

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 6th February 2025

09:00 – 16:05

(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)
Rachel Fernandez (RF)	NHS England member (Data Protection Office Representative (Delegate for Jon Moore))
Kirsty Irvine (KI)	AGD independent member (Chair)
Dr. Jonathan Osborn (JO)	NHS England member (Caldicott Guardian Team Representative) (Not in attendance for items 1 to part of item 5.2)
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:
Garry Coleman (GC)	NHS England SIRO Representative
Joseline Dzakpata (JD)	Information Governance Specialist, Data Protection and Trust, Privacy, Transparency and Trust (PTT), Delivery Directorate (Observer: items 5.1 to 5.7)
Dan Goodwin (DG)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.2)
Suzanne Hartley (SH)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: items 5.1 and 5.2)

Andrew Ireland (AI)	Information Governance Specialist, IG Risk and Assurance, Privacy, Transparency, and Trust (PTT), Delivery Directorate (Observer: items 3.1 and 3.2)
Joe Lawson (JL)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.4)
Nicki Maher (NM)	Information Governance Lead, IG Assurance and Risk, IG Audit Services Lead (Interim), Privacy, Transparency, and Trust (PTT), Delivery Directorate (Observer: items 3.1 and 3.2)
Harry Millard (HM)	Information Governance Officer, IG Risk and Assurance, Privacy, Transparency, and Trust (PTT), Delivery Directorate (Observer: items 3.1 and 3.2)
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 5.2)
Jodie Taylor Brown (JTB)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.3)
Emma Whale (EW)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.5)
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)
Prof. Nicola Fear (NF)	AGD independent member (Specialist Academic Adviser)
Dr. Robert French (RF)	AGD independent member (Specialist Academic / Statistician Adviser)
Jon Moore (JM)	NHS England member (Data Protection Office Representative)
Jenny Westaway (JW)	AGD independent member (Lay Adviser)

1	<p>Welcome and Introductions:</p> <p>The AGD Chair welcomed attendees to the meeting.</p> <p>AGD noted that, due to unforeseen circumstances, only two AGD NHS England members were in attendance for item 5.1 and part of item 5.2.</p> <p>Noting that the AGD Terms of Reference state that “<i>The quorum for meetings of the Group or a Sub-Group is five members, including at least three independent members, one of whom may be the Chair, Deputy Chair or Acting Chair and two of the three NHSE Members...</i>”, the Group agreed that, as there were two AGD NHS England members present, the meeting was still quorate for all agenda items and agreed to proceed on that basis.</p>
2	<p>Review of previous AGD minutes:</p> <p>The minutes of the AGD meeting on the 30th January 2025 were reviewed and, after several minor amendments, were agreed as an accurate record of the meeting.</p>
3	<p>Declaration of interests:</p> <p>Dr. Jonathan Osborn noted a previous working relationship with a member of staff involved with NIC-742898-S7N0V (NHS Blood and Transplant (NHSBT)) application. It was agreed this did not represent a substantive conflict of interest.</p>
<p>4 BRIEFING PAPER(S) / DIRECTIONS:</p>	
<p><i>There were no items discussed</i></p>	
<p>5 EXTERNAL DATA DISSEMINATION REQUESTS:</p>	
5.1	<p>Reference Number: NIC-356980-Z5B9G-v0.22</p> <p>Applicant and Data Controller: MAC Clinical Research Finance Ltd</p> <p>Application Title: Enhancing access to clinical trials for consented volunteers</p> <p>Observers: Suzanne Hartley and Joseline Dzakpata</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 25th May 2023.</p> <p>The application and relevant supporting documents were previously presented / discussed at the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) meeting on the 15th July 2021.</p> <p>The application and relevant supporting documents were previously presented / discussed at the IGARD COVID-19 response meetings on the 3rd November 2020.</p> <p>Application: This was an advice application.</p>

