Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 10th September 2026

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)
Claire Delaney-Pope (CDP)	AGD independent member (Specialist Information Governance Adviser)
Dr. Jon Fistein (JF)	AGD independent member (Chair)
Prof. Jo Knight (JK)	AGD independent member (Specialist Academic / Researcher Adviser)
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)
Prof. Matthew Sydes (MS)	NHS England member (Data and Analytics Representative (Delegate for Michael Chapman)) (Not in attendance for items 1 to 4.1)
Miranda Winram (MW)	AGD independent member (Lay Adviser)
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	**Role / Area:**
Garry Coleman (GC)	NHS England SIRO Representative (Not in attendance for part of item 5.4 and item 5.5)
Tom Counsell (TC)	Deputy Director of Research and Development (**Presenter / Observer**: item 4.1)
Ayse Depsen (AD)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer**: item 5.1)
Claire Edgeworth (CE)	Head of Strategic IG – Consultancy, Head of Information Governance, NHS England Data for R&D (**Presenter / Observer**: item 4.1)
Dan Goodwin (DG)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer**: item 5.3)
Suzanne Hartley (SH)	Data Applications Service (DAS) - Senior Manager, Data Access and Partnerships, Transformation Directorate (**Observer**: item 5.5)

Melissa Hofman (MH)	Associate Director of NHSE Research SDE Network, Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Presenter / Observer**: item 4.1)
Joe Lawson (JL)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer**: item 5.2)
Humphrey Onu (HO)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer**: item 5.2 and 5.5)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Technology, Digital and Data
Jodie Taylor-Brown (JTB)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer**: item 5.4)
Emma Whale (EW)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer**: item 5.6)
AGD INDEPENDENT MEMBERS / NHS ENGLAND MEMBERS NOT IN ATTENDANCE:	
Name:	**Role / Area:**
Mr Christopher Barben (CB)	AGD independent member (Specialist Clinician Adviser)
Michael Chapman (MC)	NHS England member (Data and Analytics Representative)
Dr. Mark McCartney (MM)	AGD independent member (Specialist GP / Clinician Adviser)
Jon Moore (JM)	NHS England member (Data Protection Office Representative)
Jenny Westaway (JW)	AGD independent member (Lay Adviser)

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 1 to 4.1. 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. 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 and item 5.5. 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 Group were advised that the NHS England SIRO Representative had confirmed contentment for part of item 5.4 and item 5.5 to be discussed in their absence.	
2	**Review of previous AGD minutes:** The minutes of the AGD meeting on the 27th August 2026 were reviewed out of committee by the Group and were agreed as an accurate record of the meeting by the AGD Chair, on behalf of the Group.	
3	**Declaration of interests:** Claire Delaney-Pope noted a professional link the subject matter of item 4.1 (Regional Secure Data Environment (RSDE)) as part of her role within the South-East London Integrated Care System (SEL ICS). It was agreed this did not preclude Claire from taking part in the discussion. Prof. Jo Knight noted that she had some involvement with the subject matter of item 4.1 (Regional Secure Data Environment (RSDE)), through her Lancashire and South Cumbria NHS Secure Data Environment role. It was agreed this did not preclude Prof. Knight from taking part in the discussion. Dr. Jon Fistein noted a professional link to the University of Oxford but noted no specific connections with the application (NIC-793088-Z9Y0Z), and it was agreed that this was not a conflict of interest. Prof. Matthew Sydes noted a professional link to University College London and the applicant of NIC-804103-Q6P5S. It was agreed this did not preclude Prof. Sydes from taking part in the discussion for this application.	
4 BRIEFING PAPER(S) / DIRECTIONS / DPIAs / PRECEDENTS / REUSEABLE DECISIONS / TEMPLATES		
4.1	**Title:** Regional Secure Data Environment (RSDE) Strategy update **Presenter:** Claire Edgeworth, **Observers:** Melissa Hofman and Tom Counsell **Previous Reviews:** The Regional SDEs / associated internal application assessment forms were previously discussed at the AGD meetings on the 18th June 2026, 26th March 2026, 26th February 2026, 29th January 2026, 11th December 2025, 11th September 2025 and the 8th August 2024. The purpose of the item, is for NHS England to provide an update on the Regional SDE Network Strategy and seek advice on the points below. NHS England were seeking advice on the following points: 1. The RSDE Assurance Framework. 2. The RSDE Technical Assurance Framework. 3. The RSDE Data Sharing Agreement (DSA). **Summary of discussion:** AGD welcomed the briefing and made the following observations / comments:	

4.1.1 In addition to the information provided prior to the meeting, AGD were provided with a spoken update / overview on the current position with the Regional SDEs. The Group noted and thanked NHS England for the update / additional information provided.

