

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 21st November 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)
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)
Dr. Jonathan Osborn (JO)	NHS England member (Caldicott Guardian Team Representative)
Tom Wright (TW)	NHS England member (Data and Analytics Representative (Delegate for Michael Chapman))
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	Role / Area:
Vicky Byrne-Watts (VBW)	Senior Assurance Manager, Data Governance and Assurance, Data Access and Partnerships, Transformation Directorate (Observer: items 5.1 and 5.4)
Garry Coleman (GC)	NHS England SIRO Representative
Dave Cronin (DC)	Applications Lead, Data Governance and Assurance, Data Access and Partnerships, Transformation Directorate (Observer: item 5.4)
Suzanne Hartley (SH)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.5)
Andrew Ireland (AI)	Information Governance Specialist, IG Risk and Assurance (Presenter: item 8.1 and 8.2)
Abi Lucas (AL)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: items 5.4 and 5.5)

Nicki Maher (NM)	Information Governance Lead, IG Assurance and Risk, IG Audit Services Lead (Interim), Privacy, Transparency, and Trust (PTT), Delivery Directorate (Observer : items 8.1 and 8.2)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Delivery Directorate
Jodie Taylor-Brown (JTB)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer : items 5.1 to 5.3)
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)
Prof. Nicola Fear (NF)	AGD independent member (Specialist Academic Adviser)
Jon Moore (JM)	NHS England member (Data Protection Office Representative)
Jenny Westaway (JW)	AGD independent member (Lay Adviser)
Miranda Winram (MW)	AGD independent member (Lay Adviser)
EXTERNAL STAFF IN ATTENDANCE (PART OF ITEM 5.4)	
Andy Boyd (AB)	Director of the UK Longitudinal Linkage Collaboration, University of Bristol

1	<p>Welcome and Introductions:</p> <p>The AGD Chair welcomed attendees to the meeting.</p> <p>AGD noted that, due to the lack of availability of members, four independent AGD independent members and only two AGD NHS England members were in attendance for the meeting.</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</p>
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	<p>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> <p>The NHS England SIRO representative noted that the majority of members were independent should AGD members be required to vote on any issues in the meeting, to ensure the appropriate balance of votes, i.e. that the majority was by AGD independent members. The Group noted and agreed with this proposal.</p>
2	<p>Review of previous AGD minutes:</p> <p>The minutes of the AGD meeting on the 14th November 2024 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 professional link to the subject matter of NIC-769062-G5F1K (University College London) as part of his clinical / GP role, but noted no specific connection with the application or applicant and it was agreed that there was no conflict of interest.</p> <p>An AGD member noted a personal perspective to the study outlined in NIC-769062-G5F1K (University College London). It was agreed this did not preclude the AGD member taking part in the discussion about this item and welcomed their insight.</p> <p>Paul Affleck noted that he was a public contributor to the UK Longitudinal Linkage Collaboration referenced in NIC-748729-Z8B3M (University of Bristol), but noted no specific connections with the application or staff involved and it was agreed that this was not a conflict of interest.</p> <p>Dr Robert French noted a professional link to the applicant of NIC-748729-Z8B3M (University of Bristol), but noted no specific connection with this application and it was agreed this was not a conflict of interest.</p> <p>Kirsty Irvine noted a personal link to the Chief Investigator of NIC-769062-G5F1K (University College London). It was agreed this did not preclude Kirsty from taking part in the discussion about this application.</p>
4 BRIEFING PAPER(S) / DIRECTIONS:	
There were no items discussed	
5 EXTERNAL DATA DISSEMINATION REQUESTS:	
5.1	<p>Reference Number: NIC-147922-T7W2F-v1.21</p> <p>Applicant and Data Controller: University College London (UCL)</p> <p>Application Title: Centre for Longitudinal Studies (CLS) - National Child Development Study 1958 (NCDS)</p> <p>Observer(s): Jodie Taylor-Brown and Vicky Byrne-Watts</p>

Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 27th June 2024.

Linked applications: This application is linked to NIC-431565-K9V9N, NIC-17218-B0W9X and NIC-147860-0RSHN.

Application: This was an amendment application.

