

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 23rd October 2025

09:00 – 14:15

(Remote meeting via videoconference)

AGD INDEPENDENT / NHS ENGLAND MEMBERS IN ATTENDANCE:	
Name:	Role:
Dave Cronin (DC)	NHS England member (Data and Analytics Representative (Delegate for Michael Chapman))
Claire Delaney-Pope (CDP)	AGD independent member (Specialist Information Governance Adviser)
Dr. Arjun Dhillon (AD)	NHS England member (Caldicott Guardian Team Representative)
Dr. Robert French (RF)	AGD independent member (Specialist Academic / Statistician Adviser Representative (In attendance for items 1 to 3, 5.1 to 5.2 and 5.5 to 5.6))
Andrew Martin (AM)	NHS England member (Data Protection Office Representative (Delegate for Jon Moore))
Jenny Westaway (JW)	AGD independent member (Lay Adviser) (Chair)
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	Role / Area:
Noela Almeida (NA)	Senior Information Governance Manager, Data Protection Officer's (DPO) Team, Privacy, Transparency, and Trust (PTT), Deputy Chief Executive Directorate (Observer: Items 1 to 3, 5.1 to 5.2 and 5.5 to 5.6)
Svetlana Batrakova (SB)	NHS England HGA Evaluation and Research Lead (Observer: item 5.1)
Deniz Budak (DB)	IG Officer, Privacy, Transparency, and Trust (PTT), Deputy Chief Executive Directorate (Observer: item 5.1)
Helen Douglas (HD)	Senior IG Manager, Transparency, and Trust (PTT), Deputy Chief Executive Directorate (Observer: item 5.1)
Dan Goodwin (DG)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: items 5.5 and 5.6)
Dickie Langley (DL)	NHS England SIRO Representative (delegate)
Sara Lubbock (SL)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: items 5.5 and 5.6)

Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Deputy Chief Executive Directorate
Suzanne Shallcross (SS)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: items 5.5 and 5.6)
Jodie Taylor-Brown (JTB)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: items 5.1 and 5.2) (Presenter: item 4.1)
Gemma Walker (GW)	Information Governance Specialist, IG Risk and Assurance, Privacy, Transparency, and Trust (PTT), Deputy Chief Executive Directorate (Presenter: item 4.2)
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Deputy Chief Executive Directorate
INDEPENDENT ADVISER OBSERVERS IN ATTENDANCE	
Mr Christopher Barben (CB)	AGD independent adviser
Dr. Jon Fistein (JF)	AGD independent adviser
AGD INDEPENDENT MEMBERS / NHS ENGLAND MEMBERS <u>NOT</u> IN ATTENDANCE:	
Name:	Role / Area:
Paul Affleck (PA)	AGD independent member (Specialist Ethics Adviser)
Michael Chapman (MC)	NHS England member (Data and Analytics Representative)
Kirsty Irvine (KI)	AGD independent member (Chair)
Jon Moore (JM)	NHS England member (Data Protection Office Representative)
Dr. Jonathan Osborn (JO)	NHS England member (Caldicott Guardian Team Representative)
Miranda Winram (MW)	AGD independent member (Lay Adviser)
NHS ENGLAND STAFF NOT IN ATTENDANCE	
Garry Coleman (GC)	NHS England SIRO Representative

