

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 29th February 2024

09:30 – 12:30

(Remote meeting via videoconference)

INDEPENDENT ADVISERS IN ATTENDANCE:	
Name:	Role:
Claire Delaney-Pope (CDP)	Specialist Information Governance Adviser
Dr. Robert French (RF)	Specialist Academic / Statistician Adviser
Kirsty Irvine (KI)	Chair
Dr. Geoffrey Schrecker (GS)	Specialist GP Adviser
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	Role / Area:
Garry Coleman (GC)	NHS England SIRO Representative (Presenter: item 9.3)
Kate Fleming (KF)	NHS England Data and Analytics Representative (Delegate for Michael Chapman)
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
Jonathan Osborn (JO)	NHS England Caldicott Guardian Team Representative
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Delivery Directorate
INDEPENDENT ADVISERS NOT IN ATTENDANCE:	
Paul Affleck (PA)	Specialist Ethics Adviser
Prof. Nicola Fear (NF)	Specialist Academic Adviser
Dr. Imran Khan (IK)	Specialist GP Adviser
Dr. Maurice Smith (MS)	Specialist GP Adviser

Jenny Westaway (JW)	Lay 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) 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> <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 22nd February 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>AGD Action Log:</p> <p>The group noted that since the meeting on the 11th January 2024, the meeting agendas had included a standard item to review the AGD action log.</p>

	The group reviewed the 'open actions' on the AGD action log, and agreed where actions could be moved to the 'non-live actions' list, or where further information was required.
4	Declaration of interests: There were no declarations of interest.
EXTERNAL DATA DISSEMINATION REQUESTS:	
5.1	<p>Reference Number: NIC-698171-K4M0B-v0.3</p> <p>Applicant: Home Office</p> <p>Application Title: Home Office Drugs Indicators</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 18th January 2024.</p> <p>Application: This was a new application.</p> <p>The purpose of the application is for drug policy analysis and monitoring.</p> <p>The Home Office aims to improve the design and implementation of drugs policy by using evidence and analysis to better understand the drugs landscape and the impact of government policies on this landscape.</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 at the AGD meeting on the 18th January 2024, 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 for the Home Office to process the data; and noting the 'high bar' to meet this legal basis, it was suggested that the internal application assessment form and section 5 (Purpose / Methods / Outputs) should be updated to provide a justification for using this Article 9 legal basis. It was noted and acknowledged that following the meeting on the 18th January 2024, this point had been extensively reviewed by the Home Office; however, the justification for relying on this legal basis and how the relevant conditions of the Data Protection Act (DPA) 2018 had been satisfied should be in section 5 of the application, which also forms part of NHS England's Data Uses Register, aligning with the purpose of the processing being connected to health and care. (Please see the "<i>subsequent to the meeting</i>" text at the end of the minutes for further information on this point).</p> <p>5.1.2 The group noted that they remained concerned that the Article 9(2)(g) exemption does not cover the full breadth of the research planned with this data, i.e. does not cover the 'pure research' aspects of the application, where there is no link to benefitting specific individuals; and reiterated previous advice that there may be a</p>

more suitable additional / alternative Article 9 UK GDPR exception, for example Article 9(2)(j) (Archiving, research and statistics); and suggested that this was reviewed / considered further by the Home Office.

5.1.3 The independent advisers noted the statement in the internal application assessment form that “...*certain drugs such as opioids could relate to **legitimate** or illicit drug use and these cannot be distinguished within *HES. It is requested that such admissions are included*”. It was suggested that for transparency, the application was updated to reflect that legal use of opioids would be captured in the data provided, for example, palliative care patients taking fentanyl; and that NHS England clarify with the Home Office that they are aware that this data will be included, and seek clarification as to how they will address this when assessing the data, noting this will be reflected in the outcomes.

*HES – Hospital Episode Statistics

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

5.1.4 The group noted that at the AGD meeting on the 18th January 2024, the independent advisers had suggested that the applicant approached the Home Office Ethics Advisory Group (EAG) to seek advice from them on the proposed work under this application. It was noted in the Home Office e-mail correspondence dated the 31st January 2024, provided as a supporting document (SD3), that the work proposed under this application would probably be out of scope for the Home Office EAG; however noted the suggestion that a sub-group of the EAG could be assembled to review if it was thought to be beneficial. The group did think it would be beneficial and suggested that the Home Office request a review by the Home Office EAG or sub-group, to seek advice on the proposed work outlined in this application.