The purpose of the application is for the following amendments: **1)** to receive data on all those who have ever participated in the study including those who have withdrawn from the study; **2)** to use the data to update participant details on the CLS database so that they can maintain contact with those actively engaging with the study; and **3)** the addition of sub-licencing and onward sharing.

NHS England were seeking advice on the following points only:

1. The use of the template in relation to the four linked applications.
2. How the previous AGD minutes have been addressed.
3. The amendments outlined.

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

Outcome of discussion: AGD were supportive of the templated application for the four linked applications but were providing comments in response to NHS England's request for advice on specific points rather than all aspects of the templated application for the four linked applications. AGD wished to draw to the attention of the SIRO the following observations in relation to the advice points:

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.

In response to point 1:

5.1.1 In respect of the use of the template for the four linked applications, AGD noted that they were supportive of this, noting it supports consistency of approach, workflow management for NHS England's Data Access Service (DAS), consistency for applicants, and helps build public trust.

5.1.2 Separate to the application and for NHS England to consider, AGD did however highlight a general risk to a templated approach, that each application / scenario would come with its own nuances and issues that would need addressing. The Group suggested that a possible mitigation for this, would be to implement the rigour shown with this application, by having a rolling document that highlights any previous advice received from independent bodies, including, but not limited to, AGD, the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) and NHS England's SIRO Representative.

In response to point 2:

<p>5.1.3 AGD welcomed the template application and commended the work undertaken by NHS England’s Data Access Service (DAS) and the applicant. AGD also noted the diligence undertaken in collating a repository of answers to previous comments made across the four UCL applications, for previous iterations of the applications by AGD and its predecessors.</p> <p>5.1.4 AGD noted the previous point raised on NIC-147922-T7W2F on the 27th June 2024 (point 6.1.5), in respect of having a withdrawal form detailing the various withdrawal options, and noted that the applicant had considered this point, and did not think it was necessary. The Group accepted this, but maintained that it would be best practice to have a withdrawal form.</p> <p>5.1.5 AGD noted the previous point raised on NIC-147922-T7W2F on the 27th June 2024 (point 6.1.7), in respect of relevant permissions being in place to access the health records of everyone to be included in the cohort. Noting the response provided on this from the applicant in respect of the NDO to avoid data flowing under s251, the Group suggested that the NHS England SIRO Representative review and consider if they are content with this approach, noting the wider implications opting out via the NDO.</p> <p>5.1.6 In addition, the response on this point as outlined in point 5.1.5 above, referred to IGARD “<i>granting us permission</i>”; which was also reflected in some of the published privacy notices. The Group reminded applicants that neither IGARD nor AGD provide “permission” for data to flow; and suggested that any public-facing materials were updated to reflect this fact.</p> <p>5.1.7 AGD noted that there was an outstanding point (point 6.1.9) from the previous discussion on NIC-147922-T7W2F on the 27th June 2024, in respect of the technical controls to stop access outside of the UK. It was noted in the supporting document provided that addressed all of the previous points made, that there were ongoing discussions between UCL CLS and the UK Data Service (UKDS) on this point; and suggested that this was followed up by NHS England.</p> <p>5.1.8 AGD noted and reiterated the outstanding point / action for the AGD NHS England Data Protection Office (DPO) Representative, as outlined in the AGD minutes from the 9th May 2024 as part of the discussion on NIC-49826-T0J7C (point 6.1.8).</p> <p>5.1.9 Separate to this application, for NHS England to consider: Reflecting on this application, and recognising that the points may already be covered, the Group felt it helpful to make some observations for the AGD NHS England Data Protection Officer (DPO) Representative to consider. Firstly, that consideration of whether to inform research participants should include possible ethical obligations to participants as well as data governance considerations. Secondly, to consider whether the flow of data from NHS England needs to be assessed as a breach, separate to the flow of data into NHS England.</p>	
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	<p>ACTION: The AGD NHS England DPO Representative to consider whether to inform research participants should include possible ethical obligations to participants as well as data governance considerations. Secondly, to consider whether the flow of data from NHS England needs to be assessed as a breach, separate to the flow of data into NHS England.</p> <p>5.1.10 AGD noted that as part of the discussion on NIC-49826-T0J7C on the 9th May 2024 (point 6.1.10), AGD had suggested that, for transparency and public reassurance, UCL disclose any breaches on their website, and advise the steps taken following the breach; and clarify how a similar breach will be prevented in the future. It was noted that NHS England's DAS had fed this back to the applicant of NIC-49826-T0J7C, however queried if it had been shared with the relevant parties of the other three linked applications. A representative from NHS England's DAS advised that this information had also been fed back to the relevant Principal Investigators of the linked applications.</p> <p>5.1.11 AGD noted the previous point raised on NIC-51342-V1M5W on the 30th March 2023 (point 5.4.2), in respect of researchers being registered with the UKDS; and suggested the consent materials were reviewed to see if this was also relevant to researchers accessing cohort data in the UK LLC (separate to this application).</p> <p>In response to point 3:</p> <p>5.1.12 AGD noted that they were supportive of the proposed amendments outlined. AGD made the following observations on the templated application, at the request of the NHS England SIRO Representative:</p> <p>5.1.13 Noting this was a one year DSA, AGD suggested that, to future proof the application in the event of a renewal or extension, section 6 (Special Conditions) of the application 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>	DPO Rep
5.2	<p>Reference Number: NIC-769062-G5F1K-v0.3</p> <p>Applicant: University College London (UCL)</p> <p>Data Controller(s): Care England, UCL and The Outstanding Society Community Interest Company</p> <p>Application Title: Vivaldi Social Care</p> <p>Observer: Jodie Taylor-Brown</p> <p>Application: This was a new application.</p> <p>The purpose of the application is for a study, with the aim to pilot a system of surveillance for infection and antimicrobial resistance in care homes for older adults, and to demonstrate its capacity to deliver as a trial infrastructure for public health research.</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 (four members) were not supportive of the application at this time. A minority of the Group (two members) were supportive of the application. The Group wished to draw to the attention of the SIRO the following substantive comments:</p> <p>5.2.1 The Group welcomed the application and noted the importance of the study.</p> <p>5.2.2 The NHS England SIRO Representative suggested that further work / discussions should be undertaken with relevant colleagues within NHS England, to determine whether NHS England should / would be supportive of the application from an NHS England policy perspective; noting that this would determine how this application is progressed. The Group noted and supported this approach, and suggested that these issues should have been addressed prior to the application being submitted to AGD for review; and were advised by the NHS England SIRO Representative that there was ongoing work within NHS England to address this issue.</p> <p>5.2.3 AGD noted that prior to the meeting, an AGD member had raised a query with NHS England's Data Access Service (DAS) that the proposal outlined, is to pilot a platform jointly controlled by a University, a Community Interest Company and a Trade Organisation / Charity, for health surveillance purposes, doubling as a research database; and if successful, will become a national resource with access for researchers via sublicensing of data. AGD queried how this was compatible with the Department of Health and Social Care (DHSC) Data Access Policy, in respect of the NHS Research Secure Data Environment (SDE) Network becoming the primary way for external bodies to access health and social care data. Noting the query remained outstanding, the Group requested that the NHS England SIRO Representative provide an update on this query, noting that this may impact on other applications going forward.</p> <p>ACTION: The NHS England SIRO Representative to provide a response to AGD in respect of the NHS Research Secure Data Environment (SDE) Network becoming the primary way for external bodies to access health and social care data in line with (DHSC) Data Access Policy.</p> <p>5.2.4 Prior to the meeting, an AGD member had highlighted to the Group that they were concerned how the project and the opt out were presented to residents. For example, the patient information sheet (SD8) stating <i>"We are giving everyone who lives in your care home the chance to take part in this project..."</i>, when care home residents are automatically included in the study unless they object. AGD noted that it was unclear as to what extent the care home resident had been consulted.</p>	<p>SIRO Rep</p>
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5.2.5 The Group noted that whilst the National Data Opt-out would be respected in terms of care home residents exercising an opt-out, there was concern that there may be circumstances where a resident may be opted out by a relative exercising the local opt out, even though the resident was capable of choosing for themselves.

5.2.6 AGD queried what the opt-out rates were, for example, if this was zero or if the opt-out rates were high, raising issues that would need consideration. It was suggested that the opt-out process was reviewed to ensure that the care home residents could opt-out if they had capacity to do so; or if a capacity assessment shows that the care home resident does not have capacity or the relative has the relevant power of attorney, then the relative can opt-out on their behalf.

