# Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 3rd October 2024

09:00 – 15:50

*(Remote meeting via videoconference)*

| **AGD INDEPENDENT / NHS ENGLAND MEMBERS IN ATTENDANCE:** | |
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| **Name:** | **Role:** |
| Paul Affleck (PA) | AGD independent member (Specialist Ethics Adviser) |
| Dave Cronin (DC) | NHS England member (Data and Analytics Representative (Delegate for Michael Chapman)) |
| 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) |
| Miranda Winram (MW) | AGD independent member (Lay Adviser) |
| **NHS ENGLAND STAFF IN ATTENDANCE:** | |
| **Name:** | **Role / Area:** |
| Steven Hardy (SH) | NDRS Head of Genomics and Rare Disease, Data and Analytics (**Presenter:** item 5.1) |
| Wendy Harrison (WH) | Deputy Director of IG Delivery (Data and Analytics), Privacy, Transparency, and Trust (PTT), Delivery Directorate (**Observer**: item 5.2) |
| Dickie Langley (DL) | NHS England SIRO Representative (Delegate for Garry Coleman) |
| Nicki Maher (NM) | Information Governance Lead, IG Assurance and Risk, IG Audit Services Lead (Interim), Privacy, Transparency, and Trust (PTT), Delivery Directorate (**Observer**: Items 1 to 11) |

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| Karen Myers (KM) | AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Delivery Directorate |
| Kat Roe (KR) | Data Operations Principal Manager (National Radiotherapy Dataset), Data and Analytics, Transformation Directorate (**Presenter**: item 5.1) |
| Jodie Taylor-Brown (JTB) | Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer:** items 6.3 and 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) |
| **NHS ENGLAND STAFF NOT IN ATTENDANCE** | |
| Garry Coleman (GC) | NHS England SIRO Representative |
| **NHS NORTH OF ENGLAND COMMISSIONING SUPPORT UNIT (CSU) STAFF IN ATTENDANCE (ITEM 5.2)** | |
| Katie Barrett (KB) | Implementation Consultant, FDF Virtual Wards Delivery Lead, NHS North of England Commissioning Support Unit (CSU) (**Presenter:** item 5.2) |
| Amy Soutter (AS) | Senior Consultant, FDF Virtual Wards Delivery Lead, NHS North of England Commissioning Support Unit (CSU) (**Presenter:** item 5.2) |

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| **1** | **Welcome and Introductions:**<br>The AGD Chair welcomed attendees to the meeting. |
| **2** | **Review of previous AGD minutes:** |

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| | The minutes of the AGD meeting on the 26th September 2024 were reviewed and, after several minor amendments, were agreed as an accurate record of the meeting. | |
| **3** | **Declaration of interests:**<br><br>Dr Jonathan Osborn noted an historic professional link to the professor working at the London School of Hygiene and Tropical Medicine (NIC-683852-F5X4W-v0.10). It was agreed this did not preclude Dr. Osborn from taking part in the discussion on this application | |
| **4** | **AGD Action Log:**<br><br>*The action log was not discussed.* | |
| **5 BRIEFING PAPER(S) / DIRECTIONS:** | | |
| **5.1** | **Title:** Patient Level Contract Monitoring (PLCM) Dataset Briefing Paper / Data Protection Impact Assessment (DPIA)<br><br>**Presenters:** Kat Roe and Steven Hardy<br><br>The National Disease Registration service (NDRS) and the Genomics Unit (GU), both within NHS England, have been asked to undertake a joint project to understand the use and possible variation of genetic testing within England for individuals with cancer and rare diseases.<br><br>The purpose of the project is looking at the processing the PLCM data linked to the cancer registration and rare disease data held within NDRS; which can be used to identify the populations that may be eligible for genetic testing. The PLCM data can be used to monitor genetic testing, to understand the progress of increasing genetic testing where appropriate and successfully meet the strategic deliverables of the GU, NDRS and the wider Data and Analytics Directorate.<br><br>This is an initial short-term project to look at the value of using multiple NHS England datasets already established therefore reducing the burden of additional data collections for NHS trusts and organisations. The aim is for the groups to work together to develop a single solution to overlay and analyse genomic data from multiple sources, generating a Management Information platform suitable for all anticipated audiences. In so doing, the analysis of this data will also contribute towards the strategic priority area of *"Delivering equitable genomic testing for improved prediction, prevention, diagnosis and precision medicine"* by identifying variation in testing coverage. This pilot will be evaluated to determine the feasibility of further use of the PLCM data within NDRS for other projects.<br><br>NHS England is directed to collect, analyse and link data to deliver the National Disease Registration Service by virtue of the National Disease Registries Directions 2021.<br><br>NHS England were seeking advice on the following points: | |

1. Does the processing raise any risks which have not been adequately addressed.
2. Are there reputational risks resulting to NHSE which may outweigh the benefits to patients.

