

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 21st March 2024

09:30 – 13:45

(Remote meeting via videoconference)

INDEPENDENT ADVISERS IN ATTENDANCE:	
Name:	Role:
Paul Affleck (PA)	Specialist Ethics Adviser
Claire Delaney-Pope (CDP)	Specialist Information Governance Adviser
Kirsty Irvine (KI)	Chair
Dr. Imran Khan (IK)	Specialist GP Adviser
Jenny Westaway (JW)	Lay Adviser
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	Role / Area:
Dan Goodwin (DG)	Data Access and Partnerships, Data and Analytics (Observer: item 4.3)
Narissa Leyland (NL)	NHS England Data and Analytics Representative (Delegate for Michael Chapman)
Nicki Maher (NM)	IG Risk and Assurance, Privacy, Transparency and Trust (PTT), Delivery Directorate (Observer: items 1 to 11.4)
Jorge Marin (JM)	Data Access and Partnerships, Data and Analytics (Observer: item 4.1)
Andrew Martin (AM)	NHS England Data Protection Office Representative (Delegate for Jon Moore)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Delivery Directorate (Presenter: item 11.2)
Jonathan Osborn (JO)	NHS England Caldicott Guardian Team Representative
Jodie Taylor-Brown (JTB)	Data Access and Partnerships, Data and Analytics (Observer: items 4.1 and 4.2)
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Delivery Directorate (Presenter: items 8 and 11.3)
INDEPENDENT ADVISERS NOT IN ATTENDANCE:	

Prof. Nicola Fear (NF)	Specialist Academic Adviser
Dr. Robert French (RF)	Specialist Academic / Statistician Adviser
Dr. Geoffrey Schrecker (GS)	Specialist GP Adviser
Dr. Maurice Smith (MS)	Specialist GP Adviser
Miranda Winram (MW)	Lay Adviser
NHS ENGLAND STAFF NOT IN ATTENDANCE:	
Michael Chapman (MC)	NHS England Data and Analytics Representative
Jon Moore (JM)	NHS England Data Protection Office Representative

1	<p>Welcome and Introductions</p> <p>The NHS England Senior Information Risk Owner (SIRO) Representative, noting the Advisory Group for Data (AGD) meeting had been arranged prior to the Terms of Reference (ToR) being agreed, proposed that :</p> <ul style="list-style-type: none"> • Kirsty Irvine (as an independent adviser) will be asked to Chair the AGD meetings; • The meeting will be minuted, with advice and minutes published; • Attendees will include both independent advisers from outside NHS England and representatives from within NHS England. Attendees from NHS England include representatives covering the offices of the Data Protection Officer (DPO); the Caldicott Guardian; Data and Analytics; and the SIRO. • Attendees would not be listed as “members” in minutes during the transitional period; • NHS England representatives would not, during the transitional period, be formally part of any consensus that is reached, but would be active participants in the meeting; • It was agreed to use the Data Access Service (DAS) Standards / Precedents in relation to applications for external data sharing. <p>The attendees present at the meeting considered the proposal put forward by the NHS England SIRO Representative and, as no objections were raised, it was agreed that the meeting would proceed on this basis.</p> <p>Kirsty Irvine noted and accepted the request from the NHS England SIRO Representative to chair; and welcomed attendees to the meeting.</p>
2	<p>Review of previous AGD minutes:</p> <p>The minutes of the 14th March 2024 meeting were reviewed and subject to a number of minor amendments were agreed as an accurate record of the meeting.</p>
3	<p>Declaration of interests:</p>

	<p>Paul Affleck noted a professional link to the University of Leeds (NIC-332338-X1N2G) 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>Paul Affleck noted professional links to AIMES Management Service (NIC-148232-CPHLL and NIC-656811-F7T9C) National Institute for Health Research (NIHR)) but no specific connection with the application or staff involved and it was agreed that there was no conflict of interest.</p>
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EXTERNAL DATA DISSEMINATION REQUESTS:

4.1	<p>Reference Number: NIC-687582-X2P3K-v0.10</p> <p>Applicant: Department for Business and Trade</p> <p>Application Title: Understanding the extent of product-related injuries through Emergency Care Data Set</p> <p>Observers: Jodie Taylor-Brown, Jorge Marin</p> <p>Application: This was a new application.</p> <p>The purpose of the application is to support the Office for Product Safety and Standards (OPSS) operations to protect the public from product-related harm.</p> <p>NHS England were seeking advice on the following points:</p> <ol style="list-style-type: none"> 1. Are AGD supportive of the justification given for the data required. 2. If not, do AGD support that more should be done in terms of efforts to filter and minimise the extract. 3. If filtering is not possible, are AGD in support of the special condition proposed in Section 8.3 of the internal application assessment form – which would commit the applicant to regular reviews and deletion of the data. <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 supportive of the concept of using data in this way. However, the group made the following observation / points of advice on the application and / or supporting documentation provided as part of the review:</p> <p>In response to points 1 to 3:</p> <p>4.1.1 The group noted the specific advice points requested by NHS England Data Access Team (DAS); and noting that it was currently not fully clear how the data would be used to fulfil the project's objectives, it was suggested that the applicant produce a protocol (or provide a copy if a protocol has already been written), to address a number of points, including, but not limited to, a justification for the volume of data requested, the process for approving projects, the parameters for approval of the projects and a clearer articulation of the relevant project objectives.</p> <p>4.1.2 The group noted that Article 9(2)(g) (Reasons of substantial public interest (with a basis in law)) of the UK General Data Protection Regulation (UK GDPR) had been cited as the legal basis to process the data; and that NHS England's DAS had been engaging with the applicant to explore this further. Noting the 'high bar' to meet</p>	
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this legal basis, it was suggested that the internal application assessment form and section 5 (Purpose / Methods / Outputs) of the application, which also forms part of NHS England's [Data Uses Register](#), should be updated to provide a justification for using this Article 9 legal basis, including how the relevant conditions of the Data Protection Act (DPA) 2018 would be satisfied.

4.1.3 In addition, it was noted by the NHS England Data Protection Office (DPO) representative, that section 4.5 (evidence assessment) of the internal application assessment form referred to an *"appropriate policy document"* that addresses how the relevant conditions of the DPA 2018 are addressed; and suggested that there may have been a misunderstanding of what was being asked of the applicant by NHS England. It was suggested that NHS England clarify with the applicant that there is a requirement to have an appropriate policy document in place under Schedule 1 Part 4 of the DPA 2018 when applying the Article 9(2)(g) (Reasons of substantial public interest (with a basis in law)) of the UK GDPR legal basis.

4.1.4 The group queried the statement in section 5(a) (Objective for Processing) when referring to data minimisation *"...inclusivity in the data collection ensures that the Department for Business and Trade capture all relevant information for analysis"*; and suggested that this was removed, noting that this does **not** satisfy the data minimisation requirements as per the [NHS England DAS Standard for data minimisation](#).

4.1.5 It was noted by the independent advisers that advice point 3 (outlined above) referred to committing the applicant to *"...regular reviews and deletion of the data"*; and it were unclear how this would be compatible with supporting *"ad-hoc queries"*, as outlined in the application.

4.1.6 The group queried whether the Emergency Care Data Set (ECDS) requested was actually able to meet the objective for processing as outlined in section 5(a) of the application; and suggested that NHS England seek further advice on this point from NHS England's Chief Statistician.

4.1.7 It was suggested that NHS England and the applicant could explore whether providing a limited sample of the data would be feasible. The group supported the proposal and noting this would also support the production of a protocol; and help identify what (if any) data minimisation could be undertaken.

4.1.8 The group noted the references in the application to *"Artificial Intelligence (AI) and Machine Learning (ML) techniques"*; and queried whether AI and/or ML would actually be employed.

4.1.9 If the references to AI and ML were correct, then for the purpose of transparency, it was suggested that section 5 of the application was updated with further information on this, including, but not limited to, what information would be fed into the AI and ML; who may benefit from developing a tool or algorithm; what the expected outputs were from AI and ML; and whether the applicant had considered whether any algorithm generated may be biased.

