

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 18th April 2024

09:00 – 16:00

(Remote meeting via videoconference)

AGD INDEPENDENT / NHS ENGLAND MEMBERS IN ATTENDANCE:	
Name:	Role:
Paul Affleck (PA)	AGD independent member (Specialist Ethics Adviser)
Dave Cronin (DC)	NHS England member (Data and Analytics Representative (Delegate for Michael Chapman))
Dr. Robert French (RF)	AGD independent member (Specialist Academic / Statistician Adviser)
Kirsty Irvine (KI)	AGD independent member (Chair)
Jon Moore (JM)	NHS England member (Data Protection Office Representative) (In attendance for item 1, 2, 3, 6.1, 6.2 and 8.1 only)
Dr. Jonathan Osborn (JO)	NHS England member (Caldicott Guardian Team Representative) (not in attendance for items 1, 2, 3, 6.1, 6.2 and 8.1 only)
Jenny Westaway (JW)	AGD independent member (Lay Adviser)
Miranda Winram (MW)	AGD independent member (Lay Adviser)
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	Role / Area:
Garry Coleman (GC)	NHS England SIRO Representative
Louise Dunn (LD)	Data Access & Partnerships, Data & Analytics (Observer: item 6.2)
Nicki Maher (NM)	IG Risk and Assurance, Privacy, Transparency and Trust (PTT), Delivery Directorate (Observer: items 9.1 and 9.2)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Delivery Directorate
Frances Perry (FP)	Data Applications Team Lead, Data Access & Partnerships, Data & Analytics (Observer: item 5.1)

James Watts (JW)	Senior Case Officer, Data Access & Partnerships, Data & Analytics (Observer: items 6.2 and 6.3)
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Delivery 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)
Claire Delaney-Pope (CDP)	AGD independent member (Specialist Information Governance Adviser)
Prof. Nicola Fear (NF)	AGD independent member (Specialist Academic Adviser)
Jon Moore (JM)	NHS England member (Data Protection Office Representative)

1	Welcome and Introductions: The AGD Chair welcomed attendees to the meeting. AGD noted that only two AGD NHS England members would be in attendance for the whole meeting; noting that the AGD Terms of Reference states that two of the three NHS England members must be in attendance. The Group agreed that the meeting was still quorate for all agenda items.
2	Review of previous AGD minutes: The minutes of the AGD meeting on the 11 th March 2024 were reviewed and, after several minor amendments, were agreed as an accurate record of the meeting.
3	Declaration of interests: Paul Affleck noted a professional link to the University of Leeds (NIC-656825-X7T4K) but noted no specific connections with the application or staff involved and it was agreed that this was not a conflict of interest.
4	AGD Action Log: <i>The action log was not discussed.</i>
5 BRIEFING PAPER(S) / DIRECTIONS:	
5.1	Title: Local Authority Primary Care Mortality Data (PCMD) renewal pilot Legal Basis

Observer(s): Frances Perry

Previous Reviews: This was discussed at the AGD meeting on the 11th April 2024 (item 9.1 in the AGD meeting minutes).

The briefing (**for information only**) was to advise the Group that the legal basis for data sharing has been changed on the Local Authority Renewals data sharing agreement (DSA) template to Regulation 3 of the Health Service (Control of Patient Information) Regulations 2002.

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

5.1.1 AGD noted that NHS England were **not** seeking specific advice on the briefing paper provided, and that this had been primarily submitted to the Group for information only. Notwithstanding this, NHS England welcomed the comments and suggestions summarised below.

5.1.2 The **majority** of the Group were **not** currently supportive of the legal basis cited unless the issues outlined were suitably addressed.

5.1.3 AGD suggested that the briefing paper, and any relevant supporting documentation, was updated to clarify which limb of Regulation 3 of the Health Service (Control of Patient Information) Regulations 2002 (COPI) was applicable.

5.1.4 AGD noted that Regulation 3 of COPI legal basis was for the purpose of “*Communicable disease and other risks to public health*”; and queried how all of the listed purposes of processing, as currently described, were to diagnose, recognise trends or control and prevent the spread of such risks to public health. The Group suggested that the briefing paper and any relevant supporting documentation was updated to ensure that the language used aligned with the relevant limb cited including how the proposed processing was to address a risk to public health. Specific examples in the DSA template discussed by the Group included the processing to identify older mothers (see also 5.1.7 below) and the general reference to planning for “*service providers*”.

5.1.5 AGD noted that they had **not** been provided with any documentation / evidence of advice sought from NHS England’s Legal Team to support the legal basis cited; and suggested that if advice or an opinion had not already been sought, then this was obtained; and that the briefing paper was updated to reflect any advice received from the Legal Team or external legal advisers. The Group noted that this was a specific legal matter of statutory interpretation and not a general Information Governance or policy point.

