Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 16th October 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 part of item 2, 3 and 5.1)
Dave Cronin (DC)	NHS England member (Data and Analytics Representative (Delegate for Michael Chapman)) (**Presenter**: item 4.1)
Claire Delaney-Pope (CDP)	AGD independent member (Specialist Information Governance Adviser)
Dr. Arjun Dhillon (AD)	NHS England member (Caldicott Guardian Team Representative
Dr. Robert French (RF)	AGD independent member (Specialist Academic / Statistician Adviser) (In attendance for items 5.5 to 10.3)
Kirsty Irvine (KI)	AGD independent member (Chair) (not in attendance for part of item 2, 3 and part of item 5.1)
Ellie Ward (EW)	NHS England member (Data Protection Office Representative (Delegate for Jon Moore))
Jenny Westaway (JW)	AGD independent member (Lay Adviser)
Miranda Winram (MW)	AGD independent member (Lay Adviser)
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	**Role / Area:**
Eleanor Berg (EB)	Senior Information Governance Manager, Data Protection Office & Trust (DPOT), Privacy, Transparency, and Trust (PTT), Deputy Chief Executive Directorate (**Observer:** items 5.1 to part of 5.6)
Garry Coleman (GC)	NHS England SIRO Representative (**Presenter**: item 4.1) (Not in attendance for items 1 to 4, part of 5.1 and 5.4)
Dan Goodwin (DG)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer:** item 5.1 and 5.2)

Andrew Ireland (AI)	Information Governance Specialist, IG Risk and Assurance, Privacy, Transparency, and Trust (PTT), Deputy Chief Executive Directorate (**Presenter**: item 4.2)
Tiaro Micah (TM)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer:** item 5.4)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Deputy Chief Executive Directorate
Humphrey Onu (HO)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer:** item 5.6)
James Watts (JW)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer:** items 5.3 and 5.4)
Emma Whale (EW)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer:** item 5.5 and 5.6)
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
Dr. Mark McCartney (MM)	AGD independent adviser
AGD INDEPENDENT MEMBERS / NHS ENGLAND MEMBERS NOT 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)
Dr. Jonathan Osborn (JO)	NHS England member (Caldicott Guardian Team Representative)

1	**Welcome and Introductions:** The AGD Chair welcomed attendees to the meeting. AGD noted that, due to an urgent work commitment, there would not be an NHS England SIRO Representative or delegate in attendance for items 1 to 4, part of 5.1 and 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 Group were advised that, prior to the meeting, the NHS England SIRO Representative had confirmed contentment for items 1 to 4, part of 5.1 and 5.4 to be discussed in his absence.
2	**Review of previous AGD minutes:** The minutes of the AGD meeting on the 9th October 2025 were reviewed and, after amendments, were agreed as an accurate record of the meeting.
3	**Declaration of interests:** Paul Affleck noted a previous professional link to the University of Leeds but noted no specific connections with the application (NIC-791529-K1J8C), or staff involved, and it was agreed that this was not a conflict of interest. Dr Jon Fistein noted a professional link to the University of Leeds but noted no specific connections with the application (NIC-791529-K1J8C), or staff involved, and it was agreed that this was not a conflict of interest.
4 BRIEFING PAPER(S) / DIRECTIONS:	
4.1	**Title:** Expired Data Sharing Framework Contract (DSFC) and Data Sharing Agreement (DSA) Conditions **Presenters:** Garry Coleman and Dave Cronin Currently, NHS England's Data Access and Partnerships (DA&P) and IG Risk and Assurance manage the handling of expired DSFCs and Data Sharing Agreements DSAs via a two-pronged approach with escalation after eight weeks before expiry. The purpose of this briefing paper, is to advise AGD of plans to strengthen the current approach, streamlining the process and enabling the implementation of escalating conditions against non-compliant organisations. The proposed approach is to have escalating conditions (one for expired DSFCs, one for expired DSAs) applicable following the expiration of a DSFC and/or DSA. These conditions intend to complement, rather than replace existing processes that DA&P have developed for chasing of DSFCs and DSAs that are expiring. NHS England were seeking advice on the following points: 1. Does AGD support the proposed approach? 2. Does AGD feel that the levels and actions are appropriate? If not, what amends are advised? 3. Does AGD support the timelines for escalations? If not, what amends are advised? **Outcome of discussion:** AGD welcomed the briefing paper and made the following observations / comments: **In response to points 1 to 3:** **4.1.1** AGD noted the proposal outlined and advised that they were supportive of the concept.

