

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 22nd February 2024

09:30 – 15:30

(Remote meeting via videoconference)

INDEPENDENT ADVISERS IN ATTENDANCE:	
Name:	Role:
Paul Affleck (PA)	Specialist Ethics Adviser
Kirsty Irvine (KI)	Chair
Dr. Imran Khan (IK)	Specialist GP Adviser
Jenny Westaway (JW)	Lay Adviser
Miranda Winram (MW)	Lay Adviser (items 4.1, 4.2 and 6 only)
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	Role / Area:
Garry Coleman (GC)	NHS England SIRO Representative (Presenter: item 8 and 9)
Dave Cronin (DC)	Assurance Lead, Data Governance and Assurance, Data and Analytics (Presenter: item 6)
Narissa Leyland (NL)	NHS England Data and Analytics Representative (Delegate for Michael Chapman) (Presenter: item 4.2)
Andrew Martin (AM)	NHS England Data Protection Office Representative (Delegate for Jon Moore)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Delivery Directorate (Presenter: items 11.1 and 11.2)
Jonathan Osborn (JO)	NHS England Caldicott Guardian Team Representative (Presenter: items 11.4)
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Delivery Directorate (Presenter: items 10)
Tom Wright (TW)	Assurance Lead, Data Governance and Assurance, Data and Analytics (Presenter: item 4.1)
INDEPENDENT ADVISERS NOT IN ATTENDANCE:	

Claire Delaney-Pope (CDP)	Specialist Information Governance Adviser
Prof. Nicola Fear (NF)	Specialist Academic Adviser
Dr. Robert French (RF)	Specialist Academic / Statistician Adviser
Dr. Geoffrey Schrecker (GS)	Specialist GP Adviser
Dr. Maurice Smith (MS)	Specialist GP Adviser
NHS ENGLAND STAFF NOT IN ATTENDANCE:	
Michael Chapman (MC)	NHS England Data and Analytics Representative
Jon Moore (JM)	NHS England Data Protection Office Representative

1	<p>Welcome and Introductions</p> <p>The NHS England Senior Information Risk Owner (SIRO) Representative, noting the Advisory Group for Data (AGD) Terms of Reference (ToR) had not yet been agreed, proposed that:</p> <ul style="list-style-type: none"> • Kirsty Irvine (as an independent adviser) will be asked to Chair the AGD meetings; • The meeting will be minuted, with advice and minutes published; • Attendees will include both independent advisers from outside NHS England and representatives from within NHS England. Attendees from NHS England include representatives covering the offices of the Data Protection Officer (DPO); the Caldicott Guardian; Data and Analytics; and the SIRO. • Attendees would not be listed as “members” in minutes during the transitional period; • NHS England representatives would not, during the transitional period, be formally part of any consensus that is reached, but would be active participants in the meeting; • It was agreed to use the Data Access Service (DAS) Standards / Precedents in relation to applications for external data sharing. <p>The attendees present at the meeting considered the proposal put forward by the NHS England SIRO Representative and, as no objections were raised, it was agreed that the meeting would proceed on this basis.</p> <p>Kirsty Irvine noted and accepted the request from the NHS England SIRO Representative to chair; and welcomed attendees to the meeting.</p>
2	<p>Review of previous AGD minutes:</p> <p>The minutes of the 8th February 2024 AGD meeting were reviewed and subject to a number of minor amendments were agreed as an accurate record of the meeting.</p>

3	<p>Declaration of interests:</p> <p>Dr. Jonathan Osborn noted a declaration of interest with NIC-613522-Q7Z8N (University of Newcastle Upon Tyne), as part of his role as Trustee of the Doctors in Distress charity; 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>BRIEFING PAPER(S):</p>	
4.1	<p>Title: Remote Access from outside the UK – Briefing Paper</p> <p>Presenter: Tom Wright</p> <p>The purpose of the briefing paper was to set out NHS England’s procedure for managing requests for remote access within the respective territories of England/Wales, UK, EEA and Worldwide.</p> <p>NHS England has developed principles and associated standard wording for inclusion in section 5(b) (Processing Activities) of the application / data sharing agreement (DSA) to manage the potential risks inherent with remote access to data.</p> <p>NHS England were seeking advice on the following points:</p> <ol style="list-style-type: none"> 1. Has NHS England assessed the risk levels correctly. 2. Are there any other considerations or criteria that need including. <p>Outcome of discussion: the group welcomed the briefing paper and made the following observations / comments:</p> <p>In response to point 1:</p> <p>4.1.1 The independent advisers discussed the risk levels and instances where the risk may be low or high; and advised that for access outside the UK / EEA, the safeguards felt right, however it did not seem appropriate to define this as “low risk”, since data subjects for example don’t have the same rights as those in ‘adequate’ countries.</p> <p>In response to point 2:</p> <p>4.1.2 It was suggested by the independent advisers that where an applicant had an unresolved breach, or there were concerns / issues flagged in an audit, that there should be some additional exclusion criteria.</p> <p>4.1.3 The NHS England Caldicott Guardian Team representative queried NHS England’s transparency on remote access arrangements, how this could be achieved and suggested that NHS England should give this further consideration.</p> <p>4.1.4 The independent advisers queried whether the standard wording could be updated to include a requirement on the applicant to ensure transparency materials were updated / published, following an amendment to remote access arrangements.</p> <p>4.1.5 The independent advisers suggested that it was essential that a clear justification for requiring remote access from another territory was provided by the applicant, and that NHS</p>

