Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 9th October 2025

09:00 – 16:05

(Remote meeting via videoconference)

AGD INDEPENDENT / NHS ENGLAND MEMBERS IN ATTENDANCE:	
Name:	**Role:**
Paul Affleck (PA)	AGD independent member (Specialist Ethics Adviser) (Chair for part of item 5.2 to item 5.4)
Dave Cronin (DC)	NHS England member (Data and Analytics Representative (Delegate for Michael Chapman))
Claire Delaney-Pope (CDP)	AGD independent member (Specialist Information Governance Adviser)
Dr. Robert French (RF)	AGD independent member (Specialist Academic / Statistician Adviser) (In attendance for items 1 to part of item 5.1)
Kirsty Irvine (KI)	AGD independent member (Chair) (not in attendance for part of item 5.2 to part of item 5.4)
Andrew Martin (AM)	NHS England member (Data Protection Office Representative (Delegate for Jon Moore))
Dr. Jonathan Osborn (JO)	NHS England member (Caldicott Guardian Team Representative)
Jenny Westaway (JW)	AGD independent member (Lay Adviser)
Miranda Winram (MW)	AGD independent member (Lay Adviser)
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	**Role / Area:**
Laura Bellingham (LB)	Deputy Director, Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer**: item 5.1)
Garry Coleman (GC)	NHS England SIRO Representative (not in attendance for items 1 to 3 and part of item 4.1)
Ayse Depsen (AD)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer:** item 5.4)
Duncan Easton (DE)	Senior Operational Delivery Manager, Data Access and Partnerships, Transformation Directorate (**Presenter**: item 5.1)

Sally Hall (SH)	Senior FOI Manager, Freedom of Information Team, Communications, Strategy Directorate (**Presenter:** item 9.1)
Suzanne Hartley (SH)	Data Applications Service (DAS) - Senior Manager, Data Access and Partnerships, Transformation Directorate (**Observer**: item 5.2)
Madeline Laughton (ML)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer:** item 5.3)
Carolyn Lawley (CL)	Deputy Head of External Affairs, Communications, Chief Strategy Officer Directorate (**Presenter:** item 9.1)
Grace Mhora (GM)	Senior Implementation and Business Change Manager, Data Access and Partnerships, Transformation Directorate (**Observer**: item 5.1)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Deputy Chief Executive Directorate
Azeez Oladipupo (AO)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer:** item 5.5)
Humphrey Onu (HO)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer:** item 5.6)
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)
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Deputy Chief Executive Directorate
INDEPENDENT ADVISER OBSERVERS IN ATTENDANCE	
Mr Christopher Barben (CB)	AGD independent adviser
Dr Jon Fistein (JF)	AGD independent adviser (In attendance for items 1 to 5.3)
Professor Jo Knight (JK)	AGD independent adviser
Dr. Mark McCartney (MM)	AGD independent adviser
AGD INDEPENDENT MEMBERS / NHS ENGLAND MEMBERS <u>NOT</u> IN ATTENDANCE:	
Name:	**Role / Area:**
Michael Chapman (MC)	NHS England member (Data and Analytics Representative)
Jon Moore (JM)	NHS England member (Data Protection Office Representative)

