Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 25th May 2023

09:30 – 15:30

(Remote meeting via videoconference)

INDEPENDENT ADVISERS IN ATTENDANCE:	
Name:	**Role:**
Paul Affleck (PA)	Specialist Ethics Adviser / Co-Deputy Chair (Items 1 to 5.3)
Dr. Imran Khan (IK)	Specialist GP Adviser / Co-Deputy Chair (Chair)
Dr. Geoffrey Schrecker (GS)	Specialist GP Adviser (Items 1 to 5.1)
Dr. Maurice Smith (MS)	Specialist GP Adviser
Jenny Westaway (JW)	Lay Adviser
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	**Role / Area:**
Michael Chapman (MCh)	Data and Analytics representative
Garry Coleman (GC)	NHS England SIRO Representative
Kate Croft (KC)	Information Lead Manager and IAO, Community, National Obesity Audit, and Mental Health of Children and Young People Survey Wave 4 (**Presenter**: item 4.2)
Dave Cronin (DC)	Data Access Request Service Senior Approval Team (DARS SAT) (**SAT Observer**: item 5.1)
Cath Day (CD)	Data Access Request Service Senior Approval Team (DARS SAT) (**SAT Observer**: items 5.4 to 5.5)
Mujiba Ejaz (ME)	Data Access Request Service (DARS) (**Presenter**: item 5.3)
Dan Goodwin (DG)	Data Access Request Service (DARS) (**Presenter**: item 5.1)
Carla Howgate (CH)	Clinical Audit Manager, Population Health, Clinical Audit and Specialist Care (**Observer**: item 4.2)
Dickie Langley (DL)	Data Protection Officer (DPO) representative (Delegate for Jon Moore)
Chris Leary (CL)	Head of Delivery, Wayfinder Programme (**Observer**: item 4.3)

Karen Myers (KM)	Secretariat Team (**Presenter**: item 9.2)
Dr. Jonathan Osborn (JO)	Caldicott Guardian Team representative
Denise Pine (DP)	Data Access Request Service (DARS) (**Presenter**: items 5.4 to 5.5)
Jodie Taylor-Brown (JTB)	Data Access Request Service (DARS) (**Observer**: item 5.1)
Alison Ward (AW)	Programme Director, Wayfinder Programme (**Presenter**: item 4.3)
Kimberley Watson (KW)	Data Access Request Service Senior Approval Team (DARS SAT) (**SAT Observer**: item 5.2 to 5.3)
Vicki Williams (VW)	AGD Secretariat Team (**Presenter**: items 8 and 9.1)
Clare Wright (CW)	Data Access Request Service (DARS) (**Presenter**: item 5.2)
Tom Wright (TW)	Head of Service, Data Services for Commissioners (DSfC) (**Presenter**: item 4.1)
INDEPENDENT ADVISERS NOT IN ATTENDANCE:	
Prof. Nicola Fear (NF)	Specialist Academic Adviser
Dr. Robert French (RF)	Specialist Academic / Statistician Adviser
Kirsty Irvine (KI)	Chair

1	**Welcome and Introductions** The NHS England Senior Information Risk Owner (SIRO) Representative advised attendees that, noting the statutory guidance and the AGD Terms of Reference (ToR) had not yet been agreed, the meeting could not be held under the draft ToR, until they have been approved, and recognised that the draft ToR may change as the statutory guidance evolves. As NHS England would like to seek advice on a number of areas, the NHS England SIRO Representative therefore proposed that: • Kirsty Irvine (as an independent adviser) will be asked to Chair the AGD meetings; • The meeting will be minuted, with advice and minutes published; • Attendees will include both independent advisers from outside NHS England and representatives from within NHS England. Attendees from NHS England include representatives covering the offices of the Data Protection Officer (DPO); the Caldicott Guardian; and the SIRO. • Attendees would not be listed as “members” in minutes during the transitional period; • NHS England representatives would not, during the transitional period, be formally part of any consensus that is reached, but would be active participants in the meeting; • It was agreed to use the Data Access Request Service (DARS) Standards / Precedents in relation to applications for external data sharing.