1	Welcome and Introductions: The AGD meeting Chair welcomed attendees to the meeting.
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	<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 items 1 to 3, 5.1 to 5.2 and 5.5 to 5.6; but for items 4.1 to 4.3, 5.3 to 5.4 and 9 to 10 only, two AGD independent members and three AGD NHS England members were in attendance at 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>The NHS England SIRO representative stated that should AGD members be required to vote (items 1 to 3, 5.1 to 5.2 and 5.5 to 5.6), then one AGD NHS England member would be asked to not participate, to ensure the appropriate balance of votes, i.e. that the majority was by AGD independent members. The Group noted and agreed with this proposal.</p> <p>The NHS England SIRO representative stated that for items 4.1 to 4.3, 5.3 to 5.4 and 9 to 10, it would not be possible to ask one AGD NHS England member to not participate, without affecting the NHS England member quoracy. Accordingly, a balance of votes was not available for those items. The Group noted and agreed with this proposal.</p> <p>Noting that the AGD Terms of Reference state at clause 7.13: <i>“The quorum for meetings of the Group or a Sub-Group is five members, including at least three independent members, one of whom may be the Chair, Deputy Chair or Acting Chair and two of the three NHSE Members. In addition, a representative of the SIRO must also be in attendance for any meetings of the Group or a Sub-Group. 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 and provide details of the number of NHSE members and independent members who were in attendance and provided advice on any matters”</i>; the Group agreed that the meeting was quorate for items 1 to 3, 5.1 to 5.2 and 5.5 to 5.6, but was not quorate for agenda items 4.1 to 4.3, 5.3 to 5.4 and 9 to 10. The Chair and the SIRO representative agreed to proceed in “exceptional circumstances” in accordance with clause 7.13.</p> <p>The members in attendance for each item are noted in the table above.</p>
2	<p>Review of previous AGD minutes:</p> <p>The minutes of the AGD meeting on the 16th October 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> <p>The AGD NHS England representatives in attendance, noted a professional link to NIC-788663-G4F2D (NHS England); they all confirmed that they had no additional knowledge / engagement with the application, and it was agreed that the application would be discussed / reviewed as per usual process and that this was not a conflict of interests.</p>
<p>4 BRIEFING PAPER(S) / DIRECTIONS:</p>	

<p>4.1</p>	<p>Title: Office for Health and Disparities (OHID) Federated Data Platform (FDP) Migration</p> <p>Presenter: Jodie Taylor-Brown</p> <p>The purpose of the briefing paper is to advise AGD that the UK Health Security Agency (UKHSA) are in the process of migrating data delivered under NIC-343380-H5Q9K-v20.2 from being held in the UKHSA Data Lake over to the Enterprise Data and Analytics Platform (EDAP), due to the UKHSA Data Lake being decommissioned.</p> <p>The Office for Health Improvement and Disparities (OHID) currently access pseudonymised and identifiable data in the UKHSA Data Lake. As part of the UKHSA Data Lake decommissioning, OHID will move to a new processing location (Federated Data Platform (FDP)) for the data they receive under NIC-343380-H5Q9K-v20.2 and NIC-635697-P0C5M-v2.2 and new Data Processors will be involved in this work.</p> <p>NHS England were seeking advice on the following points:</p> <ol style="list-style-type: none"> 1. Note the background outlined in this paper and the approach noting the organisational commitment NHS England has made to finding a solution for OHID's data access requirements. 2. AGD are asked to advise on any particular risks associated with the approach outlined in this paper. <p>Outcome of discussion: AGD acknowledged that they would not be quorate for the discussion of this briefing paper noting only two independent members and three AGD NHS England members were available; noting that the AGD Terms of Reference states 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..."</i> the Group agreed to discuss the briefing paper (see Section 1 above).</p> <p>AGD welcomed the briefing paper and made the following observations / comments:</p> <p>In response to points 1 and 2:</p> <p>4.1.1 AGD noted that advice was being sought from the Group on the appropriateness on the testing and migration phase of this work, and any related risks; and that further advice may be sought on future phases of the work.</p> <p>4.1.2 AGD suggested that NHS England carefully consider which FDP tenant the data should be held on; and consider the associated risks and benefits of the options available.</p> <p>4.1.3 The NHS England SIRO Representative suggested that NHS England assure themselves that the OHID processing aligns with the NHS England FDP Information Governance Framework, which sets out the five permitted uses of the FDP.</p> <p>4.1.4 AGD thanked NHS England for the clear information in the briefing paper provided and advised that they would support a further update / review of future phases of this work, as may be required by NHS England.</p>	
<p>4.2</p>	<p>Title: Public Health England (PHE) NDRS Novations</p> <p>Presenter: Gemma Walker</p> <p>Following the dissolution of Public Health England (PHE) in September 2021, the management of National Disease Registration Service (NDRS) Data Sharing Agreements</p>	

