# Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 27th June 2024

09:00 – 16:05

*(Remote meeting via videoconference)*

| **AGD INDEPENDENT / NHS ENGLAND MEMBERS IN ATTENDANCE:** | |
|---|---|
| **Name:** | **Role:** |
| Paul Affleck (PA) | AGD independent member (Specialist Ethics Adviser) |
| Claire Delaney-Pope (CDP) | AGD independent member (Specialist Information Governance Adviser) |
| 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) |
| **NHS ENGLAND STAFF IN ATTENDANCE:** | |
| **Name:** | **Role / Area:** |
| Laura Bellingham (LB) | Deputy Director, Data Access and Partnerships, Data and Analytics (**Observer:** item 5.1) |
| Garry Coleman (GC) | NHS England SIRO Representative (**not** in attendance for items 1, 2, 3, 4, part of 6.1 and part of 5.1) |
| Ben Cromack (BC) | Data Access and Partnerships, Data and Analytics (**Observer**: item 10) |
| Louise Dunn (LD) | Internal & System Data Flows Lead, Data Portfolio Management, Data and Analytics (**Presenter:** item 10) |
| Elaine Fletcher (EF) | NHS England Legal Team, Chief Delivery Officer Directorate (**Presenter**: item 10) |

| | |
|---|---|
| Dan Goodwin (DG) | Data Access and Partnerships, Data and Analytics (**Observer**: items 6.5 to 6.6) |
| James Murphy (JM) | Deputy Director of GIRFT Academy, Getting It Right First Time (GIRFT), NHS England (**Presenter**: item 5.1) |
| Jodie Taylor-Brown (JTB) | Data Access and Partnerships, Data and Analytics (**Observer**: items 6.1 to 6.3) |
| James Watts (JW) | Data Access and Partnerships, Data and Analytics (**Observer**: item 6.4) |
| 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:** |
| 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) |
| Miranda Winram (MW) | AGD independent member (Lay Adviser) |
| **ROYAL NATIONAL ORTHOPAEDIC HOSPITAL NHS TRUST STAFF IN ATTENDANCE (ITEM 5.1)** | |
| Julian Johnson (JJ) | Commercial Director, GIRFT Projects Directorate, Royal National Orthopaedic Hospital NHS Trust (**Presenter**: item 5.1) |

| | |
|---|---|
| **1** | **Welcome and Introductions:**<br>The AGD meeting Chair welcomed attendees to the meeting. |
| **2** | **Review of previous AGD minutes:**<br>The minutes of the AGD meeting on the 20th June 2024 were reviewed and, after several minor amendments, were agreed as an accurate record of the meeting. |
| **3** | **Declaration of interests:** |

| | |
|---|---|
| | There were no declarations of interest. |
| **4** | **AGD Action Log:**<br>*The action log was not discussed.* |
| **5 BRIEFING PAPER(S) / DIRECTIONS:** | |
| **5.1** | **Title:** Advice on the arrangement for data sharing relationship between NHS England and Royal National Orthopaedic Hospital (RNOH) – Briefing Paper<br>**Presenters:** Julian Johnson and James Murphy<br>**Observer:** Laura Bellingham<br>The AGD Chair welcomed Julian Johnson from the RHOH, James Murphy and Laura Bellingham who were in attendance to seek advice on the arrangement for data sharing relationship between NHS England and the RNOH.<br>The Getting it Right First Time (GIRFT) Programme is an improvement programme that was conceived by the Royal National Orthopaedic Hospital (RNOH) in 2008 and ultimately transferred to NHS England in 2021.<br>Upon transfer of the GIRFT programme to NHS England it was agreed that RNOH would continue to develop and deliver additional GIRFT related services through a 'GIRFT extension programme' in close collaboration with NHS England. This would enable RNOH to continue providing *ad hoc* GIRFT review services for NHS providers in England and other providers (including independent sector and devolved administrations) that are outside the scope of NHS England's statutory responsibilities.<br>NHS England can see considerable public benefit in collaborating with RNOH in this way. However, to ensure consistency of GIRFT metric outputs, it is vital that all GIRFT branded metrics are calculated in exactly the same way from the same source dataset used for the NHS England GIRFT programme. In order to facilitate this, NHS England needs to: **1)** share its GIRFT dataset and provide RNOH with access to the GIRFT coding recipes in the NHS England UDAL data environment; and **2)** enable receipt and processing of RNOH client data within UDAL for processing so that outputs can be compared accurately against GIRFT metrics for NHS providers (client data will not be linked to NHS data). This will include processing private patient data for independent sector providers that also provide significant NHS services.<br>NHS England were seeking advice on the following points:<br>1. Whether the proposed data sharing approach represents the simplest way to arrange the relationship between NHS England and RNOH, enabling processing of RNOH GIRFT client acute services data (NHS and private patients) in UDAL; and,<br>2. If not, how best the arrangement be streamlined to provide the most efficient and sustainable solution for this collaboration. |