5.1.6 The Group suggested that if it was not possible to clarify how all of the work outlined was to address risks to public health, then NHS England should explore other legal basis options that clearly aligned with the purpose of processing to cover off all strands of the work, which the Group agreed were in the public interest and connected with health.

5.1.7 AGD noted the statement in section 5(a) (Objective for Processing) of the templated application “*Age of mother is required to investigate trends in...older mothers (to support service planning for higher risk pregnancies)...*”; and suggested that this was reviewed and

	<p>updated further, to be clear as to how this was a risk to public health rather than addressing a risk to the health of the individual mother or baby.</p> <p>5.1.8 The Group looked forward to receiving the finalised briefing paper addressing the points raised, either out of committee (OOC) or tabled at a future meeting.</p>
6 EXTERNAL DATA DISSEMINATION REQUESTS:	
6.1	<p>Reference Number: NIC-709865-W9X6H-1.4</p> <p>Applicant: The Royal College of Surgeons of England</p> <p>Application Title: National Cancer Audit Collaborating Centre (NATCAN)</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 28th September 2023.</p> <p>The item was withdrawn by the NHS England Data and Analytics representative.</p>
6.2	<p>Reference Number: NIC-616027-W7K5H-v0.2</p> <p>Applicant: NHS Norfolk and Waveney Integrated Care Board (ICB)</p> <p>Application Title: Integrated Care Board - Hospital Episode Statistics Data'</p> <p>Observers: James Watts and Louise Dunn</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 29th February 2024 and the 2nd November 2023.</p> <p>Application: This was a new application.</p> <p>The purpose of the application is to support NHS Norfolk and Waveney Integrated Care Board (ICB) to fulfil its functions towards health care as per the National Health Service Act 2006; including allowing the ICB to compare / benchmark services commissioned by other ICBs with their own to show their effectiveness and adjust their future commissioning decisions; comparing rare patient conditions where local data does not provide a sufficient cohort count so they can understand the most effective patient pathways; comparing levels of inequality nationally to understand any shortcomings in their local area; nationally compare specific demographics of patients to understand areas of low performance and understand national trends in health care and public health risks in order to support capacity planning.</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 for NHS Norfolk and Waveney ICB and wished to draw to the attention of the SIRO the following comments in point 6.2.2. below.</p> <p>6.2.1 It was noted that the NHS Norfolk and Waveney ICB application would support the development of template wording for a Precedent for other ICB applications of</p>