	The attendees present at the meeting considered the proposal put forward by the NHS England SIRO Representative and, as no objections were raised, it was agreed that the meeting would proceed on this basis. Dr. Imran Khan, on behalf of Kirsty Irvine, noted and accepted the request from the NHS England SIRO Representative to chair; and welcomed attendees to the meeting.
2	**Review of previous AGD minutes:** The minutes of the 18th May 2023 AGD meeting were reviewed and subject to a number of minor amendments were agreed as an accurate record of the meeting.
3	**Declaration of interests:** Dr. Imran Khan noted a potential conflict with 'National Obesity Audit (NOA) Directions 2023, including new use of Cardiovascular Prevent Audit (CVDP) briefing paper', as part of his roles as Deputy Chair of the Health Informatics Group at the RCGP and Co-deputy Chair of the Joint GP IT Committee.
BRIEFING PAPER(S)	
4.1	**Title:** National Theatres Productivity Dataset **Presenter:** Tom Wright **Previous Reviews:** The National Theatres Productivity Dataset briefing paper was previously presented at the IGARD meetings on the 18th July 2019 and the 12th September 2019. The updated briefing paper provided details that, to support COVID-19 recovery of services and management, the theatre productivity data collection will now need to include the patient NHS number, which is an identifiable data field. The overall purpose of the briefing paper was to provide details of the Theatres Productivity Data Collection, which has, to date, been operational as a voluntary anonymous collection managed by NHS England; and is used to capture information on elective and emergency care surgery on a fortnightly basis. The purpose for the collection was to identify theatre productivity opportunities and support continuous improvements in line with NHS England's statutory improvement functions. Data is processed into metrics which are then loaded to the Model Health System for display at whole Trust and Specialty level. These metrics have provided a means to share benchmarking data with NHS Trusts to identify unwarranted variation in theatre productivity; and allows providers to look for best practice and to learn from peers and other providers nationally. The data collected to date has **not** included confidential data (subject to the duty of confidentiality) or patient personal data but does contain consultant level / case level theatre data. Currently trusts send a scrambled reference number which is just used for the purposes of removing duplicate records. **Outcome of discussion:** The group welcomed the updated briefing paper and made the following observations / comments: **4.1.1** The independent advisers noted that Article 6(1)(c) (legal obligation) of the UK General Data Protection Regulation (UK GDPR) had been cited in the briefing paper; and queried whether this was the correct legal basis.

	4.1.2 The independent advisers noted concerns about the use of the COVID-19 public health NHS England Directions 2020, and whether this use extends beyond that which may be reasonably expected; and highlighted this as a risk to NHS England. **4.1.3** It was suggested by the independent advisers that, noting the significant update to the data collection, that this was now classed as a *"new"* data collection built on an existing collection, for example, noting that identifiable data is now part of the collection, and there is no option for patients to opt-out. **4.1.4** The independent advisers noted the importance of including patients as key stakeholders and suggested that this was reflected in the briefing paper. **4.1.5** In addition, it was suggested by the independent advisers that there was some patient and public involvement and engagement (PPIE), including but not limited to, seeking views on how information about this data collection could be communicated to patients, for example, pre-operative, updated privacy notices, press releases etc. **4.1.6** The independent advisers advised NHS England that they were supportive of the need to have access to this type of data to support the NHS and NHS services, now and beyond the COVID-19 recovery period; and offered support to any frameworks and consultations. **4.1.7** The group looked forward to receiving the finalised briefing paper, either out of committee (OOC) or tabled at a future meeting (before, or contemporaneously with, any first of type applications received by AGD).
4.2	**Title:** National Obesity Audit (NOA) Directions 2023, including new use of Cardiovascular Prevent Audit (CVDP) **Presenter:** Kate Croft **Observer:** Carla Howgate **Previous Reviews:** The CVDP Audit briefing paper was previously presented at the AGD meeting on the 18th May 2023; the IGARD BAU meeting on the 10th December 2020; and the IGARD COVID-19 response meeting on the 8th December 2020. The paper submitted to the group was to provide further information on the background of the audit and why the National Obesity Audit (NOA) Directions 2023 are to be established, which include a new use of a subset of the CVDP data. The NOA was launched in 2022 and has been established by NHS England as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP). A new NOA Direction is being established to permit this collection (reuse) of a subset of the CVDP data set and linkage to other approved data sets to create a new data asset for NOA purposes. The NOA Directions establish the legal bases for the processing of the new NOA data asset. This request covers the purpose of the new NOA Directions, this will permit NHS England to collect certain data items from the CVDP data flow for these new NOA purposes, creating a separate NOA CVDP Asset. Therefore, whilst there is one practical flow from GP systems, the NOA will provide a new legal basis for collection of these data items, which also permits analysis and linkage of data named above for NOA purposes. **Outcome of discussion:** The group welcomed the updated briefing paper and made the following observations / comments:

	4.2.1 The independent advisers noted that they were supportive of the use of this data to support the work outlined in the briefing paper; and the use of GP data in this manner. **4.2.2** The independent advisers raised concerns about the multiple Directions being used for the flow of this data, and noted the potential confusion around the purposes, restrictions on uses and how they interplay. **4.2.3** In addition, the independent advisers suggested that further consideration was given on the data being collected or used beyond the CVDP Audit and whether the CVDP direction needs to be amended to remove the restrictions on how the data can be linked, used and shared. **4.2.4** The independent advisers suggested that the Data Protection Impact Assessment (DPIA) was updated to reflect the linkage and the data retrieved from the CVDP Audit. **4.2.5** It was suggested that some of the clinical areas may not be aware of the programme, and suggested by the independent advisers that further consideration should be given to the appropriate transparency, noting the breadth of the areas this may impact. **4.2.6** The independent advisers highlighted the requirement to understand the 'missingness' of the data not collected through GP collection and what this means for the programme; and suggested this was explored further. **4.2.7** Noting the reference to the *"ICO's Anonymisation code of practice"*, the independent advisers suggested that this was removed as it was no longer current. **4.2.8** The group looked forward to receiving the finalised briefing paper, either out of committee (OOC) or tabled at a future meeting (before, or contemporaneously with, any first of type applications received by AGD).
4.3	**Title:** NHS Wayfinder Services Direction **Presenters:** Alison Ward **/** Chris Leary The paper submitted to the group is to provide an overview of the draft Wayfinder Directions 2023 (Directions) which will be issued to NHS England by the Secretary of State for Health and Adult Social Care. These are issued under section 254 of the Health and Social Care Act 2012, regulation 32 of the National Institute for Health and Care Excellence (Constitution and Functions) and the Health and Social Care Information Centre (Functions) Regulations 2013, and section 13ZC of the National Health Service Act 2006. The purpose of the Directions is to require NHS England to develop and operate the NHS Wayfinder programme and related services (collectively the NHS Wayfinder Services). These services will enable patients in England to access details of appointments and additional information about NHS Trust referrals and their elective care via the NHS App. They will also generate anonymous statistical data which may be used by NHSE to better understand health issues and challenges, and to support strategies which may improve health outcomes for the population and reduce inequalities in health. These Directions will replace the Wayfinder (NHS App) Services Directions 2022 issued by NHS England to NHS Digital. **Outcome of discussion:** The group welcomed the updated briefing paper and made the following observations / comments: **4.3.1** The independent advisers discussed concerns on providing both information for NHS app users about their appointments and to manage the health service; and suggested that the purpose was