	4.1.2 AGD noted the bigger risk to NHS England by not having a DSFC in place, and suggested that NHS England consider having a clear distinction, in terms of the implications for organisations who do not have a DSFC in place, versus a DSA having expired. **4.1.3** AGD suggested that the mechanism for compliance should be outlined in the DSFC and DSA, both for transparency and to support compliance. **4.1.4** AGD noted the potential implications for charging non-compliant organisations for administration and handling, and how this may be perceived by the public, in particular with regard to other public sector organisations in the current economic climate; and the impact this may have on such organisations. **4.1.5** In addition, AGD queried whether a charging model would have an effective impact on some organisations, and whether an alternate approach could instead be considered, for example, a pause on the flow / processing of all data until they resolved any issues with the DSFC / DSA, which may have a much bigger impact. **4.1.6** The NHS England SIRO Representative stressed the importance of ensuring all organisations are treated the same when it comes to non-compliance. **4.1.7** AGD suggested that NHS England could seek views / co-design the escalation and the implication of being non-compliant with stakeholders as may be appropriate. **4.1.8** AGD suggested that NHS England seek views from colleagues in the NHSE Legal Team, to ensure that the process / implications outlined are enforceable. **4.1.9** The NHS England SIRO Representative advised that further consideration would be given to the comments provided by the Group, and an updated briefing paper would be provided at a future AGD meeting. **4.1.10 ACTION:** The AGD Secretariat to add 'DSFC and DSA Conditions – updated briefing paper' to the AGD internal forward planner.	AGD Sec
4.2	**Title:** Data Security Protection Toolkit (DSPT) Data Sharing Agreement (DSA) Assurance **Presenter:** Andrew Ireland Achieving the standards of the DSPT is a special condition in NHS England's data sharing agreements (DSA). The general responsibilities in the data sharing framework contract reiterate this for organisations. The purpose of the briefing paper is to advise AGD on the work being undertaken by NHS England's IG Risk and Assurance Team, to check the DSPT status of every applicant organisation which holds a DSA with NHS England and uses DSPT as their method of security assurance; and the lessons learnt / next steps. NHS England were seeking advice on the following points: 1. Advice on any suggested changes to the current approach to non-compliance **Outcome of discussion:** AGD welcomed the briefing paper and made the following observations / comments: **4.2.1** AGD were provided with an overview of the DSPT DSA Assurance, including, but not limited to, the process for all organisations accessing NHS patient data to have met the	

	DSPT minimum standards; the role of the NHS England's IG Risk and Assurance / SIRO Team; timelines and next steps. **In response to point 1:** **4.2.2** AGD suggested that the process / expectations from NHS England, aligns with the process / expectations from Health Research Authority Confidentiality Advisory Group (HRA CAG) on respect of DSFC; and were advised that there were ongoing discussions with HRA CAG about this, and the relevant transparency. **4.2.3** AGD advised that they would welcome any further updates as may be appropriate at a future AGD meeting.	
5 EXTERNAL DATA DISSEMINATION REQUESTS:		
5.1	**Reference Number:** NIC-791529-K1J8C-v0.1 **Applicant and Data Controller:** University of Leeds **Application Title:** "Digital- My Arm Pain Programme (D-MAPP) - DigiTrials Recruitment Service" **Observer:** Dan Goodwin **Application:** This was a new application. NHS England were seeking advice on the following point, including general advice on any other aspect of the application: 1. AGD support for NHS DigiTrials recruitment applications to be brought to AGD in parallel with applicant applications to the Health Research Authority Confidentiality Advisory Group (HRA CAG) for s251 support and for AGD to give support on condition that s251 support is obtained (applications would not be brought back to AGD for further review once s251 support was confirmed). 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 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). **5.1.1** AGD queried the lack of information provided in the form in respect of data minimisation, and suggested that this was completed with sufficient detail, to ensure that this aligned with the HRA CAG support (which referred to approximately 30,000 invitations being issued in order to reach the desired cohort size). **5.1.2 Separate to the application and for NHS England to consider:** AGD noted that whilst NHS DigiTrials recruitment applications used a template, these should be amended as appropriate, to ensure that any bespoke data minimisation undertaken was clearly outlined, specific to each application.	D&A Rep / SIRO Rep

