Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 26th June 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) (Chair for items 1 to 4.1)
Claire Delaney-Pope (CDP)	AGD independent member (Specialist Information Governance Adviser) (not in attendance for item 5.6)
Dr. Arjun Dhillon (AD)	NHS England member (Caldicott Guardian Team Representative (Delegate for Dr. Jonathan Osborn)) (In attendance for items 1 to 5.5)
Rachel Fernandez (RF)	NHS England member (Data Protection Office Representative (Delegate for Jon Moore)) (not in attendance for part of item 5.5, 5.6, 7.1, 9.3 to 10.1)
Kirsty Irvine (KI)	AGD independent member (Chair for items 4.2 to 10.1) (not in attendance for items 1 to part of 4.1)
Jenny Westaway (JW)	AGD independent member (Lay Adviser)
Tom Wright (TW)	NHS England member (Data and Analytics Representative (Delegate for Michael Chapman)) (not in attendance for part of item 5.5, 5.6, 7.1, 9.3 to 9.4)
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	**Role / Area:**
Garry Coleman (GC)	NHS England SIRO Representative (not in attendance for part of item 5.4)
Claire Corney (CC)	Senior Information Governance Manager, Privacy, Transparency and Trust (PTT), Delivery Directorate (**Observer:** item 4.2)
Dr. Kevin Dunbar (KD)	Deputy Director of Public Health, Vaccination and Screening Directorate (**Presenter**: item 4.1)
Jenny Friday (JF)	Senior Programme Manager, Digital Medicines Programme, Transformation Directorate (**Presenter:** item 4.2)

Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Delivery Directorate
Azeez Oladipupo (AO)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer**: item 5.5)
Rahima Oliver (RO)	IG Lead, IG Delivery (Digital & Operations), Privacy, Transparency, and Trust (PTT), Deputy Chief Executive Directorate (**Observer**: item 4.1)
Laboni Paul (LP)	Data Product Manager, Digital Screening, Transformation Directorate (**Observer**: item 4.1)
Jodie Taylor-Brown (JTB)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer**: items 5.2, 5.3 and 5.6)
Emma Whale (EW)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer**: items 5.1 and 5.2)
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Delivery Directorate (not in attendance for part of item 5.5, 5.6, 7.1, 9.3 to 10.1)
AGD INDEPENDENT MEMBERS / NHS ENGLAND MEMBERS NOT IN ATTENDANCE:	
Name:	**Role / Area:**
Michael Chapman (MC)	NHS England member (Data and Analytics Representative)
Dr. Robert French (RF)	AGD independent member (Specialist Academic / Statistician Adviser)
Jon Moore (JM)	NHS England member (Data Protection Office Representative)
Dr. Jonathan Osborn (JO)	NHS England member (Caldicott Guardian Team Representative)
Miranda Winram (MW)	AGD independent member (Lay Adviser)

1	**Welcome and Introductions:** The Chair welcomed attendees to the meeting. AGD noted that, due to the lack of availability of independent members, there was an even number of AGD independent members (three) and AGD NHS England members (three) in attendance for **part of item 4.1**. The importance of the AGD independent member majority was acknowledged by those present, and it was suggested that an annual review / possible inclusion in the AGD annual report of the number of meetings where an independent majority had not been present would be useful, as this would allow