<p>NHS England were seeking general advice on the application.</p> <p>Should an application be approved by NHS England, further details would be made available within the Data Uses Register.</p> <p>Outcome of discussion: AGD were supportive of the application if the following substantive comments were addressed, and wished to draw to the attention of the SIRO the following substantive comments:</p> <p>5.1.1 AGD noted that ‘MAC Clinical Research Finance Ltd’ was the applicant and Data Controller, and suggested that this organisational name was used throughout the application. AGD advised that any involvement from any of the other MAC entities, for example, a parent, sister or subsidiary company would not be permitted under this Data Sharing Agreement (DSA) in line with NHS England DAS Standard for Data Controllers and NHS England DAS Standard for Data Processors.</p> <p>5.1.2 It was suggested that NHS England clarify / re-emphasise with the applicant, that only the named Data Controller will have access to the data under this DSA.</p> <p>5.1.3 AGD noted the statement in section 5(b) <i>“The Data will be stored in MAC’s Envision database on servers at MAC”</i>; and suggested that this was updated to clarify the specific MAC entity, in line with the application.</p> <p>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.1.4 The NHS England SIRO Representative noted the references to <i>“specialist contractors”</i> within the consent materials provided, and suggested that these were updated to be clear that they were <i>“individual specialist contractors”</i>.</p> <p>5.1.5 AGD queried the statement in section 5(b) (Processing Activities) <i>“Access is restricted to employees or agents of...”</i> and suggested that either further information was provided as to who would be covered by <i>“agents”</i>; or that this word was removed as may be necessary to reflect the facts, in line with point 5.1.1.</p> <p>5.1.6 ACTION: Separate to the application and for NHS England to consider: The AGD NHS England Data and Analytics Representative to agree a consistent approach for the use of the term <i>“agents”</i> in applications (noting that it is used in the Data Sharing Framework Contract (DSFC); and to ensure this information is cascaded to colleagues.</p> <p>5.1.7 AGD noted that data would be flowing from NHS England on a monthly basis, and suggested that 1) NHS England satisfy themselves that the mechanics / practical arrangements for this are workable, to avoid duplication of data flows, in line with NHS England DAS standard for data minimisation; and 2) the application is updated to be clear on the process for this, to ensure there is a contractual description of the process which is auditable.</p>	<p>D&A Rep</p>
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	<p>5.1.8 In addition, noting the contractual clauses in the application in respect of data destruction, AGD suggested that these were reviewed by NHS England to ensure they were practicable and will enable any potential breaches to be identified in a timely manner.</p> <p>5.1.9 AGD noted that the territory of use was 'England and Wales', however, noting the references in the consent materials to 'worldwide' access, suggested that NHS England clarify / re-emphasise with the applicant the geographical restrictions on access to and use of data as outlined in the application, to avoid an inadvertent breach.</p> <p>5.1.10 AGD discussed the applicant's transparency materials and endorsed the advice by NHS England's Data Access Service (DAS) to improve these; and in addition, made the following suggestions: 1) to update the privacy notice to refer to the specific data flowing under this application from NHS England; 2) to specifically reference the UK General Data Protection Regulation (UK GDPR) Article 6 legal basis and Article 9 condition relied upon.</p> <p>5.1.11 AGD suggested that the commercial aspect of the application in section 5(e) (Is the Purpose of this Application in Anyway Commercial), was replicated for transparency in (the published) section 5(a) (Objective for Processing), in line with NHS England's DAS Standard for Objective for Processing and NHS England's DAS Standard for Commercial Purpose.</p> <p>5.1.12 AGD noted that this was a three-year data sharing agreement (DSA), and advised that they were supportive of this, noting the preparatory work undertaken, and with robust Annual Compliance Reports (ACRs) as per the special condition in section 6 (Special Conditions).</p> <p>5.1.13 AGD noted and commended NHS England's DAS and the applicant on the update provided on the points previously raised by the Group.</p> <p>5.1.14 AGD noted that there was a commercial aspect to the application.</p>	
5.2	<p>Reference Number: NIC-719923-Q5H1S-v0.6</p> <p>Applicant and Data Controller: Imperial College London</p> <p>Application Title: London Life Sciences Population Study (LOLIPOP)</p> <p>Observers: Dan Goodwin, Suzanne Hartley, Suzanne Shallcross and Joseline Dzakpata</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. Whether the consent is compatible. 2. Whether AGD support includes the 2003 - 2008 cohort or just the 2020 - 2024 cohort. 	

