

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 20th August 2026

09:00 – 15:50

(Remote meeting via videoconference)

AGD INDEPENDENT / NHS ENGLAND MEMBERS IN ATTENDANCE:	
Name:	Role:
Mr Christopher Barben (CB)	AGD independent member (Specialist Clinician Adviser)
Dr. Jon Fistein (JF)	AGD independent member (Chair) (AGD independent member for items 5.6 to 5.7)
Prof. Jo Knight (JK)	AGD independent member (Specialist Academic / Researcher Adviser) (Chair for items 5.6 to 5.7)
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))
Ellie Ward (EW)	NHS England member (Data Protection Office Representative (Delegate for Jon Moore)) (not in attendance for item 4.2, part of 5.7 and 7.1, 9.1)
Jenny Westaway (JW)	AGD independent member (Lay Adviser)
Miranda Winram (MW)	AGD independent member (Lay Adviser)
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	Role / Area:
Garry Coleman (GC)	NHS England SIRO Representative
Dave Cronin (DC)	Applications Service Owner, Data Access and Partnerships, Transformation Directorate, Transformation Directorate (Presenter: item 4.1) (Observer: items 5.1 and 5.7)
Ayse Depsen (AD)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: items 5.2 to 5.3)
Dan Goodwin (DG)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: items 4.1 and 5.1)
Suzanne Hartley (SH)	Data Applications Service (DAS) - Senior Manager, Data Access and Partnerships, Transformation Directorate (Observer: items 4.1 and 5.1)

Joe Lawson (JL)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: items 5.4 to 5.5)
James Watts (JWa)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: items 5.6 to 5.7)
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Technology, Digital and Data
AGD INDEPENDENT MEMBERS / NHS ENGLAND MEMBERS <u>NOT</u> IN ATTENDANCE:	
Name:	Role / Area:
Paul Affleck (PA)	AGD independent member (Specialist Ethics Adviser)
Michael Chapman (MC)	NHS England member (Data and Analytics Representative)
Claire Delaney-Pope (CDP)	AGD independent member (Specialist Information Governance Adviser)
Dr. Mark McCartney (MM)	AGD independent member (Specialist GP / Clinician Adviser)
Jon Moore (JM)	NHS England member (Data Protection Office Representative)

	Pre-meeting discussion Jf – away last week Oct / not first week in November
1	Welcome and Introductions: The AGD Chair welcomed attendees to the meeting. AGD noted that, due to unforeseen circumstances, only two AGD NHS England members were in attendance for items 4.2, part of 5.7, 7.1 and 9.1. Noting that the AGD Terms of Reference state that “<i>The quorum for meetings of the Group or a Sub-Group is five members, including at least three independent members, one of whom may be the Chair, Deputy Chair or Acting Chair and two of the three NHSE Members...</i>”, the Group agreed that, as there were two AGD NHS England members present, the meeting was still quorate for all agenda items and agreed to proceed on that basis.
2	Review of previous AGD minutes: The minutes of the AGD meeting on the 6th August 2026 were reviewed out of committee by the Group and were agreed as an accurate record of the meeting by the AGD Chair, on behalf of the Group.
3	Declaration of interests: Dr. Jon Fistein noted a professional link to the University of Oxford but noted no specific connections with the application (NIC-808601-D2G5B-v0), and it was agreed that this was not a conflict of interest.

