Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 13th June 2024

09:00 – 15:35

(Remote meeting via videoconference)

AGD INDEPENDENT / NHS ENGLAND MEMBERS IN ATTENDANCE:	
Name:	**Role:**
Paul Affleck (PA)	AGD independent member (Specialist Ethics Adviser)
Michael Chapman (MC)	NHS England member (Data and Analytics Representative)
Claire Delaney-Pope (CDP)	AGD independent member (Specialist Information Governance Adviser)
Kirsty Irvine (KI)	AGD independent member (Chair)
Andrew Martin (AM)	NHS England member (Data Protection Office Representative (Delegate for Jon Moore))
Dr. Jonathan Osborn (JO)	NHS England member (Caldicott Guardian Team Representative)
Jenny Westaway (JW)	AGD independent member (Lay Adviser)
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	**Role / Area:**
Hark Atwal (HA)	NDC Data and Insight Programme Engagement Lead, Transformation Directorate (**Observer**: item 5.1)
Fay Beck (FB)	Digital Insight and Engagement Lead, Transformation Directorate (**Presenter**: item 5.1)
Laura Bellingham (LB)	Deputy Director, Data Access and Partnerships, Data and Analytics (**Presenter:** item 10)
Garry Coleman (GC)	NHS England SIRO Representative
Claire Corney (CC)	Senior IG Manager (IG Delivery - Data & Analytics Team), Privacy, Transparency and Trust (PTT), Delivery Directorate (**Observer**: item 5.2)
Ben Cromack (BC)	Data Access and Partnerships, Data and Analytics (**Observer**: item 6.1)

Dan Goodwin (DG)	Data Access and Partnerships, Data and Analytics (**Observer**: item 6.3)
Emma Harrison (EH)	NDC Data and Insight Programme and Analytics Management Lead, Transformation Directorate (**Observer**: item 5.1)
Dickie Langley (DL)	Assistant Director of IG (Digital Operations), Privacy, Transparency and Trust (PTT), Delivery Directorate (**Observer**: item 5.1)
Sara Lubbock (SL)	Data Access and Partnerships, Data and Analytics (**Observer**: item 6.4)
Abigail Lucas (AL)	Data Access and Partnerships, Data and Analytics (**Observer**: item 6.2)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Delivery Directorate
Simon Snowden (SS)	Senior Manager - specialist analytical support functions, Data Product Development, Data and Analytics, Transformation Directorate (**Presenter**: item 5.2)
James Watts (JW)	Data Access and Partnerships, Data and Analytics (**Observer**: item 6.5)
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Delivery Directorate
Tom Wright (TW)	Assurance Lead, Data Governance and Assurance, Data Access and Partnerships Directorate (**Observer**: item 6.4)
AGD INDEPENDENT MEMBERS / NHS ENGLAND MEMBERS NOT IN ATTENDANCE:	
Name:	**Role / Area:**
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)
Miranda Winram (MW)	AGD independent member (Lay Adviser)
ACCENTURE STAFF IN ATTENDANCE (ITEM 10):	

Aneka Shah (AS)	Accenture (Presenter)
David Hurley (DH)	Accenture (Observer)
Melissa Luque (ML)	Accenture (Observer)
Oliver Wickens (OW)	Accenture (Presenter)
Dawud Ahmed (DA)	Accenture (Observer)

1	**Welcome and Introductions:** The AGD meeting Chair welcomed attendees to the meeting.
2	**Review of previous AGD minutes:** The minutes of the AGD meeting on the 6th June 2024 were reviewed and, after several minor amendments, were agreed as an accurate record of the meeting.
3	**Declaration of interests:** Jenny Westaway noted that she had undertaken some paid contract work for Templar Executives to contribute to the development of a general e-learning course on data protection for Our Future Health. It was agreed this did not preclude the Jenny from taking part in the discussions about the Our Future Health application (NIC-411795-X5N2V). Jenny Westaway noted that she had some involvement in discussions about the common law of confidentiality as relates to one of the activities outlined in NIC-742629-H5M4F, through her National Data Guardian (NDG) role. It was agreed this did not preclude the Jenny from taking part in the discussions about the London Ambulance Service NHS Trust application.
4	**AGD Action Log:** *The action log was not discussed.*
5 BRIEFING PAPER(S) / DIRECTIONS:	
5.1	**Title:** The National Digital Channels (NDCs) Demographics from Data Processing Services (DPS) Briefing Paper **Presenter:** Fay Beck **Observers:** Dickie Langley, Hark Atwal and Emma Harrison The NDCs comprise the citizen-facing NHS App and NHS Website, as well as enabling and underpinning capabilities such as NHS login. The ambition for the NDCs is to enable people (NHS App is 13+) in England to access digital health and care services in order to stay well, get well, and manage their health and care.