	5.1.3 Separate to the application and for NHS England to consider: AGD noted that there may be benefits of NHS England discussing with HRA CAG, how literally statements in HRA CAG documentation should be perceived in respect of cohort numbers quoted, for example, should this be taken as an absolute limit, or as a 'ballpark' figure. The Group noted that this may impact the volume of data shared with an applicant for processing. **5.1.4** AGD noted the content of the draft NHS DigiTrials letter provided, and noted that they were supportive of the updates made to ensure the content was in language suitable for a lay reader, however, raised the following suggestions / queries, including, but not limited to, **1)** updating the links provided in the letter to the patient information sheet (PIS), to ensure this takes you straight to the PIS; **2)** to review / update the presumptive and hyperbolic reference to *"life changing research"*; **3)** whilst the Group were supportive of the Research Team being the first point of contact for recipients of the letter, it was suggested that further clarity be provided as to what queries could be raised with their *"GP or healthcare provider"*; and that the information relating to this was updated, to avoid unnecessary burden on GPs / healthcare providers; and **4)** AGD queried whether the draft letter provided was the same copy provided to HRA CAG. In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review: **In response to point 1:** **5.1.5 Separate to the application and for NHS England to consider:** AGD noted that the Group had a variety of views as to whether they would be supportive of NHS DigiTrials recruitment applications being brought to AGD in parallel with applicants' applications to HRA CAG for s251 support and for AGD to give support on the condition that s251 support is obtained. The Group noted that, whilst they would be supportive of a change in process if there was a clear benefit, for example, if it would support the progression of applications through the system quicker; they had a number of concerns, including **1)** that there currently appeared to be limited benefits to this approach; and **2)** that it may cause further delays and frustrate applicants. AGD advised that they would welcome a further discussion on this at a future AGD meeting. **5.1.6** AGD noted the reference to the *"aggregate data quality report"* in section 3.1 (Dataset), and whilst noting the benefit of including this in the form for transparency, suggested that NHS England clarify **1)** whether this was an output as opposed to a disseminated dataset; and **2)** whether this report was also small numbers supressed; and suggested that the form was updated as may be appropriate. **5.1.7** AGD noted that online consent was being taken for this specific application, and discussed the importance / implications of ensuring that everyone had capacity to do this; and noted that whilst this was out of scope for AGD to provide advice on, suggested that NHS England discuss this further with the applicant, who may wish to engage with their Research Ethics Committee (REC) for a view. **5.1.8** AGD noted, and applauded the applicant on, the patient and public involvement and engagement (PPIE) undertaken, specifically noting that views had been sought on using the NHS DigiTrials Recruitment Service. **5.1.9** AGD noted that they had some comments on the PIS, specifically on the potentially restrictive language used for obtaining follow-up date in the future; however, advised that	D&A Rep / SIRO Rep D&A Rep / SIRO Rep

	these would be shared with NHS England out of committee, and suggested that NHS England explore this further with the applicant. **5.1.10** AGD noted that whilst no commercial aspect had been noted, suggested that NHS England discuss with the applicant whether there was a commercial element to any of the online tools they would be using; and that the form was updated as may be appropriate. **5.2.11** 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 had reviewed the updated application. **5.1.12** AGD noted that there **was** a commercial aspect to the application.	
5.2	**Reference Number:** NIC-730384-H8G0Q-v0.2 **Applicant and Data Controller:** University of Birmingham **Application Title:** "Long-term health assessment of children following first trimester progesterone treatment in the PRISM trial (PRISM Follow-up)" **Observer:** Dan Goodwin **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. Is the consent compatible to permit the flow of identifiers to NHS England for the purpose of obtaining latest address in order to contact the cohort. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** AGD were supportive of the application and wished to draw to the attention of the SIRO the following substantive comments: 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 that they were assuming that data would flow for both the mother and child, however suggested that the form was updated to be clear on **1)** whose data would flow; and **2)** how the processing is being achieved using the data flows. **5.2.2** AGD noted that there was potentially substantial value in ensuring that accurate and timely notification of death is received by the researchers for both the mother and child; and suggested that NHS England engage with the applicant, to ensure that the most appropriate data is flowing that captures this data, and that a justification for this data is provided in the form. **5.2.3** AGD suggested that NHS England check and clarify the approach to 'sensitive flags' (S-flags), or any other safeguards that would be in place, to avoid inadvertently disclosing information relating to children no longer residing with their parent(s). In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:	