| | |
|---|---|
| | **Outcome of discussion**: The Group thanked Julian Johnson for attending the meeting, and for the information provided, recognising the importance of what GIRFT were trying to achieve.<br><br>Following the departure from the meeting by Julian, and noting the NHS England SIRO Representative was **not** in-meeting to receive the advice from AGD, the Group made the following observations / comments:<br><br>**In response to points 1 and 2**:<br><br>**5.1.1** The Group noted that the key issue was how the parties allocated the Data Controller / Data Processor roles in line with the UK General Data Protection Regulation (UK GDPR) and the NHS England DARS Standard for Data Controllers and NHS England DARS Standard for Data Processors, and borne of the facts, for example it may be a joint Data Controllership arrangement, or a Data Controller / Data Processor arrangement. The Group noted that colleagues had engaged with legacy NHS England's information governance team and legal team previously on a number of topics, however the AGD NHS DPO Representative suggested that the Data Controller / Data Processor relationship aspect be discussed again with NHS England's IG and Legal teams. The AGD Chair supported this suggestion.<br><br>**5.1.2** The Group had concerns around the potential commercial exclusivity of the approach, noting that other organisations were looking to do work in this area, separate to GIRFT. The Group cautioned the Unified Data Access Layer (UDAL) being used exclusively for private work by one organisation.<br><br>**5.1.3** The Group queried what transparency materials would be available for data subjects.<br><br>**5.1.4** AGD suggested that NHS England may wish to bring early versions of data sharing agreements (DSAs) for advice in general, or specific advice points, to future meetings of AGD. |
| **5.2** | **Title:** IG10154 Outcomes Registers and Trauma Registry / DPIA approval<br><br>**Previous Reviews:** The briefing paper and relevant supporting documents were previously presented / discussed at the AGD meeting on the 14th September 2023.<br><br>The Outcomes and Registries Directions 2023 is to require NHS England to collect and analyse information from across both the NHS and the private sector for the purposes of improving clinical safety and patient outcomes, reducing variation in clinical practice, and also to support the government response to the recommendations of the Independent Medicines and Medical Devices Safety Review and the Paterson Inquiry.<br><br>The purpose of the briefing paper had been to seek advice from AGD on the approach under the new Directions to consolidate approved outcomes and registries collections under one Direction.<br><br>**Outcome of discussion:** AGD welcomed the finalised briefing paper and confirmed that they had no further substantive comments. The briefing paper was therefore finalised as an artefact to be included as a supporting document, as and when required. |

| | |
|---|---|
| | AGD provided the following observations / comments, separate to the finalised briefing paper:<br><br>**5.2.1** AGD suggested, as a process point, that all DPIAs should have the relevant link(s) to the Direction(s) covered.<br><br>**5.2.2** AGD also suggested, as a process point, that there should be specific analysis in the DPIA of the relevant Direction(s). |
| **5.3** | **Title:** Secondary Care ePMA Data Collection 2023<br><br>**Previous Reviews:** The briefing paper and relevant supporting documents were previously presented / discussed at the AGD meeting on the 30th March 2023.<br><br>The paper provided to the group, provided details of the proposal to collect patient-level (identifiable) data for medicines prescribed and administered to patients by secondary care providers in England, when this is recorded on electronic Prescribing and Medicines Administration (ePMA) systems. NHS England aim to make the data comparable and make it available for analysis purposes to organisations with a lawful basis.<br><br>**Outcome of discussion:** AGD welcomed the finalised briefing paper and confirmed that they had no further observations / comments. The briefing paper was therefore finalised as an artefact to be included as a supporting document, as and when required. |
| **6 EXTERNAL DATA DISSEMINATION REQUESTS:** | |
| **6.1** | **Reference Number:** NIC-147922-T7W2F-v1.21<br><br>**Applicant:** University College London<br><br>**Application Title:** Centre for Longitudinal Studies- National Child Development Study 1958 (NCDS)<br><br>**Observer:** Jodie Taylor-Brown<br><br>**Linked applications:** This application is linked to NIC-431565-K9V9N, NIC-17218-B0W9X, and NIC-147860-0RSHN<br><br>**Application:** This was a new application.<br><br>The purpose of this new application is to **1)** update participant details on The Centre for Longitudinal Studies (CLS) database; **2)** understand the Mortality outcomes of the National Child Development Study (NCDS) cohort and investigate how individual behaviours and social or economic determinations of health behaviours such as drug and alcohol use, sexual health, diet and exercise; **3)** support further research within the CLS; and **4)** support further research outside the CLS.<br><br>NHS England were seeking advice on the following point:<br><br>1. Request for a change not covered by existing reusable (precedent) decision: This is an amendment required to the 4 UCL Centre for Longitudinal studies DSAs. The proposal is to seek approval for this application and then seek a reusable decision that can be applied to the three other studies: NIC-431565- |

K9V9N – Next Steps study, NIC-17218-B0W9X- 1970 British Cohort Study, and NIC-147860-0RSHN- Millenium cohort study

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

**Outcome of discussion:** the Group were broadly supportive of the processing outlined in the application, but were **not** supportive of the application **at this time** and wished to draw to the attention of the SIRO the following significant comments, and suggested that the application be brought back to a future meeting

AGD noted that they had only been provided with limited documentation and noted that they would be providing observations based on these documents only.

