

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 16th January 2025

09:00 – 16:20

(Remote meeting via videoconference)

AGD INDEPENDENT / NHS ENGLAND MEMBERS IN ATTENDANCE:	
Name:	Role:
Paul Affleck (PA)	AGD independent member (Specialist Ethics Adviser)
Claire Delaney-Pope (CDP)	AGD independent member (Specialist Information Governance Adviser)
Dr. Robert French (RF)	AGD independent member (Specialist Academic / Statistician Adviser)
Kirsty Irvine (KI)	AGD independent member (Chair)
Andrew Martin (AM)	NHS England member (Data Protection Office Representative (Delegate for Jon Moore))
Dr. Jonathan Osborn (JO)	NHS England member (Caldicott Guardian Team Representative)
Jenny Westaway (JW)	AGD independent member (Lay Adviser)
Miranda Winram (MW)	AGD independent member (Lay Adviser)
Tom Wright (TW)	NHS England member (Data and Analytics Representative (Delegate for Michael Chapman))
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	Role / Area:
Eleanor Berg (EB)	Senior Information Governance Manager, Data Protection Office & Trust (DPOT), Privacy, Transparency, and Trust (PTT), Delivery Directorate (Observer: items 5.1 to 5.5, 7.1 to 7.6 and 8.1)
Garry Coleman (GC)	NHS England SIRO Representative (Presenter: items 8.1, 10.1 and 10.2) (Not in attendance for part of item 8.1)
Dan Goodwin (DG)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: items 5.5 and 5.6)

Suzanne Hartley (SH)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.1)
Andrew Ireland (AI)	Information Governance Specialist, IG Risk and Assurance, Privacy, Transparency, and Trust (PTT), Delivery Directorate (Observer: item 8.1)
Nicki Maher (NM)	Information Governance Lead, IG Assurance and Risk, IG Audit Services Lead (Interim), Privacy, Transparency, and Trust (PTT), Delivery Directorate (Presenter: item 8.1)
Harry Millard (HM)	Information Governance Officer, IG Risk and Assurance, Privacy, Transparency, and Trust (PTT), Delivery Directorate (Observer: item 8.1)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Delivery Directorate
Suzanne Shallcross (SS)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.6)
Jodie Taylor-Brown (JTB)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.4)
James Watts (JW)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: items 5.2 and 5.3)
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Delivery Directorate (Presenter: 8.1 and 9.2)
AGD INDEPENDENT MEMBERS / NHS ENGLAND MEMBERS <u>NOT</u> IN ATTENDANCE:	
Name:	Role / Area:
Michael Chapman (MC)	NHS England member (Data and Analytics Representative)
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.
2	Review of previous AGD minutes:

	The minutes of the AGD meeting on the 12 th December 2024 were reviewed out of committee by the Group and, after several minor amendments, were agreed as an accurate record of the meeting by the AGD Chair, on behalf of the Group.	
3	Declaration of interests: Jenny Westaway noted that she had some involvement in discussions about the common law duty of confidentiality in relation to one of the activities outlined in NIC-768785-V7L6D, through her National Data Guardian (NDG) role. It was agreed this did not preclude Jenny from taking part in the discussions about the London Ambulance Service NHS Trust application.	
4 BRIEFING PAPER(S) / DIRECTIONS:		
There were no items discussed		
5 EXTERNAL DATA DISSEMINATION REQUESTS:		
5.1	Reference Number: NIC-748653-S9J4H-v0.4 Applicant and Data Controller: Office for National Statistics (ONS) Application Title: Waiting List Minimum Data Set (WLMDS) - for the purposes of Statistics and Statistical Research, under section 45 of the Statistics and Registration Services Act 2007 as amended by the Digital Economy Act 2017 Observers: Suzanne Hartley and Eleanor Berg Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 24 th October 2024 and the 9 th May 2024. 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) meeting on the 15 th March 2024. Linked applications: This application is linked to NIC-748645-R5G3D. Application: This was a new application. NHS England were seeking advice on the following points only : <ol style="list-style-type: none">1. Whether any additional evidence or activity is required from ONS to strengthen their response on the previous patient and public involvement and engagement (PPIE) point previously raised by AGD; and what should be included in the PPIE Special Condition.2. The update on the purpose and statutory legal basis.3. Whether a non-mandatory request under section 45(a) Statistics and Registration Service Act (SRSA) 2007 would be supported for the purpose of	

