# Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 4th July 2024

09:00 – 15:20

*(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) (Chair items 5.1 and 6.3 to 11.1) |
| Claire Delaney-Pope (CDP) | AGD independent member (Specialist Information Governance Adviser) |
| Dr. Robert French (RF) | AGD independent member (Specialist Academic / Statistician Adviser) |
| Kirsty Irvine (KI) | AGD independent member (Chair) (Items 1 to 4 and 5.2 to 6.2) |
| 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) |
| Tom Wright (TW) | NHS England member (Data and Analytics Representative (Delegate for Michael Chapman)) (Not in attendance for items 10.1 to 10.4) |
| **NHS ENGLAND STAFF IN ATTENDANCE:** | |
| **Name:** | **Role / Area:** |
| Sara Buck (SB) | Programme Manager, Cohorting as a Service (CaaS) (**Observer:** Item 5.1) |
| Vicky Byrne-Watts (VBW) | Data Access and Partnerships, Data and Analytics (**Observer:** items 5.2 and 6.1) |
| Dan Goodwin (DC) | Data Access and Partnerships, Data and Analytics (**Observer:** item 6.6) |

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| Lisa Harris (LH) | Account Management & Engagement, Data & Analytics (**Presenter:** Item 5.1) |
| Suzanne Hartley (SH) | Data Access and Partnerships, Data and Analytics (**Observer:** items 5.2 and 6.1) |
| Nicki Maher (NM) | NHS England SIRO Representative (Delegate for Garry Coleman) |
| Karen Myers (KM) | AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Delivery Directorate |
| Jodie Taylor-Brown (JTB) | Data Access and Partnerships, Data and Analytics (**Observer:** items 5.2 to 6.5) |
| Andy Whyton (AW) | Business Analyst, Cohorting as a Service (CaaS) (**Observer:** item 5.1) |
| 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) |
| Jon Moore (JM) | NHS England member (Data Protection Office Representative) |
| Miranda Winram (MW) | AGD independent member (Lay Adviser) |
| **NHS ENGLAND STAFF NOT IN ATTENDANCE:** | |
| Garry Coleman (GC) | NHS England SIRO Representative |

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| **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 27th June 2024 were reviewed and, after several minor amendments, were agreed as an accurate record of the meeting. |
| **3** | **Declaration of interests:** |

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| | Dr. Rob French noted that, in his role at Cardiff University, he was a recipient of English Longitudinal Study of Ageing (ELSA) data (NIC-739463-H4P9N and NIC-759062-F2L6B), but noted he had no specific connection with the applications or staff involved and it was agreed that this was not a conflict of interest. |
| **4** | **AGD Action Log:**<br>*The action log was not discussed.* |
| **5 BRIEFING PAPER(S) / DIRECTIONS:** | |
| **5.1** | **Title:** UKHSA COVID Therapeutics Briefing Paper<br>**Presenter:** Lisa Harris<br>**Observer:** Sara Buck and Andy Whyton<br>The purpose of the briefing paper is to make AGD aware of a new onboarded product and welcome any advice they have specific to this use case.<br>Targeted Therapeutics was an NHS England commissioned service that identified citizens who could be eligible for COVID-19 antivirals if they contracted the virus. Eligibility was based on clinical conditions and treatments that clinical policy determined rendered people vulnerable and at risk of hospitalisation if they were to contract COVID-19.<br>This is a shell onboarded product to support the UK Health Security Agency (UKHSA) to monitor and manage the delivery, efficacy and safety of immunisation and other infectious disease preventative treatment programmes including novel anti-COVID-19 therapeutics.<br>The data will be used for surveillance, modelling, analysis and reporting to inform the implementation and development of the COVID-19 therapeutics programme by the NHS, and to inform the ongoing national response to COVID-19. At the current time, this is expected to be a one-off request for UKHSA. Full onboarding of this dataset is **not** planned.<br>NHS England were seeking advice on the following points:<br>1. Any advice AGD have specific to this use case.<br>**Outcome of discussion:** AGD welcomed the briefing paper and made the following observations / comments:<br>**In response to point 1:**<br>**5.1.1** AGD welcomed early sight of the briefing paper and noted that there was further work ongoing in respect of the new dataset, that would be reflected in an updated briefing paper.<br>**5.1.2** AGD noted that as per the usual process, any request for the General Practice Extraction Service (GPES) Data for Pandemic Planning & Research (COVID-19) |

