Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 27th February 2025

09:00 – 16:00

(Remote meeting via videoconference)

AGD INDEPENDENT / NHS ENGLAND MEMBERS IN ATTENDANCE:	
Name:	**Role:**
Paul Affleck (PA)	AGD independent member (Specialist Ethics Adviser) (not in attendance for item 5.6)
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)
Andrew Martin (AM)	NHS England member (Data Protection Office Representative (Delegate for Jon Moore))
Dr. Jonathan Osborn (JO)	NHS England member (Caldicott Guardian Team Representative)
Jenny Westaway (JW)	AGD independent member (Lay Adviser)
Miranda Winram (MW)	AGD independent member (Lay Adviser)
Tom Wright (TW)	NHS England member (Data and Analytics Representative (Delegate for Michael Chapman)) (not in attendance for items 7.4 to 10.2)
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	**Role / Area:**
Gosia Bartkowska (GB)	Data Operations Principal Administrator, DigiTrials, Data and Analytics, Transformation Directorate (**Observer:** item 5.1)
Ricky Brooks (RB)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer:** item 5.1 and 5.2)
Garry Coleman (GC)	NHS England SIRO Representative (not in attendance for part of item 9.6)

Ayse Depsen (AD)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer:** item 5.3)
David Evans (DE)	Information Governance Lead, Privacy, Transparency and Trust (PTT), Delivery Directorate (**Observer**: item 9.6)
Louise Garnham (LG)	Data Operations Manager, DigiTrials, Data and Analytics, Transformation Directorate (**Observer**: item 5.1)
Dan Goodwin (DG)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer:** item 5.4)
Suzanne Hartley (SH)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer:** item 5.2)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Delivery Directorate
Humphrey Onu (HO)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer:** item 5.5)
Simon Snowden (SS)	Senior Manager - specialist analytical support functions, Data Collection, Curation and Product, Data Product Development, Data and Analytics, Transformation Directorate (**Presenter**: item 4.1)
Jodie Taylor-Brown (JTB)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer:** item 5.6)
James Watts (JWa)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer:** item 5.3)
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Delivery Directorate
Sarah Woodhouse (SW)	Principal Consultant, NHS England Outcomes and Registries Programme (ORP) (**Observer**: item 4.1)
AGD INDEPENDENT MEMBERS / NHS ENGLAND MEMBERS <u>NOT</u> 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)

1	**Welcome and Introductions:** The AGD Chair welcomed attendees to the meeting. AGD noted that, due to unforeseen circumstances, only two AGD NHS England members were in attendance for items 7.4 to 10.2. Noting that the AGD Terms of Reference state that *"The quorum for meetings of the Group or a Sub-Group is five members, including at least three independent members, one of whom may be the Chair, Deputy Chair or Acting Chair and **two of the three NHSE Members**…",* the Group agreed that, as there were two AGD NHS England members present, the meeting was still quorate for **all** agenda items and agreed to proceed on that basis.	
2	**Review of previous AGD minutes:** The minutes of the AGD meeting on the 6th February 2025 were reviewed out of committee by the Group and, after several minor amendments, were agreed as an accurate record of the meeting by the AGD Chair, on behalf of the Group.	
3	**Declaration of interests:** AGD noted that some of the members noted a previous working relationship with a member of staff at Quality by Randomization Limited (Trading as Protas) (NIC-775420-M7D8Z). It was agreed that this would not impact on the discussion, or the advice provided to the NHS England SIRO Representative. Dr. Robert French noted professional link to the 'Secure Anonymised Information Linkage' (SAIL) Databank and the staff involved with SAIL through his role at Cardiff University. It was agreed this did not preclude Dr. French taking part in the discussion about this application. Paul Affleck noted a professional link to CORECT-R (NIC-656885-M7T5X) as part of his role at the University of Leeds; and it was agreed that Paul would **not** remain in the room for the discussion of this application. Kirsty Irvine noted a personal link to the Head of Legal at Health Data Research UK (HDRUK) (NIC-680176-M2P2Y-v0), but noted no specific connection with the application or other staff involved, and it was agreed that this was not a conflict of interest.	
4 BRIEFING PAPER(S) / DIRECTIONS / DPIAs:		
4.1	**Title:** Medical Devices Outcomes Registry (MDOR) National Vascular Registry (NVR) Devices Data Protection Impact Assessment (DPIA) **Presenter:** Simon Snowden **Observer:** Sarah Woodhouse	