	The digital channels will become the mainstream 'front door' through which the population can interact with the NHS, receive personalised services, self-serve, and actively participate in their health and care. The NDCs are fundamental to delivering the ambitions set out in NHS England's Long-Term Plan and the Digital Health and Care Plan, giving people and their carers the digital tools to access information and services directly and self-serve. This supports the improvement of patient experience, drives efficiencies in the delivery of care and aims to improve health outcomes for all. In order to deliver efficient and effective services NHS England need to understand the userbase across the channels; and understand engagement and retention across core demographic groups which will allow NHS England to maximise reach and effectiveness of the NDCs ultimately improving access to care and driving improvements in health outcomes and reducing health inequalities. To generate actionable insights, it is proposed to ingest ethnicity and gender (source: Hospital Episode Statistics (HES) submission) attributes at person level from Data Processing Services (DPS) into the NDC Data and Insights Services. These attributes would then be available to conduct analysis on the demographic profile of NHS App users based on activities conducted within the NHS App. The Core20PLUS5 framework is an approach, at both national and system level, which aims to reduce healthcare inequalities. A target population is defined in the approach (the Core20PLUS), along with five clinical areas of focus which require accelerated improvement. NHS England were seeking advice on the following points: 1. Do you see any significant risks associated with sourcing ethnicity and gender from HES for the following primary use cases: i) Allow us to understand the reach of the app and measure engagement within groups that may be at risk of health inequalities. ii) Allow us to understand the value of future channel propositions e.g., do we have good engagement within key cohorts that could increase effectiveness of health interventions (e.g., cervical screening, health checks) 2. Do you have any advice on the type of gender i.e., gender identity or gender at birth that we should ingest to support the primary use cases? 3. Do you have any advice from either a patient, clinical or risk perspective on additional Core20PLUS5 attributes which we may want to use in the future? E.g., Disability status, employment, language, care cluster, patient postcode (LSOA), preferred language and/or deceased flag. **Outcome of discussion:** AGD welcomed the briefing paper and made the following observations / comments: **In response to points 1 to 3:** **5.1.1** AGD noted that they were broadly supportive of the proposal outlined in the briefing paper, and noted the potential benefits that this may bring to patients.

	5.1.2 AGD suggested that further work was undertaken by NHS England, to consider whether individuals could be given the choice to volunteer the information required themselves (via the NHS App) recognising their autonomy and ensuring quality / accuracy of the data, as opposed to NHS England relying on the HES dataset. **5.1.3** The Group noted concerns about whether the gender and ethnicity fields in the HES dataset were sufficient in terms of quality (accuracy) to achieve the aims of the analysis; and suggested that this was explored / clarified by NHS England. **5.1.4** The AGD NHS England Caldicott Guardian Team representative noted that whilst the NHS England App could invite individuals to provide information on gender (amongst other required information), highlighted the importance of also requesting details on an individual's biological 'sex' at birth, since biological sex was critical for medical use for example screening, risk factors and certain health conditions. **5.1.5** AGD highlighted the importance of clear and direct questions posed to individuals via the NHS App, to support with the accuracy of the data submitted, and suggested using public involvement and engagement (PPIE) groups for pulling together the questions for the NHS App. **5.1.6** An AGD independent member noted that some individuals may be surprised that other datasets were being used to gather information / data about them, also noting the genesis of the NHS App compared to the NHS COVID-19 App. However, others expressed the view that many users may assume the NHS App already contains this information and user engagement carried out by NHS England would seem to support this. **5.1.7** It was suggested by the Group, that the NHS App was utilised to provide transparency on the data requested and why it was required, for example, via a pop-up window, alongside improving the current privacy notice which could highlight the work to improve the NHS App plus inform about the future research and service evaluation work. **5.1.8** In addition, it was noted that NHS England should consider transparency / communication to the public via a number of communication channels, i.e. not just in the NHS App, to avoid digital exclusion. **5.1.9** AGD noted that using the patient's GP practice postcode as an economic indicator could be misleading, for example, in rural areas; and suggested that NHS England consider using patient postcodes instead. **5.1.10** AGD suggested that PPIE groups could provide further support to NHS England on some of the points raised above. **5.1.11** AGD queried the legal basis for NHS England to collect, disseminate and use the data, for example, the UK General Data Protection Regulation (UK GDPR), the Health and Social Care Act 2012 and the Common Law Duty of Confidentiality; and suggested that this was clarified within the application and relevant supporting documents, noting that this information may well be in the Data Protection Impact Assessment (DPIA) which was not provided as a supporting document and could be simply copied across.