	<p>England should ensure that this access is not required to support other roles that an individual may have.</p> <p>4.1.6 The independent advisers suggested that NHS England clearly define what is meant by a “secure location”, to support the request for remote access.</p> <p>4.1.7 The NHS England Data Protection Office (DPO) representative noted that for those countries where an adequacy decision had been made, then legally it was permissible since those countries had similar or the same level of data protection in place, with equivalent safeguards available in those countries; however advised that NHS England would need to ensure that sufficient safeguards / technical measures / contractual clauses are in place for remote access where adequacy for those countries was not in place and that for worldwide access, advice should be sought from NHS England’s Privacy, Transparency and Trust (PTT).</p> <p>4.1.8 The NHS England Data Protection Office (DPO) representative noted that the reasonable expectations of citizens would need to be considered, and how they may feel about their data being processed outside of the UK; and that although there may be a legal basis for the remote access NHS England should always consider whether it is the right thing to do.</p> <p>4.1.9 The group looked forward to receiving the finalised briefing paper, either out of committee (OOC) or tabled at a future meeting.</p>
<p>4.2</p>	<p>Title: Research for commissioners’ sub-licence Precedent</p> <p>Presenter: Narissa Leyland</p> <p>The Integrated Care Boards’ (ICBs) existing data sharing agreements (DSAs) support the use of data for commissioning activities. This currently does not extend to research and therefore could inhibit health service developments through research evidence.</p> <p>The Research for Commissioners Precedent supports the additional purpose to be included in the ICB’s DSA (if required) through the sub-licencing of access to permissible datasets with research organisations. The research for commissioners sub-licencing arrangement is only permissible where the research is ICB led or enacted and must relate to its commissioning activities to the health and care benefit for its Integrated Care System (ICS).</p> <p>The sub-licencing arrangement can support multiple ICBs as Data Controllers, working in collaboration to achieve the health and care benefits from the research across their ICS.</p> <p>NHS England were seeking advice on the following point:</p> <ol style="list-style-type: none"> 1. Support for the ICB’s ability to sub-license the permissible datasets within their DSA for an additional purpose of research for commissioning uses. <p>Outcome of discussion: the group welcomed the briefing paper and made the following observations / comments:</p> <p>In response to point 1:</p>

- 4.2.1** The independent advisers queried who the permitted sub-licensees were; and were advised by NHS England that the permitted sub-licensees would be organisations that the ICBs would like to partner with, for example, where the skills / knowledge required was not currently available within the ICB. The independent advisers noted the verbal update and that currently there was no exclusion criteria to the partners an ICB could engage with.
- 4.2.2** The independent advisers queried what the risk criteria referred to in the document were; and were advised by the NHS England Data and Analytics representative, that this was outlined within a separate document which had not been provided to the group and would need adding as an appendix to the paper.
- 4.2.3** The independent advisers suggested that NHS England gave further thought to an ICB permitting a sub-licence to an organisation, for example, would they need to be registered in England and Wales, were commercial companies permitted, if permitted commercial companies were only those that currently holding NHS England data or new entrants to the market, and what, if any, process this would require in order to remove any subjectivity.
- 4.2.4** The independent advisers noted some inconsistent information in the document with regard to what governance an ICB would need to have in place around the granting of sub-licences for research and who in an ICB could approve such sub-licences; and suggested that this was clarified and updated as appropriate.
- 4.2.5** Noting the [NHS England Standard for Sub-Licensing and Onward Sharing](#), it was queried by the independent advisers what the oversight, public participation and transparency requirements would be for ICBs that wished to issue sub-licences for research; and suggested that this was given further consideration by NHS England.
- 4.2.6** The independent advisers noted the importance of ensuring that work undertaken under a sub-licence had benefits to health and social care, in line with [NHS Digital DAS Standard for Expected Measurable Benefits](#) and the National Data Guardian (NDG) [guidance on benefits](#).
- 4.2.7** The independent advisers queried whether ICBs would have the capacity and skills to manage sub-licences and the associated risks; and suggested that this was given further consideration.
- 4.2.8** The independent advisers noted that section 5(c) (Specific Outputs Expected) of the application template, only reflects commissioning activities; and noted there may be a challenge from the ICBs in respect of the activities / outputs and any restrictions that they have.
- 4.2.9** The independent advisers queried the purposes for which sub-licensing would be permitted in section 5(a) (Objective for processing), noting that these had been taken from a document suggesting potential avenues of research to ICBs. Advisers queried whether these were broad enough and well-defined enough for the purposes of this template and suggested this was reviewed.
- 4.2.10** The independent advisers queried whether this would be an amendment to the existing data sharing agreements (DSA), or whether a new DSA would be required; and were advised by the NHS England Data and Analytics representative and the SIRO representative, that it