5.1.5 In addition, it was suggested that to support the ethics review by the Home Office EAG or sub-group, that a copy of the minutes from this meeting **and** the AGD meeting on the 18th January 2024 AGD meeting are provided for information and further context.

5.1.6 The independent advisers noted the statement in the Home Office e-mail correspondence dated the 31st January 2024, provided as a supporting document (SD3) that the Data Protection Impact Assessment (DPIA) has been signed off by the Data Privacy Professional (DPP) and the Data Protection Officer (DPO) and that it was unlikely that the Home Office EAG could add anything further; it was noted by the group that the DPIA does **not** expressly address ethical issues and the DPIA should not be used as a substitute for an ethical review by an appropriate body.

5.1.7 The group noted the clear health purposes outlined within the application (and the restriction of use to those purposes), but noted that public health input was not identified within the application. It was noted that this may well be covered by wider Home Office and Department of Health and Social Care (DHSC) engagement, but

	<p>recommended that the Home Office ensured that sufficient public health expertise was available and made transparent as part of this work and policy development.</p> <p>5.1.8 The independent advisers noted that the application was not clear on what (if any) patient and public involvement and engagement (PPIE) had taken place; and suggested that the application was updated to provide further information on the PPIE undertaken to date and any future PPIE, for example, is there a specialist group involved, that may help inform the outputs and turn into effective policy.</p> <p>5.1.9 The NHS England Data and Analytics representative noted that the application did not provide sufficient detail on how they are going to use the data, and suggested that for transparency, section 5(a) (Objective for Processing) was updated to clarify this point further, for example, inclusion of the model strategies outlined in the internal application assessment form, the types of evaluation they are using and details of the analysis plan.</p> <p>5.1.10 The NHS England SIRO representative noted the point raised by the group at the AGD meeting on the 18th January 2024, in respect of whether access to the Secure Data Environment (SDE) would be more appropriate; and advised that as part of ongoing communication / engagement on this application, the Home Office had advised prior to the meeting, that the method / process for analysing the data could not be done within the SDE. The NHS England SIRO representative noted that he was content with the justification provided to him on this point by the Home Office.</p> <p>5.1.11 Noting the special condition (4.0) in section 6 (Special Conditions) of the application that states <i>“Any processing of the Data under this Agreement must be connected with health and care”</i>; it was suggested by the independent advisers that NHS England amend this to state <i>“Any processing and outcomes produced in accordance with this Agreement must be connected with health and care”</i>.</p> <p>5.1.12 Separate to this application: it was suggested by the independent advisers that the amended wording outlined above (point 5.1.11) was reflected in NHS England’s standard wording documents for future applications.</p> <p>ACTION: The NHS England Data and Analytics representative to ensure that colleagues in the Data Access Service (DAS) are aware of the amended special condition wording for future applications <i>“Any processing and outcomes produced in accordance with this Agreement must be connected with health and care”</i>.</p> <p>5.1.13 In addition, it was suggested by the independent advisers that the third and fourth benefit outlined in section 5(d) (Benefits) (ii) (Expected Measurable Benefits to Health and / or Social Care) were reviewed and updated to be clear on the benefits to health and care in line with the special condition (4.0) in section 6, NHS England’s DAS Standard for Expected Measurable Benefits and NHS England’s legislative requirements.</p>	D&A
--	--	-----

5.1.14 Noting that Ipsos Mori UK Limited were **not** listed as a Data Processor in the application, the independent advisers queried the statement in section 5(b) (Processing Activities) of the application “*Access is restricted to...employees or agents of **Ipsos Mori UK Limited*”; and suggested that either this statement was removed and the relevant parties informed that Ipsos Mori UK Limited were not permitted access to the data; or, if Ipsos Mori UK Limited were considered a Data Processor, that the application was updated accordingly, in line with [NHS England’s DAS Standard for Data Processors](#).

****Ipsos Mori UK Limited - *****(Institut Public de Sondage d'Opinion Secteur Market and Opinion Research International)*

5.1.15 The independent advisers noted in the internal application assessment form, that “*The DPIA...specifies that the unsuppressed data will be retained for 7 years by the Home Office, although ***LSE and ****RAND will destroy their cuts of the data by **October 2024***”; and suggested that the date was reviewed and updated as appropriate, noting the data has not yet flowed and may impact on this date.