**6.1.1** AGD noted that they had discussed NIC-49826-T0J7C-v5.2 University College London (which was linked to: NIC-51342-V1M5W, NIC-49297-Q7G1Q and NIC-384504-N2V5B) on the 9th May 2024.

**6.1.2** Noting that the suite of longitudinal studies had been subject to a number of reviews by the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) and AGD; it was suggested by AGD, that a careful review was undertaken on the previous points raised; and that for future reference, it was clearly noted in the internal DAS escalation form, or separate supporting document, how each point had been addressed. Some of the studies had had significant points raised during previous reviews and it was not apparent whether those issues had been addressed. Furthermore, some of the studies may have been identified as not suitable for precedent route in the future and should have been considered for a full review by AGD. The Group therefore expressed the view that while they were happy to give advice on the specific point as noted above, they were not offering their support for all aspects of every application and would expect each of the applications to undergo a thorough review and independent oversight in the future.

**6.1.3** AGD noted that at the 9th May 2024 meeting with regard to NIC-49826-T0J7C-v5.2 University College London (which was linked to: NIC-51342-V1M5W, NIC-49297-Q7G1Q and NIC-384504-N2V5B) they had **not** been provided with an update on how each of those points had been addressed, and prior to consideration of this application, and therefore felt they did **not** have all the necessary information available to make a full assessment for this application.

**In response to point 1**:

**6.1.4** AGD noted that the advice provided on this application in relation to point 1, **could not** be used as a 'reusable decision' to be applied to the other three linked studies / applications (NIC-431565-K9V9N, NIC-17218-B0W9X, and NIC-147860-0RSHN)

**6.1.5** AGD had a lengthy discussion with regard to transparency and the mechanism to withdraw from the study. The Group were concerned that there was a risk that the applicant was **not** respecting the autonomy of the cohort members since the

| | | |
|---|---|---|
| | presumption seemed to be that a withdrawal from the study only covered withdrawal from follow up if the individual explicitly said so. AGD suggested the applicant consider using a withdrawal form detailing the various withdrawal options and link to the privacy notice on their website and relevant participant materials.<br><br>**6.1.6** AGD noted that the Health Research Authority (HRA) Research Ethics Committee (REC) had reviewed documentation provided by the applicant, however it was unclear what documentation they had reviewed and if the same documentation had been provided to AGD as part of this review. AGD thought there was a potential ethical concern whether the autonomy of data subjects was being respected.<br><br>**6.1.7** The Group noted this was health data, not just admin data or contact data, noting SD4 provided as a support document, and other information on the study website clearly states to participants that their permission is needed to add information from NHS health records that "*we will only obtain this information with your permission*". The Group therefore suggested that NHS England should assure itself that relevant permissions were in place to access the health records of everyone to be included in the cohort, and noting the applicant had HRA Confidentiality Advisory Group (CAG) support, suggested the applicant provide relevant evidence that HRA CAG noted that s251 covered those that had **not** given their permission for additional information from health records; or, if it was unclear, to contact HRA CAG to confirm if the s251 support extends to those that had **not** given permission. It was noted that data subjects may be happy to be part of the study however, some had **not** given permission for health records to be accessed, and it was unclear from the documentation provided if the applicant was only accessing the data for those that had given specific permission to access their health records.<br><br>**6.1.8** The Group also noted that the applicant intended to hold onto contact details for those that had withdrawn their consent, and noted that there was a risk of overprocessing if continuing to hold contact details just for the purpose of ensuring they did not contact them again, and suggested the applicant reconsider this point or provide further justification.<br><br>**6.1.9** AGD were unclear how the applicant would know whether or not anyone had accessed the data from outside of the UK and suggested, for example, the applicant consider proactive auditing, rather than only investigating if concerns were raised. The Group noted there is currently **no** technical control to stop access from outside of the UK, but noted that if technical security assurances were not the same as NHS England's secure data environment (SDE) model that there is proactive monitoring of access in place.<br><br>**6.1.10 Separate to the application:** Noting there were a number of SDEs having different approaches to managing access, including from outside of the UK, the Group suggested that as such approaches move to more common standards, such standards should also apply to other SDEs / trusted research environments (TREs), including this request. | |

