

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 11th December 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)
Mr Christopher Barben (CB)	AGD independent member (Specialist Clinician Adviser)
Dr. Jon Fistein (JF)	AGD independent member (Chair)
Dr. Robert French (RF)	AGD independent member (Specialist Academic / Statistician Adviser) In attendance for items 5.2, 5.6 and 7.1 to 10)
Prof. Jo Knight (JK)	AGD independent member (Specialist Academic / Researcher Adviser)
Dickie Langley (DL)	NHS England member (Data Protection Office Representative (Delegate for Jon Moore)) (Items 1 to 5.3)
Dr. Mark McCartney (MM)	AGD independent member (Specialist GP / Clinician Adviser)
Dr. Jonathan Osborn (JO)	NHS England member (Caldicott Guardian Team Representative)
Andy Rees (AR)	NHS England member (Data and Analytics Representative (Delegate for Michael Chapman))
Miranda Winram (MW)	AGD independent member (Lay Adviser)
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	Role / Area:
Garry Coleman (GC)	NHS England SIRO Representative (In attendance for items 1 to 5.3)
Ayse Depsen (AD)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.2)
Laura Evans (LE)	Data Operations Management Officer, NHS DigiTrials, Transformation Directorate (Observer: items 4.1 and 5.1)
Louise Garnham (LG)	Service Delivery Manager, NHS DigiTrials, Transformation Directorate (Observer: items 4.1 and 5.1)

Dan Goodwin (DG)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: items 5.1 and 5.2)
Dickie Langley (DL)	NHS England SIRO Representative (delegate) (Presenter: item 5.1(a)) (Items 5.4 to 10)
Joe Lawson (JL)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.6)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Deputy Chief Executive Directorate
Narinder Sandhu (NS)	Head of Programme Delivery, Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: items 1 to 5.3)
Jodie Taylor-Brown (JTB)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: items 5.3 and 5.4)
James Watts (JW)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.5)
Emma Whale (EW)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.3)
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Deputy Chief Executive Directorate

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)
Kirsty Irvine (KI)	AGD independent member (outgoing Chair)
Jon Moore (JM)	NHS England member (Data Protection Office Representative)
Jenny Westaway (JW)	AGD independent member (Lay Adviser)

1	Welcome and Introductions: <p>The AGD Chair welcomed attendees to the meeting.</p> <p>AGD noted that, due to unforeseen circumstances, only two AGD NHS England members were in attendance for items 3.4 to 10. Noting that the AGD Terms of Reference state that “<i>The quorum for</i></p>
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	<p><i>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 NHS England Members...</i></p> <p>the Group agreed that, as there were two AGD NHS England members present, the meeting was still quorate for all relevant agenda items and agreed to proceed on that basis.</p>
2	<p>Review of previous AGD minutes:</p> <p>The minutes of the AGD meeting on the 4th December 2025 were reviewed and, after minor amendments, were agreed as an accurate record of the meeting.</p>
3	<p>Declaration of interests:</p> <p>Andy Rees noted a professional link to the 'DigiTrials Recruitment Service - Reminders Service' and NIC-791694-D2J8T (Akrivia Health) due to his NHS England role as NHS DigiTrials and Research Products Operations Manager; it was agreed that the items would be discussed / reviewed as per usual process and that this was not a conflict of interests.</p>
4 BRIEFING PAPER(S) / DIRECTIONS:	
4.1	<p>Title: NHS DigiTrials Template Review – 'Remote STrOke Rehabilitation' (ReSTORE) (NIC-793709-R9M3D)</p> <p>Presenters: Laura Evans and Louise Garnham</p> <p>At the AGD meeting on the 13th November 2025, as part of the 'DigiTrials Recruitment Service - Invitation Letter Standards' review / discussion, AGD had agreed that the first three instances of the finalised standard (which will form part of the NHS DigiTrials Precedent) used to assess an NHS DigiTrials invitation letter would come to AGD for review. AGD noted that this was the second instance of where the finalised standard had been used to assess an NHS DigiTrials invitation letter.</p> <p>NHS England were seeking advice on the following points:</p> <ol style="list-style-type: none"> 1. Provide advice on the points raised in the template review document. 2. Confirm if this letter was correctly brought to AGD for advice based on the points identified in the review document. <p>Outcome of discussion: AGD welcomed the briefing paper and made the following observations / comments:</p> <p>In response to point 1 above:</p> <p>4.1.1 AGD noted the question (Q6) posed to the Group in the template review document, in respect of whether a stroke should be considered of a "Sensitive Nature" under cognitive impairment; and advised that they were in agreement that it should be. In addition, the Group noted that individuals who have suffered a stroke could be vulnerable individuals because of possible cognitive or physical impairment.</p> <p>4.1.2 In respect of the question relating to incentives (Q7), AGD agreed that whilst there were no incentives used in this work, some of the language around "<i>undue inducement</i>" in the template (Q7) required further refinement and suggested using the clearer text from Annex 2 of the Template.</p>