1	**Welcome and Introductions:** The AGD Chair welcomed attendees to the meeting.	
2	**Review of previous AGD minutes:** The minutes of the AGD meeting on the 25th September 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:** Dr Jon Fistein noted a professional link to the University of Cambridge but noted no specific connections with the application (NIC-771170-Y3J8Z), or staff involved, and it was agreed that this was not a conflict of interest.	
4 BRIEFING PAPER / DATA PROTECTION IMPACT ASSESSMENT (DPIA):		
4.1	**Title:** Intestinal Failure Registry DPIA and Briefing Paper **Presenter:** Simon Snowden The Intestinal Failure Registry (IFR) is a clinical registry and patient monitoring system for use by all healthcare providers of Intestinal Failure services. Historically, provider involvement has been voluntary, but the national adoption of the clinical service specification for Intestinal Failure produced by NHS England has mandated that all commissioned providers of this service routinely input information to the Registry. No other comparable solution or coding activity relating to Intestinal Failure exists in the UK. In early 2025, the IFR's technical supplier gave notice that it would cease support for the Registry by April 2026. As part of its 2025/26 commercial arrangements, NHS England's Outcomes and Registries Programme has commissioned its third-party technical provider, NEC Software Solutions (NEC), to emulate the current IFR and develop a duplicate collection mechanism. 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 – specifically whether Legal / Info Law should be consulted due to the transfer of the Registry into NHS England? **Outcome of discussion:** AGD welcomed the DPIA and briefing paper and made the following observations / comments: **In response to points 1 to 3:** **4.1.1** AGD discussed the transfer from the 'British Association for Parenteral and Enteral Nutrition' (BAPEN) to NHS England, and strongly endorsed that clarification / advice was sought on **1)** the UK General Data Protection Regulation (UK GDPR) legal basis currently being relied on; **2)** the common law duty of confidentiality basis that BAPEN was relying on to process confidential data; and **3)** the role for NHS England. The Group noted that moving	

	from one UK GDPR legal basis to another, may have an impact on the rights of data subjects and transparency. **4.1.2** In respect of transparency, AGD suggested that NHS England **1)** seek further clarification as to what information has been shared with data subjects to date; and **2)** give further consideration as to what information will be shared with data subjects going forward, noting that an update to a privacy notice may **not** be sufficient. **4.1.3** AGD noted that there seemed to be **no** opt-out, and suggested that NHS England explore with BAPEN whether those on the Registry have been offered an opt-out in the past. **4.1.4** AGD noted the statement in the DPIA that *"…section 251 processing agreements being in place for healthcare providers in Northern Ireland, Scotland and Wales"*; and advised that s251 did **not** extend to Northern Ireland and Scotland, however, there were equivalent processes to ensure there is an appropriate legal basis for the processing. **4.1.5** AGD noted a discrepancy of numbers in the DPIA, in respect of Type II and Type III categories and the numbers associated with these; and suggested that DPIA was reviewed and updated as may be necessary to reflect the correct information. **4.1.6** AGD noted in the 'data minimisation' section of the DPIA the reference to the IFR running since 2018, and suggested that NHS England assure itself by undertaking a subsequent review of the data specification and to ensure alignment with the relevant data protection principles. **4.1.7** AGD noted that 'person stated gender' data would be going in the Registry, and suggested that 'sex at birth' data would be an important data field to capture in addition. **4.1.8** In addition, and in respect of monitoring equity, AGD advised that they would be supportive of the Registry having as many data fields as may be required, for example, demographics data, with the appropriate justifications and legal bases. **4.1.9** AGD noted the statement in the DPIA *"…to review appropriateness of ongoing treatment…"*; and suggested that this was reviewed and updated as may be appropriate, noting that this may cause some alarm / distress if this was interpreted in a certain way by a member of the public. **4.1.10** AGD suggested that if the Registry was relied on by clinicians when delivering direct care, the DPIA was reviewed and updated as appropriate, to be clear **1)** what the direct care process is; and **2)** what activities are 'direct care'. AGD noted the importance of this information, to ensure that NHS England appropriately categorises and handles the data internally. **4.1.11** AGD noted in the DPIA that a System Level Security Policy (SLSP) was being relied upon for security assurance; and queried why the Data Security and Protection Toolkit (DSPT) was not being relied on. The Group suggested that this was reviewed and updated as may be appropriate, and encouraged the use of DSPT where possible. If an SLSP was relied on, AGD suggested that NHS England satisfy themselves that this aligned with the s251 support in place. **4.1.12** AGD noted that they would be happy to provide any further information on this DPIA as may be appropriate. AGD provided the following observations / comments, separate to the DPIA / briefing paper.	