	consideration of whether any action needed to be taken to improve the proportion of meetings with an AGD independent member majority. The NHS England SIRO representative stated that should AGD members be required to vote on any issues in the meeting, then one AGD NHS England member would be asked to not participate, to ensure the appropriate balance of votes, i.e. that the majority was by AGD independent members. The Group noted and agreed with this proposal. Noting that the AGD Terms of Reference state that *"The **majority** of the members of the Group or Sub-Group involved in any meeting **should** be independent members…"*, the Group agreed that the meeting was still quorate for **all** agenda items and agreed to proceed on that basis. AGD noted that, due to the lack of availability of members, only **four** AGD independent members and only **one** AGD NHS England member were in attendance for the full discussion on **item 5.5** (noting all three NHSE members were in attendance for part of the discussion of item 5.5; and only **three** AGD independent members and **no** AGD NHS England members were in attendance for the full discussion on **item 5.6**. Noting the AGD Terms of Reference clause 7.13: *"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. In addition, a representative of the SIRO must also be in attendance for any meetings of the Group or a Sub-Group. **In exceptional circumstances the Chair and the representative of the SIRO may agree for the Group to still meet and conduct its business, but the minutes should note the meeting was not quorate and provide details of the number of NHSE members and independent members who were in attendance and provided advice on any matters***"; the Group agreed that the meeting was **not** quorate for agenda items 5.5 and 5.6. The Chair and the SIRO representative agreed to proceed in *"exceptional circumstances"* in accordance with clause 7.13. The members in attendance for each item are noted in the table above. AGD noted that, due to an urgent work commitment, there would not be an NHS England SIRO Representative or delegate in attendance for part of **item 5.4**. Noting that the AGD Terms of Reference (ToR) state that: *"…a representative of the SIRO must also be in attendance for any meetings of the Group or a Sub-Group…"*, the NHS England SIRO Representative confirmed contentment for items 5.4 to be discussed in his absence; and noted that he would be in attendance for all other items on the agenda. The Group noted that item 5.4 was not quorate because of this, and, on this occasion, the Chair agreed to proceed in accordance with clause 7.13 of the AGD ToR. This clause provides that: *"In exceptional circumstances the Chair and the representative of the SIRO may agree for the Group to still meet and conduct its business, but the minutes should note the meeting was not quorate..."*.
2	**Review of previous AGD minutes:** The minutes of the AGD meeting on the 19th June 2025 were reviewed and, after several minor amendments, were agreed as an accurate record of the meeting.
3	**Declaration of interests:**

	Claire Delaney-Pope noted a professional link to NIC-774448-Q4C6X (Beamtree UK Limited) and would **not** be part of the discussion. It was agreed that Claire would **not** remain in the room for the discussion of this application. Claire Delaney-Pope noted a professional link to NIC-754054-P3H3V (King's College London) as part of her role within the South London and Maudsley NHS Foundation Trust. It was agreed this did not preclude Claire from taking part in the discussion on this application. Jenny Westaway noted that she had some involvement with the subject matter of item 4.1 (NHS Public Health Functions Screening Directions 2025), through her National Data Guardian (NDG) role. It was agreed this did not preclude Jenny from taking part in the discussion.	
4 BRIEFING PAPER(S) / DIRECTIONS:		
4.1	**Title:** NHS Public Health Functions Screening Directions 2025 (Briefing Paper and Data Protection Impact Assessment (DPIA)) **Presenter:** Dr. Kevin Dunbar **Observers:** Rahima Oliver and Laboni Paul The NHS public health functions agreement sets out the arrangements under which the Secretary of State for Health and Social Care delegates responsibility to NHS England for certain public health services (these known as section 7A services), including national screening programmes in England. The Screening Programme is requesting a Direction to cover establishing and operating a system for collecting, linking and analysing information from the Programme through the development of the existing technology and the established service. It is anticipated that there will be multiple data collections within the scope of these Directions. Each collection will have a requirements specification published alongside these Directions. The initial specifications, being drafted for these Directions, are for breast, bowel and cervical screening services. NHS England were seeking **early advice** on the following points: 1. Does the processing raise any risks for NHS England which have not been adequately addressed within the documents provided? 2. Is there any specific advice regarding transparency to patients around moving from the HRA CAG s251 to a Direction? 3. Are there any elements of the proposed data collection or processing which may result in harm to patients? **Outcome of discussion:** AGD welcomed the briefing paper and DPIA and made the following observations / comments: **4.1.1** AGD noted the purpose of the proposed Direction, and advised that they were supportive of the proposal outlined. **In response to point 1 above:**	