	<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 those cohort members where there is a legal gateway only, and wished to draw to the attention of the SIRO the following substantive comments:</p> <p>5.2.1 AGD noted that part of the LOLIPOP study had previously been reviewed by the Data Access Advisory Group (DAAG) under NIC-203503-X7K8K between 2014 and 2016; however, no reference of this had been made in the application or supporting documents provided; and AGD suggested that the application / NHS England Data Access Service (DAS) internal application assessment form was updated to make reference to this historical information for future reference, and this be drawn to the applicant's attention.</p> <p>In response to points 1 and 2:</p> <p>5.2.2 AGD reviewed the consent materials for the 100,000 cohort members (2020-2024), and advised that there was a legal gateway in consent for this cohort.</p> <p>5.2.3 AGD reviewed the consent materials for the 2003 cohort, and noted a number of ambiguities, including, but not limited to, 1) the mechanics of the data being flowed and linked; 2) the breadth of access to the data; 3) the length of time the follow-up was being undertaken and continuing; and 4) the incorrect reference in the early consent documents to data being "<i>anonymised</i>".</p> <p>5.2.4 AGD noted the active engagement with the participant group, and assumed that this was for the later cohort, not the 2003 cohort.</p> <p>5.2.5 AGD suggested that NHS England satisfy itself that in order to establish that processing was still within the reasonable expectations of the 2003 cohort 1) the applicant engage with a small group of those cohort members (more than 3 but less than 10), to test whether they would be surprised by the longer-term follow-up; 2) the cohort be engaged in respect of acceptability of the proposed processing in line with Caldicott Principle 8; and 3) that the applicant provide evidence of this engagement. The Group did note that it may be difficult to ascertain how many of the 2003 cohort members were still living and suggested that NHS England review to ensure engagement is proportional to the group size.</p> <p>5.2.6 AGD noted that it was the responsibility of the applicant to ensure there was an appropriate legal gateway for the processing, and suggested the applicant consider whether s251 support from Health Research Authority Confidentiality Advisory Group (HRA CAG) would offer a robust gateway for future processing.</p> <p>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p>	
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	<p>5.2.7 AGD suggested that section 5(a) (Objective for Processing) was updated by the applicant, to be clear that this was a PhD study that fits into a wider study of work, in line with NHS England DAS Standard for Objective for Processing.</p> <p>5.2.8 AGD suggested that section 2(c) (Territory of Use) was updated to reflect that the territory of use is “<i>England and Wales</i>” and not “<i>UK</i>”.</p> <p>5.2.9 Noting this was a three year data sharing agreement (DSA), AGD suggested that, section 6 (Special Conditions) was updated to include a special condition relating to the Annual Confirmation Report (ACR), in line with NHS England DAS Standard for Special Conditions.</p> <p>5.2.10 AGD noted that the applicant may submit an amendment in the future for mental health datasets and the National Diabetes Audit (NDA); and advised that they would be supportive of this amendment if there was a legal gateway for this data to flow and a justification, and subject to the usual NHS England DAS review.</p> <p>5.2.11 AGD suggested that section 5(e) (Is the Purpose of this Application in Anyway Commercial) was updated to reflect the information in the consent materials, that there may be a future commercial purpose to the work being undertaken, in line with NHS England DAS Standard for Commercial Purpose.</p> <p>5.2.12 No AGD member noted a commercial aspect to the current application.</p>	
5.3	<p>Reference Number: NIC-736310-S6T1Z-v2.2</p> <p>Applicant and Data Controller: NHS Counter Fraud Authority</p> <p>Application Title: NHSE UDAL- NHSCFA- For the purposes of the prevention and detection of crime</p> <p>Observers: Jodie Taylor Brown and Joseline Dzakpata</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 4th July 2024 and the 23rd May 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 the following substantive 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>5.3.1 AGD noted that a number of points from the last review on the 4th July 2024 had not been adequately addressed in the application; and reiterated the following:</p>	

