Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 9th July 2026

09:00 – 14:15

(Remote meeting via videoconference)

AGD INDEPENDENT / NHS ENGLAND MEMBERS IN ATTENDANCE:	
Name:	**Role:**
Paul Affleck (PA)	AGD independent member (Specialist Ethics Adviser)
Mr Christopher Barben (CB)	AGD independent member (Specialist Clinician 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. Mark McCartney (MM)	AGD independent member (Specialist GP / Clinician Adviser)
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))
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	**Role / Area:**
Garry Coleman (GC)	NHS England SIRO Representative
Laura Evans (LE)	Data Operations Management Officer, NHS DigiTrials, Data and Analytics, Transformation Directorate (**Observer**: item 10.2)
Maddie Laughton (ML)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer**: items 5.2 to 5.3)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Technology, Digital and Data
Azeez Oladipupo (AO)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer**: item 5.4)
Andy Rees (AR)	NHS DigiTrials and Research Products Operations Manager, Data and Analytics, Transformation Directorate (**Observer**: item 10.2)

Jodie Taylor-Brown (JTB)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer**: items 5.1 to 5.3)
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Technology, Digital and Data
AGD INDEPENDENT MEMBERS / NHS ENGLAND MEMBERS NOT IN ATTENDANCE:	
Name:	**Role / Area:**
Michael Chapman (MC)	NHS England member (Data and Analytics Representative)
Claire Delaney-Pope (CDP)	AGD independent member (Specialist Information Governance Adviser)
Dr. Robert French (RF)	AGD independent member (Specialist Academic / Statistician Adviser)
Jon Moore (JM)	NHS England member (Data Protection Office Representative)
Jenny Westaway (JW)	AGD independent member (Lay Adviser)
Miranda Winram (MW)	AGD independent member (Lay Adviser)

1	**Welcome and Introductions:** The AGD Chair welcomed attendees to the meeting.	
2	**Review of previous AGD minutes:** The minutes of the AGD meeting on the 2nd July 2026 were reviewed and were agreed as an accurate record of the meeting.	
3	**Declaration of interests:** There were no declarations of interest.	
4 BRIEFING PAPER(S) / DIRECTIONS:		
There were no items discussed		
5 EXTERNAL DATA DISSEMINATION REQUESTS:		
5.1	**Reference Number:** NIC-793829-Z2H4B-v0 **Applicant and Data Controller:** London School of Hygiene and Tropical Medicine (LSHTM) **Application Title:** "HPRU in Climate Change and Health Security" **Observer:** Jodie Taylor-Brown **Previous Reviews:** The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 23rd October 2025.	

Application: This was a new application.

NHS England were seeking advice on the following points:

1. Whether the previous AGD advice has been appropriately addressed.
2. If the wide scope of purpose is sufficiently detailed and provides sufficient clarity on the permitted purposes for using the data.
3. If the scope of purpose and the level of delegated decision-making is appropriate.
4. If the governance controls give sufficient assurance that risks associated with the delegation of decision-making will be mitigated.

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

Outcome of discussion: AGD advised that major concerns had been identified and advised NHS England against providing data access until the following had been addressed:

In response to points 1 to 4:

5.1.1 AGD noted that whilst they did not specifically discuss each of the advice requests individually, a number of points were raised as part of the general discussion, that cut across the questions asked by NHS England.

5.1.2 AGD noted that, prior to the meeting, an AGD independent member had raised a query with NHS England, in respect of the role of the UK Health Security Agency (UKHSA), noting that the supporting documentation states that the work being undertaken is not under the controllership of UKSHA, and that LSHTM are the sole data controller determining the purpose and means of processing; however, the 'Management Committee' referenced (previously called the 'Data Access Committee'), contains both an UKHSA lead and UKHSA theme leads / co-leads. The Group noted that the applicant had confirmed that the 'Management Committee' is not for the purpose of planning the research, its remit is to ensure that the projects and deliverables remain on track, and therefore no decisions are made there about data usage. The Group advised that the information provided does indicate that LSHTM would not be the sole Data Controller as is currently presented; and advised that in line with NHS England DARS Standard for Data Controller(s) NHS England explore the role of the 'Management Committee' further with the applicant, including, but not limited to:

5.1.2.1 obtaining detailed Terms of Reference (ToR);

5.1.2.2 clarification of the membership;

5.1.2.3 the role of the patient and public involvement and engagement (PPIE) members;

5.1.2.4 the limit of any advice they are providing;

5.1.2.5 clarifying who is making decisions; and

5.1.2.6 obtaining any historical minutes.