4.1.3 The Group noted the importance of ensuring that any information in respect of inducement presented to the Research Ethics Committee (REC) was also presented to NHS England; and that NHS England may take a different view from the REC if it feels the inducements offered may cause reputational risks to NHS England.

4.1.4 In respect of the question (Q13) raised in respect of why an individual has been invited to take part, AGD suggested that the letter should be clearer that data may already be held on some of the individuals receiving the letter who have previously volunteered via another route.

4.1.5 AGD noted that the appendix does not include text in respect of “*does the study have my data*”; and suggested that this was reviewed and added.

4.1.6 AGD noted that consultee advice was not referred to, as it was not mentioned in the current study, however suggested that **1)** there may be some involvement from carers in assisting patients to participate; or **2)** consultee advice would be excluded, which may lead to a gap in the research; and queried if an NHS DigiTrials process was required to ask these questions of applicants.

4.1.7 AGD discussed equity of access, and queried whether there may be a gap in the research, for example, for those who do not speak English as a first language; and queried if an NHS DigiTrials process was required to flag this with applicants, noting that this may be a reputational risk to NHS England.

4.1.8 AGD also suggested that further consideration should be given to who the letter is from, noting that this is currently the Chief Investigator. The Group were of the view that a co-branding exercise would not be appropriate in this case, but suggested that the letter was updated to **1)** be clear on the role of NHS England; and **2)** ensure there is a NHS England contact number for queries about the contact / data use process, separate to the trial.

In response to point 2 above:

4.1.9 AGD noted the invitation letters provided, and advised that the rigour undertaken by NHS England in respect of reviewing the letters against the template was excellent, and that this had identified the right issues in this letter to bring to AGD.

5 EXTERNAL DATA DISSEMINATION REQUESTS:

5.1	<p>Reference Number: NIC-791694-D2J8T-v0</p> <p>Applicant: Akrivia Health</p> <p>Data Controllers: Cristal Health Ltd t/a Akrivia Health</p> <p>Application Title: “GlobalMinds - DigiTrials Recruitment Service”</p> <p>Observers: Dan Goodwin, Laura Evans and Louise Garnham</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 20th November 2025.</p> <p>Application: This was a new application.</p> <p>NHS England were seeking general advice on the application.</p>
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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 asked **not** to review the application for this item, and had instead been provided with a new NHS England DARS internal form that contained summary information that, once finalised, would be transferred into the usual data sharing agreement (DSA) template.

5.1.1 Noting point 5.1.6 raised by the Group on the 20th November 2025, AGD noted that only **provisional** s251 had been provided by the Health Research Authority Confidentiality Advisory Group (HRA CAG); and supported the position by NHS England, that **no** data will flow until the s251 unconditional support had been provided.

5.1.2 Given the s251 point raised by the Group, the NHS England SIRO Representative noted this application could **not** progress until such time as a **senior** NHS England colleague had reviewed the updated application.

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

5.1.3 AGD noted that the majority of points raised by the Group on the 20th November 2025 had now been addressed. However, AGD noted, in the responses to the previous points, that the applicant had advised that additional information may be added to the letters once they had been tested. The Group suggested that NHS England remind the applicant that any updates to the letters would be subject to the usual process both internally within NHS England, but also with Research Ethics Committee (REC) approval etc.

5.1.4 AGD suggested that the form should be updated to **1)** provide further clarity on the number of people to be contacted, not just the number of people sought for the cohort; and **2)** the exclusion criteria.

5.1.5 AGD noted the reference in section 4.8 (Expected Measurable Benefits) to "*clinical trial*" and suggested that this was reviewed and updated with the correct information.

5.1.6 AGD noted that, whilst a consent review was not a requirement at the current time, it would be sensible to undertake such a review if the applicant is likely to request follow up data from NHS England in the future.

5.1.7 AGD noted and commended the work undertaken by NHS England's Data Access Request Service (DARS) and the applicant on the work undertaken on this application.