| | | |
|---|---|---|
| **6.2** | **Reference Number:** NIC-431736-X6C4F-v0.11<br><br>**Applicant:** Kingston University<br><br>**Application Title:** SkillMix-ED Study (Phase Two)<br><br>**Observer:** Jodie Taylor-Brown<br><br>**Previous Reviews:** The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 24th August 2023.<br><br>**Application:** This was a new application.<br><br>The purpose of the application was for a research project to explore how non-medical practitioners, as part of the clinical workforce, are being deployed; and the impact of different skill-mix including non-medical practitioners in emergency departments and urgent treatment centres on patient experience, quality of care, clinical outcomes, activity, staff experience and costs in acute NHS trusts in England, in order to inform workforce decisions of clinicians, managers and commissioners.<br><br>Should an application be approved by NHS England, further details would be made available within the Data Uses Register.<br><br>**Outcome of discussion:** AGD were supportive of the application and wished to draw to the attention of the SIRO the following comments:<br><br>**6.2.1** The Group acknowledged the work undertaken by NHS England Data Access Service (DAS) to address the previous points raised on the 24th August 2023 and were broadly content with the responses provided with the exception of point 5.4.5 "*Noting that this was a National Institute for Health & Care Research (NIHR) funded project and the group would not usually comment on the benefits section of a DSA, the independent advisers suggested that the applicant may wish to consider the issue of 'causality' and suggested seeking further advice from their steering group / advisory panel on this point, and updating section 5(d) (Benefits) of the application, as appropriate*." The commitment to further consider the issue of causality was appreciated by the Group, given the importance of distinguishing causality from correlation.<br><br>**6.2.2** The Group noted that work on the applicant's privacy notice was ongoing, and suggested that since the privacy notice appeared to be still in draft that the applicant consider updating further to clearly articulate the UK General Data Protection Regulation (UK GDPR) legal basis for article 6 and relevant condition under Article 9.<br><br>**6.2.3** The Group noted that the applicant had referred to having a 'legitimate interest' in their draft privacy notice, and noting that it is unusual for a university to cite legitimate interests as a legal basis, suggested that the applicant carefully review the legal basis cited prior to publication of the privacy notice. | |

| | | |
|---|---|---|
| | **6.2.4** In addition, noting this was a consented study, the Group suggested the draft privacy notice be further updated to reflect this.<br><br>**6.2.5** AGD noted the reference in section 5(d) (Benefits) of the application to *"clients"*; and suggested that this was removed. | |
| **6.3** | **Reference Number:** NIC-681645-M2G8X-v0.8<br><br>**Applicant:** Swansea University<br><br>**Application Title:** Predictive Risk Stratification Models: Assessment of Implementation Consequences (PRISMATIC 2)<br><br>**Observer:** Jodie Taylor-Brown<br><br>**Application:** This was a new application.<br><br>The purpose of the application is for Work Package 1 of the PRISMATIC 2 research project; which is to analyse aggregated routine anonymised data on emergency admissions, Emergency Department attendances and days spent in hospital and in Intensive Care Unit (ICU) at study site (CCG) level between 2010 and 2021, linked to the dates of introduction of predictive risk stratification.<br><br>Should an application be approved by NHS England, further details would be made available within the Data Uses Register.<br><br>**Outcome of discussion:** AGD were supportive of the application and wished to draw to the attention of the SIRO the following substantive comments:<br><br>**6.3.1** AGD noted the rigour and assistance provided by NHS England's Data Access Service (DAS) Team to the applicant with regard to data minimisation questions asked, but suggested that the onus was on the applicant to explain why they needed such a quantum of data (circa 150 million data records) and why they cannot undertake any further data minimisation, in line with the NHS England DARS Standard for Data Minimisation.<br><br>**6.3.2** AGD noted that the applicant had informed NHS England that they didn't need access to the NHS England Secure Data Environment (SDE) because they already had arrangements in place via the University's SePR UK trusted research environment, however due to the volume of data requested and lack of a clear robust justification around data minimisation, the Group suggested that the internal application assessment form was updated to consider the language used, given the direction of travel by NHS England to use SDEs which is **not** based on an applicant's preference.<br><br>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:<br><br>**6.3.3** AGD noted reference to focus groups and interviews with patients in section 5(a) (Objective for Processing) of the application and were supportive of the approach taken by the applicant, and suggested that the internal application | |

| | | |
|---|---|---|
| | assessment form be updated to reflect the factual scenario as outlined in section 5(a).<br><br>**6.3.4** The Group noted reference to "*Swansea University will analyse aggregated routine anonymised data on…*" in section 5(a) of the application and suggested this was updated to remove reference to "*aggregated*" so that it reflects the processing outlined elsewhere in the application.<br><br>**6.3.5** In addition, AGD queried the statement in section 5(a) *"…Access is restricted to employees **or agents** of Swansea University who have authorisation from the Chief Investigator…"* and suggested that either further information was provided as to who would be covered by "*agents*", and whether this aligned with the Data Sharing Framework Contract (DSFC); or that this was removed as may be necessary to reflect the facts.<br><br>**6.3.6 Separate to the application:** AGD suggested that NHS England Data & Analytics discuss with the Health Research Authority Research Ethics Committee (HRA REC) with regard to an agreed position around HRA REC review of research involving pseudonymised data, in order to support applicants.<br><br>**ACTION:** NHS England Data and Analytics Representative to speak to HRA REC with regard to an agreed position for REC review for research involving pseudonymised data. | D&A Rep |
| **6.4** | **Reference Number:** NIC-682567-L6Q5Q-v0.7<br><br>**Applicant:** Queen's University Belfast<br><br>**Application Title:** Age, sex, deprivation, and ethnicity-related under-treatment for lung cancer by Integrated Care System areas in England<br><br>**Observer:** James Watts<br><br>**Application:** This was a new application.<br><br>The purpose of the application is for a research project, which aims to **1)** further develop and test a causal inference method to measure under treatment robustly; **2)** to measure under-treatment in sub-groups of the population characterised by: sex, age, ethnicity, and socioeconomic deprivation; **3)** to measure variation in undertreatment in these sub-groups across Integrated Care Systems (ICSs); and **4)** to identify potential determinants of under-treatment by relating ICS (or hospital Trust) estimates of under-treatment to summary characteristics of the ICSs across the following domains: demographic, clinical, and cancer services.<br><br>Should an application be approved by NHS England, further details would be made available within the Data Uses Register.<br><br>**Outcome of discussion:** AGD were supportive of the application and wished to draw to the attention of the SIRO the following comments: | |