	Prof. Matthew Sydes noted a professional link to University College London, but noted no specific connections with the application (NIC-804103-Q6P5S-v0), or staff involved, and it was agreed that this was not a conflict of interest. Jenny Westaway noted a professional link to the Royal College of Anaesthetists (NIC-773376-M4M7B-v0). It was agreed this did not preclude Jenny from taking part in the discussion about this application.	
4 BRIEFING PAPER(S) / DIRECTIONS:		
4.1	Title: Draft “Approving purposes within an authorised scope” Standard Presenter: Dave Cronin Observers: Dan Goodwin and Suzanne Hartley Previous Reviews: Previously discussed at the AGD meeting on the 2nd July 2026; and previously discussed as part of ‘AGD project work’ on the 9th July 2026 and the 2nd July 2026. The purpose of the briefing paper is to provide clarity on the inclusion and exclusion criteria for the proposed draft “Approving purposes within an authorised scope” Standard. NHS England were seeking general advice on the draft Standard. Summary of discussion: AGD welcomed the draft Standard and made the following observations / comments: 4.1.1 In advance of the meeting, two AGD independent members provided comments and a marked-up copy of the draft Standard to NHS England in order support further revisions of the draft Standard, alongside suggested edits made in-meeting. 4.1.2 The NHS England SIRO Representative suggested that AGD look retrospectively at three applications that have already been to AGD against the draft Standard to test whether they would or would not fit under the new draft Standard in order to support NHS England finalising the document and adopting the Standard. The Group agreed with the approach and looked forward to receiving three previously reviewed applications to test against the draft Standard.	DARS
4.2	Title: National Institute for Cardiovascular Outcomes Research (NICOR) update of business-as-usual processing – Data Protection Impact Assessment (DPIA) Previous Reviews: Previously discussed at AGD meeting on the 5th June 2025 (briefing paper) and 13th March 2025 (verbal update) Initially NICOR was hosted at University College London and then by Barts Health NHS Trust as a Data Processor and commissioned by the Healthcare Quality Improvement Programme (HQIP). During 2022 the commissioning and location of this work was changed to NHS England and a migration exercise undertaken. The finalised DPIA analyses, identifies and minimises the data protection risk associated with the NICOR. Summary of discussion AGD welcomed the finalised DPIA. 4.2.1 In advance of the meeting, an AGD independent member queried whether the request was now in place from NHS Wales to NHS England to establish and operate a system for	

	collecting NICOR data from Wales, i.e. is this formal governance arrangement now in place, noting the DPIA risk table indicated an action due date of 31 st March 2026, but the language in the DPIA suggests this arrangement is not yet in place. The NHS England SIRO Representative agreed to come back to a future AGD Meeting with an update on this point.	SIRO Rep
5 EXTERNAL DATA DISSEMINATION REQUESTS:		
5.1	Reference Number: NIC-16016-Y9H1D-v16.4 Applicant and Data Controller: HSJ Information Ltd (<i>*Previously "Wilmington Healthcare"</i>) Application Title: "Hospital Episode Statistics (HES), ECDS, Diagnostic Imaging Dataset (DIDs) and sensitive Mental Health data to assist disease awareness, commissioning, and help to produce longitudinal rare disease analysis and reports" Observers: Dave Cronin, Dan Goodwin and Suzanne Hartley Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 16th November 2023 and the 21st September 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 4th August 2022, 7th July 2022, 5th November 2020, 1st August 2019, 16th May 2019, 26th July 2018, 11th January 2018, 21st December 2017, 2nd November 2017, 19th October 2017 and the 5th October 2017. Application: This was an amendment application. NHS England were seeking advice on the following points: 1. Whether NHS England should continue to support the use of its data by HSJ Information Ltd for all / some of the purposes that were previously supported, specifically considering whether: a) the purposes are sufficiently defined in the DSA; b) the governance, as described, is adequate; and c) the details of uses and benefits provided justify the renewal of this DSA. 2. Noting the assessment against the draft standard, whether this example indicate any issues, challenges or positive feedback in respect of that standard. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. Summary of discussion: In response to points 1 and 2: 5.1.1 There was a lengthy and far-reaching discussion. The Group noted that the application as presented was not in line with all the NHS England DARS Standards and considered advising NHSE to potentially stop the flow of data completely. However, the Group agreed on a way forward which would include appropriate and proportionate further steps and also allow a flow of data to continue. 5.1.2 The Group was dismayed to note that previous advice provided by the AGD on 16th November 2023 had not been acted upon, including but not limited to:	