5.1.8 AGD noted that there **was** a commercial aspect to the application.

In addition, AGD made the following observations **separate to the application**:

5.1.9 Separate to the application and for the AGD NHS England Data and Analytics Representative: As a wider point, AGD suggested that the NHS England DARS internal form for this type of application should routinely include the number of invitations to be sent, not just the size of cohort aimed for.

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5.2	<p>Reference Number: NIC-753327-M0G1F-v0</p> <p>Applicant and Data Controller: University Hospitals Birmingham NHS Foundation Trust</p> <p>Application Title: "West Midlands Sub-national Secure Data Environment for Research and Development (WM SNSDE)"</p> <p>Observer: Dan Goodwin and Ayse Depsen</p> <p>Application: This was a new application.</p> <p>NHS England were seeking general advice on the application.</p> <p>Should an application be approved by NHS England, further details would be made available within the Data Uses Register.</p> <p>Outcome of discussion: At the request of the SIRO representative in-meeting, AGD provided preliminary advice only on this application, and suggested that the application be brought back to a future meeting.</p> <p>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 asked not to review the application for this item, and had instead been provided with a new NHS England DARS internal form that contained summary information that, once finalised, would be transferred into the usual data sharing agreement (DSA) template.</p> <p>5.2.1 AGD noted that this was a first-of-type application to transfer substantial amounts of National NHS England data to a Regional Secure Data Environment (SDE) for onwards access by others. The Group noted the principle and the potential importance of the work outlined to support research. AGD noted that they would usually be presented with a briefing paper prior to a first of type application, and asked that this process was adhered to moving forward.</p> <p>5.2.2 AGD noted the complexity and importance of the application, and were supportive of any steps to look at elements of the application in more detail to provide assurance and were willing to engage with that approach out of committee.</p> <p>5.2.3 AGD queried the relationship between the Secure Data Environment (SDE) host and the sub-licensees, and whether there are any data controllership arrangements that need identifying; and suggested that NHS England explore this further in line with NHS England DARS Standard for Data Controllers.</p> <p>5.2.4 AGD suggested that NHS England discuss data minimisation further with the applicant, including, but not limited to, the use of resident versus registered population and any overlaps, for example, where individuals may come into a geographical area following referral.</p> <p>5.2.5 AGD discussed the 'West Midlands SDE Data Trust Committee' referred to in the form, and suggested that further information was provided, including, but not limited to, 1) who is on the Data Trust Committee; 2) what criteria is used for the risk assessment used for accessing the data; and 3) what are the mechanics for the approvals going via the appropriate channels; 4) to review the language used when referring to the Data Trust Committee, for example "<i>public good</i>" and "<i>approved countries</i>".</p>	
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5.2.6 AGD noted that the Data Trust Committee Chair may oversee a process of proportionate review, whereby applications that have been deemed low risk by the Information Asset Owner may progress if they receive favourable review, whereas other projects progress to full review. The Group suggested that any proportionate review process was deferred until the full review process had been operating for a period of time, for example, a minimum of six months, to determine where a proportionate review process would be possible.

5.2.7 AGD suggested that further clarification was provided on the onward sharing of data, for example, **1)** the legal basis; **2)** governance processes; and **3)** whether the data will be anonymised in context.

5.2.8 In respect of potential linkage of data to other datasets, AGD suggested that clarity was provided as to **1)** what data linkage would be taking place; **2)** a justification for the linkage; and **3)** clarification that any linkage would not compromise any anonymisation that has taken place.

5.2.9 AGD noted that this was quite a broad application, and suggested that NHS England engage with the applicant to discuss having a more restricted purpose, for example, for the purpose of research, noting that this aligns with the support received from the Health Research Authority Confidentiality Advisory Group (HRA CAG) and the HRA Research Ethics Committee (REC).

5.2.10 AGD noted that some of the text in the purpose section of the form was repetitive; and suggested that this was reviewed and updated / edited as may be necessary.

5.2.11 AGD suggested that the purpose section was reviewed and updated to ensure the number of projects referenced was correct.

5.2.12 AGD noted the reference to artificial intelligence (AI) in the form; and suggested that this was in line with any emerging guidance from the HRA or other bodies (such as NHS England).

5.2.13 AGD noted the need for appropriate transparency to data subjects.

5.2.14 AGD suggested that NHS England may wish to consider releasing a subset of the data without onward sharing to the sub-national SDE, as part of a pilot to understand the challenges in the establishment of the subnational SDEs.