	<p>the work outlined. If so, that would enable the WLMDS data to be provided without requiring a formal legal notice from ONS.</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 providing comments on the wider application as requested by NHS England; comments were limited to the specific points of advice requested. AGD wished to draw to the attention of the SIRO the following observations in relation to the advice points:</p> <p>In response to point 1:</p> <p>5.1.1 AGD noted and commended the applicant on the PPIE undertaken to date, in particular the efforts made to engage often hard to reach groups.</p> <p>5.1.2 AGD suggested to the applicant that there was ongoing PPIE throughout the lifecycle of the work and that there were ongoing efforts to ensure there was appropriate representation of diverse groups. The HRA guidance on Public Involvement is a useful guide.</p> <p>5.1.3 AGD noted in the NHS England Data Access Service (DAS) internal application assessment form that a PPIE report was being produced by the applicant and that this would be shared with NHS England by the end of 2024, however, as it was still in the process of being drafted, the Group advised that they were unable to offer a definitive view as to whether public support had been established.</p> <p>5.1.4 Separate to the application and for NHS England to consider: AGD noted that NHS England's published transparency materials state that NHS England, as the custodian of national datasets will only make data available to approved users for the purpose of improving health and care; which did not align with all the purposes outlined in this application.</p> <p>5.1.5 The AGD NHS England Data Protection Office (DPO) Representative advised the Group that there was ongoing work within NHS England to review and update NHS England's transparency materials and that this issue would be reviewed as part of this work. The Group suggested that this was a risk to NHS England, and that this issue required more urgent attention and should be addressed before any processing under this application starts.</p> <p>ACTION: the Caldicott Guardian Team Representative agreed to take forward the action to address in relation to 5.1.5 above.</p> <p>In response to point 2 and point 3:</p> <p>5.1.6 AGD advised that they were supportive of a non-mandatory request and noted the extensive work undertaken in establishing the legal basis and linking this with the proposed purpose; however, advised that if the non-mandatory route was used, NHS England must assure themselves there was public support for this work (see</p>	<p>CG Rep</p>
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	<p>point 5.1.3), noting the non-health related uses of the data and lack of transparency by NHS England about such uses.</p> <p>5.1.7 Noting AGD was only asked to advise on specific points reviewed, no AGD member noted any substantive commercial aspects.</p>	
5.2	<p>Reference Number: NIC-419335-H5P8T-v3.2</p> <p>Applicant: University of Oxford</p> <p>Data Controllers: Intensive Care National Audit & Research Centre (ICNARC) and University of Oxford</p> <p>Application Title: Outcomes of Patients who survived Treatment on an Intensive Care unit for COVID-19 in England and Wales (OPTIC-19): a comparative retrospective cohort study</p> <p>Observers: James Watts and Eleanor Berg</p> <p>Previous Reviews: The application was previously discussed at the AGD meetings on the 22nd June 2023 and the 15th June 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 16th September 2021 and the 15th July 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) meeting on the 9th June 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. The new dissemination of COVID-19 Vaccination Status dataset. <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 noted that they would be providing observations based on these documents.</p> <p>In response to point 1:</p> <p>5.2.1 AGD advised that they were supportive of the addition of the COVID-19 Vaccination Status dataset to the application. The Group noted that the protocol provided a clear justification for the addition of this dataset and suggested that this</p>	

	<p>was added to section 5(a) (Objective for Processing) for transparency, in line with NHS England DAS Standard for Objective for Processing.</p> <p>5.2.2 AGD suggested that section 5(d) (benefits) (iii) (Yielded Benefits) was updated to provide further information on the yielded benefits, in line with NHS England DAS Standard for Expected Measurable Benefits.</p> <p>5.2.3 ACTION: The Group queried with the AGD NHS England Caldicott Guardian Team Representative, whether this application required a further review by PAG; and were advised by the AGD NHS Caldicott Guardian Team Representative that this would be given further consideration out of committee with the NHS England SIRO Representative and NHS England's Data Access Service (DAS).</p> <p>AGD made the following observations on the application and / or supporting documentation provided, at the request of the NHS England SIRO Representative:</p> <p>5.2.4 AGD noted that at the IGARD meeting on the 15th July 2021, it was unclear how many years of data the Health Research Authority Confidentiality Advisory Group (HRA CAG) support enabled linkage to, and the Group suggested that the applicant confirmed with HRA CAG that the support given covered the data requested under this Data Sharing Agreement (DSA), for example, 5-years of data. The Group were unable to see an update on this point, and suggested that NHS England discuss this further with the applicant.</p> <p>5.2.5 AGD noted that the HRA CAG support was due to expire on the 31st August 2025; however, noting that this did not align with the DSA end date on the 19th January 2026, suggested that the applicant and NHS England discuss this further, for example, to agree that an extension to the HRA CAG support would be sought by the applicant; or to amend the application end date to align with the HRA CAG support.</p> <p>5.2.6 AGD noted the mismatch of dates / years referred to in section 3 (Datasets Held / Requested) in respect of the Maternity Services Dataset; and suggested that this was reviewed and updated to ensure the correct information was reflected.</p> <p>5.2.7 ACTION: Separate to the application and for NHS England to consider: AGD requested that, where available, the Annual Compliance Report (ACR) was submitted to AGD as part of the meeting pack of papers, to support the review of future applications.</p> <p>5.2.8 Noting AGD was only asked to advise on specific points reviewed, no AGD member noted any substantive commercial aspects.</p>	<p>CG Rep</p> <p>D&A Rep</p>
5.3	<p>Reference Number: NIC-534549-M1N3P-v1.4</p> <p>Applicant: University of Bristol</p> <p>Data Controllers: London School of Hygiene and Tropical Medicine and University of Bristol</p>	