4.1.2 The Group noted and commended NHS England on the volume of work undertaken to date and advised that they were supportive of the move to a more consistent standard for approved nationwide access to data.

In response to points 1 to 3 above:

4.1.3 AGD advised that NHS England should ensure that, where possible, work should be done in advance of any data access, rather than relying on an audit, to reduce the risk of a breach occurring; including, but not limited to, ensuring there is appropriate governance in place for each of the Regional SDEs.

4.1.4 In addition, AGD advised that, when looking at the governance structures / processes, NHS England should consider:

4.1.4.1 draft NHS England Standards that are progressing e.g. the draft 'Programme Standard'.

4.1.4.2 existing NHS England Standards already in place, for example, the NHS England DARS standard for sub-licencing and onward sharing.

4.1.4.3 patient and public involvement and engagement (PPIE)

4.1.4.4 transparency

4.1.4.5 how limits on data use are defined

4.1.4.6 appropriate escalation routes

4.1.5 In respect of the Regional SDE accreditation process, the Group advised that further details should be considered / clarified in respect of the advisory committee structures and processes, in line with existing NHS England Standards.

4.1.6 AGD commended the work undertaken on the Regional SDE Technical Assurance Framework, however advised that this should not inadvertently introduce a new set of controls that may potentially be inconstant with other modes of access; and that as a result some organisations are not following different sets of Standards / technical controls.

4.1.7 AGD queried whether the National Data Opt-out would be applied, and advised that this was reviewed and updated in the DSA to reflect the correct information.

4.1.8 AGD noted that some organisations may hold both pseudonymised and identifiable data for different purposes, and may run national projects in Regional SDEs; and advised that NHS England provide further clarity as to how this will work.

4.1.9 AGD advised that further detailed comments / queries on the three draft documents provided, would be shared out of committee with the presenter / observers.

4.1.10 AGD welcomed the opportunity to provide advice on this area of work, and advised that they would support further advice being sought as may be necessary either in-meeting or out of committee.

5 EXTERNAL DATA DISSEMINATION REQUESTS:

5.1	**Reference Number:** NIC-808600-B4C8V-v0 **Applicant and Data Controller:** University of Bristol **Application Title:** "DEPILL-CKD_ DEPrescribing In peopLe Living with advanced Chronic Kidney Disease – understanding patterns and outcomes" **Observer:** Ayse Depsen **Previous Reviews:** The application and relevant supporting documents were previously presented / discussed at the Profession Advisory Group (PAG) meetings on the 27th July 2026. **Application:** This was a new application. NHS England were seeking advice on the following points: 1. Whether this is an application which could be approved under a new OpenSAFELY Precedent (noting the queries which have been put to NHS England by AGD); and 2. If not, then **a)** what exclusion criteria may apply; and **b)** are there additional question/answer pairs that might have made this suitable for being a precedent. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Summary of discussion:** AGD noted that the PAG had reviewed the application as per process on the 27th July 2026, and that feedback was available in the published PAG minutes from the meeting. **In response to point 1:** **5.1.1** AGD noted that they were broadly supportive of the proposed use of OpenSAFELY for the specified purpose. **In response to point 2:** **5.1.2** Notwithstanding the ongoing work being undertaken by NHS England on the draft OpenSAFELY Precedent, following comments previously provided by the Group, AGD noted that this application would be suitable for approval under a finalised Precedent. **5.1.3 Separate to the application**: AGD noted that following on from the advice provided at the AGD meeting on the 23rd July 2026 (point 5.1.6.3), the Group advised that this application provided a further OpenSAFELY example of where there are multiple organisations involved; and where there may be joint data controllership / responsibility; and that they looked forward to receiving an update from NHS England on this point at a future AGD meeting. In addition to their advice on the specific points raised by NHS England, AGD made the following observations on the application and / or supporting documentation provided as part of the review: **5.1.4** AGD noted the statement in the internal form / application *"The focus will be on commonly prescribed, non-specialist medicines, including…**but are not limited to**…";* and advised that this was reviewed and updated if possible, to include more detailed / explicit information to support transparency / public trust.	