	5.1.2.1 The Healthcare Advisory Board's Terms of Reference (ToR) did not appear to have been updated to reflect the ethical consideration (point 4.1.3); and 5.1.2.2 The Healthcare Advisory Board's ToR still did not appear to have been updated to address the usual practice of half plus one for consensus of a Board (point 4.1.5). 5.1.3 The Group expressed their discomfort at the large extract of data under this data sharing agreement (DSA) with activities that might now be more suited to other routes of access, and noting the applicant was amenable to other routes of access, suggested that NHS England explore this further. 5.1.4 Noting the commercial nature of the application, the applicant had outlined a number of high-level benefits they had contributed to, however the Group's view was that the evidence provided was insufficient to demonstrate that it was consistent with the NHS England DARS Standard for Expected Measurable Benefits, and AGD suggested that more evidence be provided on tangible benefits accruing, which would also provide evidence for the applicant's transparency including their data uses register. 5.1.5 The Group also observed that since the last independent review in 2023 greater information in respect of the balance between public and commercial benefit should also be provided, in line with the National Data Guardian (NDG) guidance on benefits. 5.1.6 Noting the applicant had had access to extracts of monthly data for some years, the Group and NHS England SIRO Representative agreed the applicant could continue to receive monthly extracts for existing projects only, with the only update to the DSA being the removal of the Data Processor as outlined in the internal form / application. 5.1.7 AGD and the NHS England SIRO Representative were clear that the applicant could not self-approve new projects until compliance with the NHS England DARS Standards had been demonstrated. Should the applicant wish to undertake any new projects, they would need to come back to NHS England for an amendment to their DSA. 5.1.8 Given the points raised by the Group, the NHS England SIRO Representative noted this application could not progress via delegated authority until such time as the NHS England SIRO Representative and an NHS England senior colleague within Data and Analytics had reviewed the updated application, except in relation to the removal of the Data Processor uplift which could progress under delegated authority.	
5.2	Reference Number: NIC-808571-P5B0J-v0 Applicant and Data Controller: University of Bristol Application Title: "Estimating neurodegenerative disease burden, underdiagnosis and quality of care in England using linked electronic health records" Observer: Ayse Depsen Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the Profession Advisory Group (PAG) meetings on the 30th June 2026. Application: This was a new application. NHS England were seeking advice on the following points:	

	1. Whether this is an application which could be approved under a new OpenSafely Precedent; and 2. If not, then a) what exclusion criteria may apply; and b) are there additional question/answer pairs that might have made this suitable for being a Precedent. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. Summary of discussion: AGD noted that the PAG had reviewed the application as per process on the 30th June 2026, and that feedback was available in the published PAG minutes from the meeting. In response to points 1 and 2: 5.2.1 Notwithstanding the ongoing work currently being undertaken by NHS England on the draft OpenSAFELY Precedent, following comments previously provided by the Group; AGD noted that this application would be suitable for approval under Precedent once finalised; however noted the internal inconsistency in the narrative within the internal form / application, for example the lay summary (section 4.4) and expected measurable benefits (section 4.8) talked primarily about dementia, but the purpose for processing included Parkinson's Disease and Motor Neuron Disease (MND) alongside dementia. AGD suggested further narrative be included throughout the internal form / application on Parkinson's Disease and MND, or to remove them entirely. 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: 5.2.2 The Group noted the patient and public involvement and engagement (PPIE) outlined in the internal form / application, however noted this was only via the Alzheimer's Society, and it was not clear that this would include those affected by MND or Parkinson's Disease. AGD suggested that further narrative be included to explain how the PPIE undertaken reaches all of the diverse patient group and to update the internal form / application as appropriate. 5.2.3 AGD suggested a clearer explanation of the relationship between the University of Edinburgh and University of Bristol and in line with the NHS England DARS Standard for Data Controllers and NHS England DARS Standard for Data Processors, noting that the ethics documentation provided was for the University of Edinburgh. 5.2.4 Separate to the application: The Group also noted that NHS England is considering the relevance of the NHS England DARS Standard for Data Controllers to OpenSAFELY applications and looked forward to an update on this in due course. 5.2.4 Given the points raised by the Group, the NHS England SIRO Representative noted this application could progress via delegated authority to NHS England's Data Access Request Service (DARS) once the AGD advice has been addressed	SIRO Rep
5.3	Reference Number: NIC-808601-D2G5B-v0 Applicant and Data Controller: University of Oxford	