In addition, AGD made the following additional general observations on the sub-national SDEs:

5.2.15 AGD suggested that NHS England consider having a national policy in respect of data minimisation and the use of resident versus registered population and any overlaps, for example, where individuals may come into a geographical area following referral.

5.2.16 AGD suggested that NHS England consider having a national policy in respect of the low risk / high risk criteria used for the risk assessment for organisations / individuals accessing the data in the sub-national SDEs.

5.2.17 AGD suggested that any further applications of this nature review the minutes from this and any other reviews of sub-national SDEs, to ensure consistency of approach.

	<p>5.2.18 AGD advised that they would welcome the opportunity to work with NHS England on this evolving area of work, as may be required, to help NHS England define a consistent approach across all of the sub-national SDEs, in line with existing NHS England Standards.</p> <p>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.2.19 AGD noted that there was a commercial aspect to the application.</p>	
5.3	<p>Reference Number: NIC-776600-D8P6R</p> <p>Applicant and Data Controller: Observational and Pragmatic Research Institute Limited</p> <p>Application Title: "Pragmatic evaluation of a quality improvement programme for people living with modifiable high-risk *COPD (PREVAIL)"</p> <p>*Chronic Obstructive Pulmonary Disease (COPD)</p> <p>Observers: Jodie Taylor-Brown and Emma Whale</p> <p>Previous Reviews: The 'Secure Data Environment (SDE) Bring your own Data – Briefing Paper' was previously presented / discussed at the AGD meeting on the 20th November 2025.</p> <p>Application: This was a new application.</p> <p>NHS England were seeking general advice on the application.</p> <p>Should an application be approved by NHS England, further details would be made available within the Data Uses Register.</p> <p>Outcome of discussion: At the request of the SIRO representative in-meeting, AGD provided preliminary advice only on this application, and suggested that the application be brought back to a future meeting:</p> <p>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 asked not to review the application for this item, and had instead been provided with a new NHS England DARS internal form that contained summary information that, once finalised, would be transferred into the usual data sharing agreement (DSA) template.</p> <p>5.3.1 By way of introduction, the NHS England SIRO Representative advised the Group that the existing Data Sharing Framework Contract (DSFC) had been signed incorrectly by the customer, and this was being addressed. The Group were advised that the applicant / sponsor is Observational and Pragmatic Research International Ltd registered in the UK (not 'Observational and Pragmatic Research Institute' which is based in Singapore). Given that a DSFC is not in place, it was recognised that AGD were unlikely to support the application, but were content to provide broad, early advice.</p> <p>5.3.2 AGD noted that the 'bring your own data' was a substantial quantity of GP data; and emphasised the importance of ensuring equity with the significant consideration given to the handling of patient consented GP data recently considered for nationally consented studies.</p> <p>5.3.3 AGD noted concerns in respect to the additional work that this study may put on GPs; and suggested that this was discussed with the applicant, and addressed in any future iterations of the form.</p>	

	<p>5.3.4 In respect of the commercial aspects of the application, AGD suggested that in line with NHS England DARS Standard for Commercial Purpose, NHS England discuss this further with the applicant, including, but not limited to 1) all commercial interests / benefits to any organisation involved with the study, including those specifically named in the form; and 2) any financial incentive to GP practices involved with the study.</p> <p>5.3.5 AGD queried the purpose of the study, noting the inconsistencies in the documents provided, for example, is this a 1) quality improvement activity; 2) screening activity; and / or 3) for the purpose of broader research; and suggested that NHS England clarify this with the applicant, and that the form was updated with the correct / factual information.</p> <p>5.3.6 AGD suggested that NHS England explore with the applicant that there is an appropriate equity in the demographic coverage across the GP practices, to ensure that different populations are not disadvantaged in terms of the access to the benefits of the study.</p> <p>5.3.7 AGD queried what opt-outs would / would not be applied, and suggested that the form was updated with further clarification on this, including, but not limited to, the mechanisms for applying opt-outs.</p> <p>5.3.8 AGD noted the anecdotal information in the form in respect of patient and public involvement and engagement (PPIE), however, suggested that this was expanded further to also provide information on the scale / numbers involved with the PPIE.</p> <p>5.3.9 AGD noted and supported the data being accessed in NHS England's Secure Data Environment.</p> <p>5.3.10 AGD noted and commended the work undertaken by NHS England's Data Access Request Service (DARS) and the applicant on the work undertaken on this application.</p> <p>5.3.11 AGD noted that there was a commercial aspect to the application.</p> <p>In addition, AGD made the following observations separate to the application:</p> <p>5.3.12 Separate to the application and action for the AGD NHS England Data and Analytics Representative: AGD noted that this was a further example of a cluster trial using s251 support; and suggested that the NHS England Data and Analytics Representative engage with colleagues to ensure that this was in line with the literature on consent in cluster trials.</p>	D&A Rep
5.4	<p>Reference Number: NIC-780923-D5L3J-v0.9</p> <p>Applicant and Data Controller: Queen Mary's University of London (QMUL)</p> <p>Application Title: "Delivery and Implementation of a Randomised Crossover Trial on Thrombosis (DIRECT)"</p> <p>Observer: Jodie Taylor-Brown</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 9th October 2025.</p> <p>Application: This was a new application.</p> <p>NHS England were seeking general advice on the application.</p>	