	5.1.5 Given the points raised by the Group, the NHS England SIRO Representative noted this application could progress via delegated authority to NHS England's Data Access Request Service (DARS) once the AGD advice has been addressed.	
5.2	**Reference Number:** NIC-793221-T4S4C-v0 **Applicant and Data Controller:** University of Liverpool **Application Title:** "United Kingdom Early Detection Initiative- Pancreatic Cancer Early Detection" **Observers:** Joe Lawson and Humphrey Onu **Application:** This was a new application. NHS England were seeking advice on the following points: 1. If the sharing of derived data assets with academic and commercial collaborators is adequately described in participant materials and consistent with the basis on which NHS England data was obtained. 2. If the NHS England DARS Standard for Commercial Purpose is met, given commercial partners as recipients of data (even in aggregated or pseudonymised form), and whether it is felt that this aligns with the public interest basis of the study, and/or participant expectations. 3. If it is appropriate for the University of Liverpool to supply the gender of UK-EDI participants for the purpose of data linkage noting that the consent materials do not state that this would be shared with NHS England. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Summary of discussion:** **5.2.1** AGD noted that the advice provided, as part of this review, was on the assumption that the data that would be shared was derived data; and that as per the usual process, NHS England should satisfy itself that the data was derived. **In response to point 1:** **5.2.2** AGD advised that the sharing of derived data with academic and commercial collaborators was consistent with the participant materials and the basis on which NHS England data was obtained. **5.2.3** AGD noted that whilst the consent materials were compatible, they were not always very clear, and advised that the applicant review and update their transparency materials to be clear how the data would be used. **5.2.4** In addition, two of the AGD members advised that the applicant undertakes some patient and public involvement and engagement (PPIE) to test the understanding of participants and determine whether they would be surprised at the proposed use of the data. **In response to point 2:** **5.2.5** AGD advised that the NHS England DARS Standard for Commercial Purpose had **not** been met, and that for the purpose of transparency, the internal form / application would need further updates to be clearer on any potential commercial benefit.	

5.2.6 The NHS England SIRO Representative noted the conversation around commercial use and the nature of consent, as well as the NHS England DARS Standard for Commercial Purpose, and asked AGD's view as to how the Standard and consent might interact. AGD's initial view, noting that this may be an area for future policy consideration, was that the commercial standard applied regardless of whether there was consent.

In response to point 3:

5.2.7 AGD advised that there was **not** consent for the University of Liverpool to supply the gender of UK-EDI participants for the purpose of data linkage noting that the consent materials do not state that this would be shared with NHS England. AGD did query whether the gender data was actually required and what benefit this would bring, and advised that this should not flow until the applicant could

5.2.7.1 provide a clear justification for the reason / benefits of this data flowing; and

5.2.7.2 clarify how this was compatible with the consent materials.

In addition to their advice on the specific points raised by NHS England, AGD made the following observations on the application and / or supporting documentation provided as part of the review

5.2.8 AGD noted the reference to a 'control group' within the documents provided, and advised that they were working on the assumption that this was part of the population requested and not a separate population; and advised that if it was separate, that this would require a separate application and would need considering on its own merits.

5.2.9 AGD noted that the of the patient materials referred to joint data controllership arrangements with the *"University of Strathclyde"*, however, the University of Liverpool appeared to be the sole Data Controller for this phase of the project. The Group advised that:

5.2.9.1 NHS England satisfy itself that the activities outlined in the internal form / application, are within the original data controllership arrangements / scope of the consent; and

5.2.9.2 the transparency materials were updated to reflect the correct information.

5.2.10 AGD noted the information in the internal form / application in respect of the prevention of data being downloaded, and queried if this was via technical or policy controls; and advised that this was clarified.

5.2.11 AGD noted the information in the internal form / application, in respect of data being shared on other platforms / infrastructures with other collaborators; and advised that this was removed, noting that this would **not** be permitted under the current data sharing agreement (DSA) and would require a separate application.

5.2.12 AGD noted the reference to *"machine learning"* in the internal form / application, and advised that further information was provided on this.

