

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 14th December 2023

09:30 – 15:45

(Remote meeting via videoconference)

INDEPENDENT ADVISERS IN ATTENDANCE:	
Name:	Role:
Paul Affleck (PA)	Specialist Ethics Adviser
Claire Delaney-Pope (CDP)	Specialist Information Governance Adviser
Dr. Robert French (RF)	Specialist Academic / Statistician Adviser (Item 7)
Kirsty Irvine (KI)	Chair
Dr. Imran Khan (IK)	Specialist GP Adviser
Jenny Westaway (JW)	Lay Adviser (Item 7)
Miranda Winram (MW)	Lay Adviser
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	Role / Area:
Noela Almeida (NA)	NHS England Data Protection Office Representative (Delegate for Jon Moore)
Susheela Andani (SA)	Information Governance Specialist, Privacy, Transparency and Trust (PTT), Delivery Directorate (Observer: items 1 to 12.3)
Laura Bellingham (LB)	Deputy Director, Data Access and Partnerships, Data and Analytics (Presenter: Item 7)
Garry Coleman (GC)	NHS England SIRO Representative (Observer: Item 7)
Duncan Easton (DE)	Assurance Team, Data Access Service (DAS) (Observer: item 4.1)
Kate Fleming (KF)	NHS England Data & Analytics Representative (Delegate for Michael Chapman)
Dickie Langley (DL)	NHS England SIRO Representative (Delegate for Garry Coleman)

Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Delivery Directorate
Jonathan Osborn (JO)	NHS England Caldicott Guardian Team Representative
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Delivery Directorate
Tom Wright (TW)	Assurance Lead, Data Governance and Assurance, Data Access and Partnership Directorate (Presenter: item 7)
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)	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 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>
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	Kirsty Irvine noted and accepted the request from the NHS England SIRO Representative to chair; and welcomed attendees to the meeting.
2	Review of previous AGD minutes: The minutes of the 7 th December 2023 AGD meeting were reviewed and subject to a number of minor amendments were agreed as an accurate record of the meeting.
3	Declaration of interests: There were no declarations of interest.
BRIEFING PAPER(S):	
4.1	<p>Title: West Yorkshire ICB request for permission to link Commissioning Datasets disseminated by NHS England to multiple non-NHS England datasets</p> <p>Observer: Duncan Easton</p> <p>The purpose of the briefing paper is to advise the group that West Yorkshire Integrated Care Board (ICB) is requesting permission to link their commissioning datasets, processed under Data Sharing Agreement (DSA) NIC-616019-B4C8W, to several non-NHS England datasets for the purposes of supporting their commissioning & population health management work.</p> <p>The datasets proposed to be linked to the NHS England data are sourced from the ICB area's Local Authorities and community care providers. Some of the proposed linkages show similarities to data linkages already permitted under the current ICB's DSA, such as Adult Social Care, however for the most part this request is a new data linkage.</p> <p>NHS England were seeking advice on the following points:</p> <ol style="list-style-type: none"> 1. Advice on whether the proposed data linkage is appropriate and whether the information provided by the ICB is sufficient in outlining the justification for the proposed data linkages. 2. That the purposes outlined within the briefing paper and the linked datasets specification (supporting document 2) align with the commissioning purposes under the DSA for NIC-616019-B4C8W (Supporting document 1) or whether these purposes extend beyond what is set out in the DSA and an amendment to the purposes would be necessary, or if further information is necessary. 3. Whether AGD agree that the purposes for re-identification are appropriate, and the example provided aligns with the purpose of direct care. 4. Whether AGD agree with the points raised by DAS* to be addressed further within this briefing in respect of: <ol style="list-style-type: none"> a. Legal basis for collecting the externally sourced datasets b. Sub-licensing of the data 5. Where members would advise DAS* to seek further information from the ICB regarding a risk / concern not currently addressed within the briefing.

6. Broadly, whether they would be supportive of NHS England data being linked to the datasets set out within the proposal for the purposes set out within the DSA for **NIC-616019-B4C8W** (Supporting document 1).