<p>this type. It was noted that a draft Precedent had not been included in the documentation pack.</p> <p>In respect of the NHS Norfolk and Waveney ICB application:</p> <p>6.2.2 It was noted that following the AGD meeting on the 29th February 2024, where the Group indicated that they would be supportive of access in a secure environment, the application had been amended significantly to reflect that data would now in fact be provided as an extract, and not accessed in NHS England's Data Access Environment (DAE) as previously described.</p> <p>6.2.3 AGD noted that the one of the justifications for the applicant requesting an extract of data, as opposed to accessing the data via the DAE, was due to the technical limitations around data being transferred out of the DAE; the limit on the number of records; and the proposed use of the data, which included analysis and reporting of the data within the ICB systems, that were not currently available within the DAE. AGD suggested that NHS England seek further clarification on the specific issues faced by the applicant with the processing of the data within the DAE, and that for transparency / future reference, this was noted in the application and internal application assessment form.</p> <p>6.2.4 It was also suggested by AGD, that further clarity was provided in the application, as to what the benefit(s) to health and care would be of the data being accessed via a data extract as opposed to the DAE.</p> <p>6.2.5 Separate to this application: AGD suggested that once further clarification had been provided on the issues faced by the ICB with the processing of the data within the DAE; that this was addressed by NHS England in respect of the development of the DAE, to see if this could be addressed for future access / applicants.</p> <p>ACTION: NHS England Data & Analytics Representative to speak to the DAE Team to gather feedback from the applicant to the development of the NHSE DAE.</p> <p>ACTION: AGD Secretariat to add NHS England DAEs, TREs, SDEs to the internal AGD meeting forward plan for discussion at a future AGD meeting.</p> <p>6.2.6 The SIRO representative noted that the application referred to "<i>benchmarking</i>"; and asked that further clarity was provided in the application and internal application assessment form on this, including, but not limited to, who was undertaking the benchmarking; and if it was an external organisation, what were the Data Processor implications; or was the benchmarking being done internally.</p> <p>6.2.7 In addition, AGD noted that the applicant's privacy notice made no reference to "<i>benchmarking</i>"; and queried whether this was actually part of the application; and suggested that for the purpose of transparency, the application and / or privacy notice were reviewed and aligned to ensure the correct information was reflected.</p> <p>6.2.8 AGD noted the special condition in section 6 (Special Conditions) of the application that stated "<i>By signing the Data Sharing Agreement, the Data Controller</i></p>	<p>D&A Rep AGD Sec</p>
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	<p><i>confirms that the Data Processors...</i>"; and noting that there were currently no Data Processors listed in section 1(c) (Data Processor(s)) of the application, suggested that the text was updated to state "...any Data Processors...".</p> <p>6.2.9 AGD noted point five in section 5(b) (Processing Activities) as part of the 'conditions of supply' information, that stated "<i>not publish the results of any analyses of the HES data unless safely de-identified in line with the anonymisation standard</i>"; and suggested that confirmation was provided as to which "<i>anonymisation standard</i>" was being referred to.</p> <p>In respect of the proposal for this data sharing agreement (DSA) wording to be used to develop template wording to support a Precedent for other ICB applications of this type. 6.2.10 NHS England advised AGD, that the application template had been developed to give the option to applicants accessing the data via a data extract or via the DAE. AGD reiterated the point made at the AGD meeting on the 29th February 2024; and suggested that NHS England should consider having two separate template applications, one for the data accessed in the DAE; and the other for a data extract; noting that this might be easier for NHS England to manage / audit etc.</p> <p>6.2.11 AGD suggested that the default should always be for the data to be accessed by in the DAE, rather than a data extract, unless a suitable and robust justification was provided as to why this could not be done, and why a data extract was required instead.</p> <p>6.2.12 AGD noted the reference in the internal application assessment form to "<i>inclusion / exclusion criteria</i>" that would be applicable for a templated DSA; and advised that they had not received any information related to the inclusion / exclusion criteria; and were therefore currently unable to offer a view on this.</p> <p>6.2.13 It was noted that along with the development of the application templates(s), a Precedent must be developed that includes the inclusion / exclusion criteria, and that the cover sheet for the Precedent should set out principles on justifications for accessing the data via a data extract instead of in the DAE.</p> <p>6.2.14 Separate to this application: the Group reiterated the point made at the AGD meeting on the 24th February 2024, and advised that the benchmarking data should be available to all ICBs (discussion on the 24th February 2024 was on the premise that access would be within a secure data environment by default, not an extract) to reduce duplication, and suggested that NHS England Data and Analytics give this further consideration.</p> <p>ACTION: NHS England Data and Analytics to consider making the benchmarking data available to all ICBs in order to reduce duplication.</p> <p>6.2.15 AGD reiterated advice from the AGD meeting on the 29th February 2024 and the 2nd November 2023, that they had still not received sufficient information from NHS England as to how the DAE differs from other environments hosted by NHS</p>	<p>D&A Rep</p>
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	<p>England, for example, the Secure Data Environment (SDE), Trusted Research Environment (TRE) etc, particularly with respect to data extracts being downloadable from the DAE by applicants.</p> <p>6.2.16 Separate to this application: the NHS England Data and Analytics representative noted the issues previously raised by AGD; and were asked that they seek support from colleagues to provide the Group with further clarification / distinctions between the different environments hosted by NHS England, to support the Groups understanding and for future application reviews.</p> <p>ACTION: The NHS England Data and Analytics representative to seek support from colleagues to provide the Group with further clarification / distinctions between the different environments hosted by NHS England, via a learning session.</p> <p>6.2.17 AGD advised that they would be happy to provide further advice on the development of the application template / Precedent etc, as may be required by NHS England.</p>	D&A Rep
6.3	<p>Reference Number: NIC-712819-X8G2J-v0.9</p> <p>Applicant: University of Oxford</p> <p>Application Title: The Effect of Operational Interventions on Maternity Care Pathways and Health Outcomes</p> <p>Observer: James Watts</p> <p>Application: This was a new application.</p> <p>The purpose of the application is for a project, to analyse maternity services and secondary care data to determine how different operational interventions impact maternity care pathways and consequently, different health outcomes.</p> <p>Should an application be approved by NHS England, further details would be made available within the Data Uses Register.</p> <p>Outcome of discussion: AGD were supportive of the application and wished to draw to the attention of the SIRO the following substantive comments:</p> <p>6.3.1 AGD noted concerns that no patient and public involvement and engagement (PPIE) had been undertaken; and noting the potential importance of the project, suggested that there was ongoing PPIE throughout the lifecycle of the project, for example, with the mothers in the cohort. The HRA guidance on Public Involvement is a useful guide.</p> <p>6.3.2 In addition, AGD suggested that the applicant could engage with appropriate groups as part of the PPIE, for example, Maternity Action and Women's Voices.</p> <p>6.3.3 AGD noted that the data requested was pseudonymised, however noted the sensitive data fields within the datasets that could potentially lead to re-identification. Notwithstanding the contractual controls in place by NHS England to manage this, public perception of the project could be negative as a result. It was suggested by</p>	

the Group that this aspect could also be addressed as part of the PPIE, to ensure that not only the design of the research is appropriate and will it produce suitable outcomes; but also, that the sensitivity of the health data and analyses were fully appreciated by the researchers.