<p>Application Title: ELUCIDate: “ELUCidate long-term consequences of Childhood Infections using administrative and research Data</p> <p>Observers: James Watts and Eleanor Berg</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 23rd May 2024 and the 18th May 2023.</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 26th March 2024.</p> <p>Application: This was an amendment 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 to the following comments:</p> <p>5.3.1 AGD noted that there was PAG support for this application.</p> <p>5.3.2 Noting the discussion at the AGD meetings on the 28th November 2024 and the 8th August 2024, on the broader scope of the NHS Business Services Authority (NHSBSA) Medicines Data Directions 2019; it was suggested that the application was reviewed and updated throughout to reflect the broader scope, including, but not limited to the removal of the restrictive special condition in section 6 (Special Conditions).</p> <p>5.3.3 Notwithstanding the Section 251 support, AGD noted the consent review provided as a supporting document (SD5.4) had referred to a study specific privacy notice being available on a website now, but did not note when it had been added to the website. It was suggested that the date of availability was provided where there is a reference to information being posted on a website, to support whether that information had been available at the relevant time (in this case at the point of study recruitment).</p> <p>5.3.4 AGD noted and commended the applicant on the patient and public involvement and engagement (PPIE), and the highlights outlined in section 5(a) (Objective for Processing).</p> <p>5.3.5 Separate to the application and for NHS England to consider: Prior to the meeting, an AGD independent member had noted a reference in the NHS England Data Access Service (DAS) internal application assessment form, to data being separately linked to the ‘COVID-19 Mapping and Mitigation in Schools’ (CoMMinS) study, and had queried how access to this data had been obtained.</p>	<p>SIRO Rep / D&A Rep</p>
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	<p>5.3.6 No AGD member noted a commercial aspect to the application.</p>	
5.4	<p>Reference Number: NIC-691697-K9L9B-v0.6</p> <p>Applicant and Data Controller: University College London (UCL)</p> <p>Application Title: Database of UK recipients of pituitary-derived human growth hormone</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: The majority of the Group were supportive of the application, a minority of the Group (1 member) were not supportive of the application at this time due to the study design / notification process.</p> <p>The Group wished to draw to the attention of the SIRO the following substantive comments:</p> <p>5.4.1 AGD welcomed the application and noted the importance of the research.</p> <p>5.4.2 AGD noted the Health Research Authority Confidentiality Advisory Group (HRA CAG) support for the application, however, noted concern on the availability / transparency of the opt-out option to data subjects; and strongly advised that the applicant provide further transparency to the cohort on this.</p> <p>5.4.3 Noting Caldicott Principle 8, AGD suggested that failure to provide transparency on the availability of the opt-out to the cohort could result in a risk to public trust and confidence. The invitation to join a contact database being an opportunity to inform data subjects of the research database and their ability to opt-out of the latter if desired.</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 discussed the GP invite mechanism and how this aligns with the overall process, and noted specific concerns for the practicalities and the utility of using GPs. Some of the AGD members, including the AGD NHS England Caldicott Guardian Team Representative, offered further views of what might / might not be possible for NHS England to explore this further with the applicant.</p> <p>5.4.5 The AGD independent Specialist Academic / Statistician Adviser noted and supported the query raised by NHS England's Data Access Service (DAS) with the applicant in respect of the potential loss to follow-up and the impact on the outputs. Noting that this point was still outstanding, the Group suggested that NHS England explore this further with the applicant.</p>	