**6.4.1** The Group queried whether or not any preliminary work had been undertaken to ensure the quantum and quality of data requested by the applicant would generate the research outcomes outlined in the application. NHS England noted that due to timing and resource pressures within NHS England the application had been presented to AGD prior to the data fields in section 3(b) (Additional Data Access Requested) being analysed by a National Disease Registration Service (NDRS) Analyst. AGD noted the update and suggested that a careful review of the data requested be undertaken and before the data flows.

**6.4.2** The NHS England SIRO Representative queried the age range (15 to 99) and suggested that section 5 (Purpose / Methods / Outputs) be updated to be clear if the age range is capturing the data subjects at the age at diagnosis, or at some other key point.

**6.4.3** AGD noted in section 5(c) (Specific Outputs Expected) that the project team will engage with relevant stakeholders including "…*PPIE experts*…", and suggested that the applicant explain within section 5(c) if the patient and public involvement and engagement (PPIE) representatives were supportive, or more engaged in the research proposals. If there is no local PPIE / local population support, the Group suggested this was considered by the applicant. The HRA guidance on Public Involvement is a useful guide.

**6.4.4** The Group observed that this was a Northern Ireland University doing research on English data subjects, and suggested that the applicant carefully think how effective the reach is to those data subjects in England in terms of transparency. Noting the NHS England data uses register would publish section 5 of this application on the NHS England website, AGD suggested that the applicant consider how they could publicise more widely to English data subjects.

**6.4.5** AGD noted in section 1(b) (Data Controller(s)) of the application and the internal applicant assessment form, that the applicant's System Level Security Policy (SLSP) was currently "*pending approval by NHS England Cyber Security*"; and suggested that once the review was concluded, that the outcome was reflected in the application and internal application assessment form.

**6.4.6** In addition, AGD queried the statement in section 5(a) (Objective for Processing)*"…Access is restricted to employees* ***or agents*** *of Queen's University Belfast Centre for Public Health…"* and suggested that either further information was provided as to who would be covered by "*agents*", and whether this aligned with the Data Sharing Framework Contract (DSFC); or that this was removed as may be necessary to reflect the facts.

**6.4.7** The independent advisers queried the references in section 5(a) to students being *"affiliated"* with Queen's University Belfast; and suggested that these references were updated to refer to the students being *"enrolled"* (assuming this is factually correct. If they are not enrolled students at the University, then their status should be explained further).

