

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 19th September 2024

09:00 – 15:10

(Remote meeting via videoconference)

AGD INDEPENDENT / NHS ENGLAND MEMBERS IN ATTENDANCE:	
Name:	Role:
Paul Affleck (PA)	AGD independent member (Specialist Ethics Adviser)
Claire Delaney-Pope (CDP)	AGD independent member (Specialist Information Governance Adviser)
Kirsty Irvine (KI)	AGD independent member (Chair)
Andrew Martin (AM)	NHS England member (Data Protection Office Representative (Delegate for Jon Moore))
Dr. Jonathan Osborn (JO)	NHS England member (Caldicott Guardian Team Representative)
Jenny Westaway (JW)	AGD independent member (Lay Adviser)
Miranda Winram (MW)	AGD independent member (Lay Adviser)
Tom Wright (TW)	NHS England member (Data and Analytics Representative (Delegate for Michael Chapman))
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	Role / Area:
Ricky Brooks (RB)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 6.4)
Garry Coleman (GC)	NHS England SIRO Representative
Suzanne Hartley (SH)	Senior Assurance Manager, Data Access and Partnerships, Transformation Directorate (Observer: Item 6.5)
Dickie Langley (DL)	Assistant Director of IG (Digital Operations), Privacy, Transparency, and Trust (PTT), Delivery Directorate (Observer: item 5.1)
Narissa Leyland (NL)	Head of Data Governance and Assurance, Data Access & Partnerships, Transformation Directorate (Presenter: item 5.1)

Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Delivery Directorate
Tania Palmariellodiviney (TP)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: part of item 6.1)
Suzanne Shallcross (SS)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 6.5)
Jodie Taylor-Brown (JTB)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 6.1)
James Watts (JW)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: items 6.3)
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Delivery Directorate
AGD INDEPENDENT MEMBERS / NHS ENGLAND MEMBERS <u>NOT</u> IN ATTENDANCE:	
Name:	Role / Area:
Michael Chapman (MC)	NHS England member (Data and Analytics Representative)
Prof. Nicola Fear (NF)	AGD independent member (Specialist Academic Adviser)
Dr. Robert French (RF)	AGD independent member (Specialist Academic / Statistician Adviser)
Jon Moore (JM)	NHS England member (Data Protection Office Representative)

1	Welcome and Introductions: The AGD Chair welcomed attendees to the meeting.
2	Review of previous AGD minutes: The minutes of the AGD meeting on the 12 th September 2024 were reviewed and, after several minor amendments, were agreed as an accurate record of the meeting.
3	Declaration of interests: Claire Delaney-Pope noted a professional link to the London NHS Research Secure Data Environment (SDE) Network (NIC-616054-M4C8K NHS Greater Manchester Integrated Care Board (ICB)), as part of her role at the South-East London Integrated Care System. It was agreed this did not preclude Claire from taking part in the discussion on this briefing paper.

	<p>Claire Delaney-Pope noted a professional link to King's College London (NIC-729128-M5N1F) as part of her role at South London and Maudsley NHS Foundation Trust. It was agreed this did not preclude Claire from taking part in the discussion on this application.</p> <p>Dr. Jonathan Osborn made a declaration of interest with NIC-209200-S9H5R Royal College of Psychiatrists), as part of his role as Trustee of the Doctors in Distress charity; but noted no specific connections with the application or staff involved and it was agreed that this was not a conflict of interest.</p> <p>Tania Palmariellodiviney noted a professional link to NHS Integrated Care Boards (ICBs) (NIC-616054-M4C8K) as part of another role outside of NHS England. It was agreed this did not preclude Tania from taking part in the discussion on this application.</p> <p>It was noted during the ratification of these minutes, that Tania had not declared an interest when discussing the '<i>Research for Commissioners' Sub-Licence Precedent</i>' on the 12th September 2024, and it was agreed that the 12th September 2024 minutes would be amended as appropriate, and after they had been published with a "<i>subsequent to the meeting</i>" inserted in the declaration of interest section of the 12th September 2024 minutes.</p>
4	<p>AGD Action Log:</p> <p><i>The action log was not discussed.</i></p>
5 BRIEFING PAPER(S) / DIRECTIONS:	
5.1	<p>Title: NHS England Secure Analytics Service Pilot Directions 2024</p> <p>Presenter: Narissa Leyland</p> <p>Observer: Dickie Langley</p> <p>Previous Review: Linked to the 'OpenSAFELY: all research analyses and participants who have consented for studies Briefing Paper' discussed at the AGD meeting on the 28th September 2023.</p> <p>NHS England and GP practices were previously required under regulation 3(4) of the Health Service (Control of Patient Information) Regulations 2002 (COPI Regulations) and the Covid-19 Public Health Directions to provide a secure analytics service for users, approved by or on behalf of NHS England to run queries on GP and NHS England pseudonymised patient data exclusively to support COVID-19 purposes.</p> <p>Under the NHS England Secure Analytics Service Pilot Directions 2024, NHS England will deliver the Secure Analytics Service Pilot system for purposes wider than COVID-19 research through the development of the existing technology and the established service.</p> <p>NHS England were seeking advice on the following points:</p> <ol style="list-style-type: none"> 1. The expansion of scope under the new Pilot Direction to include all research analyses (including service evaluation, clinical audit and health surveillance),

