Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 11th April 2024

09:00 – 12:50

(Remote meeting via videoconference)

AGD INDEPENDENT / NHS ENGLAND MEMBERS IN ATTENDANCE:	
Name:	**Role:**
Claire Delaney-Pope (CDP)	AGD independent member (Specialist Information Governance Adviser)
Kirsty Irvine (KI)	AGD independent member (Chair)
Narissa Leyland (NL)	NHS England member (Data and Analytics Representative (Delegate for Michael Chapman))
Andrew Martin (AM)	NHS England member (Data Protection Office Representative (Delegate for Jon Moore))
Dr. Jonathan Osborn (JO)	NHS England member (Caldicott Guardian Team Representative)
Jenny Westaway (JW)	AGD independent member (Lay Adviser) (not in attendance for items 1 and 2)
Miranda Winram (MW)	AGD independent member (Lay Adviser)
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	**Role / Area:**
Garry Coleman (GC)	NHS England SIRO Representative
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Delivery Directorate
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Delivery Directorate
AGD INDEPENDENT MEMBERS / NHS ENGLAND MEMBERS NOT IN ATTENDANCE:	
Name:	**Role / Area:**
Paul Affleck (PA)	AGD independent member (Specialist Ethics Adviser)
Michael Chapman (MC)	NHS England member (Data and Analytics Representative)

Prof. Nicola Fear (NF)	AGD independent member (Specialist Academic Adviser)
Dr. Robert French (RF)	AGD independent member (Specialist Academic / Statistician Adviser)
Jon Moore (JM)	NHS England member (Data Protection Office Representative)

1	**Welcome and Introductions:** The AGD Chair welcomed attendees to the meeting.	
2	**Review of previous AGD minutes:** The minutes of the AGD meeting on the 21st March 2024 were reviewed and, after several minor amendments, were agreed as an accurate record of the meeting.	
3	**Move from 'interim AGD' to 'AGD' / Final AGD Terms of Reference (ToR)** The Group noted that following approval of the AGD ToR at the Data, Digital and Technology Committee (DDAT) of the NHS England Board, on Thursday 14th March 2024 (as noted in the 21st March 2024 minutes), they would move from being the 'interim advisory group for data' to the 'Advisory Group for Data' in line with the approved AGD ToR. The SIRO representative reiterated to AGD that the finalised version of the AGD ToR would be circulated, and a copy would also be published on the (updated) AGD webpage by the AGD Secretariat as soon as possible. **ACTION:** SIRO representative to circulate the approved AGD ToR to the Group (via the AGD Secretariat). **ACTION:** AGD Secretariat to ensure the approved AGD ToR is published on the AGD webpage, once the AGD website has been updated and approved for publication.	SIRO Rep AGD Sec
4	**Declaration of interests:** An AGD member noted a potential personal connection to the study outlined in NIC-594012-C9R9H (University of Newcastle Upon Tyne). It was agreed this did not preclude the AGD member taking part in the discussion about this item.	
5	**AGD Action Log:** *The action log was not discussed.*	
6 BRIEFING PAPER(S) / LETTER OF NOTE / DIRECTIONS:		
6.1	**Title:** National Disease Registration Service (NDRS) Cancer Consolidated Data Set - Letter of Note	

