

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 1st February 2024

09:30 – 17:00

(Remote meeting via videoconference)

INDEPENDENT ADVISERS IN ATTENDANCE:	
Name:	Role:
Paul Affleck (PA)	Specialist Ethics Adviser (Items 6, 7, 8, 10, 11 and 13.1)
Claire Delaney-Pope (CDP)	Specialist Information Governance Adviser
Dr. Robert French (RF)	Specialist Academic / Statistician Adviser
Kirsty Irvine (KI)	Chair (Items 1, 4.1, 5.3, 10 and 13.1)
Dr. Imran Khan (IK)	Specialist GP Adviser (Chair for items 1 to 3, 4.2, 5.1, 5.2, 6 to 9, 11, and 13.2 to 13.5)
Jenny Westaway (JW)	Lay Adviser (not in attendance for part of item 8)
Miranda Winram (MW)	Lay Adviser (Items 6, 10 and 13.1)
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	Role / Area:
Laura Bellingham (LB)	Deputy Director, Data Access and Partnerships, Data and Analytics (Presenter: item 6)
Emma Bradbury (EB)	Business Analyst, Cohorting as a Service (CaaS), Platforms Directorate (Co-Presenter: item 4.2)
Sara Buck (SB)	Programme Manager, Cohorting as a Service (CaaS), Platforms Directorate (Co-Presenter: item 4.2)
Michael Chapman (MC)	Director of Data Access and Partnerships, Data and Analytics (Co-Presenter: item 7)
Garry Coleman (GC)	NHS England SIRO Representative (Presenter: items 13.2 To 13.4)
Dave Cronin (DC)	Assurance Lead, Data Governance and Assurance, Data and Analytics (Presenter: item 8)

Kate Fleming (KF)	NHS England Data and Analytics Representative (Delegate for Michael Chapman)
Louise Garnham	Service Delivery Manager, NHS DigiTrials, Data and Analytics (Observer: item 5.2)
Jackie Gray (JG)	Director Privacy and Information Governance, Privacy, Transparency and Trust (PTT) (Items 10 and 13.1)
Andrew Martin (AM)	NHS England Data Protection Office Representative (Delegate for Jon Moore)
Michael Murphie (MM)	Delivery Manager, Cohorting as a Service (CAAS) Platforms Directorate (Co-Presenter: item 4.2)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Delivery Directorate (Presenter: item 13.5)
Rahima Oliver (RO)	IG Lead, IG Delivery (Digital & Operations), Privacy, Transparency and Trust (Observer: item 4.2)
Jonathan Osborn (JO)	NHS England Caldicott Guardian Team Representative
Terry Service (TS)	Head of Data Access Service, Data and Analytics (Co-Presenter: item 7)
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Delivery Directorate (Presenter: item 11)
Tom Wright (TW)	Assurance Lead, Data Governance and Assurance, Data and Analytics (Presenter: item 4.1)
INDEPENDENT ADVISERS NOT IN ATTENDANCE:	
Prof. Nicola Fear (NF)	Specialist Academic Adviser
Dr. Geoffrey Schrecker (GS)	Specialist GP Adviser
Dr. Maurice Smith (MS)	Specialist GP 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) Terms of Reference (ToR) had not yet been 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 Request Service (DARS) 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 and Dr. Imran Khan noted and accepted the request from the NHS England SIRO Representative to chair; and welcomed attendees to the meeting.</p> <p>The group noted that the AGD Chair would not be in attendance for part of the meeting, however agreed, that in the absence of a final Terms of Reference, that the meeting was still quorate for all agenda items.</p>
2	<p>Review of previous AGD minutes:</p> <p>The minutes of the 25th January 2024 AGD 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>Dr. Jonathan Osborn noted a declaration of interest with NIC-641622-S4C1Q (University of Newcastle Upon Tyne), 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>Dr. Imran Khan noted a potential conflict with any applications / documents reviewed by the GPES Data for Pandemic Planning and Research – Profession Advisory Group (PAG) (item 4.2), as part of his roles as Chair of the Health Informatics Group at the RCGP and Co-Chair of the Joint GP IT Committee.</p>

BRIEFING PAPER(S) / DIRECTIONS / DATA PROTECTION IMPACT ASSESSMENT (DPIA):