6.3.4 AGD noted the information in the application in respect of benefits, but suggested that this updated to clearly articulate the benefits to health and social care; and suggested that all of the activities outlined were reviewed and, in line with [NHS England's DAS Standard for Expected Measurable Benefits](#) and the National Data Guardian (NDG) [guidance on benefits](#), it was made clear what the benefits to health and social care were.

6.3.5 AGD noted in the internal application assessment form that the applicant had **not** produced a protocol; and noting that it is standard practice for research to have a protocol, suggested that a document would helpfully provide greater clarity about the aims and methods of the project. It was suggested that one should be produced and that it could also address other aspects of the project, including but not limited to, PPIE and the expected benefits to health and social care.

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

6.3.6 AGD noted within the internal application assessment form that the applicant's System Level Security Policy (SLSP) was currently under review by NHS England; and suggested that once the review was concluded, that the outcome was reflected in the application and internal application assessment form.

6.3.7 AGD noted, and were very positive about, access to the data via NHS England's Secure Data Environment (SDE); and suggested that for ease of reference, this was made clear at the beginning of section 5(a) (Objective for Processing) of the application, and at the start of the internal application assessment form.

6.3.8 AGD also queried whether all of the objectives for processing could be achieved by processing the data with the SDE; and suggested that NHS England discuss any possible limitations with the researcher; and that for future reference, any discussions on this were noted in the internal application assessment form for future reference.

6.3.9 AGD queried what, if any data minimisation had been undertaken, and suggested that the application was updated with further clarity, in line with [NHS England's DAS standard for data minimisation](#); or that a justification was provided if no data minimisation could be undertaken.

6.3.10 Separate to this application: AGD and the SIRO representative agreed that as part of a future AGD meeting, the Group would discuss data minimisation within the SDE; and that this would feed into the ongoing work within NHS England on the SDEs (see also item 6.2.16).

