

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 11th September 2025

09:00 – 16:00

(Remote meeting via videoconference)

| AGD INDEPENDENT / NHS ENGLAND MEMBERS IN ATTENDANCE: | |
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| Name: | Role: |
| Paul Affleck (PA) | AGD independent member (Specialist Ethics Adviser) |
| Laura Bellingham (LB) | NHS England member (Data and Analytics Representative (Delegate for Michael Chapman)) (not in attendance for item 5.1) |
| Claire Delaney-Pope (CDP) | AGD independent member (Specialist Information Governance Adviser) |
| Rachel Fernandez (RF) | NHS England member (Data Protection Office Representative (Delegate for Jon Moore)) |
| Kirsty Irvine (KI) | AGD independent member (Chair) |
| Dr. Jonathan Osborn (JO) | NHS England member (Caldicott Guardian Team Representative) (not in attendance for part of item 5.3) |
| Jenny Westaway (JW) | AGD independent member (Lay Adviser) (Observer: item 2.2 only) |
| Miranda Winram (MW) | AGD independent member (Lay Adviser) |
| NHS ENGLAND STAFF IN ATTENDANCE: | |
| Name: | Role / Area: |
| Michael Chapman (MC) | Director of Data Access and Partnerships, Transformation Directorate (Observer: item 4.1) |
| Garry Coleman (GC) | NHS England SIRO Representative |
| Dave Cronin (DC) | Applications Service Owner, Data Access and Partnerships, Transformation Directorate (Observer: items 5.1 to 5.3) |
| Claire Edgeworth (CE) | Head of Strategic IG – Consultancy, NHS England (Presenter: item 4.2) |
| Suzanne Hartley (SH) | Data Applications Service (DAS) - Senior Manager, Data Access and Partnerships, Transformation Directorate (Observer: item 5.5) |
| Dickie Langley (DL) | Assistant Director of IG (Digital Operations), Privacy, Transparency, and Trust (PTT), Deputy Chief Executive Directorate (Observer: items 4.1 and 4.2) |

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| Dr. Giulia Mantovani (GM) | Head of Data Linkage Hub, Transformation Directorate (Observer: item 4.1) |
| Karen Myers (KM) | AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Deputy Chief Executive Directorate |
| Azeez Oladipupo (AO) | Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.6) |
| Efrosini Setakis (ES) | Data Science Lead, Data Linkage Hub, Transformation Directorate (Presenter: item 4.1) |
| Suzanne Shallcross (SS) | Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.4) |
| Jodie Taylor-Brown (JTB) | Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: items 5.1 to 5.3) |
| INDEPENDENT ADVISER OBSERVERS IN ATTENDANCE | |
| Mr Christopher Barben (CB) | AGD independent adviser |
| Dr Jon Fistein (JF) | AGD independent adviser |
| Professor Jo Knight (JK) | AGD independent adviser |
| Dr. Mark McCartney (MM) | AGD independent adviser |
| AGD INDEPENDENT MEMBERS / NHS ENGLAND MEMBERS <u>NOT</u> IN ATTENDANCE: | |
| Name: | Role / Area: |
| Michael Chapman (MC) | NHS England member (Data and Analytics Representative) |
| Dr. Robert French (RF) | AGD independent member (Specialist Academic / Statistician Adviser) |
| Jon Moore (JM) | NHS England member (Data Protection Office Representative) |