4.1 **Title:** Bedford, Luton, and Milton Keynes Medical Interoperability Data Index (MIDI) Data Protection Impact Assessment (DPIA)

Presenter: Tom Wright

Three major incidents within the Bedford, Luton, and Milton Keynes (BLMK) Integrated Care Board (ICB) area in the past 18 months have highlighted the need for improved emergency response coordination. The ICB's Emergency Preparedness, Resilience and Response (EPRR) plan proposes implementing the Medical Interoperability Data Index (MIDI). This vital tool would give the on-scene Ambulance Service Tactical Commander who will act as National inter-agency liaison officer (NILO) instant access to resident information during emergencies, facilitating: **1)** faster and more efficient communication between emergency services; **2)** swifter identification of vulnerable residents requiring assistance; The independent advisers) smoother and more effective evacuation processes for residents' safety.

Various levels of access are outlined in the DPIA as are the criteria used by the MIDI tool to identify potentially vulnerable residents.

NHS England were seeking advice on the following points:

1. Is AGD supportive of the initiative; and do AGD have any concerns about using NHS England Data (namely PDS) for this purpose.

Outcome of discussion: The group welcomed the cover note and DPIA and made the following observations / comments:

In response to point 1:

4.1.1 The group noted that they were supportive of the concept outlined in the DPIA and cover note provided.

4.1.2 The group noted not all sections of the DPIA had been completed; and suggested that this document was updated with further information, and that once completed, suggested that the DPIA was published to ensure transparency to the public, particularly those in the ICB's footprint area.

4.1.3 The group noted the references to "*direct care*" within the DPIA, and suggested that any reliance on implied consent to meet the common law duty of confidentiality when processing confidential information for the purpose of direct care, was carefully set out. The group suggested that this was set out in line with points 3.2 (implied consent) and 5.3 (Legal aspects of sharing in direct care) of '[The Information Governance Review](#)', and taking into account the Caldicott Principles, in particular [Caldicott Principle 2](#) "*use confidential information only when it is necessary*"

4.1.4 The independent advisers suggested that consideration could be given to relying on overriding public interest as the justification to meet the common law duty of confidentiality for processing confidential information for this project. The advisers noted that this may be more

	<p>appropriate / less restrictive, and may cover a wider range of scenarios / personnel having access to the data etc; however, the group did note the 'high bar' that would need to be met to rely on this legal basis.</p> <p>4.1.5 The NHS England Data and Analytics representative noted the proposed work in the DPIA outlined under 'phase 3 - Collaborative Data Enrichment', and advised that this appeared to be potential 'scope creep'; and suggested that the legal basis for this work was explored further, noting that this may be beyond direct care / public interest.</p> <p>4.1.6 In addition, it was suggested that ethical consideration was given to phase 3, regardless of the identifiability of the data used, in line with NHS England's DAS Standard for Ethical Approval.</p> <p>4.1.7 The independent advisers suggested that thought should be given to expand the proposed processing beyond 'household' structure, for example, to also include schools, prisons etc.</p> <p>4.1.8 The group queried when the sharing of data / information will happen, and what type of emergencies would result in the data / information being shared; and suggested that for transparency, the DPIA was updated to clarify this information.</p> <p>4.1.9 The independent advisers queried whether the 'vulnerable patient list' used during the COVID-19 pandemic would be suitable to use to support this work, however, were advised by the NHS England Data and Analytics representative that this list would not be suitable for this work, noting that this was based on respiratory susceptibility to COVID-19.</p> <p>4.1.10 In addition, it was queried by the independent advisers whether the 'Priority Services Register' could be used to support this work; however, noted that the coverage within this Register may not be sufficiently comprehensive and would therefore not be appropriate.</p> <p>4.1.11 The independent advisers queried whether there would be a feedback loop / debrief after each emergency response, and suggested that this be explored further.</p> <p>4.1.12 The group advised that they would support a further review of the updated DPIA if NHS England required, at a future AGD meeting.</p>
4.2	<p>Title: Cohort Processing System Data Protection Impact Assessment (DPIA)</p> <p>Presenter: Emma Bradbury, Sara Buck, Michael Murphie</p> <p>The COVID-19 Pandemic required the rapid identification of patients at pace for critical response initiatives including Covid Vaccination, Therapeutics, Monoclonal Antibodies, Shielded Patient List, QCovid Risk Stratification. Cohorting as a Service (CaaS) aims to provide a central operational service to support clinical teams identify groups of patients for direct care.</p> <p>A centralised function for cohorting will provide for a repeatable, efficient, and consistent means of identifying patients for requested use cases; this will provide a model which will deliver cohorts quickly. The Cohort Processing System (CPS) is a fundamental component of this ecosystem and would act as a secure single source of truth for consistent, reusable and</p>