	clarified, as primarily for direct care but also specific secondary care uses, so patients can understand what is happening with data. **4.3.2** The independent advisers expressed support for intended additional benefits, for example, reducing paper correspondence, (potentially saving significant sums in postage costs) and workload, greater efficiency through using the app etc. **4.3.3** The independent advisers discussed some of the descriptions of the use of data for secondary purposes, specifically confusion around the category of data; and that there needed to be alignment across all the documents and transparency materials, noting there was an opportunity to harness the capabilities of the NHS App to improve transparency directly to app users in respect of data protections rights, purpose of the programme etc. **4.3.4** The group looked forward to receiving the finalised briefing paper, either out of committee (OOC) or tabled at a future meeting (before, or contemporaneously with, any first of type applications received by AGD).	
EXTERNAL DATA DISSEMINATION REQUESTS:		
5.1	**Reference Number:** NIC-148161-XXPS5-v1.27 **Applicant:** UK Health Security Agency (UKHSA) **Application Title:** MR185 - UK Participants in the UK Atmospheric Nuclear Weapons Test (NWTPS) **Presenter:** Dan Goodwin **SAT Observer**: Dave Cronin **Observer:** Jodie Taylor-Brown **Linked applications:** This application is linked to NIC-682587-K5N5K. **Application:** This was a new application coming for advice. Should the application be approved by NHS England, further details would be made available within the Data Uses Register. NHS England were seeking advice on the following point: 1. AGD gave feedback on NIC-148219-ZHB4Z on the 27th April 20203, which was an application from UK Health Security Agency (UKHSA), relying on the same legal basis which is relevant to this application. The group were asked to consider the applicant's response to the feedback on NIC-148219-ZHB4Z and consider it for this application (this application being both NIC-148161-XXPS5 and NIC-682587-K5N5K). Should the application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** The group were supportive of the application and wished to draw to the attention of the SIRO the following comments: In response to point 1 **5.1.1** The independent advisers noted that two Article 9 UK General Data Protection Regulation (UK GDPR) conditions had been cited, Article 9(2)(i) *(public interest in the area*	

	of public health) and 9(2)(j) *(archiving purposes in the public interest)*; and suggested it would be more appropriate to use just one Article 9 legal basis, unless the other condition covered a different purpose. **5.1.2** The independent advisers noted the information within section 6.1 of the internal assessment form, that stated the applicant had advised NHS England that data had been shared with Brunel University for a project, and that this sharing of data was covered by a separate data sharing agreement (DSA) between NHS Digital (now NHS England) and Brunel University. The independent advisers queried whether the data shared with Brunel University was for the purpose of surveillance only, as per the purpose under this DSA and suggested that this was clarified. **5.1.3** In addition, it was also noted within section 6.1 of the internal assessment form, that the applicant had advised that they were happy to share data in the future for *"…appropriate ethically approved studies…"*; and suggested that this was queried noting that this was suggestive of research not surveillance. **5.1.4** The NHS England SIRO representative queried information within the application in terms of the difference between surveillance and research; and suggested that, for audit purposes, DARS satisfied itself that the applicant was clear that they could only do surveillance in line with Regulation 3(1)(a) *(diagnosing communicable diseases and other risks to public health)*, (b) *(recognising trends in such diseases and risks)* of the associated Health Service (Control of Patient Information (COPI)) Regulations 2002. **5.1.5** The independent advisers noted the references in the application to a *"control group of servicemen"*; and advised that the applicant should provide further information on this, including, but not limited to, whether this was classed as surveillance *o*f a risk to public health and whether this falls under Regulation 3(1) of COPI; and that this may need to be considered by UKHSA's oversight panel. **5.1.6** Noting the statement in section 5(c) (Specific Outputs Expected) *"no further analyses are planned for the next five years"*; the independent advisers queried why new data was required if there was no processing taking place; and suggested that a justification / explanation was provided within section 5.	
5.2	**Reference Number:** NIC-356980-Z5B9G-v0.15 **Applicant:** MAC Clinical Research Finance Ltd **Application Title:** Enhancing clinical research on consented patients who want to enter clinical trials **Presenter:** Clare Wright **SAT Observer**: Kimberley Watson **Application:** This was a new application. The purpose of the application is to support the applicant in assessing the eligibility of consented participants to enter clinical trials and provide care to eligible participants during the trial. The purpose is for verifying the medical history details already provided by the consented participants to the applicant at the point of consent to screen.	