5.2.7 In respect of transparency, the Group noted and commended the poster that had been provided as a supporting document (SD8.3), but advised that the link was broken on the QR code, and suggested that this was updated with the correct / accessible link. In addition, it was noted that the QR code on the poster may not be accessible by care home residents from a technology perspective; and suggested that the information accessible via the QR code should also be available in paper format.

5.2.8 AGD noted that a detailed letter was shared with the relatives, however a more simplified letter was shared with the care home residents; and suggested that if the care home residents had capacity, the same detailed letter was provided to them.

5.2.9 AGD noted the role of the Adult Social Care Engagement Collective (ASCEC) as part of the patient and public involvement and engagement (PPIE), including reviewing the transparency materials; however, noted concern that there did not appear to be any care home residents in this group.

5.2.10 In addition, noting that ASCEC were responsible for engagement activities and dissemination plans, as outlined in section 5 (Purpose / Methods / Outputs) of the application, AGD queried if any care home residents were included in this at any stage, including the oversight of the project and the dissemination of the results. If it was deemed to not be practical to include them in the ASCEC, then it was queried whether a smaller sub-group of care home residents could be co-opted.

5.2.11 AGD noted in the supporting documents provided that care homes opted in to the study; and suggested that the application was updated to outline any potential commercial benefits to the care homes, for example, if they were reflected positively in a dashboard, in line with [NHS England DAS Standard for Commercial Purpose](#).

5.2.12 In addition, it was noted that there may a negative impact, for example, not taking on certain care home residents as it may reflect poorly on their statistics.

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

5.2.13 AGD queried how the dashboard would be accessed, for example, will there be a charge for using this; and suggested that section 5(a) (Objective for

	<p>Processing) and section 5(c) (Specific Outputs Expected) of the application were updated with further information.</p> <p>5.2.14 AGD acknowledged the potential issues and ambiguity around the data controllership, however, noted in the DAS internal application assessment form that NHS England's DAS had explored data controllership with the applicant, and noted the conclusion reached. It was suggested however, that the justification for the data controllership in section 5(a) was removed as it was not necessary.</p> <p>5.2.15 Noting the role of Quantaim Limited as a Data Processor, it was suggested that section 5(a) was updated with further information, including but not limited to, a further summary of their activities; whether there was a Data Processing agreement with UCL and / or NHS England; and that Quantaim Limited consist of one individual that was also employed by UCL.</p> <p>5.2.16 AGD noted that whilst the date of death data flows in a month and year format, this may be a disclosive flow of data if this was flowing a daily basis, and suggested that this was reviewed by NHS England.</p> <p>5.2.17 AGD queried the statement in section 5(b) (Processing Activities) of the application "<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>", and whether this aligned with the Data Sharing Framework Contract (DSFC); or that this word was removed as may be necessary to reflect the facts.</p> <p>5.2.18 AGD noted in the DAS internal application assessment form that the Data Sharing Framework Contracts (DSFC) for Care England and The Outstanding Society Community Interest Company were outstanding; and supported NHS England's position that no data would flow until this was addressed / resolved.</p>	
5.3	<p>Reference Number: NIC-148334-51PXR-v4.4</p> <p>Applicant and Data Controller: University of Southampton</p> <p>Application Title: PROSPECTIVE STUDY OF OUTCOMES IN SPORADIC VERSUS HEREDITARY BREAST CANCER (POSH)</p> <p>Observer: Jodie Taylor-Brown</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 11th August 2022 and the 13th September 2018.</p> <p>Application: This was an amendment application.</p> <p>The amendments are to 1) add Hospital Episode Statistics Admitted Patient Care (HES APC) and National Disease Registration Service (NDRS) Cancer Consolidated data; 2) the renewal of Civil Registration of Deaths data; and 3) to update the objective for processing.</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>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 AstraZeneca was referenced in the application as the funder of the study; however, suggested that further information was added in section 5 (Purpose / Methods / Outputs) of the application, to outline any potential commercial benefits, for example, any drugs that may go on to the market as a result of the study in line with NHS England DAS Standard for Commercial Purpose.</p> <p>5.3.2 AGD noted and commended the applicant's privacy notice, however, suggested that this could be updated further to also include information on the AstraZeneca funding and the benefits that may accrue from them providing the funding.</p> <p>5.3.3 AGD noted and commended the work undertaken by NHS England's Data Access Service (DAS) on the internal application assessment form, which supported the review of the application.</p>	
5.4	<p>Reference Number: NIC-748729-Z8B3M-v0</p> <p>Applicant and Data Controller: University of Bristol</p> <p>Application Title: University of Bristol – UK Longitudinal Linkage Collaboration (UK LLC)</p> <p>Presenter: Andy Boyd</p> <p>Observers: Dave Cronin, Vicky Byrne-Watts, Abi Lucas</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 7th December 2023 and the 16th March 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 7th July 2022, 23rd June 2022, 4th March 2021 and the 4th February 2021.</p> <p>The application and relevant supporting documents were previously presented / discussed at the IGARD COVID-19 response meetings on the 5th October 2021, 27th April 2021, 30th March 2021, 16th March 2021, 2nd February 2021, 26th January 2021, 12th January 2021, 15th December 2020 and the 8th December 2020.</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 10th March 2021.