5.1.3 In addition, AGD advised that, to further explore this point, the NHS England Data Protection Office (DPO) and the LSHTM DPO could review the current position / role of UKHSA situation together. The NHS England SIRO Representative and NHS England DPO

	Representative agreed to discuss the current controllership position and consider whether any further engagement with the applicant is required. **5.1.4** AGD noted that the 'Management Committee' appears to have the ability to make decisions about onward data use, and that their ToR will help clarify the scope and processes around their delegated decision-making. **5.1.5** AGD noted that the purpose as currently outlined was very broad, and advised that the applicant: **5.1.5.1** review and update the current purpose to focus initially on sub-projects; **5.1.5.2** monitor the sub-projects as they progress; and **5.1.5.3** if further data is required for the broader work referenced, then the applicant should submit an amendment application to NHS England to cover this. **5.1.6** AGD noted one of the aims / objectives to "*Build capacity through training and early-career development"* and advised that this, as a primary objective, would not usually be accepted; and advised NHS England to ensure that the applicant is clear that this would be accepted as an instrumental aim based on the other aims / objectives listed. **5.1.7** AGD noted the references in the protocol provided to *"UKHSA surveillance data"*, and advised that the relationship to this data should be clarified in the internal form / application. 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: **5.1.8** AGD noted that, prior to the meeting, an AGD independent member had raised a query with NHS England, in respect of exporting results from the LSHTM system, and whether there was an 'airlock' approach or whether there were only contractual controls. The applicant had advised, via NHS England, that there were contractual controls in place. The Group noted and thanked NHS England for checking this point with the applicant, and noted a concern / risk, and advised NHS England engage with the applicant to discuss what technical controls can be established in addition to the contractual controls. **5.1.9** AGD noted the potential importance of the study and the funding by National Institute for Health and Care Research (NIHR).	
5.2	**Reference Number:** NIC-809722-T0T7B-v0.1 **Applicant and Data Controller:** University of Newcastle Upon Tyne **Application Title:** "Understanding and reducing the impacts of high outdoor temperatures on pregnancy and newborn health in England: a multi-methods study" **Observers:** Maddie Laughton and Jodie Taylor-Brown **Linked applications:** This application is linked to NIC-698114-Q1Y5L (item 5.3) **Application:** This was a new application. NHS England were seeking advice on the following points:	

	1. The acceptability of providing identifiable Maternity Services Dataset (MSDS) data for cohort identification by the applicant to be appropriate and proportionate, given that NHS England is unable to undertake this step. 2. Whether that advice would change if it were clear that Newcastle University was acting as a Data Processor for NHS England. 3. Whether the justification for identifiers (including NHS number, DOB and postcode) sufficient and proportionate for both cohort identification and subsequent environmental linkage. 4. Whether the purpose and scope of processing is sufficiently defined, particularly in light of the two-stage process involving cohort identification and subsequent broader linkage and analysis. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** AGD advised that major concerns had been identified and advised NHS England against providing data access until the following had been addressed: **In response to points 1 to 4:** **5.2.1** The Group advised they had major concerns including, but not limited to, the fact that a lack of resource / capacity within NHS England does not align with the current direction of travel for data access in NHS England nor justify the volume and breadth of data being provided to the applicant. **5.2.2** AGD advised that NHS England explore if capacity could now be found for it to undertake this cohort identification. If NHS England still does not have capacity for identifying the cohort, an alternative would be members of staff from the University of Newcastle Upon Tyne being provided with honorary contracts with NHS England to allow them access to the data on NHS England systems under NHS England's supervision. **5.2.3** The Group were aware that the applicant had sought and obtained s251 support from the HRA CAG and that any change to the approach would impact on that s251 support, however that should not stop NHS England from exploring alternative methods of data access. NHS England welcomed the advice and confirmed they would explore alternate routes of data access for the research. 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: **5.2.4 Separate to the application for NHS England to consider**: the Group would welcome early sight on complex, novel, or contentious applications in order to support NHS England in the development of applications and avoid unnecessary delay and work for applicants.	D&A Rep
5.3	**Reference Number:** NIC-698114-Q1Y5L-v0.1 **Applicant and Data Controller:** University of Newcastle Upon Tyne **Application Title:** "Understanding and reducing the impacts of high outdoor temperatures on pregnancy and newborn health in England: a multi-methods study"	