	The purpose of the DPIA is in respect of the regular flow of implantable medical device data from the National Vascular Registry (NVR) to NHS England's Medical Devices Outcomes Registry (MDOR) via Secure File Transfer Protocol. The flow is in relation to the MDOR being the national, central means of collecting patient-level implantable device data to facilitate accurate patient contact in the event of a product recall or field safety notice. NHS England expects to process and analyse NVR medical devices data for the purposes of detecting and predicting issues relating to patient safety and outcomes across clinical specialities areas, and preventing harm to future patients; maximising data for surveillance, benchmarking and recall activities; increasing transparency and accountability; and enhancing research and development. NHS England were seeking advice on the following points: 1. Does the DPIA adequately fulfil its purpose of identifying and reducing risks associated with the processing of personal data. 2. Can AGD identify gaps in the DPIA that need to be addressed. 3. Can AGD advise whether additional stakeholders should be consulted. **Outcome of discussion:** AGD welcomed the draft DPIA and made the following observations / comments: **4.1.1** AGD noted that the work outlined in the DPIA was impactful with a clear public interest. **In response to points 1 and 2 above:** **4.1.2** AGD suggested that it was made clear at the start of the DPIA that data was flowing for clinicians as well as patients. **4.1.3** AGD noted concern that that the privately funded sector provide data on a voluntary basis, and highlighted that this was a significant risk, that should be outlined in the DPIA, noting the Programme was aware of the risk. The Group were advised by NHS England that there may be steps taken to address this issue in the future. **4.1.4** AGD suggested that any restrictive statements in respect of Artificial Intelligence (AI) were reviewed and removed as may be necessary. **4.1.5** AGD noted the data collection specification criteria outlined, and suggested that consideration was given by NHS England to also including 'date of birth'. **4.1.6** AGD queried whether including the 'sex' field would be beneficial for research, and suggested that this was given further consideration by NHS England. **In response to point 3 above:** **4.1.7** AGD noted the stakeholders engaged with to date, and suggested that NHS England should also consider engaging with the Royal College of Surgeons, Royal College of Physicians and the General Medical Council.	

	AGD provided the following observations / comments separate to the advice requested: **4.1.8** AGD noted there would be a legal gateway for data to flow from the NVR to MDOR, but stressed the need to have regard for how data was included in the NVR (with consent or via s251 support) and to ensure this did not rule out onward sharing in this way. In particular, AGD suggested the NVR transparency materials were reviewed, to ensure that it was explicitly clear that data would regularly flow in this way. **4.1.9** AGD suggested that in the interests of patient safety and choice, further consideration should be given by NHSE MDOR to routinely publishing a list of privately funded sector organisations that do / do not provide data, with an explanation of how publishing this information contributes to patient safety.	
5 EXTERNAL DATA DISSEMINATION REQUESTS:		
5.1	**Reference Number:** NIC-775420-M7D8Z-v0.3 **Applicant and Data Controller:** Quality by Randomization Limited (Trading as Protas) **Application Title:** NATRIX - SBP - Recruitment Agreement - DSA 2 - ≥30 and < 40 years: A Phase 2B Randomised, Double-Blind, Placebo-Controlled Study to evaluate the efficacy, safety and pharmocokinetics of a multiple dose regimen of REGN5381 **Observers:** Ricky Brooks, Louise Garnham and Gosia Bartkowska **Application:** This was a new application. NHS England were seeking general advice on the application. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** AGD were supportive of the application and wished to draw to the attention of the SIRO the following comments: **5.1.1** AGD noted in the NHS England Data Access Service (DAS) internal application assessment form, that there were ongoing discussions with NHS England's Privacy, Transparency and Trust (PTT) to agree the s261 legal basis for the applicant to share core eligibility criteria for potential participants to receive invitations. NHS England advised AGD that this issue had now been resolved with PTT. **5.1.2** AGD suggested that the application was reviewed and updated throughout, to ensure that references to *"consent"* were removed, noting that data was flowing from NHS England under s251.	

	5.1.3 AGD noted the request for 'Customer – Data Quality Report' data in section 3(b) (Additional Data Access Requested), and noting that this was not 'personal data', suggested that the UK General Data Protection Regulation (UK GDPR) legal basis was removed. **5.1.4** AGD noted the incorrect reference to Article 6(1)(e) of the UK GDPR in section 5(a) (Objective for Processing), and suggested that this was removed. **5.1.5** AGD noted and queried the role of the University of Oxford as referenced in the NHS England DAS internal application assessment form; and noting that they were **not** referenced in the application, suggested that NHS England satisfy itself that they **do not** have a role in any of the work outlined, for example, via the staff involved and the various academic organisations that they work for. **5.1.6** AGD noted that the purpose of the application is for contact to be made with individuals who meet criteria, and suggested that **1)** the outputs in section 5(c) (Specific Outputs Expected) and the benefits in section 5(d) (Benefits) were reviewed and updated to reflect this specific purpose, in line with NHS England DAS Standard for Expected Outcomes and NHS England DAS Standard for Expected Measurable Benefits; and **2)** a brief reference was made to outputs and benefits that may flow from a subsequent study. **5.1.7** AGD suggested that section 5(a) and section 5(b) (Processing Activities) were reviewed and aligned to ensure that it was clear / consistent as to who would be responsible for recruiting participants, i.e. the GP or the Data Processor. **5.1.8** AGD suggested that the wording section 5(a) was made clearer as to how potential participants would be selected should the eligible population be larger than the target number of participants. **5.1.9** AGD noted that the invitations would be sent out in eight batches, and queried whether later batches of the invites, would not be sent out if the recruitment target was met; and were advised by the AGD Specialist Academic / Statistician Adviser that an uptake of around 2% would be likely, and that based on this, the full recruitment target may not be achieved with less batches of invites. **5.1.10** The NHS England SIRO Representative noted the statement in section 5(b) *"The Data will contain directly identifying data items **including**…"*; and asked that this was updated to remove the word *"including"* and to be specific on exactly what would be included. **5.1.11** The NHS England SIRO Representative noted the statement in section 5(b) *"Access is restricted to substantive employees of…"*; and asked that NHS England reviewed this to ensure this was correct and would not place impractical restrictions on other non-substantive employees, for example, contractors. **5.1.12** AGD suggested that the commercial aspect of the application in section 5(e) (Is the Purpose of this Application in Anyway Commercial), was replicated / expanded for transparency in (the published) section 5(a), in line with NHS	