	<p>Should an application be approved by NHS England, further details would be made available within the Data Uses Register.</p> <p>Outcome of discussion: The majority of the Group were supportive of the application if the following substantive comments were addressed. A minority of the Group (two AGD independent members) were not supportive and suggested the application be deferred due to the outstanding concerns regarding consent. AGD wished to draw to the attention of the SIRO the following substantive points; and suggested that the application be brought back to a future meeting once the previous IGARD / AGD points had been sufficiently addressed (or it was clearly highlighted / justified where points were no longer applicable):</p> <p>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 asked not to review the application for this item, and had instead been provided with a new NHS England DARS internal form that contained summary information that, once finalised, would be transferred into the usual data sharing agreement (DSA) template.</p> <p>5.4.1 AGD noted that the majority of the points raised by the Group on the 9th October 2025, had been sufficiently addressed; however, noted that the concerns raised in respect of not taking consent for participation in the study remained open. AGD repeated its previous advice that the study appears to propose an intervention that needs to be prospectively administered to individuals in a context where the participant would be expected to give their consent for the treatment. NHS England was advised therefore to explore this further with the Health Research Authority (HRA) and HRA Confidentiality Advisory Group (CAG).</p> <p>5.4.2 The AGD NHS England Caldicott Guardian Representative advised that he would provide support to the NHS England SIRO Representative and NHS England's Data Access Request Service (DARS) out of committee, on the outstanding concerns raised by the Group, that would need further clarification with the HRA and HRA CAG.</p> <p>5.4.3 AGD noted that they recognised the value of the study, given the potential impact on a large number of individuals both in the UK and around the world.</p> <p>5.4.4 No AGD member noted a commercial aspect to the application.</p>	
5.5	<p>Reference Number: NIC-778927-P3D9Z-v0.10</p> <p>Applicant and Data Controller: Imperial College London</p> <p>Application Title: "Improving Resilience against cyber-attacks in Healthcare (iReACH)"</p> <p>Observer: James Watts</p> <p>Application: This was a new application.</p> <p>NHS England were seeking general advice on the application.</p> <p>Should an application be approved by NHS England, further details would be made available within the Data Uses Register.</p> <p>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:</p> <p>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 asked not to</p>	

	<p>review the application for this item, and had instead been provided with a new NHS England DARS internal form that contained summary information that, once finalised, would be transferred into the usual data sharing agreement (DSA) template.</p> <p>5.5.1 AGD noted that information collected / obtained on risks in respects of cyber-attacks may be a source of vulnerability for the NHS; and suggested that NHS England's Data Access Request Service (DARS) engage with their internal Cyber Team to seek further advice, for example, that there would not be any inadvertent exposures caused by the work outlined.</p> <p>5.5.2 In addition, should this work proceed, the Group suggested that the applicant ensure that, prior to publication, any outcomes of this work do not expose sources of vulnerability or means of a cyber-attack.</p> <p>5.5.3 AGD suggested that the application was reviewed and updated with further information outlined in the protocol, including, but not limited to, clarifying how the data requested was sufficient and necessary to meet the objective for processing, in line with NHS England DAS Standard for Objective for Processing.</p> <p>5.5.4 AGD noted the expected benefits outlined, however queried who would receive / act on the benefits, for example, would this be at a national or local level; and suggested that further clarification was provided, in line with NHS England DAS Standard for Expected Measurable Benefits.</p> <p>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.5.5 AGD welcomed the application and noted that the initiative outlined was novel and interesting.</p> <p>5.5.6 AGD noted the references in the form to “<i>mathematical modelling</i>” and “<i>geographical equity</i>”; and suggested that a further explanation was provided on this, noting that it was currently unclear.</p> <p>5.5.7 No AGD member noted a commercial aspect to the application.</p>	
5.6	<p>Reference Number: NIC-783385-F5B1V-v0.3</p> <p>Applicant and Data Controller: The University of Manchester</p> <p>Application Title: “An evaluation of an alternative Child Friendly Dental Pathway for Paediatric patients”</p> <p>Observer: Joe Lawson</p> <p>Application: This was a new application.</p> <p>NHS England were seeking general advice on the application.</p> <p>Should an application be approved by NHS England, further details would be made available within the Data Uses Register.</p> <p>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:</p>	