**Outcome of discussion:** AGD welcomed the briefing paper / Data Protection Impact Assessment (DPIA) and made the following observations / comments:

**5.1.1** AGD noted that they were supportive of the proposal outlined in the briefing paper / DPIA; and that there was a robust use case and legal gateway.

**In response to point 1 above:**

**5.1.2** AGD noted that gender, without biological sex at birth, data had been selected in the DPIA. AGD discussed the duty placed upon NHS England to balance the clinical efficacy of screening programmes against the risk of inadvertent breach of Gender Recognition Act 2004 (legislation.gov.uk) (specifically section 22). In particular the exposure to sex hormones, together with anatomical and physiological phenotype forms a fundamental part of clinical risk assessment of screening programmes, ensuring that those with a clinical need for screening are invited. It is noted that even the invitation to screening may carry a risk of disclosure of gender affirmation treatment, let alone the actual procedure or follow up.

**5.1.3** Similarly, the use of codes for **either** 'gender' or 'biological sex at birth' may introduce bias into research findings.

**5.1.4** The AGD NHS England Caldicott Guardian Team Representative shared with AGD that work is underway within NHS England to consider ways to balance these risks.

**5.1.5** AGD noted the information provided in section 3 (purpose of the processing) in the DPIA that outlines data is obtained under the Data Services for Commissioners Directions 2015 and advised that some of the processing elements go beyond the prescriptive scope of the Directions. The Group noted that NHS England do have extensive legal powers to collect and disseminate data beyond the scope of the Directions, and suggested these were explored further and made clear within the DPIA / supporting papers, for any processing elements that **do not** align with the scope of the Directions.

**5.1.6** AGD noted that there were aspects of the processing that involve the handling of confidential patient data; and suggested that the DPIA was updated to be clear that the National Disease Registries Directions 2021 provides a legal gateway for this aspect in terms of the Common Law Duty of Confidentiality, to avoid any misunderstanding about the nature of the *"legal obligation"*.

**5.1.7** AGD noted that two Article 9 UK General Data Protection Regulation (UK GDPR) limbs had been cited, Article 9(2)(g) *(Reasons of substantial public interest)* and 9(2)(h) *(Health or social care)*; and suggested that the papers were updated to clarify what processing was being carried out under each Article 9 limb; or to amend

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| | the briefing paper / DPIA if only one Article 9 limb was relevant, in line with the Information Commissioner's (ICO) Guidance.<br><br>**5.1.8** In addition, AGD suggested that the DPIA was updated to provide further clarity on the purpose for processing the data.<br><br>**5.1.9** AGD noted that discussions were ongoing within NHS England in respect of whether the DPIA would be published; and suggested that that the DPIA was written in a way that was suitable for publication, and published.<br><br>**5.1.10** AGD noted that section 17.1 (measures to mitigate (treat) risks) had not been fully completed; and suggested that this was updated to expand on the mitigation to ensure that patients are made aware that their genetic testing data is being used to evaluate equity of genetic testing in England.<br><br>**In response to point 2 above:**<br><br>**5.1.11** AGD noted the wording in the DPIA template in respect of any risks relating to *"…reputational damage; loss of public trust, etc"*; and suggested that this was reviewed and re-worded, noting that this current text suggests risks to NHS England's reputation can outweigh benefits to patients.<br><br>In addition, AGD made the following observations on the briefing paper / supporting documents provided as part of the review:<br><br>**5.1.12** AGD were concerned at the lack of patient and public involvement and engagement (PPIE) within the documentation provided, and, noting the verbal update in-meeting from NHS England and the efforts taken around transparency, suggested that the DPIA was updated to reflect the good work undertaken.<br><br>**5.1.13** AGD suggested that NHS England give further consideration as to the future of the NDRS specific opt-out; and suggested that some PPIE was undertaken to explore this aspect further. In addition, the Group suggested that opt-out levels were monitored following any PPIE.<br><br>**5.1.14** AGD looked forward to receiving the finalised briefing paper tabled at a future meeting. | |
| **5.2** | **Title:** Virtual Wards Faster Data Flows Collection Briefing Paper / Data Protection Impact Assessment (DPIA)<br><br>**Presenters:** Amy Soutter and Katie Barrett<br><br>**Observer:** Wendy Harrison<br><br>Virtual wards allow patients of all ages to safely and conveniently receive acute care at their usual place of residence, including care homes. There is growing evidence that when these services are delivered at scale for appropriate patients, they provide a better patient experience and can improve outcomes compared to inpatient care, as well as narrow the gap between demand and capacity for hospital beds by preventing attendances and admissions and shifting acute care into the community. | |