	5.1.12 AGD noted that they would welcome a further discussion on the work outlined, including, but not limited to, a review of the DPIA when complete. **5.1.13** AGD looked forward to receiving the finalised briefing paper, either out of committee (OOC) or tabled at a future meeting.
5.2	**Title:** National Major Trauma Registry (NMTR) for NHS Wales Request 2024 **Presenter:** Simon Snowden **Observer:** Claire Corney The NHS England NMTR was established in April 2024 to drive improvements in national trauma services and patient care, and for use in trauma care research; and was implemented following closure of the former Trauma and Audit Research Network (TARN) registry. This purpose of the briefing paper, is to outline the request received by NHS England under section 255(1) and section 256(2)(c) of the Health and Social Care Act 2012 for NHS England to support Digital Health and Care Wales (DHCW) in its statutory duty to carry out functions in relation to the provision of digital health services by establishing and operating an information system for the collection and analysis of NMTR data from the Local Health Boards in Wales. NHS England were seeking advice on the following points: 1. Are there any concerns or risks regarding the submitted agenda pack that haven't been identified or mitigated. 2. The best approach for NHS England to be transparent with NHS Wales data. 3. The best approach for further disseminating and socialising the request from NHS Wales. **Outcome of discussion:** AGD welcomed the briefing paper and made the following observations / comments: **In response to points 1 to 3:** **5.2.1** AGD raised a number of points / queries in respect of the different opt-out policies in England and Wales, and discussed a number of scenarios that might occur as a result of this, for example, an individual located in Wales that attended a doctor / hospital located in England, and what opt-outs would be applied. **5.2.2** In addition, it was noted that depending on what opt-outs were applied, there may issues with data mismatch, or there may be instances where data could not be matched due to a previous application of an opt-out. **5.2.3** AGD queried whether the National Data Opt-out (NDO) in England could be applied for everyone, however noted that this may also cause some issues since it was imposing an English policy on Wales. AGD suggested that the best approach would be for NHS Wales to be transparent with regard to what was happening.

