Advisory Group for Data (AGD) - Meeting Minutes

Thursday, 6th June 2024 09:00 – 13:35

(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)			
Dr. Robert French (RF)	AGD independent member (Specialist Academic / Statistician 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 A	TTENDANCE:			
Name:	Role / Area:			
Laura Bellingham (LB)	Deputy Director, Data Access and Partnerships, Data and Analytics (Presenter: item 10)			
Garry Coleman (GC)	NHS England SIRO Representative			
Rachel Fernandez (RF)	IG Lead, Data Protection Office and Trust, Privacy, Transparency, and Trust (PTT), Delivery Directorate (Observer: items 6.1 to 12)			
Nicki Maher (NM)	IG Risk and Assurance, Privacy, Transparency and Trust (PTT), Delivery Directorate (Observer : items 9.1 and 9.2)			

Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Delivery Directorate
Jodie Taylor-Brown (JTB)	Data Access and Partnerships, Data and Analytics (Observer : item 6.3)
James Watts (JW)	Data Access and Partnerships, Data and Analytics (Observer : item 6.4)

AGD INDEPENDENT MEMBERS / NHS ENGLAND MEMBERS NOT 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)	
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 23rd May 2024 were reviewed and, after several minor amendments, were agreed as an accurate record of the meeting.

3 Declaration of interests:

Paul Affleck noted a professional link to the study team at Sandwell and West Birmingham Hospitals NHS Trust (NIC-719879-K6X3J) through his role at the University of Leeds. It was agreed this did not preclude Paul from taking part in the discussion on this application.

Paul Affleck noted a professional link to Health Data Insight (NIC-719879-K6X3J) through his role at the University of Leeds. It was agreed this did not preclude Paul from taking part in the discussion on this application.

4 AGD Action Log:

The action log was not discussed.

5 BRIEFING PAPER(S) / DIRECTIONS:

There were no items discussed

6 EXTERNAL DATA DISSEMINATION REQUESTS:

6.1 Reference Number: NIC-739822-Q8R6Yv0.2

Applicant: University of Manchester

Application Title: Investigating Causal Effects of Mental Healthcare Provision on

Labour Outcomes: A Case Study of Talking Therapies in England

Application: This was a new application.

The purpose of the application is to aid in improving the service delivery of NHS Talking Therapies for Anxiety and Depression services (formally IAPT), and provide real-world evidence of the effect of mental healthcare treatments on labour market outcomes needed to better understand the relationship of mental health and labour supply in England. This is to support the NHS to better meet the demands for treatment of the English population, and potentially further reduce the lost productivity caused by mental health conditions.

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

Outcome of discussion: AGD were **not** supportive of the application **at this time** due to the limited information / documentation provided, 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:

- **6.1.1** AGD welcomed the application, and noted that, whilst they were currently **not** supportive of the application at this time, they were supportive of the overall purpose of the application.
- **6.1.2** Noting that Article 5(1)(c) of the UK General Data Protection Regulation (UK GDPR) states "adequate, relevant and limited to what is necessary in relation to the purposes for which they are processed ('data minimisation'); AGD noted that it was unclear what, if any, possible data minimisation by field in the Secure Data Environment (SDE) has been investigated, to minimise the data to what is necessary in relation to the relevant purposes. It was suggested that data minimisation was explored further, in line with NHS England DAS standard for data minimisation and that clarification of this was noted in the DAS internal application assessment form and the application.
- **6.1.3** AGD noted that, prior to the meeting, an AGD independent member had raised a query directly with the AGD NHS England Data and Analytics representative (delegate), querying why a protocol was **not** available for this application. Prior to the meeting, a member of NHS England's Data Access Service (DAS) had advised AGD that when applying for pseudonymised data it is **not** currently a requirement for applicants to submit a protocol. AGD noted the update from DAS, however suggested that NHS England gave further consideration to the request for a protocol **or** research summary from applicants undertaking research, noting that it would be

useful to NHS England and AGD to have this information / clarification of the research; and would further support the assessment of the application.

ACTION: NHS England DAS to give further consideration to the request of a protocol or research summary from applicants, noting that it would be useful to NHS England and AGD to have information / clarification of the research; and would further support the assessment of the application.