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| | (GDPPR) dataset, would require a review from the GDPPR Profession Advisory Group (PAG). The AGD NHS England Caldicott Guardian Team representative (PAG Chair) advised that advice would be sought from PAG, once there was further clarity / understanding of the request, including, but not limited to, a clear purpose.<br><br>**5.1.3** AGD noted that further clarification was required in the briefing paper on the objective for processing, how the data was being linked and for what purpose, noting that this was currently unclear.<br><br>**5.1.4** AGD queried what the expected outcomes would be of the data processing, for example, would patient outcomes be improved and how; and suggested that further information on these points were included in the briefing paper.<br><br>**5.1.5** Noting that UKHSA do not have their own statutory responsibilities as they form part of the Department of Health and Social Care (see Framework document), it was suggested by AGD that the briefing paper, and any subsequent application(s), are clear / accurate on the role and responsibilities of UKHSA and how these relate to the proposed processing.<br><br>**5.1.6** AGD noted the Regulation 3 of the Health Service (Control of Patient Information) Regulations 2002 (COPI) legal basis cited in the briefing paper; and suggested that this was reviewed and updated to be clear which limb of Regulation 3 was applicable / relied upon for each aspect of the processing being undertaken.<br><br>**5.1.7** AGD noted that Regulation 3 of the COPI legal basis was for the purpose of *"Communicable disease and other risks to public health";* and queried how all of the listed purposes of processing, as currently described, were to diagnose, recognise trends or control and prevent the spread of such risks to public health. The Group suggested that the briefing paper and any relevant supporting documentation were updated to ensure that the language used aligned with the relevant limb (once clarified), including how the proposed processing was to address a risk to public health.<br><br>**5.1.8** AGD asked what processes were in place at UKHSA to comply with the requirements associated with use of Regulation 3 of COPI, such as record keeping and an annual review and that the briefing paper be updated with this detail.<br><br>**5.1.9 Separate to this briefing paper:** AGD repeated the query previously raised whether record keeping was undertaken by NHS England on the approval and use of Regulation 3 of COPI (as was the process within other public bodies); and suggested that the AGD NHS England Caldicott Guardian Team representative explored this further with NHS England Caldicott Guardian colleagues, given the importance of this supporting the legal basis.<br><br>**ACTION:** The AGD NHS England Caldicott Guardian Team representative to clarify with NHS England colleagues what record keeping was undertaken by NHS England on the use of Regulation 3 of COPI. | CG Rep |

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| | **5.1.10** AGD looked forward to receiving an updated briefing paper / supporting documents in due course, at a future AGD meeting and before any first of type application to the Group. | |
| **5.2** | **Title:** Department of Health & Social Care (DHSC) Pilot Briefing<br><br>**Presenter:** Tom Wright<br><br>**Observer:** Jodie Taylor-Brown, Suzanne Hartley and Vicky Byrne-Watts<br><br>This briefing paper was provided to support the review of NIC-759355-H7B9S (item 6.1); and to inform AGD of five datasets that are being made available via the Unified Data Access Layer (UDAL).<br><br>The datasets are: **1)** Cancer Patient Tracking List (CANPTL); **2)** Dental Training Posts; **3)** Better Care Fund (BCF) Additional Discharge Fund; **4)** Patient-initiated follow-up (PIFU); and **5)** Specialist Advice Broken Down by Treatment Function.<br><br>The Department of Health and Social Care (DHSC) requires access to the five datasets in the form of unsuppressed aggregate data for the purpose of data analysis aimed at supporting policy development under the duties of the Secretary of State for Health set out within the National Health Service Act 2006.<br><br>**Outcome of discussion:** AGD welcomed the briefing paper and made the following observations / comments:<br><br>**5.2.1** AGD queried what the legal basis was for the original collections, the original flows in, processing and then the dissemination of the data via UDAL; and noting that this was currently unclear, asked that the briefing paper was updated to clarify.<br><br>**5.2.2** It was noted that Article 9(2)(j) *(processing is necessary for archiving purposes in the public interest, scientific or historical* ***research purposes*** *or statistical purpose)* of the UK General Data Protection Regulation (UK GDPR) had been cited as the legal basis for processing the personal data; and suggested that this was reviewed and updated as may be necessary to ensure that the legal basis correctly aligned with the nature of the processing.<br><br>**5.2.3** AGD noted prior to submission of the briefing paper, the SIRO representative had requested that further information was provided on transparency (how will patients know that this is what NHS England are doing with the data); and noting that this had not yet been addressed, asked that the briefing paper was updated accordingly with information on transparency.<br><br>**5.2.4** AGD asked the presenter whether it was suitable for the data to be placed in UDAL and accessed now, and were advised by the presenter that they were supportive of this approach. The majority of the Group advised that they were of the view, that, in the absence of a Data Protection Impact Assessment (DPIA), there were currently too many unknown risks. | |

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| | **5.2.5** The Group queried why a DPIA had not been provided as part of the agenda pack and were advised by NHS England that work was ongoing to source the DPIA.<br><br>**5.2.6 Separate to the briefing paper:** AGD requested that for any future briefing papers submitted to AGD, copy of the DPIA was provided to support the review of documentation, where appropriate.<br><br>**ACTION:** AGD NHS England Data and Analytics representative to liaise with colleagues in Data and Analytics to request that a copy of the DPIA was provided to support the review of briefing papers, where appropriate.<br><br>**5.2.7 Separate to the briefing paper:** AGD noted that the incorrect AGD briefing paper template had been used for this briefing; and asked that any future briefing papers were submitted on the most recent template to support the review of the Group, and to ensure that all the relevant information is provided.<br><br>**ACTION:** AGD NHS England Data and Analytics representative to liaise with colleagues in Data and Analytics to ensure that any future briefing papers were submitted on the most recent template.<br><br>**5.2.8 Separate to the briefing paper:** In addition, AGD requested that if the most recent AGD briefing paper template does **not** provide enough example information to support the author in writing a briefing paper; then NHS England colleagues feed this back to the AGD Secretariat, so that appropriate updates can be made to the template. For example, it was noted that the legal basis information was important to be included on all briefing papers submitted to AGD, particularly for any new collections of data, to support AGD in their review and the advice they give to NHS England.<br><br>**5.2.9** AGD looked forward to receiving an updated briefing paper in due course, at a future AGD meeting. | D&A Rep<br><br>D&A Rep |
| **6 EXTERNAL DATA DISSEMINATION REQUESTS:** | | |
| **6.1** | **Reference Number:** NIC-759355-H7B9S-v0.1<br><br>**Applicant:** Department of Health & Social Care (DHSC)<br><br>**Application Title:** NHSE UDAL - DHSC pilot<br><br>**Observer:** Jodie Taylor-Brown, Vicky Byrne-Watts and Suzanne Hartley<br><br>**Application:** This was a new application.<br><br>The purpose of the application is for data analysis aimed at supporting policy development under the duties of the Secretary of State for Health and Social Care set out within the National Health Service Act 2006<br><br>Should an application be approved by NHS England, further details would be made available within the Data Uses Register. | |