<p>ACTION: AGD Secretariat to add data minimisation within the SDE to the internal AGD meeting forward planner, for discussion at a future AGD meeting.</p> <p>6.3.11 Noting the statement in section 5(b) (Processing Activities) of the application <i>“Following completion of the analysis the record level data will be securely destroyed”</i>; AGD suggested that this was reviewed and updated as may be necessary, noting the data would be accessed in the SDE and not via an extract, therefore the data would not be destroyed.</p> <p>6.3.12 AGD queried the references in the application and supporting documents provided to <i>“operational interventions on maternity care...”</i>; and suggested that these were reviewed and that further clarity was provided as to what an <i>“operational intervention”</i> was referring to.</p> <p>6.3.13 AGD queried whether the ethnicity fields in the Emergency Care Data Set (ECDS) were sufficient in terms of quality of data to achieve the aims of the analysis; and suggested that this was explored by NHS England. If the data was not of a sufficient standard, the Group advised that they would be supportive of the addition of an alternate dataset to the data sharing agreement (DSA) that provides the most relevant ethnicity information, with the relevant justifications added to the application.</p> <p>6.3.14 AGD queried the statement in section 5(b) <i>“Teams will conduct analyses...”</i>; and queried whether one team, or a multiple of teams would access the data; and suggested that this was reviewed and updated to reflect the correct information.</p> <p>6.3.15 AGD queried the references in section 5(b) to <i>“honorary contractors”</i>; and suggested that it was clarified in the application and internal application assessment form, whether there was one honorary contract holder, or multiple honorary contract holders; noting that the internal application assessment form referred to only one individual.</p> <p>6.3.16 In respect of the expected benefits outlined in section 5(d) (Benefits) (ii) (Expected Measurable Benefits to Health and / or Social Care) of the application, AGD noted that the initial information provided within this section, appeared to have been copied and pasted from some standard wording, and suggested that this was reviewed and amended or removed if not relevant.</p> <p>6.3.17 Noting the statement in section 5(d) (ii) of the application <i>“...effectively reduce the existing health inequality in the field of maternal services...”</i>; it was suggested by AGD, that this was updated to provide further information of how the project was expecting to reduce health inequalities.</p> <p>6.3.18 AGD noted the statement in section 5(d) (ii) <i>“...hopes to shed light on the impact of covid on different sub-groups of patients...”</i>; and noting that there were no other references to COVID-19 in the application, suggested that section 5(a) was updated with further information linked to this expected benefit.</p> <p>6.3.19 The SIRO representative requested that following any updates to the application following this review, that NHS England’s Data Access Service (DAS)</p>	<p>AGD Sec</p>
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	engage with him on the status of the application and progress on the outcomes raised by AGD.	
6.4	<p>Reference Number: NIC-482394-D4Q4R-v0.14</p> <p>Applicant: Imperial College London</p> <p>Application Title: Investigation into sex-specific differences in mortality and complications following elective abdominal aortic aneurysm repair and association with pre-operative co-morbid status</p> <p>Application: This was a new application.</p> <p>The purpose of the application is for a research project, investigating sex-specific differences in mortality and complications following elective abdominal aortic aneurysm (AAA) repair and association with pre-operative co-morbid status.</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 comments:</p> <p>6.4.1 AGD noted that the Health Research Authority Confidentiality Advisory Group (HRA CAG) annual review, was due on the 20th March 2024; and noting that there was no information provided as to whether this was in process and that the HRA CAG annual review had been submitted; suggested that NHS England seek further clarification from the applicant on this point, and that the internal application assessment form and application were updated to reflect any updated information. In addition, it was suggested that any new supporting documentation to support this, was uploaded to NHS England's customer relationships management (CRM) system for future reference.</p> <p>6.4.2 AGD noted the special condition in section 6 (Special Conditions) of the application in respect of the Medicines dispensed in Primary Care (NHSBSA) data; however, noted that this was not the standard special condition that sets out the restraints of the NHSBSA data as per the NHSBSA medicines data Direction. The Group noted the discussions at the AGD meeting on the 18th January 2024 (as part of the discussion for NIC-480151-B0M5Q University of East Anglia), 2nd November 2023 (as part of the discussion for NIC-08472-V9S6K UK Biobank), 16th November 2023 (as part of the discussion for NIC-568980-P9W7B University of Edinburgh) and the 7th December 2023 (as part of the discussion for NIC-302994-C2Q2Y University of Oxford), where the SIRO representative had advised that although the Direction did set out constraints of the use of data, it was not the only legal gateway that NHS England had to share data. It was therefore suggested that NHS England review and update the application, including the special conditions in section 6, to reflect whether the legal basis to share the NHSBSA data was in line with the restraints of</p>	

	<p>the NHSBSA medicines data Direction; or whether an alternate legal basis was being used for this dataset.</p> <p>6.4.3 Separate to the application: the Group reiterated the point made at the AGD meeting on the 18th January 2024, 7th December 2023, 16th November 2023 and the 2nd November, that for transparency and public trust, NHS England should explore how this could be explained, since the public may take at face value the constraints as set out in a Direction and as published on the website, and may not envisage NHS England using other legal powers to set aside restrictions in a Direction.</p> <p>6.4.4 Separate to the application: Noting the NHSBSA presentation to the Group on the 20th July 2023, and that the SIRO representative at AGD on the 24th August 2023 had noted that the Direction was being reviewed and would be presented back to the Group in due course; the Group also reiterated a request made at the AGD meeting on the 18th January 2024, 7th December 2023, 16th November 2023, and the 2nd November 2023, for a note setting out the work undertaken to reach the position set out in 6.4.2 above, alongside the work to review the Direction be presented to AGD as soon as practicable. In addition to the transparency and public trust points raised in 6.4.3 above, the Group queried whether this view would have retrospective or prospective impact on other applications using this dataset, or indeed any other applications where there were restrictions on use or dissemination of data due to wording in Directions.</p> <p>ACTION: NHS England SIRO representative to provide a note outlining the work undertaken to allow the applicant to use the data as outlined in the data sharing agreement (DSA), and to provide a copy of the work undertaken to review the Direction.</p> <p>6.4.5 AGD noted that the privacy notice provided as a supporting document, could be confusing to participants, due to it covering only pseudonymised data, meaning members of the cohort would need to also find and read information elsewhere to understand the full picture. In addition, it was suggested that language within the privacy notice could be updated, to ensure this is more accessible to a general audience.</p> <p>6.4.6 Separate to this application: As discussed at the AGD meeting on the 21st March 2024, AGD noted that the NHS England citation special condition in section 6 (Special Conditions) of the application differed from previous standard wording, and asked that the NHS England Data and Analytics representative discuss this with colleagues in NHS England's Data Access Service (DAS). If the incorrect wording had been added to this application in error, it was suggested that the application should be updated with the correct standard wording. If the citation standard wording had been recently updated and this application reflected the 'new' text, then the Group requested that clarification of this was provided to the Group and a copy of the updated text was provided for future reference.</p>	<p>SIRO Rep</p>
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	<p>ACTION: The NHS England Data and Analytics representative to discuss the NHS England citation special condition in section 6 of the application with colleagues, and to clarify with the Group if this has now been updated; and if so, to provide the Group with the updated text.</p> <p>6.4.7 The Group commended the applicant on the excellent patient and public involvement and engagement (PPIE) undertaken / ongoing as outlined in the application; and how the research project design reflected the PPIE received to date.</p>	D&A Rep
6.5	<p>Reference Number: NIC-345789-L9Q7J-v3.2</p> <p>Applicant: University of Surrey</p> <p>Application Title: Data for NHS hospital workforce retention project (determinants and effects on patients' outcomes)</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD / Independent Group Advising (NHS Digital) on the Release of Data (IGARD) / Data Access Advisory Group (DAAG) meetings on the 20th October 2020 and the 3rd September 2020.</p> <p>Application: This was a renewal and amendment application.</p> <p>The purpose of the application is for a research project, to investigate the determinants of hospital workforce retention (HWR) and hospital staffing levels, and the effects of these variables on patient outcomes and hospital performance (i.e. quality, efficiency) measures. Workforce retention refers to the ability of an organization to retain its employees.</p> <p>The amendment is to change the territory of use to 'Worldwide'.</p> <p>NHS England were seeking advice on the following point only:</p> <ol style="list-style-type: none"> 1. The views of AGD on data access from the United States of America (USA). <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; 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>In response to point 1:</p> <p>6.5.1 AGD noted that the request to amend the territory of use to “<i>Worldwide</i>” was to enable remote access to pseudonymised data by the Principal Investigator who is undertaking an academic visit to the USA until the end of June 2024. The application had previously been approved by the SIRO for data access in Australia and Italy (please see item 8.2).</p>	