	<p>5.4.6 AGD suggested the application was reviewed throughout and updated where appropriate to ensure 1) that the flows of data between the various parties was clear / correct; and 2) to ensure the identifiability of the data at each stage was clear / correct.</p> <p>5.4.7 AGD noted the incorrect references in the application to NHS England flowing “<i>de-identified</i>” data, and suggested that NHS England reviewed the application throughout and update where appropriate to reflect the correct information.</p> <p>5.4.8 AGD noted that NHS England’s DAS had raised a query with the applicant in respect of honorary contracts; and noting that this point was still outstanding, the Group suggested that NHS England explore this further with the applicant.</p> <p>5.4.9 In addition, AGD noted their support for the honorary contract special condition in section 6 (Special Conditions).</p> <p>5.4.10 Noting the role of the PhD students in section 5(a) (Objective for Processing), AGD suggested that NHS England discuss this further with the applicant, to ensure that 1) access to the data by PhD students is practical / workable; 2) aligns with the application; and 3) aligns with the Data Security and Protection Toolkit (DSPT).</p> <p>5.4.11 AGD noted that section 2(c) (Territory of Use) had not been populated, and suggested that the applicant update this with the territory of use, in line with NHS England DAS Standard for Territory of Use.</p> <p>5.4.12 No AGD member noted a commercial aspect to the application.</p>	
5.5	<p>Reference Number: NIC-768785-V7L6D-v0.2</p> <p>Applicant and Data Controller: East Midlands Ambulance Service NHS Trust</p> <p>Application Title: East Midlands Ambulance Service NHS Service - Service and Evaluation / Auditing purpose</p> <p>Observers: Dan Goodwin and Eleanor Berg</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 18th July 2024 and the 13th June 2024.</p> <p>Application: This was a new application.</p> <p>NHS England were seeking advice on the following points, including general advice on any other aspect of the application:</p> <ol style="list-style-type: none"> 1. The use of the Ambulance NHS Trust Service template as a Precedent for all Ambulance Trusts in England. <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 broadly supportive of the templated application under a precedent approach, and supportive of the standalone application.</p>	