D&A Rep

- **6.1.4** AGD advised that a copy of a protocol or research summary would have been useful for this review, to provide further information / clarification of a number of points, including, but not limited to, the role and seniority of the PhD supervisor; further details on the research to help understand the expected benefits; and clarification as to how the causal effects of mental healthcare provision on labour outcomes could be assessed from the data requested.
- **6.1.5** AGD suggested that NHS England satisfies itself that the researcher is aware / appropriately briefed on the sensitivity of the data, noting the different variables requested.
- **6.1.6** AGD noted that whilst the Improving Access to Psychological Therapies (IAPT) data did provide information on individual occupational status, it did **not** provide information on occupational type; and queried whether all of the objectives for processing could be achieved with this data. It was suggested that NHS England discuss any possible limitations of the data with the researcher; and that for future reference any discussions on this were noted in the DAS internal application assessment form. The AGD independent Specialist Academic / Statistician member, observed that with such a large sample size, the researcher should be able to obtain some useful information in respect of the occupation status from the IAPT data, to support the research.
- **6.1.7 Separate to the application:** AGD noted that they had reviewed the transparency / published information on the <u>IAPT data</u>, and suggested that this was reviewed by the AGD NHS England Data Protection Office (DPO) representative, and updated as may be required, including, but not limited to, providing clarity on how long the IAPT data can be held for; clarifying whether the data can be transferred outside of the UK; and reviewing the reference to the opt-out, noting that the data here was pseudonymised.

ACTION: The AGD NHS England DPO representative to review the transparency information on the IAPT data, and update as may be required, including, but not limited to, providing clarity on how long the IAPT data can be held for; whether the data can be transferred outside of the UK; and reviewing the reference to the optout, noting that the data here was pseudonymised.

DPO Rep

6.1.8 NHS England advised AGD, that in addition to the data sharing agreement (DSA), there was also a 'User Agreement' for those individuals accessing data in

- NHS England's Secure Data Environment (SDE), that covers off key points, including, but not limited to, specific user access and restrictions on exporting data.
- **6.1.9** It was suggested by the Group that the application was updated to specifically reference the 'User Agreement' document, and that this was linked to the compliance with the DSA, for example, by the addition of a special condition in section 6 (Special Condition) of the application, stating that any breach of the 'User Agreement' would also be a breach of the DSA.
- **6.1.10** AGD noted that although section 5.2 (Did the applicant seek opinion from a non-HRA REC) of the DAS internal application assessment form stated that the applicant had consulted the University of Manchester Ethics Committee; it was not clear from the documentation provided, whether the committee had reviewed the research and if they were supportive or not. It was suggested that NHS England seek further confirmation on this from the applicant, and upload any supporting documentation to NHS England's customer relationships management (CRM) system for future reference.
- **6.1.11** AGD noted the information in section 3(c) (Patient Objections) of the application, stating that patient objections were **not** applied; however, suggested that this was updated as per the usual process, to state why they were not applied, i.e. because the data requested was pseudonymised.
- **6.1.12** AGD queried the statement in section 5(a) (Objective for Processing) "The University of Manchester project **team** will…"; and suggested that this was reviewed and updated to reflect that there was **one** individual PhD student working on the research; or if there was a team involved, suggested that the application and DAS internal application assessment form were updated with further information.
- **6.1.13** AGD queried the statement in section 5(a) "There is an **identified need** for evidence of the impact of mental healthcare treatments on labour market outcomes of real-world patients with common mental disorders..."; and suggested that for transparency, further clarification was provided as to who had identified this need, as this was currently not clear.
- **6.1.14** AGD noted the expected benefits in section 5(d) (Benefits) of the application; and suggested that these were reviewed and updated as may be necessary in line with NHS England DAS Standard for Expected Measurable Benefits, to reflect the scale of the study by a PhD student; and to also ensure that the inclusion of the templated wording in its entirety in this section was correct and appropriate (including because any Annual Confirmation Report or revised DSA would need to update progress against all of the expected benefits).
- **6.1.15** In addition, it was suggested that the benefits in section 5(d) of the application were reviewed and updated, to ensure that they related to benefits to health and social care, in line with NHS England's DAS Standard for Expected Measurable Benefits.

