHS England should ensure that the points raised have been addressed, irrespective of whether a renewal was due.</p> <p>7.1.4 AGD noted the statement in section 5(e) (Is the Purpose of this Application in Anyway Commercial) "<i>Carnall Farrar (CF) is a commercial organisation. However, the data are not used for commercial purposes such as sales targeting or commercial insurance</i>"; and suggested that this was reviewed and updated in line with NHS England DAS Standard for Commercial Purpose.</p> <p>Subsequent to the meeting: ACTION: AGD suggested that the AGD NHS England Data and Analytics Representative review processes within NHS England's DAS to ensure that they are being followed, in respect of applications progressing for SIRO approval.</p>	D&A Rep
7.2	<p>Reference Number: NIC-402963-P0Y5D-v3.8</p> <p>Applicant: University of Liverpool</p> <p>Data Controller: University of Oxford</p> <p>Application Title: "ISARIC4C (ISARIC Coronavirus Clinical Characterisation Consortium) - Clinical Characterisation Protocol (CCP-UK)"</p>	

	<p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 15th May 2025 and the 6th March 2025.</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 13th January 2022, 23rd September 2021, 22nd October 2020 and the 24th September 2020.</p> <p>The application and relevant supporting documents were previously presented / discussed at the IGARD COVID-19 response meetings on the 22nd September 2020.</p> <p>The application and relevant supporting documents were previously presented / discussed at the General Practice Extraction Service (GPES) Data for Pandemic Planning and Research (GDPPR) – Profession Advisory Group (PAG) meetings on the 15th September 2021 and the 23rd September 2020.</p> <p>The SIRO approval was for an amendment to expand the scope from COVID-19 to all outbreaks and threats of public health importance.</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>	
7.3	<p>Reference Number: NIC-148044-RGS7W-v6.2</p> <p>Applicant: University of Oxford</p> <p>Data Controllers: London School of Hygiene and Tropical Medicine, University College London (UCL) and University of Oxford</p> <p>Application Title: “Whitehall Study of London Civil Servants”</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 25th May 2023.</p> <p>The application and relevant supporting documents were previously presented / discussed at the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) meetings on the 15th November 2018 and the 11th October 2018.</p> <p>The SIRO approval was for an extension to the data sharing agreement until the 1st March 2026.</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>	
8 OVERSIGHT AND ASSURANCE		
<i>There were no items discussed</i>		

9	<p>Precedent (reusable decision) for Additional datasets for the same purpose- no confidential flows, section 251 and Consent (Observer: Jodie Tylor-Brown)</p> <p>AGD were provided with an overview of the qualifying / exclusion criteria, of where a Data Controller(s) would like to link their cohort to additional NHS England dataset(s), without requiring additional approval from the SIRO representative or additional advice from AGD subject to meeting the qualifying criteria and none of the exclusion criteria applying.</p> <p>This reusable decision covers three scenarios: 1) where the DSA does not include a flow of confidential of data; 2) consent; and 3) s251.</p> <p>AGD made a number of suggestions to NHS England on this Precedent / reusable decision, including, but not limited to 1) updating the header to “<i>Precedent for additional datasets for the same purpose – pseudonymised data, identifying data supported by s251 and identifying data with consent</i>”; 2) in point 3 of the ‘qualifying criteria’ to separate out transparency, which is a legal obligation; and patient and public involvement and engagement (PPIE) which is important to maintain but not a legal requirement; 3) to be clear on the sign-off requirement / steps for this reusable decision; and 4) to amend the exclusion criteria referring to the SIRO concern list, to include Data Controllers and Data Processors and to limit to the concern being relevant to the application and 5) to highlight the risk to NHS England of the additional layers of risk of handling confidential data and that it must be within the scope of consent / s251 approval.</p>
10	<p>Precedent (reusable decision) for NHS DigiTrials Recruitment Service</p> <p>AGD were provided with an overview of the qualifying / exclusion criteria, of where an application to use the NHS DigiTrials Recruitment service can be approved without requiring further SIRO Authorisation or AGD review.</p> <p>AGD made a number of suggestions to NHS England on this Precedent / reusable decision, including, but not limited to 1) that there should be a quarterly review of opt-outs and complaints as a form of oversight and assurance; 2) a transparent method of expressing communication preferences, for example, no invitations for any research studies that is separate to the National Data Opt-out (as discussed in previous AGD meetings); 3) use of any method other than a letter should be in the inclusion criteria; and 4) that the ‘significant commercial aspect’ exclusion criterion may not be practical to implement.</p> <p>AGD advised that they were supportive of the underlying templated application only being precedent.</p> <p>AGD noted concerns on invitation letters to be sent by NHS DigiTrials not receiving an independent review and confirmed that they would not be supportive of this, noting 1) the NHS logo may be on the letters; and 2) the significant points raised on letters previously submitted to AGD for review.</p> <p>AGD advised that they would welcome the proposed invitation letters and plan for follow-up to be submitted to AGD, for review in the AGD collaboration area, and followed up with a brief discussion at the next AGD meeting.</p>
11 AGD OPERATIONS	
11.1	<p>Risk Management Framework</p> <p>AGD has been previously informed that a risk management framework is being developed by Data Access and had commented on early thinking about such a Framework.</p>

	<p>Nonetheless, presently AGD were still operating using the precedent and standard framework as an interim arrangement since February 2023 and AGD were concerned that the permanent Risk Management Framework was not in place. The Group discussed the NHS England corporate risk management framework (see minutes of 14th November 2024) and the AGD Chair subsequently formally asked via email if the NHS England corporate risk management framework could be used. The NHS England SIRO Representative updated the Group that NHS England was still considering the request, including how the NHS England corporate risk management framework could be adapted for AGD.</p> <p>ACTION: The NHS England SIRO Representative to provide a written response to AGD on the progress, and expected time frame for implementation, of the risk management framework.</p>	SIRO Rep
11.2	<p>Standard Operating Procedures (SOPs)</p> <p>The Group noted that the 'AGD member Declaration of Interest' SOP was in the process of being finalised and published on the AGD webpage.</p> <p>AGD queried if the review of the AGD Terms of Reference, forwarded to the Director of Privacy and Information Governance on the 14th March 2025 had been considered and asked that an update be provided as to next steps.</p> <p>ACTION: NHS England SIRO Representative to update the Group at a future AGD Meeting.</p>	SIRO Rep
11.3	<p>AGD Stakeholder Engagement</p> <p><i>There were no items discussed</i></p>	
11.4	<p>AGD Project Work</p> <p><i>There were no items discussed</i></p>	
12 Any Other Business		
12.1	<i>There were no items discussed</i>	
<p>Meeting Closure</p> <p>As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.</p>		