	England's DAS Standard for Objective for Processing and NHS England's DAS Standard for Commercial Purpose. **5.1.13** AGD suggested that in line with NHS England DAS Standard for Special Conditions, NHS England should consider adding a special condition in section 6 (Special Conditions), in respect of the fortnightly data destruction requirement. **5.1.14** In respect of the draft participant invitation letter provided as a supporting document (SD8), AGD suggested that **1)** the statement that *"…NHS England is inviting potentially eligible people…"* is updated to be clear that NHS England is sending invitations **on behalf** of the applicant; and **2)** whist AGD applauded the inclusion of the legal basis for sending out the participant invitation letters (s251), the Group suggested that it was clear that the s251 support was sought / obtained by the applicant and not NHS England. **5.1.15** AGD suggested the applicant give consideration to whether they might need to obtain follow-up data from NHS England in the future and, if so, to consider adjusting the consent materials to encompass this. **5.1.16** AGD noted that there was a study specific opt-out and noted that information about this would be on the study website, however suggested that this was also noted in the letter and the patient information sheet that would be shared with potential participants and that it was clear what this would opt-out participant out of. **5.1.17 ACTION: Separate to this application and for NHS England to consider:** Further to the actions raised at AGD on the 12th December 2024 and the 18th July 2024, AGD asked that an update was provided by the NHS England Data and Analytics Representative and / or the NHS England SIRO Representative, as to whether there would be a process for participants to opt out of all DigiTrials invitations without submitting an NDO. **5.1.18** AGD noted and commended the applicant on the patient and public involvement and engagement (PPIE) undertaken to date, however, suggested that there was ongoing PPIE throughout the lifecycle of the work. The HRA guidance on Public Involvement is a useful guide. **5.1.19** AGD also suggested that the applicant should undertake some PPIE to seek views on the **final** draft of the participant invitation letter before this is sent to potential participants. **5.1.20** AGD noted that the consent materials supplied had been drafted to obtain consent to access Summary Care Records (SCR), however noted that this data could **not** be used for research purposes, and suggested that NHS England bring this to the attention of the applicant. **5.1.21** AGD noted that there **was** a commercial aspect to the application.	D&A Rep / SIRO Rep
5.2	**Reference Number:** NIC-680176-M2P2Y-v0	

Applicant: Health Data Research UK (HDRUK)

Application Title: BHF Data Science Centre UK Clinical Cohorts (UK CliC) Trusted Research Environment

Observers: Ricky Brooks and Suzanne Hartley

Previous Reviews: The British Heart Foundation Data Science Centre (BHF DSC) UK Clinical Cohorts TRE (UK CliC) Briefing Paper / Data Protection Impact Assessment (DPIA) was previously presented / discussed at the AGD meeting on the 10th October 2024.

Application: NHS England were seeking early advice on a proposal; a draft application was **not** submitted.

NHS England were seeking advice on the following points **only**:

1. Do AGD consider that HDRUK should be considered as a Data Controller for the purposes of this project. What are AGD expectations regarding HDRUK entering into a Data Sharing Framework Contract (DSFC) and Data Sharing Agreement (DSA) with NHS England.
2. Following the initial briefing in October 2024, and with additional detail provided in the supporting documentation; do AGD support the concept proposed by HDRUK in principle. Do AGD have any concerns or recommendations that could be addressed in the planned application or supporting documents.
3. Do AGD support the use of the 'BHF DSC Cohorts platform consent review and assurance process' and 'UK CliC Consent and assurance review template'. Would AGD support the delegation of consent reviews to HDRUK for the purpose of decisions relating to onboarding of new cohorts.
4. Can AGD recommend an appropriate schedule for HDRUK reporting newly onboarded cohorts to NHS England. Would reports submitted with an Annual Compliance Report (ACR) be sufficient.