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| | The existing fortnightly Virtual Wards SitRep which collects data at aggregate level is currently the only mechanism for capturing virtual wards activity data. The health and care system has difficulty in drawing consistent and reliable insights from this data because the data flow is not frequent or granular enough, and there is great variability in coding practices and data standards meaning it has limited use in supporting planning at a national, system and local level.<br><br>Therefore, there is a need to introduce a mechanism for the regular flow of a patient level, daily minimum data set (MDS) from providers to the NHS England national Federated Data Platform (FDP) instance; which will produce data dashboards and a data quality dashboard that will support providers to improve data quality. The data insights will support local systems to have better operational oversight of virtual wards, and enable national benchmarking and evaluation.<br><br>There are two submission routes planned for the Virtual Ward MDS:<br><br>• Provider source systems > local FDP tenant > NHS Privacy Enhancing Technology > National FDP<br><br>• Provider source systems > FDF API > NHS Privacy Enhancing Technology > National FDP<br><br>NHS England were seeking advice on the following points:<br><br>1. Any issues placing the Virtual Wards Minimum Dataset (MDS) collection under the Healthcare Operational Data Flows: Acute Direction.<br>2. Any concerns or issues with the Virtual Wards MDS flow.<br>3. Any general advice on the data collection.<br><br>**Outcome of discussion:** AGD welcomed the briefing paper / Data Protection Impact Assessment (DPIA) and made the following observations / comments:<br><br>**5.2.1** AGD noted that they were supportive of the proposed processing, and that there was a clear legal gateway.<br><br>**In response to point 1 above:**<br><br>**5.2.2** AGD noted that two Article 9 UK General Data Protection Regulation (UK GDPR) limbs had been cited, Article 9(2)(g) *(Reasons of substantial public interest)* and 9(2)(h) *(Health or social care)*; and suggested that the papers were updated to clarify what processing was being carried out under each Article 9 limb; or to amend the briefing paper / DPIA if only one Article 9 limb was relevant, in line with the Information Commissioner's (ICO) Guidance.<br><br>**5.2.3** AGD queried the current privacy notices and FAQs and were advised by NHS England that both the NHS England and the FDP privacy notices / FDP FAQs would be updated once this processing is approved. AGD noted and supported his.<br><br>**In response to point 2 above:** | |

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| | **5.2.4** The AGD Chair noted that there had been numerous discussions on Virtual Wards as part of the Independent Group Advising (NHS Digital) on the Release of Data (IGARD); and that one of the queries raised as part of these discussions was the benefits and risks to patients. The Group queried whether any patient and public involvement and engagement (PPIE) had been undertaken, and what feedback had been received. The Group were advised by NHS England that some PPIE had been undertaken in the South East of England and that feedback had been positive. It was noted that further work needed to be undertaken at a wider level to gain further views / understanding of patient satisfaction as the feedback would be subjective and gathered only from those who were able to receive care via a virtual ward and also alive (see 5.2.7 below).<br><br>**5.2.5** AGD also referred to research that was in the public domain, in respect of the accuracy of Pulse Oximeters; whether the equipment was suitable within the Virtual Wards; and whether this led to lower effectiveness of virtual wards and / or health inequalities for those from the Black, Asian and Minority Ethnic (BAME) community. The Group queried whether those concerns had been addressed in the benefits analysis (noting the supporting document evidenced a lower uptake of virtual wards by patients from a BAME background).<br><br>**In response to point 3 above:**<br><br>**5.2.6** Noting the data collection would be aligned with other FDF collections, AGD suggested that the DPIA was updated to address any risks in respect of the quality of the data, and the mitigations in place.<br><br>**5.2.7** The Group suggested a new use of the data; that the data collected was also used to assess the objective benefits to **patients** of virtual wards (for example reduced morbidity or mortality) as the benefits outlined in the supporting documents largely focussed on cost savings to the system.<br><br>**5.2.8** AGD looked forward to receiving the finalised briefing paper tabled at a future meeting. | |
| **6 EXTERNAL DATA DISSEMINATION REQUESTS:** | | |
| **6.1** | **Reference Number:** NIC-764470-N9W3S-v0.1<br><br>**Applicant:** Office for National Statistics (ONS)<br><br>**Application Title:** Reuse of NHS England Data by Approved Researchers<br><br>**Previous Reviews:** A briefing paper relating to this application was previously presented / discussed at the AGD meeting on the 25th April 2024.<br><br>**Application:** This was a new application.<br><br>The purpose of the application is for ONS to grant access to personal data to approved researchers for statistical and research purposes approved by ONS, subject to limitations. | |