supported by the GP profession (British Medical Association and Royal College of General Practitioners (RCGP)).

Outcome of discussion: AGD welcomed the Direction / briefing paper and made the following observations / comments:

In response to point 1 above:

5.1.1 AGD noted that they were supportive of the purpose of the Direction and the potential public benefits that this may bring.

5.1.2 It was noted by AGD that the documents provided with the Direction were subject to ongoing internal governance and therefore still in draft; and may be subject to further changes.

5.1.3 AGD noted that when the '*OpenSAFELY: all research analyses and participants who have consented for studies – Briefing Paper*' was discussed by interim AGD on the 28th September 2023, a number of points had been made that were still relevant to this Direction and accompanying papers, including, but not limited to, transparency from the perspective of citizens whose data was being used; ongoing communication with the GP profession, including the GP Data Protection Officers (DPOs); and further stakeholder engagement via already established networks within NHS England, for example, the DPO webinars with GP DPOs. AGD suggested that NHS England review the advice given in September 2023 in conjunction with the advice given at this meeting.

5.1.4 It was noted by NHS England that the ongoing engagement / transparency would be undertaken concurrently with the progression / launch of the Direction; however, it was suggested by the Group, that the Direction does **not** progress further without a communication / engagement plan being in place.

5.1.5 In respect of the Secure Analytics Service Pilot system, AGD made a number of suggestions, including, but not limited to, developing clear metrics; clarifying what 'success' looks like and how this will be measured; and having a clear justification of the three-year timeframe for the pilot.

5.1.6 Noting the reference to the involvement of "*Citizen juries*" in the Direction, the Group suggested that the involvement / support of the juries was more limited than the text suggested; and advised that the relevant text was updated / caveated to reflect this.

5.1.7 The Group noted that public consultation on this project would be more contemporary and focused than the citizen jury work. They noted that planned public consultation had been delayed, and were supportive of this being progressed as soon as possible, so that the Direction and supporting documents could reflect any relevant feedback.

5.1.8 AGD noted the potential inconsistency in the Direction, in respect of the role of the General Practice Extraction Service (GPES) Data for Pandemic Planning and Research (GDPPR) – Profession Advisory Group (PAG), and their role / governance