	4.1.13 AGD suggested that as part of the DPIA process for any registry being brought into NHS England, clarification should be sought on **1)** the current (i.e. pre transfer) UK GDPR legal basis; **2)** the common law duty of confidentiality up until the point it came under the Direction; **3)** transparency and communication; **4)** any consent model (for example to assess whether any statements had been made that would cause ethical issues for the registry to move into a new controllership arrangement); and **5)** opt-out arrangements. **4.1.14** AGD suggested that the use of the previous NHS Digital checklist could be helpful when any registry was onboarded to minimise the risk that any of these aspects were overlooked and assure NHS England that the appropriate factors were being addressed.	
5 EXTERNAL DATA DISSEMINATION REQUESTS:		
5.1	**Application Title:** Local Authority (LA) Template **Presenter:** Duncan Easton **Observers:** Laura Bellingham and Grace Mhora **Application:** This was a seeking early advice template application. NHS England were seeking advice on the following points, including general advice on any other aspect of the template application: 1. Suitability for use as a template for all Local Authorities to access a range of Pseudonymised data for their geographic area. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** AGD were broadly supportive of the templated application under a precedent approach. The Group wished to draw to the attention of the SIRO the following significant comments: 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 as part of an NHS England Data Access Request Service (DARS) pilot (discussed at the AGD meeting on the 7th August 2025), the Group had been provided with a new NHS England DARS form that contained summary information that, once finalised, would be included in the data sharing agreement (DSA). **In response to point 1:** **5.1.1** AGD noted the value of the proposed linkages outlined, and advised that they were supportive of the overall purpose. **5.1.2** AGD discussed the grounds for re-identification of the data, and suggested that clarification was provided that the intention (at the outset of a project) to provide direct care would **not** be a purpose for running analysis and then re-identification being undertaken. AGD noted that previous applications had noted that analysis, undertaken for a non-direct care purpose, may incidentally reveal a need to identify an individual for their care, and suggested the wording in the LA template was updated to reflect this. **5.1.3** AGD noted that the mechanism in place within the Integrated Care Boards (ICB) for re-identification for the purpose of direct care, required advice being sought from their Caldicott	