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| 1 | <p>Welcome and Introductions:</p> <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 item 5.1 and part of item 5.3. 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</i>”</p> |
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| | three NHSE Members... ”, the Group agreed that, as there were two AGD NHS England members present, the meeting was still quorate for all agenda items and agreed to proceed on that basis. |
| 2 | Review of previous AGD minutes: The minutes of the AGD meeting on the 4 th September 2025 were reviewed and, after several minor amendments, were agreed as an accurate record of the meeting. |
| 3 | Declaration of interests: Claire Delaney-Pope noted that she had some involvement with the London Regional Secure Data Environment (SDE) as discussed as part of item 4.2 (NHS Research SDE Network – regional SDE / NHS England joint data service proposal), as part of her role within South-East London Integrated Care System (SEL ICS). It was agreed this did not preclude Claire from taking part in the discussion. |
| 4 BRIEFING PAPER(S) / DIRECTIONS: | |
| 4.1 | <p>Title: Subject of Care (SoC) Index – Briefing</p> <p>Presenter(s): Efrosini Setakis</p> <p>Observer(s): Michael Chapman, Dr. Giulia Mantovani and Dickie Langley</p> <p>The purpose of the briefing was to provide AGD with an overview of the Subject of Care (SoC) Index, which is a foundational data asset designed to be the single ‘source of truth’ for identifying individuals receiving NHS care. It underpins the development of a Single Patient Record (SPR) – a longitudinal, event-based dataset enabling the NHS to accurately and consistently link patient data across multiple systems and services.</p> <p>The SoC Index is built as a scalable, interoperable, and governed identity framework for all NHS England patients. It integrates fragmented patient identity data from multiple sources, ensuring each patient is represented once and only once.</p> <p>NHS England were seeking advice on the following point:</p> <ol style="list-style-type: none"> 1. Feedback regarding NHS England’s considerations on how we will use NHS data to inform a mastered subject of care index. <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 advised that they were supportive of the concept and the aspirations of the SoC.</p> <p>4.1.2 AGD suggested that 1) NHS England undertook patient and public involvement and engagement (PPIE) on the SoC; and 2) stakeholder engagement should include expertise from Integrated Care Boards (ICB) and Local NHS Trusts, and that AGD could provide further support on links into these stakeholder channels if required. The AGD NHS England Data and Analytics Representative said that they would engage / support the team with this programme of work.</p> <p>4.1.3 In addition, the NHS England SIRO Representative advised that the PPIE was a full workstream, with clear engagement points, and specific routes in for the patient view before developments occur.</p> |

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| | <p>4.1.4 AGD noted that there may be challenges around the ethnicity data and the accuracy of capturing this data correctly; and suggested that this could form part of the PPIE discussions.</p> <p>4.1.5 Acknowledging the inherent challenges in naming such a wide-ranging data set, AGD suggested that NHS England may wish to review the name of the data asset, noting that 'Subject of Care Index' may not be clear to the general public; and suggested that this could form part of the PPIE discussions.</p> <p>4.1.6 AGD queried how the work outlined would impact on an individual who has a sensitive data flag (s-flag); and suggested that this was considered / reviewed further.</p> <p>4.1.7 AGD suggested that the Data Protection Impact Assessment (DPIA) was updated to note and acknowledge the data / records that will not be part of the SoC and the risks associated with this, for example, public trust.</p> <p>4.1.8 AGD advised that they would welcome and support further / ongoing involvement with the SoC as this develops.</p> | |
| 4.2 | <p>Title: *NHS Research Secure Data Environment (SDE) Network – Regional SDE / NHS England joint data service proposal</p> <p>Title: **Framework for Secure Data Environments (SDE) when processing NHS England data</p> <p>Presenters: Claire Edgeworth and Laura Bellingham</p> <p>Observer: Dickie Langley</p> <p>*The purpose of the briefing was to provide AGD with an overview of how NHS England can work with the NHS Research Network of SDEs (hosted by NHS organisations and funded by NHS England) to ensure that national NHS data is made available for high-value research by trusted organisations: securely, on time, to quality, and in a way that supports the development of enhanced data services.</p> <p>**The purpose of the briefing was to provide AGD with permitted processing activities for each NHS England Regional SDE. It provides an overview of 1) a list of permitted processing activities; 2) a list of prohibited processing activities; and 3) controls that must be in place when processing NHS England data.</p> <p>NHS England were seeking advice on the following points:</p> <ol style="list-style-type: none"> 1. AGD are asked to review and note the proposal papers so detailed development work in line with next steps can proceed. <p>Outcome of discussion: AGD welcomed the briefing paper and made the following observations / comments:</p> <p>4.2.1 AGD noted the content of the briefing papers provided, and noted that whilst the work outlined was in the early stages of development, advised that they were broadly supportive in principle of the concept outlined.</p> <p>4.2.2 Concerns were expressed, however, that it may be a case of simply moving support for data applications and access from one part of the NHS to other parts of the NHS without any gains in speed of access or simplification of process. There was the related concern</p> | |