	<p>with other GP data as outlined in their published Terms of Reference; and made reference to NHS England's transparency on this. It was noted that there needs to be consistency with the handling of data and if there is an inconsistency, then this should be clearly justified.</p> <p>5.1.9 AGD noted point 5.1.4(ii) of the Direction that requires research studies to have appropriate Research Ethics Committee (REC) review prior to being permitted access to the Service. As previously raised in September 2023, this may present a practical issue as the Health Research Authority (HRA) may not judge all such studies within their remit. It was suggested that obtaining HRA database approval was explored.</p> <p>5.1.10 AGD noted that the National Director Briefing Note and the Data Protection Impact Assessment (DPIA), provided as supporting documents, referred to confidential data; and advised that this would suggest that the data is being handled as 'identifying' data, however, AGD noted that the data would be pseudonymised at source. AGD noted that, whilst they were not questioning the legal gateway, this approach as outlined in the briefing paper may be inconsistent with how NHS England handles other pseudonymised datasets and suggested that this was reviewed by NHS England. AGD suggested that any implications this may have, for example, in respect of the duty of confidence; and the stance on the level of processing required for data to cease to be confidential but remain personal be explored and explained further.</p> <p>5.1.11 AGD noted that NHS England shared some updated wording in-meeting, in respect of paragraph 5.1.2 of the draft Direction letter provided as a supporting document. The Group discussed the updated wording and, notwithstanding it was a non-exhaustive definition, suggested that this was updated to also include reference to "<i>audit</i>", if this was already known to be a likely activity.</p> <p>5.1.12 In addition, AGD suggested that any references to "<i>Research</i>" in the draft Direction letter were either amended to "<i>research</i>"; or that the term "<i>Research</i>" was given a definition as a defined term.</p> <p>5.1.13 AGD advised that they would welcome a further discussion on the Direction and accompanying documents at a future meeting.</p>	
6 EXTERNAL DATA DISSEMINATION REQUESTS:		
6.1	<p>Reference Number: NIC-616054-M4C8K-v2.2</p> <p>Applicant: NHS Greater Manchester Integrated Care Board (ICB)</p> <p>Application Title: DSfC - NHS Greater Manchester Integrated Care Board - Commissioning / Invoice Validation / Risk Stratification and Research</p> <p>Observer: Jodie Taylor-Brown / Tania Palmariellodiviney</p>	

Previous Reviews: The briefing paper was previously presented / discussed at the AGD meeting on the 12th September 2024.

Application: This was an amendment application.

The purpose of this application is for access to pseudonymised commissioning datasets, identifiable risk stratification datasets, and identifiable invoice validation datasets to support the ICB's use of data for commissioning purposes.

The amendments are **1)** to add 'research' as an additional purpose; and **2)** the removal of two Data Processors, Deloitte LLP and Rochdale Council.

NHS England were seeking advice on the following points only:

1. The updated template; and,
2. A reusable decision for other ICB agreements where this amendment is required.

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

Outcome of discussion: AGD were supportive of the application and wished to draw to the attention of the SIRO the following comments:

AGD were supportive of the reusable decision subject to a number of substantive points and wish to draw to the attention of the SIRO the following comments:

AGD noted that they had been provided with a curated set of documentation and noted that they would be providing observations based on these documents.

In response to points 1 and 2:

6.1.1 AGD made a number of comments / observations relating to this application, that would also need addressing in the Precedent presented to the Group at the AGD meeting on the 12th September 2024; and before a reusable decision could be used for ICB applications.

6.1.2 AGD noted that following the discussion of the 'Research for Commissioners' Sub-Licence Precedent' at the AGD meeting on the 12th September 2024; an AGD independent member had provided some additional comments / feedback out of committee to NHS England. One point that was raised as part of this feedback, was whether the ICB's Data Access Committee (DAC) could have the role of initially reviewing / supporting requests for sub-licenses (rather than approving), and then the approval could be made by the ICB's SIRO. The Group supported the point made and suggested that this was given further consideration by NHS England, both in relation to the Precedent **and** this application.

6.1.3 AGD suggested a number of governance arrangements for the DACs, including, but not limited to, the governance in respect of how projects were selected, for example, Terms of Reference, covering assessment of benefits to health and social care; an assessment of the commercial benefits and proportionate balancing with public benefits; oversight of the nature of the funding; data