| | | |
|---|---|---|
| | **6.4.8 Separate to this application:** noting that the word *"affiliated"* had been incorrectly used in other applications, it was suggested by the independent advisers that the NHS England Data and Analytics Representative remind DAS that this should only be used in an application if it is correct in context, i.e. for those with an association with an organisation but who are not substantially employed or enrolled, and then explained further. The aim should be to describe the relationship in the most specific sense possible.<br><br>**ACTION:** NHS England Data and Analytics Representative to remind DAS that the word *"affiliated"* should only be used in an application if correct in context; the aim should be to describe the relationship in the most specific sense possible.<br><br>**6.4.9** In addition AGD noted that any reference to students processing data was quantified to be clear that they are students of Queen's University Belfast, rather than students in general.<br><br>**6.4.10** AGD suggested reference in section 5(d)(ii) (Expected Measurable Benefits) to "*the primary analysis will describe the variation in undertreatment across the **UK**…* to *"England",* since the applicant was only received data for England from NHS England.<br><br>**6.4.11** The Group also suggested that on first use the term "*undertreatment*", in section 5, was explained for a lay reader, noting section 5 forms NHS England's data uses register. | D&A Rep |
| **6.5** | **Reference Number:** NIC-714765-G1P5S<br><br>**Applicant:** University of Oxford<br><br>**Application Title:** Waiting times in Emergency Departments: Inequalities and impact on health outcomes<br><br>**Observer:** Dan Goodwin<br><br>**Application:** This was a new application.<br><br>The purpose of the application is for a research project, which aims to answer the following questions: **1)** are there inequalities in Emergency Department (ED) waiting times by socioeconomic status, between and within hospitals, allowing for severity of the patient's presenting condition; **2)** do longer waits translate into worse patient health outcomes, by severity of condition? There is a further work package (WP2) in the overall project which will use qualitative research methods (and none of the data in this application) which seeks to answer; and **3)** are there differences in professional behaviour and organisational cultures in EDs that influence waiting times. Are these patterned by socioeconomic status and other patient characteristics.<br><br>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:<br><br>**6.5.1** The Group welcomed the application and noted the valuable research and outputs which may help tackle health inequalities.<br><br>**6.5.2** The Group noted concerns about whether the ethnicity fields in the Hospital Episode Statistics (HES) dataset were sufficient in terms of quality of data (accuracy) to achieve the aims of the analysis; and suggested that this was explored / clarified by NHS England. If the data was not of a sufficient standard, the Group advised that they would be supportive of the addition of an alternate dataset to the data sharing agreement (DSA) that provides the most relevant ethnicity information, with the relevant governance and justifications added to the application and internal application assessment form. However, if the applicant still wanted the data sets requested, AGD suggested that the applicant ensure any adjustments to outputs, for example, and to be careful around extrapolation.<br><br>**6.5.3** Noting that this concern as noted in 6.5.2 above had been raised a number of times by AGD and its predecessor the Independent Group Advising (NHS Digital) on the Release of Data (IGARD), the Group would be supportive of NHS England exploring what more could be done to improve the breadth and quality of the ethnicity data captured in the existing data collections.<br><br>**ACTION:** the AGD NHS England Data and Analytics Representative to explore what more can be done to improve the breadth and quality of ethnicity data captured in existing data collections.<br><br>**6.5.4** Noting that the HES datasets had been minimised to exclude "*all maternity related variables*" and "*all psychiatric related variables*" the Group, including the AGD NHS England Caldicott Guardian Team Representative who provided his clinical perspective, could not understand why these two groups had been excluded from the data requested and were not part of the research. AGD suggested that the applicant reconsider the exclusion of these two groups, or provide in section 5 (Purpose / Methods / Outputs) a robust justification for their removal from the research. The Group advised that they would be supportive of the addition of the maternity related variables and psychiatric related variables back into the HES datasets with the relevant governance and justifications added to the application and internal application assessment form.<br><br>**6.5.5** AGD noted referenced within section 5(b) to "*The data will not be linked with any other data. It will however be combined (for the individual) with freely available data such as the number of beds at the trust level…*" and suggested that the first sentence of that paragraph be removed.<br><br>**6.5.6** Noting reference in section 5(b) (Processing Activities) to the NHS England secure data environment (SDE), and as discussed on the 6th June 2024 (NIC-739822-Q8R6Y), the Group suggested that standard proforma text be developed for section 5 of relevant data sharing agreements (DSAs) that explained that the 'User | D&A Rep |

| | | |
|---|---|---|
| | Agreement' for those individuals accessing the data in NHS England's SDE covering off the key points including, but not limited to, specific user access and restrictions on exporting data.<br><br>**ACTION:** the AGD NHS England Data and Analytics Representative to speak to the DAS Team to develop proforma text.<br><br>**6.5.7** The Group applauded the applicant's excellent patient and public involvement and engagement (PPIE) which engages with the population and addresses the aims of the research. | D&A Rep |
| **6.6** | **Reference Number:** NIC-719601-J7Z2S-v0.9<br><br>**Applicant:** University of Hull<br><br>**Application Title:** Assessing Diabetes' Influence on Cardiovascular Health: A Machine Learning Analysis of NICOR Database Patients<br><br>**Observer:** Dan Goodwin<br><br>**Application:** This was a new application.<br><br>The purpose of the application is for a research project, which aims to use various machine learning algorithms to understand the Relative Influence (RI) of diabetes on survival, stent-stenosis, and recurrent myocardial infarction in people with cardiovascular disease.<br><br>Should an application be approved by NHS England, further details would be made available within the Data Uses Register.<br><br>**Outcome of discussion:** AGD were supportive of the application and wished to draw to the attention of the SIRO the following significant comments:<br><br>**6.6.1** The Group noted the work undertaken by the NHS England Data Access Service (DAS) and, in particular, that the team had reminded the applicant that healthcare data, although pseudonymised, is still classified as personal data under UK General Data Protection Regulation (UK GDPR) and that there is a requirement for transparency. AGD noted their concern that a study specific privacy notice was **not** published and suggested that the NICOR data releases are in line with all other NHS England data releases.<br><br>**6.6.2** The Group reminded the applicant that they were required to maintain a UK GDPR compliant, publicly accessible transparency notice for the lifetime of the agreement, in line with the contractual requirement in section 4 (Privacy Notice) of the data sharing agreement (DSA) and suggested that this requirement be included as a special condition in section 6 that a privacy notice is published within 30 days of receipt of the data.<br><br>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review: | |