	<p>The Group wished to draw to the attention of the SIRO the following significant comments:</p> <p>AGD noted that they had been provided with a curated set of documentation and noted that they would be providing observations based on these documents.</p> <p>5.5.1 The Group reiterated a point from the 18th July 2024 meeting which had also been raised in advance of the meeting again, suggesting that NHS England ensured that the approach relating to legal basis aligned with the approach taken by other relevant stakeholders such as the National Data Guardian (NDG).</p> <p>5.5.2 AGD noted the response provided on the point above by the NHS England Service Lead, however, wished to make the following points: 1) that there was potential parallel processing, for different projects, with a different legal basis; 2) there would be duplicate / excessive processing of data if the projects were covering the same work. If the various processing was being undertaken under a s251 legal basis and a Direct Care legal basis, this may lead to differences in data quality, outputs and benefits, noting that the Direct Care legal basis will not have the National Data Opt-out (NDO) applied. 3) AGD noted that it may inadvertently identify holders of the NDO, which would not be in accordance with the NDO policy.</p> <p>5.5.3 Separate to the application: The NHS England SIRO Representative noted the concerns raised in 5.5.2 and that this would be discussed further with the NHS England Service Lead.</p> <p>5.5.4 AGD suggested that NHS England clearly articulate to those Ambulance Service NHS Trusts who are relying on s251 support, that there may be a potential alternate legal basis for them to carry out this work, that would not require the annual upkeep of the s251 support or the NDO to be applied.</p> <p>5.5.5 AGD noted that the Ambulance Service NHS Trust opt-out is a requirement of the s251 support, and is referred to in the privacy notice and briefing note provided as a supporting document. The Group noted that this was not referred to in the application, and information on this opt out could not be located online; and suggested that this is explored with the applicant and NHS England satisfy themselves that this mechanism is readily available.</p> <p>5.5.6 AGD queried how the data would flow back to the Ambulance Service NHS Trust if the opt-out was applied; and suggested that NHS England clarify this.</p> <p>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.5.7 AGD suggested that section 5(a) (Objective for Processing) of the templated application was reviewed by NHS England, and updated to be clearer that 1) there are two separate levels of data; 2) the identifiability of the data; and 3) how the data will be used.</p>	<p>SIRO Rep</p>
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	<p>5.5.8 AGD suggested that section 5(b) (Processing Activities) of the templated application was reviewed by NHS England, and updated to provide less detail on the internal NHS England processing, to ensure that this is not restrictive in the future.</p> <p>5.5.9 AGD suggested that the language in section 5(b) was reviewed by NHS England, and updated where appropriate to be clearer and more specific about what can / cannot happen, for example using language such as “<i>will not</i>” or “<i>may not</i>”, as opposed to referring to an intention.</p> <p>5.5.10 AGD suggested that NHS England remove the proforma wording at the end of section 5(d) (Benefits) of the templated application, noting this is not necessary to include.</p> <p>5.5.11 AGD noted the inclusion and exclusion criteria in the briefing note provided; and suggested that 1) the first two exclusion criteria points were removed as they were already covered in the inclusion criteria; and 2) the criteria was updated to be clear that the application was related to one Ambulance Service NHS Trust only.</p> <p>5.5.12 It was the view of AGD that there was no commercial aspect to the application.</p>	
5.6	<p>Reference Number: NIC-07289-G8J6C-v12.4</p> <p>Applicant: NEC Software Solutions UK Limited</p> <p>Data Controllers: Healthcare Quality Improvement Partnership (HQIP) and NHS England</p> <p>Application Title: National Joint Registry Annual Extract</p> <p>Observers: Dan Goodwin and Suzanne Shallcross</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) meetings on the 15th April 2021, 11th March 2021, 30th July 2020, 9th July 2020, 11th June 2020, 7th May 2020, 16th November 2017, 9th November 2017, 5th October 2017 and the 6th April 2017.</p> <p>The application and relevant supporting documents were previously presented / discussed at the Data Access Advisory Group (DAAG) meeting on the 10th January 2017.</p> <p>Application: This was an amendment 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>5.6.1 Prior to the meeting, the Caldicott Guardian Team had undertaken a review regarding those individuals who had previously submitted a National Data Opt-out (NDO), but were recruited via consultee advice as per the Mental Capacity Act 2005. It was the view of the Caldicott Guardian Team, that, as NHS England could not be certain that the individual providing consultee advice had been aware of the person's wishes regarding data sharing (for research and planning) and NHS England now have evidence of the patient's wishes via their NDO status, that the decision of least harm, would be to respect the patient's autonomy, and to not share the data for this specific group of data subjects.</p> <p>5.6.2 In addition, the Group were advised that in respect of sub-groups for which s251 was in place, specific attention had been paid by Health Research Authority Confidentiality Advisory Group (HRA CAG) to public interest in the data sharing, resulting in Secretary of State approval for the NDO to be over-ridden. Noting that this is an uncommon occurrence, it was suggested by the Caldicott Guardian Team that NHS England's SIRO should pay due regard to the HRA CAG opinion when making their decision regarding data dissemination.</p> <p>5.6.3 ACTION: AGD discussed the points raised, and suggested a public interest test was performed to see if the NDO should be applied, or not, to the cohort relying on consultee advice to ensure consistency / justification for inconsistency of approach. The AGD NHS England Caldicott Guardian Team Representative advised that he would provide a further update to the NHS England SIRO Representative and NHS England's Data Access Service (DAS) in due course, once this had been discussed with the Caldicott Guardian Team.</p> <p>5.6.4 AGD suggested that NHS England clarify with the applicant 1) that the relevant hospitals are aware they will be responsible for carrying out the re-consent process for individuals once they reach the age of 18, noting that this would be a significant number; 2) what the process is; and if there is a robust mechanism in place; 3) if the individual declines to provide consent once they turn 18, or there is no response, are they removed from the cohort; and 4) if they are removed from the cohort, what is mechanism to ensure that this happens.</p> <p>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.6.5 Noting the ongoing discussions on the NDO, AGD suggested that section 3(c) (Patient Objections) was updated to reflect that that patient objections were "<i>mixed</i>".</p> <p>5.6.6 AGD suggested that section 3(c) was updated to reflect how the data is re-purposed from 'audit' to 'research'.</p> <p>5.6.7 AGD suggested that NHS England satisfy themselves that 1) section 2(c) (Territory of Use) reflects the correct territory of use, in line with NHS England DAS Standard for Territory of Use; and 2) that NHS England remind the applicant that the territory of use must align with the data sharing agreement (DSA).</p>	<p>CG Team</p>
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	<p>ensure that the description of what data is submitted by NHS Trusts maps to other documents, such as transparency information on the NJR website.</p> <p>5.6.18 AGD noted the statement in section 5(b) <i>“where a compelling case is made for a release of data directly to the applicant, the applicants will be transferred a data file using a SFTP”</i>, and suggested that this was updated to state <i>“...directly to the applicant, and in line with any applicable national policy...”</i>.</p> <p>5.6.19 An AGD independent member noted that blocking access to the NJR Data Access Portal in the event of a breach of the terms and conditions appeared to be a very limited sanction if they had already received an extract of the data; and suggested that NHS England give this further consideration.</p> <p>5.6.20 AGD noted the reference in section 5(d) (Benefits) to <i>“clients”</i>; and suggested that this was updated to refer to <i>“organisations”</i>.</p> <p>5.6.21 AGD suggested that special condition 5 in section 6 (Special Conditions) was reviewed and updated as may be appropriate, for example to refer to <i>“aggregate small numbers suppressed”</i>.</p> <p>5.6.22 ACTION: Separate to the application and for NHS England to consider: AGD suggested that if special condition 5 in NIC-07289-G8J6C-v12.4 was updated to refer to <i>“aggregate small numbers suppressed”</i>, then NHS England should consider updating the standard wording in other applications as may be appropriate.</p> <p>5.6.23 AGD suggested that special condition 6 in section 6 was reviewed and updated as may be appropriate, for example to rule out any linkage between the old and new datasets, to undertake any identification of NDO holders.</p> <p>5.6.24 In respect of the NJR Register, AGD suggested that the applicant review whether 1) it is up to date; 2) could all the relevant dates be added to the Register; and 3) could they improve the accessibility / make it more user friendly.</p> <p>5.6.25 AGD noted the variation of acronyms in the application, for example <i>“NEC”</i> and <i>“NECWS”</i>; and suggested that, for consistency, these were reviewed and updated / aligned as appropriate.</p> <p>5.6.26 AGD advised that they would be supportive of NHS England seeking further advice from the Group on a public interest assessment if required.</p> <p>5.6.27 AGD noted that there are commercial aspects of the application including: commercial Data Processor, commercial use and potential issue with commercial use of data which includes PROMS data, which was possibly in contravention of the special condition in section 6.</p>	D&A Rep
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-667559-J3L9G-v1.4</p> <p>Applicant: University of Oxford</p> <p>Data Controllers: University of Bristol and University of Oxford</p> <p>Application Title: Evaluating Clinical Outcomes in Hip, Knee, Foot, and Ankle Surgery</p> <p>Previous Reviews: The application and relevant supporting documents had previously been presented / discussed at the AGD meeting on the 23rd March 2023. The SIRO approval was for an amendment to add the University of Bristol as a Data Controller.</p> <p>Outcome of discussion: AGD noted that the NHS England SIRO had already provided SIRO approval and confirmed that they were supportive of this. AGD thanked NHS England for the written update and advised that they had no further comments to make on the documentation provided. The NHS England SIRO representative thanked AGD for their time.</p>	
7.2	<p>Reference Number: NIC-20951-D2K6S-v13.6</p> <p>Applicant: Office for National Statistics (ONS)</p> <p>Application Title: Provision of data via PDS to ONS</p> <p>Previous Reviews: The application and relevant supporting documents had previously been presented / discussed at the AGD meetings on the 3rd August 2023 and the 27th April 2023.</p> <p>The application and relevant supporting documents had previously been presented / discussed at the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) meetings on the 16th June 2022, 17th March 2022, 9th December 2021, 22nd July 2021, 19th November 2020 and the 15th October 2020.</p> <p>The application and relevant supporting documents had previously been presented / discussed at the Data Access Advisory Group (DAAG) meeting on the 22nd March 2016.</p> <p>The SIRO approval was for ONS to note an output they have produced which they considered to be 'derived data' which they intend to onwardly share with accredited researchers in their Trusted Research Environments (TRE).</p> <p>Outcome of discussion: AGD noted that the NHS England SIRO had already provided SIRO approval.</p> <p>AGD thanked NHS England for the written update and made the following observations on the documentation provided:</p> <p>7.2.1 AGD noted that prior to the meeting, an AGD independent member had raised a query with the NHS England SIRO Representative in respect of whether the Admin</p>	