	Following the closure of Public Health England (PHE) on the 31st October 2021, a number of datasets previously managed by the National Disease Registration Service (NDRS) within PHE moved into NHS England. As a result, a subset of these datasets were onboarded into NHS England's Data Access Service (DAS) (formerly 'Data Access Request Service' (DARS)); which led to the creation of 22 Shell Products (i.e. products with limited meta data which allow customers to request entirely bespoke data requests via physical extract). The briefing (**for information only**) was to advise the Group of a new product the **NDRS Cancer Consolidated Data Set**; which is a fully defined, package-based product offering, which contains data from three source data sets, National Cancer Registrations, Rapid Cancer Registrations and Cancer Pathways. The main purpose of creating this new product is to allow customers to access data in the Secure Data Access Environment (SDE) given the pre-existing shell products allow access via physical extract only. **Outcome of discussion:** AGD welcomed the briefing paper and made the following observations / comments: **6.1.1** AGD noted that NHS England were not seeking specific advice on the briefing paper provided, and that this had been primarily submitted to the Group for information only. Notwithstanding this, NHS England welcomed the brief comments and suggestions summarised below. **6.1.2** AGD queried whether the new product accessed within the SDE would allow customers to access data that was additional to their requirements, noting that bespoke data packages would not be provided within the SDE; and suggested that NHS England address this point within the Letter of Note in line with NHS England's DAS standard for data minimisation including, but not limited to, the identifiability status of any additional data that may be accessed. **6.1.3** In addition, it was suggested by AGD that the Data Protection Impact Assessment (DPIA) for the new product was updated to reflect the data minimisation / identifiability aspects; and confirmation that NHS England had satisfied itself that data minimisation efforts had been met in line with NHS England's DAS standard for data minimisation and the UK General Data Protection Regulation (UK GDPR). **6.1.4** AGD queried whether any additional data accessed, would increase the risk of potential 'scope creep', that may be beyond the initial purpose of what access to the data was permitted for; and suggested that this was addressed within the DPIA, including, but not limited to, how this would be managed by NHS England and how this would be audited. **6.1.5 Separate to this application:** the SIRO representative noted that there was ongoing work within NHS England on meta data; and advised that further information would be provided to the Group by colleagues within Data and Analytics, at a future AGD meeting.	

	ACTION: The Data and Analytics Representative to work with colleagues within Data and Analytics and bring a meta data item to a future AGD meeting. **6.1.6** AGD looked forward to receiving the finalised Letter of Note addressing the point raised in 6.1.2, either out of committee (OOC) or tabled at a future meeting.	D&A Rep
7 EXTERNAL DATA DISSEMINATION REQUESTS:		
7.1	**Reference Number:** NIC-594012-C9R9H-v0.11 **Applicant:** University of Newcastle Upon Tyne **Application Title:** Recovery, Renewal and Reset of Services to Disabled Children **Application:** This was a new application. The purpose of the application is for a study to establish which reconfigurations of services, practices and strategies for disabled children arising from COVID-19 work well and should inform policy on system recovery and planning for future emergencies. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** AGD were broadly supportive of the application and wished to draw to the attention of the SIRO the following significant comments: **7.1.1** AGD noted that the Health Research Authority Confidentiality Advisory Group (HRA CAG) conditions of support had been met and that HRA CAG were satisfied that in particular the transparency / opt-out condition had been met; however, the Group advised that in relation to the HRA CAG condition on patient notification / opt-outs, it was difficult to determine how this had been met, because it was unclear which five NHS Foundation Trusts were involved in the study. **7.1.2** It was also suggested by the Group, that the privacy notice should be clearer that s251 support had been obtained to gather the study cohort. In addition, the Group made the following observations on the application and / or supporting documentation provided as part of the review: **7.1.3** AGD welcomed the application and noted the importance of the research. **7.1.4** AGD noted that that the HRA CAG and HRA Research Ethics Committee (REC) support was due to expire at the end of May 2024; and suggested that NHS England satisfy themselves that sufficient steps had been taken by the applicant to extend the HRA CAG and HRA REC support. **7.1.5** AGD noted the various components of the programme within the application; but suggested that the application was updated with a very brief overview of the wider programme of work, and to be clearer that this application was specifically for the purpose of 'Work Package 2' (WP2) only.	