**DAS – Data Access Service*

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

4.1.1 The group noted that the briefing paper was currently in early draft, although that was not clear in the documentation presented, and that further updates would be made to the briefing paper and associated documentation following the comments and feedback from AGD.

In response to points 1 and 6:

4.1.2 The group advised that they were generally supportive of the concept and could see public benefit in such data linkages.

4.1.3 The group noted that the documents provided, for example, the linked datasets specification spreadsheet, were helpful to understand the proposal and supported the review of the briefing paper by the group.

4.1.4 The Caldicott Guardian Team representative noted that this proposal was still undergoing further work, however noted that further work would need to be progressed on a number of areas, including, but not limited to, transparency; which the group noted and supported.

4.1.5 Noting that the National Data Opt-out (NDO) is not applied to pseudonymised data released for the purpose of commissioning, the independent advisers and SIRO representative noted that if people knew their data was, for example, being linked to other data such as housing or domestic abuse services provided by the Council, they may wish to opt out; and suggested that NHS England give this more thought. The group noted their concerns around individuals possibly withdrawing from services to prevent their data being shared.

In response to point 2:

4.1.6 The group queried whether the proposal outlined could be done under the commissioning work outlined already in NIC-616019-B4C8W; or whether it would be more appropriate for the applicant to use identifying data under a new data sharing agreement (DSA) and the ICB act as a link to the other organisations involved, for example, the housing provider and the GP.

In response to point 3:

4.1.7 The group noted that it was logical that ICBs would want to undertake the linkage of datasets, however, noted that ICBs **do not** have a statutory function to provide direct care (and this point was expressly noted in the relevant DSA). Working within the parameters of the existing DSA (NIC-616019-B4C8W), it was noted that there a brief reference to “*direct care*”, however the group noted that it was clear that it was **not** the ICB that was providing the direct care, and that the assessment of the risk was with the healthcare provider, and that this be clearly articulated within the briefing paper.

4.1.8 If this model was brought within this DSA structure, it was suggested by the group that it be made explicitly clear within the documentation that any re-identification for the purpose of direct

	<p>care, was being undertaken at the request of healthcare professionals and that the ICB was part of a wider process, between the various parties involved.</p> <p>In response to point 4:</p> <p>4.1.9 The group queried what the current level of re-identification requests were to the Data Services for Commissioners Regional Office (DSCRO) responsible for West Yorkshire ICB; and what the projected re-identification requests were; and suggested that further information was provided within the briefing paper.</p> <p>4.1.10 The group also suggested that further clarity was provided within the briefing paper as to how the DSCRO addresses the Common Law Duty of Confidentiality (CLDoC) for the healthcare data in each case.</p> <p>4.1.11 The SIRO representative noted that there was a risk to NHS England that the providers of the externally sourced data may not be complying with their own statutory, regulatory or CLDoC requirements / obligations; and asked that this was addressed within the briefing paper, noting that NHS England cannot oversee this.</p> <p>4.1.12 The group queried how the externally sourced data will be linked, for example, what is the unique identifier that is used to generate a common pseudonym enabling the datasets to be linked together; and if this was NHS numbers, as per the linked datasets specification spreadsheet. It was suggested by the group that further clarification was provided within the briefing paper as to how this is happening and what the legal basis is for this.</p> <p>In response to point 5:</p> <p>4.1.13 The group queried whether the data providers have consulted with their data subjects, for example, have they completed a DPIA and what are the plans for communication, engagement, and transparency with the cohort.</p> <p>4.1.14 The group noted that, for any future reviews of this briefing paper, it would be helpful to also have sight of information governance advice from NHS England's Privacy, Transparency and Trust (PTT) (formerly Privacy, Transparency, Ethics and Legal (PTEL)); and would also welcome a member of PTT attending for the next discussion.</p> <p>4.1.15 The group looked forward to receiving an updated briefing paper at a future meeting.</p>
4.2	<p>Title: Cancer Programme Pilots Evaluation Directions 2023 Briefing Paper</p> <p>Previous Reviews: The briefing paper and relevant supporting documents were previously presented / discussed at the AGD meeting on the 9th November 2023.</p> <p>The purpose of the briefing paper was to inform AGD that the Cancer Programme is requesting a Direction to cover establishing and operating a system for collecting, linking and analysing information from Cancer Programme pilots. It is anticipated that there will be multiple data collections (one for each pilot) within the scope of these Directions. Each collection will have a requirements specification published alongside these Directions.</p>