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| | The initial project, which will test the governance arrangements, is 'The Health and Labour Market Project', which will focus on exploring the link between obesity health interventions and labour market outcomes, more specifically assessing the economic impacts and benefits of bariatric surgery versus the costs to the NHS.<br><br>NHS England were seeking general advice on the application.<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 **only** supportive of the **'**The Health and Labour Market Project' and the NHS England analysts working in the ONS TRE environment.<br><br>AGD were **not** supportive of any other aspect of this application, and wished to draw to the attention of the SIRO the following substantive comments:<br><br>AGD noted that they had been provided with a curated set of documentation and noted that they would be providing observations based on these documents.<br><br>**6.1.1** AGD recognised the importance of the initial project outlined in the application (The Health and Labour Market Project), however suggested that NHS England and the applicant consider a two phased approach, for example, progress with the initial project; and continue to address the points raised, and address any lessons learnt from the initial project as this progresses.<br><br>**6.1.2** AGD advised that they were supportive of the NHS England Analysts collaborating with ONS and working in the ONS TRE environment.<br><br>**6.1.3** AGD noted that when the application was reviewed at the AGD meeting on the 25th April 2024, AGD had noted the role of the UK Statistics Authority (UKSA) Research Accreditation Panel (RAP), as the main approval body for researchers wanting to access the data; and had advised that it would be very difficult to achieve an appropriate balance of expertise by adding members to the RAP, because out of the existing 18 members only one had a specifically health focussed expertise / background, plus there was no lay or ethical representation. As a result, AGD had queried whether UKSA RAP was the most appropriate body for approving such requests; or whether a separate group / body should be created specifically for this purpose.<br><br>**6.1.4** Given the existing large size of the group and the ensuing challenge of ensuring a proportionate health / lay voice, AGD noted no clear proposal had been made to address the balance of expertise / lay representation on UKSA RAP. AGD were therefore supportive of the proposal outlined in section 5(a) (Objective for Processing) of the application, that AGD could review project proposals in parallel with UKSA RAP for the first 12-months, if NHS England were supportive. | |

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| | **6.1.5** AGD noted that there was limited information in the documentation on the future governance processes and were therefore unable to proffer any further advice on this aspect.<br><br>**6.1.6** AGD noted the application focussed on the financial benefits of the initial project, i.e. supporting the allocation of public funds; and noted concerns that this **did not** sufficiently address the benefits to health and social care, in line with the NHS England DAS Standard for Expected Measurable Benefits. This was also noted as a concern in terms of the wider governance for future requests from researchers when submitting requests to access the data.<br><br>**6.1.7** AGD noted the statement in section 5(a) that *"ONS have statutory powers to onwardly disclose personal data to approved researchers under section 39(4)(i) of the Statistics and Registration Service Act (SRSA) 2007. An "approved researcher" means an individual to whom the Statistics Board (known as the Office for National Statistics) has granted access, for the purposes of* ***statistical research****, to personal information held by it*". The Group had a discussion as to whether the work under this application was statistical research, and suggested that NHS England Data Access Service (DAS) sought legal advice on this point.<br><br>**6.1.8** An AGD independent member queried whether NHS England were satisfied that its analysts would be undertaking research to produce official statistics. If the research was for a wider purpose, then it was noted that this may not be supported by the legal basis for the original data flow.<br><br>**6.1.9** In addition, it was noted that this would also have wider implications in terms of the National Data Opt-out (NDO) policy, and it was suggested, by the AGD NHS England Data Protection Office Representative, that NHS England DAS may want to seek legal advice on what would solely fall under 'official statistics'.<br><br>**6.1.10** AGD suggested that NHS England seek advice from the National Data Guardian, as to whether the work under this application was exempt from NDO in line with the NDO policy. The Group requested that the AGD Secretariat send a copy of the ratified minutes from this meeting, and the 25th April 2024 to the Office of the NDG for information.<br><br>**ACTION:** AGD Secretariat send a copy of the ratified minutes from the 3rd October 2024 and the 25th April 20204 to the Office of the NDG for information.<br><br>**6.1.11** AGD queried whether ONS have access to other health data; and suggested that NHS England discuss with ONS where other health bodies across the regions stand, including, but not limited to, on how data will be managed, to ensure consistency of approach across the health sector.<br><br>**6.1.12** AGD advised that they would welcome a further discussion on this application and suggested that if the application does come back to AGD, it was allocated a double slot on the AGD meeting agenda. | AGD Sec |