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| | **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:<br><br>**6.1.1** AGD noted that a briefing paper to support this application had been provided, please refer to item 5.2.<br><br>**6.1.2** AGD noted that s261(2)(a) of the Health and Social Care Act 2012 had been cited in the DAS internal application assessment form as the legal basis for processing; however, it was suggested that NHS England review this, noting that this legal basis would **not** cover the processing of data covered under a Direction.<br><br>**6.1.3** AGD noted that section 4.1 (UK GDPR / DPA 2018 Article 6) of the DAS internal application assessment form referred to Article 6(1)(f) *(legitimate interests)* of the UK General Data Protection Regulation (UK GDPR); and noting that this appeared to have been an error and did not align with the application, suggested that this was removed.<br><br>**6.1.4** AGD noted that Article 9(2)(j) *(processing is necessary for archiving purposes in the public interest, scientific or historical **research purposes** or statistical purpose)* had been cited in the application; however noted the statement in section 7 (Ethics Approval) of the application, that stated the data would be used "…*for **non-research** purposes"*. It was therefore suggested that NHS England explore this further with the applicant, and that the application and DAS internal application assessment form were updated to reflect the correct / factual information.<br><br>**6.1.5** Noting that section 7 of the application stated that ethical approval was **not** required; AGD noted that as part of the review of NIC-463165-H3R4K (DHSC) on the 5th October 2023, the *"DHSC Ethics Team"* had been referred to. The Group queried whether the DHSC ethics team had been approached to review this application; and if not, suggested that the applicant engage with them, in line with NHS England's DAS Standard for Ethical Approval.<br><br>**6.1.6** AGD noted that it was currently unclear at what level the data has been aggregated; and suggested that this was clarified in the application and DAS internal application assessment form.<br><br>**6.1.7** In addition, the Group noted concern as to why there was a lack of data suppression, and suggested that this was clarified in section 5(b) (Processing Activities) of the application, for example, was unsuppressed data necessary to fulfil the purposes, or was it due to technical or capacity issues.<br><br>**6.1.8** It was also suggested that section 5(b) was updated to reflect that small numbers will be supressed in the outputs; and that further information was provided as to the process for checking outputs had been supressed.<br><br>**6.1.9** It was suggested that any rules around suppression were reflected in the application, for example, via a special condition in section 6 (Special Conditions). | |

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| | **6.1.10** AGD noted from NHS England that work was ongoing to source a Data Protection Impact Assessment (DPIA); and requested that a copy of the DPIA was provided to support a future review of the application.<br><br>**6.1.11** AGD noted that if data were to be processed in UDAL **prior** to being covered by a DPIA, it would be a risk to NHS England in terms of public confidence / perception.<br><br>**6.1.12** AGD noted that standard wording had been added to section 4 (Privacy Notice) of the application in respect of having a UK General Data Protection Regulation (UK GDPR) compliant, publicly accessible transparency notice(s) for the lifetime of the agreement; however, given the points raised on the briefing paper and documentation provided for this application in respect of transparency, the Group were concerned as to whether the transparency was adequate, noting that personal data was being processed.<br><br>**6.1.13** AGD noted that section 2.3 (benefits evaluation) of the DAS internal application assessment form had **not** been completed, and advised that it would have been helpful for this to be populated with some key information, which could have then aligned with the application. It was suggested that in line with the NHS England DAS Standard for Expected Measurable Benefits this was updated.<br><br>**6.1.14** AGD suggested that the outputs in section 5(c) (Specific Outputs Expected) and the benefits in section 5(d) (Benefits) of the application were reviewed and updated, to ensure that they related to outputs and benefits to health and social care, in line with NHS England DAS Standard for Expected Outcomes and NHS England's DAS Standard for Expected Measurable Benefits, including, but not limited to, the patient initiated follow up (PIFU) and outpatient (OP) transformation benefit.<br><br>**6.1.15** AGD queried the statement in section 5(b) *"Access is restricted to employees or **agents** of…"* 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>**6.1.16** AGD noted in section 8.1 (security assurance) of the DAS internal application assessment form, that the DHSC security assurances expired on the 30th June 2024; and suggested that this was reviewed and updated with the most up to date information. | |
| **6.2** | **Reference Number:** NIC-736310-S6T1Z-v1.2<br><br>**Applicant:** NHS Counter Fraud Authority (NHSCFA)<br><br>**Application Title:** NHSE UDAL - NHSCFA - For the purposes of the prevention and detection of crime<br><br>**Observer:** Jodie Taylor-Brown | |