	<p>There are two initial specifications being drafted for these Directions, these cover the data collection for 1) The Targeted Lung Health Check Pilot Evaluation; and 2) The Community Pharmacy Pilot Evaluation.</p> <p>Outcome of discussion: The group welcomed the finalised briefing paper and confirmed that they had no further observations / comments. The briefing paper was therefore finalised as an artefact to be included as a supporting document, as and when required.</p> <p>The group provided the following observations / comments, separate to the finalised briefing paper:</p> <p>4.2.1 The independent advisers noted that whilst they had no further comments on the briefing paper, they had noted the responses from NHS England to the queries / comments previously raised in respect of consent not being adequately considered as an alternative to a Direction, and whether s251 of the NHS Act 2006, should be explored (paragraph 4.4.9); and suggested that NHS England should give both of these points further consideration for future / similar work going forward.</p> <p>4.2.2 It was noted that there was an NHS England presentation scheduled for an AGD meeting in January 2024 in response to these comments previously raised and that members could discuss these concerns in that session.</p>
EXTERNAL DATA DISSEMINATION REQUESTS:	
5.1	<p>Reference Number: NIC-392012-L7T4Q-v0.3</p> <p>Applicant: Nottingham University Hospitals NHS Trust</p> <p>Application Title: Incidence of peri-prosthetic fracture with the cemented collarless polished taper stem</p> <p>Application: This was a new application.</p> <p>The purpose of the application is for a study to identify if any of the patients who have had a collarless taper stem total hip replacement in Nottingham University Hospitals have suffered a periprosthetic fracture after surgery.</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 substantive comments:</p> <p>5.1.1 The group noted that section 5(e) (Is the Purpose of this Application in Anyway Commercial) of the application stated that there was no commercial aspect to the application; and the internal application assessment form stated that Zimmer Biomet (the funder) “...do not determine the purpose or means of the processing and have no Data Controllorship responsibilities”. It was noted that Zimmer Biomet not having data controllership responsibilities was not determinative of whether there would be a commercial benefit. It was suggested that the internal application assessment form, and section 5(a) (Objective for Processing) and section 5(e) of the application,</p>

were updated to fully explain the full breadth of the potential commercial benefit to the funder, in line with [NHS England's DAS Standard for Commercial Purpose](#).

5.1.2 In addition, it was noted by the group that Zimmer Biomet would benefit from the study, regardless of whether the implant is deemed to be successful or not, noting that they manufacture a range of implants, and would therefore be interested in the outcomes of the study. It was suggested that, for transparency, this was made clear in section 5(a) and section 5(e) of the application, in line with [NHS England's DAS Standard for Commercial Purpose](#).

5.1.3 It was queried by the group what proportion of the funding was being provided by Zimmer Biomet, for example, was this funding only for the fee payable to NHS England or were other aspects of the study being funded; and suggested that this was made clear in the internal application assessment form and section 5(a) of the application.

5.1.4 In respect of data controllership, it was suggested by the group that NHS England clarify with the applicant, whether Nottingham University Hospitals NHS Trust approached Zimmer Biomet to fund the study, or vice versa; and to consider whether the outcome of this question had any impact on data controllership. If it was deemed that Zimmer Biomet were considered a joint Data Controller, the group suggested that the internal application assessment form and the application were updated as appropriate, in line with [NHS England's DAS Standard for Data Controllers](#).

5.1.5 The independent advisers noted the Health Research Authority Confidentiality Advisory Group (HRA CAG) condition of support in the letter of support dated the 2nd November 2021 (SD6.2), that stated "*the applicant should provide a report on the study specific patient and public involvement undertaken at the first annual review*". It was noted that in the HRA CAG annual review form (SD5.4) that although the applicant had submitted an update on this point, there was no information in respect of what **study specific** patient and public involvement had been undertaken. It was suggested that NHS England clarify with the applicant and HRA CAG that the HRA CAG specific condition of support had been met.