Linked applications: This application is linked to NIC-420229-G9H9S.

Application: This was a new application.

The UK LLC is a 'Trusted Research Environment' designed to link study data from major inter-disciplinary Longitudinal Population Studies participants to a wide range of participants' health and non-health administrative records.

The purpose of the application is to set out the process that the University of Bristol will follow to determine that inclusion in the UK LLC satisfies the common law duty of confidentiality for each person in each cohort prior to requesting their data from NHS England and prior to processing their data.

There will be two applications for the purpose outlined in this application, this application is for the consented cohorts; and a separate variation covering the s251 cohorts would be created when approval is in place.

NHS England were seeking general advice on the application.

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

Prior to the review / discussion of the application by AGD and prior to providing advice to the NHS England SIRO Representative, Andy Boyd (the applicant) attended the meeting to provide a brief overview to the Group on the work being undertaken by the University of Bristol and UK Longitudinal Linkage Collaboration (UK LLC). The Group thanked Andy for attending the meeting, and for the brief overview and update provided around UK LLC.

Outcome of discussion: AGD were supportive of the draft application and wished to draw to the attention of the SIRO the following comments:

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

5.4.1 AGD noted that the consent model outlined in the robust suite of supporting documentation provided was appropriate for NHS England to delegate the consent review to the cohort studies and the applicant.

5.4.2 The Group noted the importance of all of the cohorts being included in the UK LLC and understood that they would all be going through the same process, prior to the switch to consent or being newly ingested into the UK LLC.

5.4.3 The NHS England SIRO Representative queried whether AGD could offer an assessment of a small sample of consent reviews that had been undertaken by the applicant. The Group discussed and advised that they would be broadly supportive

of this, however, highlighted potential risks of difference of opinion and how this would be managed.

5.4.4 AGD noted and commended the work undertaken by the applicant and NHS England's Data Access Service (DAS) on the papers provided, which supported the review of the application.

5.4.5 The Group did however suggest that the documents, for example the 'risk Assessment Guidance for UK LLC Confidentiality Due Diligence Panel' (SD3.5) was reviewed and updated to give some examples of restrictive concepts, i.e. a geographical restriction; or restriction with a commercial company making a profit; or a statement that there would be no data linkage.

5.4.6 In addition, the Group noted that the UK LLC Confidentiality Due Diligence Panel minute template was updated, to reflect that the 'amber' category section that refers to "*restrictive statements*" was rephrased to refer to "*ambiguous*", noting that it would be difficult to rebut a restrictive statement merely by way of transparency.

5.4.7 AGD suggested that if s251 support was sought that, in the case of a restrictive statement, it was clearly highlighted to Health Research Authority Confidentiality Advisory Group (HRA CAG), that there was a restrictive statement; and that the applicant also consider the ethical implications of seeking s251 support to address restrictions placed via a restrictive statement.

5.4.8 The NHS England SIRO Representative noted that the National Data Opt-out (NDO) would need to be respected for any flows of data under s251, which may sit alongside local opt-outs; and it was suggested that the applicant gave consideration as to how they would manage different flows of data and different variations of opt outs.

5.4.9 AGD noted the COVID-19 datasets requested and suggested that part 1 of section 5(a) (Objective for Processing) of the application was updated to reflect that all processing of the COVID-19 datasets, must be undertaken within the scope of the [COVID-19 Public Health Directions 2020](#).