	4.1.2 AGD suggested that the point in the documents provided related to the 'equality and inclusion obligations' was expanded to provide further information relating to the processing undertaken to achieve this objective. **4.1.3** AGD noted the information within the DPIA in respect of individual rights and processes to manage this (point 13); and suggested that this was updated with further information to ensure the relevant information is clear and transparent. **In response to point 2 above:** **4.1.4** AGD suggested that the DPIA **and** all public facing transparency materials are updated to be clear on **1)** the processing being undertaken for the purpose of direct care; **2)** what research is being undertaken; and 3) the pseudonymised data and the identifiable data that will be processed. **In response to point 3 above:** **4.1.5** AGD noted that they had no specific comments on any elements of the proposed data collection or processing which may result in harm to patients; however, advised that they would welcome sight of the draft Direction once available, to provide advice as may be required.	
4.2	**Title:** Section 255 Health and Social Care Act 2012: Electronic Prescription Service for Isle of Man Request 2025 (Briefing Paper and Data Protection Impact Assessment (DPIA)) **Presenter:** Jenny Friday **Observers:** Claire Corney The Isle of Man Department of Health and Social Care intends to issue a non-mandatory statutory request under s255 of the Health and Social Care Act 2012 to request NHS England to establish and operate an information system for the collection and analysis of information as is necessary to provide the existing English Electronic Prescription Service (EPS) to the Isle of Man. The EPS is a delivery mechanism enabling the transmission of a prescription electronically from a prescribing system through to a dispensing system. The service is already operational in England and Wales and this s255 Request will enable the service to be rolled out to the Isle of Man. A new *"prescription type"* needs to be configured to identify Isle of Man prescriptions; this has been assessed by the platform team as a small change. NHS Spine directories will also need to accommodate additional site information for pharmacies and dispensing appliance contractors in the Isle of Man. NHS England were seeking advice on the following points: 1. Feedback on the draft s255 Request. 2. Feedback on the adequacy of the transparency/privacy information to Isle of Man patients **Outcome of discussion:** AGD welcomed the briefing paper and made the following observations / comments: **In response to point 1 above:**	

	4.2.1 AGD noted that the Isle of Man had implemented the General Data Protection Regulation (GDPR) into it law, to process data and that they had received an adequacy decision from the UK's Information Commissioner's Office. **4.2.2** AGD discussed the joint data controllership arrangements outlined, and advised that they were supportive of NHS England being a joint Data Controller. **In response to point 2 above:** **4.2.3** AGD suggested that the transparency materials were updated to be clear that the Isle of Man is a self-governing dependency of the British Crown, not a part of the UK. **4.2.4** AGD suggested that the privacy notice was updated to **1)** be clear that name and address would be shared with the pharmacy; and **2)** assure the public of the common law duty of confidentiality. **4.2.5** AGD suggested that the transparency information also include a Frequently Answered Questions (FAQ) document for the Isle of Man, and these could be drafted using FAQ's information already available for other countries. AGD provided the following observations / comments, separate to the briefing paper: **4.2.6** AGD noted the query from NHS England as to whether there should be a Precedent approach for **any** other jurisdictions requested EPS. AGD advised that there should not be a precedent approach, because of the unique arrangements of each jurisdiction. However, as part of the supporting pack of papers for such applications, other related applications and previous AGD advice could be included for background. AGD also noted that these reviews would not require a full slot on the AGD meeting agenda. **4.2.7** AGD looked forward to receiving the finalised briefing paper, either out of committee (OOC) or tabled at a future meeting.	
5 EXTERNAL DATA DISSEMINATION REQUESTS:		
5.1	**Reference Number:** NIC-754054-P3H3V-v0.6 **Applicant and Data Controller:** King's College London **Application Title:** "Naloxone Prospective Observational Cohort Research Study (NalPORS)" **Observer:** Emma Whale **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 touched on the extensive ethical considerations related to this research, and noted that the applicant had discussed these with an NHS Health Research Authority Research Ethics Committee (HRA REC).	