	<p>4.1.10 The group also noted that if the AI and ML was 'profiling' in any way, this would raise additional questions and assurances, and that consideration be given to relevant UK GDPR requirements.</p> <p>4.1.11 The group suggested that a Data Protection Impact Assessment (DPIA) could be a useful tool to help explore some of the issues raised, for example in respect the scale of processing and the AI and ML. For the purpose of transparency, the group suggested that the applicant published such a DPIA.</p> <p>4.1.12 Noting the statement in section 5(b) (Processing Activities) of the application to the role of a third party "...<i>securely transfer the data into the secured Cloud-Based Analytical System</i>"; it was suggested by the independent advisers that this was explored further to determine whether the third party should be considered a Data Processor, in line with NHS England's DAS Standard for Data Processors; and to update the application and internal application assessment form as appropriate to reflect the outcome / factual information and to name the third party.</p> <p>4.1.13 In addition, the group suggested that the Cloud-Based Analytical System be named in section 5(b), for transparency.</p> <p>4.1.14 The SIRO representative noted that the Data Security and Protection Toolkit (DSPT) had been met for the Department for Business and Trade; and queried whether this covered the whole of the organisation or the part of the organisation that would be involved in this application; and had suggested that clarification was provided. It was also suggested that this information was reflected in section 5(a) of the application for transparency and accountability.</p>	
<p>4.2</p>	<p>Reference Number: NIC-684835-V0W0X-v0.7</p> <p>Applicant: University of Oxford</p> <p>Application Title: Supporting people with type 2 diabetes in effective use of their medicine through a system comprising mobile health technology integrated with clinical care compared with usual care: a randomised controlled trial</p> <p>Observer: Jodie Taylor-Brown</p> <p>Application: This was a new application.</p> <p>The purpose of the application is for a study, comparing the effectiveness and cost-effectiveness of brief messaging to support patients with type 2 diabetes taking diabetes medicine (glucose, blood pressure, or lipid lowering) in reducing risk factors for diabetes complications, with usual care.</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 supportive of the application and wished to draw to the attention of the SIRO the following comments:</p> <p>4.2.1 The group noted and commended NHS England's Data Access Service (DAS) for the consent review provided as a supporting document; and agreed that there was a legal gateway to meet the common law duty of confidentiality for sharing the data via consent, which mapped to the processing outlined in the application.</p>	

	<p>4.2.2 Noting the information in section 5(e) (Is the Purpose of this Application in Anyway Commercial) of the application, that stated there may be some commercial interest in the study results following press interest; it was suggested by the independent advisers that if it was general goodwill and positive press for the university, then in line with NHS England's DAS Standard for Commercial Purpose this may not result in a specific commercial benefit, and the current information could be removed from the application. If, however, any entity involved may be looking to reap a commercial benefit from press interest or commercialise any aspect of the study, then this should be explored further and the application updated accordingly.</p> <p>4.2.3 The independent advisers noted the restrictive access statement in section 5(b) (Processing Activities) of the application, that <i>"The Data will be accessed onsite at the premises of Bangor University only"</i>; and noted that there was an assumption that this restriction had been included as per the wishes of the applicant. If the applicant did, however, require some flexibility on where the data could be accessed from, then it was noted that this should be discussed with NHS England, and the application updated accordingly.</p>	
4.3	<p>Reference Number: NIC-661742-Y2K8L-v0.9</p> <p>Applicant: University of Leicester</p> <p>Application Title: Improving physical health care in older people in mental health settings: The ImPreSs-Care Quantitative Study</p> <p>Observer: Dan Goodwin</p> <p>Application: This was a new application.</p> <p>The purpose of the application is to provide contemporary information on the physical health needs, and their relationship with health outcomes for older people accessing mental health care in England.</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 independent adviser dissenting) were supportive of the application and wished to draw to the attention of the SIRO the following significant comments:</p> <p>4.3.1 In respect of the flow of data and data minimisation; the group suggested that the application was updated, to be explicitly clear as to exactly what data items were contained within the data flow, i.e. is the entire Mental Health Services Data Set (MHSDS) flowing; and at what stage, to what extent and by whom will the data be minimised, in line with NHS England's DAS standard for data minimisation.</p> <p>4.3.2 Noting the significant volume of data flowing, the independent advisers suggested that sufficient steps were taken to ensure that all data minimisation efforts had been explored to ensure that the minimum amount of data was flowing, noting current resource issues within NHS England; and that the minimum amount of processing was being undertaken, in line with NHS England's DAS standard for data minimisation.</p>	