	5.2.4 AGD noted the importance of the follow-up study and the research questions they are trying to answer. **In response to point 1:** **5.2.5** AGD discussed whether the consent was compatible, to permit the flow of identifiers to NHS England for the purpose of obtaining latest address in order to contact the cohort; and advised that on balance, the consent **was** compatible with the proposed processing. **5.2.6** In respect of the follow-up consent form provided, AGD made a number of suggestions, including, but not limited to, **1)** simplifying the form and undertaking some patient and public involvement and engagement (PPIE) to ensure its comprehensibility; **2)** reviewing **point 4** *(withdrawal)* noting that this is a consent form not an opt-out form; and that this point may also conflict with **point 7** *(NHS England may be used to source any outstanding data not provided in the questionnaire)*; **3)** to consider having a separate, optional consent item for follow-up using electronic health records, including a time frame and an example of where data could come from; **4)** to clarify how, if data is shared with other researchers as outlined in **point 13**, research data is only stored for ten years; **5)** to review **points 7, 8** *(follow-up contact)* and **9** *(keeping in touch)* to ensure these clauses describe both the type and extent of data that may be sought by NHS England, and what this data will be used for. **5.2.7** AGD noted that there was a contradiction in section 4.7 (expected outputs), which refers to the data being used to update the PRISM database; and section 4.5 (processing activities) which says that the data will **not** be linked with any other data; and suggest that this was reviewed and updated to correctly reflect what is happening. **5.2.8** AGD suggested that sections 3.1 to 3.4 (dataset / periods / reasons for requirements / justification) of the form were reviewed and updated to reflect **1)** the data minimisation that will be undertaken, and **2)** the data fields required. **5.2.9** In respect of the proposal to flow participant e-mail addresses, AGD suggested that **1)** NHS England consider, whether the data quality would be sufficient so that a reasonable proportion would be correct, in order for the information to reach the correct individuals; and **2)** the applicant consider whether some patient and public involvement and engagement (PPIE) could be undertaken, to determine whether cohort members would be surprised and/or concerned to receive information via e-mail. **5.2.10** No AGD member noted a commercial aspect to the application.	
5.3	**Reference Number:** NIC-786843-Y6V6G-v0.2 **Applicant and Data Controller:** Department of Health and Social Care (DHSC) **Application Title:** "Adult Social Care migration to DHSC (excluding ASC CLD)" **Observer:** James Watts **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 (three AGD independent members and three AGD NHS England members) were supportive of the application; and a minority of the Group (one AGD independent member) was supportive of the application **if** the point raised on the Direction was adequately addressed. A minority of the Group (one AGD independent member) was **not** supportive of the application **at this time** as not all the necessary information was available to make a full assessment. 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). **5.3.1** AGD recognised the importance of increasing availability and use of Social Care data, and the need to facilitate NHS England / DHSC integration. **5.3.2** AGD suggested that for the purpose of the Data Uses Register, further information was provided on the wider content and background on this data sharing, including, but not limited to, to what extent the 'Adult social care data collection: September 2025 notice' is being relied upon. **5.3.3** AGD noted that the data was stated as being *"anonymous"* in the NHS England Data Access Request Service (DARS) internal application assessment form; and suggested that it may be useful to refer to the recently published Information Commissioner's Office (ICO) guidance on anonymisation. AGD suggested that this was reviewed and updated as may be appropriate to reflect the correct / factual information. **5.3.4** In addition, AGD noted in the 'Adult Social Care Data Collection Specification' a reference to data being used by researchers, including the Personal Social Services Research Unit (PSSRU) at the University of Kent; and queried if they were receiving truly anonymous data, or is the data sufficiently derived, so it can no longer considered NHS England data; and suggested that this was explored further and clarified. **5.3.5** AGD suggested the processing activities clearly set out at each stage what is happening, in line with NHS England DARS Standard for processing activities. **5.3.6** AGD suggested that the special conditions were reviewed and updated to ensure that the correct security assurance, specific for DHSC is included. **5.3.7** No AGD member noted a commercial aspect to the application.	
5.4	**Reference Number:** NIC-776828-L9R1G-v0.11 **Applicant:** University Hospitals Birmingham NHS Foundation Trust **Data Controller:** The University of Manchester **Application Title:** "Routinely collected treatment data to evaluate the uptake and utility of UK paediatric early phase trial infrastructure" **Observer:** James Watts and Tiaro Micah **Previous Reviews:** The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 18th September 2025 and the 7th August 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: The **majority** of the Group (four AGD independent members and one AGD NHS England member) were supportive of the application **if** the following substantive comments were addressed. A **minority** of the Group (two AGD NHS England members and one AGD independent member) were **not** supportive of the application **at this time**. The Group wished to draw to the attention of the SIRO the following substantive comments:

5.4.1 AGD noted that whilst the majority of the Group were supportive if the substantive points were addressed, notwithstanding this, strongly emphasised that the approach taken to facilitate data access in this instance *had caused a number of difficulties in NHSE assuring itself of the arrangements and*, should not be used as a model for future access. While the Group did not question that the s251 support provided a common law legal basis, the arrangements for NHSE were challenging due to the Data Processor being the party having the s251 support. The Group also noted the substantive amount of time and resources taken, to get to this point with the application; and the amount of resources still required to support access to the data.

5.4.2 AGD noted significant concerns around transparency, and suggested that there was a clear / aligned approach, that clearly sets out which parties are involved with processing the data; to support research participants having the opportunity to know their data is being processed.

5.4.3 One AGD independent member advised that it was essential that NHS England establish that the s251 support covered the linkage of people who were in the consented research study, since it appeared they may have consented to the linkage.

5.4.4 AGD discussed the access arrangements and agreed that appropriate processing agreements were required; and suggested that NHS England explore this further with the applicant, and the application be updated as appropriate with further information.

5.4.5 AGD were provided with a verbal update on the sub-licensing arrangements; however, were advised by the NHS England SIRO Representative that the current sub-licensing arrangements would **not** be possible, noting that only the Data Controller (The University of Manchester) would be able to issue sub-licences; not the Data Processor.

5.4.6 AGD noted in the NHS England Data Access Request Service (DARS) internal application assessment form, in response to a previous query raised by the Group, that the applicant did **not** consider the data to be personal under UK General Data Protection Regulation (UK GDPR); and the Group noted and agreed with the view of NHS England, that this was incorrect.

In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:

5.4.7 AGD noted the responses provided to the previous points raised by the Group on the 18th September 2025 in the NHS England Data Access Request Service (DARS) internal application assessment form; and that in addition to these written responses, the Group

	were provided with a verbal update from NHS England colleagues, in respect of the previous points and how they had been addressed. **5.4.8** The NHS England SIRO Representative advised the Group that due to the complexities of this application, and the significant amount of time by the Group reviewing / providing advice, that a further update should be provided in due course on how the application is developed in response to their advice.**5.4.9** No AGD member noted a commercial aspect to the application.	
5.5	**Reference Number:** NIC-152414-W3P6Q-v5.5 **Applicant and Data Controller:** University of Bristol **Application Title:** "Continuation of AVON LONGITUDINAL STUDY OF PARENTS AND CHILDREN (ALSPAC): **consent**" **Observer:** Emma Whale **Previous Reviews:** The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 14th March 2024. The application and relevant supporting documents were previously presented / discussed at the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) meetings on the 19th April 2018, 15th February 2018 and the 25th January 2018. **Linked applications:** This application is linked to NIC-789772-N6S1N (item 5.6) **Application:** This was an amendment 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:** At the request of the SIRO representative in-meeting, AGD were only offering early advice, and suggested that the application be brought back to a future meeting. 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). 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 **5.5.1** AGD noted the list of proposed amendments outlined in the NHS England Data Access Request Service (DARS) internal application assessment form, and advised that **1)** it is **not** clear if the 'national database' reflects a different model separate from the sub-licensing; and **2)** given the scope, history and complexity of the application a quoracy of AGD were **not** in a position to review the sub-licensing documents in detail, and suggested that further time was allocated at a future AGD meeting, to review this element. **5.5.2** AGD noted the references to data being *"effectively anonymous"* in the form, and suggested that this was reviewed and updated as appropriate, noting that NHS England were not necessarily of the view that the data would be effectively anonymous.	