	Guardian or similar, and suggested that there was a similar process outlined in the LA template. **5.1.4** AGD noted that high A&E attendance was an example given in the LA template of a purpose for re-identification, so that the LA can notify the relevant GP, and that the LA template set out that a benefit of this was potentially reducing future costs and minimising future risk; however, the Group noted that the value to the individual was the key benefit and the justification for the re-identification. **5.1.5** AGD also discussed whether data quality would be a valid reason to undertake re-identification, and noted that there were some arguments in favour of this, however, suggested that NHS England seek advice from NHS England's Legal Team, as to whether this was permitted under the legal basis outlined in the LA template. If this was permitted, then it may be acceptable, however the Group suggested that this was reflected in the transparency for the data subjects. **5.1.6** AGD suggested that when determining what counts as direct care and data quality, NHS England should refer to the 2013 Caldicott review: information in the health and care system for further information / clarification. AGD also suggested that if further advice / clarification was required, that NHS England could engage with the National Data Guardian. **5.1.7** AGD suggested that the specific statutory functions were referred to in the LA template. **5.1.8** AGD queried the datasets that would be provided, as outlined in the LA template, and noted that this would include **1)** the LA datasets; and **2)** datasets for the statutory functions. AGD noted and were content that data would be stored in the Commissioning Support Unit (CSU) Secure Data Environment (SDE). **5.1.9** AGD noted that the LA template would be the default option for LAs, and that any exceptions to this would be brought to AGD for review, for example, where there is an extract, or where new datasets were added. AGD noted that they were supportive of this approach. **5.1.10** AGD requested that they would welcome an update on the LA template in 4-6 months, for example, to see how the use of the LA template was proceeding, what benefits there were, and how re-identification mechanisms were operating. **5.1.11** AGD noted **no** commercial aspect to the LA template.	
5.2	**Reference Number:** NIC-780525-J4L3S-v0.3 **Applicant:** NHS England **Data Controller:** Department of Health and Social Care (DHSC) **Application Title:** "NHS England and Department for Health and Social Care – joint working in pseudonymised data environments" **Observer:** Suzanne Hartley **Previous Reviews:** The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 12th June 2025. **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 **if** the following substantive comments were addressed, and wished to draw to the attention of the SIRO the following substantive comments: 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, as part of an NHS England Data Access Request Service (DARS) pilot (discussed at the AGD meeting on the 7th August 2025), the Group had been provided with a new NHS England DARS form that contained summary information that, once finalised, would be included in the data sharing agreement (DSA). **5.2.1** AGD noted the previous point raised (5.2.1) on the 12th June 2025, in respect of the relationship between DHSC and NHS England, and whether they are jointly controlling a single project, or whether there is a different arrangement; and that, in the response, an 'agency model' arrangement had been referred to. The Group queried whether, if only one of the parties had a statutory function, the other party would then be a Data Processor since the statutory function could **not** extend to the other party; and suggested that NHS England explore this further with the applicant, and that the necessary and appropriate arrangements were in place depending on the outcome. **5.2.2** AGD noted in section 4.3.1 (Who is eligible to request and be given access to the data) that requests for access to the data may be submitted by DHSC or NHS England substantive employees; and queried if this was too restrictive, noting the current organisational changes within NHS England and DHSC; and suggested that this was explored with the applicant, and any relevant changes were made to the application, for example, by adding 'agency staff' and / or 'contractors'. One AGD independent lay member did, however, stress the value of restricting access to substantive employees. In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review: **5.2.3** AGD noted the previous point raised (5.2.2) on the 12th June 2025, in respect of the relevant statutory powers for the Data Controllers; and that, in the response, reference had been made to this being addressed in a Data Protection Impact Assessment (DPIA); and queried the sign-off process for the DPIA. AGD were advised by NHS England that the DPIA had followed the usual institutional sign-off procedure. **5.2.4** AGD noted the previous point raised (5.2.4) on the 12th June 2025, in respect of whether ethical approval was required if the processing being undertaken was for "research", that it was still unclear if there was research being undertaken; and, notwithstanding that the word "research" can be context specific, suggested that NHS England clarify this with the applicant, in line with NHS England DARS Standard for Ethical Approval. **5.2.5** AGD suggested that section 4.3.2 (what purposes can the data be used for) was updated to include further clarity that all of the three purpose points outlined were required, and none were optional. **5.2.6** AGD suggested that section 4.3.5 (what criteria are used by the approver(s)) was updated to add a criterion to ensure that this was connected to health and social care.	

	5.2.7 AGD noted the reference in section 4.7 (expected outputs) to the creation of software tools, and suggested that this was removed. **5.2.8** AGD noted and commended NHS England Data Access Request Service (DARS) and the applicant on the responses to the previous points raised. **5.2.9** No AGD member noted a commercial aspect to the application.	
5.3	**Reference Number:** NIC-776747-P6B6V-v0.2 **Applicant and Data Controller:** University of Oxford **Application Title:** "Artificial intelligence for prediction of different outcomes in patients with chronic heart failure (24 NHFA 01)" **Observer:** Madeline Laughton **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:** The Group were broadly supportive of the purpose 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: **5.3.1** Noting that the data under this application was via a dissemination, AGD suggested that this was reviewed in line with the DHSC Data Access Policy (consultation) that states *"Secure data environments (SDEs) will become the default route for accessing NHS data for research and external uses. Instances of disseminating NHS data outside of an SDE for research and external uses will be extremely limited"*. **5.3.2** AGD were disappointed at the limited efforts to undertake patient and public involvement and engagement (PPIE) on the AI aspects of the project, and whilst noting the challenge of explaining the detail of methodology, suggested that there was still scope for PPIE to explore the use of AI in this context. AGD suggested that there was ongoing PPIE throughout the lifecycle of the work. The HRA guidance on Public Involvement is a useful guide. **5.3.3** AGD suggested that 'Work Package 1' *(analysis of outcome trends in patients with heart failure)* and 'Work Package 3' *(Stratified analyses of model performance in variety of subgroups)* seemed relatively straight forward, compared to 'Work Package 2' *(development of AI Models for prediction of a variety of clinical outcomes)* which is more complex; and suggested that one option would be for the applicant to consider starting with 'Work Package 1', and adding 'Work Package 2' and 'Work Package 3' at a later date once any issues had been resolved. **5.3.4** AGD noted the methodology outlined in section 5(a) (Objective for Processing), in particular in respect of 'Work Package 2', that would use 80% of registry data for training / derivation and 20% for held-out validation; and queried how this would work in respect of prediction and validation; and suggested that this was clarified.	