	5.1.2 AGD noted and commended the work undertaken by NHS England's DAS on the NHS England internal consent review; and agreed that there was a legal gateway in consent. **5.1.3** The Group suggested that the applicant needed to have a clear plan on the study end date, and suggested that this was made clear to the cohort, and that transparency information was updated to reflect this information, so that individuals are aware of how long their identifiers are being held. **5.1.4** AGD noted there was a legal gateway in consent to have mortality data for the entire cohort, however, noted that the applicant was only requesting this data for a small section of the cohort; and suggested that NHS England explore this further with the applicant, noting that it may be beneficial for the researchers to receive this data for the whole cohort. AGD noted that they would be supportive of this update to the application, with a further review by the Group. **5.1.5** AGD noted the statement in section 5 (Purpose / Methods / Outputs) of the application *"There will be no requirement and no attempt to reidentify individuals…"*; and noting that this was a consented cohort, suggested that there may be instances where it would be beneficial to re-identify individuals, for example in respect of patient safety. It was suggested that this was reviewed and updated as may be necessary to reflect the correct information; or that the statement was removed. **5.1.6** AGD noted the role of Mundipharma outlined in the application, however suggested that section 5(a) (Objective for Processing) was updated further, to make it explicit clear that Mundipharma will benefit from the research study. **5.1.7** AGD also noted that the finding from the study will be used for Mundipharma's "post authorisation marketing"; and suggested that section 5(a) was updated with a brief explanation of what this is. **5.1.8** In addition, AGD discussed the Mundipharma's "post authorisation marketing" in line with the NHS England DAS Standard for Commercial Purpose, and felt that it was appropriate, in that Mundipharma will use the summary information to support the activities necessary to meet regulatory requirements for "post-authorisation marketing". **5.1.9 Separate to this application and for NHS England to consider:** AGD suggested to the AGD NHS England Data and Analytics Representative, that when the NHS England DAS Standard for Commercial Purpose is next reviewed and updated, it defined what prohibited marketing was and considered expressly acknowledging permitted use to support "post authorisation marketing". **5.1.10** AGD noted the NHS England citation special condition in section 6 (Special Conditions), in particular the statement that *"…NHS England collates patient data and gives permission for publicly beneficial uses…"*; and suggested that the source of this wording was determined to ensure a standard approach is taken. **5.1.11** AGD noted and commended NHS England's Data Access Request Service (DARS) on the clear explanation as to why the data was deemed to be *"identifiable"*; and suggested that this was an exemplar for other application. **5.1.12** AGD noted that there **was** a commercial aspect to the application.	D&A Rep
5.2	**Reference Number:** NIC-786702-B8R5P-v0.2	

	Applicant and Data Controller: Sanius Health **Application Title:** "Sickle Cell Disease (SCD) Unmet Patient Needs, Standards of Care & National Clinically Established Treatment Costing project" **Observers:** Jodie Taylor-Brown and Emma Whale **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 item was withdrawn by the NHS England SIRO Representative and the NHS England's Data Access Request Service (DAS) in-meeting, however, noting the usual process that when an application is withdrawn points are not usually included in published minutes, the NHS England SIRO Representative asked that any AGD advice be published and AGD made the following observations on the application and / or supporting documentation provided: **5.2.1** AGD acknowledged the need for research into sickle cell disease and the potential value of national, standardised costs of care for sickle cell disease; however, AGD were unclear as to the scope of the application. **5.2.2** AGD noted a number of queries in relation to the purpose of processing, including but not limited to, **1)** being unclear on what the specific research project was; **2)** the role of Sanius Health with the research project and their commercial interest; **3)** the role of Vertex Pharmaceuticals Incorporated and their commercial interest; and **4)** if / how artificial intelligence (AI) or advanced machine learning would be used within this project AGD suggested the application was reviewed and updated to be clear on the points raised. **5.2.3** AGD noted that the data under this application would be accessed via the SDE, however noted that this still raised a number of concerns, including, but not limited to, **1)** being unclear on the plan for the use of the data; **2)** the relevance of the *"app"* referred to in the application; **3)** if the cost of not treating sickle cell is being looked at; and **4)** if the applicant has a vested interest in the outcomes of the research. AGD suggested that these points were addressed within the application. **5.2.4** AGD queried if the research had any clinical support, noting information within the public domain, and suggested that this was included in section 5 (Purpose / Methods / Outputs) as may be appropriate. **5.2.5** AGD noted the statement in section 5(a) (Objective for Processing) *"Data is collected through ethically approved consent processes…"*; and suggested that further information was provided on this, for example, is this relating to data on the app. **5.2.6** AGD noted that section 7 (Ethics Approval) contained text that was not standing wording, and suggested that this was reviewed and updated to ensure the correct wording. **5.2.7** AGD noted in the NHS England Data Access Request Service (DARS) internal application assessment form, that Sanius Health do **not** currently have a Data Sharing Framework Contracts (DSFC); and supported NHS England's position that no data would flow until this was addressed / resolved.	