	<p>Based Census (ABC) data meets the second part of the definition for derived data in the Data Sharing Framework Contract (DSFC), whereby it <i>“is not capable of use as a substitute for the Data”</i>. The Group discussed this point and did not reach a definitive conclusion. However, it was noted that the data could not be identified as originating from NHS England, and that this particular form of derivation is unlikely to be possible under agreements with other Data Controllers because they would need other identifying datasets.</p> <p>The NHS England SIRO representative thanked AGD for their time.</p>	
7.3	<p>Reference Number: NIC-175120-W5G2X-v15.4</p> <p>Applicant and Data Controller: Office for National Statistics (ONS)</p> <p>Application Title: D5 - Office for National Statistics requirements for NHS-England (formerly NHS Digital) data, for the purposes of Statistics and Statistical Research, under section 45 of the Statistics and Registration Services Act 2007 as amended by the Digital Economy Act 2017</p> <p>Previous Reviews: The application and relevant supporting documents had previously been presented / discussed at the AGD meetings on the 15th June 2023 and the 16th March 2023.</p> <p>The SIRO approval was for ONS to note an output they have produced which they considered to be ‘derived data’ which they intend to onwardly share with accredited researchers in their Trusted Research Environments (TRE).</p> <p>Outcome of discussion: AGD noted that the NHS England SIRO had already provided SIRO approval</p> <p>AGD thanked NHS England for the written update and made the following observations on the documentation provided:</p> <p>7.3.1 AGD noted that prior to the meeting, an AGD independent member had raised a query with the NHS England SIRO Representative in respect of whether the Admin Based Census (ABC) data meets the second part of the definition for derived data in the Data Sharing Framework Contract (DSFC), whereby it <i>“is not capable of use as a substitute for the Data”</i>. The Group discussed this point and did not reach a definitive conclusion. However, it was noted that the data could not be identified as originating from NHS England, and that this particular form of derivation is unlikely to be possible under agreements with other Data Controllers because they would need other identifying datasets.</p> <p>The NHS England SIRO representative thanked AGD for their time.</p>	
7.4	<p>Reference Number: NIC-392201-S6C3W-v6.2</p> <p>Applicant and Data Controller: Telstra Health UK Limited</p>	