	5.3.5 AGD suggested that it would be appropriate to use the data to develop an AI prediction model, but needed careful handling, noting that any implementation would be beyond the scope of the data sharing agreement (DSA). **5.3.6** AGD stressed the importance of considering, when using the data in the AI prediction model, whether this increased the risk of re-identification of those individuals; and whether outputs may then contain personal data. AGD did note that any implementation would be subject to other controls and processes, such as those of the Medicines and Healthcare products Regulatory Agency (MHRA). **5.3.7** AGD noted that the benefits described in section 5(d) (Benefits) did not align with the objectives in section 5(a) and suggested they were reviewed and aligned. Specifically, it was noted that the benefits described would be achieved from the implementation and utilisation of the AI prediction model whereas the objectives described were limited to the development, testing and evaluation of that model. **5.3.8** AGD noted that they welcomed the correspondence out of committee, which related to the applicant's commitment to the FUTURE-AI guideline, and suggested that this was reflected in the application for future reference. **5.3.9** AGD did note that the data requested was pseudonymised, however suggested that, in line with NHS England DARS Standard for Ethical Approval, the applicant sought ethical advice, noting the considerable ethical issues of using AI with such a large dataset. **5.3.10** AGD noted that the work outlined was part of a wider Horizon Europe project, and noted that they were unclear how it fed into their commitment to producing a prediction tool; and suggested further clarity was given to what the role was of any collaborating institutions in this project. **5.3.11** AGD noted in section 1(b) (Data Controller(s)) that in respect of the Data Security and Protection Toolkit (DSPT) for the University of Oxford, that a support call had been raised to review the assessment; and suggested that NHS England ensure that the correct code had been used, noting that the University of Oxford have a number of DSPTs. **5.3.12** AGD noted the statement in section 5(b) (Processing Activities) that *"Access is restricted to employees of the University of Oxford…"*; and noting the intention to involve students, suggested that **may** be incompatible with the information in the application currently. **5.3.13** AGD noted the incorrect statement in section 3 (Datasets Held / Requested) that *"Statutory exemption to flow confidential data without consent";* and suggested that this was revised to reflect the facts. **5.3.14** AGD suggested that the datasets requested in section 3(b) (Additional Data Access Requested) were reviewed and updated to ensure they correctly reflected whether the data was *"identifiable"* or *"pseudonymised"*. **5.3.15** AGD noted the information in section 5(b) that referred to internal NHS England data flows, and suggested that this was removed, noting that this was not necessary to include. **5.3.16** AGD noted that there may be possible implications for automated decision making, however agreed that it was too early stage for the Group to give advice on this.	

	5.3.17 AGD suggested that NHS England consider how they handle applications like this, for example, in terms of creation / development **and** implementation of software tools. **5.3.18** AGD noted the reference to *"support tools"*, and suggested that whilst there was currently no commercial aspect identified, the development of support tools may have a commercial aspect; and suggested that NHS England explore this with the applicant. **5.3.19** AGD noted and commended the work undertaken by NHS England's Data Access Request Service (DARS) in respect of the questions asked to the applicant in respect of the AI. **5.3.20 Separate to the application:** AGD noted that the emergence of AI related data access requests is being considered by NHS England, and that a formal policy may be established in due course. Given the time lag that the development of such a policy is likely to have, AGD suggested that there was an urgent need to establish interim guidance for reviewing such applications. **5.3.21** No AGD member noted a commercial aspect to the application with the possible exception of the development of support tools.	
5.4	**Reference Number:** NIC-771170-Y3J8Z-v0.4 **Applicant:** University of Cambridge **Data Controllers:** Cambridge University Hospitals NHS Foundation Trust, NHS England and University of Cambridge **Application Title:** "Specialist surgical care systems (EPI-SPEC-SURG) and their relevance to patient outcome and experience: learning from an improvement study in the care of chronic subdural haematoma (IMPROVE-CSDH)" **Observer:** 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: **5.4.1** The AGD NHS England Data and Analytics Representative noted that NHS England had been incorrectly added as a Data Controller, and advised that the application would be updated as appropriate to remove these references. **5.4.2** AGD noted the information in section 3(b) (Additional Data Access Requested) that data would be minimised to data between 2013/14 and 2024/25; and that further minimisation would be undertaken by the applicant once they had access to NHS England's Secure Data Environment (SDE). The Group suggested that NHS England consider undertaking more data minimisation, with any exceptions having a clear rationale for why the applicant needs to do it. **5.4.3** AGD discussed the objective for processing outlined in section 5(a) (Objective for Processing), and noted that there was some ambiguity on the full extent of the project; however, advised that reassurance was provided by the information in the protocol, including,	