	<p>minimisation; purpose limitation; compliance with UK General Data Protection Regulation (UK GDPR) principles; and compliance with the NHS England data sharing agreement (DSA). In addition, the Group suggested that details of the membership of the DAC, the DAC's terms of reference, and minutes were published. The Group supported the points made, and suggested that this was given further consideration by NHS England, both in relation to the Precedent and this application.</p> <p>6.1.4 In addition, it was suggested that NHS England have the ability to attend a DAC as may be appropriate; and that NHS England should be notified of any potential changes to the suite of governance documents, and provide written approval to the applicant on any changes to the suite of documents associated with this data sharing agreement (DSA) and the sub licensing.</p> <p>6.1.5 It was suggested that a special condition be added to section 6 (Special Conditions) of the application reflecting the governance arrangements outlined; and that the Precedent was also updated to reflect this addition to the data sharing agreements (DSA).</p> <p>6.1.6 AGD suggested that there should be more prescriptive governance arrangements for those DACs that were not fully developed / less mature than other DACs; and suggested that NHS England give further consideration as to how they can support these DACs.</p> <p>6.1.7 AGD suggested that NHS England give further consideration to having / formalising a mechanism to encompass the 'freedom to speak up' route / process for individuals and the ICBs, should they have any concerns about any aspect of the DAC.</p> <p>6.1.8 AGD suggested that all references in the Precedent and this application, to the ICBs "<i>commissioning</i>" the research were updated to state "<i>commissioning or facilitated</i>", for example "<i>The research is commissioned or facilitated by the ICB...</i>".</p> <p>6.1.9 AGD noted that the National Data Opt-out (NDO) was being applied locally to data used for the purpose of research; and noting that this data was pseudonymised, suggested that further clarification be provided in the application as to why the NDO was being applied and that it complied with the NHS England NDO policy.</p> <p>6.1.10 AGD noted the reference in the application to a sub-Data Processor; and suggested that this was explored further by NHS England, to ensure that all of the processing and security arrangements were in place, for example incorporating by reference the relevant terms of the NHS England Data Sharing Framework Contract (DSFC) in any relevant security documents, to ensure NHS England have the ability to undertake an audit if required on any organisation named on the DSA.</p> <p>6.1.11 AGD noted the statement in section 5(a) "<i>...may request re-identification for that direct care purpose...</i>"; and suggested further clarification on this point.</p>	
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6.2	<p>Reference Number: NIC-147982-J7KGV-v8.2</p> <p>Applicant: University of Liverpool</p> <p>Application Title: The Roy Castle Lung Cancer Research Programme, Liverpool Lung Project</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 23rd February 2023.</p> <p>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 23rd July 2020, 21st June 2018, 12th April 2018 and the 20th July 2017.</p> <p>The item was withdrawn by NHS England's Data Access Service (DAS) prior to the meeting.</p>	
6.3	<p>Reference Number: NIC-729128-M5N1F-v0.3</p> <p>Applicant: King's College London</p> <p>Application Title: The South London Stroke Register: Preliminary List Clean</p> <p>Linked applications: This application is linked to NIC-696708- J3L1R.</p> <p>Application: This was a new application.</p> <p>The purpose of the application is to derive a 'list clean'.</p> <p>The overall purpose of the application is for King's College London and Guy's and St Thomas' NHS Foundation Trust, to access the NHS England data, for the purpose of a research programme - The South London Stroke Register (SLSR): Improving the lives of stroke survivors with data. The SLSR is a long-running observational study which investigates the incidence, care, and outcomes of stroke in a geographically defined area of London.</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>6.3.1 AGD queried the information in section 1.8 (comments) of the NHS England Data Access Service (DAS) internal application assessment form, that the National Data Opt-out (NDO) would be applied to the entire cohort; and suggested that NHS England satisfy themselves that this aligned with the National Data Opt-out (NDO) policy, for example, should this only be applied to those participants included under consultee advice.</p>	

	<p>6.3.2 In addition, it was suggested by the Group that section 3(c) (Patient Objections) of the application was updated as necessary to reflect the correct / factual information with regard to NDOs, in line with the NHS England DAS Standard for Duty of Confidentiality.</p> <p>6.3.3 Separate to the application: AGD advised NHS England, that they would welcome the opportunity to feed into any updates to the NHS England DAS Standard for Duty of Confidentiality / guidance.</p> <p>ACTION: AGD NHS England Data and Analytics Representative and NHS England SIRO Representative to engage with AGD as may be required to feed into updates to the NHS England DAS Standard for Duty of Confidentiality / guidance.</p> <p>6.3.4 Noting the multiple Data Security and Protection Toolkit (DSPT) entries that King’s College London have, that section 1(b) (Data Controllers) was checked to ensure the correct DSPT was listed within the application.</p> <p>6.3.5 AGD reiterated a point from the 3rd August 2023 AGD meeting (point 5.1.4) where NIC-696708- J3L1R was discussed. In relation to those consented on materials pre-2022, it was suggested that further work was undertaken with the Stroke Research Patients and Family Group (SRPFG) to check their understanding of the processing of the data, accessibility, and newsletter updates.</p>	D&A / SIRO Reps
6.4	<p>Reference Number: NIC-736273-V5T6V-v0.2</p> <p>Applicant: Adelphi Group Limited</p> <p>Application Title: Incidence, healthcare resource utilisation and mortality of invasive fungal infections (IFI) in hospitalised paediatric patients with and without ever having had an IFI-related hospitalisation in England: a retrospective cohort study using HES data</p> <p>Observer: Ricky Brooks</p> <p>Application: This was a new application.</p> <p>The primary objective of the application is to estimate the incidence of IFI-related hospitalisation among all hospitalised paediatric patients (aged 0-17 years) in England. The primary objective will be further stratified by age group, sex, geographic region (hospital provider region), time period of hospitalisation, length of stay in hospital, specific diagnoses associated with immunosuppression, and socioeconomic status using the index of multiple deprivation (IMD).</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 substantive comments:</p>	