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

Outcome of discussion: AGD were supportive of the initial **high-level concept**, but were providing comments in response to NHS England's request for advice on specific points **only**. AGD wished to draw to the attention of the SIRO the following observations in relation to the advice points:

AGD noted that they had been provided with a curated set of documentation, which **did not** include an application, and noted that they would be providing observations based on these documents.

In response to point 1:

5.2.1 AGD advised that they were unable to offer advice on whether HDRUK should be considered a Data Controller, and whether HDRUK should enter into a DSFC and

	DSA with NHS England; and suggested that NHS England's Data access Service (DAS) should engage / seek advice with NHS England's Privacy, Transparency and Trust (PTT) on this point. **In response to point 2:** **5.2.2** AGD advised that they were supportive of the high-level concept outlined and the use of health data for the purpose of research within a Trusted Research Environment (TRE); however, suggested that the applicant could undertake an initial scoping exercise, to see if it was realistic that the consent taken for existing research studies would cover such an approach. **In response to point 3:** **5.2.3** AGD advised that the use of the 'BHF DSC Cohorts platform consent review and assurance process' and 'UK CliC Consent and assurance review template' to support the delegation of consent reviews to HDRUK, for the purpose of decisions relating to onboarding of new cohorts, would **not** be sufficient. **5.2.4** AGD advised that there would need to be a clear legal gateway for **1)** the data to flow into the TRE; **2)** for the data to be processed; and **3)** for external researchers to process the data within the TRE. **5.2.5** AGD advised that in respect of the consent reviews, there would need to be a clear and transparent process / rigor for the consent and assurance, including engagement with members of the relevant cohort and NHS England's DAS. If it was not possible to engage cohort members there could be engagement with lay advisers within HDRUK. **In response to point 4:** **5.2.6** AGD advised that based on the information provided, it would seem unlikely that an ACR would be sufficient; and suggested that this was reviewed / revisited as the application progresses. **5.2.7** Noting AGD was only asked to advise on specific points reviewed, no AGD member noted any substantive commercial aspects.	
5.3	**Reference Number:** NIC-682565-F6C6T-v0.6 **Applicant and Data Controller:** Queen Mary University of London (QMUL) **Application Title:** United Kingdom COVID and Gynaecological Cancer Study - UKCOGS (ODR2021_178) **Observers:** James Watts and Ayse Depsen **Application:** This was a new application. NHS England were seeking general advice on the application. Should an application be approved by NHS England, further details would be made available within the Data Uses Register.	

	Outcome of discussion: AGD were supportive of the application and wished to draw to the attention of the SIRO the following comments: **5.3.1** AGD noted the specific time period being researched, and queried whether the data requested was sufficient to achieve the research aims and objectives; and advised that they would be supportive of additional data being requested / flowing to support the aims of the study if there was a legal gateway to flow this data and a justification, in line with NHS England's Data Access Service (DAS) standards. **5.3.2** AGD suggested that section 5(a) (Objective for Processing) was updated to be clear that whilst the study was looking at diagnosis within a one-year period, there was a five-year follow-up. **5.3.3** AGD noted in the NHS England DAS internal application assessment form, that data was **not** required for transgender and non-binary people; and suggested that the applicant consider data minimisation by filtering the diagnostic codes, rather than filtering by gender. **5.3.4** AGD noted that section 5(a) stated that the National Disease Registration Service (NDRS) Consolidated dataset had been requested to *"…give a better picture to assess whether delay in treatment was due to patients' **hesitance** to seek medical help…"*; and queried how "*hesitance*" could be established via access to the NDRS data, and suggested that was reviewed and clarified. **5.3.5** AGD suggested that section 5(b) (Processing Activities) was updated to provide further information on *"REDCap"* to cover whether the data was on premises or in the cloud, and suggested if it was a study specific database that its name be removed since any change in database names would constitute a breach of the data sharing agreement. **5.3.6** AGD noted the reference in section 5(b) to data being backed-up by QMUL, and suggested that **1)** further information was provided, for example, is this an off-site back-up; and **2)** whether an additional Data Processor should be added to the application, in line with NHS England DAS Standard for Data Processors. **5.3.7** AGD noted that the National Data Opt-out (NDO) would be applied, and suggested that section 5(b) was updated to clarify at what point the NDO would be applied. **5.3.8** The NHS England SIRO Representative noted that the 'identifiability' fields had been replicated in section 3(b) (Additional Data Access Requested) and asked that the duplicated text was removed. **5.3.9** The NHS England SIRO Representative noted that QMUL had a number of Data Security and Protection Toolkits (DSPTs); and suggested that NHS England satisfy themselves that **all** the individuals accessing, processing and / or analysing the data are covered by the relevant DSPTs, and that the application was updated as may be appropriate.	