	Should the application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** The group were **not** supportive of the application and wished to draw to the attention of the SIRO the following substantive comments. **5.2.1** The group recognised the potential benefits to reducing the burden on the NHS, and encouraging participation in clinical trials, however significant concerns were raised in relation to the legal bases cited, the handling of the data, and the statements made within the application. The group supported the view of the DARS team that the application should be rejected. **5.2.2** NHS England advised the group that as highlighted in section 1 (Abstract) of the application, there had been ongoing discussions with the applicant in respect of the legal basis for processing under Article 6 and Article 9 of the UK General Data Protection Regulation (UK GDPR). **5.2.3** In addition, NHS England had advised that they had made the applicant aware that the UK GDPR legal basis cited in the applicant's published privacy notice, Article 6(1)(f) *(legitimate interests)* and Article 9(2)(j) *(archiving purposes in the public interest)* did **not** align with legal basis cited in the application, Article 6(1)(c) *(legal obligation)* and Article 9(2)(i) *(public interest in the area of public health);* and that, prior to the meeting, the applicant had advised that they had updated the legal basis in the privacy notice to align with the application. **5.2.4** The NHS England SIRO Representative expressed concern and surprise that the applicant had changed their UK GDPR legal basis within their privacy notice on their website without providing a justification for doing so; and that this did not align with the usual process for amending a legal basis; and advised that they would be happy to discuss this further with the applicant. **5.2.5** In addition, the SIRO Representative advised that further discussions had taken place prior to the meeting in respect of the legal basis cited in the application and that although the group would not usually comment / query the legal basis cited, it seemed appropriate in this case to challenge and address this. **5.2.6** The independent advisers noted and agreed with the comments / concerns raised by the SIRO representative; and expressed concern that the current legal bases cited in the application restrict data protection rights to individuals; and suggested that the applicant review this and provide a clear justification for the legal bases cited, in line with the ICO guidance, including the confirming the rights of individuals to opt-out. **5.2.7** The independent advisers queried when the data would be destroyed and when it was retained, for example when participants were screened but not selected for a clinical trial; and how the legal basis applied to each of these cohorts; and suggested that this was made clear within section 5 (Purpose / Methods / Outputs) of the application. **5.2.8** The independent advisers noted support for the premise of setting up a clinical trial database; however, suggested that further, rigorous scrutiny of the consent materials was required before the database was in place. **5.2.9** The independent advisers queried the purpose for processing outlined in section 5(a) (Objective for Processing), and queried the references to supporting primary care	

	practitioners, and suggested that this appeared to be overstated; and suggested that this was reviewed and updated, for example, if the purpose was to ensure quality of the data, then should be front and central to the purpose section. **5.2.10** The independent advisers noted the output in section 5(c) (Specific Outputs Expected) that stated "…*new therapies ensure that patients have access to the latest health innovations which offer advancements to clinical care and improved patient outcomes both in the UK and around the world*"; and suggested that this was updated to reflect that the trial treatment/innovation may not be released in the market, and that safety monitoring would continue beyond the trial. **5.2.11** Noting the statement in section 5(e) (Is the Purpose of this Application in Anyway Commercial) that *"clients are 95% pharmaceutical companies and 5% NHS"*; it was suggested by the independent advisers that section 5(a) was updated to make this detail clear and to make clear that an assessment had been undertaken that the commercial benefit accruing to the commercial organisation is proportionate to the benefit to health and social care, in line with the NHS England DARS Standard for Commercial Purpose. **5.2.12** The independent advisers noted the funding information outlined in section 5(e) and suggested that this was added to section 5(a) for transparency; and suggested that the statement *"The funding comes from multiple sources"* was removed. **5.2.13** The independent advisers also queried the statement in section 5(e) that *"…the commercial element is incidental to the processing of patients [sic] data…"*; and suggested this was removed. **5.2.14** The group would welcome consideration of an application once the significant comments raised by the group were substantively addressed.	
5.3	**Reference Number:** NIC-692602-Q6P4F-v0.3 **Applicant:** Neosypher Limited **Application Title:** Medicines dispensed in Primary Care NHS Business Services Authority data **Presenter:** Mujiba Ejaz **SAT Observer**: Kimberley Watson **Application:** This was a new application. The application is for the purpose of providing services to NeoSypher Limited's clients in the health sector. The data will be used to provide the following services only: **1)** Benchmarking, **2)** Service evaluation, and **3)** Treatment Evaluation. Should the application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** The group were **not** supportive of the application and wished to draw to the attention of the SIRO the following substantive comments, and suggested that the application be brought back to a future meeting: **5.3.1** NHS England advised the group that following submission of the application to the group for review, they had identified further updates to the application: **1)** the text used in section 3(c) (Patient Objections) had been amended to reflect the latest wording in respect	