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| | **ACTION:** AGD Secretariat to ensure that if NIC-764470-N9W3S is submitted for a further AGD review, that it is allocated a double slot. | AGD Sec |
| **6.2** | **Reference Number:** NIC-263738-V6V9N-v2.4<br><br>**Applicant:** University of Bristol<br><br>**Application Title:** Improving Medicines use in People with Polypharmacy in Primary Care (IMPPP)<br><br>**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 22nd July 2021.<br><br>**Application:** This was an amendment application.<br><br>The amendments are to **1)** permit the University of Bristol to share details of hospital admissions with the relevant GP, via NHS mail, for the purposes of capturing complete information on Serious Adverse Events (SAEs); **2)** to reflect that the data will be identifiable and not pseudonymised; and **3)** to enable data access to an individual under honorary contract.<br><br>NHS England were seeking general advice on the application.<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>AGD noted that they had been provided with a curated set of documentation and noted that they would be providing observations based on these documents.<br><br>**6.2.1** AGD noted that this application had been submitted to the Group for review following a breach of the data sharing agreement (DSA) that was identified during a discussion between NHS England and the applicant on the 15th August 2024, where it was noted that a list of hospital admissions had been shared with GP surgeries when this was **not** permitted under this DSA. AGD noted that they were supportive of the steps outlined by NHS England to address this breach, including the approach taken to agreeing amendments to the application, and advised that they were supportive of the DSA being added to the NHS England's audit schedule as outlined in the NHS England Data Access Service (DAS) internal application assessment form.<br><br>**6.2.2** AGD noted the importance of the work being undertaken by the University of Bristol and that the steps taken that resulted in the breach were in line with advice received from the independent Data Monitoring and Ethics Committee (DMEC).<br><br>**6.2.3** Noting the amendment to this application to permit the University of Bristol to share details of hospital admissions with the relevant GPs, AGD queried whether there was a DSA / data processing agreement between the University of Bristol and | |

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| | the GPs; and, if not, suggested that there was one, to ensure that all GPs are aware that they may be receiving data on patients under their care.<br><br>**6.2.4** In addition, it was suggested that a special condition was added to section 6 (Special Conditions) of the application to address point 6.2.3 above, and it was suggested that this was reviewed as part of the NHS England audit.<br><br>**6.2.5** AGD noted that the Chief Investigator had moved from the University of Bristol to the University of Exeter during the previous iteration of the DSA; and was accessing the data remotely under an honorary contract (breaching the agreement). The Group suggested that this was explored further by NHS England to determine whether the University of Exeter should be a Data Controller in line with the NHS England DAS Standard for Data Controllers, for example, was the Chief Investigator determining the purpose and means of processing; which organisation would the Chief Investigator be publishing work under. It was suggested that the application was updated as may be necessary to reflect the correct / factual information.<br><br>**6.2.6** The AGD NHS England Data Protection Office Representative advised that if it was determined that an honorary contract was required, that this aligned with NHS England's DAS Standard for Honorary Contracts; and that a copy of the honorary contract was provided to NHS England as per the usual process; and a copy uploaded to the customer relationship management (CRM) system. | |
| **6.3** | **Reference Number:** NIC-484452-H8S1L-v6.5<br><br>**Applicant:** Department of Health and Social Care (DHSC)<br><br>**Application Title:** Department of Health and Social Care (DHSC) SDE access - Enabling Policy Analysis<br><br>**Observer:** Jodie Taylor-Brown<br><br>**Previous Reviews:** The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 11th July 2024, 25th January 2024 and the 14th December 2023.<br><br>The application and relevant supporting documents were previously presented / discussed at the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) meetings on the 8th September 2022, 19th May 2022, 7th April 2022. 21st October 2021 and the 16th September 2021.<br><br>The application was previously presented at the GPES Data for Pandemic Planning and Research – Profession Advisory Group (PAG) on the 24th November 2021, 3rd November 2021, 15th September 2021 and the 25th August 2021.<br><br>**Application:** This was an amendment application.<br><br>The amendments are to **1)** update section 5(b) of the application to accommodate collaborative cross government working; and **2)** a reusable decision for other agreements where this amendment is required. | |