5.1.6 The independent advisers noted the statement in the HRA Research Ethics Committee (REC) letter of support dated the 21st February 2022 (SD6.5) that "*Therefore no honorary research contracts or letters of access are expected for this study*"; however noted the references within the application and internal application assessment form to a "*letter of access*"; and suggested that NHS England clarify with the applicant whether the HRA REC support needed to be updated to reflect that there will be a letter of access.

5.1.7 In addition the independent advisers suggested that NHS England review the 'letter of access' to ensure this meets [NHS England's DAS Honorary Contracts Standard](#).

<p>5.1.8 The group also suggested that NHS England add a special condition to section 6 (Special Conditions) to specify the contractual clauses of anyone operating under a 'letter of access'.</p> <p>5.1.9 In respect of data minimisation, it was noted by the SIRO representative that the Hospital Episode Statistics Admitted Patient Care (HES APC) data had been requested from 2009, and suggested that section 3(b) (Additional Data Access Requested) and section 5 (Purpose / Methods / Outputs) of the application were updated to be clear on what data will flow for which members of the cohort, noting that this was currently unclear.</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>5.1.10 Noting in the internal application assessment form that Zimmer Biomet require thirty days to review the draft publication before Nottingham University Hospitals NHS Trust publish; it was suggested by the independent advisers that the application was updated to strengthen the contractual clause, for example, to state that Zimmer Biomet will not suppress or alter any outcomes of the study.</p> <p>5.1.11 Noting the statement in the internal application assessment form that the data supplied from the National Joint Registry (NJR) was "<i>not sufficient</i>"; the group suggested that further clarification was provided as to why this data was not considered sufficient. The independent advisers suggested the protocol (SD2.0), provided as a supportive document, had useful narrative around this point.</p> <p>5.1.12 The DPO Representative noted the applicant's Data Security and Protection Toolkit (DSPT) status stated that the "<i>standards not fully met</i>", and that an improvement plan had been agreed with NHS England. It was suggested that the application and internal application assessment form were updated, as per usual process, to reflect whether the DSPT standards not met were relevant to the processing outlined in the application.</p> <p>5.1.13 It was noted that the description of the implant differed throughout the documents provided (the application, protocol and the HRA CAG letter of support etc); and suggested that this was reviewed and updated as may be necessary, to reflect the correct / factual information in line with the HRA CAG support provided.</p> <p>5.1.14 The independent advisers noted that some text from the National Data Guardian (NDG) guidance on benefit had been copied into section 5(d) (Benefits) of the application; and suggested that this was reviewed and tailored to reflect the benefits specific to this application, rather than a direct cut and paste of the full text.</p> <p>5.1.15 The independent advisers queried the statement in section 5(d) (ii) (Expected Measurable Benefits to Health and / or Social Care) "<i>The impact of this study may be profound, the collarless tapered stem is the 2nd most-used implant for total hip replacements in the UK, averaging around 7000 per year</i>"; and noting this figure seemed quite low, suggested that this was reviewed and updated if not correct.</p>	
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	<p>5.1.16 Separate to the application: The SIRO representative noted the difference between EU-funding (which may carry particular obligations) and funding from within Europe.</p> <p>ACTION: Data and Analytics to review how the teams are applying the 'Q&A' and NHS England DAS* Standards, including but not limited to commercial, honorary contracts, and EU funding.</p> <p><i>*DAS – Data Access Service</i></p> <p>ACTION: The independent advisers stated that they would welcome a review of the 'Q&A' document at a future AGD meeting, to support Data and Analytics and its ongoing learning and development programme across NHS England.</p>	<p>KF / DAS</p> <p>KF / DAS</p>
5.2	<p>Reference Number: NIC-637916-K3L3D-v0.2</p> <p>Applicant: University of Bristol</p> <p>Application Title: Aspirin after hospitalisation with Pneumonia to prevent cardiovascular Events randomised Controlled Trial (ASPECT)</p> <p>Application: This was a new application.</p> <p>The purpose of the application is for a study, aiming to test whether aspirin reduces the risk of a heart attack or stroke in patients who are admitted to hospital with pneumonia.</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>5.2.1 The independent advisers noted and commended the work undertaken by the applicant and NHS England's Data Access Service (DAS) on the application</p> <p>5.2.2 The independent advisers noted and commended the applicant on the ongoing work / engagement with the cohort.</p> <p>5.2.3 The independent advisers noted that the privacy notice did not align with the information on the applicant's website; and suggested that the privacy notice was updated to be clear that whilst you could withdraw your consent on future processing of your data, it is not possible for your data to be extracted from the data processing that had already taken place.</p> <p>5.2.4 Noting the information in section 3(b) (Additional Data Access Requested) that states that five years of historic Hospital Episode Statistics Admitted Patient Care (HES APC) data would flow; it was suggested that section 5(a) (Objective for Processing) was updated with clarification as to why this data was required, noting that this was currently unclear.</p>	