	<p>5.3.1.1 AGD noted that the application was currently drafted with a focus on public interest, however, suggested that the application was reviewed and updated throughout, to ensure that there was a clear focus on the connection with health and social care, noting that this was a legal requirement for NHS England to permit access to the data.</p> <p>5.3.1.2 AGD noted the broad statement in section 5(b) (Processing Activities) “<i>NHSCFA will not share data disseminated via the DSA with any third party other than as part of their investigation as forensic evidence</i>”; and suggested that this was updated to be clearer as to who the third parties may be.</p> <p>5.3.1.3 AGD queried the benefit in section 5(d) (Benefits) in respect of reducing fraud; and suggested that this was updated further with further information as to how this would benefit health and social care, for example, by the reallocation of funds and reassurance to the public that resources are being appropriately used.</p> <p>5.3.1.4 AGD noted that two Article 9 UK General Data Protection Regulation (UK GDPR) limbs had been cited, Article 9(2)(g) (<i>Reasons of substantial public interest (with a basis in law)</i>) and 9(2)(j) (<i>processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purpose</i>); and suggested that section 5(a) (Objective for Processing) of the application was updated to clarify what processing was being carried out under each Article 9 limb. Alternatively, that it was clearly stated that both conditions applied to all processing of all special category data.</p> <p>5.3.2 The AGD independent Specialist Information Governance Advisor and the AGD NHS England Data Protection Office (DPO) Representative (delegate) reiterated and endorsed the point made on the 4th July 2024, in respect of producing / providing a copy of the Data Protection Impact Assessment (DPIA).</p> <p>5.3.3 The Group advised that a DPIA would support the proposed processing, for example, by offering clarity on the UK GDPR Article 9 conditions (see point 5.3.1.4), and should be clear whether 1) both Article 9 conditions apply to all processing; or 2) whether one or the other Article 9 conditions applies to the processing.</p> <p>5.3.4 The AGD NHS England Data Protection Office (DPO) Representative (delegate) advised that if Article 9(2)(g) (<i>substantial public interest</i>) was being relied upon, then the applicant would need an appropriate policy to support this; and suggested that NHS England discuss this further with the applicant.</p> <p>5.3.5 AGD suggested that NHS England clarify with the applicant whether all of the proposed processing, expected outputs and benefits, are able to be achieved with pseudonymised data.</p>	
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	<p>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.3.6 No AGD member noted a commercial aspect to the application.</p>	
5.4	<p>Reference Number: NIC-776147-F5N3V-v0.4</p> <p>Applicant: Queen Mary University of London</p> <p>Data Controllers: Cambridge University Hospitals NHS Foundation Trust and University of Cambridge</p> <p>Application Title: BEST-4 Heartburn Health Programme - Outcomes (NHS Numbers)</p> <p>Observer: Joe Lawson and Joseline Dzakpata</p> <p>Linked applications: this application is linked to NIC-753801-J5B3X.</p> <p>Application: This was a new application.</p> <p>NHS England were seeking advice on the following points only:</p> <ol style="list-style-type: none"> 1. Does AGD support the provision of the requested data service to the named organisations for the stated purpose. 2. Does AGD agree that the consent is compatible with the proposed flows and processing of data outlined in this application. 3. Do AGD believe that the Research Ethics Committee (REC) support in place for this study covers the proposed flows and processing of data outlined in this application. <p>Should an application be approved by NHS England, further details would be made available within the Data Uses Register.</p> <p>Outcome of discussion: AGD were not providing comments on the wider application as requested by NHS England. AGD wished to draw to the attention of the SIRO the following observations in relation to the advice points:</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 points 1 and 2:</p> <p>5.4.1 The majority of the Group agreed the consent was not compatible with the processing of the cohort member's addresses. It was noted by the majority of the Group that some of the cohort members may be surprised that their address had been furnished and used.</p> <p>5.4.2 A minority of the Group (one independent member) agreed the consent was compatible with the processing of the cohort member's addresses.</p> <p>5.4.3 AGD noted that as there was reference in some of the transparency materials to telephone numbers being used to contact cohort members via text messaging (and there may be a legal basis to initiate contact), queried whether cohort</p>	