	5.2.4 It was suggested by the Group that NHS England explore the issues raised on opt-outs further, and update the briefing paper / supporting documents, as may be required, to reflect the correct information. **5.2.5** AGD queried the mechanics of how the data had been requested; and suggested that NHS England ensure there is a clear paper / audit trail, including, but not limited to, a clear and direct written request by DHCW for NHS England to collect and disseminate the data, with clarification of the objective for processing and purposes for using the data. **5.2.6** Noting that the TARN registry was previously managed by the University of Manchester, it was suggested by AGD that for transparency, the University of Manchester ensure that their website was updated with a re-direct to the relevant NHS England webpage. **5.2.7** In addition, the Group suggested that NHS England ensure that their webpage and any related transparency materials were updated with the current / most up to date information of TARN / NMTR. **5.2.8** AGD also suggested that for transparency, DHCW ensure that their webpages were also updated to reflect the current information on the NMTR. **5.2.9** AGD noted the references to *"anonymous"* and *"anonymised"* data in the transparency materials with regard to research; and suggested that these were reviewed and updated as may be required, noting that these descriptions could be restrictive; and to also ensure that it was clear to a lay audience. **5.2.10** AGD suggested that further support on the points raised above in respect of the opt-outs and transparency could be supported by patient and public involvement and engagement (PPIE). **5.2.11** In addition, it was noted that the networks / groups used for PPIE appeared to have little involvement from patient representatives; and suggested that this was explored further, to ensure there was more engagement with patient representatives moving forward. It was also suggested that further work was done to determine what PPIE was previously undertaken with the TARN registry, and that any good practices were replicated. **5.2.12** AGD looked forward to receiving the finalised briefing paper, either out of committee (OOC) or tabled at a future meeting.	
6 EXTERNAL DATA DISSEMINATION REQUESTS:		
6.1	**Reference Number:** NIC-617755-B4F1L-v0.7 **Applicant:** East Sussex County Council **Application Title:** Access to Civil Registration Deaths – Local Authority Collaborative Suicide Prevention Strategy **Observer:** Ben Cromack **Application:** This was a new application.	

	The purpose of the application is for Local Authority Teams at East Sussex County Council, Brighton and Hove City Council and West Sussex County Council to work collaboratively on a suicide prevention strategy; to understand and monitor the situation in Sussex, identify trends and further insights that will inform work to reduce the risk of suicide in the population. NHS England were seeking advice on the following points: 1. Review of the application as a first of type variant from the standard template Local Authority Primary Care Mortality Database (PCMD) Data Sharing Agreements. 2. Consideration of this request establishing a reusable decision for applications of this type. 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 standalone application. The majority of the group were supportive of establishing this as a reuseable decision for standalone DSAs, a minority of the group were not supportive due to the expectations of the public in local authority areas. The Group wished to draw to the attention of the SIRO the following substantive comments: **6.1.1** AGD noted that they had only been provided with limited documentation and noted that they would be providing observations based on these documents only. **In response to points 1 and 2:** **6.1.2** AGD suggested that the application and any relevant supporting documentation, was updated to clarify which limb of Regulation 3 of the Health Service (Control of Patient Information) Regulations 2002 (COPI) was applicable. **6.1.3** AGD noted that Regulation 3 of the COPI legal basis was for the purpose of *"Communicable disease and other risks to public health";* and queried how all of the listed purposes of processing, as currently described, were to diagnose, recognise trends or control and prevent the spread of such risks to public health. The Group suggested that the application and any relevant supporting documentation were updated to ensure that the language used aligned with the relevant limb (once clarified), including how the proposed processing was to address a risk to public health. **6.1.4** AGD noted that section 5(a) (Objective for Processing) of the application states *"The Caldicott Guardian/Clinical Director is a **health professional** and acts as a guardian responsible for safeguarding the confidentiality of patient information"*; however suggested that this was updated to note that this was in-line with the specific requirement of Regulation 7(2) of COPI.	

	6.1.5 AGD noted the references in the application to *"Accidental deaths" and" accident prevention"* , and observed that the application was in relation to suicide not accidental deaths. AGD asked for further clarification of this aspect of the work, given that it may not be covered by Regulation 3. **6.1.6** AGD also noted that in some cases the coroner may not list a death as suicide and that these accidental / preventable deaths may be in a "grey area" and therefore suggested that this was clarified in the application and the internal Data Access Service (DAS) Escalation Form and whether this work fell under Regulation 3 of COPI, and if so how. **6.1.7** AGD noted that they were supportive of this collaborative work being undertaken under a standalone data sharing agreement (DSA) (rather than added to an existing DSA), particularly where Regulation 3 is cited as the legal basis and there is joint data controllership. **6.1.8** AGD were supportive of other organisations working collaboratively on a suicide prevention strategy; however it was noted that NHS England should make them aware of Regulation 7(2) of COPI in respect of the specific role of a health professional. **6.1.9** In addition, it was suggested by AGD, that there should be a clear relationship between the collaborators and why they are collaborating, for example, they are all in the same geographical region. **6.1.10** The Group suggested that NHS England consider an AGD review for all applications where there are collaborations **and** COPI was being relied on as the legal basis for processing. In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review: **6.1.11** AGD queried whether it would be obvious to citizens within the various regions, that data was being accessed / processed by other Local Authorities, and suggested that East Sussex County Council, Brighton and Hove City Council and West Sussex County Council, as a priority, update their published privacy notices to make this clear. **6.1.12** AGD suggested that more granular, focussed patient and public involvement and engagement (PPIE) was undertaken, to explore a number of points, including, but not limited to, the use of the data to aid the dissemination; and how the analysis of the data many benefit local communities and / or nationally. **6.1.13** AGD noted the expected benefits in section 5(d) (Benefits) of the application; and suggested that these were reviewed and updated as may be necessary in line with NHS England DAS Standard for Expected Measurable Benefits, to reflect the specific work under this application; and to also ensure that the inclusion of the templated wording in its entirety in this section was correct and appropriate	