	5.3.10 AGD noted the statement in section 5(b) of the application *"There will be no requirement and no attempt to reidentify individuals…"*; and suggested that there may be instances where it would be beneficial to re-identify individuals, for example in respect of patient safety or other ethical reasons. It was suggested that this was reviewed and updated as may be necessary to reflect the correct information; or that the statement was removed. **5.3.11** AGD suggested that section 5(a) was updated to amend the reference to *"Chief Investigator**s**"*, noting that there was only one. **5.3.12** AGD noted and commended the applicant on the wide range of stakeholders that have been engaged to support the design of the study. **5.3.13** AGD noted and commended the work undertaken by NHS England's DAS on the internal application assessment form, which supported the review of the application. **5.3.14** AGD queried the statement in section 5(b) *"Access is restricted to employees or **agents** of…"* and suggested that that either further information was provided as to who would be covered by "*agents*"; or that this word was removed as may be necessary to reflect the facts, **5.3.15** AGD noted that there was **no** commercial aspect to the application.	
5.4	**Reference Number:** NIC-764229-C0C7B-v0.4 **Applicant and Data Controller:** University Hospitals Birmingham NHS Foundation Trust **Application Title:** Long-term clinical outcomes for the Rate Control Therapy Evaluation in Permanent Atrial Fibrillation (RATE-AF) trial **Observer:** Dan Goodwin **Linked applications:** **Application:** This was a seeking early advice application. NHS England were seeking advice on the following points **only**: 1. Does AGD consider the consent materials to provide a legal basis under the common law duty of confidentiality. 2. Does AGD support the flow of NHS number from the controller to NHS England for the purpose of increased successful tracing of cohort participants. 3. Does AGD support the provision of access to the requested data to the named organisations for the stated purpose. 4. Would AGD recommend any actions or points of clarification which must be resolved before the provision of access to the data. 5. Noting that section 5 would be updated using the standard model, would AGD wish to highlight any particular text in the current application to retain in the	

	updated version for clarity and transparency about the purpose, methods, outputs or benefits. NHS England were seeking general advice on the application. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** AGD were **not** providing comments on the wider application as requested by NHS England; comments were limited to the specific points of advice requested. AGD wished to draw to the attention of the SIRO the following observations in relation to the advice points: 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. AGD noted that this application was a first of type review under the 'AGD first' concept. **In response to point 1:** **5.4.1** AGD noted that whilst they had been asked for specific advice on the consent materials, they had **not** been provided with an NHS England Data Access Service (DAS) internal consent review document. **5.4.2** AGD noted that based on the information / documentation provided, the consent materials do provide a legal basis under the common law duty of confidentiality. **5.4.3** AGD noted that if there was reliance on the May 2016 consent form, then this would **not** have provided a legal gateway; however, they were assured by the confirmation provided by the applicant that all cohort members had signed the later 'optional consent form' that proved a legal gateway for the data to flow. **In response to point 2:** **5.4.4** AGD advised that they were supportive of the flow of NHS number from the Data Controller to NHS England, for the purpose of increased tracing of cohort participants. **In response to point 3:** **5.4.5** AGD advised that they were supportive of the provision of access to the requested data to the named organisations for the stated purpose. **In response to point 4:** **5.4.6** AGD suggested that there was further transparency to the cohort members, on the benefits of flowing the NHS number. **In response to point 5:** **5.4.7** AGD suggested that section 5(a) (Objective for Processing) was reviewed and updated to ensure that it was clear as to the processing taking place and why, and	

	that this was in language accessible by a lay reader, in line with NHS England DAS Standard for Objective for Processing. **5.4.8** AGD noted and commended NHS England's DAS on the work to elicit the relevant additional information provided by the applicant to support the advice requested. **5.4.9** Noting AGD was only asked to advise on specific points reviewed, no AGD member noted any substantive commercial aspects.	
5.5	**Reference Number:** NIC-701727-S2X0Q-v0.4 **Applicant:** University Hospitals Bristol and Weston NHS Foundation Trust **Data Controllers:** Change Grow Live and University of Bristol **Application Title:** Natural Experiment of the impact of supervised Opiate Agonist Therapy (OAT) consumption on drug related harm and treatment outcomes **Observer:** Humphrey Onu **Application:** This was a new application. NHS England were seeking general advice on the application. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** AGD were supportive of the application and wished to draw to the attention of the SIRO the following substantive comments: **5.5.1** Noting that service users who are members of the cohort may be surprised that their data was being processed, AGD suggested that in line with Caldicott Principle 8, the applicant review / update **all** transparency materials to **1)** update the incorrect references to data being retained for no longer than eight years; **2)** review / update the information / assurances on confidentiality on their website; **3)** remove incorrect references to consent being taken; and **4)** to be clear that in certain circumstances, data may be used in other ways; and if available to provide examples / benefits of where this has occurred. **5.5.2** AGD noted that a privacy notice had been provided as a supporting document (SD5), however suggested that this was reviewed and updated throughout to ensure this contained correct / relevant information, including **1)** updating / removing the statement that *"You can request for your data to be erased at any point during the study by contacting CGL"*; and **2)** updating the statement that *"You can also request for your data to be erased at any point during the study through the National Data Opt-Out"*. **5.5.3** In respect of the patient and public involvement and engagement (PPIE), AGD suggested that **1)** section 5(a) (Objective for Processing) was updated with further	