	<p>Application Title: Telstra Health UK - HES, ECDS, Civil Registration (Deaths) Secondary Care Cut</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 29th September 2022, 22nd October 2020 and the 1st October 2020.</p> <p>The SIRO approval was for an amendment to enable Telstra Health UK to meet the changing needs of the NHS and to share record-level pseudonymised reporting and analysis back to NHS organisations working in collaboration, or partnership or with shared functions, pathways and services, often within the same Integrated Care System (ICS) or Acute Provider Collaborative (APC).</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>7.4.1 AGD noted that the following criteria point for data sharing was quite broad <i>“NHS organisations serving a shared patient population...”</i>; and suggested that this should be reviewed by NHS England and the applicant.</p> <p>The NHS England SIRO representative thanked AGD for their time.</p>	
7.5	<p>Reference Number: NIC-331142-P5K6M-v3.4</p> <p>Applicant: University of Bristol</p> <p>Data Controllers: Healthcare Quality Improvement Partnership (HQIP) and NHS England</p> <p>Application Title: National Child Mortality Database (NCMD)</p> <p>Previous Reviews: The application and relevant supporting documents had previously been presented / discussed at the AGD meetings on the 18th July 2024 and the 19th June 2023.</p> <p>The application and relevant supporting documents had previously been presented / discussed at the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) meetings on the 18th November 2021, 19th August 2021 and the 9th July 2020.</p> <p>The application and relevant supporting documents were previously presented / discussed at the IGARD COVID-19 response meetings on the 26th November 2020.</p> <p>The SIRO approval was for a six-month extension to hold and process, but not to disseminate further data.</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>7.5.1 Separate to the application and for NHS England to consider: AGD noted that when this application had last been reviewed by IGARD on the 19th August 2021, IGARD advised that they would wish to review this application when it came up for renewal, extension or amendment and that this application would not be suitable for NHS Digital's Precedent route, including the SIRO Precedent, due to the unusual statutory arrangements and the sensitivity of the data and the processing. It was noted that this had not been acknowledged / justified in the documentation provided as part of this SIRO approval, and that it should have been.</p> <p>7.5.2 AGD noted that prior to the meeting, an AGD independent member had raised a query with the NHS England SIRO Representative in respect of the legal basis cited, Regulation 3(4) under The Health Service Control of Patient Information (COPI) Regulations 2002, as the legal basis for processing. Noting that this had now expired, it was suggested that this was reviewed by NHS England.</p> <p>The NHS England SIRO representative thanked AGD for their time.</p>	D&A Rep / SIRO Rep
7.6	<p>Reference Number: NIC-648561-Z8L8M-v2.2</p> <p>Applicant and Data Controller: Archus Limited</p> <p>Application Title: Archus Limited direct HES data feed</p> <p>Previous Reviews: The application and relevant supporting documents had previously been presented / discussed at the AGD meetings on the 20th April 2023.</p> <p>The application and relevant supporting documents had previously been presented / discussed at the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) meeting on the 1st December 2022.</p> <p>The SIRO approval was for an amendment to a previously approved special condition which stipulated that the applicant could only hold five years of HES/ECDS data, this has now been changed to six years so they can retain 2019/ 2020 data.</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		
8.1	Oversight and Assurance (Presenters Nicki Maher and Vicki Williams)	