5.2.13 AGD noted that there were patient and public engagement representatives on the access committee; and advised that they encouraged further patient and public involvement and engagement (PPIE) as the project progresses.

	5.2.14 AGD noted that there were two citation special conditions in the internal form / application; and advised that NHS England review and remove one of the special conditions as may be appropriate. **5.2.15** Given the points raised by the Group, the NHS England SIRO Representative noted this application could progress via delegated authority to NHS England's Data Access Request Service (DARS) once the AGD advice has been addressed.	
5.3	**Reference Number:** NIC-793713-B3Y5P-v0 **Applicant and Data Controller:** University of Leicester **Application Title:** "Personalised Exercise Rehabilitation FOR people with multiple long-term conditions (multimorbidity) The PERFORM Trial" **Observer:** Dan Goodwin **Application:** This was a seeking early advice application. NHS England were seeking advice on the following points: 1. Whether the consent package, when considered as a whole, provides sufficient transparency and participant expectation for the proposed processing. To assist deliberations, sub-questions are given within the paper to assist in reaching a conclusion around: **a)** interpretation of existing participant materials; **b)** scope of consent; **c)** proposed participant letter; and **d)** content of proposed letter. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Summary of discussion:** AGD noted that a briefing had been provided, and not an internal form / application, on this project that was coming for early advice. **In response to point 1:** **5.3.1** AGD had a detailed discussion in respect of the content of the consent materials, and felt that there was **1)** some ambiguity as to whether the data flows outlined were included, noting the nature of the wording used, for example, *"local health records"*, *"GP records"* and *"study data"*; and **2)** inconsistencies between the consent materials; and that it was unclear whether participants would expect the data flows requested to be included as part of this. The Group did however advise that it was not necessarily incompatible with the consent materials; and advised that the applicant undertakes some patient and public involvement and engagement (PPIE) to check the understanding of participants as to what they had consented to, and then take a decision as to whether to proceed with the application or not. **5.3.2** If the PPIE indicated that participants were content that there was compatibility, then sending a letter to clarify some points may be acceptable; however, advised that the letter was updated to ensure that the information relating to an *"opt-out"* was updated to be clear that this was the option to withdraw consent. In addition to their advice on the specific points raised by NHS England, AGD made the following observations on the application and / or supporting documentation provided as part of the review:	

	5.3.3 AGD discussed the potential international transfers of data, in particular noting the patient information sheet (PIS) stated that there would need to be an adequacy statement in place for the country where the data was flowing. Noting the intention to share data with Australia, the Group advised that there was not currently an adequacy statement in place for this country, therefore the data would not be able to flow as it would be incompatible with the PIS; and this could not be addressed via a letter to participants. **5.3.4** Given the points raised by the Group, the NHS England SIRO Representative noted this application could **not** progress via delegated authority until such time as the NHS England SIRO Representative and an NHS England senior colleague within Data and Analytics had reviewed the updated application.	
5.4	**Reference Number:** NIC-793088-Z9Y0Z **Applicant:** University of Oxford **Application Title:** "Oxford Pre-cancerous Lymphoproliferative Disorders (OxPLoreD) study" **Observers:** Jodie Taylor-Brown **Application:** This was a seeking early advice application. NHS England were seeking advice on the following points: 1. The consent obtained from participants provides a sufficient basis for linkage to NHS England datasets for the purpose of identifying time to first CLL treatment and, if relevant, date of death; and 2. If not, what additional approaches would AGD suggest before such linkage could proceed. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Summary of discussion:** AGD noted that a briefing had been provided, in addition to an internal form / application on this project that was coming for early advice. **In response to points 1 and 2:** **5.4.1** AGD advised that the consent obtained from participants was likely to be compatible with the proposed linkage to NHS England datasets. The Group however advised there was some ambiguity. In particular section 13 of the consent form which could be interpreted as permitting sharing data with the participant; or allowing provision of data from NHS England to the study team. **5.4.2** The Group advised that before this application progresses: **5.4.2.1** the applicant undertake some patient and public involvement and engagement (PPIE) to ensure that the more permissive interpretation would not cause any surprises to participants. **5.4.2.2** the transparency materials are updated in line with any feedback as part of the PPIE. In addition, the Group advised that the transparency would need to be in place for the duration of the study in line with the NHS England DARS Standard for Transparency.	