Application Title: “CIPHER – Cardiovascular Inequalities in Primary care – an electronic Health records study focusing on Equitable management of cardiovascular Risk in England” Observer: Ayse Depsen Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the Profession Advisory Group (PAG) meetings on the 21st July 2026. Application: This was a new application. NHS England were seeking advice on the following points: 1. Whether this is an application which could be approved under a new OpenSafely Precedent; and 2. If not, then a) what exclusion criteria may apply; and b) are there additional question/answer pairs that might have made this suitable for being a Precedent. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. Summary of discussion: AGD noted that the PAG had reviewed the application as per process on the 21st July 2026, and that feedback was available in the published PAG minutes from the meeting. In response to points 1 and 2: 5.3.1 Notwithstanding the ongoing work currently being undertaken by NHS England on the draft OpenSAFELY Precedent, following comments previously provided by the Group; AGD noted that this application would be suitable for approval under Precedent once finalised. 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: 5.3.2 In advance of the meeting, an AGD independent Member had raised a query with regard to the review and approvals by the Programme Management Team, and whether 1) the Programme Management Team includes those that would be allowed to request an analysis; 2) if yes, could the requester take part in the approval; and 3) were there any other members of the Programme Management Team apart from those listed within section 1.7 of the internal form / application. NHS England confirmed that the Programme Management team included those listed in section 1.7 of the internal form / application; the person leading the request cannot take part in the approval meetings; and there were no other members in the Programme Management Team. AGD thanked NHS England the applicant for providing clarity on these points. 5.3.3 AGD suggested further clarity be provided in the internal form / application on the level of decision making given to participants in the programme, the processes in place to define those decisions, and to clarify those are limited to new analysis in existing purposes only and should not trespass into the territory of any new purposes within the programme, which would be beyond the scope of the existing data sharing agreement (DSA). 5.3.4 Separate to the application: the Group suggested that the Precedent be updated to include “<i>delegated decision making</i>” as an exclusion criteria.	D&A Rep
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	5.3.5 Given the points raised by the Group, the NHS England SIRO Representative noted this application could progress via delegated authority to NHS England's Data Access Request Service (DARS) once the AGD advice has been addressed.	
5.4	Reference Number: NIC-804103-Q6P5S-v0 Applicant and Data Controller: University College London (UCL) Application Title: "The Impact of Patient Choice on the Efficiency of Secondary Healthcare Delivery" Observer: Joe Lawson Application: This was a new application. NHS England were seeking advice on the following points: 1. Whether they would advise that this application should fall under a low-risk Precedent (currently in draft); and 2. Whether it would if the draft Precedent were currently active (and how we could adjust the Precedent if these answers are inconsistent). Should an application be approved by NHS England, further details would be made available within the Data Uses Register. Summary of discussion: 5.4.1 AGD noted that the 'Assessment of draft Precedent eligibility - Precedent for the approval of low-risk new applications' had been discussed at the AGD meeting on the 23rd July 2026 and the 16th July 2026; and had been provided to the Group as part of the review of this application. In response to points 1 and 2: 5.4.2 AGD had a lengthy discussion around the nature of the study, noting that it had already successfully been through an independent peer review process; and whether this type of study would fall under the low-risk precedent. AGD noted that there were a number of issues outstanding that would need to be addressed before this application could potentially proceed via the low-risk Precedent, including but not limited to: 5.4.2.1 Clarification of how the NHS England DARS Standard for Expected Measurable Benefits would be met given the study would be limited to NHS delivered / funded outcomes via the Hospital Episode Statistics Admitted Patient Care (HES APC) data, noting the HES APC data did not include data on privately-funded private sector activity which would potentially be relevant to the outcomes of this work; 5.4.2.2 how the benefits accruing to NHS delivered / funded care only would be significant enough not to impact on the patient choice or other research outputs, for example waiting times; 5.4.2.3 AGD were unable to opine as to whether limitations in the HES APC dataset were so significant as to impact any potential findings due to missing data 5.4.2.4 the applicant to demonstrate how limitations of the data could be overcome or how they were irrelevant to the study; and suggested the applicant consult experts	