	<p>would be an amendment to the ICB's existing DSA. The independent advisers noted the verbal update and suggested that the templated wording would need a careful review to remove any reference such as "<i>cannot do research</i>", to ensure that any updates to the DSA were enforceable and auditable.</p> <p>4.2.11 The group noted that a further discussion on this would take place at the AGD meeting on the 14th March 2024.</p> <p>ACTION: AGD Secretariat to add this item to the AGD internal agenda forward plan.</p>
EXTERNAL DATA DISSEMINATION REQUESTS:	
5.1	<p>Reference Number: NIC-596002-V3N9J-v0.14</p> <p>Applicant: Harvey Walsh Ltd</p> <p>Application Title: Avon Community Acquired Pneumonia (CAP) Surveillance Study: A Panpandemic Acute Lower Respiratory Tract Disease Surveillance Study - Denominator by risk group only</p> <p>The item was withdrawn by the NHS England Data and Analytics representative.</p>
5.2	<p>Reference Number: NIC-613522-Q7Z8N-v0.5</p> <p>Applicant: University of Newcastle Upon Tyne</p> <p>Application Title: Establishing evidence to inform culturally competent mental health services (EVOLVE)</p> <p>Application: This was a new application.</p> <p>The purpose of the application is for a research project, with the aim of identifying and quantifying changes in engaging NHS mental health services (both primary and secondary care) for people who are ethnic minorities select areas within North East and North Cumbria (NENC) area, before and after the COVID-19 pandemic and the impact on their health-related outcomes.</p> <p>Should an application be approved by NHS England, further details would be made available within the Data Uses Register.</p> <p>Outcome of discussion: The group were supportive of the application and wished to draw to the attention of the SIRO the following substantive comments:</p> <p>5.2.1 The group queried how individuals would know they were part of the cohort, and suggested that a number of amendments were made to the transparency materials, including but not limited to, updating the poster to ensure the content is factually correct, for example in respect of the description of the data; ensuring the poster and any other transparency materials were available on the study specific website; and to investigate publishing the information contained in the poster on the landing pages of the websites and/or patient portals of the six GP practices who were part of the research study.</p>

	<p>5.2.2 The independent advisers queried the information section 1.7 (other organisations involved) of the internal application assessment form, that stated the names of the six GP practices had been removed from the application to “<i>decrease the risk of identification</i>”, and had been replaced with more generic wording. Noting that it was unclear who had made this decision, it was suggested that consideration is given to reinstating this back into the application for the purpose of transparency.</p> <p>5.2.3 The group noted in the Health Research Authority Confidentiality Advisory Group (HRA CAG) application form (SD2.1) provided as a supporting document, that “<i>North of England Commissioning Support Unit (NECS) has been involved as a project collaborator and has agreed to process data requests, extraction and processing of primary care data and NHS Digital data flows and linkage to primary care data</i>”. It was suggested by the group that, noting NHS Digital no longer exists, NHS England explore if there is a more efficient way to flow the data; and the role of NECS was clarified, for example, what their role is, who are they undertaking the work for, and how Type 1 objections are handled.</p> <p>5.2.4 Noting that HRA CAG were supportive of the data being retained for 35 months after the study has completed to allow for any requests to check data analysis following publication, it was suggested by the independent advisers that NHS England reviewed the length of the term of the application, noting that this was currently due to end on the 28th February 2024; and advised that they would be supportive of a longer data sharing agreement (DSA) to align with the HRA CAG support.</p> <p>In addition, the group made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.2.5 The group welcomed the application and noted the potential benefits of the study.</p> <p>5.2.6 The independent advisers noted the statement in the draft privacy notice (SD5.1), provided as a supporting document, that data would be shared with “<i>approved collaborators</i>”, and suggested that NHS England advise the applicant that any data shared with collaborators would require an amendment to the data sharing agreement (DSA) via the usual NHS England process.</p> <p>5.2.7 The independent advisers queried the statement in section 5(a) (Objective for Processing) “<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 was amended as may be necessary to reflect the correct / factual information.</p> <p>5.2.8 The group commended the applicant on the excellent patient and public involvement and engagement (PPIE) undertaken / ongoing as outlined in the application.</p>	
5.3	Reference Number: NIC-683842-M6S8N-v0.9	