<p>(DSAs, previously overseen by the PHE Office for Data Release (ODR) was transferred to NHS Digital (and subsequently NHS England).</p> <p>In May 2022, NHS Digital initiated a programme of work to migrate the 145 DSAs that were novated from PHE into the Data Access Request Service (DARS) Customer Relationship Management system, which is used by DARS to manage applications to request data access and DSAs. In August 2023, the ODR Precedent was agreed with AGD, which allowed DARS to process Extensions and Renewals on DSAs that had been novated from PHE without the request needing to meet all applicable DARS Data Sharing Standards. Upon the creation of the Extension, Renewals and Amendments (ERA) process the ODR Precedent was retired, and agreements that were novated from PHE are now progressed as per existing agreed processes.</p> <p>NHS England's IG Risk and Assurance currently have a draft risk registered in relation to the novated DSAs not aligning to the DARS Data Sharing Standards, potentially leading to the inappropriate release of data and a lack of adequate controls against which NHS England can monitor use.</p> <p>The purpose of the briefing paper is to advise AGD of the breakdown of DSAs, which include Group 1 – expired DSAs; Group 2 – DSAs that expire prior to December 2026; and Group 3 – DSAs that expire beyond December 2026; and suggested actions.</p> <p>NHS England were seeking advice on the following points:</p> <ol style="list-style-type: none"> 1. Confirm whether AGD is content with the work undertaken so far. 2. Confirm whether AGD is content with the proposed next steps, and if not highlight any additional work or actions it feels is required. <p>Outcome of discussion: AGD acknowledged that they would not be quorate for the discussion of this briefing paper noting only two independent members and three AGD NHS England members were available; noting that the AGD Terms of Reference states 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..."</i> the Group agreed to discuss the briefing paper (see Section 1 above).</p> <p>AGD welcomed the briefing paper and made the following observations / comments:</p> <p>In response to points 1 and 2:</p> <p>4.2.1 AGD noted that a small number of the migrated DSAs were still not visible on NHS England's Data Uses Register; and whilst the information within these DSAs was on the PHE data release register, the Group suggested that for the purpose of transparency, NHS England consider adding them to the NHS England Data Uses Register, noting that the DSAs were now held with NHS England not PHE.</p> <p>4.2.2 The AGD NHS England Data and Analytics Representative advised that further work would be undertaken within NHS England's Data and Analytics, to determine to what extent DSA's migrated from PHE aligned with NHS England's Data Access Request Service (DARS) Standards.</p> <p>4.2.3 AGD advised that they would welcome supporting NHS England as may be required, with the action plan outlined in the briefing paper in respect of this work; including, but not</p>	
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	<p>limited to, 1) providing a review of the DSAs in Group 3; and 2) reviewing some of the Group 2 DSAs as part of oversight and assurance.</p> <p>4.2.4 AGD thanked NHS England for the clear information in the briefing paper provided and that they would welcome a further update on this area of work as may be appropriate at a future AGD meeting.</p>	
4.3	<p>Title: NHS Public Health Functions Screening Directions 2025</p> <p>Previous Reviews: The NHS Public Health Functions Screening Directions 2025 were discussed on the 26th June 2025; and the Office for Data Release (ODR) Precedent Briefing Paper was presented / discussed at AGD on the 1st August 2023.</p> <p>The NHS public health functions agreement sets out the arrangements under which the Secretary of State for Health and Social Care delegates responsibility to NHS England for certain public health services (these known as section 7A services), including national screening programmes in England.</p> <p>The Screening Programme is requesting a Direction to cover establishing and operating a system for collecting, linking and analysing information from the Programme through the development of the existing technology and the established service.</p> <p>AGD were provided with a final draft Direction and specification for information only.</p> <p>Outcome of discussion: AGD acknowledged that they would not be quorate for the discussion of this Direction noting only two independent members and three AGD NHS England members were available; noting that the AGD Terms of Reference states 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...”</i> the Group agreed to discuss the application (see Section 1 above).</p> <p>AGD noted the briefing paper / draft Direction had been updated in line with points previously raised, and confirmed they had no further observations / comments. The briefing paper was therefore finalised as an artefact.</p> <p>4.3.1 AGD welcomed the updated draft Direction and supporting documents; and noted that this was returning to the Group for information only.</p>	
5 EXTERNAL DATA DISSEMINATION REQUESTS:		