5.4.10 In addition, it was suggested that a special condition was added to section 6 (Special Conditions) of the application, to reflect that all processing of the COVID-19 datasets, must be done within the scope of the [COVID-19 Public Health Directions 2020](#).

5.4.11 It was also suggested by AGD that NHS England ensure that the applicant has the appropriate processes in place, that will ensure that the restriction on the COVID-19 datasets is adhered to now and in the future, noting the number of datasets and multiple uses of the data that are anticipated.

5.4.12 Noting that the UK LLC has a higher bar than NHS England for the commercial use of data, and that this must be academic led; the Group suggested that the applicant actively look for restrictive statements that might preclude a cohort being ingested and subsequently used by a commercial partner. The Group noted

	<p>that one example of a restrictive statement, is within the ‘Northern Ireland Cohort for the Longitudinal Study of Ageing’ (NICOLA) privacy notice, that states <i>"We do not conduct research for commercial gain – all our research aims to benefit Society and is not for profiting other companies/organisations"</i>.</p> <p>5.4.13 AGD suggested that the User Agreements were reviewed to ensure that there were appropriate and robust audit arrangements.</p> <p>5.4.14 AGD suggested that there was a recalibration with regard to risk, so that the risks to the data subjects is noted and acknowledged, and not just the risk to the applicants.</p> <p>5.4.15 AGD noted that a draft application had been provided, and suggested that queries raised in respect of linkage with <i>"administrative data"</i> were followed up and that the application reflects the current and potential use of the data.</p>	
5.5	<p>Reference Number: NIC-769782-X5C1F-v0.3</p> <p>Applicant and Data Controller: Digital Health and Care Wales</p> <p>Application Title: Benchmarking in UDAL</p> <p>Observer(s): Suzanne Hartley and Abi Lucas</p> <p>Application: This was a new application.</p> <p>The purpose of the application is for a benchmarking dashboard, which will enable Health Boards in Wales to be able to compare their own metrics with England.</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>5.5.1 AGD noted that the territory of use in section 2(c) (Territory of Use) of the application was <i>"England and Wales"</i>; however, suggested that this was reviewed and updated as may be necessary, in line with NHS England DAS Standard for Territory of Use (noting that this is occasionally updated).</p> <p>5.5.2 AGD queried what data minimisation had been considered for this application, and noting that this was currently unclear, suggested that the NHS England Data Access Service (DAS) internal application assessment form was updated with further information, in line with NHS England DAS standard for data minimisation.</p> <p>5.5.3 AGD queried the references in section 5(b) (Processing Activities) of the application to remote processing / access taking place in <i>"secure locations"</i>; and suggested that this was reviewed and updated if not correct, for example, to refer to the security of the remote connection and not the physical location.</p>	

	<p>5.5.4 AGD queried the statement in section 5(b) of the application “<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>”, and whether this aligned with the Data Sharing Framework Contract (DSFC); or that this word was removed as may be necessary to reflect the facts.</p>	
6 INTERNAL DATA DISSEMINATION REQUESTS:		
<i>There were no items discussed</i>		
7 EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL		
<i>There were no items discussed</i>		
8 OVERSIGHT AND ASSURANCE		
8.1	<p>Oversight and Assurance Process</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) eight applications (selected by the AGD Secretariat); 2) internal application assessment forms and / or Escalation Forms for each of the applications (where available); and 3) an oversight and assurance template to complete via MS Forms.</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 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 eight applications.</p>	
8.2	<p>Oversight and Assurance Conclusion / Review</p> <p>AGD and the NHS England SIRO Representative noted that, for some of the 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 an application down NHS England’s Precedent route. The NHS England SIRO Representative asked the AGD NHS England Data and</p>	