	<p>Applicant: Lane Clark & Peacock LLP</p> <p>Application Title: NHS data to assess the impact of treatment delays for gynaecological care, ethnic inequalities for patients with coronary heart disease and broader health inequalities in cardiovascular disease</p> <p>Application: This was a new application.</p> <p>The purpose of the application is to provide analytics and consultancy services to clients in the health sector.</p> <p>The Data will be used to provide the following service areas only: 1) system factors for delays and the clinical impact of treatment delays for gynaecological care; 2) Ethnic inequalities in coronary heart disease treatment; and 3) LCP's Population Health Hub: An online tool for quantifying inequalities in care and outcomes for cardiovascular disease.</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 group were not supportive of service area 3 (LCP's Population Health Hub) of the application.</p> <p>The group were supportive of service areas 1 (treatment delays for gynaecological care) and 2 (Ethnic inequalities in coronary heart disease treatment) of the application and wished to draw to the attention of the SIRO the following substantive comments:</p> <p>5.3.1 The independent advisers noted that section 5 (Purpose / Methods / Outputs) was not as clear / transparent as it could be on the commercial nature of the applicant; and suggested that section 5(e) (Is the Purpose of this Application in Anyway Commercial) was reviewed and updated as may be necessary to fully outline the commercial nature of the application in line with NHS England's DAS Standard for Commercial Purpose and NHS England's DAS Standard for Objective for Processing.</p> <p>5.3.2 In addition, following the update as outlined in point 5.3.1, the independent advisers suggested that the information on the commercial aspect of the application in (the unpublished) section 5(e); 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.</p> <p>5.3.3 The Data Protection Office (DPO) representative and the independent advisers noted the content of the Legitimate Interest Assessment (LIA), however suggested, as a point of advice to the applicant only, that this was updated with further information of the benefits to Lane Clark & Peacock LLP, as a commercial company, from the work outlined in the application. The DPO representative noted this information would usually be captured in the LIA to show the balance between the</p>	
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interests of the Data Controller and the interests of third parties and the data subjects, and in line with the Information Commissioner's Office [guidance](#).

5.3.4 It was suggested that more consideration was given in section 2.3 (benefits evaluation) and section 2.4 (commercial benefit evaluation) of the internal application assessment form, as to whether there is a proportionate balance between public and commercial benefit, in line with [NHS Digital DAS Standard for Expected Measurable Benefits](#) and the National Data Guardian (NDG) [guidance on benefits](#).

5.3.5 The independent advisers noted that failure to be transparent on all of the commercial elements in the application may undermine the credibility of the applicant and public confidence / trust in NHS England handling data.

5.3.6 Noting the information in section 5(a) in respect of Lane Clark and Peacock LLP being "*commissioned*" by the Royal College of Obstetrics and Gynaecology (RCOG) and British Heart Foundation (BFH); it was suggested by the independent advisers that NHS England confirm with the applicant, whether RCOG and BHF were Data Controllers in line with [NHS England's DAS Standard for Data Controllers](#). If it was deemed that they were considered joint Data Controllers, the group advised that the internal application assessment form and the application were updated as appropriate to reflect this information.

5.3.7 In respect of service area 3 (LCP's Population Health Hub), the group noted that whilst they were **not** supportive of this as currently described, suggested that NHS England had a further discussion with the applicant, to ascertain issues such as whether there is a demand for the Hub; and, whether the hub could be developed with synthetic data. It was also suggested that if the Hub was progressed further by the applicant, that there was a clear justification / clarification of the purpose of the Hub, and what the benefits to health and social care, would be and the balance with commercial benefits in line with [NHS Digital DAS Standard for Expected Measurable Benefits](#) and the National Data Guardian (NDG) [guidance on benefits](#).

5.3.8 In addition, the group noted that the processing outlined in the application for service area 3 appeared to be a form of programmatic access; and queried whether this application had been aligned to other similar applications / applicants given programmatic access to data, and whether NHS England had undertaken the same checks and balances. It was suggested that NHS England satisfied themselves that the proposed access to data was appropriate and within scope of relevant NHS England policies.