5.1	<p>Reference Number: NIC-788663-G4F2D</p> <p>Applicant: NHS England</p> <p>Data Controller: NHS England and Office for National Statistics (ONS)</p> <p>Application Title: “Health and Growth Accelerator (HGA) Programme National Evaluation”</p> <p>Observers: Jodie Taylor-Brown, Svetlana Batrakova, Deniz Budak and Helen Douglas</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 if the following substantive comments were addressed, and wished to draw to the attention of the SIRO the following substantive comments:</p> <p>AGD noted that as part of an NHS England Data Access Request Service (DARS) pilot (discussed at the AGD meeting on the 7th August 2025), the Group had been provided with a new NHS England DARS application form that contained summary information that, once finalised, would be included in the data sharing agreement (DSA).</p> <p>5.1.1 AGD discussed the role of ONS in the first tier / phase of the project, and their role as a joint Data Controller; and notwithstanding the legal advice sought / received by NHS England on the Data Protection Impact Assessment (DPIA), the Group also suggested that legal advice was also sought on the data controllership arrangements outlined.</p> <p>5.1.2 Separate to this application and for NHS England to consider: AGD noted, that as discussed at the AGD meeting on the 17th August 2023, NHS England had reviewed and accepted external legal advice received, that independent advisers on the Group were part of the client group and were able to receive legally privileged advice. The Group suggested that where appropriate, this information was shared for future reviews of applications and other documents as requested by NHS England.</p> <p>5.1.3 AGD queried if ONS had sought an ethical review for the proposed processing; and advised that if not, they would support an ethical review being undertaken, and suggested that NHS England discuss this further with the applicant.</p> <p>5.1.4 In addition, AGD queried whether a NHS Research Ethics Committee (REC) has reviewed the proposed processing, with a particular focus on whether the early stages of this work was an intervention that should be subject to ethical review. AGD suggested that NHS England gave this further consideration, and seek advice from REC as may be appropriate.</p> <p>5.1.5 AGD noted that the National Data Opt-out (NDO) would not apply for confidential data flowing to ONS, under section 45A - section 45C of the Statistics and Registration Service Act 2007; however, noting that ONS were not using the data for the purpose of “official statistics”, suggested that NHS England review this position, to ensure that this aligned with the NDO policy.</p> <p>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.1.6 AGD noted that in this instance, the permissive route was being utilised to share NHS England data with ONS, and that as part of this, NHS England was not, at this time, permitting ONS to share the data with any third parties.</p> <p>5.1.7 AGD noted that NHS England will be publishing a privacy notice that other parties can link their privacy notice(s) to, and was meeting its obligation in line with NHS England DARS Standard for Transparency; however suggested that NHS England work with the intervention providers to further increase the transparency of the processing outlined.</p> <p>5.1.8 AGD suggested that the special conditions in section 4.10 (Special Conditions) were reviewed to 1) revise the citation special condition wording; and 2) ensure that each of the special conditions were attributed to a specific party given the joint controllership arrangements, in line with NHS England DARS Standard for Special Conditions.</p>	<p>SIRO Rep</p>
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	<p>5.1.9 AGD noted that in the first tier / phase, the outputs would not be sufficiently robust for the findings to be made public.</p> <p>5.1.10 AGD noted, and applauded the applicant on, the patient and public involvement and engagement (PPIE) undertaken, specifically noting that views had been sought on linking health and non-health data.</p> <p>5.1.11 AGD noted, and commended NHS England's DARS on the work undertaken on this application to date.</p> <p>5.1.12 AGD advised that they would welcome a further review of this application as this progresses into further tiers / phases of the project.</p> <p>5.1.13 No AGD member noted a commercial aspect to the application.</p>	
5.2	<p>Reference Number: NIC-793829-Z2H4B</p> <p>Applicant and Data Controller: London School of Hygiene and Tropical Medicine</p> <p>Application Title: "LSHTM - HPRU in Climate Change and Health Security"</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: At the request of the NHS England SIRO representative in-meeting, AGD provided preliminary advice only on this application, and suggested that the application be brought back to a future meeting.</p> <p>AGD noted that as part of an NHS England Data Access Request Service (DARS) pilot (discussed at the AGD meeting on the 7th August 2025), the Group had been provided with a new NHS England DARS application form that contained summary information that, once finalised, would be included in the data sharing agreement (DSA).</p> <p>5.2.1 AGD noted that prior to the meeting, they were advised by AGD NHS England Data and Analytics Representative that consideration was still being given by NHS England, in respect of how data would be provisioned for this project / similar projects; and therefore, requested the Group provide advice on the purpose and the proposals for how the programme would operate if given delegated permission to approve access to NHS England data for the programme's purposes. The Group noted the update / request, and advised that they would proceed on this basis.</p> <p>5.2.2 AGD advised that this area of research was potentially beneficial to the public, noting the research questions this project could address; and suggested that if there was a robust way to examine the research questions, then there would be a clear benefit to health and care. The Group did however discuss potential challenges, of gaining the insight sought, given the potential limitations of the data requested and the linkage to provide an historic picture, for example, noting that there may be issues where an individual has moved from one area to another. The Group advised and encouraged NHS England to explore this</p>	