	<p>6.5.2 AGD noted that NHS England had been liaising with the applicant to determine the reason why the remote access was required; however, suggested that further clarification was sought as to whether the work undertaken by the Principal Investigator could wait until they returned from the USA; or if the work could be continued by a colleague / team based in the UK until they returned from the USA. It was suggested by the Group that the outcome of this discussion should be recorded in the internal application assessment form for transparency.</p> <p>6.5.3 AGD suggested that if NHS England supported access to the data in the USA, then it should be made clear in the application that there was a robust justification for this; and that this would not set a precedent for other applicants of NHS data.</p> <p>6.5.4 The SIRO representative advised that along with the usual restrictions / security arrangements that would be in the data sharing agreement (DSA) for access to the data in the USA; additional conditions could be added to the DSA in respect of laptop security and restrictions on the downloading of data. AGD advised that they were supportive of this proposal.</p> <p>6.5.5 AGD suggested that all correspondence on this issue between NHS England and the applicant, were uploaded to NHS England's customer relationships management (CRM) system for future reference and audit purposes.</p> <p>6.5.6 AGD noted that whilst they were only asked to provide advice on a specific point, they did highlight that data controllership had not been reviewed since 2020, and that NHS England may wish to explore this further to ensure the application accurately reflected the correct Data Controllers, in line with NHS England DAS Standard for Data Controllers.</p> <p>6.5.7 The SIRO representative advised that if NHS England supported the request for access to the data in the USA, this would be communicated back to AGD via an 'approved SIRO application' as per usual process.</p>	
7 INTERNAL DATA DISSEMINATION REQUESTS:		
<i>There were no items discussed</i>		
8 EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL		
8.1	<p>Reference Number: NIC-13925-Q7R2D-v12.2</p> <p>Applicant: IQVIA Ltd</p> <p>Application Title: Hospital Treatment Insights</p> <p>Previous Reviews: The application and relevant supporting documents had previously been presented / discussed at the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) meetings on the 24th March 2022, 2nd December 2021 and the 29th April 2021.</p>	