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| | **Previous Reviews:** The application and relevant supporting documents were previously presented / discussed at the meeting on the 24th May 2024.<br><br>**Application:** This was a renewal application.<br><br>The application is for the purpose of preventing and detecting fraud and other criminal offences within the NHS; and will support NHSCFA in determining if there is a case for the commencement of a criminal investigation.<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 the following points were addressed, and wished to draw to the attention of the SIRO the following substantive comments:<br><br>**6.2.1** AGD advised that they were unable to locate a published privacy notice, and suggested the applicant was reminded that they were required to maintain a UK General Data Protection Regulation (UK GDPR) compliant, publicly accessible transparency notice(s) for the lifetime of the agreement, in line with the contractual requirement in section 4 (Privacy Notice) of the data sharing agreement (DSA).<br><br>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:<br><br>**6.2.2** AGD noted that Uncurated Low Latency data had been requested under this application and suggested that NHS England discuss this with the NHS Counter Fraud Authority.<br><br>**6.2.3** 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 (with a basis in law))* and 9(2)(j) *(processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purpose)*; and suggested that section 5(a) (Objective for Processing) of the application was updated to clarify what processing was being carried out under each Article 9 limb.<br><br>**6.2.4** AGD noted that the application was currently drafted with a focus on public interest, however, suggested that the application was reviewed and updated throughout, to ensure that there was a clear focus on the connection with health and social care, noting that this was a legal requirement for NHS England to permit access to the data.<br><br>**6.2.5** AGD noted the statement in section 5(a) *"The relationship between public sector fraud and "public interest" has been discussed at length in recent years and in particular, against the duty of confidentiality - to that end, the 2021 consultation by the Academy of Medical Royal Academies, supported by the National Data Guardian provides some useful insight identifying that protecting the public sector from fraud supports disclosure and that effective protection of public services and effective management of the public purse in this circumstance falls within the public interest test (even where this breaches confidentiality)"* and suggested that this was | |

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| | removed, noting that the description of the conclusions of this exercise was not accurately represented.<br><br>**6.2.6** AGD noted the statement in section 5(b) (Processing Activities) that *"The Data will not be linked with any other data"*; and queried if this was correct, noting that it may be problematic to build legal cases without linkage. It was suggested that NHS England explore this further with the applicant, and that the application and DAS internal application assessment form were updated as may be necessary to reflect the correct / factual information.<br><br>**6.2.7** AGD noted the restrictions in section 5(b) of the application, in respect of there being no re-identification; and suggested that NHS England explore this further with the applicant, in terms of any potential re-identification either now or in the future. It was suggested that if the applicant wished to undertake any re-identification, then this should be discussed further with the NHS CFA Caldicott Guardian and / or AGD.<br><br>**6.2.8** AGD noted the broad statement in section 5(b) *"NHSCFA will not share data disseminated via the DSA with any **third party** other than as part of their investigation as forensic evidence"*; and suggested that this was updated to be clearer as to who the third parties may be.<br><br>**6.2.9** AGD queried the benefit in section 5(d) (Benefits) in respect of reducing fraud; and suggested that this was updated further with further information as to how this would benefit health and social care, for example, by the reallocation of funds and reassurance to the public that resources are being appropriately used.<br><br>**6.2.10** AGD queried the statement in section 5(b) *"Access is restricted to employees or **agents** of…"* 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>**6.2.11** AGD noted that the NHS England citation special condition in section 6 (Special Conditions) of the application differed from previous standard wording, and suggested that the application should be updated with the correct standard wording.<br><br>**6.2.12** AGD noted that a Data Protection Impact Assessment (DPIA) had **not** been provided by DAS as part of the meeting papers pack; and advised the AGD NHS England Data and Analytics representative that for any future applications submitted to AGD, it would be helpful to the Group if, where available, a copy of the DPIA was provided to support the review of the application, where appropriate.<br><br>**ACTION:** AGD NHS England Data and Analytics representative to liaise with colleagues in Data and Analytics to request that, for any future applications submitted to AGD, a copy of the DPIA was provided to support the review of the application where appropriate.<br><br>**6.2.13** AGD suggested that, given the inherent and necessary lack of specifics about the processing in this application, and noting this was a three-year data sharing | D&A Rep |