	<p>members could be sent text messages asking them to provide their latest address rather than applying to NHS England.</p> <p>5.4.4 AGD advised that they would be supportive of a 'list clean' being undertaken by NHS England, to remove deceased members from the cohort; and advised that there was a clear legal basis for this.</p> <p>In response to point 3:</p> <p>5.4.5 AGD suggested that it was the responsibility of the applicant to satisfy themselves that the REC support covers the proposed flows and processing of data; however, advised that if the consent was not compatible, then this would impact on the REC support.</p> <p>In addition, AGD made the following observations on the application and / or supporting documentation provided, at the request of the NHS England SIRO Representative:</p> <p>5.4.6 The Group suggested that NHS England explore with the applicant the involvement of the Chief Investigators and to seek assurance that these individuals were not responsible for determining the purpose and means of processing, and were therefore not carrying out any data controllership activities, in line with the NHS England's DARS Standard for Data Controllers, for example, noting that one of the Chief Investigators was an employee of the Data Processor (Queen Mary University of London).</p> <p>5.4.7 AGD suggested that section 5(a) (Objective for Processing) was updated to provide an indicative number of the number of records involved, due to the large quantum of data that will be processed.</p> <p>5.4.8 AGD was only asked to advise on specific advice points, however noted that there was a commercial aspect to the application.</p>	
5.5	<p>Reference Number: NIC-743125-M0K1Y-v0.7</p> <p>Applicant: Royal College of Anaesthetists</p> <p>Data Controller(s): Healthcare Quality Improvement Partnership (HQIP) and NHS England</p> <p>Application Title: NELA NoLap</p> <p>Observer: Emma Whale and Joseline Dzakpata</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 (one independent member) was not supportive of the application at this time due to being unclear on the status of the data.</p> <p>The Group wished to draw to the attention of the SIRO the following substantive comments:</p> <p>5.5.1 AGD noted a number of comments / suggestions in respect of the identifiability of the data and the controls that are in place, including, but not limited to 1) ensuring the identifiability of the cohort provided needs to accurately described in the application and reflect the dual flows of data; 2) to review / update the application throughout to ensure the identifiability of the data is described / aligned; 3) to describe what controls are in place for the data to address the common law duty of confidentiality, for example role based access controls, and 4) in respect of the data that is out of scope for the s251 support, to clarify the necessary approvals that are in place to process this data.</p> <p>5.5.2 AGD noted that the NHS England Security Team had set out specific requirements for this application; and advised that the Group's support for this application, was on the basis that these requirements would be satisfied before any data flows.</p> <p>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.5.3 The Group were provided with a verbal overview from the AGD NHS England Caldicott Guardian Team Representative and noted that they were supportive of the purpose / aims as described to them verbally, and noting that the complex application had had to be explained in-meeting, suggested that for ease of understanding, section 5(a) (Objective for Processing) was updated by the applicant, to provide a brief description, in language suitable for a lay reader, to clarify why this audit is being set-up and how it will inform current practice.</p> <p>5.5.4 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>5.5.5 AGD suggested that following the update to section 2(c) as outlined in point 5.5.4, to reflect that the territory of use was 'England and Wales'; section 5(b) (Processing Activities) of the application was updated to be clear that only data related to 'England' would flow.</p> <p>5.5.6 AGD suggested that the application was updated to be clear that those individuals from the Royal College of Surgeons of England (RCS) would be working on honorary contracts.</p> <p>5.5.7 AGD suggested that the application was updated to clarify the legal basis for the onward flow of data to the NHS Trusts, and how this will meet the intended purpose, as outlined in the application.</p>	
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	<p>5.5.8 An AGD independent member offered some suggestions to the applicant, to ensure that. when the website is updated, it this reflects the revisions, including, but not limited to, ensuring the drop-down options reflect the correct / recent information.</p> <p>5.5.9 No AGD member noted a commercial aspect to the application.</p>	
5.6	<p>Reference Number: NIC-656845-G9J9W-v3.3</p> <p>Applicant and Data Controller: Southampton City Council</p> <p>Application Title: Audit of cancer health inequalities in Southampton (ODR1819_291)</p> <p>Observer: Joseline Dzakpata</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) meeting on the 19th January 2023.</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 comments:</p> <p>5.6.1 AGD noted that the addition of the GP practice code had been discussed by the IGARD Co-Deputy Chairs out of committee on the 19th January 2023, and a number of comments had been made which had been addressed; however, the Group reiterated the point made, as to why there was a Primary Care Networks (PCNs) focus, and asked that further information was provided on this, for example, were there cancer nurses engaged on a PCN basis.</p> <p>5.6.2 The AGD NHS England Caldicott Guardian Team Representative noted that there was a risk, that it could be perceived as being used as a performance management tool for GP practices.</p> <p>5.6.3 No AGD member noted a commercial aspect to the application.</p>	
5.7	<p>Reference Number: NIC-742898-S7N0V-v0.5</p> <p>Applicant and Data Controller: NHS Blood and Transplant (NHSBT)</p> <p>Application Title: Equity of access to liver transplantation in the UK (EquiLT-UK): impact of socio-demographic characteristics on registration, organ offering, allocation and transplant outcomes</p> <p>Observer: Joseline Dzakpata</p>	