	<p>The application and relevant supporting documents had previously been presented / discussed at the Data Access Advisory Group (DAAG) meetings on the 27th July 2017, 20th July 2017, 8th June 2017, 10th January 2017, 20th December 2016 and the 15th November 2016.</p> <p>The SIRO approval was for the applicant to hold but not otherwise process the data up until the end of January 2025; with sub-licensing not permitted.</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 made the following observations on the documentation provided:</p> <p>8.1.1 AGD noted that whilst they were supportive of the SIRO approval to hold but not otherwise process the data up until the end of January 2025; they would not be supportive of any future SIRO approvals, noting that there were a number of outstanding issues that needed addressing by the applicant, and that the application had already received a number of SIRO approvals previously.</p> <p>8.1.2 AGD noted and endorsed the special condition in section 6 (Special Conditions) of the application, that sets out the expectations / requirements of the applicant to address the outstanding issues.</p> <p>The NHS England SIRO representative thanked AGD for their time.</p>	
8.2	<p>Reference Number: NIC-345789-L9Q7J-v3.2</p> <p>Applicant: University of Surrey</p> <p>Application Title: Data for NHS hospital workforce retention project (determinants and effects on patients' outcomes)</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD / Independent Group Advising (NHS Digital) on the Release of Data (IGARD) / Data Access Advisory Group (DAAG) meetings on the 20th October 2020 and the 3rd September 2020.</p> <p>The SIRO approval was to permit access to pseudonymised data in Australia and Italy.</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 made the following observations on the documentation provided:</p> <p>8.2.1 AGD noted that permission for access to pseudonymised data in the United States of America (USA), had been discussed under item 6.5.</p> <p>The NHS England SIRO representative thanked AGD for their time.</p>	

9 OVERSIGHT AND ASSURANCE

9.1 Oversight and Assurance Process

The [Statutory Guidance](#) states that the data advisory group (AGD) should be able to provide NHS England with advice on: *“Precedents for internal and external access, including advising in accordance with an agreed audit framework whether processes for the use of precedents are operating appropriately, to provide ongoing assurance of access processes”*.

In advance of the meeting, the AGD independent members were provided with **1)** ten applications (selected by the AGD Secretariat); **2)** internal application assessment forms for each of the ten applications; and **3)** an oversight and assurance template to complete.

Following review of the applications by the AGD independent members **out of committee**, the completed oversight and assurance templates were sent to the AGD Secretariat prior to the meeting.

It was noted that only **high-level points** would be discussed in meeting (and noted in the minutes); however, the full suite of comments and feedback from AGD independent members on the oversight and assurance templates would be collated by the AGD Secretariat and shared with the SIRO representative and relevant NHS England colleagues as may be appropriate.

Please see **appendix A** for high-level points raised in-meeting on the ten applications.

9.2 Oversight and Assurance Conclusion / Review

AGD noted that as the oversight and assurance process had only been in progress since the 21st March 2024; this was still being reviewed and that changes to processes would be agreed and updated as may be appropriate.

AGD agreed, that for the next oversight and assurance review, the oversight and assurance template would be uploaded to the internal AGD SharePoint site by the AGD Secretariat (as opposed to each reviewer filling out individual forms), where AGD independent members could note their comments, prior to the next discussion at the AGD meeting on the 2nd May 2024. This would ensure AGD members could identify where similar themes / issues had been identified; and ensure the feedback to NHS England via the oversight and assurance template was more succinct.

ACTION: AGD Secretariat to upload the oversight and assurance templates to the internal AGD SharePoint site for the next oversight and assurance review.

AGD
Sec

10 AGD OPERATIONS

10.1 AGD Standard Operating Procedures (SOPs)

The ongoing forward plan of work for creating the AGD Standard Operating Procedures was discussed; and noting that the AGD Terms of Reference (ToR) had now been approved, it

	<p>was noted that work was progressing in order to finalise the AGD SOPs in line with the approved AGD ToR.</p> <p>It was noted that a further update would be provided to AGD in due course.</p>	
10.2	<p>AGD Annual Report</p> <p>AGD noted at previous AGD meetings there was a requirement within the published Statutory Guidance for an ‘annual review’. Following the discussion at the AGD meeting on the 11th April 2024, a ‘skeleton’ draft annual report document was shared with the Group for review / comments / updates.</p> <p>AGD discussed the comments / updates made by AGD members on the document and made some further tweaks / refinements.</p> <p>AGD noted that they were not aware of any questions from NHS England or its Committees and therefore the document had been drafted in line with the discussion on the 2nd April 2024, with Jackie Gray, Director of Privacy and Information Governance, Privacy, Transparency and Trust (PTT), Garry Coleman, AGD SIRO representative, Vicki Williams, AGD Secretariat Manager, Kirsty Irvine, AGD Chair, and Ross Thornton, PTT Chief of Staff.</p> <p>It was noted that the final draft of the AGD Annual Review would be submitted to Jackie Gray following the meeting, noting the deadline was the 18th April 2024.</p> <p>ACTION: AGD Chair / AGD Secretariat to finalise the final draft and circulate to Jackie Gray by close of play on the 18th April 2024.</p>	AGD Chair / Sec
10.3	<p>AGD Stakeholder Engagement</p> <p><i>There were no items discussed</i></p>	
10.4	<p>AGD Project Work</p> <p><i>There were no items discussed</i></p>	
11 Any Other Business		
11.1	<p><i>There were no items discussed</i></p>	
<p>Meeting Closure</p> <p>As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.</p>		