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| | <p>that having multiple SDEs poses challenges to transparency if a person has to find and consult numerous data use registers rather than one.</p> <p>4.2.3 AGD noted that there were risks to not having the data accessed centrally, and suggested that this was noted and acknowledged in the briefing paper(s) along with details of possible risks.</p> <p>4.2.4 AGD suggested that any transparency materials should be lay friendly and easy for the general public to understand the change to how data may be processed.</p> <p>4.2.5 An AGD independent member noted that they had made a number of specific comments in the briefing papers, and that these would be provided to the AGD Secretariat out of committee (OOC), to share with the presenters.</p> <p>ACTION: AGD Secretariat to share comments on the briefing by an AGD independent member with the presenters OOC.</p> | AGD Sec |
| 5 EXTERNAL DATA DISSEMINATION REQUESTS: | | |
| 5.1 | <p>Reference Number: NIC-698157-B0L5B-v0.2</p> <p>Applicant and Data Controller: Certara UK</p> <p>Application Title: “Fitness for purpose of data sources relevant for real-world data (RWD) studies on CAR-T cell therapy”</p> <p>Observers: Jodie Taylor-Brown and Dave Cronin</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 Group were broadly supportive of the purpose outlined in the application, but were not supportive of the application at this time and wished to draw to the attention of the SIRO the following significant comments, and suggested that the application be brought back to a future meeting:</p> <p>5.1.1 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 application form that contained summary information that, once finalised, would be transferred into the usual data sharing agreement (DSA) template.</p> <p>5.1.2 AGD welcomed the ‘application’ and advised that they were supportive of the purpose / aims of the study.</p> <p>5.1.3 AGD noted that both Certara UK and Certara France were involved with the work outlined, and noted that whilst it is feasible that the Data Controller is in the UK and the Data Processor is in France, suggested that NHS England seek further clarity on 1) the role / responsibilities of Certara UK; 2) the role / responsibilities of Certara France; 3) why Certara UK could not undertake the data processing; and 4) that Certara UK is the sole Data Controller in line with NHS England DARS Standard for Data Controllers.</p> | |