	but not limited to, the reference to National Institute for Health and Care Research (NIHR) support and the patient and public involvement and engagement (PPIE). AGD suggested that, whilst the work brought in scope appeared to be appropriate, the researcher may wish to consider prioritising and focussing on specific pathways of concern. **5.4.4** AGD welcomed the student access with the appropriate supervision, however, suggested that section 5(a) and section 5(b) (Processing Activities) were reviewed and updated / aligned as appropriate, for example, noting that section 5(b) states that *"access is restricted to employees or agents of Cambridge University Hospitals NHS Foundation Trust and the University of Cambridge"*. **5.4.5** AGD noted that in addition to the data sharing agreement (DSA), there was also a 'User Agreement' for those individuals accessing data in NHS England's SDE, that covers off key points, including, but not limited to, specific user access and restrictions on exporting data; and suggested that this was referred to in section 5(b) of the application. AGD noted that if the 'User Agreement' was referred to in the application, then the text regarding access could be simplified. **5.4.6** No AGD member noted a commercial aspect to the application.	
5.5	**Reference Number:** NIC-780923-D5L3J-v0.5 **Applicant and Data Controller:** Queen Mary University of London **Application Title:** "Delivery and Implementation of a Randomised Crossover Trial on Thrombosis (DIRECT)" **Observer:** Azeez Oladipupo **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:** The majority of the Group **deferred** the application as not all the necessary information was available to make a full assessment. The minority of the Group (one AGD independent member) was **not** supportive of the application **at this time** due to the fact that consent would **not** be taken. AGD wished to draw to the attention of the SIRO the following substantive points; and suggested that the application be brought back to a future meeting once the previous IGARD / AGD points had been sufficiently addressed (or it was clearly highlighted / justified where points were no longer applicable): AGD noted that as part of an NHS England Data Access Request Service (DARS) pilot (discussed at the AGD meeting on the 7th August 2025), the Group had been provided with a new NHS England DARS form that contained summary information that, once finalised, would be included in the data sharing agreement (DSA). **5.5.1** Noting the clarification that external data from the National Hip Fracture Database (NHFD) would be used solely to identify the cohort but would not be otherwise linked with the NHS England data nor used in the analysis, it was unclear why the data could not be accessed in the SDE. AGD suggested that this was reviewed in line with the DHSC Data Access Policy (consultation) that states *"Secure data environments (SDEs) will become the default route for accessing NHS data for research and external uses. Instances of*	