fast patient identification for direct care cohorts. The CPS will hold a Superjournal, which is a single view of the patient's demographic and medical data. It is a cache of patient data from the data sets that meet the use case requirements. The Superjournal will be refreshed at regular intervals based on frequency of updates to the national health datasets and the use case campaign dates. This cache of patient data will be retained based on the timescales detailed in the use case DPIA.

CPS facilitates a repeatable aspect of work that cannot happen within the current Data Processing Service (DPS), this means less processing time. CPS allows for improved configuration of technical coding which can be amended based the requirements of the cohort.

This DPIA is a framework DPIA which describes the approach to developing a new clinically assured cohorting infrastructure. It is currently restricted to Covid Vaccinations as the initial use case and has undergone a phased approach; over the coming months, further use cases will be onboarded. Each use case will be assured in its own right ensuring appropriate governance documents are in place before data can be processed within CPS.

NHS England were seeking advice on the following points:

1. The approved Framework DPIA is provided for information only and has a specific use case. AGD are asked to consider this approach for future cohorts which will require specific DPIAs and approvals.

Outcome of discussion: The group welcomed the cover note and DPIA and made the following observations / comments:

4.2.1 NHS England provided a brief overview of the Cohort Processing System to the group, including, but not limited to, the vision, objective, and purpose.

In response to point 1:

4.2.2 The group noted that advice was being sought on "*new use cases*", which would require a number of approvals before utilising the Cohort Processing System, for example, an information governance (IG) and clinical safety review.

4.2.3 The independent advisers queried the governance process for "*new use cases*", for example, if there was a new dataset requested; and were advised by NHS England, that there would be engagement with the Information Asset Owner (IAO) and that the DPIA would be updated to reflect any new datasets.

4.2.4 The group noted that they had a high level of confidence with regard to how risks in the DPIA provided had been considered by NHS England and the proposed governance route for new use cases. It was therefore suggested by the independent advisers that not all "*new use cases*" would need to be discussed with AGD and that they would be supportive of only novel or contentious cases being discussed at an AGD meeting as may be appropriate, for example where there were any potential high risks or significant new use cases that might be unexpected by the public.

	<p>4.2.5 Based on the discussion, NHS England advised that they would uplift this DPIA for new direct care uses, but it was agreed that those can be considered via usual NHS England approval channels; and that NHS England would only seek additional advice from AGD where the risk was high or the use case was novel or contentious.</p> <p>4.2.6 The independent advisers noted and commended NHS England on the information within the DPIA that addressed potential risks, noting their high level of confidence that the risks had been thoughtfully identified and addressed appropriately and would continue to be addressed appropriately within the DPIA.</p> <p>4.2.7 The independent advisers highlighted the importance of liaising with the General Practice Extraction Service (GPES) Data for Pandemic Planning and Research – Profession Advisory Group (PAG) on this area of work in order to build on previous discussions with the profession.</p> <p>4.2.8 The group noted potential concerns in respect of transparency and patients being contacted as a result of this work, and highlighted the importance of ongoing transparency, noting that the website had some good information but that it could be further improved by ensuring new purposes and screening were added, as and when.</p> <p>4.2.9 The group advised that they would be supportive of a further review of the updated DPIA if NHS England required, at a future meeting.</p>
EXTERNAL DATA DISSEMINATION REQUESTS:	
5.1	<p>Reference Number: NIC-641622-S4C1Q-v0.6</p> <p>Applicant: University of Newcastle Upon Tyne</p> <p>Application Title: Emerging evidence on the impact of COVID-19 on mental health services and health inequalities in highly deprived communities (DEEP)</p> <p>Application: This was a new application.</p> <p>The purpose of the application is for a study, which aims to examine the impact of the COVID-19 pandemic and lockdown periods on patterns of engagement with mental health services for people from the most deprived communities in North East and North Cumbria, and determine whether these patterns were associated with health-related outcomes.</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: At the request of the SIRO representative in-meeting, the group provided preliminary advice only on this application, and suggested that the application be brought back to a future meeting.</p> <p>5.1.1 Noting the information in the study protocol provided as a supporting document (SD1.1) that suggested there would be linkage to primary and secondary care data; it was suggested by the group, that the internal application assessment form and application were updated to provide further clarity on the processing of this data,</p>