	7.1.6 In addition, it was suggested that any references within the application to the data of parents / carers being studied were removed, noting that this was **not** relevant to WP2. **7.1.7** AGD queried whether enough data and a sufficient number of NHS Trusts were involved with the study, to ensure a meaningful view across England was obtained; and advised that they would be supportive of additional data flowing from additional NHS Trusts if a suitable justification for this was provided within the application; and the correct NHS England processes / Standards were adhered to as per usual process. **7.1.8** AGD noted and commended NHS England's Data Access Service (DAS) for the work undertaken with the applicant to determine the Data Controller(s) / Data Processor(s) arrangements; which supported the review of the application. The Group confirmed that they were supportive of the outcome of this work and offered no further comments on this aspect. **7.1.9** The SIRO representative noted the outdated organisational information within section 5(b) of the application; and suggested that this was reviewed and updated as necessary to reflect current organisational structures, for example, the information in respect of the Data Services for Commissioners Regional Offices (DSCRO). **7.1.10** AGD noted acronyms in section 5, and suggested that these were reviewed, to ensure they were correctly defined upon first use, for example *"NECS"*. **7.1.11** The SIRO representative noted the statement in section 5(b) *"The identifying details will be stored in a separate database at NECS…"*; and suggested that this was reviewed and aligned with the rest of the application, noting the lengths taken to avoid NECS holding identifiable data related to this application.	
8 INTERNAL DATA DISSEMINATION REQUESTS:		
There were no items discussed		
9 EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL		
9.1	**Application Title:** Local Authority Civil Registration Template Agreements The SIRO approval was for an update to the Local Authority Civil Registration Template Agreements, which were initially produced, to allow Local Authorities to carry out their statutory Public Health function. To date, the products on the Local Authority Civil Registration Template were Primary Care Mortality Data (PCMD), Civil Registration (Births) and a tabulation called Vital Statistics. It was noted that the Local Authority Civil Registration Templates now need to be updated, to remove the PCMD product and replace it with the Civil Registration (Deaths) product, due to the PCMD product being decommissioned.	

	As PCMD is created from Civil Registration (Deaths) (using different field names and adding some geographic/organisation derivations) there will be no change to the data being provided. However, as the Civil Registration (Deaths) product needs to be developed, to add the necessary derivations, the swap cannot be carried out immediately (all the data sharing agreements (DSA) are being renewed), so both products are being added to the DSA to allow the swap to happen during the period of the DSA, avoiding the need to bring them all through the NHS England Data Access Service (DAS) Applications process again. Once the Civil Registration (Deaths) product is ready for these DSAs, a full refresh of the data (minimised to their locality area as before) will be provided under each DSA to ensure backwards compatibility; and the Local Authority will be required to provide evidence of the data destruction of all the PCMD they have held. This has been specifically outlined in section 5(b) (Processing Activities) of the DSA; and the data destruction is covered by a special condition in section 6 of the DSA. Additionally, the Vital Statistics product is being removed as this has proven difficult to produce over the last three years. **Outcome of discussion:** AGD noted that the NHS England SIRO had already provided SIRO approval and confirmed that they were supportive of this. The Group thanked NHS England for the written update and made the following observations on the documentation provided: **9.1.1** The SIRO representative advised the Group, that a further update on this template, in respect of the legal basis for flowing the Civil Registration (Deaths) data as part of this templated application, would be discussed at a future AGD meeting. The NHS England SIRO representative thanked AGD for their time.	
9.2	**Reference Number:** NIC-233512-B7C4W-v5.1 **Applicant:** NEC Software Solutions UK Limited **Application Title:** Neurosurgical National Audit Programme (NNAP) **Previous Reviews:** The application and relevant supporting documents had previously been presented / discussed at the AGD meeting on the 22nd June 2023. The application and relevant supporting documents had previously been presented / discussed at the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) meeting on the 29th September 2022, 28th May 2020, 30th April 2020, 11th July 2019 and the 11th April 2019. The SIRO approval was for a 9-month renewal. **Outcome of discussion:** AGD noted that the NHS England SIRO had already provided SIRO approval and confirmed that they were supportive of this.	