	<p>In addition, the group made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>4.3.3 The SIRO representative noted that the group had not reviewed the sensitive data fields; and that NHS England data would need to look at the meta data fields to ensure they had been handled appropriately.</p> <p>4.3.4 The group noted in the internal application assessment form that there are various honorary contract holders, and confirmed that whilst the contracts appeared to be in line with NHS England's DAS Honorary Contracts Standard it did raise some queries in respect of the practicalities of the honorary contracts, including, but not limited to, the geographical spread of the honorary contract holders; the training of honorary contract holders; and whether they would work under a 'bring your own device' policy or whether the IT equipment would be provided by the Data Controller. It was suggested that NHS England explored these points further with the applicant, and that for transparency, the application and internal application assessment form were updated as appropriate.</p> <p>4.3.5 The NHS England Data Protection Office (DPO) representative and independent advisers noted the content of the applicant's published privacy notice; and suggested that this was reviewed and updated to ensure it reflects the current / correct information, including, but not limited to, the rights of the data subjects and the removal / update of "NHS Digital" references.</p> <p>4.3.6 Noting the information within section 5(a) (Objective for Processing) in respect of the patient and public involvement and engagement (PPIE) undertaken, the independent advisers suggested that this was updated to clarify what the outcome(s) of the PPIE was (if any).</p> <p>4.3.7 Separate to this application: the independent advisers noted that the NHS England citation special condition in section 6 (Special Conditions) of the application differed from previous standard wording, and asked that the NHS England Data and Analytics representative discuss this with colleagues in NHS England's Data Access Service (DAS). If the incorrect wording had been added to this application in error, it was suggested that the application should be updated with the correct standard wording. If the citation standard wording had been recently updated and this application reflected the 'new' text, then the group requested that clarification of this was provided to the group and a copy of the updated text was provided for future reference.</p> <p>ACTION: The NHS England Data and Analytics representative to discuss the NHS England citation special condition in section 6 of the application with colleagues, and to clarify with the group if this has now been updated; and if so, to provide the group with the updated text.</p>	NHSE D&A
Oversight and Assurance		
5.1	<p>Oversight and Assurance Process</p> <p>The Statutory Guidance states that the data advisory group (AGD) should be able to provide NHS England with advice on: "<i>Precedents for internal and external access, including advising</i></p>	

	<p><i>in accordance with an agreed audit framework whether processes for the use of precedents are operating appropriately, to provide ongoing assurance of access processes”.</i></p> <p>In advance of the meeting, the AGD independent advisers were provided with 1) eight applications (selected by the AGD Secretariat); 2) internal application assessment forms for each of the eight applications; and 3) an oversight and assurance template to complete.</p> <p>Following review of the applications by the AGD independent advisers out of committee, the completed oversight and assurance templates were sent to the AGD Secretariat prior to the meeting.</p> <p>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 advisers on the oversight and assurance templates would be collated by the AGD Secretariat and shared with the SIRO representative and relevant NHS England colleagues as may be appropriate.</p> <p>Please see appendix A for high-level points raised in-meeting on the eight applications.</p>
5.2	<p>Oversight and Assurance Conclusion / Review</p> <p>The SIRO representative noted that following the oversight and assurance review by the AGD independent advisers, work would be done out of committee with Data and Analytics colleagues to review all of the areas to consider comments made in-meeting, and the feedback provided on the oversight and assurance templates.</p> <p>The SIRO representative noted that further work was required with colleagues in Data and Analytics to review the process for the progression of applications via NHS England’s Precedent route, where more than one Precedent had been / should be applied.</p> <p>The SIRO representative noted that ahead of the next oversight and assurance review by AGD independent advisers, further discussions would take place with the AGD Secretariat to agree the types of applications selected for the next / future reviews, for example should this be by organisation type.</p> <p>It was noted by the group that the oversight assurances processes and reviews would be discussed / amended as may be appropriate / agreed, as this remit of work progresses.</p>
AGD Operations	
6	<p>Statutory Guidance</p> <p>The independent advisers again noted the reference to reviewing materials in accordance with “<i>a clearly understood risk management framework</i>” within the published Statutory Guidance and advised that they were not aware of an agreed risk management framework, and requested that NHS England provide further information/ clarity on this, 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: Written questions, answers and statements – UK Parliament.</p> <p>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 the interim data advisory group to use the NHS England DAS Standards and Precedents model to assess the risk factors in relation to items</p>