5.3.9 The independent advisers suggested that for service area 3, this application should show evidence of alignment with other programmatic applications, including, but not limited to, the applicant having an internal advisory committee, Terms of Reference (ToR), published minutes and a publicly accessible data uses register. AGD noted that a number of these aspects had been addressed but cautioned NHS England about ensuring a consistency of approach across all applicants.

	<p>In addition, the group made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.3.10 Noting that Lane Clark & Peacock LLP was a new recipient of NHS England data, the independent advisers reiterated the query raised at the AGD meetings on the 16th June 2023 and the 8th June 2023, what, if any, due diligence had been undertaken by NHS England on this new organisation.</p> <p>5.3.11 Separate to this application: if NHS England do not currently undertake any due diligence on new applicants, the independent advisers suggested that this was given further consideration.</p> <p>ACTION: NHS England Data and Analytics to consider undertaking additional due diligence for new recipients of NHS England data; or providing an update to the group (for information) on what due diligence was undertaken.</p> <p>5.3.12 Noting the statement in section 5(a) of the application “<i>RCOG, who are now partnering with Theramex, a life sciences company...</i>”, it was suggested by the independent advisers, that further clarification was provided on the role / involvement of Theramex as this was not clear.</p> <p>5.3.13 The independent advisers noted the statement in section 3(b) (Additional Data Access Requested) of the application “<i>LCP is minimising the data requested to only the necessary ICD-10 codes across gynaecology, CVD and CVD risk factors</i>”; and noted that this conflicted with previous advice from NHS England, that data could not be minimised in NHS England’s Secure Data Environment (SDE). It was suggested that either the statement was reviewed and amended to reflect the correct information, in line with NHS England’s previous advice; or if the position had changed, the group were provided with further information at a future meeting to ensure they were up to date with the most current information.</p> <p>ACTION: NHS England Data and Analytics to provide further advice on whether or not data can be minimised within the SDE.</p>	<p>NL</p> <p>NL</p>
6	<p>Approval Process (escalation forms) (Presenter: Dave Cronin)</p> <p>The group noted that prior to the meeting, information had been provided as part of the meeting pack, that outlined a variation of the established ‘SIRO Approval’ process.</p> <p>It was noted that as part of the established Process, an application is approved under SIRO Authorisation and the group receive the input (previously the SIRO Authorisation Request form) and the output (previously the email confirming SIRO Authorisation) from the SIRO Authorisation and can review and comment on the decision.</p> <p>It was noted that the proposed variation to the process, is as follows:</p> <ol style="list-style-type: none"> 1. Where an application for an Extension, Renewal or Amendment (ERA) cannot be approved under the existing scope of delegated authority, a Data 	

	<p>Access Service (DAS) Escalation Form is submitted to the SIRO representative and discussed at a weekly meeting between Data Governance and Assurance (DG&A) and the SIRO representative.</p> <ol style="list-style-type: none"> 2. If the Deputy SIRO representative agrees to approve the application under the SIRO Authorisation Precedent, the details of the decision are recorded in the DAS Escalation Form during the meeting and this serves as the output (rather than requiring a separate email). 3. There is further discussion in the meeting over whether the decision is potentially a reusable decision and, if so, the qualifying criteria and any exclusion criteria for the reuse of the decision are captured in the DAS Escalation Form. 4. The DAS Escalation Form is submitted to the AGD Secretariat and allocated a slot at the next available AGD meeting. 5. The group are invited to comment on the SIRO decision and separately (where relevant) are invited to comment on the proposed reuse of the decision including the qualifying and exclusion criteria. 6. Advice is received by the Deputy SIRO representative and a decision is confirmed. 7. Approved reusable decisions (which include clarifications of changes that can be considered in scope of the Simple Amendment Precedent) are logged in the DG&A-owned Knowledgebase from which decisions can be accessed by DAS. <p>It was noted that examples of DAS escalation forms had been provided to the group for NIC-381078-Y9C5K and NIC-484452-H8S1L; and that the group were asked to comment specifically on the potential reusable decision for these applications.</p> <p>The group noted the process outlined and made a number of comments on the DAS escalation forms provided, including, but not limited to, the judgement made on the risk profile.</p> <p>It was agreed that a further discussion would be held on this process / the DAS escalation forms at a future AGD meeting.</p> <p>ACTION: AGD Secretariat to add this item to the internal AGD meeting forward planner.</p>	VW / KM
EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL / DATA ACCESS SERVICE (DAS) APPLICATIONS (EXTENSION, RENEWAL AND / OR AMENDMENT (ERA))		
7.1	<p>Reference Number: NIC-147852-RV70L-v5.7</p> <p>Applicant: University of Newcastle Upon Tyne</p> <p>Application Title: Long term sequelae of radiation exposure due to computed tomography and fluoroscopic cardiology in childhood</p>	