- **6.1.16** AGD noted that the applicant would **not** be required to complete an Annual Confirmation Report (ACR) due the length of the DSA (12 months); and were advised by NHS England that any extension or renewal for this application would require compliance with the NHS England DAS <u>Standards</u>, which would address the same points as the ACR.
- **6.1.17** AGD noted that the named applicant in this application would **not** have the authority to bind the University of Manchester to the DSA as the contract signatory; and that the DSA would need to be signed by the appropriate individual / organisation from the Data Controller organisation.
- **6.1.18 Separate to this application:** AGD suggested to the AGD NHS England Data and Analytics representative that, for future reviews, it would be helpful to have clarification in either the application or the DAS internal application assessment form confirming the individual / organisation who would be signing the DSA.

ACTION: NHS England DAS to consider providing clarification in either the application or the DAS internal application assessment form confirming the individual / organisation who would be signing the DSA.

Subsequent to the meeting: The AGD Data and Analytics member (delegate) advised that following discussion of this item, colleagues within NHS England DAS had communicated that, in relation to point 6.1.2, although the applicant does not have the ability to request specific data fields when initially applying for the data, the specific data fields required can be requested within the DSA once in progress.

D&A Rep

6.2 | Reference Number: NIC-726177-R0H8Vv0.3

Applicant: University of Newcastle Upon Tyne

Application Title: Investigating and explaining contemporary patterns and trends in inequalities across the head and neck cancer pathway: understanding the roles of deprivation and region

Application: This was a new application.

The purpose of the application is for a research project to **1)** develop a database of head and neck cancer (HNC) incidence and survival estimates; **2)** understand how deprivation is related to survival (Mediation model analyses); and **3)** development of recommendations for HNC policy, intervention development, and research.

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

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:

6.2.1 Noting the information with the Data Access Service (DAS) internal application assessment form, AGD queried if the applicant would be able to access **all** of the

data fields for the cohort. Noting that Article 5(1)(c) of the UK General Data Protection Regulation (UK GDPR) states "adequate, relevant and limited to what is necessary in relation to the purposes for which they are processed ('data minimisation'); AGD noted that it was unclear what, if any, possible data minimisation by field in the SDE has been investigated in relation to the relevant purposes. It was suggested that data minimisation was explored further, in line with NHS England DAS standard for data minimisation and that clarification of this was noted in the DAS internal application assessment form and the application.

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

- **6.2.2** AGD noted and applauded the efforts taken by NHS England's DAS in respect of attempting to identify the correct Data Controller(s) with the applicant, as outlined in the DAS internal application assessment form. It was suggested, however, that some of the responses received from the applicant would need further exploration. For example, the tenor of the comments suggesting that those with advisory roles were **not** Data Controllers as they were not handling the data, which is not determinative of data controllership or their responsibilities as a Data Controller. The Group suggested that NHS England explore this further with the applicant, to seek assurance that these individuals are **not** responsible for determining the purpose and means of processing, and are therefore **not** carrying out any data controllership activities, in line with the NHS England's DARS Standard for Data Controllers.
- **6.2.3** AGD queried how the various advisors from the different organisations work together; and noting that this was currently unclear, suggested that NHS England clarify this with the applicant, and update section 5(a) (Objective for Processing) of the application and the DAS internal application assessment form with further information.
- **6.2.4** AGD noted the information provided in section 5.3 (Did the applicant seek opinion from a non-HRA REC) of the DAS internal application assessment form in respect of the ethical review; however, advised that it was still unclear if ethical support had been sought / received from the University of Newcastle Upon Tyne Ethics Committee. It was suggested that this was clarified with the applicant, and any supporting papers on this were uploaded to NHS England's customer relationships management (CRM) system for future reference.
- **6.2.5** In addition, it was noted that the statement in section 7 (Ethics Approval) of the application "Ethics approval is required but not in place because no identifying information of patients or service users will be processed" was not in line with the usual standard wording; and did not align with the information in the DAS internal application assessment form. The Group suggested that this reviewed and updated to reflect the correct information, and to align with usual standard wording.
- **6.2.6** NHS England advised AGD that in addition to the data sharing agreement (DSA), there was also a 'User Agreement' for those individuals accessing data in

NHS England's Secure Data Environment (SDE), that covers off key points, including, but not limited to, specific user access and other ways of exporting the data that were prohibited.