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| | agreement (DSA), NHS England should consider bringing this application to AGD on an annual basis, to assess the appropriateness of the contract arrangements and access to data | |
| **6.3** | **Reference Number:** NIC-739463-H4P9N-v0.2<br><br>**Applicant:** NatCen Social Research<br><br>**Application Title:** Research on Health and Ageing using English Longitudinal Study of Ageing (ELSA) data linked to NHS data<br><br>**Observer:** Jodie Taylor-Brown<br><br>**Linked applications:** There are currently three Data Sharing Agreements (DSA) (NIC-311182-N0L1Y, NIC-32854-Y8P8B, NIC-30493-Y0C0K) which have been merged into one DSA.<br><br>The resulting DSA has been split into 2 DSAs - NIC-739463-H4P9N and NIC-759062-F2L6B (item 6.4) to accommodate a cohort split resulting from the consent model used.<br><br>**Application:** This was a new application.<br><br>The purpose of the application is for a well-established, on-going, multi-disciplinary cohort study involving a collaboration between University College London (UCL), the Institute for Fiscal Studies (IFS), the University of Manchester (UoM), the University of East Anglia (UEA), and NatCen Social Research (NatCen), who constitute the ELSA research group. ELSA aims to provide valuable insights into a range of social, health and economic issues.<br><br>The Data will be used for a programme of research on health and ageing in England; which aims to improve understanding of the ageing process, and how the use of health care affects this ageing process and the evolution of health over the lifecycle.<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>**6.3.1** AGD noted the five Data Controllers in the application form, and advised that they were all deemed to be appropriate. It was noted however, that whilst not previously noted as Data Controllers, the University of Manchester and the University of East Anglia may have had previous data controllership responsibilities (before they received data).<br><br>**6.3.2** AGD noted in the DAS internal application assessment form that NHS England had discussed honorary contract numbers with the applicant, and that whilst there were currently no individuals on honorary contracts, this may change in the future. It | |

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| | was suggested by the Group that NHS England should keep this under review, noting that there were five Data Controllers, and the possible number of honorary contracts could exceed a reasonable upper limit.<br><br>**6.3.3** AGD queried whether, in respect of the three previous DSAs (NIC-311182-N0L1Y, NIC-32854-Y8P8B, NIC-30493-Y0C0K), the applicants had received Hospital Episode Statistics (HES) data **not** covered by the consent; and were advised by NHS England that this had been reviewed internally, and that HES data had **not** flowed for any of the participants who had signed the earlier version of the consent form.<br><br>**6.3.4** AGD noted that the numbers cited for those who had signed the consent forms was **not** consistent across the documents provided; and suggested that this was reviewed and aligned as may be necessary to reflect the correct / factual information.<br><br>**6.3.5** Noting the information in the consent materials that states *"The ELSA study is part of the UK Longitudinal Linkage Collaboration (UK LLC) UK Longitudinal Linkage Collaboration"*; it was suggested that the application was updated with further information of this, including, but not limited to, any potential overlap of data flow and processing of the data.<br><br>**6.3.6** AGD noted and commended the work undertaken by NHS England's Data Access Service (DAS) on the consent review provided as a supporting document. The Group did however note that the consent review stated that consultees had **not** been asked to advise about record linkage and therefore that individuals recruited on consultee advice *"...would never be included in the cohort sent to NHS England"*, and suggested that the applicant consider changing the consultee process so that they could be included in the future.<br><br>**6.3.7** AGD noted and commended the applicant on the annual newsletters to participants, however queried what proportion of the cohort receives them and whether the applicant would benefit from a list clean to support the distribution of the newsletter; and suggested that NHS England explore this further with the applicant.<br><br>**6.3.8** AGD noted the potential public interest in the onward sharing of data, and suggested this was given further consideration by the applicant going forward, for example via a sub-licensing model.<br><br>**6.3.9** AGD queried why the territory of use was *"UK"* and not *"England and Wales"*, noting that there did not appear to be any processing of the data outside of England and Wales; and suggested that this was reviewed and updated; or that a rationale for this was provided in the application.<br><br>**6.3.10** AGD noted that the privacy notice made reference to data protection legislation, however, suggested that this was updated with further information on the specific data legislation, for example, the UK General Data Protection Regulation (UK GDPR). | |

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| | **6.3.11** AGD suggested that the benefits in section 5(d) (Benefits) of the application were reviewed and updated, to ensure that they related to benefits to health and social care, in line with NHS England's DAS Standard for Expected Measurable Benefits.<br><br>**6.3.12** AGD queried the statement in section 5(d) (iii) (Yielded Benefits) of the application *"…the Department for Work and Pensions (DWP) uses ELSA data…"*; and suggested that further information was provided as to what data DWP were accessing and how, noting that they were not permitted to access any data under this application.<br><br>**6.3.13** AGD queried the statement in section 5(a) (Objective for Processing) of the application *"Access is restricted to employees or **agents** of…"* 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>**6.3.14** AGD noted the reference in section 5(d) of the application to *"clients"*; and suggested that this was removed.<br><br>**6.3.15** AGD noted that the NHS England citation special condition in section 6 (Special Conditions) of the application differed from previous standard wording, and suggested that the application should be updated with the correct standard wording. | |
| **6.4** | **Reference Number:** NIC-759062-F2L6B-v0.2<br><br>**Applicant:** NatCen Social Research<br><br>**Application Title:** Research on Health and Ageing using English Longitudinal Study of Ageing (ELSA) data linked to NHS data<br><br>**Observer:** Jodie Taylor-Brown<br><br>**Linked applications:** There are currently 3 Data Sharing Agreements (DSA) (NIC-311182-N0L1Y, NIC-32854-Y8P8B, NIC-30493-Y0C0K) which have been merged into one DSA.<br><br>The resulting DSA has been split into 2 DSAs - NIC-739463-H4P9N (item 6.3) and NIC-759062-F2L6B to accommodate a cohort split resulting from the consent model used.<br><br>**Application:** This was a new application.<br><br>The purpose of the application for a well-established, on-going, multi-disciplinary cohort study involving a collaboration between University College London (UCL), the Institute for Fiscal Studies (IFS), the University of Manchester (UoM), the University of East Anglia (UEA), and NatCen Social Research (NatCen), who constitute the ELSA research group. ELSA aims to provide valuable insights into a range of social, health and economic issues. | |