	disseminating NHS data outside of an SDE for research and external uses will be extremely limited". **5.5.2** AGD noted concern that consent would **not** be taken, however the applicant had received s251 and NHS Research Ethics Committee (REC) support. AGD noted several concerns, including, but not limited to, **1)** consent not being taken for access to data when it would be practical; and **2)** consent not being taken for a trial comparing two different drugs (aspirin and low molecular weight heparin). **5.5.3** AGD noted the statement in the study protocol that this was not a drug trial and the rationale given for this randomised controlled cluster trial not requiring consent. AGD members understood this to be a trial comparing treatment in line with current NICE guidance versus the use of aspirin and therefore appeared to be a drug trial. Also, the independent specialist ethics member stated that the rationale in the protocol for not taking consent was not supported by the stated references. In fact, they indicated that consent would be required. The Group suggested that NHS England explore these points further with the Health Research Authority (HRA) and asked the REC and HRA CAG to re-examine this study. In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review: **5.5.4** AGD noted that they recognised the value of the study, given the potential impact on a large number of individuals both in the UK and around the world. **5.5.5** AGD noted the information in section 3.1 (Datasets), and suggested that NHS England clarify with the applicant whether there would be any flow of identifiers into NHS England, and suggested that the application was updated as appropriate with the correct information. **5.5.6** AGD suggested that section 3.6 (data subjects) was updated with clarification of all of the data minimisation being undertaken, in line with NHS England DARS standard for data minimisation. **5.5.7 Separate to the application and for NHS England to consider**: AGD queried whether section 3 (data) of the new NHS England DARS application form would be available in the Data Uses Register; and asked that the AGD NHS England Data and Analytics Representative provided clarification to the Group. **5.5.8 Separate to the application and for NHS England to consider**: AGD noted that the version of the new NHS England DARS application form provided (version 0.9) did not list higher risk data items that will be provided. The AGD NHS England Data and Analytics Representative acknowledged that this was omitted from version 0.9 but had been included in version 0.10 and committed to instruct the team to provide information and justifications for any higher risk data items or to confirm that no sensitive data was being provided in whichever version of the form they use. **5.5.9** AGD noted and commended NHS England's Data Access Request Service (DARS) on the date of death analysis provided in the new NHS England DARS application form. **5.5.10** No AGD member noted a commercial aspect to the application.	D&A Rep D&A Rep
5.6	**Reference Number:** NIC-788684-Y5P8C-v0.3 **Applicant:** National Centre for Stereotactic Radiosurgery	

	Data Controller: Sheffield Teaching Hospitals NHS Foundation Trust **Application Title:** "Risk of malignancy after stereotactic radiosurgery" **Observer:** Humphrey Onu 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: AGD noted that as part of an NHS England Data Access Request Service (DARS) pilot (discussed at the AGD meeting on the 7th August 2025), the Group had been provided with a new NHS England DARS form that contained summary information that, once finalised, would be included in the data sharing agreement (DSA). **5.6.1** AGD noted the s251 support in place, and that Health Research Authority Confidentiality Advisory Group (HRA CAG) had reviewed some patient materials; however, the Group suggested that NHS England engage with the applicant on a number of points, including, but not limited to, **1)** the efficacy and utility of the opt-out model, for example, how many opt-outs had been received; **2)** that the patient leaflet is clear / factually correct, on the options / process for withdrawing from the research, which should contain at least **two** methods of contact for participants (post, telephone and / or e-mail); **3)** whether the patient materials / transparency materials need to be revised / updated based on an analysis of communications and opt-outs to date, and **4)** whether a poster or similar could be made available to improve transparency on the study and opt-out options. **5.6.2** AGD noted there was currently no project specific privacy notice and the generic centre notice was out of date. AGD suggested NHS England ensures the applicant understands that the Data Sharing Agreement will require that a UK General Data Protection Regulation (UK GDPR) compliant, publicly accessible transparency notice is maintained throughout the life of the agreement. **5.6.3** AGD suggested that section 4.10 (Special Conditions) was updated to revise the citation special condition wording, in line with NHS England DARS Standard for Special Conditions. **5.6.4** AGD noted and commended NHS England Data Access Request Service (DARS) and the applicant for the work undertaken on this application to date. **5.6.5** No AGD member noted a commercial aspect to the application.	
6 INTERNAL DATA DISSEMINATION REQUESTS:		
There were no items discussed		
7 EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL		
7.1	**Reference Number:** NIC-10094-P6P4B-v9.2 **Applicant and Data Controller:** City St George's University of London	