- **6.2.7** It was suggested by the Group that the application was updated to reference the 'User Agreement' document, and that this was linked to the compliance with the DSA, for example, by the addition of a special condition in section 6 (Special Conditions) of the application, staying that any breach of the 'User Agreement' would also be a breach of the DSA.
- **6.2.8** AGD noted that the DSA potentially permits a number of under-graduates working on this research project to access the data, and queried whether there were any numerical restrictions in the 'User Agreement'; and if not, suggested that NHS England include a numerical cap on the under-graduates noting the expansive terms of the DSA.
- **6.2.9** AGD suggested that section 5(c) (Specific Outputs Expected) and section 5(d) (Benefits) of the application were updated to clarify where access to the data for under-graduate / post-graduate study is **not** permitted, unless already stated under the terms of the DSA.
- **6.2.10** AGD noted the reference in section 5(d) of the application to "clients"; and suggested that this was removed / updated as may be appropriate, noting that this reference was incorrect / not relevant.
- **6.2.11** AGD noted the outputs in section 5(c) of the application, however, suggested that these were updated further to also include indicative target dates, in line with NHS England DAS Standard for Expected Outcomes.

Subsequent to the meeting: The AGD Data and Analytics member (delegate) advised that following discussion of this item, colleagues within NHS England DAS had communicated that, in relation to point 6.2.1, although the applicant does not have the ability to request specific data fields when initially applying for the data, the specific data fields required can be requested within the DSA once in progress.

6.3 Reference Number: NIC-717428-M3S8Hv0.8

Applicant: University of Birmingham

Application Title: Discovery and evaluation of patient pathways using Emergency

Care Dataset (ECDS)

Observer: Jodie Taylor-Brown

Application: This was a new application.

The purpose of the application is for a research project that aims to **1)** evaluate ECDS as a resource for applying the field or process mining to emergency care within NHS hospitals; **2)** describe patient flows within NHS trust hospitals, and a graphical flow-chart like representation of these flows; **3)** compare patient flows in

terms of high-level patient outcomes, such as patient waiting times, discharge rates, inpatient admission rates.

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

Outcome of discussion: The **majority** of the Group were **not** supportive of the application **at this time**, due to the issues around data minimisation and the use of the low latency dataset, which is raw and unchecked data, and whether it was appropriate for this to be used to compare the performance of NHS Trusts.

A **minority** of the Group were supportive of the application.

The Group wished to draw to the attention of the SIRO the following significant comments.

- **6.3.1** AGD noted the information in the Data Access Service (DAS) internal application assessment form, that states that only **one** sensitive field 'ethnic category' was required, however that only 'all sensitive fields' or no sensitive fields can be requested under the uncurated ECDS product, and that therefore **all** sensitive fields have been requested. Noting that Article 5(1)(c) of the UK General Data Protection Regulation (UK GDPR) states "adequate, relevant and limited to what is necessary in relation to the purposes for which they are processed ('data minimisation'); AGD noted that it would not be appropriate to provide all sensitive data fields and suggested that NHS England explore whether a more nuanced approach could be taken, to minimise the data to what is necessary in relation to the relevant purposes, in line with NHS England DAS standard for data minimisation and that clarification of this was noted in the DAS internal application assessment form and the application.
- **6.3.2** AGD noted that section 2.3 (benefits evaluation) of the DAS internal application assessment form had **not** been completed, and advised that it would have been helpful for this to be populated with some key information, which could have then aligned with the application. It was suggested that in line with the <u>NHS England DAS Standard for Expected Measurable Benefits</u> this was updated to include a number of points, including, but not limited to, the use of the low latency dataset, which is raw and unchecked data, and whether it was appropriate for this to be used to compare the performance of NHS Trusts; to explore the experience of the computer science student, their supervisor and their use of health data; and whether / how the stated outputs and benefits link to health and care.