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| | The Data will be used for a programme of research on health and ageing in England; which aims to improve understanding of the ageing process, and how the use of health care affects this ageing process and the evolution of health over the lifecycle.<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 the five Data Controllers in the application form, and advised that they were all deemed to be appropriate. It was noted however, that whilst not previously noted as Data Controllers, the University of Manchester and the University of East Anglia may have had previous data controllership responsibilities (before they received data).<br><br>**6.4.2** AGD noted in the DAS internal application assessment form that NHS England had discussed honorary contract numbers with the applicant, and that whilst there were currently no individuals on honorary contracts, this may change in the future. It was suggested by the Group that NHS England should keep this under review, noting that there were five Data Controllers, and the possible number of honorary contracts could exceed a reasonable upper limit.<br><br>**6.4.3** AGD queried whether, in respect of the three previous DSAs (NIC-311182-N0L1Y, NIC-32854-Y8P8B, NIC-30493-Y0C0K), the applicants had received Hospital Episode Statistics (HES) data **not** covered by the consent; and were advised by NHS England that this had been reviewed internally, and that HES data had **not** flowed for any of the participants who had signed the earlier version of the consent form.<br><br>**6.4.4** AGD noted that the numbers cited for those who had signed the consent forms was **not** consistent across the documents provided; and suggested that this was reviewed and aligned as may be necessary to reflect the correct / factual information.<br><br>**6.4.5** Noting the information in the consent materials that states *"The ELSA study is part of the UK Longitudinal Linkage Collaboration (UK LLC) UK Longitudinal Linkage Collaboration"*; it was suggested that the application was updated with further information of this, including, but not limited to, any potential overlap of data flow and processing of the data.<br><br>**6.4.6** AGD noted and commended the work undertaken by NHS England's Data Access Service (DAS) on the consent review provided as a supporting document. The Group did however note that the consent review stated that consultees had **not** been asked to advise about record linkage and therefore that individuals recruited on consultee advice *"...would never be included in the cohort sent to NHS England"*, | |

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| | and suggested that the applicant consider changing the consultee process so that they could be included in the future.<br><br>**6.4.7** AGD noted and commended the applicant on the annual newsletters to participants, however queried what proportion of the cohort receives this and whether the applicant would benefit from a list clean to support the distribution of the newsletter; and suggested that NHS England explore this further with the applicant.<br><br>**6.4.8** AGD noted the potential public interest in the onward sharing of data, and suggested this was given further consideration by the applicant going forward, for example via a sub-licensing model.<br><br>**6.4.9** AGD queried why the territory of use was *"UK"* and not *"England and Wales"*, noting that there did not appear to be any processing of the data outside of England and Wales; and suggested that this was reviewed and updated; or that a rationale for this was provided in the application.<br><br>**6.4.10** AGD noted that the privacy notice made reference to data protection legislation, however, suggested that this was updated with further information on the specific data legislation, for example, the UK General Data Protection Regulation (UK GDPR).<br><br>**6.4.11** AGD suggested that the benefits in section 5(d) (Benefits) of the application were reviewed and updated, to ensure that they related to benefits to health and social care, in line with NHS England's DAS Standard for Expected Measurable Benefits.<br><br>**6.4.12** AGD queried the statement in section 5(d) (iii) (Yielded Benefits) of the application *"…the Department for Work and Pensions (DWP) uses ELSA data…"*; and suggested that further information was provided as to what data DWP were accessing and how, noting that they were not permitted to access any data under this application.<br><br>**6.4.13** AGD queried the statement in section 5(a) (Objective for Processing) of the application *"Access is restricted to employees or **agents** of…"* 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>**6.4.14** AGD noted the reference in section 5(d) of the application to *"clients"*; and suggested that this was removed.<br><br>**6.4.15** AGD noted that the NHS England citation special condition in section 6 (Special Conditions) of the application differed from previous standard wording, and suggested that the application should be updated with the correct standard wording.<br><br>**6.4.16** AGD noted that Article 6(1)(e) *(public interest)* of the UK General Data Protection Regulation (UK GDPR) had not been cited in section 3(b) (Additional Data Access Requested) of the application, and suggested that this was added. | |