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| | <p>5.1.4 AGD, including the AGD Caldicott Guardian Team Representative, expressed concerns on the large volume of data requested via a data extract, and suggested that 1) NHS England clarify with the applicant why so many years of data had been requested, in line with the NHS England DARS standard for data minimisation and UK General Data Protection Regulation (UK GDPR), noting that data had been requested from 2013, however the application was looking at those who had been administered a drug from 2018; 2) to update the NHS England DARS internal application assessment form with further clarification of what, if any, data minimisation would be undertaken, in line with the NHS England DARS standard for data minimisation; and 3) NHS England clarify with the applicant whether all / some of the data processing could be undertaken in NHS England's Secure Data Environment (SDE).</p> <p>5.1.5 AGD suggested that section 4.2 (Purpose for Processing) would need updating with further clarification of 1) the objective for processing in line with the NHS England DARS Standard for Objective for Processing; 2) the benefits that would flow from the processing of the data, in line with NHS England DARS Standard for Expected Measurable Benefits.</p> <p>5.1.6 AGD suggested that the statement in section 4.5 (Processing Activities) "<i>Personnel are prohibited from downloading or copying data to local devices</i>", was reviewed and updated as may be necessary, noting that this precludes the applicant from exporting results.</p> <p>5.1.7 AGD noted the generic outputs in section 4.7 (Expected Outputs) and suggested that this was reviewed and updated as may be appropriate, in line with NHS England DARS Standard for Expected Outcomes.</p> <p>5.1.8 AGD noted that whilst this application did have unique arrangements, this was still a commercial company undertaking work from which there may be direct or indirect benefits flowing; and suggested that 1) NHS England explore this further with the applicant, in line with NHS England DARS Standard for Commercial Purpose; and 2) the balance between public and commercial benefits was proportionate, in line with NHS England DARS Standard for Commercial Purpose and / or the NDG guidance on benefits.</p> <p>5.1.9 AGD noted and commended the work undertaken by NHS England's Data Access Request Service (DARS) on the NHS England DARS internal application assessment form.</p> <p>5.1.10 AGD noted that there was a commercial aspect to the application.</p> | |
| <p>5.2</p> | <p>Reference Number: NIC-782158-W5V8C-v0.3</p> <p>Applicant and Data Controller: Synapsys IQ</p> <p>Application Title: "Informing and supporting prescribing behaviour, decision making and research with medicines dispensed in primary care and NHS hospital activity"</p> <p>Observers: Jodie Taylor-Brown and Dave Cronin</p> <p>Linked application: This application is linked to NIC-692602-Q6P4.</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> | |

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| <p>Outcome of discussion: The majority of the Group (four AGD independent members and two AGD NHS England members) were supportive of the application if the following substantive comments were addressed; a minority of the Group (one NHS England member) was supportive of the application as is. The Group wished to draw to the attention of the SIRO the following substantive comments:</p> <p>5.2.1 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 application form that contained summary information that, once finalised, would be transferred into the usual data sharing agreement (DSA) template.</p> <p>5.2.2 AGD noted that data requested under NIC-782158-W5V8C had previously flowed under NIC-692602-Q6P4 for NeoHealthHub Limited; however, noted that due to personnel / organisational changes, this data was now being requested under a new application. AGD noted the careful analysis and due diligence by NHS England on this new organisation applying for data; and suggested that that NHS England satisfy itself that the work under NIC-692602-Q6P4 1) generated sufficient benefits; 2) the balance between public and commercial benefits was proportionate, in line with NHS England DARS Standard for Commercial Purpose and / or the NDG guidance on benefits; and 3) the Annual Confirmation Report (ACR) had been completed / submitted.</p> <p>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.2.3 AGD noted the restriction that the data cannot be used for promotional or commercial activities by pharmaceutical companies; and suggested that this was reviewed to ensure that the proposed business model aligns with this, for example, data won't be used for commercial activities by pharmaceutical companies. AGD advised that, if the appropriate safeguards were in place, they would be supportive of pharmaceutical companies receiving bespoke analysis.</p> <p>5.2.4 AGD noted that Synapsys IQ had undertaken an internal ethical review, and that the relevant paper from this review had been provided as a supporting document prior to the meeting. Some of the AGD members suggested that, for consistency and in line with other delegated decision making type models, that NHS England consider whether or not appropriate terms of reference should be provided and reviewed; and that 1) as a minimum these should include the review of whether the balance between public and commercial benefits was proportionate, was embedded; and 2) consideration should be given by the applicant to having a lay member as part of the ethics group, to provide a balance to the pharmaceutical member views.</p> <p>5.2.5 AGD suggested that section 5(a) (Objective for Processing) of the application was updated to include 1) the ethical review as outlined in section 4.9 (Commercial Benefits Evaluation) of the NHS England DARS internal application form; 2) a brief summary of the commercial aspects, in line with NHS England DARS Standard for Objective for Processing; and 3) the balance between public and commercial benefits was proportionate, in line with NHS England DARS Standard for Commercial Purpose and / or the NDG guidance on benefits.</p> |
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| | <p>5.2.6 AGD suggested that the citation special condition in section 6 (Special Conditions) included an update to ensure that this flows down to other contracts, in line with NHS England DARS Standard for Special Conditions.</p> <p>5.2.7 Separate to this application: AGD suggested that NHS England consider the involvement of AGD with the development of guidance on export from the NHS England Secure Data Environment (SDE), noting, under this application, that whilst outputs from the SDE would be aggregated with small numbers suppressed, it would be possible to compare one of the outputs with another, which would yield small number results, which may be disclosive.</p> <p>5.2.8 AGD noted that there was a commercial aspect to the application.</p> | |
| 5.3 | <p>Reference Number: NIC-782449-Z6G3F-v0.2</p> <p>Applicant and Data Controller: University College London (UCL)</p> <p>Application Title: “Generation New Era”</p> <p>Observers: Jodie Taylor-Brown and Dave Cronin</p> <p>Linked application: This application is linked to NIC-482185-K8G0F.</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 Group (with one AGD independent member dissenting) were supportive of the application and wished to draw to the attention of the SIRO the following substantive comment.</p> <p>5.3.1 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 application form that contained summary information that, once finalised, would be transferred into the usual data sharing agreement (DSA) template.</p> <p>5.3.2 AGD noted that two NHS England DARS internal application forms had been provided for 1) the flow of pseudonymised Birth Notifications and Civil Registration Births data for all babies born between October 2025 - December 2026 (phase 1a/b); and 2) the flow of identifying details from Personal Demographics Service (PDS), for the sample that was established using the Birth Notifications and Civil Registration Births data processed as part of phase 1a/b (phase 2). It was noted that both flows of data would have separate applications / DSAs. The Group noted that due to time constraints, advice would be provided on phase 2 only as part of this review; and that the NHS England SIRO Representative may wish to give a view on phase 1a/b.</p> <p>5.3.3 AGD noted that, prior to the meeting, an AGD independent member had raised a query, in respect of the telephone follow-up survey that took place with 449 participants after the main fieldwork had been completed; and noting that 89% of participants were generally happy with the opt-out approach; and queried if the 11% of those who participated were unhappy with the opt-out approach, what they were asked and if there was any information</p> | |