	(including because any Annual Confirmation Report or revised DSA would need to update progress against all of the expected benefits). **6.1.14** AGD noted the UK General Data Protection Regulation (UK GDPR) legal basis cited in section 3(b) (Additional Data Access Requested) of the application, for Civil Registrations of Death dataset; and were advised by the AGD NHS England Data Protection Office (DPO) representative that although UK GDPR does **not** apply to deceased individuals, it does apply to their spouses. AGD noted that this information was not currently reflected on the NHS England Civil Registrations of Death dataset webpage, and suggested that this was reviewed by the AGD NHS England DPO representative, and updated as may be required. Also, the Civil Registration of Deaths Dataset does not appear in the register of processing activities. **ACTION**: The AGD NHS England DPO representative to review the transparency information on the NHS England Civil Registrations of Death dataset webpage, and update as may be required to reflect that UK GDPR does apply to spouses of the deceased.	DPO Rep
6.2	**Reference Number:** NIC-411795-X5N2V-v1.3 **Applicant:** Our Future Health (OFH) **Application Title:** Our Future Health Outcomes TRE Data Linkage Application with Sublicensing **Observer:** Abigail Lucas **Previous Reviews:** The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 7th September 2023 and the 13th July 2023. The application and relevant supporting documents were previously presented / discussed at the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) meeting on the 22nd September 2022. **Linked applications:** This application is linked to NIC-414067-K8R6J. **Application:** This was an amendment application. The purpose of the application is for the addition of the United States of America (USA), Japan and Canada as countries from which the OFH Trusted Research Environment (TRE) can be accessed. NHS England were seeking advice on the following points: 1. Are the assurances in this application sufficient to create a precedent / reuseable decision. 2. Whether OFH have the technical ability to restrict access to these countries, and what audit measures OFH have in place.	