| | | |
|---|---|---|
| | **6.6.3** NHS England explained that, with the merger in 2023 of NHS Digital and NHS England, the NICOR database now falls under NHS England, and there was now no external flow of confidential information. AGD noted the update, however queried the legal and policy restraints in place by NHS England and how these were satisfied in respect of this application. The Group suggested that the internal application assessment form and section 5 (Purpose / Methods / Outputs) of the application be updated as appropriate.<br><br>**6.6.4 Separate to the application;** the Group suggested that the NICOR privacy notice be reviewed to ensure the relevant legal gateways, current law and policies were outlined. The AGD NHS DPO Representative agreed to take action on this point.<br><br>**ACTION:** The AGD NHS DPO Representative to speak to colleagues in NHS England to update the NICOR privacy notice.<br><br>**6.6.5** AGD suggested that NHS England assure itself that the correct entities were named as Data Controllers in the data sharing agreement and in line with the NHS England DAS Standard for Data Controllers, and to ask the University of Hull directly whether or not they are carrying out any data controllership activities, noting the source of funding and that the student is from the University.<br><br>**6.6.6** The Group noted the applicant's response in the internal application form that "…*such studies typically do not require direct patient or public involvement, as they do not require active participation from patients*", and there had been **no** patient and public involvement and engagement (PPIE); however, suggested that to further support the potential benefits outlined, that the applicant should consider undertaking some PPIE. The HRA guidance on Public Involvement is a useful guide.<br><br>**6.6.7** Noting the vast amount of data being processed under this application plus the statement in 5(a) (Objective for Processing) that "*this processing is in the public interest because it adheres to the UK Policy Framework for Health and Social Care research, which protects and promotes the interests of patients, service users and the public*…" the Group suggested that a robust justification be provided in section 5 as to why processing such a quantum of data in the public interest did not warrant PPIE.<br><br>**6.6.8** The Group suggested that the applicant may wish to engage with the NICOR Community Representative Group (NICOR CRG) with regard to PPIE.<br><br>**6.6.9 Separate to the application:** AGD noted that NHS England should take a position on PPIE and consider whether or not a brief NHS England DAS Standard, referring to current best practice, should be drafted as a pragmatic approach to address this point in the interim.<br><br>**ACTION:** the NHS England SIRO Representative to discuss the practicalities and implementation of a new NHS England DAS Standard for PPIE with the AGD NHS England Data and Analytics Representative. | DPO Rep<br><br>SIRO Rep |

| | | |
|---|---|---|
| | **6.6.10** In line with the NHS England DAS Standard for Data Minimisation, the Group suggested that the data minimisation efforts or lack of data minimisation efforts be explored further in section 5(b) (Processing Activities) to clearly explain why the quantum of data was required for the machine learning.<br><br>**6.6.11** Noting section 5(d) (Benefits) appeared to contain an abridged version of the standard proforma wording, the Group suggested that the section be careful edited to clearly outline the bespoke benefits and unusual nature of the benefits that may be realised from this application using machine learning, and in line with the NHS England DAS Standards for Expected Measurable Benefits.<br><br>**6.6.12** AGD suggested that the application be audited within 6 months of the applicant receiving the data, and such audit should review the processing and storage of data; the publication and promotion of the privacy notice; and whether the quantum of data originally requested had been necessary for the machine learning.<br><br>**6.6.13** In addition, AGD queried the statement in section 5(a) *"…Employees **or agents** of HUTH NHS Trust are permitted to access pseudonymised data only…"* and suggested that either further information was provided as to who would be covered by "*agents*", and whether this aligned with the Data Sharing Framework Contract (DSFC); or that this was amended / removed as may be necessary to reflect the correct / factual information.<br><br>**6.6.14** AGD noted that the tables in section 3(b) (Additional Data Access Requested) stated the data was "*identifiable*" and suggested this was updated to correctly refer to the data being "*pseudonymised*". | |
| **7** | **Approach on data sharing with the International Agency for Research on Cancer (IARC) (Presenter: Louise Dunn / Elaine Fletcher)**<br><br>NHS England noted that the Data Sharing Framework Contract (DSFC), which is the overarching document used by NHS England as part of the DARS process, specifies the basis for data to be shared and outlines the terms and conditions of how data must be managed once released to the requesting organisation as Data Controller. NHS England noted that IARC had been provided with a bespoke DSFC which reflects the terms agreed in principle between NHS England and IARC for the specific case use application.<br><br>AGD were not opining on the proposed changes to the DSFC, since that was not part of their remit as outlined in their Terms of Reference. The Group noted the work undertaken by the various teams within NHS England following NIC-670080-S6J0Y-v0.2 IARC at AGD on the 2nd November 2023, where AGD had noted their support. The Group noted that the proposed changes to the standard DSFC would be made either by way of side letter to the DSFC or the changes added to the data sharing agreement (DSA) as a special condition, such change mechanism(s) having been adopted previously with other organisations. | |