<p>further, noting this important area of research; and suggested that further work was undertaken to ascertain whether sufficient benefit could be achieved by using the data.</p> <p>5.2.3 In addition, noting that the data under this application was via a dissemination, AGD suggested that this was reviewed in line with the DHSC Data Access Policy (consultation) that states “<i>Secure data environments (SDEs) will become the default route for accessing NHS data for research and external uses. Instances of disseminating NHS data outside of an SDE for research and external uses will be extremely limited</i>”.</p> <p>5.2.4 AGD noted a number of queries in respect of data controllership, including, but not limited to, 1) it being unclear whether other parties, i.e. those who are involved with the Data Access Committee (DAC) have a data controllership role; 2) whether UK Health Security Agency (UKHSA) were considered a joint Data Controller. AGD suggested that this was discussed further with the applicant, in line with NHS England DAS Standard for Data Controllers; and that the query in respect of the role of UKHSA, was discussed with the UKHSA Data Protection Officer (DPO), which was strongly endorsed by the AGD DPO Representative.</p> <p>5.2.5 AGD noted that there was insufficient information in respect of how the DAC would operate, including, but not limited to 1) who is involved with DAC; 2) the involvement of lay representation in DAC; 3) to what extent DAC would be advising / making decisions; and 4) what criteria DAC would be applying to their considerations. The Group suggested that NHS England explore this further with the applicant, to assure itself that sufficient detail was available on DAC to ensure compliance with NHS England DARS Standard for Sub-licencing and Onward Sharing of Data.</p> <p>5.2.6 In addition, AGD queried the role of the Health Security Health Protection Research Unit (HPRU) Management Group, and whether this was a parallel process for gaining access to the data; and suggested that NHS England clarify this with the applicant.</p> <p>5.2.7 AGD noted that the purposes outlined in the form were relatively broad, and suggested that these were reviewed and updated with further clarity / information, to be clear on the type of projects are / are not permitted.</p> <p>5.2.8 AGD noted a lack of clarity in respect of who could request a project under this piece of work, for example, external public health officials or other government departments; and whether this aligned with the proposed data controllership arrangements; and suggested that NHS England explore this further with the applicant.</p> <p>5.2.9 AGD queried who could access the data, for example solely substantive employees of London School of Hygiene and Tropical Medicine, or whether these also included students; and suggested that the application was reviewed and updated to reflect the correct information.</p> <p>5.2.10 AGD queried whether funding was in place to support the programmatic access as outlined, and would run for the duration of the project / data sharing agreement (DSA); and suggested that NHS England clarify this with the applicant.</p> <p>5.2.11 AGD noted that ethical support had been obtained from the London School of Hygiene and Tropical Medicine Observational / Interventions Research Ethics Committee, with specific conditions of support; and suggested that NHS England assure itself that these had been met.</p>	
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	<p>5.2.12 AGD noted that a protocol had not been provided as part of the suite of documents for review, and suggested that if / when this application returns for a further review, that this would be useful for the Group to see.</p> <p>5.2.13 No AGD member noted a commercial aspect to the application.</p>	
5.3	<p>Reference Number: NIC-787209-F3W7J-v0.4</p> <p>Applicant and Data Controller: University College London (UCL)</p> <p>Application Title: “Health, education and social outcomes of children with visual impairment and blindness (VI/SVIBL) - SHINE study”</p> <p>The item was withdrawn by NHS England’s Data Access Request Service (DARS) prior to the meeting.</p>	
5.4	<p>Reference Number: NIC-381078-Y9C5K-v11.3</p> <p>Applicant: British Heart Foundation</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>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 12th June 2025 and the 22nd February 2024.</p> <p>The application and relevant supporting documents were previously presented / discussed at the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) meetings on the 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.</p> <p>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.</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 28th July 2021 and the 24th June 2020.</p> <p>Application: This was a briefing paper seeking specific advice on the project proposals only. NHS England were seeking advice on the following points only:</p> <ol style="list-style-type: none"> 1. Do the revised project proposals sufficiently address the previous feedback and meet the qualifying criteria of being ‘COVID-19 research’. 	