	The Group thanked NHS England for the written update and made the following observations on the documentation provided: **9.2.1** AGD noted that the Data Protection Act (DPA) Registration for one of the Data Processors under this data sharing agreement (DSA) had expired in November 2023. **9.2.2** AGD noted that the Society of British Neurological Surgeons is the Data Controller and advised that it was important that NHS England should engage with the Data Controller, as well as the Data Processor, in relation to the issues discussed in the supporting documentation as the Data Controller also has accountability under the UK General Data Protection Regulation (UK GDPR).The NHS England SIRO representative thanked AGD for their time. The NHS England SIRO representative thanked AGD for their time.	
10 OVERSIGHT AND ASSURANCE		
There were no items discussed		
11 PRECEDENTS AND STANDARDS		
11.1	**Title:** Research for Commissioners' Sub-Licence Precedent **Presenter:** Narissa Leyland **Previous Reviews:** The Precedent and supporting paper were previously discussed at the AGD meeting on the 22nd February 2024. 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. 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. 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). 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. The paper has been updated to address the comments made at the interim AGD meeting on the 22nd February 2024; and to provide clarity on: 1. the governance the data controllers must have in place to support research for commissioners sub-licencing arrangement;	

2. the requirements where a commercial aspect is identified as part of research activities under the sub-licencing agreement;
3. the auditability and enforceability of the controls in place.

NHS England were seeking advice on the following points:

1. To provide advice for the SIRO to recommend accepting the Precedent allowing ICBs to sub-license the permissible datasets within their DSA for an additional purpose of research for commissioning uses.

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

In response to point 1:

11.1.1 AGD noted that the updated paper was not clear how each of the points previously made by AGD had been addressed; and suggested that for ease of reference, the paper was updated with further clarity of all the points made by AGD and how they had been addressed, noting that some key points raised at that meeting had **not** been addressed

11.1.2 AGD reiterated the request that a **separate document** was provided, that outlined what the risk criteria referred to in the document were (and that it was updated as may be necessary; for example, if the risk criteria precluded sub-licensing, then that risk criteria would also need to be amended).

11.1.3 AGD reiterated the suggestion 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.

11.1.4 AGD reiterated the previous point, that NHS England should give further consideration as to whether ICBs would have the capacity and skills to manage sub-licences and the associated risks.

11.1.5 In addition, AGD discussed whether NHS England could produce / provide a training package for ICB staff; and suggested that this was given further consideration by NHS England.

11.1.6 AGD reiterated the previous point, in respect of whether there would be an amendment to the existing data sharing agreements (DSA), or whether a new DSA would be required; and suggested that the templated DSA wording would need a careful review to remove any reference such as *"cannot do research"*, to ensure that any updates to the DSA were enforceable and auditable.

11.1.7 It was noted that there could potentially be a benefit to commercial partners, for example, in respect of expanding the research and the ICB meeting its statutory

	function; however suggested that NHS England gave further thought as to any limits / restriction in respect of any commercial access to the data. **11.1.8** AGD queried any potential competitive advantages gained by commercial organisations moving into this new sublicensing opportunity first and whether this raised the risk of anti-competitive practice developing ; and suggested that NHS England gave this further consideration. **11.1.9** AGD noted the reference to an oversight board within the Precedent template, however suggested that NHS England align the requirements of the board with other applicants who use sub-licences, for example, by ensuring it has Terms of Reference and aligns with NHS England DAS Standard for Expected Measurable Benefits and NHS England DAS Standard for Commercial Purpose. **11.1.10** AGD noted that some ICBs may wish to opt to use honorary contacts as opposed to sub-licences; but noted caution on this approach, noting that an honorary contract should not be used as a substitute for sub-licences; and noted the restrictions attached to an honorary contract, for example, in relation to the involvement of commercial organisations. **11.1.11** AGD noted that the precedent required that any research must be commissioned by the ICB; and suggested that this could be defined further so that it was clear what constituted an ICB *"commissioning"* research for the purpose of this precedent. **11.1.12** AGD noted that the exclusion criteria within the Precedent referred to restrictions on permitted *"linkage"*; but that it was not clear in the Precedent what linkage would or would not be allowed and suggested that the document was updated to be clear if the general linkage allowed elsewhere in the ICB Precedent for commissioning purposes also applied to research. **11.1.13** AGD noted that the Precedent requires that where an ICB is sub-licensing for research, that it must be for the benefit of health and social care; however noted that this does not seem to apply when the ICB is doing the research; and suggested any research permitted by this Precedent should be connected with health and care that this was reviewed and updated as may be necessary by NHS England. **11.1.14** AGD noted that the Precedent template provides templated outputs and benefits; and suggested that these were removed to ensure that ICBs define the outputs and benefits to reflect their own ICB strategy. **11.1.15** AGD noted the special condition that states *"Re-identification of data by the sub-licensee is strictly prohibited unless it is for the purpose of direct care"*; and suggested that this was expanded or removed, noting that there were limited cases of where re-identification would happen for the purpose of direct care. **11.1.16** AGD advised that they would welcome seeing an updated version of this precedent, risk criteria, and the amended template DSA in tracked changes.	