	<p>including, but not limited to, clarification on who can access the primary care and secondary care data.</p> <p>5.1.2 The SIRO representative noted the risk of re-identification should the data be linked to GP data; and asked that the application was updated to be clear that the data could not be linked with the GP data, noting that there was not a clear legal basis to do this.</p> <p>5.1.3 The SIRO representative also noted that there was a further risk, if the applicant had access to Personal Demographics Service (PDS) data or other Spine services, they may be able to directly identify patients; and suggested that this was addressed / mitigated as appropriate within the application.</p> <p>5.1.4 The independent advisers noted in the internal application assessment form that one of the identifiers required for analysis was “<i>occupation</i>”; and noting that the application was currently silent on this point, advised that the application be updated to reflect this, including how the “<i>occupation</i>” data would be processed.</p> <p>5.1.5 The independent advisers and the NHS England Caldicott Guardian Team representative noted concern that engagement with mental health services by some professional groups would be missed in this study, for example, medical colleagues who use private or practitioner mental health support services / networks and those not seeking mental health support.</p> <p>5.1.6 The group noted that there would be differential reasons for individuals accessing mental health services initially, and queried if / how a comparison group would be built; and suggested that the application form was updated with further clarification, noting that this was currently unclear.</p> <p>5.1.7 Noting that the data sharing agreement (DSA) was due to expire on the 1st February 2025, the independent advisers expressed concern as to whether the planned objectives, outcomes and benefits could be achieved within this timeframe.</p> <p>5.1.8 The independent advisers noted that the s251 support was no longer required, and that the data would be limited to a study cohort identified by the Data Services for Commissioners Regional Office (DSCRO); and suggested that it was made clear in the application that there was a clear legal basis for this within NHS England’s vires.</p> <p>5.1.9 The group noted concern on the content of the GP poster provided as a supporting document (SD5.2), including but not limited to, the information outlining who is eligible to take part in the study, which incorrectly implies patients have a choice; the references to Health Research Authority Confidentiality Advisory Group (HRA CAG), which are no longer relevant / correct; the opt out information was not clear / correct; and the inconsistent language in respect of the type of data being processed.</p> <p>5.1.10 It was also noted by the group, that the processing outlined in the transparency materials did not accurately align with the processing outlined in the</p>	
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	<p>application; and suggested that this was reviewed and addressed as may be appropriate to ensure consistency and accuracy.</p> <p>5.1.11 The group queried why the University of Newcastle Upon Tyne do not have a study-specific privacy notice, or a more accessible privacy notice; and suggested that this was reviewed and addressed, in line with NHS England's DAS Standard for Transparency.</p> <p>5.1.12 The independent advisers noted in the internal application assessment form, and the application, that ethics approval was not required and had not been sought by the applicant, due to the category of data requested. However, suggested that the applicant approach their institutional ethics committee and ask whether an ethical review is required; and that any supporting documentation is uploaded to NHS England's customer relationships management (CRM) system for future reference.</p> <p>5.1.13 Separate to the application: it was reiterated by the independent advisers that as discussed on the 5th October 2023, the NHS England's Ethical Approval Standard was reviewed, to ensure that there is an obligation on the applicant to seek ethical support from their institution and in line with their organisation's policy; or for the institution to confirm that ethical support was not required.</p> <p>ACTION: NHS England DAS to review the NHS England's Ethical Approval Standard, to ensure that there is an obligation on the applicant to seek ethical support from their institution and in line with their organisation's policy; or for the institution to confirm that ethical support was not required.</p>	DAS
5.2	<p>Reference Number: NIC-647363-F3R4R-v0.8</p> <p>Applicant: University of Oxford</p> <p>Application Title: An open label Phase I/IIa clinical trial to assess the safety, immunogenicity and efficacy of the malaria vaccine candidate RH5.2-virus-like particle (VLP) (BIO001) – NHS DigiTrials Recruitment Service</p> <p>Observer: Louise Garnham</p> <p>Application: This was a new application.</p> <p>The purpose of the application is for a study, is specifically to support the recruitment of a cohort for the BIO-001 study by writing out to approximately 4,000 individuals who meet the initial recruitment eligibility criteria of age and postcode area.</p> <p>Should an application be approved by NHS England, further details would be made available within the Data Uses Register.</p> <p>Outcome of discussion: The group were broadly supportive of the application and wished to draw to the attention of the SIRO the following substantive comments:</p> <p>5.2.1 The group noted that the invitation letter had not been provided as a supporting document in line with usual process, and they were therefore unable to comment on this as part of the review; and suggested that NHS England review the</p>	