	<p>Analytics Representative to provide feedback on this point as a matter of urgency; and advised that an update on this would be feedback to the Group at the AGD meeting on the 28th November 2024.</p> <p>ACTION: The AGD NHS England Data and Analytics Representative to provide feedback as to why there was no audit trail outlining how the decision had been reached to progress an application down NHS England's Precedent route for some applications.</p> <p>ACTION: The AGD NHS England Data and Analytics Representative and the NHS England SIRO Representative to provide feedback to AGD as to why there was no audit trail outlining how the decision had been reached to progress an application down NHS England's Precedent route for some applications.</p> <p>AGD also noted concern that a number of applications had progressed down NHS England's Precedent route, when a further independent review may have been suggested previously by the Independent Group Advising (NHS Digital) on the Release of Data (IGARD); and queried if there was a process / justification as to why this advice would / would not be followed. The AGD NHS England Data and Analytics Representative advised the Group that this would be explored further, and an update would be provided to the Group.</p> <p>ACTION: The AGD NHS England Data and Analytics Representative to update the group as to whether there was a process / justification for applications progressing down NHS England's Precedent route, when a further independent review may have been suggested previously by IGARD.</p> <p>In respect of the new MS Form used by AGD to complete as part of the oversight and assurance process, the Group suggested that this was updated to enable the form to be saved prior to submission, as opposed to having to complete the form during one log-in.</p> <p>ACTION: Nicki Maher and Andrew Ireland to explore whether the MS Teams form could be updated to allow AGD to log in and out with updates, as opposed to having to update all of the form during one log-in.</p> <p>The Group also suggested that the MS Teams form was updated with a 'free text box'.</p> <p>ACTION: Nicki Maher and Andrew Ireland to explore whether the MS Teams form could be updated to include a 'free text box'.</p> <p>It was noted by Nicki Maher that the MS Teams form was much more efficient and enabled the results of the oversight and assurance review to be collated automatically rather than manually.</p>	<p>D&A Rep</p> <p>D&A Rep / SIRO Rep</p> <p>D&A Rep</p> <p>SIRO Team</p> <p>SIRO Team</p>
9 AGD OPERATIONS		
9.1	Risk Management Framework	

	<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 framework standard as an interim arrangement since March 2024 and AGD were concerned that the permanent Risk Management Framework was not in place.</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 that the NHS England SIRO Representative was still considering the use of the NHS England corporate risk management framework, as outlined in the 14th November 2024 minutes.</p>	SIRO Rep
9.2	<p>Standard Operating Procedures (SOPs)</p> <p>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 was noted that work was progressing in order to finalise relevant AGD SOPs in line with the approved AGD ToR.</p>	
9.3	<p>AGD Stakeholder Engagement</p> <p>The AGD Chair noted to the Group that she had met with Jackie Gray, Director of Privacy and Information Governance, Privacy, Transparency, and Trust on the 19th November 2024; this was in line with clause 9.2 of the AGD Terms of Reference that states: <i>“The Chair and the Deputy SIRO shall meet at least every six months to review the operation of the Group”</i>.</p>	
9.4	<p>AGD Project Work</p> <p>Kirsty Irvine and Paul Affleck attended the NHS England Data Access Service (DAS) Standards Working Group on the 19th November 2024 with regard to the NHS England DAS Standard for Ethical Approval.</p> <p>Kirsty Irvine and Claire Delaney Pope attending the NHS England Data Access Service (DAS) Standards Working Group on the 5th November with regard to the special conditions standard.</p>	
10 Any Other Business		
10.1	<p>AGD Pay and Recruitment (Presenter: Garry Coleman)</p> <p>The Group noted that a request had been made at the AGD meeting on the 5th September 2024 for the NHS England SIRO Representative to provide an update on AGD recruitment, changes to pay rates, and contract arrangements for new recruits and / or current AGD independent members.</p> <p>The NHS England SIRO Representative provided an overview to the Group, on the future AGD pay structure including new pay rates and contract type for AGD</p>	

	<p>independent members, agreed with the relevant senior NHS England colleagues and NHS England Human Resources (HR).</p> <p>The NHS England SIRO Representative noted that two independent members were not in attendance at today's meeting, and that the same information would be shared with them out of committee.</p> <p>The Group thanked the NHS England SIRO Representative for the update, and looked forward to future updates in the coming weeks.</p> <p>ACTION: The NHS England SIRO Representative to provide a further update to the Group on AGD pay and recruitment.</p>	SIRO Rep
10.2	<p>New internal Data Access Service (DAS) Escalation Form (Presenter: Jodie Taylor-Brown)</p> <p>Jodie noted that a new internal DAS Escalation Form had been provided as part of the meeting papers pack for NIC-148334-51PXR-v4.4 and asked AGD if they had any feedback on the new style escalation form.</p> <p>AGD noted that the new DAS Escalation Form appeared to be more streamlined and had a more stepwise approach. Jodie noted that, where applicable, the DAS internal application form would still be shared with AGD, since this gave the opportunity to provide more detail.</p> <p>Jodie thanked AGD for their feedback.</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 – 21st November 2024