	of opt-outs; and **2)** to make clear that Neosypher Limited would provide the dashboards to NHS organisations without any charge, and that charges would only be applied to private organisations. **5.3.2** In addition, NHS England advised that discussions had been held with the applicant and the NHS BSA Information Asset Owner (IAO), who had confirmed that they were content that the purpose of the study aligned with the Direction. The independent advisers noted the verbal update from NHS England, however advised that it was their view that the purposes outlined within the application did not always align with the Direction. The NHS England SIRO representative advised the group that the NHS BSA Information Asset Owner (IAO) was due to attend an AGD meeting in June 2023 (as advised in the AGD minutes from the 18th May 2023); and in respect of this specific application, he would seek further clarification from the IAO on the review undertaken, to ensure consistency across all applications. **5.3.3** NHS England also noted that **only** Neosypher Limited would be involved with this application, and not any linked organisations; and that data would only be processed within England and Wales; and advised that this was made clear in the internal application assessment form and the application. The independent advisers noted the verbal update from NHS England, however, did note a potential reputational risk to NHS England in terms of the chain of ownership of Neosypher Limited noting some of the negative information available within the public domain with regard to their American parent owner. **5.3.4** The independent advisers advised that a primary risk was that it appeared the benefits to commercial clients may be to support their marketing activities, that this was not as clear as it could be in the application, and that the commercial aspect of the application was more significant than was initially proposed in the application. **5.3.5** It was suggested by the independent advisers that section 5(a) was updated to make clear that an assessment had been undertaken that the commercial benefit accruing to the commercial organisation is proportionate to the benefit to health and social care, in line with NHS England's DARS Standard for Commercial Purpose. **5.3.6** In addition, it was suggested by the independent advisers, that section 5(d) was reviewed and updated to ensure the benefits aligned with the terms of the Direction; and in line with NHS England's DARS Standard for Expected Measurable Benefits. **5.3.7** The independent advisers noted that the services provided by Neosypher Limited under this application appeared to be distinct from other services they provide; and suggested that there was further transparency around the use of data in this application. **5.3.8** The independent advisers queried the statement in the Legitimate Interest Assessment (LIA provided as a supporting document *"all users of NHS services are informed that pseudonymised data will be used for the purposes of market research…"*; and suggested that this was amended noting that the data cannot be used for market research. **5.3.9** In addition, the independent advisers noted the statement in section 5(e) *"Processing conducted by NeoSypher Limited for this purpose will not be used to market specific drugs"*; and suggested that this was revised or removed to accurately reflect proposed the use of the data by NeoSypher and by its clients. **5.3.10** The independent advisers queried the statement in section 5(a) *"…processing is necessary for the purposes of the legitimate interests pursued by the controller or by a* ***third***	