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| **6.5** | **Reference Number:** NIC-126676-G1X4M-v1.19<br><br>**Applicant:** University College London (UCL)<br><br>**Application Title:** Extended follow-up of the TARGIT A Trial<br><br>**Observer:** Jodie Taylor-Brown<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) meetings on the 22nd July 2021, 7th March 2019 and the 7th February 2019.<br><br>**Application:** This was an amendment application.<br><br>The amendments are: **1)** renewal of Civil Registrations of Death - Secondary Care Cut; **2)** the addition of five additional datasets: a) HES Civil Registration (Deaths) bridge; b) HES Outpatients (HES OP); c) HES Admitted Patient Care (HES APC); d) Cancer Registration Data and e) HES Critical Care; **3)** to change the territory of use from 'England and Wales' to 'Worldwide' to permit one statistician to access the data from Australia (Access will be within the UCL Data Safe Haven).<br><br>NHS England were seeking advice on the following points:<br><br>1. Whether AGD agree that Consent is sufficient to meet common law duty of confidence; and,<br>2. Whether AGD support the access from Australia given the controls outlined.<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>**In response to point 1:**<br><br>**6.5.1** AGD noted that they were of the view that the consent was sufficient to meet the Common Law Duty of Confidentiality and that it would be in the reasonable expectations of participants. The Group did note however that the purposes stated in the application did not fully reflect the extent of the processing to which participants had consented, and suggested that section 5(a) (Objective for Processing) of the application was updated / aligned with the consent to reflect the correct / factual information.<br><br>**In response to point 2:**<br><br>**6.5.2** AGD noted that that they were supportive of data access for the Professor on the honorary contract undertaking the statistical work based in Australia, noting their | |

relevant experience. The Group did however suggest that NHS England liaise with the Professor's home institution, the University of Notre Dame (Australia), to seek their view as to whether they were / should be considered a Data Controller, in line with NHS England DAS Standard for Data Controllers.

**6.5.3** AGD queried if a risk assessment had been undertaken on the data access from Australia, for example, were there appropriate controls in place. AGD suggested that NHS England seek the relevant written confirmation / assurances from the applicant, and that this was uploaded to NHS England's customer relationships management (CRM) system for future reference.

**6.5.4** AGD queried the statement in section 5(b) (Processing Activities) of the application *"The individual will act as an agent of UCL* ***at all times under supervision*** *from employees of UCL…";* and noting that the Professor in Australia would **not** be supervised at all times due to the geographical / time difference, suggested that this was reviewed and updated to reflect the correct / factual information.

In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:

**6.5.5** AGD noted that prior to the meeting, an AGD member had queried whether, given that this was a follow up to an existing study, all of the 382 participants in the extended follow up signed version 1.1 of the consent form. It was noted that NHS England had responded to confirm that all 382 participants signed the extended follow up consent form. It was also noted that original cohort consisted of 608 participants, therefore 226 did not sign the follow-up consent form.

**6.5.6** AGD queried the statement in the internal DAS Escalation Form that the study had arisen from an international study; and suggested that further clarification was provided as to what the relationship is with the international study.

**6.5.7** In addition, it was suggested that further clarification was provided as to how many participants approached provided consent; and suggested that this was clarified in the internal DAS Escalation Form and section 5 (Purpose / Methods / Outputs) of the application.

**6.5.8** AGD noted in the internal DAS Escalation Form, reference to a newsletter being sent to participants, and suggested that if this had not yet been sent, that this was updated to refer to *"NHS England"* and not *"NHS Digital"*; or if the newsletter had already been sent, suggested that any further newsletter correctly referenced *"NHS England"*.

**6.5.9** In addition, AGD suggested that the study team at UCL ensure that all communication avenues are utilised when sending the newsletter out, to ensure as many participants as possible receive this.

**6.5.10** Noting the information in the Protocol provided as a supporting document on intellectual property and commercial points; it was suggested that the information on

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| | the commercial aspect of the application was added to (the unpublished) section 5(e) (Is the Purpose of this Application in Anyway Commercial) in line with NHS England DAS Standard for Commercial Purpose; and replicated for transparency in (the published) section 5(a), in line with NHS England's DAS Standard for Objective for Processing.<br><br>**6.5.11** AGD noted the benefits outlined in section 5(d) (Benefits) of the application, however suggested that these were reviewed and updated as may be necessary to ensure that the benefits outlined reflect the purposes in section 5(a) of the application, in line with NHS England DAS Standard for Expected Measurable Benefits.<br><br>**6.5.12** AGD noted the reference in section 5(a) of the application, to the data being *"pseudonymised"*; and suggested that this was updated to reflect that the data is *"identifiable"*, in line with the rest of the application.<br><br>**6.5.13** AGD noted that the application makes no reference to the safety of medicines as being one of the purposes of the study; and suggested that section 5(a) was updated to include this.<br><br>**6.5.14** Noting the statement in section 5(b) of the application *"**All members of staff** who access the UCL DSH are required to complete Information Governance training…"*; and suggested that this was updated to be clear that this included individuals on honorary contracts.<br><br>**6.5.15** AGD noted inconsistency within the application when referring to those on honorary contracts, and suggested that the application was reviewed and updated to constantly refer to *"individual"* or *"individual**s**"*.<br><br>**6.5.16** AGD noted in the internal DAS Escalation Form that there was a query as to whether a previous special condition should still be included in the application "*Carl Zeiss will not have influence on the outcomes nor suppress any of the findings of the research";* and it was suggested by the Group that this was still included in section 6 (Special Conditions) of the application. | |
| **6.6** | **Reference Number:** NIC-717832-F6F3H-v0.3<br><br>**Applicant:** University of Oxford<br><br>**Application Title:** Outcomes Data for A Study of Cardiovascular Events iN Diabetes – PLUS (ASCEND PLUS)<br><br>**Observer:** Dan Goodwin<br><br>**Application:** This was a new application.<br><br>The purpose of the application is to follow-up participants recruited to ASCEND PLUS. The trial aims to provide evidence about both the efficacy and safety of prolonged treatment with oral semaglutide in individuals aged at least 55 years, with | |