	in NHS England data regarding what is and is not in the HES APC, and to look at other studies via the NHS England Data Uses Register that were also studying improving variables such as patient choice and travel. 5.4.2.5 noting the study was not focusing on direct patient outcomes gave the Group some comfort, however more clarity was required around the methodology, for example and not limited to, providing an explanation when looking at waiting times and the patient choice of travelling a long distance to a private health care provider verse travelling to a local NHS provider. 5.4.2.6 the Group noted there was a lack of transparency which was not in line with the contractual requirements of section 4 of the data sharing agreement (DSA) and the NHS England DARS Standard for Transparency (fair processing), and suggested that no data was released until this specific point had been addressed. 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: 5.4.3 AGD were asked by the NHS England SIRO Representative to vote on whether the applicant had clearly demonstrated that the public benefits standard had been met. The majority of the Group (three AGD NHS England Representatives and three independent members) did not agree the benefits standard had been clearly demonstrated as met, a minority (two independent members) agreed that the benefits standard had been met. The NHS England SIRO Representative welcomed the vote. 5.4.4 Separate to the application: The AGD NHS England D&A Representative agreed to find out whether and when data relating to healthcare treatments in the private sector flow back to NHS England datasets. 5.4.5 Given the points raised by the Group, the NHS England SIRO Representative noted this application could not progress via delegated authority until such time as the NHS England SIRO Representative and an NHS England senior colleague within Data and Analytics had reviewed the updated application.	D&A Rep
5.5	Reference Number: NIC-779400-J2J4Z-v0 Applicant and Data Controller: University of Plymouth Application Title: “Care of people at the end of their lives in the rural and coastal communities of the South West Peninsula of England: A participatory realist evaluation” Observer: Joe Lawson NHS England were seeking advice on the following points: 1. Whether they would advise that this application should fall under a low-risk Precedent (currently in draft); and 2. Whether it would if the draft Precedent were currently active (and how we could adjust the Precedent if these answers are inconsistent). Should an application be approved by NHS England, further details would be made available within the Data Uses Register. Summary of discussion:	

	5.5.1 AGD noted that the 'Assessment of draft Precedent eligibility - Precedent for the approval of low-risk new applications' had been discussed at the AGD meeting on the 23rd July 2026 and the 16th July 2026; and had been provided to the Group as part of the review of this application. In response to points 1 and 2: 5.5.2 AGD noted that this application would be suitable for approval under the Precedent once finalised; and no further edits were suggested. In addition to their advice on the specific points raised by NHS England, AGD made the following observations on the application and / or supporting documentation provided as part of the review: 5.5.3 The Group wished to draw to the attention of the applicant the implication of the small number suppression policy, which may impact on the outputs; and suggested that the applicant give this aspect more thought. 5.5.4 Separate to the application: the Group noted that the applicant was applying for access to data via the National Secure Data Environment (SDE) and a Regional SDE and suggested that consideration be given by the wider system as to a single route of access for future applicants. 5.5.5 Given the points raised by the Group, the NHS England SIRO Representative noted this application could progress via delegated authority to NHS England's Data Access Request Service (DARS) once the AGD advice has been addressed.	SIRO Rep
5.6	Reference Number: NIC-798603-K9L2F-v0 Applicant and Data Controller: University of Manchester Application Title: "Mastering Effectiveness Research by Meta-Analysing Trial and Real World Evidence in Immune-mediated inflammatory Diseases (MERMAID)" Observer: James Watts Application: This was a new application. NHS England were seeking advice on the following points: 1. Whether the purpose is sufficiently specific, and if not, how it might be suitably updated. 2. Whether the risk of re-identification is sufficiently mitigated, and if not, how it might be suitably further mitigated. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. Summary of discussion: In response to point 1: 5.6.1 The Group discussed their concerns that the purpose was too broad and not significantly bounded, and advised: 5.6.1.1 as written workstream 2 was too broad, for example patient characteristics compared between groups, and suggested more granular information be provided;	