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

6.3.3 AGD noted, in the DAS internal application assessment form and the application, that the applicant had approached their institutional (University of Birmingham) ethics committee to seek their view as to whether an ethical review was required; however **the outcome** was unclear. It was therefore suggested that

- NHS England explore this further with the applicant, as it was the view of the Group that the research project did appear to fall within the remit of the ethics committee as described on the university's website; and that any supporting documentation is uploaded to NHS England's customer relationships management (CRM) system for future reference.
- **6.3.4** AGD noted the reference in section 5(a) (Objective for Processing) of the application, to the Health Data Research UK (HDRUK) patient and public involvement and engagement (PPIE) group; and suggested that this information was updated to include details of their suggestions / support provided.
- **6.3.5** AGD noted the information in section 5(a) of the application, in respect of the primary public and patient engagement channels used for this project via the OPTIMAL project **patient** advisory group (PAG), and noted that this was stated to be "...a group of clinicians, healthcare administrators and academic healthcare researchers"; and suggested that this was reviewed and edited as appropriate to reflect the correct information, noting that these were not patient representatives.
- **6.3.6** NHS England advised AGD that, in addition to the data sharing agreement (DSA), there was also a 'User Agreement' for those individuals accessing data in NHS England's Secure Data Environment (SDE), that covers off key points, including, but not limited to, specific user access and restrictions on exporting data.
- **6.3.7** It was suggested by the Group, that the application was updated to reference the 'User Agreement' document, and that this was linked to the compliance of the DSA, for example, by the addition of a special condition in section 6 (Special Conditions) of the application, staying that any breach of the 'User Agreement' would also be a breach of the DSA.
- **6.3.8** Noting the statements in section 5(b) (Processing Activities) of the application "Access is restricted to **students** of the University of Birmingham..." and "**Analysts** from the University of Birmingham will analyse the Data ..."; it was suggested that further clarification was provided in the DSA / 'User Agreement' as to how many students and analysts would be accessing the data, noting that, as it currently stands, this is quite open / wide ranging.
- **6.3.9** AGD queried the statement in section 5(a) of the application "The patient flow diagrams are designed to be interpreted and scrutinised by clinical and operational managers..."; and suggested that this was updated with further information, for example, whether it was part of the research project to enable this to happen.
- **6.3.10** AGD noted the potentially hyperbolic statement in section 5(a) "Being able to compare multiple trusts across a whole country has never been attempted and would provide a truly unique piece of research"; and suggested that this was reviewed and the tone amended as may be appropriate, noting other similar areas of research that may have been undertaken previously or were ongoing.

- **6.3.11** AGD noted the statement in section 5(a) "...NHS England will provide access to internal channels and policy groups..."; and suggested that this was reviewed by NHS England for accuracy, and amended as may be appropriate. In addition, it was queried whether NHS England would have any data controllership responsibilities, depending on their role and suggested that this was reviewed in line with NHS England DAS Standard for Data Controllers.
- **6.3.12** AGD noted the volume of expected outputs in section 5(c) (Specific Outputs Expected) and benefits in section 5(d) (Benefits) of the application; and suggested that these were reviewed and edited as may be necessary in line with NHS England DAS Standard for Expected Outcomes and NHS England DAS Standard for Expected Measurable Benefits; and to also ensure that the inclusion of the templated wording in its entirety in this section was correct and appropriate (including because any Annual Confirmation Report or revised DSA would need to update progress against all of the expected benefits).
- **6.3.13** In addition, it was suggested that the benefits in section 5(d) were reviewed and updated, to ensure that they related to benefits to health and social care, in line with NHS England's DAS Standard for Expected Measurable Benefits.
- **6.3.14** AGD noted that the named applicant in this application would **not** have the authority to bind the University of Birmingham to the DSA as the contract signatory; and that the DSA would need to be signed by the appropriate individual / organisation from the Data Controller organisation.
- **6.3.15 Separate to this application:** AGD suggested to the AGD NHS England Data and Analytics representative that, for future reviews, it would be helpful to have clarification in either the application or the DAS internal application assessment form confirming the individual / organisation who would be signing the DSA.

ACTION: NHS England DAS to consider providing clarification in either the application summary document or the DAS internal application assessment form confirming the individual / organisation who would be signing the DSA.