	5.5.3 AGD noted the volume of new datasets requested, and suggested the form was updated with **1)** a clear justification for each dataset; **2)** a clear use case for each dataset; and **3)** a clear output and benefit for each of the new datasets, in line with NHS England DARS Standard for Expected Outcomes and NHS England DARS Standard for Expected Measurable Benefits. **5.5.4** AGD noted the request to grant access under sub-license to commercial organisations, and suggested that whilst NHS England could support this in line with NHS England DARS Standard for Commercial Purpose, the Group noted the very specific requirements of what is permitted in relation to commercial gain and for profit uses, outlined in the consent materials provided, appeared poorly aligned with the parameters outlined in the application. It was therefore suggested that the process for approving any commercial access outlined in the application needs to be revised / narrowed down significantly, to ensure that this aligns with the consent taken from participants. **5.5.5** AGD suggested that the applicant update their website, to provide clear information on how a participant can withdraw consent for specific projects, for example and for ease of access, this information could be made available on the 'keeping data safe' page, in addition to this being noted elsewhere. **5.5.6** AGD queried the information in the ALSPAC Cohort Linkage Booklet (p24) provided as a supporting document, in respect of participants not being able to view what is in their *"official records"*; and suggested that NHS England discuss this with the applicant to see if this was correct, and that any updates were made as may be appropriate to reflect the factual information. **5.5.7** AGD and the AGD NHSE Data and Analytics Representative suggested that when the two linked applications return to the Group for a further review, that **two** separate NHS England DARS internal application assessment forms are provided for each application. **5.5.8** No AGD member noted a commercial aspect to the application.	
5.6	**Reference Number:** NIC-789772-N6S1N-v0.3 **Applicant and Data Controller:** University of Bristol **Application Title:** "Continuation of AVON LONGITUDINAL STUDY OF PARENTS AND CHILDREN (ALSPAC): **section 251**" **Observer:** Emma Whale **Linked applications:** This application is linked to NIC-152414-W3P6Q (item 5.5) **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:** At the request of the SIRO representative in-meeting, AGD were only offering early advice, and suggested that the application be brought back to a future meeting. 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). 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 **5.6.1** AGD noted the previous point raised (5.2.5) on the 14th March 2024 (as part of the review for NIC-152414-W3P6Q) , in respect of the whether the s251 support cohort would be included in any linkage to crime and education data or not, and whether this had been explored with Health Research Authority Confidentiality Advisory Group (HRA CAG). Noting that this point had **not** been clarified, it was suggested that this NHS England explore this key point with the applicant further. **5.6.2** Noting the specific HRA CAG conditions of support, in respect of engaging with the cohort, as outlined in the HRA CAG letter dated the 23rd April 2025; AGD suggested that NHS England assure itself this condition has been met at the relevant time; noting that if the condition of support has not been met, then there would not be a legal gateway for the processing of the data. **5.6.3** AGD noted the list of proposed amendments outlined in the NHS England Data Access Request Service (DARS) internal application assessment form, and advised that **1)** it is **not** clear if the 'national database' reflects a different model separate from the sub-licensing; and **2)** given the scope, history and complexity of the application a quoracy of AGD were **not** in a position to review the sub-licensing documents in detail, and suggested that further time was allocated at a future AGD meeting, to review this element. **5.6.4** AGD noted the references to data being *"effectively anonymous"* in the form, and suggested that this was reviewed and updated as appropriate, noting that NHS England were not necessarily of the view that the data would be effectively anonymous. **5.6.5** AGD suggested that the form was clearly updated with a clear explanation of whose data is being processed at what point, and under what legal basis. **5.6.6** AGD suggested that any reference to the G0 cohort all being consented, is reviewed and updated, noting this do not seem aligned with the documents provided. **5.6.7** AGD noted the volume of new datasets requested, and suggested the form was updated with **1)** a clear justification for each dataset; **2)** a clear use case for each dataset; and **3)** a clear output and benefit for each of the new datasets, in line with NHS England DARS Standard for Expected Outcomes and NHS England DARS Standard for Expected Measurable Benefits. **5.6.8** AGD suggested that the applicant update their website, to provide clear information on how a participant can withdraw, for example and for ease of access, this information could be made available on the 'keeping data safe' page, in addition to this being noted elsewhere. **5.6.9** AGD queried the information in the ALSPAC Cohort Linkage Booklet (p24) provided as a supporting document, in respect of participants not being able to view what is in their "official records"; and suggested that NHS England discuss this with the applicant to see if this was correct, and that any updates were made as may be appropriate to reflect the factual information.	