	5.6.1.2 more clarity be provided around the programme of work and whether delegated decision making was included; and 5.6.1.3 more clarity around the statistical plan, for example which trials were being compared. In response to point 2: 5.6.2 AGD noted they had been asked whether there was a risk of re-identification, noting that lots of information was being shared which was potentially being linked or held in the same place, and suggested the applicant undertakes an assessment to reassure NHS England that all possible steps had been taken to mitigate the risk of re-identification; In addition to their advice on the specific points raised by NHS England, AGD made the following observations on the application and / or supporting documentation provided as part of the review: 5.6.3 Noting the Health Research Authority Confidentiality Advisory Group (HRA CAG) support and advice, AGD noted that no local opt outs had been received from the circa 125,000 participants on the IBD registry during the 6-week window suggested by the HRA CAG. The AGD NHS England DPO Representative and AGD suggested that the applicant take every opportunity to expand the awareness of the IBD Registry, noting that the SD4 '<i>MERMAID IBD Registry Social Media v1.0 05Nov25</i>' provided as part of the agenda pack was blank, so it was not possible to opine on whether this document provided additional social media awareness. 5.6.4 Queries were also raised by the AGD NHS England DPO Representative and AGD that, recognising the applicant has s251 support, as to NHS England's role in determining whether the registry data may be used for research, since it was unclear in the documentation provided what relevant Directions the collection was relying on. AGD therefore suggested that NHS England satisfy itself as to the necessary basis for establishing that this data can be used for research, and then subsequently whether the applicant's s251 provides support. 5.6.5 Separate to the application: it was agreed that more information around the IBD Registry Directions would be provided to the Group via a briefing. 5.6.6 Separate to the application: Noting that the NHS England website contains some information about the transfer of the IBD Registry to NHS England, NHS England should ensure that all transparency for the IBD Registry and how it can be used is updated / consistent across all materials, including the NHS England website, 5.6.7 The Group noted that the applicant was using a platform called 'VIVLI', and suggested the internal form / application be updated to clearly stated that only derived data would be uploaded to the platform rather than "...<i>aggregated, categorised anonymised form...</i>", alongside a clear description of the process. 5.6.8 Separate to the application: the application focuses on data available at NHS England and could be in the National Secure Data Environment (SDE). There was also mention that the project overall, outside of this application to NHS England, would be applying to access regional data from elsewhere in the SDE Network. The AGD NHS England D&A Representative agreed to raise with the Data for R&D team whether this could be simplified for future applications.	SIRO Rep DPO Rep D&A Rep
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	5.6.9 Given the points raised by the Group, the NHS England SIRO Representative noted this application could not progress via delegated authority until such time as the NHS England SIRO Representative and an NHS England senior colleague within Data and Analytics had reviewed the updated application.	
5.7	Reference Number: NIC-773376-M4M7B-v0 Applicant and Data Controller: Queen Mary University of London (QMUL) Application Title: “A national perioperative platform trial to improve outcomes for surgical patients PROTECT” Observers: Dave Cronin and James Watts Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 12th February 2026 and the 16th April 2026. Application: This was a new application. NHS England were seeking advice on the following points: 1. Is this a model NHS England can / should support noting the challenges around the proposed scope and controllership / third party collaboration, and, if so, how. 2. Does the existing consent support the proposed model. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. Summary of discussion: 5.7.1 The Group welcomed the briefing that had been provided alongside the usual documentation as part of the review, in order to consider the many complex aspects of the application In response to point 1: 5.7.2 The Group noted their support of the work being undertaken to try to enable use of data in clinical trials, noting that NHS England had already spent considerable resource on this application, AGD reached a pragmatic way forward in order to find a solution. 5.7.3 There was a lengthy discussion, and the Group was agreed that they could not support the application as presented because of statements around 1) future research; 2) lack of sufficient parameters / bounding; and 3) insufficient detail around the governance process for example the public verse commercial weight of benefits, detail around the steering committee and a copy of the Committee’s Terms of Reference (ToR). In response to point 2: 5.7.4 A minority of the Group (two independent members and one AGD NHS England Representative) thought the new consent was adequate and supported the proposed model; the majority of the Group (three independent members and one AGD NHS England Representative) thought that consent materials were currently inadequate, but considering that recruitment had only recently started, this could still be addressed by uplifting the materials to include, but not limited to;	