	5.4.3 In addition to their advice on the specific points raised by NHS England, AGD made the following observations on the application and / or supporting documentation provided as part of the review: **5.4.4** AGD advised that the papers provided were not clear on **1)** the potential follow-up period and when this starts from; and **2)** the volume of data requested. The Group advised that both of these points should be explored as part of any PPIE (in addition to the points raised under 5.4.2) **5.4.5** Given the points raised by the Group, the NHS England SIRO Representative noted this application could **not** progress via delegated authority until such time as the NHS England SIRO Representative and an NHS England senior colleague within Data and Analytics had reviewed the updated application.	
5.5	**Reference Number:** NIC-781159-J1J1N **Applicant and Data Controller:** Clarivate Analytics (UK) Limited **Application Title:** "European Procedure Finder – England data" **Observers:** Suzanne Hartley and Humphrey Onu **Previous Reviews:** The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 4th June 2026. **Linked applications:** This application is linked to NIC-568585-G9G9Y. **Application:** This was a new application. NHS England were seeking advice on the following points: 1. Whether AGD agrees with the assessment that the application continues not to meet the NHS England DARS standards and whether there are any additional considerations that should be taken into account before a final decision is made on the application; and 2. Whether the applicant has sufficiently demonstrated a direct and proportionate benefit to health and social care in England and Wales and whether the requested data can be justified as the minimum necessary to achieve the stated purpose. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Summary of discussion:** **In response to points 1 and 2:** **5.5.1** AGD advised that they agreed with the NHS England assessment that the application does **not** meet the DARS Standards, including, but not limited to, NHS England DARS Standard for Commercial Purpose, NHS England DARS standard for Data Minimisation and NHS England DARS Standard for Expected Measurable Benefits. **5.5.2** AGD also advised that the applicant has **not** sufficiently demonstrated a direct and proportionate benefit to health and social care in England and Wales; and that further information on this would need to be provided if this application was to proceed.	

	5.5.3 The Group noted that whilst the applicant has had access to tabulated data for a number of years, there were very limited yielded benefits identified, which may have further supported this application. **5.5.4** AGD advised that in respect of data minimisation: **5.5.4.1** further justification was required as to why specific datasets have been requested, and for what periods, in line with NHS England DARS standard for Data Minimisation; and **5.5.4.2** the benefits that will accrue from the data requested. In addition to their advice on the specific points raised by NHS England, AGD made the following observations on the application and / or supporting documentation provided as part of the review: **5.5.5** The Group advised that it was their view that this application should **not** progress further in the current form; and if this does progress, then the applicant should look at undertaking the work on a smaller basis to start with, where they may be able to identify benefits to health and social care in England and Wales that were proportionate to the commercial benefit, and potentially build on this over time. **5.5.6** Noting the extensive work to date on this application, and its limited progress, the Group queried whether further NHS England resources should be used to support it. **5.5.7** Given the points raised by the Group, the NHS England SIRO Representative noted this application could **not** progress via delegated authority.	
5.6	**Reference Number:** NIC-787221-X3M8G-v0 **Applicant and Data Controller:** Swansea University **Application Title:** "STALLED: What works to address ambulance handover delays at Emergency Departments" **Observer:** Emma Whale **Previous Reviews:** The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 23rd July 2026 and the 25th June 2026. **Application:** This was a new application. NHS England were seeking advice on the following points: 1. Whether the points previously raised have been sufficiently addressed, in particular whether **a)** the cohort structure is now sufficiently clear, including the distinction between the NHS England-generated ED cohort and the customer-supplied cohort, and how the case note review, questionnaire, SWAP and ambulance elements sit within or overlap with those cohorts; and **b)** the legal basis for each cohort is now sufficiently clear, particularly the distinction between the NHS England-generated cohort, where the data made available to the Controller is described as pseudonymised/no confidential patient information, and the customer-supplied cohort, where section 251 support applies to the flow of identifiable data into NHS England for linkage.	

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

Summary of discussion:

5.6.1 AGD noted the applicant was in the process of amending their existing s251 support with **the** Health Research Authority Confidentiality Advisory Group (HRA CAG); and advised that, as per the usual process, the applicant provide the relevant paperwork to NHS England once any updated s251 support is in place.

In response to point 1:

5.6.2 AGD advised that they were broadly satisfied that the previous AGD comments had been addressed, and that the cohort structure; relationship between the cohorts; and the legal basis for each cohort was much clearer.