	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 application and wished to draw to the attention of the SIRO the following comments: **6.2.1** AGD noted that they had only been provided with limited documentation and noted that they would be providing observations based on these documents only. **In response to point 1:** **6.2.2** AGD advised that they were supportive of NHS England creating a precedent / reuseable decision. **6.2.3** AGD noted the 'exclusion criteria' for a reusable decision outlined in section 4.4 (Exclusion Criteria for Reusable Decision) of the internal Data Access Service (DAS) Escalation Form, and suggested that this was updated to also include applications where consent had been obtained from the cohort and the consent review indicated that such processing may not be within reasonable expectations, noting that this may require advice from AGD. **In response to point 2:** **6.2.4** The Group noted that they were broadly supportive of the technical ability OFH have in place. However, it was queried whether TRE access logs captured location data and, if so, how often these logs are reviewed. It was also queried whether there is a technical control to ensure access was restricted to the USA, Japan and Canada. **6.2.5** AGD noted the response in the internal DAS Escalation Form from OFH regarding the identifiability of genomic data and that OFH wished to balance the need to minimise data with participant expectations that genomic information about them would be used in research. AGD noted the consent to share de-identified data, and suggested that OFH ensure that the wording around genomic data emphasised its alignment with the consent taken.	
6.3	**Reference Number:** NIC-661406-H4V1B-v0.4 **Applicant:** University College London Hospitals NHS Foundation Trust **Application Title:** MAPS: Mental Health Admissions to Paediatric Wards Study **Observer:** Dan Goodwin **Application:** This was a new application. The purpose of the application is for a research project, which aims to understand and improve the quality of care for children and young people (CYP) presenting with mental health (MH) crises and who are admitted to acute inpatient services. 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 application and wished to draw to the attention of the SIRO the following comments: **6.3.1** AGD noted that the applicant had obtained ethical support from the Health Research Authority Research Ethics Committee (HRA REC), however, noting that the data requested was pseudonymised and not identifiable; AGD suggested that the applicant make HRA REC aware of this. **6.3.2** AGD noted and commended the applicant on the excellent patient and public involvement and engagement (PPIE) undertaken to date, but suggested that the PPIE group were updated on the status of the data requested, and that this was now pseudonymised and not identifiable. **6.3.3** The NHS England SIRO representative queried whether the Civil Registrations date of death data would be the full date or a partial date. AGD advised that if the applicant only needed month and year, flowing full date of death would need a justification. **6.3.4** AGD noted the statement in section 7.1 (Datasets) of the DAS internal application assessment form that *"Data is held at UCL and **will be accessed remotely**"* and the statement in section 5(b) (Processing Activities) of the application that *"**The Data will be accessed onsite** at the premises of UCL only"*; and suggested that the statements were revised and aligned, to ensure the correct information was reflected. **6.3.5** AGD queried the statement in section 3.4 (Data Subjects) of the DAS internal application assessment form that filtering / minimisation of the Mental Health Services Data Set (MHSDS) was a *"labour-intensive task"* and NHS England were therefore not able to carry out data minimisation in this instance. The Group suggested that NHS England satisfy itself that sufficient data minimisation had been undertaken, in line with NHS England DAS standard for data minimisation. **6.3.6** AGD noted that reference in the DAS Escalation Form and the application to a number of *"co-investigators"* and that no data would be shared with the organisations of the co-investigators. The Group noted that the co-investigators not handling the data, was not determinative of data controllership or their responsibilities as a Data Controller; and suggested that NHS England explore this further with the applicant, to seek assurance that these individuals were **not** responsible for determining the purpose and means of processing, and were therefore **not** carrying out any data controllership activities, in line with the NHS England's DARS Standard for Data Controllers. **6.3.7** AGD noted the outputs and benefits in the application, and queried whether the researchers required additional data for the cohort, beyond their 18th birthday in order to complete the cycle. The Group advised that they would be supportive of any additional data flows of data for this purpose if the relevant approvals were in place, and suggested that a further review by the Group would **not** be required for this.	

	6.3.8 AGD noted the reference in section 5(d) (Benefits) of the application to *"clients"*; and suggested that this was removed / updated as may be appropriate, noting that this reference was incorrect / not relevant. **6.3.9** AGD noted in the internal DAS application assessment form, that the applicant had considered accessing the data in NHS England's Secure Data Environment (SDE), however had opted for an extract instead, due to issues with the ongoing commitment to continuous invoices once the funding had expired. The Group suggested that NHS England continue to explore all avenues / barriers to applicants accessing the SDE and how they can support this, including, but not limited to, the timing and mechanics of payment, and acknowledging the transitional cost of asking users to use / pay for the SDE when they have may have already invested in their own internal systems. **ACTION:** NHS England Data and Analytics Representative explore all avenues / barriers to applicants accessing the SDE and how they can support this.	D&A Rep
6.4	**Reference Number:** NIC-742629-H5M4F-v0.2 **Applicant:** London Ambulance Service NHS Trust **Application Title:** London Ambulance Service NHS Trust – Service and Evaluation/Auditing purpose **Observer:** Sara Lubbock and Tom Wright **Application:** This was a new application. The purpose of the application is to use linked outcome data to analyse patterns, which will aim to inform development needs and best practice identification. The provision of linked data will allow ambulance service clinicians to continue to build on their confidence, competence, and knowledge to improve the delivery of care to patients through the understanding of the impact of their own clinical practice on the patient outcomes through the clinical supervision process. 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 templated application under a precedent approach, but were **not** supportive of this standalone application at this time as not all the necessary information was available to make a full assessment. The Group wished to draw to the attention of the SIRO the following significant comments: **6.4.1** AGD noted that the majority of the Group had reviewed the application and supporting documents based on the information in section 3(c) (Patient Objections) of the application, that stated *"In line with the national data opt-out (NDO) policy, opt-outs are **not** applied because the data is not Confidential Patient Information…"*	