	<p>letter and seek further advice from the group, should there be any concerns over risks associated with the content of this letter.</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>5.2.2 The independent advisers noted and commended the information that had been included in the application, in respect of the role of the commercial companies involved and investigators' interests. However they suggested that this was updated to be more specific as to how the commercial organisations contribute to the study; (for example by providing drugs cost-free) and the potential benefits that could accrue to the commercial organisations (for example if the treatments were approved), in line with NHS England's DAS Standard for Commercial Purpose.</p> <p>5.2.3 The independent advisers noted the reference to the "OVG <i>opt out</i>" within the Health Research Authority Confidentiality Advisory Group (HRA CAG) Integrated Research Application System (IRAS) form, provided as a supporting document (SD4.0); and suggested that the applicant review the transparency materials to ensure the right of participants in respect of withdrawing from the trial is accurately reflected, as well as clarification as to what happens to their data if they do withdraw consent.</p> <p>5.2.4 In addition, it was queried whether the "OVG <i>opt out</i>" had any impact on the DigiTrials cohort; and suggested that this was clarified in the application for transparency</p> <p>5.2.5 Noting that it was currently unclear, the independent advisers suggested that the application was updated to be specific on the rationale for the inclusion and exclusion criteria for the study cohort; and noted that the applicant should review / consider underrepresented groups or that specific groups are targeted.</p> <p>5.2.6 The SIRO representative asked that the application was updated to be clear that the study would not include deceased individuals.</p> <p>5.2.7 The independent advisers noted that this specific trial was difficult to recruit to; and suggested that this was noted / acknowledged within the application, and that there was an explanation as to why there had been difficulty with recruitment.</p> <p>5.2.8 It was also suggested by the independent advisers that for transparency, it was clear within section 5 (Purpose / Methods / Outputs) of the application, why the University of Oxford had chosen to recruit the cohort via DigiTrials, noting the vast amount of knowledge and experience with the University of Oxford.</p> <p>5.2.9 The independent advisers noted that there was not a clear narrative on the analysis that was going to be undertaken on the response rates to DigiTrials; and suggested that this was defined within the application, and to clearly define what "success" should look like, to support future / wider work undertaken by DigiTrials.</p>	
5.3	Reference Number: NIC-147757-8SVGP-v3.6	