	11.1.17 AGD noted that that given the significant change that this Precedent would enable in terms of ICB's use of data, they would welcome seeing first of type applications for amendments to ICB DSAs to enable research.	
12 AGD OPERATIONS		
12.1	**AGD Standard Operating Procedures (SOPs)** The ongoing forward plan of work for creating the AGD Standard Operating Procedures was discussed; and noting that the AGD Terms of Reference (ToR) had now been approved, it was noted that work was progressing in order to finalise the AGD SOPs in line with the approved AGD ToR. It was noted that a further update would be provided to the Group in due course.	
12.2	**AGD Annual Report** AGD noted, that as discussed at previous AGD meetings, there was a requirement within the published Statutory Guidance for an 'annual review'; and were advised by the Chair, that a meeting had taken place on the 2nd April 2024, with Jackie Gray, Director of Privacy and Information Governance, Privacy, Transparency and Trust (PTT), Garry Coleman, AGD SIRO representative, Vicki Williams, AGD Secretariat Manager and Ross Thornton, PTT Chief of Staff, to discuss this further. The AGD Chair advised that following this meeting, a skeleton draft annual report document had been produced; and that this would be shared with the Group for review / comments / updates; before a further discussion at the AGD meeting on the 18th April 2024, prior to this document being shared with Jackie Gray. **ACTION:** AGD Secretariat to share the skeleton draft annual report document with the Group for review / comments / updates.	AGD Sec
12.3	**AGD Stakeholder Engagement** The AGD Chair provided feedback to the Group with regard to her meeting with Dr. Tony Calland, the Chair of the Health Research Authority Confidentiality Advisory Group (HRA CAG) and Dr. Nicola Byrne, the National Data Guardian for health and adult social care in England, on Tuesday 26th March 2024, as part of their regular engagement.	
12.4	**AGD Project Work** *There were no items discussed*	
13 Any Other Business		
13.1	**NIC-698171-K4M0B-v0.3 Home Office**	

	AGD noted that following the review of the above application at the AGD meeting on the 29th February 2024 and the 18th January 2024; the Home Office had confirmed to NHS England, that Article 9(2)(j) (Archiving, research and statistics) of the UK General Data Protection Regulation (UK GDPR) would be the correct legal basis to process the data under this application; as opposed to Article 9(2)(g) (Reasons of substantial public interest (with a basis in law)) as cited originally. In addition, it was noted that the Home Office had advised that an ethics review would be undertaken following feedback from the Group at previous meetings. AGD noted the content of the update; thanked the SIRO representative for the update and commended the careful work that had been undertaken to consider AGD advice on this application. In addition, AGD made the following comments: **13.1.1** The Group noted that on the 29th February 2024, a point had been raised in respect of patient and public involvement and engagement (PPIE); and had suggested that the application was updated to provide further information on the PPIE undertaken to date **and** any future PPIE. It was noted that the response on this point in the papers provided, appeared to be very brief, and suggested that the Home Office gave further consideration to ongoing PPIE for the specific project outlined in the application.
13.2	**Our Future Health** As part of the discussion of NIC-414067-K8R6J at the AGD meeting on the 18th January 2024; the specialist academic / statistician independent adviser in attendance had taken an action to produce a paper for Our Future Health, with some proposed additional follow-up questions, that would further examine the case for targeted letters with names and addresses. AGD noted that a copy of the paper had been provided to them **for information**; and that the paper had been produced and shared with the SIRO representative to share / discuss with Our Future Health. The SIRO representative noted his thanks to the independent adviser for the paper.
Meeting Closure As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.	