2. Do the revisions to the scope and focus of the projects impact the potential benefits of the research in a negative way.
3. Should NHS England authorise the use of the data for the purpose of these project proposals.
4. Should NHS England consider the other two revised project proposals and, if so, reflecting on the approach here, would AGD recommend any different approaches, analyses or questions to be asked.

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

Outcome of discussion: AGD acknowledged that they would **not** be quorate for part of the discussion of this application noting only one AGD NHS England member was available for the full discussion (*and two for the discussion part only but not for the outcome discussion); noting that the [AGD Terms of Reference](#) states that “*In exceptional circumstances the Chair and the representative of the SIRO may agree for the Group to still meet and conduct its business...*” the Group agreed to discuss the application (see Section 1 above).

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

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

5.4.1 AGD noted that a briefing paper had been provided to the Group for this agenda item; and that they had been asked to provide specific advice on the four points noted above only, and **not** provide a review of the application.

In response to points 1 and 2:

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)

5.4.2 AGD reiterated the point made at the AGD meeting on the 12th June 2025, that NHS England and the applicant ensure that appropriate data minimisation is undertaken, in line with the [NHS England DAS standard for data minimisation](#). In addition, AGD suggested that as part of the data minimisation, NHS England should clarify with the applicant a number of points, including, but not limited to **1)** the inclusion / exclusion criteria; **2)** the time period of the data requested; and **3)** that the data requested aligns with the expected outcomes.

5.4.3 The Group noted the revised project proposals, and agreed that COVID-19 was now sufficiently central, in line with the requirements of the data sharing agreement (DSA).

5.4.4 AGD noted and agreed that the revision to the scope and focus of the project will deliver benefits to justify the use of the data.

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))

5.4.5 AGD reiterated the point made at the AGD meeting on the 12th June 2025, that NHS England and the applicant ensure that appropriate data minimisation is undertaken, in line with the [NHS England DAS standard for data minimisation](#). In addition, AGD suggested that as part of the data minimisation, NHS England should clarify with the applicant a number of

	<p>points, including, but not limited to 1) the inclusion / exclusion criteria; 2) the time period of the data requested; and 3) that the data requested aligned with the expected outcomes.</p> <p>5.4.6 The Group noted the revised project proposals, and agreed that COVID-19 was now sufficiently central, in line with the requirements of the data sharing agreement (DSA).</p> <p>5.4.7 AGD noted and agreed that the revision to the scope and focus of the project will deliver benefits to justify the use of the data.</p> <p>5.4.8 AGD noted that the clinical members of the Group, highlighted the importance of looking at how the use of ambulances changed for people who were very unwell during the COVID-19 pandemic.</p> <p>In response to point 3:</p> <p>5.4.9 AGD noted and thanked NHS England for providing the Group with the opportunity to further review the Project 2 and Project 8 proposals.</p> <p>In response to point 4:</p> <p>5.4.10 AGD advised NHS England that they would be supportive of the two further revised project proposals being brought to the Group for a further review, if they were sufficiently revised.</p> <p>In addition, AGD made the following observations on the supporting documentation provided as part of the review:</p> <p>5.4.11 AGD noted, and commended NHS England's DARS on the information provided in the briefing paper, which supported the review.</p> <p>5.4.12 Noting AGD was only asked to advise on specific points reviewed, no AGD member noted any substantive commercial aspects.</p>	
5.5	<p>Reference Number: NIC-774055-M9R7R-v0.5</p> <p>Applicant: The University of Manchester</p> <p>Data Controller: The University of Manchester and University of East Anglia</p> <p>Application Title: "Norfolk Arthritis Register (NOAR)" – s251</p> <p>Observers: Suzanne Shallcross, Sara Lubbock and Daniel Goodwin</p> <p>Linked applications: This application is linked to NIC-779765-J4L1V (Item 5.6), NIC-147811-YTH88 and NIC-333021-B6W2C.</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 not supportive of the application and one AGD NHS England member abstained from offering a view of the application, noting that they had been involved with the application as part of their NHS England role. AGD wished to draw to the attention of the SIRO the following substantive comments:</p>	