	<p>presented to the interim data advisory group for advice; however the independent advisers noted that the wording in the statutory guidance “...<i>using a clearly understood risk management framework, precedent approaches and standards that requests must meet...</i>”, 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 the Deputy Director, Data Access and Partnerships, Data and Analytics attended the meeting on the 23rd November 2023, and noted that plans for this work were in train.</p> <p>It had been noted previously that the Oversight and Assurance Programme of applications that had not be subject to AGD review could form part of this Risk Management Framework.</p> <p>The AGD Chair referred to the requirement within the published Statutory Guidance for an annual review; and that further thought / consideration was needed, on how the annual report would be presented, for example, on an NHS England standard template or other means.</p> <p>ACTION: The group to give further thought / consideration as needed, on how the annual report would be presented, for example, on an NHS England standard template or other means.</p> <p>The AGD Chair advised the group that a meeting would be held in early April 2024 (date TBC) with Jackie Gray, Director of Privacy and Information Governance, Privacy, Transparency and Trust (PTT) (and any relevant colleagues within PTT) to discuss the annual report further. It was noted that the AGD Chair had requested that the AGD Secretariat attend this meeting, to ensure they have the correct / relevant information to support this work. The group noted that the AGD Chair would provide further information in due course.</p> <p>ACTION: AGD Chair to update the group at an April 2024 meeting with regard to the annual report.</p> <p>The 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>AGD</p> <p>AGD Chair</p> <p>NHSE SIRO Rep</p>
7	<p>AGD Terms of Reference (ToR)</p> <p>The SIRO representative advised the group that the finalised draft AGD ToR had been discussed and approved at the Data, Digital and Technology Committee (DDAT) of the NHS England Board, on Thursday 14th March 2024.</p> <p>The SIRO representative noted that the finalised version of the AGD ToR would be circulated to the group and a copy would also be published on the (updated) AGD webpage by the AGD Secretariat as soon as possible.</p> <p>ACTION: SIRO representative to circulate the approved AGD ToR to the group (via the AGD Secretariat).</p>	<p>SIRO Rep</p>

	<p>ACTION: AGD Secretariat to ensure the approved AGD ToR is published on the AGD webpage, once the AGD website has been updated and approved for publication.</p> <p>The group noted that from the next AGD meeting on the 11th April 2024, the group would move from the 'interim advisory group for Data' to the 'Advisory Group for Data' in line with the approved AGD ToR.</p> <p>ACTION: The AGD Secretariat to include a 'ways of working in line with the finalised AGD ToR' agenda item to the 11th April meeting agenda.</p>	<p>AGD Sec</p> <p>AGD Sec</p>
8	<p>Standard Operating Procedures (SOPs) (Presenter: Vicki Williams)</p> <p>The ongoing forward plan of work for creating 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.</p> <p>It was noted that a further update would be provided to the group in due course.</p>	To note
9	<p>AGD Stakeholder Engagement</p> <p>As initially discussed at the AGD meeting on the 7th March 2024, it was noted that an AGD independent adviser had joined the Federated Data Platform (FDP) Data Governance Group as an AGD representative in an advisory capacity.</p>	
10	<p>AGD Chair engagement with Health Research Authority Confidentiality Advisory Group (HRA CAG) / National Data Guardian</p> <p>The AGD Chair noted that as part of the regular engagement, she was due to meet with Dr. Tony Calland, the Chair of the Health Research Authority Confidentiality Advisory Group (HRA CAG) and Dr. Nicola Byrne, the National Data Guardian for health and adult social care in England, on Tuesday 26th March 2024.</p>	
Any Other Business		
11.1	<p>AGD minutes clarification – 7th March 2024</p> <p>The group noted that following publication of the AGD minutes from the 7th March 2024; the AGD Secretariat had been advised by the presenter of item 6 'Public attitudes to data', that some of the information within the published minutes could benefit from further clarification .</p> <p>It was noted that the minutes should therefore state the following:</p> <p>Public attitudes to data (Presenter: Ellie Munari)</p> <p>Ellie presented 'public attitudes to data'. The group were advised that a programme of research had been undertaken to develop insight into public and NHS staff audiences, and how these audiences segment, in order to: 1) develop a proactive communications plan, with messages that are targeted, timely and impactful; 2) meet NHS England's duty of transparency; 3) understand how to support people in making informed decisions around data</p>	