Observers: Maddie Laughton and Jodie Taylor-Brown

Linked applications: This application is linked to NIC-809722-T0T7B (item 5.2).

Application: This was a new application.

NHS England were seeking advice on the following points:

1. A single Data Controller is appropriate given the role of Project Advisory Group (PAG).
2. If sub-licensing may be needed for other organisations accessing data.
3. Additional controls are required to ensure data deletion.

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

Outcome of discussion: AGD advised that major concerns had been identified and advised NHS England against providing data access until the following had been addressed:

In response to points 1 and 2:

5.3.1 The Group noted the role of the PAG and the multiple organisations involved, however, based on the evidence provided, were of the opinion that those organisations were not acting as Data Controllers. The Group advised that NHS England:

5.3.1.1 obtain a copy of the detailed Terms of Reference (ToR);

5.3.1.2 clarify the limit of any advice they are providing; and

5.3.1.3 clarify who has responsibility for decision making.

5.3.2 Notwithstanding 5.3.1 above, AGD noted the role of the visiting researchers from the London Schools of Hygiene and Tropical Medicine (LSHTM) and advised that NHS England satisfy themselves that the LSHTM are not a joint Data Controller and determining the purpose and means, in line with the NHS England DARS Standard for Data Controllers.

5.3.3 The Group noted that some institutions were accessing anonymous data, and advised that NHS England satisfy itself that this data is aggregated with small numbers suppressed.

5.3.4 AGD queried whether there were only contractual controls, with regard to exporting data, in place and advised that NHS England engage with the applicant to discuss what technical controls can be established.

In response to point 3:

5.3.5 The Group noted that the applicant was proposing to delete different parts of the data at different periods of times and advised that NHS England establish a clear timetable for data deletion throughout the lifetime of the research programme / data sharing agreement (DSA), and the applicant provide the requisite evidence at each point to NHS England.

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:

5.3.6 Noting the request by the applicant for two flows of the same data, AGD advised that NHS England provide a single flow of data which would not only meet the research requirements of the applicant but would reduce the risk of retaining the identifiers for longer than is necessary. NHS England noted that due to the practicalities of developing the

	application up to the point of releasing the data, that a single provision of data, covering all of the requested timepoints, would be the only option available later in the year. **5.3.7** AGD noted inconsistencies in the internal form / application at sections 5b and 5f around the data identifiers and advised that the text be updated to align with the s251 support in place. **5.3.8 Separate to the application and action for the AGD NHS England DPO Representative:** The Group would welcome advice and guidance from the NHS England DPO about how they would make the determination about sole / joint / multiple data controllers in order to support their ongoing learning and understanding. The AGD NHS England DPO Representative agreed to come back to a future meeting with an update.	DPO Rep
5.4	**Reference Number:** NIC-147776-69CX7-v6 **Applicant and Data Controller:** The University of Manchester **Application Title:** "UKMYONET Identification of disease susceptibility genes associated with development and clinical characteristics of primary inflammatory muscle diseases, PM, DM and IBM" **Observer:** Azeez Oladipupo **Previous Reviews:** The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 2nd November 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 31st March 2022 and the 15th November 2018. **Application:** This was an amendment application. NHS England were seeking advice on the following points: 1. Participants would reasonably expect the extent of ongoing and evolving data linkage proposed. 2. The commitment from the University of Manchester to release a study webpage and study specific privacy notice to be sufficient in addressing the concerns raised by DAS regarding the consent. If not, what further engagement with the participants would AGD advise. 3. Sufficient controls and commitments are in place, noting the history of 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 advised that major concerns had been identified and advised NHS England against providing data access until the following had been addressed: **In response to points 1 and 2:** **5.4.1** AGD noted that the majority of patient information materials were historic and referred to historic organisations, and whilst it was acknowledged that this did not necessarily mean that the proposed data flows were incompatible, it was recognised that the applicant had been advised previously to **1)** undertake some patient and public involvement and	