	<p>The SIRO approval was for a six month DAS ERA extension to hold but not otherwise process the data.</p> <p>Outcome of discussion: The group noted that the NHS England SIRO had already provided SIRO approval and confirmed that they were supportive of this.</p> <p>The group thanked NHS England for the written update and made the following observations on the documentation provided:</p> <p>7.1.1 The group noted that, prior to the meeting, the independent advisers had raised some queries directly with the SIRO representative, in respect of the territory of use stated in the application, which was “UK and EEA”. It was noted that section 5(b) of the application states the data will be stored on servers at Newcastle University; and also states “<i>The National Cancer Institute is not permitted to process any onwardly shared linked NHS England data until a Data Sharing Agreement between the National Cancer Institute (NCI) and NHS England is in place</i>”, however noted that it was not explained why the NCI is holding data. It was not clear whether the data release register would actually give transparency when it is updated. Similarly, there was no explanation within the application as to why data is being held in France. It was queried whether the Data Uses Register will be transparent on this point.</p> <p>7.1.2 It was noted that the SIRO representative had provided an update out of committee: where it was confirmed that there is no permission to onwardly share data; and that NCI may be able to process data that has been shared with them but only once a data sharing agreement (DSA) is in place, which in turn needs to go through due process. It was advised that the wording is intended to be very explicit about something that is not permitted, and that the Data Uses Register would be clear because the NCI agreement will have to be considered and approved.</p> <p>The NHS England SIRO representative thanked the group for their time.</p>	
7.2	<p>Reference Number: NIC-374190-D0N1M-v6.4</p> <p>Applicant: Genomics England</p> <p>Application Title: GenOMICC COVID-19 Study</p> <p>Previous Reviews: The application and relevant supporting documents had previously been presented / discussed at the IGARD meetings on the 5th October 2022, 16th December 2021, 15th October 2020, 6th August 2020 and the 25th June 2020.</p> <p>The application and relevant supporting documents had previously been presented / discussed at the IGARD COVID-19 Response meetings on the 20th March 2021, 6th October 2020, 21st July 2020, 14th July 2020, 23rd June 2020, 16th June 2020, 12th May 2020, 5th May 2020 and the 28th April 2020.</p>	

	<p>The application and relevant supporting documents had previously been presented / discussed at the GPES Data for Pandemic Planning and Research – Profession Advisory Group (PAG) on the 29th July 2020 and the 17th June 2020.</p> <p>The SIRO approval was for a six month DAS ERA extension.</p> <p>Outcome of discussion: The group noted that the NHS England SIRO had already provided SIRO approval and confirmed that they were supportive of this.</p> <p>The group thanked NHS England for the written update and made the following observations on the documentation provided:</p> <p>7.2.1 The independent advisers noted in the DAS escalation form that there was an outstanding query (ticket) with Privacy, Transparency and Trust (PTT) in respect of “worldwide” territory of use. Concern was noted on the turnaround of PTT queries (tickets), that in his was case was delaying the progression of the application.</p> <p>7.2.2 The SIRO representative noted the concern raised, and advised that there were ongoing discussions on this issue within PTT, and that further information would be shared within NHS England in due course.</p> <p>The NHS England SIRO representative thanked the group for their time.</p>	
7.3	<p>Reference Number: NIC-381078-Y9C5K-v10.4</p> <p>Applicant: Health Data Research UK</p> <p>Application Title: R14.2 - COVID-IMPACT-UK. Cardiovascular disease and COVID19: using UK-wide linked routine healthcare data to address the impact of cardiovascular disease on COVID-19 and the impact of COVID-19 on cardiovascular diseases</p> <p>Previous Reviews: The application and relevant supporting documents had previously been presented / discussed at the IGARD meetings on the 24th November 2022, 5th May 2022, 29th July 2021, 25th February 2021, 6th August 2020, 3rd December 2020, 22nd October 2020, 15th October 2020, 20th August 2020, 23rd July 2020 and the 25th June 2020.</p> <p>The application and relevant supporting documents had previously been presented / discussed at the IGARD COVID-19 Response meetings on the 29th June 2021, 19th January 2021, 24th November 2020, 23rd June 2020, 16th June 2020, 9th June 2020, 2nd June 2020 and the 26th May 2020.</p> <p>The application and relevant supporting documents had previously been presented / discussed at the GPES Data for Pandemic Planning and Research – Profession Advisory Group (PAG) on the 28th July 2021 and the 24th June 2020.</p> <p>The SIRO approval was for a DAS ERA amendment to 1) to add an additional Data Controller; 2) expand the territory of use to include the EEA.</p>	