	being an error. The Group suggested that NHS review this carefully, noting **1)** the special condition in section 6 (Special Conditions) that of the application that refers to the NDO being applied; **2)** the information in the special condition that refers to the NDO being applied under previous versions of the application, **3)** the special condition stating that *"the data released without national data opt-out being applied may only be used for the purposes of the Clinical Audit and not in relation to research or any other purpose"*; and **4)** the Health Research Authority Confidentiality Advisory Group (HRA CAG) support stating that opt-outs should be applied. It was suggested that the application and DAS internal application assessment form were updated to reflect the correct information. **6.4.2** In addition, AGD noted that HRA CAG had reviewed and approved the revised privacy notice, but advised that it was still unclear if the opt-out referred was the NDO or a local opt-out, or both, noting that HRA CAG had asked that both opt-outs were offered. It was suggested that in addition to the points raised in 6.4.1, further clarification was provided on this point in the application and the internal DAS internal application assessment form. **6.4.3** AGD noted the references in section 5(a) (Objective for Processing) and section 5(d) (Benefits) of the application to *"benchmarking clinician activity"*; and noted a number of concerns with this, including, but not limited to **1)** if the data is confidential, does the Common Law Duty of Confidentiality apply; **2)** the HRA CAG support would not cover this data as it only applies to 'patient' confidential data; **3)** is the benchmarking covered by employment policies, for example, have the relevant Trade Unions been consulted and are the Clinicians supportive; and, **4)** is the data requested adequate for the processing outlined and are they able to meet their objective for processing. In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review: **6.4.4** AGD queried the statement in section 5(a) (Objective for Processing) of the application that NHS Arden and Greater East Midlands Commissioning Support Unit (AGEM) *"…**acting under instruction of NHS England**"*; and suggested that this was removed as it was incorrect. **6.4.5** The NHS England SIRO representative noted the information in section 5 (Purpose / Methods / Outputs) of the application, on the role of AGEM in respect of other datasets not relevant to the processing, for example, the Emergency Care Data Set (ECDS); and suggested that this was reviewed and updated / removed as may be appropriate. **6.4.6** The NHS England SIRO representative noted the reference in section 5 to AGEM being a Data Processor, and suggested that this was updated to reflect that they were a Data Processor for the London Ambulance Service NHS Trust for this application **only**.	

	6.4.7 AGD noted the wide ranging statements in section 5(a) of the application to *"operational practices and systems"*; and suggested that the application was updated to reflect that this related to London Ambulance Service NHS Trust and not, for example, GPs.	
6.5	**Reference Number:** NIC-334745-L4J6P-v2.2 **Applicant:** University Hospital Southampton NHS Foundation Trust **Application Title:** Risk Of Aneurysm Rupture Study (ROAR) **Observer:** James Watts **Previous Reviews:** The application and relevant supporting documents were previously presented / discussed at the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) meeting on the 1st December 2022. **Application:** This was an amendment application. The amendments are **1)** the addition of the following datasets: Demographics dataset, Maternity Services Dataset v1.5, Maternity Services Dataset v2; and **2)** to increase the cohort size search increase from 8,000 to 20,000 patients. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** The Group (with one AGD independent member dissenting) were supportive of the application and wished to draw to the attention of the SIRO the following substantive comment: **6.5.1** AGD noted the number of fields requested in the Demographics data, as outlined in section 3(b) (Additional Data Access Requested) of the application; and noted that it was unclear why this volume of data had been requested, noting that the only information required from this dataset, was to confirm the correct patient linkage. AGD suggested that NHS England satisfies itself that the Demographics data was minimised to what is necessary in relation to the relevant purpose, in line with the NHS England DAS standard for data minimisation and that clarification of this was noted in the internal Data Access Service (DAS) Escalation Form and the application. In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review: **6.5.2** AGD noted the paragraph in section 5(a) (Objective for Processing) of the application that starts *"The level of the Data will be identifiable…"*; and queried whether this information was relevant, or had been incorrectly copied over from another application; and suggested that this was reviewed and updated / removed as may be appropriate. **6.5.3** AGD noted that reference in the DAS Escalation Form to the University of Oxford Statistician working in an *"…advisory capacity only…"* and that no data would	