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| | NHS England were seeking general advice on the application.<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 **not** supportive of the application (proposed amendment and reusable decision) until the following substantive comments were addressed, and wished to draw to the attention of the SIRO the following substantive points:<br><br>AGD noted that they had been provided with a curated set of documentation and noted that they would be providing observations based on these documents.<br><br>**6.3.1** AGD noted that at the meeting on the 11th July 2024 (point 6.1.8), AGD had suggested that a special condition was added to section 6 (Special Conditions) of the application, requesting that a copy of the DHSC Data Access policy document, which outlined the applicant's patient and public involvement and engagement (PPIE), was provided to NHS England by February 2025.<br><br>**6.3.2** AGD noted that this point had been addressed in the NHS England Data Access Service (DAS) internal application assessment form, by a link that had been provided by DHSC; however, it was noted by the Group that they were unable to locate the applicant's PPIE policy or details of the patient and public involvement and engagement they had undertaken via this link. AGD suggested that NHS England discuss this further with DHSC, emphasising the high-profile nature of the work being undertaken, the novel use of data, and the impact on public trust and confidence. The Group suggested that noting that this had been ongoing for some time, this may need a further discussion between relevant senior colleagues within NHS England and DHSC.<br><br>**6.3.3** In addition, AGD stressed / reiterated the previous advice made from the 11th July 2024 meeting (point 6.1.9), that there was ongoing patient and public involvement and engagement (PPIE) throughout the lifecycle of the work. The HRA guidance on Public Involvement is a useful guide.<br><br>**6.3.4** The AGD NHS England Data and Analytics Representative noted that the relationship between DHSC and the Department for Work and Pensions (DWP) was not clear; and suggested that NHS England DAS explore this further with DHSC to clarify this, and to determine whether DWP were a Data Controller, in line with NHS England DAS Standard for Data Controllers, and that the application was updated as may be necessary to reflect the correct / factual information.<br><br>**6.3.5** AGD noted that once the relationship between DHSC and DWP had been explored / clarified and depending on the facts, a data processing agreement may be appropriate, since an honorary contract arrangement would not seem to be appropriate in this instance.<br><br>**6.3.6** AGD noted that there was a benefit to health and social care from the processing outlined within the application, and that they may be supportive of a | |

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| | reusable decision once the substantive points above had been sufficiently addressed. | |
| **6.4** | **Reference Number:** NIC-148056-T6T5Z-v10.4<br><br>**Applicant:** Imperial College London<br><br>**Application Title:** Airwave Health Monitoring Study<br><br>**Observers:** Jodie Taylor-Brown<br><br>**Previous Reviews:** The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 18th April 2024 and the 2nd March 2024.<br><br>The application and relevant supporting documents were previously presented / discussed at the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) meetings on the 19th September 2019, 18th October 2018, 30th August 2018, 31st August 2017 and the 16th March 201<br><br>**Application:** This was an amendment application.<br><br>The amendments are to **1)** broaden the objective for processing; **2)** remove Swansea University as a Data Processor; **3)** the addition of the following datasets: Hospital Episode Statistics (HES) Admitted Patient Care (APC), Accident & Emergency (A&E), Critical Care, and Outpatients; Mental Health Minimum data set; Mental Health and Learning Disabilities data set; Mental Health Services data set; COVID-19 Vaccination status; and COVID-19 non antigen testing results (Pillar 2)-April 2020; and **4)** renewal of the following datasets: Civil Registration Mortality; Cancer Registration; and Demographics.<br><br>NHS England were seeking general advice on the application.<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>AGD noted that they had been provided with a curated set of documentation and noted that they would be providing observations based on these documents.<br><br>**6.4.1** AGD noted that there was a legal gateway in consent for the processing of the data; however, it was noted that the processing should be compatible at all times with the consent taken; and given the expansion in the number of datasets and the research undertaken this needed to be regularly reviewed, preferably with members of the cohort.<br><br>**6.4.2** AGD noted the process for withdrawing consent in the protocol provided as a supporting document (SD2.3); and noting that the process appeared to be complex, | |