	<p>Outcome of discussion: The group noted that the NHS England SIRO had already provided SIRO approval and confirmed that they were supportive of this.</p> <p>The group thanked NHS England for the written update and made the following observations on the documentation provided:</p> <p>7.3.1 The group noted that, prior to the meeting, the independent advisers had raised some queries directly with the SIRO representative, in respect of the rationale for researchers needing to access the data from the EEA. It was noted that the internal application assessment form states “...<i>extension to the Territory of Use to permit processing when data processors are travelling within the EEA...</i>”, and queried why access was required when travelling. It was also noted that section 5(b) of the application states “<i>Remote access will only be from secure locations</i>”, and advised that this raised the question of what secure locations would be available to researchers whilst travelling.</p> <p>7.3.2 In addition, the independent advisers noted the statement that access must comply with the organisation’s remote access policy; and queried whether all of the Universities have remote access policies that define ‘secure locations’; and whether researchers were aware of the relevant policy and follow it. It was suggested that NHS England clarify with the applicant, whether there was a robust justification for needing to access the data while ‘travelling’.</p> <p>7.3.3 The SIRO representative noted and thanked the independent advisers for the points raised in advance of the meeting; and noted that the points would be given due care and consideration and would be addressed as part of the update to the application.</p> <p>The NHS England SIRO representative thanked the group for their time.</p>	
7.4	<p>Reference Number: NIC-05429-H7X6R-v10.2</p> <p>Applicant: Device Access UK Ltd</p> <p>Application Title: Device Access - HES Application 2023</p> <p>Previous Reviews: The application and relevant supporting documents had previously been presented / discussed at the AGD meeting on the 12th October 2023.</p> <p>The application and relevant supporting documents had previously been presented / discussed at the IGARD meetings on the 4th August 2022, 26th May 2022, 21st December 2017, 6th July 2017, 8th June 2017, 25th May 2017 and the 16th March 2017.</p> <p>The SIRO approval was for a three month renewal.</p> <p>Outcome of discussion: The group noted that the NHS England SIRO had already provided SIRO approval and confirmed that they were supportive of this.</p>	

	<p>The group 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 the group for their time.</p>	
AGD Operations		
8	<p>Statutory Guidance</p> <p>The independent advisers again noted the reference to reviewing materials in accordance with “<i>a clearly understood risk management framework</i>” within the published Statutory Guidance and advised that they were not aware of an agreed risk management framework, and requested that NHS England provide further information/ clarity on this, noting this topic had been raised by Lord Hunt in the House of Lords on the 26th June 2023, and was answered by Lord Markham on the 5th July 2023: Written questions, answers and statements – UK Parliament.</p> <p>The NHS England SIRO Representative had provided further clarity on the risk management framework via email to the group, which confirmed that NHS England were asking the interim data advisory group to use the NHS England DAS Standards and Precedents model to assess the risk factors in relation to items presented to the interim data advisory group for advice; however the independent advisers noted that the wording in the statutory guidance “...<i>using a clearly understood risk management framework, precedent approaches and standards that requests must meet...</i>”, suggested that the risk management framework is separate to the DAS Standards and Precedents, and asked that this be clarified by NHS England. The group noted that the Deputy Director, Data Access and Partnerships, Data and Analytics attended the meeting on the 23rd November 2023, and noted that plans for this work were in train.</p> <p>It had been noted previously that an Oversight and Assurance Programme of applications that had not be subject to AGD review could form part of this Risk Management Framework.</p> <p>The AGD Chair referred to the requirement within the published Statutory Guidance for an annual review; and that further thought / consideration was needed, on how the annual report would be presented, for example, on an NHS England standard template or other means.</p> <p>ACTION: The group to give further thought / consideration as needed, on how the annual report would be presented, for example, on an NHS England standard template or other means.</p> <p>The SIRO representative noted an outstanding action in respect of providing a written response to AGD on the risk management framework; and noted that this was progressing under the NHS England Precedents and Standards work.</p>	AGD
9	AGD Terms of Reference (ToR)	