<p>6.4.1 AGD noted that this application was a first of type review under the ‘AGD first’ concept; and advised that they were supportive of having sight of these applications at an earlier stage than usual.</p> <p>6.4.2 Notwithstanding this, the Group noted that at the AGD meeting on the 8th August 2024 NIC-703431-L0W3R <i>“Incidence and characteristics of Invasive Fungal Infections in patients treated with Systemic Anti-cancer Therapies (SACT) in England”</i> had been reviewed, which was an Adelphi Group Limited application, with a similar subject matter and the same commercial parties, raising the same commercial issues. It was suggested by the Group, that both NIC-736273-V5T6V and NIC-703431-L0W3R were reviewed in tandem, including, but not limited to, ensuring the points made on the 8th August 2024 on NIC-703431-L0W3R were addressed in NIC-736273-V5T6V; and that both applications were progressed / signed together.</p> <p>6.4.3 In addition, although unlikely given the different ages of targeted data subjects, AGD queried whether there was any duplication / overlap of data flowing under NIC-736273-V5T6V and NIC-703431-L0W3R; and suggested that this was explored by DAS, in line with NHS England DAS standard for data minimisation; including whether there were any options to streamline the data flow.</p> <p>6.4.4 Separate to this application: AGD suggested that the AGD NHS England Data and Analytics Representative liaise with colleagues in DAS, to ensure similar applications from the same organisations are worked on / progressed more collaboratively within NHS England and that specific feedback about commercial applicants is handled in a more coordinated fashion.</p> <p>ACTION: AGD NHS England Data and Analytics representation to work with colleagues in DAS to ensure similar applications from the same organisation, and/or specific feedback about commercial parties, are worked on / progressed more collaboratively.</p> <p>6.4.5 AGD noted that Article 6(1)(f) (<i>legitimate interests</i>) of the UK General Data Protection Regulation (UK GDPR) had been cited as the legal basis for processing, but the application did not clearly explain the controller’s legitimate interests in respect of the proposed data processing. The Group suggested that the applicant should provide a copy of their Legitimate Interests Assessment to NHS England in order to clarify the relevant legitimate interests being relied on, so that the application could be updated to include this information.</p> <p>6.4.6 It was suggested that section 5(a) (Objective for Processing) of the application was updated to be clear that Pfizer Limited in the future may or may not develop a drug, or repurpose an existing drug, in order to meet an unmet need identified by this research.</p> <p>6.4.7 Noting the commercial nature of the applicant and the funder, it was suggested that more information was provided in section 5(a) and section 5(d) (Benefits) of the application, as to the commercial benefits to both organisations, and whether there</p>	<p>D&A Rep</p>
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is a proportionate balance between public and commercial benefit, in line with [NHS Digital DAS Standard for Expected Measurable Benefits](#) and [NHS England's DAS Standard for Commercial Purpose](#) and the National Data Guardian (NDG) [guidance on benefits](#).

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

6.4.8 AGD noted the statement in section 5(a) of the application “*Adelphi Group Limited, in the form of their subsidiary Adelphi Real World...*”; and suggested that NHS England satisfy themselves that the correct legal entity (or entities) was named as the Data Controller(s), in line with [NHS England DAS Standard for Data Controllers](#).