| | | |
|---|---|---|
| | NHS England noted that more applications would be coming to the Group from IARC, and AGD noted that each DSA should be carefully reviewed to ensure it fits with the IARC DSFC, and more importantly to ensure that any bespoke terms or special conditions for IARC about their DSFC are not inadvertently flowed down to other organisations where this would not be appropriate.<br><br>AGD observed that IARC has limited transparency to data subjects in England and suggested that NHS England may wish to update its own privacy notice to draw out this particular applicant, including, but not limited to, the applicant having its own special international status, the limited references in transparency to the new data platform and how it is managed, that NHS England cannot audit the organisation, and how any other party to these arrangements - such as a University - may need to update their privacy notice carefully with regard to how data subject rights are affected.<br><br>AGD thanked NHS England colleagues for attending and would welcome any further discussions on this matter, or providing advice on any future IARC applications. | |
| **8 INTERNAL DATA DISSEMINATION REQUESTS:** | | |
| *There were no items discussed* | | |
| **9 EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL** | | |
| *There were no items discussed* | | |
| **10 OVERSIGHT AND ASSURANCE** | | |
| *There were no items discussed* | | |
| **11 AGD OPERATIONS** | | |
| **11.1** | **Risk Management Framework**<br><br>As last noted previously, 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.<br><br>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.<br><br>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.<br><br>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.<br><br>**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)**<br><br>The ongoing forward plan of work for creating the AGD Standard Operating Procedures was discussed; and noting that the AGD Terms of Reference (ToR) had now been approved, it was noted that work was progressing in order to finalise relevant AGD SOPs in line with the approved AGD ToR.<br><br>Vicki Williams noted that most of the SOPs were in fact operating processes and procedures for the running of AGD and had been badged accordingly, and noted she would engage with members over the coming weeks and provide an update in due course. | |
| **11.3** | **AGD Stakeholder Engagement**<br><br>*There were no items discussed* | |
| **11.4** | **AGD Project Work**<br><br>*There were no items discussed* | |
| **11.5** | **AGD Annual Report**<br><br>Following on from the submission of the final draft AGD Annual Report v0.6 to Jackie Gray following the 18th April 2024 AGD meeting, the NHS England SIRO Representative had asked AGD to provide further narrative based on what AGD had been seeing in terms of requests for advice to date, in support of the drafting of the NHS England annual report: 'what themes/areas could we improve on?' and 'what themes/areas are we doing well and should build on?'. The Group noted that they had provided a response to the two questions, via email to Jackie Gray and Garry Coleman, on the 26th June 2024.<br><br>AGD noted that a request had been received yesterday from Garry Coleman, on behalf of Jackie Gray, with an urgent response deadline, to review Jackie's | |

| | | |
|---|---|---|
| | comments on v0.6 (uplifted to v0.7 by the AGD Secretariat) of the draft AGD Annual Report and to provide some additional management information and narrative.<br><br>**ACTION:** AGD to review v0.7 of the draft AGD Annual Report circulated via email and provide responses centrally by close of play on Monday, 1st July 2024.<br><br>**ACTION:** AGD Chair and AGD Secretariat to review the responses and circulate back to Jackie Gray and Garry Coleman, and prior to the next meeting of AGD. | AGD<br><br>AGD Chair / AGD Sec |
| **12 Any Other Business** | | |
| **12.1** | **AGD Independent Member Recruitment (Presenter: Garry Coleman)**<br><br>At the request of AGD independent members and ahead of the AGD Chair rolling off AGD in September 2024, Garry provided a brief update on AGD independent member recruitment ahead of the substantive AOB at next week's meeting.<br><br>Garry noted that the discussions around recruitment were nearing conclusion and that NHS England were behind in terms of AGD Chair recruitment and it was likely that Kirsty Irvine would be offered an extension to her current contract, subject to NHS England HR approval.<br><br>Garry noted that he expected to have recruited to all current vacancies and vacancies for those that roll off next year, by the end of the calendar year.<br><br>Vicki Williams noted that draft documentation was in place including, but not limited to adverts, job descriptions, and overarching timeline. Garry noted that NHS England would still ensure an assessment centre took place alongside interviews for independent members.<br><br>As noted previously and as requested by NHS England HR, Vicki noted there was a need to engage with current independent members ahead of AGD recruitment on any changes to pay rates, contract arrangements for new recruits and / or current members, via a bespoke recruitment model (rather than using NHS England's recruitment model for staff members).<br><br>The AGD NHS England Caldicott Guardian Representative also noted he'd give an update to work he'd been undertaking on behalf of the NHS England SIRO Representative with regard to independent clinical representation on AGD.<br><br>**ACTION:** NHS England SIRO Representative to give an update on AGD independent recruitment including timescales for updating members on any new pay rates etc.<br><br>**ACTION:** AGD NHS England Caldicott Guardian Team Representative to give an update on work around independent clinical representation on the Group.<br><br>**ACTION:** AGD Secretariat to include on a future AGD agenda | SIRO Rep<br><br>CG Rep<br><br>AGD Sec |

| | |
|---|---|
| **12.2** | **National Disease Registration Service (NDRS) Severe Combined Immunodeficiency (SCID)**<br>Kirsty Irvine noted that the NHS England SIRO Representative had asked for her advice on a SIRO approval for SCID, which she had provided by return last Friday. Garry Coleman thanked Kirsty for her advice and noted that the request would be sent to AGD to seek the Group's advice, to enable transparency to the public via the published minutes. |

**Meeting Closure**

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