	information as to who was involved; and **2)** the applicant could undertake further PPIE to support the points raised in 5.5.1 and 5.5.2. In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review: **5.5.4** AGD queried whether University Hospitals Bristol and Weston NHS Foundation Trust had any role or stake in the application; and suggested that NHS England's Data Access Service (DAS) explore this further with the applicant. **5.5.5** In respect of the UK General Data Protection Regulation (UK GDPR) legal basis, AGD suggested that the application was updated to **1)** remove the incorrect reference to Article 6(1)(e); and **2)** to add an Article 9 condition. **5.5.6** AGD queried whether the honorary contracts were for those individuals employed by Change Grow Live; however, suggested that if anyone was on an honorary contract from another organisation, then this should be made clear in the application. **5.5.7** AGD noted the statement in section 5(b) (Processing Activities) that individuals from Change Grow Live would be acting as *"…an agent of The University of Bristol at all times…"*; and queried whether an Access Agreement had been considered by the applicant, which would recognise Change Grow Live as a Data Controller in their own right and remove any text from the application that suggests otherwise. The Group suggested that NHS England explore this further with the applicant; or update the NHS England DAS internal application assessment form to provide clarity for future reference that this had been explored. **5.5.8** In addition, AGD suggested that if the terms *"honorary contracts"* and *"agents"* are being used so that it facilities the data access, then section 5 (Purpose / Methods / Outputs) was updated to clarify this. **5.5.9** The NHS England SIRO Representative noted that the University of Bristol had a number of Data Security and Protection Toolkits (DSPTs); and suggested that NHS England satisfy themselves that **all** the individuals accessing, processing and / or analysing the data are covered by the relevant DSPTs, i.e. the University of Bristol Medical School, and that the application was updated as may be appropriate. **5.5.10** In addition, AGD queried if the University of Bristol DSPT covered the Safe Haven where the linked data will be stored; and suggested that the application was updated with clarification. **5.5.11** AGD suggested that the DSPT dates in section 1(b) (Data Controller(s)) for Change Grow Live are reviewed and updated as may be necessary to reflect the correct information. **5.5.12** No AGD member noted a commercial aspect to the application.	
5.6	**Reference Number:** NIC-656885-M7T5X-v4.2	

Applicant and Data Controller: University of Oxford

Application Title: Establishing a UK Colorectal Cancer Intelligence Hub - The COloRECTal Cancer Data Repository (CORECT-R) (ODR2021_249)

Observer: Jodie Taylor-Brown

Application: This was an amendment application.

NHS England were seeking advice on the following points **only**:

1. The amendment to align to the Data Sharing Standards for Sub-licencing and onward sharing of data (to permit sub-licencing).

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

Outcome of discussion: AGD were **not** providing comments on the wider application as requested by NHS England; comments were limited to the specific point of advice requested. AGD wished to draw to the attention of the SIRO the following observations in relation to the advice point:

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.

In response to point 1:

5.6.1 AGD noted that this application was one of many applications that had been migrated to NHS Digital (now NHS England) from Public Health England (PHE) following the transfer of functions in October 2021. The Group noted that the University of Oxford had previously been permitted to onwardly share data via sub-licence under the terms of the previous PHE data sharing agreement (DSA); however, this had **not** been reflected in the new DSA with NHS Digital (NHS England), and noted that this was therefore the purpose of the amendment.

5.6.2 The NHS England SIRO Representative advised the Group that NHS England's Data Access Service (DAS) were undertaking a review of migrated applications from PHE, to ensure that sublicensing had not been inadvertently omitted from any other applications.

5.6.3 AGD advised that they were supportive of the amendment to the application, to align to the NHS England DAS Standard for Sub-licencing and Onward Sharing of Data to permit sub-licencing.

5.6.4 In addition, AGD advised that they would be supportive of the applicant's access to the data being reinstated whilst the application was progressing through the NHS England system.

5.6.5 AGD queried if there was a process in place to manage those individuals who leave and would therefore no longer require a sub-licence; and suggested that the application was updated with further information on this point.