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| | <p>concerning the views of those who declined to take part. AGD noted that they had been provided with a detailed response prior to the meeting, and advised that the majority of the Group were satisfied with the rate of responses provided and the subsequent response to the queries raised; however, one AGD independent member noted that in the follow-up survey, 11% had expressed concerns with the opt-out approach to 'door step' visits. Given all of the survey participants had agreed to take part in the study, it raised the question for that AGD independent member of what proportion of those that had declined had concerns given 50,000+ families will be contacted, the 11% rate suggested over 5,000 families would have concerns with the approach.</p> <p>5.3.4 AGD suggested that section 5(b) (Processing Activities) was updated to include a brief outline of the restrictions designed, to ensure there was no processing of sensitive data, including, but not limited to, those individuals adopted.</p> <p>5.3.5 AGD noted and commended the work undertaken by NHS England's Data Access Request Service (DARS) and the applicant to address the previous points raised on NIC-482185-K8G0F.</p> <p>5.3.6 No AGD member noted a commercial aspect to the application.</p> | |
| 5.4 | <p>Reference Number: NIC-784100-W4B7T-v0.4</p> <p>Applicant and Data Controller: The University of Manchester</p> <p>Application Title: "Childhood Arthritis Prospective Study (CAPS): NHS data linkage"</p> <p>Observer: Suzanne Shallcross</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 comment:</p> <p>5.4.1 AGD noted that, prior to the meeting, an AGD independent member had raised a query, in respect of the scope of the consent and assent that was previously taken; and whether the s251 support covers data from the birth of the participant. AGD suggested that the applicant confirm with Health Research Authority Confidentiality Advisory Group (HRA CAG), that the s251 supports this; and that section 5(a) (Objective for Processing) is updated as may be appropriate.</p> <p>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.4.2 AGD noted it is an accepted practice for NHS England to allow the applicant to minimise the data themselves, where justified. Noting in this case the applicant would be minimising to the date of diagnosis, the Group suggested that NHS England establish whether there was any other means that this could be done by NHS England, in line with NHS England DARS standard for data minimisation.</p> | |