	***party**…"*; and suggested that the reference to *"third party"* was removed and clarification was sought from the applicant that no other parties were considered data controllers, in line with NHS England's DARS Standard for Data Controllers. **5.3.11** The independent advisers suggested that the application may have overstated the commercial demand for the service Neosypher Limited want to provide; and suggested that NHS England seek further information on this, for example, evidence of demand for the product.	
5.4	**Reference Number:** NIC-148044-RGS7W-v5.6 **Applicant:** University of Oxford **Application Title:** MR1471 (MR865 & MR850) - Whitehall Study of London Civil Servants **Presenter:** Denise Pine **SAT Observer:** Cath Day **Previous Reviews:** The application and relevant supporting documents were previously presented / discussed at the IGARD meetings on the 11th October 2018 and the 15th November 2018. **Application:** This was an extension application. The purpose of the application is for a research project to **1)** determine the combined influence on cause-specific mortality in old age of lifestyle, socioeconomic circumstances, and cardiovascular disease (CVD) risk factors measured both in middle and in old age; **2)** to provide reliable estimates of mortality risks associated with these factors and plasma markers when measured in old age alone; **3)** to ascertain whether mortality differentials by employment grade before retirement persist into old age and assess whether these are modified by additional circumstances measured in old age alone; **4)** to examine the associations between characteristics measured at the original survey and morbidity 25 years later including CVD morbidity, and self-assessment of physical and mental health. Should the application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** The group were supportive of the application and wished to draw to the attention of the SIRO the following comments: **5.4.1** The independent advisers commended NHS England and the applicant on the work undertaken on the application. **5.4.2** NHS England advised the group that following submission of the application to the group for review, they had identified further updates to the application: **1)** the start and end date of the data sharing agreement (DSA) were incorrect and would need updating; **2)** to edit section 5(c) (Specific Outputs Expected) and section 5(d) (Benefits) (iii) (Yielded Benefits) to ensure the outputs and yielded benefits were in the correct section; **3)** to edit section 5(c) and section 5(d) (iii) to ensure the outputs and yielded benefits do not relate to the data breach identified under a previous iteration of the DSA *(which has been addressed)*, whereby derived data was shared with the University of Cambridge; **4)** to remove duplicate information from section 5(d); and **5)** to amend grammatical errors	

	identified throughout the application. The group noted the verbal updates from NHS England. **5.4.3** In addition, NHS England advised the group, that the applicant had advised that all identifiable data previously supplied by NHS Digital that had s251 support had been destroyed; however, noting the applicant was still providing evidence of the annual review to Health Research Authority Confidentiality Advisory Group (HRA CAG); and therefore advised that section 3(a) (Data Access Already Given) had been updated to reflect that common law duty of confidentiality was addressed by s251, and that s261(2)(a) was the legal basis for the pseudonymised data; and that section 3(c) (Patient Objections) would need to be updated to clarify that the data was pseudonymised and that the common law duty of confidentiality does not need to be met. The independent advisers noted the verbal update, however advised that even if the applicant no longer holds any identifiers, they will still need s251 in order to allow NHS England to hold the identifiers for the cohort on their behalf. **5.4.4** The independent advisers noted the information within the privacy notice that states that participants can withdraw from the study if they wished, and queried how they could be withdrawn if the identifiers are held by NHS England; and suggested that this was explored further.	
5.5	**Reference Number:** NIC-147755-C5H4X-v6.8 **Applicant:** University of Oxford **Application Title:** 15-year follow-up of the Arterial Revascularisation Trial (ART) **Presenter:** Denise Pine **SAT Observer:** Cath Day **Application:** This was a renewal, extension and amendment application. The amendments are to **1)** now use the data for a 15-year follow up of the cohort; **2)** to request Hospital Episode Statistics Accident and Emergency (HES A&E), HES Admitted Patient Care (APC), HES Critical Care and HES Outpatients data. Civil Registration Deaths data is also being requested, which replaces the historic Medical Research Information Service (MRIS) Cause of Death report and is not an additional dataset; **3)** removal of the reuse of the data for sub-studies. Should the application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** The group were supportive of the application and wished to draw to the attention of the SIRO the following substantive comments: **5.5.1** The independent advisers noted that as part of the supporting documents provided for review / information, there were three newsletters, each containing slightly different information to the cohort about the 15-year follow up; for example, two of the letters asked that participants responded to say they were content with the 15-year follow-up, and the latest version provided the information but did **not** ask for contentment from participants. The independent advisers suggested that NHS England seek further clarity from the applicant, to determine who the letters were sent to, and when.	