	5.6.6 Noting AGD was only asked to advise on specific points reviewed, no AGD member noted any substantive commercial aspects.	
6 INTERNAL DATA DISSEMINATION REQUESTS:		
There were no items discussed		
7 EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL		
7.1	**Reference Number:** NIC-616961-X1J9B-v2.2 **Applicant and Data Controller:** NHS Humber and North Yorkshire ICB **Application Title:** DSfC - NHS Humber and North Yorkshire Integrated Care Board - Comm/IV/RS The SIRO approval was for an amendment to the application, so that it now includes provision of pseudonymised data for commissioning purposes for individual's resident within the Craven area, or registered with a GP within that area. **Outcome of discussion:** AGD noted that the NHS England SIRO had already provided SIRO approval and confirmed that they were supportive of this. AGD thanked NHS England for the written update and made the following observations on the documentation provided: **7.1.1** AGD noted that based on the information provided, it appeared that, despite NHS England requesting it, the applicant had **not** provided NHS England with a data destruction certificate in the correct format, and that the applicant had responded that it was too difficult to contact the relevant people to do this. AGD did **not** think this was an acceptable response and suggested that NHS England ensure that **1)** the data had been destroyed; and **2)** all the relevant paperwork had now been received. **7.1.2** AGD suggested that in developing this amendment for use as a precedented decision, further consideration is given to the wording requiring there to be a "formal signed agreement" between the ICB and the Local Authority and whether this could be made clearer, for instance as to the substance of the agreement and that this was explored further by NHS England and the application updated accordingly. **7.1.3** AGD noted that the NHS England SIRO Representative had queried whether this could be a reusable decision within NHS England's Data Access Service (DAS); and were advised by the Group that they would **not** be supportive of this being a reusable decision. The NHS England SIRO representative thanked AGD for their time.	
7.2	**Reference Number:** NIC-484452-H8S1L-v7.2 **Applicant and Data Controller:** Department of Health and Social Care (DHSC)	

	Application Title: Department of Health and Social Care (DHSC) SDE access - Enabling Policy Analysis **Previous Reviews:** The application and relevant supporting documents were previously presented / discussed at the meetings on the 3rd October 2024, 11th July 2024, 25th January 2024 and the 14th December 2023. The application and relevant supporting documents were previously presented / discussed at the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) meetings on the 8th September 2022, 19th May 2022, 7th April 2022, 21st October 2021 and the 16th September 2021. The application and relevant supporting documents were previously presented / discussed at the General Practice Extraction Service (GPES) Data for Pandemic Planning and Research (GDPPR) – Profession Advisory Group (PAG) meetings on the 24th November 2021, 3rd November 2021, 15th September 2021 and the 25th August 2021. The SIRO approval was for an amendment to section 5(b) (Processing Activities) of the application, to state that *"Access to the data is restricted to either substantive employees of the Department of Health and Social Care or seconded staff from NHS England who are equipped with DHSC-issued technology and have successfully been through DHSC security checks"*. **Outcome of discussion:** AGD noted that the NHS England SIRO had already provided SIRO approval and confirmed that they were supportive of this. AGD thanked NHS England for the written update and made the following observations on the documentation provided: **7.2.1** AGD reiterated previous advice that the applicant consider ongoing patient and public involvement and engagement (PPIE) throughout the lifecycle of the work. The NHS England SIRO representative thanked AGD for their time.	
7.3	**Reference Number:** NIC-147811-YTH88-v5.2 **Applicant:** The University of Manchester **Data Controllers:** The University of Manchester and the University of East Anglia **Application Title:** MR559 - The Norfolk Arthritis Register (NOAR) **Previous Reviews:** The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 30th January 2025, 12th December 2024 and the 1st August 2024. 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 3rd February 2022 and the 15th April 2021.	

	The SIRO approval was for a five-month extension to hold but not otherwise process the data. **Outcome of discussion:** AGD noted that the NHS England SIRO had already provided SIRO approval and confirmed that only some of the Group were supportive of this. AGD thanked NHS England for the written update and made the following observations on the documentation provided: **7.3.1** AGD noted that there were ongoing issues, and advised that there were mixed views within the Group as to how NHS England should manage this going forward, i.e. should a further extension be provided if the updated application had **not** been submitted by the end of the five-month extension; and should the applicant be asked to destroy the data. The NHS England SIRO Representative noted the views / concerns raised. The NHS England SIRO representative thanked AGD for their time.	
7.4	**Reference Number:** NIC-333021-B6W2C-v4.2 **Applicant:** The University of Manchester **Data Controllers:** The University of Manchester and the University of East Anglia **Application Title:** The Norfolk Arthritis Register (NOAR) a longitudinal observational study **Previous Reviews:** The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 30th January 2025, 12th December 2024 and the 1st August 2024. The application and relevant supporting documents were previously presented / discussed at the Data Access Advisory Group (DAAG) meetings on the 2nd March 2017 and the 31st January 2017. The SIRO approval was for a five-month extension to hold but not otherwise process the data. **Outcome of discussion:** AGD noted that the NHS England SIRO had already provided SIRO approval and confirmed that only some of the Group were supportive of this. AGD thanked NHS England for the written update and made the following observations on the documentation provided: **7.4.1** AGD noted that there were ongoing issues, and advised that there were mixed views within the Group as to how NHS England should manage this going forward, i.e. should a further extension be provided if the updated application had **not** been submitted by the end of the five-month extension; and should the applicant be asked	