*****LSE** - London School of Economics

******RAND** – RAND Europe CIC

5.1.16 The independent advisers noted the statement in section 5(c) (Specific Outputs Expected) of the application “*Suppressed versions of the data to be used in research by **other analysts** who do not require access to unsuppressed versions*”; and suggested that for transparency, further clarification was provided as to who the “*other analysts*” were and that the unsuppressed data would not be used by any “*other analysts*”.

5.1.17 The independent advisers queried if a data destruction certificate for the unsuppressed data during the life of the application was required; and suggested that NHS England gave this further consideration.

5.1.18 In addition, it was queried by the independent advisers whether the timeline and reference to “*October 2024*” was correct in respect of the unsuppressed data outputs; and suggested that this was reviewed and amended as may be appropriate.

5.1.19 The independent advisers noted that they would be supportive of NHS England undertaking a routine audit of this data sharing agreement (DSA), noting that this would be a useful tool to aide transparency and support public confidence.

5.1.20 In addition, it was suggested by the group, that a special condition was added to section 6 of the application stating that the Home Office must commit to an audit being undertaken at a future date; and that NHS England have a discussion with the Home Office on this special condition, prior to this being added to the application.

Subsequent to the meeting: following the meeting, it was subsequently confirmed that the Home Office intends to use Article 9(2)(g) of UK GDPR as the legal basis to process the data; which in turn means that since it is substantial public interest then Schedule 1 Part 2 of Data Protection Act (DPA) 2018 applies (rather than Part

	<p>1). The need for benefit to specific individuals does not apply in relation to this Part of the Act, which may not be the case for a number of other legal basis which are typical of applications seen by AGD. The feedback in the minutes therefore in relation to this point no longer applies.</p> <p>The Home Office have also confirmed that DPA 2018 Schedule 1 Part 2 paragraph 5 (requirement for an appropriate policy document and additional safeguards) is satisfied.</p>	
5.2	<p>Reference Number: NIC-616027-W7K5H-v0.2</p> <p>Applicant: NHS Norfolk and Waveney Integrated Care Board</p> <p>Application Title: Integrated Care Board - Hospital Episode Statistics Data</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 2nd November 2023.</p> <p>Application: This was a new application.</p> <p>The purpose of the application is to support NHS Norfolk and Waveney Integrated Care Board (ICB) to fulfil its functions towards health care as per the National Health Service Act 2006; including to allowing the ICB to compare / benchmark services commissioned by other ICBs with their own to show their effectiveness and adjust their future commissioning decisions; comparing rare patient conditions where local data does not provide a sufficient cohort count so they can understand the most effective patient pathways; comparing levels of inequality nationally to understand any shortcomings in their local area; nationally compare specific demographics of patients to understand areas of low performance and understand national trends in health care and public health risks in order to support capacity planning.</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 purpose outlined with the application. The group made the following observation / points of advice on the application and / or supporting documentation provided as part of the review:</p> <p>5.2.1 The independent advisers noted that following the review of this application at the AGD meeting on the 2nd November 2023, the application had been updated to reflect that data would be accessed in NHS England's Data Access Environment (DAE). The independent advisers noted that they had not received sufficient information from NHS England as to how the DAE differs from other environments hosted by NHS England, for example, the Secure Data Environment (SDE), Trusted Research Environment (TRE) etc, particularly with respect to data extracts being downloadable from the DAE by applicants, so were unable to review / provide advice on this aspect of the application.</p> <p>5.2.2 Separate to this application: the NHS England Data and Analytics representative noted the issues raised by the independent advisers; and advised</p>	

	<p>that they would seek support from colleagues to provide the group with further clarification / distinctions between the different environments hosted by NHS England, to support the groups understanding and for future application reviews.</p> <p>ACTION: NHS England Data and Analytics representative to seek support from colleagues to provide the group with further clarification / distinctions between the different environments hosted by NHS England.</p> <p>5.2.3 The group confirmed that whilst they were supportive of the data under this application being processed within the DAE; it was noted that the application provided conflicting information between data being accessed in the DAE and data being disseminated. It was suggested that the application was reviewed throughout, and any references to the data being disseminated were updated or removed.</p> <p>5.2.4 The independent advisers queried if data could be downloaded from the DAE and distributed further; and suggested that further clarification was provided on this point in the application, including, but not limited to, in what circumstances data could be downloaded, what can happen with the data once downloaded, how the data can be stored, the policy on retention of data, and the data destruction policy.</p> <p>5.2.5 In addition, the independent advisers suggested that NHS England should consider having two separate applications, one for the data accessed in the DAE; and the other for data downloaded from the DAE; noting that this might be easier for NHS England to manage / audit etc.</p> <p>5.2.6 The independent advisers noted the benefits outlined in section 5(d) (Benefits), however suggested that this section was reviewed and any 'outputs' were moved to section 5(c) (Specific Outputs Expected) in line with NHS England's DAS Standard for Expected Outcomes.</p> <p>5.2.7 Separate to this application: the independent advisers suggested that NHS England Data and Analytics to consider having a DAE template application for benchmarking.</p> <p>ACTION: NHS England Data and Analytics to consider having a DAE template for benchmarking.</p> <p>5.2.8 Separate to this application: the group advised that the benchmarking data should be available to all Integrated Care Boards (ICBs) to reduce duplication and suggested that NHS England Data and Analytics to give this further consideration.</p> <p>ACTION: NHS England Data and Analytics to consider making the benchmarking data available to everyone.</p>	<p>D&A</p> <p>D&A</p> <p>D&A</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</p>	