	5.7.4.1 removing the restriction that data would only be shared with QMUL, in order to broaden consent should there be structural change in the future; 5.7.4.2 further clarity around the nature of the plan to create a platform and to run multiple associated trials some of which the applicant would not be made aware; and 5.7.4.3 to align the narrative in the PIS with the consent. 5.7.5 AGD noted the response to their advice in relation to the retention period (point 5.7.5 from 16th April 2026) and notwithstanding the applicant had provided clarity that the retention period would start from the date of the end of each research study / question hosted within the PROTECT platform the participants were enrolled in, the retention period was not clearly justified in line with the NHS England DARS Standard for Data Minimisation. 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: 5.7.8 AGD noted the response to their advice in relation to sub-licensing (point 5.5.1 from 16th April 2026) and noted that the applicant had wanted the sub-licensing clause removed from their data sharing agreement (DSA) because all projects would be sponsored by QMUL, however AGD suggested that the applicant may wish to reconsider since they may want to invite external trials to be part of their platform to support the work of improving outcomes for surgical patients, and currently as written they would be precluded. 5.7.9 Separate to the application: Notwithstanding point 5.7.8 above, AGD noted the ongoing development in the National Secure Data Environment (SDE), and suggested that NHS England consider whether this application was using the right approach, since recent changes to the SDE included bring your own data, and other structures / policies over the coming months may make a differing approach / model more preferable. 5.7.10 Given the points raised by the Group, the NHS England SIRO Representative noted this application could not progress via delegated authority until such time as the NHS England SIRO Representative and an NHS England senior colleague within Data and Analytics had reviewed the updated application.	SIRO Rep
6 INTERNAL DATA DISSEMINATION REQUESTS:		
<i>There were no items discussed</i>		
7 EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL		
7.1	Reference Number: NIC-808477-T8P0S-v0.1 Applicant and Data Controller: Children's Commissioner's Office Application Title: "Children detained under the Mental Health Act" The SIRO approval was for tabulated data without small number suppression. Outcome of discussion: AGD noted that the NHS England SIRO had already provided SIRO approval on the 30th July 2026 and confirmed that they were supportive of this. AGD thanked NHS England for the written update and advised that they had no further comments to make on the documentation provided.	

8 OVERSIGHT AND ASSURANCE

There were no items discussed

9 AGD OPERATIONS

9.1 AGD ways of working

The AGD Chair noted that the 'AGD Themed Questions' had been discussed with Jackie Gray, Director of Privacy and Information Governance, Privacy, Transparency, and Trust (PTT) at a recent meeting and that a further iteration of the document would be circulated in due course.

AGD
Chair

9.2 AGD collaboration on in-meeting documentation

Noting the trial of collaborating on application summaries in 2024 / 2025 (see AGD minutes: 26th September 2024, 12th December 2024, 16th January 2025, 23rd January 2025 and 30th January 2025) and the conclusion at the 13th March 2025 plenary meeting that the trial had increased pre-meeting preparation time for AGD Members / AGD Secretariat without any clear benefits, but that there was a clear benefit for collaborating on briefing papers, DPIAs, Directions etc in order to provide drafting comments back to NHS England; the Director of Privacy and Information Governance had requested that AGD trial the collaboration and reviewing of applications / internal forms by correspondence as opposed to in-meeting.

It was agreed that a process for reviewing via correspondence should be agreed at a future AGD meeting, prior to any commencement of the collaboration trial.

AGD

9.3 AGD Annual Report 2025/26

The AGD Chair reiterated the point made at the AGD meeting on the 6th August 2026, that the proposed AGD Annual Report 2025/26 had been discussed with Jackie Gray, Director of Privacy and Information Governance, Privacy, Transparency, and Trust (PTT) who was giving this further consideration. It was noted that a further update would be provided in due course.

AGD
Chair

9.4 AGD Stakeholder Engagement

There were no items discussed

9.5 AGD Project Work

There were no items discussed

10 Any Other Business

10.1 Independent Voice

Following complex discussions at the meeting, an AGD independent member noted the value of the independent voice in the health and care system. Noting health and care were key drivers in the economy, the NHS holds a unique dataset and it was incredibly important for continued independent oversight and assurance of the use of that data, so as not to erode its value or lose the trust of the public.

Meeting Closure

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