	5.2.8 Separate to this application and for NHS England to consider: AGD queried what the due diligence process was for new applicants of data; and were advised by the NHS England SIRO Representative that further information would be shared with the Group on the regional SDE's process at a future AGD meeting. **5.2.9** AGD noted the application had been withdrawn, however noted that there **was** a potential commercial aspect to the application.	SIRO Rep
5.3	**Reference Number:** NIC-331142-P5K6M-v5.6 **Applicant:** University of Bristol **Data Controllers:** NHS England and Healthcare Quality Improvement Partnership (HQIP) and NHS England **Application Title:** "National Child Mortality Database (NCMD)" **Observer:** Jodie Taylor Brown **Previous Reviews:** The application and relevant supporting documents were previously discussed at the AGD meetings on the 16th January 2025, 18th July 2024, and the 19th June 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 18th November 2021, 19th August 2021 and the 9th July 2020. The application and relevant supporting documents were previously presented / discussed at the IGARD COVID-19 response meetings on the 26th November 2020. **Application:** This was an amendment application. NHS England were seeking advice on the following points only: 1. The request for additional datasets; 2. The change in legal basis; and 3. The Change in data flow / linkage methodology. 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:** **5.3.1** AGD noted that two Article 9 UK General Data Protection Regulation (UK GDPR) limbs had been cited, Article 9(2)(h) *(Health or social care (with a basis in law)),* and 9(2)(j) *(processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purpose)*; and suggested that the application was updated to **1)** clarify what processing was being carried out under each Article 9 limb; or **2)** remove one of the Article 9 limbs.	

	In response to point 2: **5.3.2** AGD noted that they were unable to provide any advice on the change in legal basis from Regulation 3 of The Health Service (Control of Patient Information) (COPI) Regulations 2002, to s16N of the Children's Act 2004; noting that the Group had not been furnished with the relevant paperwork. **5.3.3 Separate to this application and for NHS England to consider:** AGD noted, that as discussed at the AGD meeting on the 17th August 2023, NHS England had reviewed and accepted external legal advice received, that independent advisers on the group were part of the client group and were able to receive legally privileged advice. The Group suggested that where appropriate, this information was shared for future reviews of applications and other documents as requested by NHS England. **5.3.4** AGD noted the statement in the NHS England internal application assessment form *"External researchers might apply to access this data…"*; and queried **1)** under what arrangements these researchers would access the data, and **2)** under what legal basis they would access the data. **In response to point 3:** **5.3.5** AGD suggested that the application was updated to clarify the role of the Integrated Care Boards (ICBs). **5.3.6** AGD noted the various statements in the public domain, for example, academic papers, that referred to "*research*"; and suggested that **1)** the application is updated to reflect any research undertaken; and **2)** clarify how the research is compatible with s16N of the Children's Act 2004. In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review: **5.3.7** Noting AGD was only asked to advise on specific points reviewed, no AGD member noted any substantive commercial aspects.	D&A Rep / SIRO Rep
5.4	**Reference Number:** NIC-778449-V2L5D-v0.5 **Applicant and Data Controller:** University Hospital Southampton NHS Foundation Trust **Application Title:** "FLuid Optimisation in Emergency LAparotomy (FLO-ELA) trial" **Observer:** Joe Lawson **Linked applications:** This application is linked to NIC-786257-W9C8P and NIC-60714-M4T1M. **Application:** This was an amendment application. NHS England were seeking advice on the following points, including general advice on any other aspect of the application: 1. The request for additional datasets; 2. The role of Queen Mary University of London (QMUL); and 3. Advice for the separate application which has been created to cover the request of data recruited through Consultee Advice under the Mental Capacity Act 2005 (NIC-786257-W9C8P).	