6.4.9 AGD noted the information in the Data Access Service (DAS) internal application assessment form about the named Professor and their role, i.e. that they will have access to the derived outputs only and may therefore have an honorary contract; and suggested that NHS England explore this further with the applicant, to clarify that the Professor was not determining the purpose and means of processing and were therefore not carrying out any data controllership activities in line with the [NHS England DAS Standard for Data Controllers](#). It was noted that if an honorary contract was required, that this aligned with [NHS England's DAS Standard for Honorary Contracts](#); or that the application was updated with any additional Data Controllers.

6.4.10 AGD queried the information in section 5(b) (Processing Activities) to “*both collaborators*” and “*Box.Com Ltd*”; and suggested that this was reviewed and updated, or the reference to joint processing was removed.

6.4.11 The Group discussed whether the research was identifying an unmet need at the exclusion of other groups which may benefit from the research and noted that the age range for the cohort was 0-17 years; and asked that further information was provided in section 5(a) of the application as to why this age range had been selected and why other age groups had been excluded, noting that this was currently unclear within the application.

6.4.12 AGD also suggested that section 5(a) was updated to include further information on the indicative size of the study population, noting that this was currently unclear.

6.4.13 AGD noted the information in section 2.4 (commercial benefit evaluation) of the DAS internal application assessment form in respect of the findings of the research not being suppressed; and suggested that a special condition was included in section 6 to reflect that no parties will be able to influence the outcomes nor suppress any findings of the research.

	<p>6.4.14 AGD noted the reference in section 5(a) to individuals opting out of the Hospital Episode Statistics (HES) data; and suggested that this was removed, noting that Opt-outs would not be applied.</p> <p>6.4.15 The independent advisers queried the statement in section 5(a) “<i>There are no substantive moral or ethical concerns...</i>”; and suggested that this statement was removed.</p> <p>6.4.16 AGD noted the statement in section 5(a) “<i>*HRA REC consultation agreed with the Pfizer internal ethics team assessment that an ethics review is not required for this study</i>”; and queried whether HRA REC had been advised about the commercial interests; and, if not, suggested that this statement was removed.</p> <p><i>* Health Research Authority Research Ethics Committee</i></p> <p>6.4.17 AGD noted the header / information in section 5(a) in respect of the ethical consideration; and suggested that for ease of reference, this was reviewed and updated where necessary, to ensure that the correct information was under the correct header.</p> <p>6.4.18 AGD noted the patient and public involvement and engagement (PPIE) planned at the end of the research; however, the Group suggested that there was ongoing PPIE throughout the lifecycle of the project. The HRA guidance on Public Involvement is a useful guide.</p> <p>6.4.19 AGD noted that the data would flow via an extract and would not be accessed in NHS England’s Secure Data Environment (SDE) and that the applicant had noted they had only learnt about the SDE option after the finance and other study logistics with Pfizer Limited were already in place. AGD suggested that the justification was provided in the application as to why the SDE was not being utilised for this data.</p> <p>6.4.20 Separate to this application: As discussed at the AGD meetings on the 12th September 2024, 18th July 2024 and the 13th June 2024, the Group suggested that NHS England continue to explore how they can remove barriers to applicants accessing the SDE.</p> <p>ACTION: NHS England Data and Analytics Representative to explore removing barriers to applicants accessing the SDE.</p>	D&A Rep
6.5	<p>Reference Number: NIC-209200-S9H5R-v4.6</p> <p>Applicant: Royal College of Psychiatrists</p> <p>Application Title: National Clinical Audit of Psychosis (NCAP)</p> <p>Observer: Suzanne Hartley and Suzanne Shallcross</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the Independent Group Advising (NHS Digital)</p>	

on the Release of Data (IGARD) meetings on the 12th May 2022, 21st May 2020 and the 19th March 2020.

Application: This was an amendment application.

NCAP aims to improve the quality of care that the NHS mental health services provide to people with psychosis.

The amendments are **1)** to allow Royal College of Psychiatrists to conduct a pilot exercise alongside the pre-approved purpose.; and **2)** for the purpose of the pilot, Royal College of Psychiatrists will require additional datasets, Hospital Episodes Statistics (HES) Admitted Patient Care (APC) and Civil Registration Death data.

NHS England were seeking advice on the following points only:

1. The proposed pilot.

NHS England were also seeking general advice on the application.