Ref:	NIC Number:	Organisation:	Areas to consider:
241121a	NIC-06605-X1L9Z-v13.3	University Hospitals Birmingham NHS Foundation Trust	<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. • No SDA / escalation form provided (noting the document was not available in CRM for Secretariat to download). • IGARD noted significant issues when discussed under O&A on 4th February 2021 and advised that the next iteration of the DSA have a full independent review. • The ACR special condition refers to sub-licensing, the DSA does not allow for sub-licensing – the question should have been answered “N/A”. • The DSA relies on Article 9(i) which is inconsistent with the applicant’s privacy notice Article 9(j).
241121b	NIC-33499-F9N8F-v7.2	Plymouth City 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. • No SDA / escalation form provided (noting the document was not available in CRM for Secretariat to download). • AGD queried if a change in legal basis would be an exclusion criterion.

			<ul style="list-style-type: none"> Minutes of previous independent reviews not included.
241121c	NIC-148286-3RWRG-v9.4	University of Birmingham	<ul style="list-style-type: none"> AGD queried if a co-investigator replaced by another co-investigator from the same organisation constitutes a simple amendment. AGD queried whether that organisation should be considered as a joint Data Controller, noting the co-investigators were via honorary contracts. Noting the co-investigator will be “<i>under supervision</i>” at all times by employees of the applicant, AGD queried if the applicant’s employees have access to the data. Annual reviews submitted to HRA CAG appear to be outstanding. Where a DSPT is for a division or section of an organisation, the DSA should be clear the data is restricted to that division or section of the organisation. AGD asked the NHS England SIRO Representative to consider types of applications that should have an independent review after a certain number of years.
241121d	NIC-196221-K4K3Y-v3.4	The University of Manchester	<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. No SDA / escalation form provided (noting the document was not available in CRM for Secretariat to download). AGD queried if this was also an amendment application (not noted on DSA). AGD queried if the correct precedent had been used.

			<ul style="list-style-type: none"> • Confirmation that the ACR has been submitted and accepted, in line with the special condition in section 6. • AGD noted that it was a well-constructed, understandable and easy to follow DSA.
241121e	NIC-248117-P2K4S-v4.4	St Helens 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. • No SDA / escalation form provided (noting the document was not available in CRM for Secretariat to download). • AGD noted this application had never had a previous independent review by DAAG / IGARD / AGD. • AGD queried how the application had progressed down the precedent route when the DARS Benefits Standard did not appear to have been met, for example no yielded benefits provided even though the applicant has been given access to 10 years of national A&E data. • AGD queried reference to “<i>academic partners</i>” in section 5(d) and suggested the local authority explains how this fulfils the public health function.
241121f	NIC-463170-V2K1Y-v1.3	NHS Surrey Heartlands Integrated Care Board	<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. • Reference to “<i>Decision 23May03</i>” knowledge based reusable decision, however AGD do not have access to this system in NHSE.

241121g	NIC-656762-V9J7N-v2.2	Queen Mary University of London	<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. • AGD queried if the correct precedent had been used. • AGD noted this application had never had a previous independent review by DAAG / IGARD / AGD, however had been noted under SIRO approvals on 20th April 2023. • Query as to whether previous PHE/ODR applications should be proceeding down the precedent route, noting there was a risk that these applications would not be brought in line with the DAS standards. • AGD noted the SDA stated that a copy of the novation letter had not been returned. • Reference to “agents” in section 5b.
241121h	NIC-656777-B0V8N-v2.2	University of Leeds	<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. • No SDA / escalation form provided (noting the document was not available in CRM for Secretariat to download). • AGD noted this application had never had a previous independent review by DAAG / IGARD / AGD, however had been noted under SIRO approvals on 20th July 2023. • Query as to whether previous PHE/ODR applications should be proceeding down the precedent route, noting

			there was a risk that these applications would not be brought in line with the DAS standards.
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