	5.5.2 In addition, there was various information within the newsletters in respect of the options to opt out of the study; and expressed concern that not all participants may have received this information. **5.5.3** The independent advisers noted the special condition in section 6 (Special Condition), that stated *"within 2 weeks of this v6 Data Sharing Agreement being activated, the cohort must be updated to remove participants who have withdrawn their consent, died, or been lost to follow-up"*; and noting the issues raised with the newsletters, queried how the study team would know who to withdraw from the study, if not all participants had received the newsletter and been asked to provide contentment with the 15-year follow-up; or given the option to withdraw from the study; and suggested that this was explored further. **5.5.4** The independent advisers suggested that **before** any data flows, the applicant should take proactive steps, such as engaging with a small representative sample of the cohort, to check their understanding of the proposed processing, including, but not limited to, the 15-year follow-up. In addition, the group made the following observations on the application and / or supporting documentation provided as part of the review: **5.5.5** NHS England advised the group that following submission of the application to the group for review, they had identified three further updates to the application: **1)** to update section 3(b) (Additional Data Access Requested) to reflect that the data requested is *"identifiable"* and not *"pseudonymised"*; **2)** to remove one of the duplicate special conditions in section 6; and **3)** to update the application throughout to ensure *"NHS England"* is referred to and not *"NHS Digital"*. The group noted the verbal updates from NHS England. **5.5.6** The independent advisers noted the technical language in section 5(d) (Benefits); and suggested that this was updated to ensure it was written in a manner suitable for a lay reader. **5.5.7** Noting the acronyms in section 5(d), the independent advisers suggested that these be correctly defined upon first use.	
AGD Operations		
6	**NHS England's protection of patient data - Statutory Guidance** The group noted that NHS England's protection of patient data - Statutory Guidance; on how NHS England should exercise the statutory functions that are intended to be transferred from NHS Digital, had been published on the 23rd May 2023.	To note
7	**AGD Terms of Reference** NHS England advised independent advisers, that further work / discussions were ongoing in respect of updating the draft Terms of Reference; and that this would be shared with stakeholders, including AGD as soon as possible. The independent advisers noted and thanked NHS England for the verbal update and looked forward to receiving an updated draft of the Terms of Reference in due course for review / comments.	To note
8	**Standard operating procedures**	

	The ongoing forward plan of work for creating Standard Operating Procedures was discussed.	To note
9	**New Operational Actions & those carried forward from previous meetings of AGD:**	
9.1	**IR35 / Zero Hours contracts for independent advisers** Vicki Williams noted that NHS England were actively working on putting zero hours contracts in place for all independent advisers.	To note
9.2	**Service Improvements** The IGARD Service Improvement Closure Report *(please see IGARD minutes from the 26th January 2023)* stated *"…and recommends that ongoing service improvement forms part of the new committee secretariat's remit following the merger of NHS Digital with NHS England on the 1st February 2023"*. At the first AGD meeting on the 2nd February 2023, an action was agreed by the group that *"**…** service improvement would be an integral part of the AGD work programme and as part of the AGD service improvements, AGD attendees would provide regular feedback on the AGD meetings, i.e. structure, processes etc to the Secretariat Team"*. A verbal update was provided to the group by the AGD Secretariat in respect of this programme of work, where a number of 'observations' and 'actions' were highlighted following initial feedback from the independent advisers and NHS England. The group were advised that the 'actions' would be addressed as part of the service improvement programme of work; and that further details on progress would be provided following the next round of service improvement engagement towards the end of August / early September 2023.	
Any Other Business		
	Meeting Closure As there was no further business raised, the Co-Deputy Chair thanked attendees for their time and closed the meeting.	