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| | <p>5.4.3 AGD noted that some of the Group had issues accessing the study website; and suggested that the applicant 1) ensure that the transparency materials are available to the public; and 2) consider how the transparency materials are targeted to the original cohort to ensure they are able to obtain information about current / recent processing.</p> <p>5.4.4 No AGD member noted a commercial aspect to the application.</p> | |
| 5.5 | <p>Reference Number: NIC-779200-S6R2D-v0.4</p> <p>Applicant and Data Controller: University College London (UCL)</p> <p>Application Title: “Cancer long-term follow-up study of clinical trial participants”</p> <p>Observer: Suzanne Hartley</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 ‘*PATCH’ trial and the ‘**RAMPART trial’; and were supportive of the ‘Add Aspirin’ trial if the following substantive comments were addressed, and wished to draw to the attention of the SIRO the following substantive comments:</p> <p><i>*‘Prostate Adenocarcinoma: TransCutaneous Hormones’ Trial (PATCH)</i></p> <p><i>**‘Renal Adjuvant MultiPle Arm Randomised’ Trial (RAMPART)</i></p> <p>5.5.1 AGD noted and commended the work undertaken by NHS England’s Data Access Request Service (DARS) on the NHS England internal consent review; and agreed that there was a legal gateway in consent for the ‘PATCH’ trial and the ‘RAMPART trial’.</p> <p>5.5.2 AGD noted that whilst the earlier versions of the consent materials for the ‘Add Aspirin trail’ could be improved if consent was being sought now, agreed that, on balance, there was a gateway in consent if the applicant can assure NHS England that, for all of the cohort members where data was flowing, that they have completed the relevant optional consent items, meaning their data was handled and disseminated with a legal gateway in consent.</p> <p>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.5.3 AGD noted that section 5(a) (Objective for Processing) stated that “...<i>data will only be provided from the date they joined the trial</i>”; however, noted that section 5(b) (Processing Activities) does not state this as part of the data fields flowing. AGD suggested that this was reviewed and updated as may be necessary to reflect the correct information.</p> <p>5.5.4 AGD noted that “AstraZeneca LP” were noted as a funder in section 5(a); however, suggested that NHS England clarify with the applicant whether AstraZeneca had any connection in any of the drugs that may be studied; and suggested that section 5 (Purpose / Methods / Outputs) was updated to reflect the outcome of this discussion for transparency.</p> <p>5.5.5 AGD advised that they were supportive of joining the three trails together under one application for ease of process and efficiency and contractual arrangements.</p> | |

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| | <p>5.5.6 AGD noted there may be a commercial aspect to the application, pending responses to the queries raised.</p> | |
| 5.6 | <p>Reference Number: NIC-772633-Y3K3T-v0.5</p> <p>Applicant and Data Controller: University College London (UCL)</p> <p>Application Title: “OPTICAL: Optimising Paediatric Transition to Intensive Care for AduLts”</p> <p>Observer: Azeez Oladipupo</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 and wished to draw to the attention of the SIRO the following comments:</p> <p>5.6.1 AGD noted that date of death was flowing, and queried whether this had been assessed to determine whether this would in fact make the data identifiable and would therefore be confidential patient data; and suggested that updates with a statement regarding the determination were made to 1) the NHS England Data Access Request Service (DARS) internal application assessment form; and 2) section 5a (Objective for Processing).</p> <p>5.6.2 AGD noted that the Health Research Authority Confidentiality Advisory Group (HRA CAG) minutes from the 30th May 2024 stated that “<i>The CAG requested clarity on the length of time NHS England would keep the identifier key. The applicant clarified that the duration would depend on NHS England’s internal policies, however, would anticipate a couple months</i>”; and suggested that NHS England clarify in section 5 (Purpose / Methods / Outputs) how long the identifier key would be kept.</p> <p>5.6.3 AGD queried what will happen if cohort members expressed a desire to opt-out after data had flowed; and suggested that NHS England discuss this further with the applicant, and that section 5(a) was updated with further information.</p> <p>5.6.4 AGD noted the statement in section 5(a) could be reworded to avoid referring to “<i>learning disabilities</i>” as a health problem, for example: “<i>...this is particularly challenging for conditions or health problems...</i>”.</p> <p>5.6.5 AGD noted and commended the work undertaken by NHS England’s Data Access Request Service (DARS) on the application and NHS England DARS internal application assessment form.</p> <p>5.6.6 No AGD member noted a commercial aspect to the application.</p> | |
| 6 INTERNAL DATA DISSEMINATION REQUESTS: | | |
| <i>There were no items discussed</i> | | |
| 7 EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL | | |