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| | it was suggested that this was simplified, including, but not limited to, referencing the online form.<br><br>**6.4.3** AGD noted the COVID-19 datasets requested and suggested that section 5 (Purpose / Methods / Outputs) of the application was updated to reflect that all processing of the COVID-19 datasets, must be done within the scope of the COVID-19 Public Health Directions 2020.<br><br>**6.4.4** In addition, it was suggested that a special condition was added to section 6 of the application, to reflect that all processing of the COVID-19 datasets, must be done within the scope of the Directions.<br><br>**6.4.5** AGD noted and applauded the applicant on the patient and public involvement and engagement (PPIE) undertaken to date; and thanked the applicant for providing some additional information prior to the meeting on this point.<br><br>**6.5.6** AGD noted that whilst General Practice Extraction Service (GPES) Data for Pandemic Planning & Research (COVID-19) (GDPPR) data had **not** been requested under this iteration of the application, as per the usual process, any request for this data, would require a review from the GDPPR Profession Advisory Group (PAG). | |
| **6.5** | **Reference Number:** NIC-683852-F5X4W-v0.10<br><br>**Applicant:** London School of Hygiene and Tropical Medicine<br><br>**Application Title:** Emergency Surgery Or noT for common Vascular conditions in the periods before and during COVID-19 (the ESORT-V study)<br><br>**Application:** This was a new application.<br><br>The purpose of the application is for a study, that aims to estimate the effectiveness and cost-effectiveness of urgent surgery versus scheduled surgery to help inform clinicians on which patients should be prioritised for urgent surgery.<br><br>NHS England were seeking general advice on the application.<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>**6.5.1** AGD noted and commended NHS England on the extensive queries raised with the applicant in respect of the role of the Co-Chief Investigators, as outlined in the NHS England Data Access Service (DAS) internal application assessment form; however, queried the information provided on one of the Co-Chief Investigators, who was providing clinical advice. The Group suggested that NHS England seek assurances that the Co-Chief Investigator was not also determining the purpose and means of processing and were therefore not carrying out any data controllership activities in line with the NHS England DAS Standard for Data Controllers. | |

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| | **6.5.2** The Group advised that, based on the information provided, the role of the Co-Chief Investigator may go beyond providing clinical advice; and suggested that in addition to the discussions between NHS England and the applicant, clarification was also sought from the Data Protection Officers (DPO) at the University of Bristol and London School of Hygiene and Tropical Medicine.<br><br>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:<br><br>**6.5.3** AGD noted the discussions between NHS England's DAS and the applicant in respect of service evaluation versus research, noting the s251 support was for non-research purposes. Given the applicant had been clear on their planned work, the Group judged the s251 support could be relied upon.<br><br>**6.5.4** AGD noted that Article 9(2)(j) *(Archiving, research and statistics)* of the UK General Data Protection Regulation (UK GDPR) had been cited; and suggested that this was reviewed and updated to reflect the contention that the work was service evaluation and not research.<br><br>**6.5.5** AGD were unclear as to how patients were included in the National Vascular Registry (whether elective patients are included only under consent) and whether the consent of elective patients covers the transfer of identifiers for this study. It was suggested that this was made clear in the application.<br><br>**6.5.6** AGD also noted that the National Data Opt-Out (NDO) has been applied to the whole cohort, however the NDO should only be applied to those under s251 support (and not those who had given consent), and suggested that this was reviewed.<br><br>**6.5.7** AGD noted that the applicant would be provided with more data than was requested, and that the applicant would be required, as per the special condition in section 6 (Special Conditions) of the application, to destroy all NHS England Data received that falls outside of the period of interest, following receipt of the data. The Group suggested that NHS England satisfy itself that sufficient data minimisation had been undertaken, in line with the s251 support, NHS England DAS standard for data minimisation and the UK General Data Protection Regulation (UK GDPR).<br><br>**6.5.8** AGD noted that if it was not possible for NHS England to undertake any further data minimisation, then a robust justification should be provided in the internal DAS Escalation Form and section 5 (Purpose / Methods / Outputs) of the application for transparency; and that if it is the responsibility of the applicant to undertake data minimisation following receipt of the full dataset, then NHS England should undertake the relevant balances and checks, in a timely manner, to ensure that this had been completed.<br><br>**6.5.9** AGD noted and commended the applicant on the excellent patient and public involvement and engagement (PPIE) undertaken that covers the lifecycle of the study. | |

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| **6.6** | **Reference Number:** NIC-729713-Y1V3N-v0.6<br><br>**Applicant:** University of Galway<br><br>**Application Title:** Climate change, health outcomes and adaptation: A micro-econometric analysis of the factors mediating the health impacts of extreme temperatures in a temperate climate and implications for health inequalities under various climate change scenarios<br><br>**Application:** This was a new application.<br><br>The purpose of the application is for a research project investigating the effect of extreme temperatures on health outcomes for the population and across population sub-groups, cost of emergency care, factors mediating and moderating the relationship and implications under various climate change scenarios.<br><br>NHS England were seeking general advice on the application.<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 if it took place in NHS England's Secure Data Environment (SDE) and wished to draw to the attention of the SIRO the following substantive comments:<br><br>AGD noted that this application was a first of type review under the 'AGD first' concept.<br><br>**6.6.1** AGD noted the University of Galway are based in Ireland and **do not** have a Data Protection Act (DPA) Registration, which is required as per clause 4.1 of the Data Sharing Framework Contract (DSFC). It was suggested that this should be acknowledged in the application, and that the special condition in section 6 of the application would need to be amended to reflect that they would be unable to comply with clause 4.1 of the DSFC; and that another clause would need to be added to the application to address / mitigate this issue.<br><br>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:<br><br>**6.6.2** Noting the territory of use in section 2(c) (Territory of Use) of the application was *"UK & EEA"*; AGD suggested that this was updated to just state *"EEA"*.<br><br>**6.6.3** AGD strongly suggested that, given the quantum of data requested under this application, NHS England explore providing access to the data under this application, via the NHS England Secure Data Environment (SDE), rather than providing an extract of data.<br><br>**6.6.4** NHS England did note and acknowledge the developing policy in respect of the NHS England SDE. AGD suggested that consideration should be given to expanding the territory of use to the EEA, since this made more sense than disseminating the data outside the UK. | |