<p>5.5.1 AGD noted that this application followed previous data sharing agreements (DSA) for this work, that had been terminated, and the data destroyed. The Group also noted that the applicant had not had any data for the work outlined since 2020; and that previous work to implement remediation plans, had not been completed by the applicant in a timely manner. AGD noted that they had low confidence that further work being undertaken on this application would give NHS England enough assurance that data should be supplied.</p> <p>5.5.2 The Group noted concern that questions asked by NHS England's Data Access Request Service (DARS) to the applicant in respect of this application had not been answered sufficiently by the applicant, with enough information for NHS England to progress the application / assure itself that it would be appropriate to put this DSA in place for this project.</p> <p>5.5.3 The Group in particular expressed concerns around the lack of clarity in respect of the data controllership arrangements in line with NHS England DARS Standard for Data Controllers, including, but not limited to, 1) whether The University of Manchester should still be considered a joint Data Controller; and 2) the role of Norfolk and Norwich University Hospital and whether they were consider a joint Data Controller.</p> <p>5.5.4 AGD noted concern about the lack of detail on the funding, both overall for the project, and in relation to the role of AstraZeneca.</p> <p>5.5.5 AGD noted that the transparency for the project appeared to be insufficient, for example, the privacy notices were only available via one of the Data Controllers.</p> <p>5.5.6 AGD noted a lack of detail on the potential commercial access, and emphasised the need to have this clearly articulated / transparent, in line with NHS England DARS Standard for Commercial Purpose.</p> <p>5.5.7 The Group noted concern about the lack of clarity around the arrangements that would be in place to ensure sufficient controls on others accessing the data, for example, visiting researchers; and felt that this did not meet the requirements of the NHS England DARS Standard for Sub-licencing and Onward Sharing of Data.</p> <p>5.5.8 AGD suggested that should NHS England choose to progress this application further, then consideration should be given to whether the scope of the application could be significantly reduced.</p> <p>5.5.9 AGD suggested that NHS England consider 1) engaging directly with the Data Sharing Framework Contract (DSFC) holders, to stress the importance of the points raised; and 2) noting the concerns around several breaches from the applicant, NHS England could consider undertaking an audit on the applicant due to the noncompliance / issues raised under this application.</p> <p>5.5.10 AGD advised that should NHS England choose to progress this application further, the resolution of the issues outlined, would not necessarily mean that the Group were therefore supportive of the application; and suggested that NHS England may wish to bring this back to the Group for a further review.</p> <p>5.5.11 AGD noted and commended the volume / amount of work and time by NHS England in supporting the application / applicant to date.</p> <p>5.5.12 AGD noted that there was a commercial aspect to the application.</p>	
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5.6	<p>Reference Number: NIC-779765-J4L1V-v0.5</p> <p>Applicant: The University of Manchester</p> <p>Data Controllers: The University of Manchester and University of East Anglia</p> <p>Application Title: “Norfolk Arthritis Register (NOAR)” – Consent</p> <p>Observers: Suzanne Shallcross, Sara Lubbock and Daniel Goodwin</p> <p>Linked applications: This application is linked to NIC-774055-M9R7R (Item 5.5), NIC-147811-YTH88 and NIC-333021-B6W2C.</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 not supportive of the application and one AGD NHS England member abstained from offering a view of the application, noting that they had been involved with the application as part of their NHS England role. AGD wished to draw to the attention of the SIRO the following substantive comments</p> <p>5.5.1 AGD noted that this application followed previous data sharing agreements (DSA) for this work, that had been terminated, and the data destroyed. The Group also noted that the applicant had not had any data for the work outlined since 2020; and that previous work to implement remediation plans, had not been completed by the applicant in a timely manner. AGD noted that they had low confidence that further work being undertaken on this application would give NHS England enough assurance that data should be supplied.</p> <p>5.5.2 The Group noted concern that questions asked by NHS England’s Data Access Request Service (DARS) to the applicant in respect of this application, had not been answered sufficiently by the applicant, with enough information for NHS England to progress the application / assure itself that it would be appropriate to put this DSA in place for this project.