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

Outcome of discussion: AGD were supportive of the application if it was clarified how the processing aligned with the s251 support, and wished to draw to the attention of the SIRO the following substantive comments:

In response to point 1:

6.5.1 AGD queried how the reference in the application to “*Care Professional Team Local ID*” and queried whether this was the ID of a particular team, or, whether this was ID that had been assigned to a patient. The Group were advised by NHS England that this was referring to the ID of a particular team. The Group noted the verbal update from NHS England, however queried how The Royal College of Psychiatrists would use this to identify a list of eligible patients, as outlined in section 4.6 of the DAS internal application assessment form. It was suggested that NHS England clarify this further with the applicant, and that the application was updated to reflect the correct / factual information.

6.5.2 AGD noted that it was unclear if / how the proposed processing outlined in the application aligned with the Health Research Authority Confidentiality Advisory Group (HRA CAG) s251 support; and suggested that NHS England explore this further with the applicant.

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

6.5.3 The AGD Chair noted that when the application was reviewed by the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) on the 19th March 2020: “*IGARD queried the reference in section 5(a) (Objective for Processing) to maternity-related data, and noted this did not appear to tie in with the information outlined in the rest of the application and asked that written confirmation was provided confirming that NHS Digital was not flowing maternity-related data*”. It

	<p>was noted that while reviewing the supporting documents it became apparent that, the applicant may have been given the incorrect impression by NHS Digital that IGARD would not support the flow of maternity-related data. As the Chair had part been of the quoracy, she was able to advise that IGARD had been supportive however of the applicant receiving maternity data, and indeed speculated that it might be essential to help ascertain incidents of post-partum psychosis, but it had not been requested in section 3(b) of the application at the time. AGD advised that if maternity-related data was required by the applicant and was permitted / desirable for the audit – particularly with a view to ascertaining cases of post-partum psychosis and there was a clear justification outlined in the application, then they would be supportive of maternity-related data flowing, without recourse to AGD.</p> <p>ACTION: NHS England’s DAS to ask applicant if any flows of maternity-related data would help support the aims of the audit and to advise that AGD would support additional flows.</p> <p>6.5.4 The NHS England SIRO Representative noted that section 3 (Datasets Held / Requested) referred to the data as being “<i>Pseudo/Anonymised</i>”; and asked that this was updated to correctly state that the data is “<i>identifiable</i>”.</p>	<u>DAS</u>
7 INTERNAL DATA DISSEMINATION REQUESTS:		
<i>There were no items discussed</i>		
8 EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL		
<i>There were no items discussed</i>		
9 OVERSIGHT AND ASSURANCE		
<i>There were no items discussed</i>		
10 AGD OPERATIONS		
10.1	<p>Risk Management Framework</p> <p>The NHS England SIRO Representative confirmed that a risk management framework was continuing to be developed by Data Access, and in the meantime asked that AGD use the agreed NHS England DAS Standards and Precedents model as a proxy in assessing the risk factors in relation to items presented to AGD for advice.</p> <p>It had been noted previously by the interim data advisory group that the Oversight and Assurance Programme of applications that were not subject to AGD review would form part of this Risk Management Framework.</p>	

	<p>The NHS England SIRO Representative noted an outstanding action in respect of providing a written response to AGD on the risk management framework; and noted that this was progressing under the NHS England Precedents and Standards work.</p> <p>ACTION: The NHS England SIRO Representative to provide a written response to AGD on the risk management framework</p>	SIRO Rep
10.2	<p>Standard Operating Procedures (SOPs)</p> <p>The ongoing forward plan of work for creating the AGD Standard Operating Procedures was discussed; and noting that the AGD Terms of Reference (ToR) had now been approved, it was noted that work was progressing in order to finalise relevant AGD SOPs in line with the approved AGD ToR.</p>	
10.3	<p>AGD Stakeholder Engagement</p> <p><i>There were no items discussed</i></p>	
10.4	<p>AGD Project Work</p> <p>Kirsty Irvine, Paul Affleck and Claire Delaney-Pope attended an NHS England Data Access Service (DAS) Standards Working Group on the 17th September 2024 and gave a brief update to AGD.</p> <p>A brief update was given by the Group’s Representative on the Federated Data Platform Data Governance Group.</p>	
11 Any Other Business		
11.1	<p><i>There were no items discussed</i></p>	
<p>Meeting Closure</p> <p>As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.</p>		