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| | **6.6.5** AGD noted that Article 6(1)(f) *(Legitimate interests)* of the UK General Data Protection Regulation (UK GDPR) had been cited; and suggested that this was reviewed and updated as may be necessary, in line with Information Commissioner's (ICO) Guidance.<br><br>**6.6.6** AGD noted that this was a PhD project, and while noting that the benefits to health and care had been established, suggested that the fact this was a PhD study was made more explicitly clear in section 5(a) (Objective for Processing) of the application, which forms NHS England's data uses register.<br><br>**6.6.7** AGD noted that the Met Office had submitted an application with a similar purpose (NIC-70235-T6P9F) that had been discussed at AGD on the 17th August 2023; and suggested that the applicant consider liaising with the Met Office on the climate and health related themes.<br><br>**6.6.8** AGD reviewed the purpose for processing in section 5(a) and queried whether some of the aims were too granular / possibly too ambitious using just HES Accident and Emergency (A&E) data; and suggested that section 5 (Purpose / Methods / Outputs) was reviewed throughout and updated to ensure the purpose, outputs and benefits were achievable with the data requested; or with the relevant justification outlined in the application whether any other additional NHS England datasets could be provided to support the aims of the study, without recourse to AGD.<br><br>**6.6.9** AGD noted in the NHS England Data Access Service (DAS) internal application assessment form that the applicant would seek ethical approval once confirmation had been received that the application had been approved. It was suggested that NHS England provide the applicant with the usual process, requesting that ethical approval was obtained prior to the data flowing, and in line with the NHS England DAS Standard for Ethical Approval. It was noted that the applicant could consider again requesting a review of the draft application by the University of Galway Research Ethics Committee (REC) with a supporting note from NHS England that most university REC's were content to review proposals **before** access to NHS England data had been granted.<br><br>**6.6.10** AGD noted the statement in section 5(b) (Processing Activities) of the application *"All organisations party to this agreement must comply with the data sharing contract requirements, including those regarding the use (and the purpose of the use) by "**personnel**"*; and suggested the reference to *"personnel"* was removed. | |
| **7 INTERNAL DATA DISSEMINATION REQUESTS:** | | |
| *There were no items discussed* | | |
| **8 EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL** | | |
| *There were no items discussed* | | |

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| **9 OVERSIGHT AND ASSURANCE** | | |
| *There were no items discussed* | | |
| **10 AGD OPERATIONS** | | |
| **10.1** | **Risk Management Framework**<br>AGD has been previously informed that a risk management framework is being developed by Data Access. However, AGD noted that the Group's Terms of Reference have been in place since March 2024 and charge the Group with operating in line with NHSE's risk management framework, and it is therefore of concern that there is still **not** a Risk Management Framework in place.<br>**ACTION:** The NHS England SIRO Representative to provide a written response to AGD on the progress, and expected time frame for implementation, of the risk management framework | SIRO Rep |
| **10.2** | **Standard Operating Procedures (SOPs)**<br>The ongoing forward plan of work for creating relevant 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. | |
| **10.3** | **AGD Stakeholder Engagement**<br>*There were no items discussed* | |
| **10.4** | **AGD Project Work**<br>*There were no items discussed* | |
| **11 Any Other Business** | | |
| **11.1** | **AGD NHS England Data and Analytics Representative**<br>It was noted that Tom Wright would be the usual AGD NHS England Data & Analytics Representative (delegate for Michael Chapman) from the 17th October 2024 meeting. | |
| **11.2** | AGD noted that in line with clause 9.1 of the AGD Terms of Reference that states: "*The Chair, the Secretariat, the SIRO Representative and at least one of the NHSE members of the Group will meet at least once every three months to review the operation of the Group*" was fulfilled at the 26th September 2024 meeting under item 5. | |
| **Meeting Closure**<br>As there was no further business raised, the thanked attendees for their time and closed the meeting. | | |