	<p>5.2.5 The independent advisers noted in section 5(a) that “<i>participants will be followed up at 3 months...</i>”; and suggested that NHS England clarify with the applicant how they will ensure that only three months of data is processed, for example, will this be filtered by NHS England.</p> <p>5.2.6 The SIRO representative queried whether special condition number five, in section 6 (Special Conditions), in relation to the cohort data flowing to NHS England was relevant to include in this application; and suggested that NHS England review and remove if not relevant.</p> <p>5.2.7 The SIRO representative noted the statement in section 3(c) (Patient Objections) that “...<i>National Data Opt-Out is not applied for those recruited under consultee advice</i>”; and suggested that NHS explore this further with the relevant team, to ensure that this was correct. If it was deemed not to be correct, then the application should be updated as required to reflect the correct information.</p>	
5.3	<p>Reference Number: NIC-679360-X9X0Y-v0.9</p> <p>Applicant: The University of Manchester</p> <p>Application Title: Invest to detect? The impact of shortfalls in hospital diagnostic imaging capacity on GP identification, management and referrals of suspected cancer cases</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 30th March 2023.</p> <p>The purpose of the application is for a study to examine how gaps in hospital-level capacity, underinvestment, and lack of maintenance of diagnostic imaging equipment (MRI, CT, and PET scans) affects the performance of cancer diagnostic activity for patients referred for cancer investigation by their GP practice.</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 not supportive of the application in its current form (and accordingly were not supportive of data flowing), until the following significant comments were addressed, and wished to draw to the attention of the SIRO the following substantive points:</p> <p>5.3.1 The group noted the efforts and progress made by the applicant and NHS England on updating the application following the comments made at the AGD meeting on the 30th March 2023; however, advised that whilst points 5.5.1, 5.5.2 and 5.5.3 as outlined in the minutes from the meeting had been addressed; points 5.5.4 and 5.5.5 had not been adequately addressed and were therefore outstanding.</p> <p>5.3.2 The group reiterated a point raised at the 30th March 2023 meeting (point 5.5.4) that the questions outlined in the protocol, may not be adequately addressed with the NHS England data requested under this application, for example, some of the questions may not be able to be answered in their current format, for example,</p>	