	be shared with the University of Oxford. The Group noted that the individual not handling the data, was not determinative of data controllership or their responsibilities as a Data Controller; and suggested that NHS England explore this further with the applicant, to seek assurance that this individual was **not** responsible for determining the purpose and means of processing, and are therefore **not** carrying out any data controllership activities, in line with the NHS England's DARS Standard for Data Controllers. **6.5.4** The AGD NHS England Caldicott Guardian Team representative noted his support for the work outlined in the application, noting the lack of research in this area. **6.5.5** The NHS England SIRO representative requested a further review of this application prior to it proceeding further by NHS England's DAS, to clarify how the points raised by AGD had been addressed.	
7 INTERNAL DATA DISSEMINATION REQUESTS:		
There were no items discussed		
8 EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL		
There were no items discussed		
9 OVERSIGHT AND ASSURANCE		
There were no items discussed		
10	**Introduction into how technology / Artificial Intelligence can be used to support the NHS England application process (Presenters: Laura Bellingham / Annie Shah / Oliver Wickens)** The AGD Chair welcomed representatives from Accenture to the meeting, who were in attendance with NHS England colleagues to provide a general overview to the Group on a proposed artificial intelligence (AI) enabled process that could support requesters of NHS England data to submit a data sharing agreement (DSA) request that is accurate and speeds up data access. This scoping work had been carried out on a pro bono basis. It was noted that at the current time, NHS England were currently only exploring what the possibilities were in terms of how technology could be used to support requesters of data; and there were ongoing discussions on this both internally within NHS England and with users of NHS England data. The Group thanked Accenture for attending the meeting, and for the information provided. Following the departure from the meeting of Accenture, AGD noted that some members were broadly supportive of the AI concept, and provided a number of comments direct to NHS England, including, but not limited to, consideration of whether an update to the Data Uses Register could be incorporated into this programme of work; how the previous IGARD / AGD	

	minutes could be incorporated into the online form and addressed; the applicant's level of knowledge / understanding of the DSA noting the involvement of technology outlined; and, the level of knowledge / understanding of NHS England staff of the DSA's noting the involvement of technology outlined and any training. The Group noted that they would welcome further information / discussion on this subject, as and when appropriate.	
11 AGD OPERATIONS		
11.1	**Risk Management Framework** As last noted in the AGD minutes from the 21st March 2024, the independent members noted the reference to reviewing materials in accordance with *"a clearly understood risk management framework"* within the published Statutory Guidance and advised that they were not aware of an agreed risk management framework, and reiterated a previous request that NHS England provide further information/ clarity on this to the Group, 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. 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 AGD (and previously 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 AGD for advice; however the independent members noted that the wording in the statutory guidance "…*using a clearly understood risk management framework, precedent approaches and standards that requests must meet*…", 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 plans for this work were in train. It had been noted previously by the interim data advisory group that the Oversight and Assurance Programme of applications that had not be subject to AGD review could form part of this Risk Management Framework. The NHS England 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. **ACTION:** The NHS England SIRO Representative to provide a written response to AGD on the risk management framework.	SIRO Rep
11.2	**AGD Standard Operating Procedures (SOPs) (Presenter: Vicki Williams)** 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.
11.3	**AGD Stakeholder Engagement** The AGD Chair noted to the Group that she had met 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 11th June 2024, as part of their regular engagement.
11.4	**AGD Project Work** *There were no items discussed*
12 Any Other Business	
12.1	*There were no items discussed*
Meeting Closure As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.	