	<p>Following recent discussions at previous AGD meetings in respect of oversight and assurance, the Group were advised that going forward, there would be four workstreams that sit under the AGD oversight and assurance process.</p> <p>The four workstreams are as follows:</p> <ul style="list-style-type: none">• Workstream 1 - Precedent approved internal and external applications – weekly.• Workstream 2 - Internal and external applications that have had an independent review in the last six months and been approved internally – monthly.• Workstream 3 - Annual Compliance Report (ACR) oversight and assurance – quarterly.• Workstream 4 - SIRO Approval of internal and external applications – added to next available agenda. <p>The Group were provided with an update on the workstreams including the frequency of each workstream review; and the responsibilities of AGD members and NHS England colleagues in supporting these workstreams.</p> <p>The Group noted and thanked Nicki and Vicki for the update provided.</p>	
9 AGD OPERATIONS		
9.1	<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. 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> <p>The Group noted the NHS England SIRO Representative’s response and asked for an update in January 2025.</p>	SIRO Rep
9.2	<p>Standard Operating Procedures (SOPs) (Update from Vicki Williams)</p> <p>The ongoing forward plan of work for creating the AGD Standard Operating Procedures was discussed.</p>	

	<p>The Group were advised by Vicki that as discussed at the AGD meeting on the 12th December 2024, the 'Applicant is a member of AGD' SOP; and the 'Registered and Regulated Clinicians on AGD' SOP had now been published on the AGD webpage.</p> <p>The Group noted that the 'AGD member Declaration of Interest' was in the process of being finalised, and a further update on this would be provided in due course, and published on the AGD webpage.</p>
9.3	<p>AGD Stakeholder Engagement</p> <p>A brief update was given by the Group's Representative on the Federated Data Platform Data Governance Group.</p>
9.4	<p>AGD Project Work</p> <p><i>There were no items discussed</i></p>
10 Any Other Business	
10.1	<p>Forward look for January 2025 (Presenter: Garry Coleman)</p> <p>The NHS England SIRO representative provided a verbal update / overview to the group, of ongoing / future work within NHS England, and the role of AGD in supporting this, including but not limited to artificial intelligence, cross government data sharing, data protection, opt outs, federated data platform, secure data environments (SDE), sub-national SDEs, new ways of working within AGD, and the oversight and assurance model. It was noted that further information would be presented to the Group in due course.</p> <p>The Group noted and thanked the NHS England SIRO representative for the verbal update and looked forward to receiving further information at future AGD meetings.</p>
10.2	<p>AGD recruitment, pay and contract type (Update from Garry Coleman)</p> <p>Following recent discussions at previous AGD meetings in respect of recruitment, pay and contract type, the NHS England SIRO Representative advised the Group that discussions were being held with AGD independent members on an individual basis to discuss contracts and / or pay.</p> <p>The NHS England SIRO Representative advised that once the discussions had taken place with AGD independent members, a further discussion would be held at the 30th January 2025 AGD meeting to discuss next steps around AGD recruitment, noting that the relevant permissions had been obtained for AGD recruitment to commence.</p>
10.3	<p>AGD collaboration on in-meeting documentation proposal</p> <p>AGD noted, that as discussed at the AGD meetings on the 12th December 2024 and the 26th September 2024, the application for item 5.6 on this week's AGD meeting agenda had been reviewed by AGD members in an internal shared space prior to the in-meeting discussion.</p>

	<p>As this process was running as a pilot throughout January 2025, the Group discussed how this had worked and whether it had supported the discussion in the meeting.</p> <p>The Group agreed that prior to the AGD meeting on the 23rd January 2025, one application would be uploaded to the internal shared space for the Group to undertake another review prior to the meeting; and that this would be reviewed under 'AOB' at the end of the meeting.</p> <p>ACTION: AGD Secretariat to select an application from the AGD meeting agenda on the 23rd January 2025, and upload to the AGD internal SharePoint site for review, prior to the meeting.</p>	AGD Sec
<p>Meeting Closure</p> <p>As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.</p>		