	<p>The independent advisers noted that over eight months had passed since the Statutory Guidance had been published, requiring a ToR to be agreed and published.</p> <p>The Director of Privacy and Information Governance, Privacy, Transparency and Trust, Jackie Gray, attended the meeting on the 1st February 2024, to advise the group that following the workshop on the 27th November 2023, the draft ToR had been updated further following feedback from other stakeholders, and that a further draft version of the updated ToR would be shared with the group for information, prior to this document being submitted to the NHS England Board / subcommittee of the Board.</p> <p>The AGD Chair noted that following the meeting on the 1st February 2024, a further iteration of the draft ToR had been shared with the Chair, SIRO representative and the Data and Analytics representative, for comments on recent updates made to the document. It was noted that as previously discussed, a final version of the draft ToR was expected to be shared with the group prior to this being submitted to the NHS England Board / subcommittee of the Board.</p> <p>ACTION: The SIRO representative to provide a copy of the final draft of the ToR prior to this document being submitted to the NHS England Board / subcommittee of the Board.</p> <p>The group reiterated the request that the version control on the ToR be updated to reflect the full circulation of the document and the timing of such circulation.</p> <p>Following Jackie Gray's attendance at the AGD meeting on the 1st February 2024, the group reiterated that they looked forward to further information as to when the ToR would be considered by the NHS England Board / subcommittee of the Board.</p> <p>ACTION: The SIRO representative to provide further information to the group as to when the draft ToR, including when this would be considered by the NHS England Board / subcommittee of the Board.</p>	<p>GC</p> <p>GC</p>
10	<p>Standard Operating Procedures (SOPs)</p> <p>The ongoing forward plan of work for creating Standard Operating Procedures was discussed and noted that although this could not progress further without sight of the final ToR, work was ongoing to progress and finalise the AGD SOPs, in line with the progression of the AGD ToR.</p> <p>It was noted that some of the independent advisers and the SIRO representative were supporting the progression of the SOPs out of committee; and that a workshop would be held with the group in March 2024, to discuss this further.</p> <p>The group noted the update and looked forward to further discussions at future AGD meetings.</p>	To note
Any Other Business		

11.1	<p>AGD webpage update (Presenter: Karen Myers)</p> <p>The group were advised that work was ongoing to design and publish an updated AGD webpage on the current NHS Digital webpage, ahead of the new NHS England website, in preparation for the final AGD Terms of Reference being finalised; and that further information would be shared with the group on progress at the AGD meeting on the 7th March 2024.</p> <p>The group noted the verbal update and looked forward to a further update on the 7th March 2024.</p>
11.2	<p>Stakeholder Engagement / AGD Project Work (Presenter: Karen Myers)</p> <p>The group noted that from the 29th February 2024, and for the purpose of transparency, there would be a standing item on the AGD agenda and in the AGD minutes, on all stakeholder engagement and / or AGD project work undertaken outside of the meeting.</p> <p>The group noted the verbal update and advised that they were supportive of the stakeholder engagement and / or AGD project work being added to future AGD meetings agendas and minutes.</p>
11.3	<p>AGD Project Work – OpenSAFELY Directions Meeting (Presenter: Dr. Imran Khan)</p> <p>The group were advised that a meeting had been held on the 19th February 2024, to discuss the OpenSAFELY Directions and had been attended by independent advisers: Dr. Imran Khan and Miranda Winram.</p> <p>The group thanked Imran for the brief verbal update and looked forward to receiving further updates in due course.</p>
11.4	<p>General Practice Extraction Service (GPES) Data for Pandemic Planning and Research – Profession Advisory Group (PAG) (Presenter: Jonathan Osborn)</p> <p>The group were advised by Jonathan that there were ongoing discussions with the British Medical Association (BMA) and the Royal College of General Practitioners (RCGP) on the future of PAG and how it will operate. It was noted that a further update would be provided in due course.</p> <p>The group noted that the current draft AGD Terms of Reference do not preclude PAG meeting in common with AGD.</p> <p>The independent advisers noted that the current PAG webpage was not up to date and suggested that NHS England update the webpage as soon as practicable, including any updates around the future of PAG.</p> <p>ACTION: The NHS England Caldicott Guardian Team Representative (PAG Chair) to review / update the current PAG webpage as soon as practicable, including any updates around the future of PAG.</p> <p>The independent advisers and Jonathan noted that the current interim PAG arrangements were still in place, as noted in the published minutes of the 27th July 2023 (item 8) and 14th September 2023 (item 5.1.1) and that NHS England should</p>

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	<p>ensure they are following that process, as outlined in the previously circulated to NHS England draft '<i>How AGD consults with the Profession re General Practice Extraction Service (GPES) Data for Pandemic Planning & Research (COVID-19) (GDPPR) Data Standard Operating Procedure</i>' .</p> <p>The group noted the verbal update from Jonathan and looked forward to further information at a future meeting.</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>		