	<p>the question relating to “<i>GP-level performance indicators of cancer-related activity</i>”; and questioned whether the data could answer this, noting that GP’s are unable to ‘identify’ cancer, and can only refer a patient for an x-ray, certain scans, or, more commonly where cancer is suspected, to an urgent 2 week wait specialist cancer service.</p> <p>5.3.3 The group noted the response regarding GP input, but reiterated the point raised at the 30th March 2023 meeting (point 5.5.5) that although it was potentially interesting work, there was a concern whether the research questions were fully articulated.</p> <p>5.3.4 To help progress the application, the Data and Analytics representative advised that they could support the applicant and the Data Access Service (DAS) out of committee, to review the questions outlined in the protocol and whether they could be achieved with the data requested; or to determine a possible way forward for the applicant / application.</p> <p>5.3.5 The group noted that whilst they were not currently supportive of the application progressing in its current form, they were broadly supportive of the overall aims and objectives of what the applicant / study was trying to achieve.</p> <p>5.3.6 The group noted that if NHS England require further advice on an updated iteration of the application, they would be supportive of this returning to a future AGD meeting with all previous comments / issues addressed.</p>	
EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL		
6.1	<p>Reference Number: NIC-484452-H8S1L-v5.0</p> <p>Applicant: Department of Health and Social Care (DHSC)</p> <p>Application Title: Department of Health and Social Care (DHSC) TRE access - Enabling Policy Analysis</p> <p>Previous Reviews: The application and relevant supporting documents had previously been presented / discussed at the IGARD meeting on the 8th September 2022, 19th May 2022, 7th April 2022, 21st October 2021 and the 16th September 2021.</p> <p>The application and relevant supporting documents had previously been presented / discussed at the GPES Data for Pandemic Planning and Research – Profession Advisory Group (PAG) on the 24th November 2021, 3rd November 2021, 15th September 2021 and the 25th August 2021.</p> <p>The SIRO approval was for an amendment to the data sharing agreement (DSA) to add the ethnicity field within the Hospital Episode Statistics (HES) Accident and emergency (A&E) dataset.</p> <p>Outcome of discussion: The group noted that the NHS England SIRO had already provided SIRO approval and confirmed that they were supportive of this.</p>	

	<p>The group thanked NHS England for the written update and advised that they had no further comments to make on the documentation provided.</p> <p>The NHS England SIRO representative thanked the group for their time.</p>	
6.2	<p>Reference Number: NIC-561357-X0F3N-v1.5</p> <p>Applicant: Evidera Ltd (AstraZeneca UK Limited)</p> <p>Application Title: Health Burden of COVID-19 and Healthcare Resource Utilisation in England - INvestigation oF cOvid-19 Risk among iMmunocompromised populations</p> <p>Previous Reviews: The application and relevant supporting documents had previously been presented / discussed at the AGD meetings on the 23rd November 2023 and the 16th November 2023.</p> <p>The application and relevant supporting documents had previously been presented / discussed at the IGARD meetings on the 20th October 2022 and the 16th June 2022.</p> <p>The application and relevant supporting documents had previously been presented / discussed at the GPES Data for Pandemic Planning and Research – Profession Advisory Group (PAG) on the 5th October 2022 and the 9th February 2022.</p> <p>The SIRO approval was for a renewal.</p> <p>Outcome of discussion: The group noted that the NHS England SIRO had already provided SIRO approval and confirmed that they were supportive of this.</p> <p>The group thanked NHS England for the written update and made the following observations on the documentation provided:</p> <p>6.2.1 The group noted that prior to the meeting, the independent advisers has raised some queries directly with the SIRO representative, in respect of 1) a breach referred to in the supporting document provided; 2) why NHS England was previously considered a Data Controller; 3) why, when section 3(c) states that the territory of use is “<i>England and Wales</i>”, one of the Data Processors has an address in Hungary; and 4) whether this application met the NHS England DAS Standard for Ethical Approval.</p> <p>6.2.1 It was noted that the SIRO representative and independent advisers had discussed the queries raised prior to the meeting and the SIRO had provided an update out of committee: 1) The breach was for not having a UK GDPR compliant transparency notice, 2) it has been clarified that NHS England are a Data Processor (not Data Controller) and that relates to the fact that data is being held within the Secure Data Environment (SDE) and is the current approach for data within a SDE, 3) the headquarters of the overarching corporate body are based in Hungary, however the work is being carried out in England and Wales, 4) the ethics point would be considered when the application returns for renewal or extension.</p> <p>The NHS England SIRO representative thanked the group for their time.</p>	