	to destroy the data. The NHS England SIRO Representative noted the views / concerns raised. The NHS England SIRO representative thanked AGD for their time.	
8 OVERSIGHT AND ASSURANCE		
There were no items discussed		
9 AGD OPERATIONS		
9.1	**AGD Terms of Reference (ToR) Annual Review (Presenter: Garry Coleman)** In line with paragraph 9.9 of the AGD ToR that states the *"…Terms of Reference will be reviewed by the Group, the SIRO Representative and the Deputy SIRO* ***annually****"*, the Group were advised by the NHS England SIRO Representative that work would commence over the coming weeks to allow AGD members to review and add suggested / relevant high-level edits to the AGD ToR and to consider operational performance against the AGD ToR. AGD were advised a further discussion on the AGD ToR Annual Review was due to be discussed at the AGD plenary meeting on the 13th March 2025; and that prior to this, a copy of the current AGD ToR would be shared with the group for review / comment.	
9.2	**AGD Annual Report 2024/25** The Group discussed the 2025/25 AGD Annual Report, in line with paragraph 8.1 of the AGD Terms of Reference that state that *"The Group will produce an annual report on its work…for the SIRO following the end of the financial year..."*. AGD noted that further thought / discussions were required on the content of the AGD Annual Report for 2024/25, and that as an initial starting point, this would be based on the content / format of the 2023/24 Annual Report. **ACTION:** The NHS England SIRO Representative to provide AGD with the finalised draft of the 2023/2024 Annual Report to support further discussions around content / format. It was noted that there would be a further discussion on the AGD Annual Report at the AGD plenary meeting on the 13th March 2025 to agree the content / format etc.	SIRO Rep
9.3	**Risk Management Framework** AGD has been previously informed that a risk management framework is being developed by Data Access and had commented on early thinking about such a Framework. Nonetheless, presently AGD were still operating using the precedent and standard framework as an interim arrangement since February 2023 and AGD were concerned that the permanent Risk Management Framework was not in place. The Group discussed the NHS England corporate risk management framework (see minutes of 14th November 2024) and the AGD chair subsequently formally asked via email if the NHS England corporate risk management framework could be used. The	

	NHS England SIRO Representative updated the Group that NHS England was still considering the request, including how the NHS England corporate risk management framework could be adapted for AGD. **ACTION:** The NHS England SIRO Representative to provide a written response to AGD on the progress, and expected time frame for implementation, of the risk management framework.	SIRO Rep
9.4	**Standard Operating Procedures (SOPs) (Update from Vicki Williams)** The ongoing forward plan of work for creating the AGD Standard Operating Procedures was discussed. The Group noted that the 'AGD member Declaration of Interest' was in the process of being finalised, and a further update on this would be provided in due course, and published on the AGD webpage.	
9.5	**AGD Stakeholder Engagement** The AGD Chair noted to the Group that she had met with Dr. Tony Calland, the Chair of the Health Research Authority Confidentiality Advisory Group (HRA CAG) and Dr. Nicola Byrne, the National Data Guardian for health and adult social care in England, on Tuesday 25th February 2025, as part of their regular engagement.	
9.6	**AGD Project Work** **Consent review for consented cohorts** As discussed at the AGD business as usual (BAU) meetings on the 6th February 2025, 30th January 2025 and the 23rd January 2025, following a request from NHS England for AGD to review and provide advice on the consent materials for consented cohorts for a small number of organisations, a workshop was held on the 13th February 2025, instead of the usual AGD BAU meeting. The Group noted that **draft** consent review proformas had been completed at the workshop, and were circulated to workshop attendees / AGD members for review. The Group discussed the suggested amendments and the **draft** consent review proforma's were agreed in-meeting as the finalised draft. The Group noted that, following the meeting, the AGD Secretariat would send a copy of the finalised draft consent reviews to Jackie Gray, Director of Privacy and Information Governance, Privacy, Transparency, and Trust and Garry Coleman, the NHS England SIRO Representative. **ACTION:** AGD Secretariat to send a copy of the finalised draft consent reviews and executive summary to Jackie Gray and Garry Coleman.	AGD Sec
10 Any Other Business		

10.1	**AGD recruitment (Update from Garry Coleman / Vicki Williams)** The NHS England SIRO Representative and AGD Secretariat Manager advised the Group that the job adverts for the AGD independent member roles were expected to go live over the coming days, and would be advertised on the NHS jobs website, alongside forwarding copies of the adverts / job descriptions to key stakeholders and uploading the documentation to the AGD webpage
10.2	**AGD Plenary Meetings 2025/26** The AGD Secretariat advised the Group that dates for the quarterly AGD plenary meetings for 2025/26 would be circulated following the meeting for information.

Meeting Closure

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