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 asked **not** to review the application for this item, and had instead been provided with a new NHS England DARS internal form that contained summary information that, once finalised, would be transferred into the usual data sharing agreement (DSA) template.

5.6.1 AGD queried what would happen to data flowed by NHS England once a participant turns 16 years of age, noting that parental consent had been provided; and noting that NHS England's Data Access Request Service (DARS) had explored this with the applicant, suggested that NHS England satisfy themselves that the appropriate arrangements are in place for these individuals, in line with the latest NHS England guidance. The Group also noted that it was a common approach to seek consent from cohort members once they have turned 16 to permit the continued processing of their identifiable data.

5.6.2 AGD noted that the follow-up period for the study was two years from the point of enrolment; however, suggested that NHS England satisfy itself that this aligns with data period requested / outlined in the form provided.

5.6.3 AGD suggested that the applicant undertake a thorough review of **all** transparency materials, including, but not limited to, the website, online video and child specific materials, to **1)** ensure that the information provided / available reflects both the consent and s251 legal basis'; and **2)** that the correct data flows are clear, for example, the data flowing to and from the Dental Referral Management System.

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

5.6.4 AGD suggested that section 4.10 (Special Conditions) was updated to revise the citation special condition wording, in line with [NHS England DARS Standard for Special Conditions](#).

5.6.5 AGD noted and commended the work undertaken by NHS England's Data Access Request Service (DARS) with the applicant in respect of the legal basis for processing.

5.6.6 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

7.1	Clustering of ICBs Proposal to manage Data Sharing Currently all 42 ICBs have Data Sharing Agreements with NHS England to cover the flow of data for the purposes of Commissioning, Risk Stratification and Invoice Validation. To meet the 50% cost reductions required by NHS England, as part of the 10-year plan, and harness economies of scale, most ICBs have agreed 'clustering' arrangements, with two or more ICBs working together across a larger footprint, either remaining separate organisations legally after 1 st April 2026, or merging into a single new ICB from that point. Three groups of ICBs have been identified:
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	<p>Group 1 - ICBs with a Ministerial Binding Merger has been agreed from April 1st, 2026.</p> <p>Group 2 - ICBs with a non-binding merger and no agreed merger date.</p> <p>Group 3 - ICBs where there are no agreed organisational changes or cluster arrangements identified.</p> <p>Several ICBs in Group 1 have contacted NHS England to urgently ask that they have permission to share data in the run up to the formal changes to enable them to have new organisational working set ups by the beginning of March 2026, at the latest, to allow at least a month of dual running.</p> <p>The SIRO representative has approved this approach.</p> <p>Outcome of discussion: AGD noted that the NHS England SIRO had already provided SIRO approval and confirmed that they were supportive of this.</p> <p>AGD thanked NHS England for the written update and advised that they had no further comments to make on the documentation provided.</p> <p>The NHS England SIRO Representative thanked AGD for their time.</p>
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8 OVERSIGHT AND ASSURANCE

There were no items discussed

9 AGD OPERATIONS

9.1	<p>Risk Management Framework</p> <p>The NHS England SIRO Representative noted the recent discussions at the AGD plenary meeting on the 4th December 2025, on a number of different scenarios that may influence the content of a Risk Management Framework; and it was noted that further work / discussions on this will take place out of committee with some of the AGD members; and that further information would be provided / discussed with the Group at a future AGD meeting.</p> <p>ACTION: The NHS England SIRO Representative, AGD Chair and AGD Secretariat to discuss out of committee work on the Risk Management Framework.</p>	SIRO Rep
9.2	<p>AGD Stakeholder Engagement</p> <p><i>There were no items discussed</i></p>	
9.3	<p>AGD Project Work</p> <p>Federated Data Platform</p> <p>A brief update was given by the Group's representative on the Federated Data Platform Data Governance Group.</p>	

10 Any Other Business

10.1	There was a brief discussion of items on the AGD internal forward planner.
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Meeting Closure

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