	<p>Applicant: University of Oxford</p> <p>Application Title: HPS 3 / TIMI 55: REVEAL (Randomized EVAluation of the Effects of Anacetrapib through Lipid-modification)</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the IGARD meeting on the 27th October 2022.</p> <p>Application: This was a renewal and amendment application.</p> <p>The purpose of the application is for a study, which aims to provide reliable evidence about the very long-term effects of anacetrapib (a cholesteryl ester transfer protein (CETP) inhibitor) on important health outcomes.</p> <p>The amendment is to expand the list of datasets provided to include Hospital Episode Statistics (HES); Emergency Care Data Set (ECDS), National Diabetes Audit (NDA) and Medicines Dispensed in Primary Care (NHSBSA) Data, which the trial had not previously received, for use in post-trial follow up.</p> <p>NHS England were seeking advice on the following points:</p> <ol style="list-style-type: none"> 1. Whether a) the extended retention/reuse of the Data and b) the collection of the additional data are likely to be in line with the participants' reasonable expectations and compliant with the Caldicott Principle setting out that <i>"A range of steps should be taken to ensure no surprises for patients and service users, so they can have clear expectations about how and why their confidential information is used, and what choices they have about this"</i>; and 2. Whether the applicant must or should be advised to undertake further steps to communicate with the study cohort. <p>Should an application be approved by NHS England, further details would be made available within the Data Uses Register.</p> <p>Outcome of discussion: The group were broadly supportive of the application and wished to draw to the attention of the SIRO the following substantive comments:</p> <p>In response to points 1 and 2</p> <p>5.3.1 The group noted the importance of the long-term follow-up and the yielded benefits to date that were succinctly described in the Data Uses Register.</p> <p>5.3.2 It was noted by the group that a consent review had not been provided by NHS England to the group, in line with usual process.</p> <p>5.3.3 The group suggested that NHS England should satisfy itself that the extended retention / reuse of the data requested under this iteration of the application, was only for those cohort members who went through the long-term follow-up process (approximately seven years ago), for example, engaging with a research nurse beyond their initial consent process. If this was confirmed, then the group advised that they would be supportive of the retention / reuse of the data.</p>	
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<p>5.3.4 The group advised that they would not be supportive of the extended retention / reuse of the data, for those cohort member who joined the cohort around 2010/2011, and have had no further contact / engagement from the study team about the long-term follow up stage; noting the statements with the original patient information sheet, that may conflict with Caldicott Principle 8, “...A range of steps should be taken to ensure no surprises for patients and service users...”.</p> <p>5.3.5 The group suggested that in order to establish that processing was still within the reasonable expectations of those cohort members, the applicant could engage with a small group of cohort members (more than 3 but less than 10), to test whether they would be surprised by the longer term follow-up.</p> <p>5.3.6 The independent advisers noted and commended the applicant on the excellent website and informative patient information sheet. The independent advisers suggested that the applicant could further utilise the website, to invite cohort members to get in touch if they would like to be involved with ongoing patient and public involvement and engagement (PPIE) work such as the communication suggested in point 5.3.5 above.</p> <p>5.3.7 In addition, the independent advisers noted that they would be supportive of any additional flows of data for a small number of cohort members, to ensure that the latest contact details were available to support PPIE for the purpose of seeking views on the longer term follow-up.</p> <p>5.3.8 The independent advisers suggested that NHS England clarify with the applicant, whether a further ethical review is required for the longer-term follow-up; and that any supporting documentation is uploaded to NHS England’s customer relationships management (CRM) system for future reference.</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>5.3.9 It was queried by the independent advisers whether the data could be minimised further to ensure that the data only captures serious illness in line with consent materials; and suggested that this was reviewed in line with NHS England’s DAS standard for data minimisation.</p> <p>5.3.10 The group advised that they would be supportive of any further reviews of this application as may be required by NHS England, to support the progression of this application.</p> <p>5.3.11 Separate to this application: The group noted that an internal ‘DAS escalation form’ had been provided as a supporting document for this application, as opposed to the usual internal application assessment form; and requested that further information was provided by colleagues in DAS to support the use of this form by the group when reviewing applications.</p> <p>ACTION: NHS England’s DAS to provide further information on the DAS escalation form.</p>	<p>DAS</p>
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	<p>5.3.12 Separate to this application: Noting the statement in the internal DAS escalation form that “<i>this application which could inform precedents for future applications of similar kinds</i>”; it was suggested by the independent advisers, that this application should not form the basis of a Precedent, due to the subjective nature of the consent review; and that this may be a high-risk approach.</p>	
6	<p>NHS England Precedents and Standards and the DSA Risk Assessment (Presenter: Laura Bellingham)</p> <p>Laura attended the meeting to provide the group with a further update on the NHS Precedents and Standards, following the last discussion at the AGD meeting on the 7th December 2023 and the 23rd November 2023.</p> <p>The group had a lengthy discussion on the information provided in the meeting, and focussed on a number of issues, including, but not limited to, the interim Precedent process, access models and DSA Risk Assessment Framework.</p> <p>It was noted from Laura that there would be weekly workshops over the next six-weeks, to discuss / progress the NHS England Precedents and Standards work, and that they would welcome an AGD independent adviser(s) to attend / contribute. The AGD Secretariat noted that names of AGD independent advisers able to attend the workshops had been shared (via e-mail) on the 12th January 2024; Laura noted and advised that further workshop information would be shared with the AGD independent advisers following the meeting.</p> <p>It was noted by Laura that a further update would be provided to the group following completion of the workshops, at the AGD meeting on the 21st March 2024.</p> <p>ACTION: AGD Secretariat to add the next NHS England Precedents and Standards update to the AGD meeting forward planner on the 21st March 2024.</p> <p>The group thanked NHS England for providing an update and looked forward to further discussions at future AGD meetings.</p>	VW / KM
7	<p>Application Compliance Report (ACR) (Presenters: Michael Chapman / Terry Service)</p> <p>The group noted that as part of the meeting pack circulated to the group in advance of the meeting, a paper had been provided, that outlined the process for ACRs, which are required where a data sharing agreement (DSA) is for longer than 12-months, to confirm compliance with the terms and conditions of the DSA and Data Sharing Framework Contract (DSFC). This is specified within the Special Conditions section of the DSA.</p> <p>The independent advisers suggested that the Statement of Truth could be strengthened, to reference the potential for incorrect statements to be taken into account in future data access, and that need for this strengthening could be</p>	