Subsequent to the meeting: The AGD NHS England Data and Analytics representative advised that following discussion of this item, colleagues within NHS England DAS had advised that, in relation to point 6.3.1, although the applicant does not have the ability to request specific data fields when initially applying for the data, the specific data fields required can be requested within the DSA once in progress.

6.4 Reference Number: NIC-719879-K6X3Jv1.2

Applicant: Sandwell and West Birmingham Hospitals NHS Trust

Application Title: PEUGIC root cause analysis project

Observer: James Watts

D&A Rep **Previous Reviews:** The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 21st September 2023.

Application: This was an amendment application.

The amendments are to **1)** include General Medical Council (GMC) and Nursing and Midwifery Council (NMC) numbers of endoscopists to the extract; **2)** to uplift the purpose section of the DSA to specifically list the variables, and the justification required; **3)** to extend the DSA end date to 2028.

NHS England were seeking advice on the following points:

- Whether the requirement to create indicators at individual level is sufficiently justified;
- 2. If so, whether there are sufficient controls in place to ensure that such indicators are not publicly available (given that the customer has stated that they do not intend to make them available);
- 3. Whether there needs to be any additional transparency specifically relating to the clinicians given that it may be argued that there is data personal to them that is being handled.

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

Outcome of discussion: AGD were supportive of the application but were providing comments in response to NHS England's request for advice on specific points rather than all aspects of the application. AGD wished to draw to the attention of the SIRO the following observations in relation to the advice points:

In response to points 1 to 3:

- **6.4.1** AGD confirmed that the requirement to create indicators at individual level was sufficiently justified.
- **6.4.2** AGD suggested that the number of professionals involved with the project are noted in the application / Data Access Service (DAS) internal application assessment form for information / transparency.
- **6.4.3** AGD noted that whilst the indicators would **not** be made publicly available, suggested that the applicant gave further consideration as to how they might respond to a Freedom of Information (FOI) request.
- **6.4.4** AGD queried what engagement had been done with the relevant professional groups in relation to the data linkage; and suggested this was outlined in the application; or, if no engagement had been undertaken, that this was suggested to the applicant.
- **6.4.5** AGD queried whether the UK General Data Protection Regulation (UK GDPR) legal basis should be reviewed / updated, noting the possible identifiability of individual's following linkage to the General Medical Council (GMC) and Nursing and Midwifery Council (NMC) numbers.

6.4.6 In addition, AGD noted that the Common Law Duty of Confidentiality may also need to be addressed following the data linkage to the General Medical Council (GMC) and Nursing and Midwifery Council (NMC) numbers. The Group noted that while this was not confidential patient information it may create confidential information in respect of the medical professionals whose data was being linked; accordingly, this information would need to be handled appropriately. It was not clear whether this aspect had been considered.

7 INTERNAL DATA DISSEMINATION REQUESTS:

There were no items discussed

8 EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL

There were no items discussed

9 OVERSIGHT AND ASSURANCE

9.1 Oversight and Assurance Process

The <u>Statutory Guidance</u> states that the data advisory group (AGD) should be able to provide NHS England with advice on: "Precedents for internal and external access, including advising in accordance with an agreed audit framework whether processes for the use of precedents are operating appropriately, to provide ongoing assurance of access processes".

In advance of the meeting, the AGD independent members were provided with 1) three applications (selected by the AGD Secretariat); 2) internal application assessment forms for each of the three applications; and 3) an oversight and assurance template to complete.

Following review of the applications by the AGD independent members **out of committee**, the completed oversight and assurance templates were sent to the AGD Secretariat prior to the meeting.

It was noted that only **high-level points** would be discussed in meeting (and noted in the minutes); however, the full suite of comments and feedback from AGD independent members on the oversight and assurance templates would be collated by the AGD Secretariat and shared with the NHS England SIRO representative and relevant NHS England colleagues as may be appropriate.

Please see **appendix A** for high-level points raised in-meeting on the three applications.

9.2 Oversight and Assurance Conclusion / Review

AGD noted that a discussion would take place at the AGD plenary meeting on the 20th June 2024, in respect of oversight and assurance undertaken to date, findings, and next steps.