7	<p>NHS England Precedents and Standards (Presenters: Laura Bellingham and Tom Wright)</p> <p>The group noted that prior to the meeting, they had been provided with a revised draft proposal for the approval process for data sharing agreements (DSA) extensions and renewals, which had been updated and amended following the discussion at the AGD meeting on the 7th December 2023.</p> <p>The group had a lengthy discussion on the information provided, and focussed on a number of issues, including, but not limited to, how to measure risks, commercial applications, the expected proportions / numbers of applications anticipated through this route, and training for NHS England Data Access Service (DAS) staff.</p> <p>The group noted that the next steps for NHS England, was to engage with staff to discuss the proposed approval process and to form a document library for audit / ease of access for staff etc; and that a further update would be provided to AGD in due course.</p> <p>The group thanked NHS England for providing them with an updated draft proposal and looked forward to further discussions at future AGD meetings.</p> <p>ACTION: The Deputy Director, Data Access and Partnerships to update the draft proposal and present / discuss with the group at a future AGD meeting.</p>	LB
AGD Operations		
8	<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 presented to the interim data advisory group for advice; however the independent advisers noted that the wording in the 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>ACTION: NHS England SIRO representative to provide a written response addressed to AGD with further clarity on the risk management framework.</p>	GC
9	<p>AGD Terms of Reference (ToR)</p> <p>The independent advisers noted that six months had passed since the Statutory Guidance had been published, requiring a ToR to be agreed and published.</p> <p>Following the update by Jackie Gray, Director of Privacy, Transparency and Trust (PTT) (formerly Privacy, Transparency, Ethics and Legal (PTEL)) at the AGD meeting on the 16th November 2023, it was noted that the group had received the updated draft ToR on Wednesday 22nd November 2023; and that a stakeholder workshop, including representatives from AGD and AGD Secretariat, took place on Monday 27th November to discuss the draft ToR and any further suggested updates and amendments.</p> <p>The SIRO representative advised that following the workshop, a further iteration of the draft ToR would be reviewed / updated by the Director of PTT; and that further outcomes from this review, including comments accepted / rejected would be shared with AGD in due course.</p> <p>The SIRO representative noted a previous request from the independent advisers, that a 'final draft' of the ToR be shared with AGD prior to this document being submitted to the NHS England Board / subcommittee of the Board; and advised that this document would be circulated on Friday 8th December 2023.</p> <p>ACTION: The SIRO representative to provide outcomes from the review of the updated draft ToR following the workshop on the 27th November 2023.</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>In addition, the group reiterated that they looked forward to further information on the timeline for progressing the ToR, including when this would be considered by the NHS England Board / subcommittee of the Board.</p> <p>ACTION: The SIRO representative to provide further information to the group on the timeline for progressing the draft ToR, including when this would be considered by the NHS England Board / subcommittee of the Board, following the workshop on the 27th November 2023.</p>	<p>GC</p> <p>GC</p> <p>GC</p>
10	<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</p>	

	final ToR, there would be further discussion in January 2024 of a work plan to progress and finalise the AGD SOPs, in line with the progression of the AGD ToR.	To note
11	<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>It was agreed that this would be reviewed as a standing item at each AGD meeting from the 11th January 2024.</p> <p>ACTION: AGD Secretariat to add the AGD Action Log to all future meeting from the 11th January 2024 for discussion.</p>	VW / KM
Any Other Business		
12.1	<p>Information Commissioner's Office (ICO) Transparency in health and social care draft guidance consultation</p> <p>The group noted that following the discussion at the AGD meeting on the 30th November 2023, the independent advisers had been reviewing the ICO's 'Transparency in health and social care' draft guidance consultation.</p> <p>The group discussed the comments and suggested amendments to this document, and noted that these would be shared with NHS England by the 18th December 2023.</p> <p>It was reiterated that, if preferred, individuals can respond directly to the ICO on an 'individual' capacity and not as a member of, or on behalf of, AGD.</p>	
12.2	<p>Independent adviser recruitment / day rate</p> <p>The independent advisers queried whether there had been any progress on the independent adviser day rate issues that remained outstanding following the move from the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) to the interim Advisory Group for Data (AGD) (NHS England), as discussed at the AGD meetings on the 9th November 2023 and the 2nd November 2023.</p> <p>The AGD Secretariat Manager, on behalf of the NHS England SIRO representative Garry Coleman, advised the group that approval had been obtained from NHS England for a 5% uplift to current independent adviser day rates (set in 2016), in line with the NHS Agenda for Change 2023/24 pay award. It was noted that it was hoped that this would be paid in January / February 2024; and that this would also include any back pay (in line with individual NHS England zero hours contract start dates).</p> <p>The independent advisers noted these details and thanked the AGD Secretariat Manager for providing an update.</p>	