	<p>Application: This was a new application.</p> <p>NHS England were seeking general advice on the application.</p> <p>Should an application be approved by NHS England, further details would be made available within the Data Uses Register.</p> <p>Outcome of discussion: AGD were supportive of the application if the following substantive comments were addressed, and wished to draw to the attention of the SIRO the following substantive comments:</p> <p>5.7.1 AGD noted that there appeared to be a UK Transplant Registry opt-out, but advised that it was unclear how and when this opt-out would be applied; and suggested that NHS England explore this further with the applicant.</p> <p>5.7.2 In addition, AGD noted that whilst out of the scope of the advice provided by the Group, transparency information on the UK Transplant Registry seems out of date; and suggested that NHS England draw this to the attention of the applicant.</p> <p>5.7.3 In addition, given the importance of the UK Transplant Registry, AGD flagged the need to ensure there was sufficient UK General Data Protection Regulation (UK GDPR) transparency information about this database and that it is referenced and linked from NHSBT's general privacy information.</p> <p>5.7.4 AGD noted that if the Chief Investigator (CI) received a "<i>direct opt-out notification</i>" the CI would re-identify them and remove their data. However, the privacy notice does not clarify that opt outs will only apply to some of the data that flows from NHS England; AGD suggested that NHS England explore this further with the applicant.</p> <p>5.7.5 AGD suggested that the information within the application in respect of opt-outs aligned with the information that was presented to Health Research Authority Confidentiality Advisory Group (HRA CAG) when seeking / obtaining the s251 support.</p> <p>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.7.6 AGD noted that funding was in place until September 2026, however the application end date was February 2028; and suggested that NHS England clarified with the applicant that there is funding in place for the duration of the data sharing agreement (DSA).</p> <p>5.7.7 AGD suggested that NHS England make clear to the applicant, that the Annual Compliance Reports (ACRs) would need to be signed by a senior member of NHSBT.</p> <p>5.7.8 AGD suggested that section 5(a) (Objective for Processing) was updated by the applicant, to be clear that this was a PhD study, in line with NHS England DAS Standard for Objective for Processing.</p>	
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	5.7.9 No AGD member noted a commercial aspect to the application.	
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-616004-J8K1K-v2.11</p> <p>Applicant and Data Controller: NHS South Yorkshire ICB</p> <p>Application Title: DSFC – NHS South Yorkshire Integrated Care Board- IV, RS & Comm</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 4th May 2023.</p> <p>The SIRO approval was for access to patients registered to GP practices within Derby and Derbyshire, and access to individual Funding Request (IFR) data linkage.</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>7.1.1 AGD noted that, prior to the meeting, an AGD independent member had raised a query with the NHS England SIRO Representative, in respect of the data linkage for Individual Funding Requests (IFRs).</p> <p>7.1.2 The Group noted that the NHS England SIRO Representative had provided a verbal update on the points raised in the meeting, and that this was linkage to inform commissioning not re-identification as part of deciding upon IFRs. Whilst the Group were satisfied with the response, they suggested that the application was updated to be clearer on the points raised for transparency.</p> <p>7.1.3 AGD noted in the NHS England Data Access Service Escalation Form provided as a supporting document, that the Annual Confirmation Report (ACR) had been requested in December 2024, and suggested that NHS England confirm that this had now been received; and that there were no non-compliances recorded.</p> <p>The NHS England SIRO representative thanked AGD for their time.</p>	
8 OVERSIGHT AND ASSURANCE		
8.1	<p>Oversight and Assurance Process</p> <p>Workstream 1 – Precedent approved internal and external applications</p>	