	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: **In response to point 1:** **5.4.1** AGD noted that there was a legal gateway in consent for the additional datasets requested. **In response to point 2:** **5.4.2** AGD noted that QMUL were now considered a Data Processor and not a Data Controller; and advised that they were content with the information provided to support this conclusion. **In response to point 3:** **5.4.3** AGD noted that all comments made on this application, should be addressed in NIC-786257-W9C8P as may be appropriate. In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review: **5.4.4** AGD noted that the application referred to data being provided 90-days *"before"* an individual joined the trial; and suggested that this was reviewed and updated to accurately reflect that would be provided 90-days **after** an individual joined the trial, in line with the patient information sheet and other information within the public domain. **5.4.5** AGD noted the conflicting statements in section 5(b) (Processing Activities) that *"The Data will be accessed by authorised personnel…"*; and *"Access is restricted to employees or agents of PCTU (Queen Mary University of London) who have authorisation from the Chief Investigator…."*. AGD suggested that **1)** this was reviewed and updated as necessary to reflect the correct / factual information; and **2)** NHS England clarify with the applicant whether the arrangement whereby the Chief Investigator provided authorisation is workable. **5.4.6** AGD queried the statement in section 5(b) *"Access is restricted to employees or **agents** of…"* and suggested that either further information was provided as to who would be covered by "*agents* "; or that this word was removed, as may be necessary to reflect the facts. **5.4.7** No AGD member noted a commercial aspect to the application.	
5.5	**Reference Number:** NIC-626153-S6J6V-v0.5 **Applicant:** King's College London **Data Controller:** University of Sheffield **Application Title:** "YORKSURe: Early detection of bladder cancer in Yorkshire: Feasibility assessments for implementing a targeted study in populations with high disease specific mortality risk (Line Listing)" **Observer:** Azeez Oladipupo **Linked applications:** This application is linked to NIC-689987-Z6D2Z.	

	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 acknowledged that they would **not** be quorate for part of the discussion of this application noting only one AGD NHS England member was available for the full discussion (*and two for the discussion part only but not for the outcome discussion); noting that the AGD Terms of Reference states that *"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 agreed to discuss the application (see Section 1 above). AGD members in attendance were supportive of the application and wished to draw to the attention of the SIRO the following comments: **5.5.1** AGD noted that prior to the meeting, an AGD independent member had queried further clarification of the cohort, noting the potentially conflicting information in the supporting documents provided; and were advised that the study team are only interested in the cohort of participants who self-tested in the study, which includes those with and without a cancer diagnosis, which is 1304 participants. These participants self-tested in the study, provided their consent and will be followed up passively to identify those who developed cancer and those who did not. AGD noted and thanked the applicant for the information provided, and suggested that the application was updated to include this information. **5.5.2** AGD noted that the data was noted as *"pseudonymised"* in the application; however, suggested that this was updated to accurately reflect that data will be *"identifiable".* **5.5.3** AGD noted and commended the work undertaken by NHS England's DAS on the NHS England internal consent review; and agreed that there was a legal gateway in consent. **5.5.4** AGD suggested that the applicant ensure there is ongoing transparency with the cohort, and that the processing is accurately described, including, but not limited to, the point at which data is deleted. **5.5.5** AGD suggested the applicant was reminded that they were required to maintain a UK General Data Protection Regulation (UK GDPR) compliant, publicly accessible **study specific** transparency notice for the lifetime of the agreement, in line with the contractual requirement in section 4 (Privacy Notice) of the data sharing agreement (DSA). **5.5.6** AGD suggested that section 5(a) (Objective for Processing) and section 5(b) (Processing Activities) were updated to be clear as to who is accessing the data, and at what point, for example, Barts Health NHS Trust via an honorary contract as noted in the NHS England Data Access Request Service (DARS) internal application assessment form. AGD suggested that if Barts Health NHS Trust were accessing the data under an honorary contract, that NHS England satisfy themselves this was in line with NHS England's DAS Standard for Honorary Contracts. **5.5.7** AGD noted the reference *to "s251"* in section 5(a), and suggested that this specific reference was removed to avoid confusion, but the rest of the information relating to patient and public involvement and engagement (PPIE) was retained.	