</p> <p>5.5.3 The Group in particular expressed concerns around the lack of clarity in respect of the data controllership arrangements in line with NHS England DARS Standard for Data Controllers, including, but not limited to, 1) whether The University of Manchester should still be considered a joint Data Controller; and 2) the role of Norfolk and Norwich University Hospital and whether they were consider a joint Data Controller.</p> <p>5.5.4 AGD noted concern about the lack of detail on the funding, both overall for the project, and in relation to the role of AstraZeneca.</p> <p>5.5.5 AGD noted that the transparency for the project appeared to be insufficient, for example, the privacy notices were only available via one of the Data Controllers.</p> <p>5.5.6 AGD noted that there was a lack of transparency about 1) how consented participants could withdraw consent; and 2) how participants had been kept up to date with the project.</p> <p>5.5.7 AGD noted the complexity arising from the various consent materials and clauses, and advised that it was unclear that the applicant had mechanisms in place, to ensure that the specific clauses could be upheld.</p>	
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	<p>5.5.8 The AGD NHS England Caldicott Guardian Team Representative and AGD review of the latest consent materials concluded that there did appear to be a legal basis for the processing of the data, however noted complexities with the various versions of the consent materials provided to the Group.</p> <p>5.5.9 AGD acknowledged that the participants who had consented had provided their wishes that they wanted their data to be used, however noted that this needed be balanced with ensuring the consent was upheld in the manner which participants would expect.</p> <p>5.5.10 AGD noted a lack of detail on the potential commercial access, and emphasised the need to have this clearly articulated / transparent, in line with NHS England DARS Standard for Commercial Purpose.</p> <p>5.5.11 The Group noted concern about the lack of clarity around the arrangements that would be in place to ensure sufficient controls on others accessing the data, for example, visiting researchers; and felt that this did not meet the requirements of the NHS England DARS Standard for Sub-licencing and Onward Sharing of Data.</p> <p>5.5.12 AGD suggested that should NHS England choose to progress this application further, then consideration should be given to whether the scope of the application could be significantly reduced.</p> <p>5.5.13 AGD suggested that NHS England consider 1) engaging directly with the Data Sharing Framework Contract (DSFC) holders, to stress the importance of the points raised; and 2) noting the concerns around several breaches from the applicant, NHS England could consider undertaking an audit on the applicant due to the noncompliance / issues raised under this application.</p> <p>5.5.14 AGD advised that should NHS England choose to progress this application further, the resolution of the issues outlined, would not necessarily mean that the Group were therefore supportive of the application; and suggested that NHS England may wish to bring this back to the Group for a further review.</p> <p>5.5.15 AGD noted and commended 1) the volume / amount of work and time by NHS England in supporting the application / applicant to date; and 2) the internal consent review provided as a supporting document, and noted that they agreed with its conclusions, and that there may be a legal basis for some of the data to flow for some of the waves of consented cohort, and that the consent should be the preferred legal basis over s251 where possible.</p> <p>5.5.16 AGD noted that there was a commercial aspect to the application.</p>	
6 INTERNAL DATA DISSEMINATION REQUESTS:		
<i>There were no items discussed</i>		
7 EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL		
<i>There were no items discussed</i>		
8 OVERSIGHT AND ASSURANCE		
<i>There were no items discussed</i>		

9 AGD OPERATIONS		
9.1	<p>Risk Management Framework</p> <p>The AGD Chair asked for an update on the risk management framework referred to in the Group’s Terms of Reference. The NHS England SIRO Representative updated the Group that there was ongoing work with this outstanding action, and that a further update would be provided at the AGD meeting on the 6th November 2025.</p> <p>ACTION: The NHS England SIRO Representative to provide a written response to AGD on the progress on the 6th November 2025, of the risk management framework.</p>	SIRO Rep
9.2	<p>AGD Stakeholder Engagement</p> <p><i>There were no items discussed</i></p>	
9.3	<p>AGD Project Work</p> <p><i>There were no items discussed</i></p>	
10 Any Other Business		
10.1	<i>There were no items discussed</i>	
<p>Meeting Closure</p> <p>As there was no further business raised, the Chair of meeting thanked attendees for their time and closed the meeting.</p>		