Appendix A

Oversight and Assurance Review – 18th April 2024

Ref:	NIC Number:	Organisation:	Areas to consider:
240418a	NIC-144057-G4S0Q-v3.6	University of Oxford	<ul style="list-style-type: none"> • Commended the efforts made by NHS England on checking the HRA CAG renewals. • Commended the efforts made to update the benefits. • Unclear on the updates to the objective of processing, therefore unclear if correct Precedent has been used. • Unclear why opt-outs were not applied. • Unclear why s251 is required, since there is no further data flowing and no access to identifiers.
240418b	NIC-148056-T6T5Z-v9.1	Imperial College London	<ul style="list-style-type: none"> • Precedent cited needs a review as appears outdated. • It was not clear how the risk profile was assigned because some substantial issues were not addressed including the fact that interim AGD were “<i>not wholly supportive</i>”. • Consent up to 2024 – risk. • Concern that risk assessment states that “<i>AGD did not state they wished to see the application on review</i>”.

240418c	NIC-219359-T5B0V-v1.3	Great Ormond Street Hospital for Children NHS Foundation Trust	<ul style="list-style-type: none"> • Last independent review was not reviewed by NHS England when progressing this application down the Precedent route. • Suggest privacy notice link is added to section 4 of application. • Has the DSA been signed by the correct person, (signed as part of another organisation, not applicant organisation)?
240418d	NIC-656770-J1L3N-v1.3	Royal Papworth Hospital NHS Foundation Trust	<ul style="list-style-type: none"> • States that the application is to be reviewed in 5 years, but it is unclear when the 5 years started. • Section 3(c) states mixed cohort and opt-outs not applied, however they do apply to the s251 cohort. • Unclear if HRA CAG support is ongoing. • If HRA CAG support not ongoing, have the identifiers been deleted?
240418e	NIC-656825-X7T4K-v2.2	University College London	<ul style="list-style-type: none"> • Not clear if the correct Precedent had been used and how Precedent 12 was assessed. • Query whether the SIRO Precedent would have been more appropriate. • Query if a new data set could be considered an exclusion criteria. • Query whether the University of Leeds should be a Data Controller.

			<ul style="list-style-type: none"> • Whether the Principal Investigator is accessing the data is not solely determinative as to whether an organisation is deemed to be a Data Controller. • Unclear what happened to those participants that did not respond to the Study Team (are they still in the cohort?).
240418f	NIC-125031-Z3D7S-v1.18	The Royal Wolverhampton NHS Trust	<ul style="list-style-type: none"> • Not clear if the correct Precedent had been used. • Noting only the application and internal application assessment form included, it appears there may be a lapse in HRA CAG support. • The NHSE risk criteria could be expanded to include lapse in HRA CAG support, which is a breach of the DSFC. • Suggest NHSE review all documentation to ensure nothing else has lapsed. • The application should have independent review or more senior NHS England sign-off.
240418g	NIC-204580-F5B0C-v3.3	Cheshire and Merseyside Cancer Alliance	<ul style="list-style-type: none"> • Not clear if the correct Precedent had been used. • Unclear if the summary of changes refer to this version of the application or earlier version, and this should be clearly articulated in the internal application assessment form.
240418h	NIC-336857-P6C9Q-v1.10	University of Bristol	<ul style="list-style-type: none"> • Not clear if the correct Precedent had been used.

			<ul style="list-style-type: none"> • A Data Controller had been removed however it was unclear if this is a simple amendment, since it is not noted in the Precedent. • The view of the remaining Data Controller is noted, but not the Data Controller removed. • Should date of death fall under simple amendment? • Unclear if this is the first extension following breach of a previous DSA – to clarify. • Ethical review information is confusing and does not align with the NHS England DAS Standard for Ethical Approval.
240418i	NIC-656867-F3Q3L-v0.2	Birmingham Women and Children's NHS Foundation Trust	<ul style="list-style-type: none"> • The DSA expires July 2024 and suggest the next iteration would need an independent review (PHE migrated application).
240418j	NIC-674976-S4T1V-v1.4	University College London	<ul style="list-style-type: none"> • Precedent appropriate and applied correctly. • Commercial purpose to be explored and for the applicant to confirm there are no commercial purposes. • When the student's PhD funding ends it is unclear what their relationship will be and whether an honorary contract will be required. • Citation special condition refers to data as part of care and support but it is part of a consented survey.