	5.5.8 AGD suggested that section 6 (Special Conditions) was updated to **1)** include a special condition relating to the Annual Confirmation Report (ACR); and **2)** to include the citation special condition, in line with NHS England DAS Standard for Special Conditions. **5.5.9** AGD noted the reference to the linked application (NIC-689987-Z6D2Z), however noting that this relates to a different cohort, the Group advised that they would not be content for advice on this application to be used for the linked application. **5.5.10** No AGD member noted a commercial aspect to the application. **Subsequent to the meeting:** The AGD NHS England Data and Analytics Representative advised that they would have given support to this application, if they had been in attendance for the 'outcome' part of the discussion.	
5.6	**Reference Number:** NIC-774448-Q4C6X-v0.5 **Applicant and Data Controller:** Beamtree UK Ltd **Application Title:** "Beamtree Evolve and NHS Confederation Collaborative" **Observer:** Jodie Taylor-Brown **Previous Reviews:** The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 15th May 2025. **Application:** This was a new application. NHS England were seeking advice on the following points, including general advice on any other aspect of the application: 1. The controls in place for the small numbers unsuppressed data. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** AGD acknowledged that they would **not** be quorate for the discussion of this application noting **no** AGD NHS England members were available for the discussion; noting that the AGD Terms of Reference states that *"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 agreed to discuss the application (see Section 1 above). AGD members in attendance were supportive of the application and wished to draw to the attention of the SIRO the following comments: **In response to point 1:** **5.6.1** The independent members noted the supporting information provided in respect of the controls in place for the small numbers unsuppressed data, and advised that they had no additional comments on this point, and thanked NHS England and the applicant for the information provided. In addition, the independent members made the following observations on the application and / or supporting documentation provided as part of the review: **5.6.2** The independent members noted the novelty of the application and the possible use of machine learning.	

	5.6.3 The independent members suggested that for the purpose of transparency, section 5(a) (Objective for Processing) was updated to state that *"Initial funding for product development is provided by Beamtree. Revenue from member trusts will* ***allow Beamtree to make a commercial profit*** *support product sustainability over time.* ***NHS Confederation will benefit financially through…".*** **5.6.4** The independent members suggested that section 5(b) (Processing Activities) was updated to provide further information on machine learning / AI that will be deployed. **5.6.5** The independent members noted that the NHS England Data Access Request Service (DARS) internal application assessment form stated that a query had been raised with the applicant, in respect of whether ethical review had been sought, and that this was still outstanding. **5.6.6** The independent members suggested that NHS England follow this up, and updated the application as appropriate to reflect the current / factual information. **5.6.7** The independent members noted the statement in section 5(b) *"The Data will not leave England at any time"*; and suggested that this was updated to also state that it would not be accessed anywhere other than the permitted territory of use. **5.6.8** The independent members noted that there **was** 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-616046-J1Q0N-v4.2 **Applicant and Data Controller:** NHS Norfolk and Waveney ICB **Application Title:** "NHS Norfolk and Waveney Integrated Care Board - Comm, RS and IV" **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 26th January 2023, 6th October 2022, 25th August 2022, 4th August 2022 and the 21st July 2022. The SIRO approval was for additional linkage of NHS England data to ICBs, Local Authorities and community care providers. **Outcome of discussion:** AGD noted that the NHS England SIRO had already provided SIRO approval and confirmed that they were supportive of this. The Group thanked NHS England for the written update and made the following observations on the documentation provided: **7.1.1** The independent members suggested that, if this had been a new ICB application, it would have needed to have come to AGD for a full review. The NHS England SIRO representative thanked AGD for their time.	

8 OVERSIGHT AND ASSURANCE		
There were no items discussed		
9 AGD OPERATIONS		
9.1	**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
9.2	**Standard Operating Procedures (SOPs)** AGD queried if the review of the AGD Terms of Reference, forwarded to the Director of Privacy and Information Governance on the 14th March 2025, had been considered and asked that an update be provided as to next steps. **ACTION:** NHS England SIRO Representative to update the Group at a future AGD Meeting.	SIRO Rep
9.3	**AGD Stakeholder Engagement** **National Patient Data Day** Paul Affleck noted that, in a personal capacity, he had attended the useMYdata National Patient Data Day event on the 24th June 2025.	
9.4	**AGD Project Work** *There were no items discussed*	
10 Any Other Business		
10.1	**Reusable Decisions / Precedents (Presenter: Garry Coleman)** The NHS England SIRO Representative advised that information would be shared with the Group in the coming weeks, in respect of potential new Reusable Decisions and Precedents. **ACTION:** AGD Secretariat to add 'New Reusable Decisions and Precedents' to the AGD internal forward planner.	AGD Sec

	The Group thanked the NHS England SIRO Representative for the update, and looked forward to further discussion.	

Meeting Closure

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