	<p>The Statutory Guidance states that the data advisory group (AGD) should be able to provide NHS England with advice on: <i>“Precedents for internal and external access, including advising in accordance with an agreed audit framework whether processes for the use of precedents are operating appropriately, to provide ongoing assurance of access processes”</i>.</p> <p>In advance of the meeting, the AGD independent members were provided with 1) two applications (selected by the AGD Secretariat); 2) relevant supporting documents; and 3) an oversight and assurance template to complete.</p> <p>Following review of the applications by the AGD independent members out of committee, the completed oversight and assurance templates were sent to the NHS England SIRO Representative Team and the AGD Secretariat prior to the meeting.</p> <p>It was noted that only high-level points would be discussed in meeting (and noted in the minutes); however, the full suite of comments and feedback from AGD independent members on the oversight and assurance templates would be collated by the AGD Secretariat and shared with the NHS England SIRO Representative and relevant NHS England colleagues as may be appropriate.</p> <p>Please see appendix A for high-level points raised in-meeting on the two applications.</p>	
8.2	<p>Oversight and Assurance Conclusion / Review</p> <p>The Group reiterated their comment from the 30th January 2025, that there should be further discussions to clearly define how AGD members decide whether they are supportive, not supportive or undecided of an application proceeding via the Precedent route in order to support AGD members reaching a conclusion when reviewing applications for oversight and assurance.</p> <p>AGD and the NHS England SIRO Representative reiterated the point raised at the 30th January 2025 AGD Meeting (point 9.1 and 9.2) and 21st November 2024 AGD meeting (point 8.2) that for both applications that were reviewed as part of oversight and assurance, there were no documents available that provided an audit trail that outlined how the decision had been reached to progress the application down the NHS England precedent route.</p> <p>ACTION: The NHS England SIRO Representative asked that the AGD NHS England Data and Analytics Representative ensure that all relevant documentation was uploaded to the customer relationship management (CRM) system as agreed previously and for audit purposes.</p>	SIRO Rep / D&A Rep
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</p>	

	<p>were concerned that the permanent Risk Management Framework was not in place. The Group discussed the NHS England corporate risk management framework (see minutes of 14th November 2024) and the AGD chair subsequently formally asked via email if the NHS England corporate risk management framework could be used. The NHS England SIRO Representative updated the Group that NHS England was still considering the request, including how the NHS England corporate risk management framework could be adapted for AGD.</p> <p>ACTION: The NHS England SIRO Representative to provide a written response to AGD on the progress, and expected time frame for implementation, of the risk management framework.</p>	SIRO Rep
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 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><i>There were no items discussed</i></p>	
9.4	<p>AGD Project Work</p>	
(a)	<p>Federated Data Platform</p> <p>A brief update was given by the Group’s Representative on the Federated Data Platform Data Governance Group.</p>	
(b)	<p>Consent review for consented cohorts</p> <p>As discussed at the AGD business as usual (BAU) meetings on the 30th January 2025 and the 23rd January 2025, the NHS England SIRO Representative advised the Group that the request from NHS England for AGD to review and provide advice on the consent materials for consented cohorts for a small number of organisations, would take place in a workshop on the 13th February 2025, instead of the usual AGD BAU meeting.</p> <p>The Group noted a draft consent review proforma had been produced to support the discussion / outcomes at the workshop on the 13th February 2025; and following discussion in-meeting, the updated proforma was circulated to workshop attendees.</p> <p>AGD noted the significant volume of work that had gone into supporting this work, and thanked the NHS England’s PTT Information Governance Risk & Assurance Team, the AGD Secretariat, AGD Chair, AGD Deputy Chair, and the AGD NHS England Caldicott Guardian Team Representative for their support with this.</p>	

10 Any Other Business

10.1 AGD recruitment (Update from Garry Coleman)

The NHS England SIRO Representative advised the Group that work was ongoing within NHS England to support the recruitment of AGD independent members, in line with current policies; and a further update would be provided in due course.