AGD noted that at the AGD meeting on the 25th April 2024, a discussion had taken place on Application Compliance Reports (ACRs); and as part of this discussion, the

Group had queried if it would be beneficial to NHS England for AGD to provide a 'light touch' review of a selection of some of the ACRs via oversight and assurance; and suggested that NHS England gave this further consideration.

The NHS England SIRO representative advised that this would be considered for a future AGD meeting.

ACTION: The AGD Secretariat to note the ACR 'light touch' review for a future oversight and assurance session once considered by the SIRO Representative.

AGD Sec

10 Unified Data Access Layer (UDAL) (Presenter: Laura Bellingham)

AGD were provided with an overview of the Unified Data Access Layer (UDAL), which will bring the majority of national NHS data together into one place, by integrating the main four existing NHS data platforms into one. UDAL will provide streamlined processing and access to date; transforming the user experience and enhancing the delivery of patient centred, data-driven services across the NHS.

AGD were advised that there was ongoing work in respect of transparency, legal frameworks, the Data Protection Impact Assessment (DPIA) and user access.

AGD noted and thanked Laura for the update and looked forward to further information on this in due course.

11 AGD OPERATIONS

11.1 | Risk Management Framework

As last noted in the AGD minutes from the 21st March 2024, the independent members noted the reference to reviewing materials in accordance with "a clearly understood risk management framework" within the published <u>Statutory Guidance</u> and advised that they were not aware of an agreed risk management framework, and reiterated a previous request that NHS England provide further information/clarity on this to the Group, noting this topic had been raised by Lord Hunt in the House of Lords on the 26th June 2023, and was answered by Lord Markham on the 5th July 2023: <u>Written questions</u>, <u>answers and statements – UK Parliament</u>.

The NHS England SIRO Representative had provided further clarity on the risk management framework via email to the Group, which confirmed that NHS England were asking AGD (and previously the interim data advisory group) to use the NHS England DAS Standards and Precedents model to assess the risk factors in relation to items presented to AGD for advice; however the independent members noted that the wording in the statutory guidance "...using a clearly understood risk management framework, precedent approaches and standards that requests must meet...", suggested that the risk management framework is separate to the DAS Standards and Precedents, and asked that this be clarified by NHS England. The Group noted that plans for this work were in train.

It had been noted previously by the interim data advisory group that the Oversight and Assurance Programme of applications that had not be subject to AGD review could form part of this Risk Management Framework.

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.

ACTION: The NHS England SIRO Representative to provide a written response to AGD on the risk management framework

SIRO Rep

11.2 | AGD Standard Operating Procedures (SOPs)

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 the AGD SOPs in line with the approved AGD ToR.

It was noted that a further update would be provided to the Group in due course.

11.3 | AGD Stakeholder Engagement

There were no items discussed

11.4 | AGD Project Work

There were no items discussed

12 Any Other Business

There were no items discussed

Meeting Closure

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

Appendix A

Oversight and Assurance Review – 6th June 2024

Ref:	NIC Number:	Organisation:	Areas to consider:	
240606a	NIC-656874-T3L9D-v2.5	University College London (UCL)	 It was unclear if the application had proceeded down the SIRO Precedent or Precedent 12 (Simple Amendment). Query as to whether previous ODR applications should be proceeding via the Precedent 20 route; or should have independent oversight. Unclear if full / accurate approval history is noted. 	
240606b	NIC-322051-S8N9N-v4.6	University of Aberdeen	 No assessment provided advising why this was suitable for Precedent route. No DAS internal application assessment form provided (noting the document was not available for Secretariat to download on CRM). Previous IGARD minutes not captured / addressed. Period of time between the DSA versions and not clear why. Privacy Notice not on the website. 	
240606c	NIC-406632-X0L2M-v1.3	Peninsula Cancer Alliance	 Supportive of the use of data. Questions over the mechanism used to govern this application. 	

 No DAS internal application assessment provided (noting the document was not for Secretariat to download on CRM). Internal flows should not go via extern Precedent route. 	ot available
 States that this is a 21 year DSA, unconcrect or typo. If it is a 21 year DSA, do not think this proceed via the Precedent route. No reference to the previous IGARD residues. 	s should review or how
the points have been addressed, i.e. points in relation to the privacy notice.	•