	<p>sharing and/or opting out; and 4) support policy and programme development.</p> <p>The group were advised that the outcomes following the programme of research would made publicly available within the coming weeks and published on the NHS England website.</p> <p>The independent advisers noted the findings of the research and made a number of observations to Ellie and Shavaun.</p> <p>The group were advised that this research would feed into a programme of large-scale public engagement on data, which is starting soon. Ellie and Shavaun would welcome any feedback from the group on plans for this engagement programme, including if there are specific questions they would want put to the public.</p> <p>ACTION: Ellie and Shavaun to share plans for the large scale engagement programme with the group (via AGD Secretariat); and AGD Secretariat to add to the AGD forward planner for a discussion at a future AGD meeting.</p> <p>The group thanked Ellie and Shavaun for attending the meeting and advised that they would be supportive of further updates / engagement as required.</p>	EM / SG
11.2	<p>AGD Webpage update (Presenter: Karen Myers)</p> <p>Following the last update at the AGD meeting on the 7th March 2024; the group were provided with a presentation showing the updated (draft) AGD webpage.</p> <p>It was noted that a final review of the AGD webpage would be undertaken by the AGD Secretariat; reviewed / signed off by the NHS England SIRO representative and the AGD Chair; before publication on the NHS Digital website and ahead of the merger of NHS England, NHS Digital and Health Education England's websites.</p> <p>The group were advised that they would be notified once the updated AGD webpage had been published in early April 2024.</p> <p>The group noted, and thanked Karen, for the update and looked forward to confirmation that the updated AGD webpage had been published in due course.</p> <p>ACTION: AGD Secretariat to provide a provide confirmation to the group when the updated AGD webpage has been published.</p>	AGD Sec
11.3	<p>AGD future ways of working (Presenters: Vicki Williams / Karen Myers)</p> <p>Following the discussion at the AGD meeting on the 7th March 2024, the AGD Secretariat provided a further update to the group about AGD's future ways of working, in line with the approved AGD Terms of Reference.</p> <p>The group agreed a number of changes to how AGD would work from April 2024 meetings onwards, including but not limited to: a new start time of 9am, meetings continuing weekly each Thursday with regular reviews, and deadline changes for NHS England submission of items to the AGD forward planning meeting, and draft agenda sign off.</p>	

	ACTION: AGD Secretariat to share further information on the new ways of working to AGD and NHS England colleagues.	AGD Sec
11.4	Dr. Imran Khan Both independent advisers and NHS England noted that this was Dr. Khan’s final meeting and wished to extend their sincere thanks for his significant contribution over the last five years during his tenure on IGARD and the interim AGD.	
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 – 21st March 2024

Ref:	NIC Number:	Organisation:	Areas to consider:
240321a	NIC-148232-CPHLL-v7.4	National CJD Surveillance Unit	<ul style="list-style-type: none"> Outstanding privacy notice issue raised by IGARD Potential ethical issues
240321b	NIC-353882-J5X9Q-v3.3	University of Warwick	<ul style="list-style-type: none"> Not complied with NHS England DAS Standard for Commercial Purpose PPIE referenced in section 5(d) only Organisational data breach not addressed PhD student honorary contract
240321c	NIC-366216-Z9H9Q-v6.5	University of Sheffield	<ul style="list-style-type: none"> Action plan in place for application – not clear if progression via Precedent route is correct Section 5(b) not aligned with section 5(a) Privacy notice Opt-outs Commercial benefit Remove reference to “<i>this raised no moral or ethical issues</i>” Access via SDE
240321d	NIC-656811-F7T9C-v1.10	The Clatterbridge Cancer Centre NHS Foundation Trust	<ul style="list-style-type: none"> Precedent document unavailable Should AIMES be a Data Processor No information on control cohort

			<ul style="list-style-type: none"> • Charitable donation • Protocol document would have been useful • Principal Investigator and Chief Investigator roles • Honorary contracts - signed by whom: risk criteria • Good to see REC support and engagement with patients.
240321e	NIC-12828-M0K2D-v10.	Imperial College London	<ul style="list-style-type: none"> • Was the correct Precedent applied • Further justification of volume of data required • Need for University ethical support to continue • Not clear if Data Processor removed • Clarity as to former(?) ICL connection with Dr Foster (commercial benefit) • Tracked changes document would have been useful
240321f	NIC-332338-X1N2G-v1.5	University of Leeds	<ul style="list-style-type: none"> • Were all of the correct Precedents applied • Addition of Data Processor • Data destruction special condition • Good update to the benefits
240321g	NIC-381634-X8H0H-v7.2	UK Health Security Agency	<ul style="list-style-type: none"> • Security assurance plan – not met • Rationale for extension not clear • Large quantity of data • Ethical review documentation supporting documentation

240321h	NIC-459114-J3C1F-v3.	AstraZeneca UK Limited	<ul style="list-style-type: none"> • Surveillance purposes not part of purpose 2 / 3 therefore not covered by the DSA. • Removal of data destruction special condition • Not complied with NHS England DAS Standard for Commercial Purpose • No independent oversight of earlier versions of DSA
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