	<p>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 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 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>	AGD
7	<p>AGD Terms of Reference (ToR)</p> <p>The independent advisers noted that over nine months had passed since the Statutory Guidance had been published, requiring a ToR to be agreed and published.</p> <p>The AGD Chair noted that on the 23rd February 2024, Jackie Gray had shared with the group, a final draft version 0.16 of the ToR and had advised that this document was being sent to Steve Russell, NHS England’s Chief Delivery Officer, National Director for Vaccinations and Screening and Senior Information Risk Owner (SIRO) for final approval, ahead of seeking approval from the Data, Digital and Technology Committee (DDAT) of the NHS England Board. It was noted that Jackie has also</p>	

	<p>advised that as per the previous commitment made to the group, if there are any changes to this version of the ToR following review by Steve Russell and / or DDAT, an updated version would be shared with the group prior to publication.</p> <p>The group noted that clarification had been provided with the final draft ToR, showing updates made to the document reviewed at the workshop on the 27th November 2023 and further updates / clarifications made by the AGD Chair in early February 2024.</p> <p>Following Jackie Gray's attendance at the AGD meeting on the 1st February 2024, and following circulation of the final draft ToR on the 23rd February 2024, the group reiterated that they looked forward to further information as to when the ToR 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 as to when the draft ToR, including when this would be considered by the NHS England Board / subcommittee of the Board.</p>	GC
8	<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 on 7th March 2024.</p> <p>The group noted the update and looked forward to further discussions at the 7th March 2024 AGD meeting.</p>	To note
Any Other Business		
9.1	<p>NHS England Data and Analytics colleagues observing AGD</p> <p>Following the discussion at the AGD meeting on the 8th February 2024 and the 14th December 2023; the group reiterated their support for colleagues from NHS England's Data and Analytics to attend future meetings to observe the applications part of the meeting to a) support the progression of the applications and b) as part of their professional learning and development.</p>	
9.2	<p>AGD remit of work</p> <p>The independent advisers noted concern to the SIRO representative, in respect of the volume / variety of agenda items submitted to AGD for review / advice; and that the knowledge and expertise in the group was not being utilised to its full potential by NHS England.</p> <p>There was an acknowledgement by the independent advisers that there had been wider organisational changes within NHS England following the merger with NHS Digital and Health</p>	

	<p>Education England; however the independent advisers noted that NHS England could have utilised the group further during this period of transition to seek advice.</p> <p>The NHS England SIRO representative noted the comments / concerns raised; and advised that there were a number of discussion items that would be submitted to the group over the coming weeks and that moving forward more work needed to be undertaken by NHS England to get items onto the AGD agenda</p>
9.3	<p>AGD future ways of working (Presenter: Garry Coleman)</p> <p>The NHS England SIRO representative advised the group that at the AGD plenary meeting on the 7th March 2024, there would be a discussion about AGD future ways of working and proposed changes (in line with the current draft v0.16 Terms of Reference); including, but not limited to, the start and end time of AGD meetings, the frequency of AGD meetings, and in-meeting quoracy of the independent advisers.</p> <p>The group noted the verbal update from the NHS England SIRO representative and looked forward to a further discussion on the 7th March 2024.</p>
9.4	<p>NHS England Data and Analytics Delegate: Kate Fleming</p> <p>The group noted that due to other work commitments, this would be the last AGD meeting that Kate Fleming would be attending as delegate for Michael Chapman (NHS England Data and Analytics representative).</p> <p>The group thanked Kate for her valuable contributions to AGD as delegate for Michael.</p>
<p>Meeting Closure</p> <p>As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.</p>	