	<p>considered alongside the messages in covering letters accompanying the ACR request.</p> <p>The independent advisers also suggested further clarifications to paragraphs 13, 14 and 16 of the ACR form.</p> <p>It was noted by Michael and Terry that completed ACRs were being received by NHS England DAS; and outlined the process taken when applicants are not completing / sending in the ACR.</p> <p>In addition, the group were advised that oversight and assurance of this process would be discussed with the group at the AGD meeting on the 21st March 2024.</p> <p>ACTION: AGD Secretariat to add the ACR oversight and assurance discussion to the AGD meeting forward planner on the 21st March 2024.</p> <p>The independent advisers noted that they would be happy to provide feedback on the core principles of the ACR Standard Operating Procedure (SOP) should NHS England require this feedback.</p> <p>It was noted by the independent advisers that, if not already in progress, the ACR process as a whole should be reviewed in a year's time, in terms of frequency of the ACR and NHS England resources.</p> <p>It was noted by Michael and Terry that, should the group have any additional feedback, they would be happy to receive this via e-mail following the meeting.</p>	<p>VW / KM</p> <p>ALL</p>
8	<p>Special Conditions and Standard Wording (Presenter: Dave Cronin)</p> <p>The group noted that as part of the meeting pack circulated to the group in advance of the meeting, version 1.2 of the special conditions and standard wording document had been included for review / discussion in-meeting.</p> <p>The group provided verbal feedback as part of this review to support the development / progression of this document / area of work.</p> <p>It was noted by Dave that an updated version of this document would be shared with the group in due course.</p> <p>ACTION: An updated version of the special conditions and standard wording document to be shared with the group.</p> <p>It was agreed by the group that should any further special conditions be discussed at future AGD meetings, they should be noted in the special conditions and standard wording document; that these would be noted in the AGD minutes with an action for colleagues in DAS.</p>	DC
AGD Operations		
9	Statutory Guidance	

	<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 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 an 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 SIRO representative noted an outstanding action in respect of providing a written response to AGD on the risk management framework; and noted that this had been discussed under item 6.</p>	
10	<p>AGD Terms of Reference (ToR)</p> <p>The independent advisers noted that over eight months had passed since the Statutory Guidance had been published, requiring a ToR to be agreed and published.</p> <p>The Director of Privacy and Information Governance, Privacy, Transparency and Trust, Jackie Gray, attended the meeting to advise the group that following the workshop on the 27th November 2023, the draft ToR had been updated further following feedback from other stakeholders, and that a further draft version of the updated ToR would be shared with the group for information, prior to this document being submitted to the NHS England Board / subcommittee of the Board.</p> <p>ACTION: The SIRO representative to provide a copy of the final draft of the ToR prior to this document being submitted to the NHS England Board / subcommittee of the Board.</p> <p>The group reiterated requested that the version control on the ToR be updated to reflect the full circulation of the document and the timing of such circulation.</p>	GC