	engagement (PPIE) to address any transparency issues; and **2)** update their privacy notice in line with the UK General Data Protection Regulation (UK GDPR); and that neither had been done. The Group therefore advised that the applicant address both of these points. **In response to point 3:** **5.4.2** AGD noted that there had been agreement breaches across a number of areas, that do not appear to have been adequately addressed by The University of Manchester, which has overall responsibility as Data Controller. The Group advised that NHS England should engage with The University of Manchester Data Protection Officer (DPO) to discuss: **5.4.2.1** any further action that needs to be undertaken; and **5.4.2.2** the timeline for this action to be completed. **5.4.3** AGD advised that, as per the usual process, the application should align with NHS England's Data Access Request Service (DARS) standards / guidance; and advised NHS England to engage with the applicant further on this, so they are clear on any further work that needs to be undertaken. **5.4.4** AGD also advised that the applicant reviews all of the previous AGD advice to ensure the points have been adequately addressed, or that it is clear where a point is no longer relevant. 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: **5.4.5** AGD discussed whether the applicants were expecting updated information for the previously defined control group, and advised that NHS England clarify the position with the applicant, and that any ongoing data flows only relate to the main consenting cohort. **5.4.6** AGD advised that NHS England approve a six-month extension that permits the applicant to hold but not process the data; and that if the issues outlined were not addressed the applicant would be required to delete the data covered by the agreement.	

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	**AGD ways of working** *There were no items discussed*

9.2	**AGD Annual Report 2025/26** The Group discussed the proposed AGD Annual Report 2025/26. It was agreed that the AGD Chair would seek clarity from the Director Privacy and Information Governance as to the timeline for production in order to feed into the Privacy, Transparency and Trust annual report.
9.3	**AGD Stakeholder Engagement** *There were no items discussed.*
9.4	**AGD Project Work** **NIC-762279-Q6S6T - University of Newcastle Upon Tyne** The Group were advised that, following the discussion on NIC-762279-Q6S6T at the AGD meeting on the 22nd January 2026, two AGD independent members had provided support to NHS England out of committee (OOC), to engage with the applicant on specific aspects of the advice provided by the Group. NHS England thanked the two independent members for their support on this OOC project work.
	Delegated Decision Making AGD noted that, following this meeting, some additional project work would be undertaken with the AGD independent members in attendance and NHS England, to discuss 'delegated decision-making', following on from discussions on the 2nd July 2026.
10 Any Other Business	
10.1	**NIC-382794-T3L3M (Queen Mary University of London (QMUL)) – "QResearch Data Linkage Project"** AGD noted that at the AGD meeting on the 7th May 2026, as part of the discussion on NIC-382794-T3L3M, the Group had advised that NHS England request that the applicant provide an update on the points raised after six-months; and suggested it be submitted to AGD for a review on progress. The Group noted that the applicant had now submitted the progress report to NHS England. The Group welcomed the rapid response of the applicant in producing / sharing this report.
10.2	**Calming Minds Study** AGD noted that at the AGD meeting on the 2nd July and 30th April 2026 the Group had discussed the NHS DigiTrials invitation letter for the 'Calming Minds Study'. NHS England had previously advised that a contact telephone number for the research team was provided. However, the applicant did not wish to follow this advice and had provided justification for this approach. Whilst the Group did not accept that the size of the research team was justification for not including a contact number, they noted the justification provided and agreed that the alternative arrangements were appropriate. The Group noted that the applicant was committed to triaging participant contact to ensure the right person was responding to participant queries with the right level of detail.

Meeting Closure

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