	5.6.10 AGD and the AGD NHSE Data & Analytics Representative suggested that when the two linked applications return to the Group for a further review, that **two** separate NHS England DARS internal application assessment forms are provided for each application. **5.6.11** No AGD member noted a commercial aspect to the application.	
5.7	**Reference Number:** NIC-779433-Q9R8N-v0.11 **Applicant and Data Controller:** London School of Hygiene and Tropical Medicine **Application Title:** "THERM-UK: Developing solutions for temperature-related health impacts in the UK" **Observer:** Humphrey Onu **Application:** This was a new application. NHS England were seeking general advice on the application. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** AGD were supportive of the application and wished to draw to the attention of the SIRO the following substantive comments. 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). **5.7.1** Noting the very large quantum of data requested, and the rationale for why the national Secure Data Environment (SDE) cannot be used, AGD suggested that the form was updated to be clear on **1)** the justification / purpose for all the data requested in line with the relevant data protection principles; **2)** why aggregated data cannot be used; **3)** why / if they need the level of granularity requested for this initial stage; and **4)** that the applicant is aware of the limitations with the data, and that the data can still be used to meeting their objectives. **5.7.2** AGD suggested that the form was updated to be clear on the expected benefits from this stage of the research, with the specific linkage outlined, in line with NHS England DARS Standard for Expected Measurable Benefits **5.7.3** 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). In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review: **5.7.4** AGD suggested that the public facing section of the form is updated, to ensure that the reference to 'Lower Layer Super Output Area' (LSOA), is updated to **1)** be clear on the specificity and identifiability of the data; and **2)** be clear that the data linkage will **not** make data subjects more identifiable.	

	5.7.5 AGD noted the reference in section 4.7 (expected outputs) to an *"open-access online platform"*; and suggested that further information was provided piece of work in section 4 (purpose) of the form, in line with NHS England DARS Standard for Objective for Processing. **5.7.6** 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		
There were no items discussed		
8 OVERSIGHT AND ASSURANCE		
There were no items discussed		
9 AGD OPERATIONS		
9.1	**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 6th November 2025. **ACTION:** The NHS England SIRO Representative to provide a written response to AGD on the progress on the 6th November 2025, of the risk management framework.	SIRO Rep
9.2	**AGD Stakeholder Engagement** The AGD Chair and Dr. Jon Fistein noted to the Group that they had met with Dr. Tony Calland, the outgoing Chair of the Health Research Authority Confidentiality Advisory Group (HRA CAG), Prof, Lorna Fraser, the incoming Chair of the HRA CAG, and Dr. Nicola Byrne, the National Data Guardian for health and adult social care in England, on Tuesday 14th October 2025, as part of their regular engagement.	
9.3	**AGD Project Work** *There were no items discussed*	
10 Any Other Business		
10.1	**AGD independent member contractual arrangements** Following on from the discussions at the AGD meetings on the 9th October, 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.	

10.2	**AGD Meeting Quoracy** AGD noted that as discussed at the AGD meeting on the 9th October 2025, there would not be a quoracy of AGD independent members available on the 23rd and 30th October 2025, due to the ongoing issue with AGD member contracts; and that in line with para 7.13 of the AGD Terms of Reference (ToR) that *"The quorum for meetings of the Group or a Sub-Group is five members, including **at least three independent members**…"*. The NHS England SIRO Representative advised the Group that whilst part of the AGD meeting scheduled for the 23rd October 2025, would be quorate (am), the other part (pm) would be held 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 NHS England SIRO Representative advised the Group that the AGD meeting scheduled for the 30th October 2025 would be quorate for the morning however the afternoon would not be quorate and would therefore be held as an internal SIRO meeting with the AGD members available, unless, the issue with AGD member contracts had been resolved prior to this date, in which case the meeting would be run as a normal / quorate AGD meeting. It was also noted that if the meeting on the 30th October 2025 was held as an internal SIRO meeting, then this would not bypass the AGD process, and that any applications / other agenda items needing a collective review by the Group would return to a future AGD meeting. The Group noted and thanked the NHS England SIRO Representative for the update. **Subsequent to the meeting** It was noted that the internal SIRO meeting scheduled to take place on the afternoon of the 30th October 2025, would **not** be taking place.	
10.3	**AGD Meeting Dates - November and December 2025** The AGD independent members noted that information had not yet been shared confirming which AGD meetings they would be attending in November and December 2025. The Group were advised, by the AGD Secretariat, that this information could not be shared until the issues with AGD independent member contracts had been resolved, noting that it was currently unclear who would be able / available to attend meetings; and that further information would be shared once this issue had been resolved.	AGD Sec
Meeting Closure As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.		