11	<p>Standard Operating Procedures (SOPs)</p> <p>The ongoing forward plan of work for creating Standard Operating Procedures was discussed and noted that although this could not progress further without sight of the final ToR, work was ongoing to progress and finalise the AGD SOPs, in line with the progression of the AGD ToR.</p> <p>It was noted that some of the independent advisers and the SIRO representative were supporting the progression of the SOPs out of committee; and that a workshop would be held with the group in March 2024, to discuss this further.</p> <p>The group noted the update and looked forward to further discussions at future AGD meetings.</p>	To note
12	<p>AGD Action Log</p> <p>The group reviewed the outstanding actions on the AGD action log, that consists of all actions captured at AGD meetings from the 2nd February 2023.</p> <p>The AGD Secretariat asked that if anyone had any further updates to the AGD action log, to ensure they were forwarded to the team before Wednesday so that that next iteration of the action log could be circulated prior to discussion at the next AGD meeting</p>	To Note
Any Other Business		
13.1	<p>Independent adviser day rate (Presenter: Jackie Gray)</p> <p>The Director of Privacy and Information Governance, Privacy, Transparency and Trust, Jackie Gray attended the meeting, to update the group on the independent adviser day rate (last discussed at the AGD meeting on the 25th January 2024).</p> <p>The group were advised by Jackie, that the request for a further 10% uplift (15% in total from the rate set in 2016 and unchanged) had been submitted to NHS England HR for consideration on the 19th January 2023; and that the request had not been approved. It was noted that further information would be shared with the group confirming why this request had not been approved.</p> <p>ACTION: The SIRO representative to provide clarity to the group as to why the request for a further 10% uplift was rejected by NHS England's HR.</p> <p>In addition, Jackie advised that further discussions were ongoing to look at other types of contracting arrangements, both for current independent advisers and future independent advisers.</p> <p>In addition, Jackie advised that benchmarking would be undertaken against other similar boards and committees, to support ongoing discussions with NHS England's HR on this issue.</p>	

	<p>The group were advised by Jackie that there would be further engagement with the group on this issue in due course.</p> <p>The independent advisers noted and thanked Jackie for the verbal update and looked forward to a further update / engagement in due course.</p>
13.2	<p>NHS England's Trusted Research Environment (TRE) – Data Controllership (Presenter: Garry Coleman)</p> <p>The NHS England SIRO representative advised the group that there were ongoing discussions in respect of NHS England's position regarding TRE data controllership, for example, the current position that indicates NHS England is a joint Data Controller with the organisation accessing the data, however, advised that this may vary depending on specific factors.</p> <p>It was noted that whilst this was in the process of being clarified, existing applications would reflect current arrangements; and for any new applications would reflect the position of NHS England as a Data Controller.</p> <p>The group noted and thanked Garry for the verbal update and looked forward to a further update in due course.</p>
13.3	<p>Audit (Presenter: Garry Coleman)</p> <p>The NHS England SIRO representative advised that Deloitte's would be undertaking a planned audit on NHS England's safe haven arrangements, commencing in the coming weeks; and that as part of this audit, NHS England's process for AGD may be looked at.</p> <p>The group noted and thanked Garry for the verbal update and looked forward to a further update in due course.</p>
13.4	<p>Health Service Journal (HSJ) article on the Federated Data Platform (FDP) (Presenter: Garry Coleman)</p> <p>The NHS England SIRO representative advised that NHS England were aware of a recent article in the HSJ on the FDP and the lawful basis.</p>
13.5	<p>AGD Webpage (Presenter: Karen Myers)</p> <p>The group were advised by Karen, that there ongoing discussions with NHS England's Web Team, in respect of 1) forthcoming updates to the AGD webpage; and 2) the current accessibility / visibility of the AGD webpage; and 3) the location of the AGD webpage.</p> <p>It was noted that further engagement / updates would be provided with / to the group over the coming weeks / months.</p>

	The group noted and thanked Karen for the update, and looked forward to a further update in due course.
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Meeting Closure

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