	Application Title: "Births and their outcome: analysing the daily, weekly and yearly cycles and their implications for the NHS" **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 14th June 2018 and the 26th April 2018. The SIRO approval was for an amendment to the data sharing agreement, to reflect the merger of City, University of London and St George's, University of London merged on the 1st August 2024; and that the updated Data Controller is now 'City St George's, University of London'. **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 funding had expired, however the application end date was December 2027; and suggested that **1)** NHS England clarify with the applicant that there is funding in place for the duration of the data sharing agreement (DSA), for example to ensure there is sufficient funds to sustain the project through to possible archiving and destruction; and **2)** the NHS England Data Access Request Service (DARS) internal application assessment form was updated to reflect any discussions on this point with the applicant. The NHS England SIRO representative thanked AGD for their time.	
8 OVERSIGHT AND ASSURANCE		
There were no items discussed		
9 LEARNING AND DEVELOPMENT		
9.1	**Freedom of Information (FOI) overview / learning session (Presenters: Sally Hall and Carolyn Lawley)** AGD were provided with an overview of the role of NHS England's FOI Team, the FOI process including timescales, what is covered under an FOI request and possible exemptions for information being released under an FOI request. The Group noted the information provided, and agreed that a further session would be held at a future AGD meeting, to discuss 'good practice', for example, what information should be retained by AGD members, and for how long. **ACTION:** AGD Secretariat to add 'FOI best practice' to the internal AGD forward planner. The Group thanked Sally and Carolyn for attending the meeting.	AGD Sec
10 AGD OPERATIONS		
10.1	**Risk Management Framework** The AGD Chair asked for an update on the risk management framework referred to in the Group's Terms of Reference. The NHS England SIRO Representative updated the Group that	

	there was ongoing work with this outstanding action, and that a further update would be provided at the AGD meeting on the 23rd October 2025. **ACTION:** The NHS England SIRO Representative to provide a written response to AGD on the progress on the 23rd October 2025, of the risk management framework.	SIRO Rep
10.2	**AGD Stakeholder Engagement** AGD noted that, as referred to at the AGD meeting on the 11th September 2025 (item 10.2), a Knowledge Sharing Workshop was held on the 6th October 2025, with NHS England, Health Research Authority (HRA), HRA Confidentiality Advisory Group (HRA CAG) and AGD members. The Group noted that the value of the information shared / discussion at the workshop, and thanked NHS England, HRA and HRA CAG colleagues.	
10.3	**AGD Project Work** **Federated Data Platform** A brief update was given by the Group's representative on the Federated Data Platform Data Governance Group.	
11 Any Other Business		
11.1	**AGD independent member contractual arrangements** Following on from the discussions at the AGD meeting on the 25th September 2025, 18th September 2025, 11th September 2025 and the 4th September 2025, in respect of AGD independent member contractual arrangements with NHS England; the Group were advised by the NHS England SIRO Representative that further discussions had taken place internally on this issue, and that an update would be shared with AGD independent members as soon as possible.	
11.2	**AGD Meeting Quoracy** AGD noted that due to the ongoing issue with AGD member contracts, there would not be a quoracy of AGD independent members available on the 23rd and 30th October 2025, in line with para 7.13 of the AGD Terms of Reference (ToR) that states *"The quorum for meetings of the Group or a Sub-Group is five members, including **at least three independent members**…"*. The Group discussed a number of options, including, but not limited to running **one** of the AGD meetings under "*exceptional circumstances*", in line with para 7.13 of the AGD Terms of Reference (ToR) that states *"In **exceptional circumstances** the Chair and the representative of the SIRO may agree for the Group to still meet and conduct its business…"*. The Group were advised by the NHS England SIRO Representative that further discussions would take place out of committee on this issue, and that further information would be shared with the Group as soon as possible. **ACTION:** NHS England SIRO Representative to provide an update to the Group on the arrangements for the AGD meetings on the 23rd and 30th October 2025.	SIRO Rep

11.3	**Research, Innovation and Development Advisory Committee (RIDAC)** An AGD independent member noted that a query had been raised with the AGD NHS England Data and Analytics Representative, Michael Chapman, in respect of the relationship between RIDAC and the Data Access Request Service (DARS). The Group noted that the AGD NHS England Data and Analytics Representative was consulting colleagues and advised that they would welcome a response in due course.	D&A Rep

Meeting Closure

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