Meeting Closure

As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.

Appendix A

Oversight and Assurance Review – 6th February 2025

Ref:	NIC Number:	Organisation:	Areas to consider:
250206a	NIC-36724-F3F7N-v8.5	North Northamptonshire Council	<ul style="list-style-type: none"> • No assessment provided advising why this was suitable for the precedent route, therefore unclear if the precedent was applied correctly. <ul style="list-style-type: none"> ○ Process point: Action for D&A Representative to ensure that it is clear in s1 of the DSA or in the SDa what documents were reviewed to make the decision with regard to the precedent route. • No SDa / escalation form provided (noting the document was not available in CRM for Secretariat to download). <ul style="list-style-type: none"> ○ Process point: Action for D&A Representative to ensure that all applications have the latest version of the requisite SDa / escalation form on CRM, since it is that form that is cited as the “working document” for NHSE. • The application was last seen as part of a group of Council applications on the 8th November 2016 and recommended for approval subject to conditions by DAAG, however it was unclear who had signed off DAAG’s conditions because the group of applications had never come back to DAAG in line with processes at the time. <ul style="list-style-type: none"> ○ Process point: Action for D&A Representative to ensure that previous minutes (including how conditions have been signed off) / oversight & assurance reviews / SIRO decisions etc. are documented within the SDa, including how each point has been addressed.

			<ul style="list-style-type: none"> • The application was relying on Regulation 3 COPI for all aspects of processing, and it was unclear if the legal basis was appropriate. <ul style="list-style-type: none"> ○ Action for the SIRO Rep: to consider whether Reg 3 COPI is the appropriate legal basis for all aspects of the processing. • Noting no SDa / escalation form had been provided, it was unclear which NHSE standards had been applied correctly for example NHSE Benefits Standard <ul style="list-style-type: none"> ○ Process point: Action for D&A Representative to ensure that is clear in the SDA / escalation form, as an audit trail, which NHSE standards have been applied.
250206b	NIC-388486-D9M5N-V6.2	University of Oxford	<ul style="list-style-type: none"> • No assessment provided advising why this was suitable for the precedent route, therefore unclear if the precedent was applied correctly. <ul style="list-style-type: none"> ○ Process point: Action for D&A Representative to ensure that it is clear in s1 of the DSA or in the SDa what documents were reviewed to make the decision with regard to the precedent route. • No SDa / escalation form provided (noting the document was not available in CRM for Secretariat to download). <ul style="list-style-type: none"> ○ Process point: Action for D&A Representative to ensure that all applications have the latest version of the requisite SDa / escalation form on CRM, since it is that form that is cited as the “working document” for NHSE. • All the supporting documents labelled “SD” had been provided by Secretariat because it was unclear what documents had been used to show how the decision had been made by NHSE to progress down the precedent route. <ul style="list-style-type: none"> ○ Process point: Action for D&A Representative to ensure that it is clear in s1 of the DSA or in the SDa what documents were reviewed to make the decision with regard to the precedent route.

			<ul style="list-style-type: none"> • The DSA was unclear around the commercial funder, whether funding was in place, and if there were any commercial benefits to the DSA, for example NHS Duty of Confidentiality Standard <ul style="list-style-type: none"> ○ Process point: Action for D&A Representative to ensure that is clear in the SDA / escalation form, as an audit trail, all aspects of funding. • Noting no SDa / escalation form had been provided, it was unclear which NHSE standards had been applied correctly. <ul style="list-style-type: none"> ○ Process point: Action for D&A Representative to ensure that is clear in the SDA / escalation form, as an audit trail, which NHSE standards have been applied
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