In addition to their advice on the specific points raised by NHS England, AGD made the following observations on the application and / or supporting documentation provided as part of the review:

5.6.3 AGD noted that the data would now be accessed in the national Secure Data Environment (SDE), in line with the 'Data Saves Lives' strategy, to support the reduction of data extracts flowing where possible. This was a position that the Group were supportive of; however, advised that this did not align with the information shared with the cohorts in the transparency materials. The Group advised that the applicant:

> **5.6.3.1** ensure that this updated information was shared with the cohorts as soon as possible; and
>
> **5.6.3.2** make sure that the option for individuals to withdraw from the study was made transparent.

5.6.4 In addition, the Group advised NHS England, that the applicant review and update the internal form / application, to ensure that access via the SDE was clear, and that any incorrect information was removed.

5.6.5 Noting the sensitive nature of this study, and the fact it may discover evidence of potential patient harm, AGD advised that whilst the applicant was aware of the Duty of candour; it would have been helpful to have had sight of the protocol which should have addressed this point / process. The Group advised that if this application was to return for a future review, that the applicant should ensure that:

> **5.6.5.1** the protocol is provided with this information outlined; and
>
> **5.6.5.2** the internal form / application is updated to provide clarity on the process taken.

5.6.6 Separate to the application: The Group discussed the inclusion of the 'date of death' field, and reiterated previous advice that for clarity / future reference, NHS England should re-confirm its position on the identifiability status of date of death.

5.6.7 In addition, the Group advised that NHS England follow its current practice and document whether inclusion of date of death under this application renders the data confidential (and only proceed if it does not render the data confidential).

	5.6.8 Given the points raised by the Group, the NHS England SIRO Representative noted this application could progress via delegated authority to NHS England's Data Access Request Service (DARS) once the AGD advice has been addressed.	

6 INTERNAL DATA DISSEMINATION REQUESTS:

There were no items discussed

7 EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL

7.1	**Reference Number:** NIC-421602-N3B0X-v3.2 **Applicant:** NorthWest EHealth Limited **Data Controller:** Novartis Pharmaceuticals UK Limited **Application Title:** "VICTORION-Spirit: Phase IIIb, multicentre, randomised controlled study to evaluate the implementation of inclisiran sodium in participants with, or at risk of, Atherosclerotic Cardiovascular Disease and elevated Low Density Lipoprotein Cholesterol using a vaccine model in an NHS primary care setting" **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) meeting on the 8th December 2022. The SIRO approval was for an amendment to reflect the removal of Restore PLC as a backup storage provider. **Outcome of discussion:** AGD noted that the NHS England SIRO had already provided SIRO approval on the 27th May 2026 and confirmed that they were supportive of this. AGD thanked NHS England for the written update and advised that they had no further comments to make on the documentation provided. The NHS England SIRO representative thanked AGD for their time.
7.2	**Reference Number:** NIC-656760-F8Y3C-v3.2 **Applicant and Data Controller:** University College London (UCL) **Application Title:** "Cancer Registry-wide study in infants with neuroblastoma; Task 11.4 of the ENNCCA Network of Excellence" **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) meeting on the 12th January 2023. The SIRO approval was for an extension to archive data already held for a further year. **Outcome of discussion:** AGD noted that the NHS England SIRO had already provided SIRO approval on the 28th August 2026 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 queried whether UCL as the Data Controller was correct, however, noted that this may be a continuation of the contractual arrangements that was previously in place with Public Health England (PHE). **7.2.2** AGD advised that, noting the length of time the applicant had been given access to the data, further extensions may not be appropriate. 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 ways of working** *There were no items discussed*
9.2	**AGD Stakeholder Engagement** **Federated Data Platform** The Group's representative on the Federated Data Platform Data Governance Group, alongside the AGD NHS England Caldicott Guardian Team Representative, provided a brief update.
9.3	**AGD Project Work** *There were no items discussed*
10 Any Other Business	
10.1	Our Future Health (OFH) The Group noted that, prior to the meeting, an AGD independent had raised a query with the NHS England SIRO Representative in respect of NHS DigiTrials as its main recruitment channel for OFH. The NHS England SIRO Representative advised that following internal discussions, further information would be provided to the Group in due course.
Meeting Closure As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.	