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| | Type 2 Diabetes (T2DM), without a history of a heart attack or stroke, and without any upper or lower Haemoglobin A1c (HbA1c) threshold.<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>**6.6.1** AGD noted the funding for the work under this application was provided by Novo Nordisk, who also had representatives on the steering committee that oversees the ASCEND PLUS trial. It was suggested that NHS England review the Terms of Reference for the steering committee, to seek assurance that these individuals were **not** responsible for determining the purpose and means of processing, and were therefore **not** carrying out any data controllership activities, in line with the NHS England's DARS Standard for Data Controllers.<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 that applicant had requested ten years of Cancer Registration data, AGD queried the statement in section 3.3 (data period(s)) of the DAS internal application assessment form that filtering / minimisation of the Cancer Registration Data *"cannot be limited to events after a specific start date…all Cancers of said individual will be reported, including those before 2013"* and NHS England were therefore not able to carry out data minimisation in this instance. The Group suggested that whilst this was not incompatible with the consent, NHS England should satisfy itself that sufficient data minimisation had been undertaken, in line with NHS England DAS standard for data minimisation.<br><br>**6.6.3** The AGD Specialist Academic / Statistician member noted in section 3(b) (Additional Data Access Requested) of the application the list of individual variables requested from the National Diabetes Audit dataset; and advised that this was reasonable and in line with the purposes outlined in the application.<br><br>**6.6.4** AGD suggested that the information on the commercial aspect of the application in (the unpublished) section 5(e) (Is the Purpose of this Application in Anyway Commercial); was replicated for transparency in (the published) section 5(a) (Objective for Processing), in line with NHS England's DAS Standard for Objective for Processing.<br><br>**6.6.5** AGD noted the statement in section 5(b) (Processing Activities) and section 6 (Special Conditions) of the application *"The University of Oxford **may share** Derived Data with Novo Nordisk…"*; and suggested that this was amended to state *"…intend to share…"*.<br><br>**6.6.6** AGD noted and commended the work undertaken by NHS England's Data Access Service (DAS) on the content of the DAS internal application assessment form, which supported the review of the application. | |

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| **7 INTERNAL DATA DISSEMINATION REQUESTS:** | |
| *There were no items discussed* | |
| **8 EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL** | |
| **8.1** | **Reference Number:** NIC-692602-Q6P4F-v1.3<br><br>**Applicant:** NeoHealthHub Ltd<br><br>**Application Title:** Data modelling and analytics<br><br>**Previous Reviews:** The application and relevant supporting documents had previously been presented / discussed at the AGD meetings on the 7th December 2023, 17th August 2023 and the 25th May 2023.<br><br>The SIRO approval was for a one month renewal.<br><br>**Outcome of discussion:** AGD noted that the NHS England SIRO had already provided SIRO approval and confirmed that they were supportive of this.<br><br>AGD thanked NHS England for the written update and advised that they had no further comments to make on the documentation provided.<br><br>The NHS England SIRO representative thanked AGD for their time. |
| **9 OVERSIGHT AND ASSURANCE** | |
| *There were no items discussed* | |
| **10 AGD OPERATIONS** | |
| **10.1** | **Risk Management Framework**<br><br>As last noted in the AGD minutes from the 21st March 2024, the independent members noted the reference to reviewing materials in accordance with *"a clearly understood risk management framework"* within the published Statutory Guidance and advised that they were not aware of an agreed risk management framework, and reiterated a previous request that NHS England provide further information/ clarity on this to the Group, noting this topic had been raised by Lord Hunt in the House of Lords on the 26th June 2023, and was answered by Lord Markham on the 5th July 2023: Written questions, answers and statements – UK Parliament.<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* |

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| | *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 |
| **10.2** | **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. | |
| **10.3** | **AGD Stakeholder Engagement**<br><br>*There were no items discussed* | |
| **10.4** | **AGD Project Work**<br><br>*There were no items discussed* | |
| **11 Any Other Business** | | |
| | **AGD Annual Report**<br><br>Following on from the submission of the draft AGD Annual Report v0.6 to Jackie Gray following the 18th April 2024 AGD meeting and the provision of further narrative based on what AGD had been seeing in terms of requests for advice to date as noted at the 20th June 2024 meeting, AGD noted that they had received a request on the 26th June 2024 via the NHSE SIRO Representative, with a deadline for a response the following week, to provide further narrative, edits and information on the draft AGD Annual Report 2023/24.<br><br>AGD members had reviewed the draft report and provided draft narrative by the 1st July 2024. The AGD Chair and AGD Secretariat had finalised the final draft v0.12 and forwarded to Jackie Gray on the 3rd July 2024. | |

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| | **ACTION:** AGD Secretariat to forward a copy of v0.12 to AGD for information | AGD Sec |
| **11.1** | **News Article**<br>Paul Affleck highlighted to the Group, for information, a recent news article published in ComputerWeekly.com on the 25th June 2024 'UK government's M365 use under scrutiny after Microsoft's 'no guarantee of sovereignty' disclosure'. | To Note |

**Meeting Closure**

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