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| <i>There were no items discussed</i> | | |
| 8 OVERSIGHT AND ASSURANCE | | |
| <i>There were no items discussed</i> | | |
| 9 AGD OPERATIONS | | |
| 9.1 | Risk Management Framework AGD Chair asked for an update on the risk management framework referred to in the Group's Terms of Reference. The NHS England SIRO Representative updated the Group that there was ongoing work with this outstanding action, and that a further update would be provided in the coming weeks. ACTION: The NHS England SIRO Representative to provide a written response to AGD on the progress in September 2025, of the risk management framework. | SIRO Rep |
| 9.3 | AGD Stakeholder Engagement Federated Data Platform A brief update was given by the Group's representative on the Federated Data Platform Data Governance Group. | |
| 9.4 | AGD Project Work <i>There were no items discussed</i> | |
| 10 Any Other Business | | |
| 10.1 | AGD independent member contractual arrangements Following on from the discussion at the AGD meeting on the 4 th September 2025, in respect of AGD independent member contractual arrangements with NHS England; the Group were advised by the NHS England SIRO Representative, that further discussions had taken place internally on this issue, and that an update would be shared with AGD independent members as soon as possible, noting that the new arrangements are intended to start from the 1 st October 2025. | |
| 10.2 | Knowledge Sharing Workshop AGD noted that a knowledge sharing workshop was taking place on the 6 th October 2025, with NHS England, Health Research Authority (HRA), HRA Confidentiality Advisory Group (HRA CAG) and AGD members. AGD agreed that Paul Affleck would undertake some work prior to the workshop, to support the discussion, including, but not limited to, pulling together some 'use cases' to discuss. It was also agreed that the work being undertaken by Paul would be discussed at the AGD meeting on the 2 nd October 2025. ACTION: Paul Affleck to pull together some 'use cases' for the workshop on the 6 th October 2025. | PA |

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| | ACTION: AGD Secretariat to add 'Workshop use cases' to the internal AGD forward planner on the 2 nd October 2025. | AGD Sec |
| 10.3 | <p>Knowledgebase Review Work Package update</p> <p>AGD noted that as part of the Knowledgebase Review Work Package update discussion at the AGD meeting on the 4th September 2025; and as discussed previously at the AGD meeting on the 18th July 2024; the Group had still not received a template for “archiving” applications or further details of a new NHS England Data Access Request Service (DARS) Archiving Standard.</p> <p>AGD noted that a “Q&A Variation of DSA for Archiving Purposes” Update for Archiving document was referred to in the Knowledgebase document. If the wording is correct, AGD asked that this be provided to AGD for review, otherwise the wording should be updated.</p> <p>ACTION: AGD Secretariat to add 'archiving documents update' to the internal AGD forward planner.</p> <p>ACTION: The NHS England SIRO Representative to confirm and provide a document for later agenda if required</p> | AGD Sec SIRO Rep |
| <p>Meeting Closure</p> <p>As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.</p> | | |