

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 16th May 2024

09:00 – 12:45

(Remote meeting via videoconference)

AGD INDEPENDENT / NHS ENGLAND MEMBERS IN ATTENDANCE:	
Name:	Role:
Paul Affleck (PA)	AGD independent member (Specialist Ethics Adviser)
Kirsty Irvine (KI)	AGD independent member (Chair)
Narissa Leyland (NL)	NHS England member (Data and Analytics Representative (Delegate for Michael Chapman))
Andrew Martin (AM)	NHS England member (Data Protection Office Representative (Delegate for Jon Moore))
Dr. Jonathan Osborn (JO)	NHS England member (Caldicott Guardian Team Representative)
Jenny Westaway (JW)	AGD independent member (Lay Adviser)
Miranda Winram (MW)	AGD independent member (Lay Adviser)
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	Role / Area:
Garry Coleman (GC)	NHS England SIRO Representative
Jackie Gray (JG)	Director Privacy and Information Governance, Privacy, Transparency and Trust (Presenter: item 7)
Louise Greenrod (LG)	Deputy Director - Data Policy, Department of Health and Social Care (DHSC) / NHS England Digital Policy Unit (Observer: item 7)
Dr. James Kent (JK)	National Advisor, Strategy Directorate (Observer: item 7)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Delivery Directorate
Frances Perry (FP)	Data Applications Team Lead, Data Access & Partnerships, Data & Analytics (Observer: item 6.3)

Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Delivery Directorate
AGD INDEPENDENT MEMBERS / NHS ENGLAND MEMBERS <u>NOT</u> IN ATTENDANCE:	
Name:	Role / Area:
Michael Chapman (MC)	NHS England member (Data and Analytics Representative)
Claire Delaney-Pope (CDP)	AGD independent member (Specialist Information Governance Adviser)
Prof. Nicola Fear (NF)	AGD independent member (Specialist Academic Adviser)
Dr. Robert French (RF)	AGD independent member (Specialist Academic / Statistician Adviser)
Jon Moore (JM)	NHS England member (Data Protection Office Representative)

1	Welcome and Introductions: The AGD meeting Chair welcomed attendees to the meeting.
2	Review of previous AGD minutes: The minutes of the AGD meeting on the 9 th May 2024 were reviewed and, after several minor amendments, were agreed as an accurate record of the meeting.
3	Declaration of interests: Dr. Jonathan Osborn noted a declaration of interest for any applications reviewed by the GPES Data for Pandemic Planning and Research – Profession Advisory Group (PAG), as part of his role as PAG Chair. It was agreed this did not preclude Dr. Osborn from taking part in the discussion on the affected application (NIC-596002-V3N9J), noting the role of the PAG Chair was to receive the feedback from PAG members.
4	AGD Action Log: <i>The action log was not discussed.</i>
5 BRIEFING PAPER(S) / DIRECTIONS:	
<i>There were no items discussed</i>	
6 EXTERNAL DATA DISSEMINATION REQUESTS:	
6.1	Reference Number: NIC-596002-V3N9J-v0.14

<p>Applicant: Harvey Walsh Ltd</p> <p>Previous Reviews: The application was previously presented at the General Practice Extraction Service (GPES) Data for Pandemic Planning and Research (GDPPR) – Profession Advisory Group (PAG) out of committee on the 25th March 2024.</p> <p>Application Title: Avon Community-Acquired Pneumonia Surveillance Study: A Pan-pandemic Acute Lower Respiratory Tract Disease Surveillance Study - Denominator by risk group only</p> <p>Application: This was a new application.</p> <p>The purpose of the application, is to produce a denominator number by risk group to support the Avon CAP: A Pan-pandemic Acute Lower Respiratory Tract Disease Surveillance Study, which is a population-based multi-hospital, active prospective surveillance study designed to determine population-based incidence rates of hospitalised adults over the age of 18 with community-acquired Lower Respiratory Tract Infection (LRTI, including CAP) in Bristol, England.</p> <p>Should an application be approved by NHS England, further details would be made available within the Data Uses Register.</p> <p>Outcome of discussion: AGD were supportive of the application and wished to draw to the attention of the SIRO the following comments:</p> <p>6.1.1 AGD noted that the General Practice Extraction Service (GPES) Data for Pandemic Planning and Research (GDPPR) – Profession Advisory Group (PAG) had reviewed the application as per process (please see Appendix A), noting that GDPPR data had been requested as part of this application.</p> <p>6.1.2 AGD noted that, as part of their feedback, PAG had advised that they would only support the use of the GDPPR data in a national Trusted Research Environment, the Group therefore concluded that PAG were not currently supportive of the flow of GDPPR data as part of this application.</p> <p>6.1.3 AGD noted that the Data Access Service (DAS) internal application assessment form noted that the NHS England Secure Data Environment (SDE) was not considered a viable option for the application and the Group supported the provision of the data as a one-off extract.</p> <p>6.1.4 AGD noted that the legal basis for flowing the GDPPR data was under the COVID-19 Public Health Directions 2020, which states that any research and planning must be in relation to COVID-19. The Group assessed the application and agreed that the purpose of the application did meet a COVID-19 purpose.</p> <p>6.1.5 AGD noted, in the DAS internal application assessment form and the application, that Health Research Authority Research Ethics Committee (HRA REC) approval was not required due to the category of data requested. However, the Group suggested that the applicant approach their institutional (University of Bristol)</p>

	<p>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>6.1.6 Separate to the application: AGD reiterated previous advice, that the AGD NHS England Data and Analytics representative remind staff in the Data Access Service (DAS) to advise applicants, that due consideration should be given to the revised (July 2023) NHS England Ethical Approval Standard (particularly for University research applications which do not require HRA REC but University-level ethical support may still be indicated); and that section 5.3 (local ethical requirements) of the DAS internal application assessment form should be completed, confirming that ethical support from their institution had been sought / obtained; or that ethical support was not required.</p> <p>ACTION: The AGD NHS England Data and Analytics representative to remind staff in DAS, to advise applicants, that due consideration should be given to the revised (July 2023) NHS England Ethical Approval Standard (particularly for University research applications which do not require HRA REC but University-level ethical support may still be indicated); and that section 5.3 of the DAS internal application assessment form should be completed.</p> <p>6.1.7 AGD noted that a protocol had not been provided as part of the meeting pack; and advised that the addition of this document would have further supported the review of the application by the Group.</p> <p>6.1.8 Separate to the application: AGD asked NHS England to furnish protocols as supporting documents (if available) as a matter of course.</p> <p>ACTION: The AGD NHS England Data and Analytics representative to ensure colleagues within the Data Access Service (DAS) ensure that protocols are provided as supporting documents to AGD (if available) as a matter of course.</p> <p>6.1.9 Noting that they were unsure if Pfizer were the sponsor of the study because they had not been provided with the study protocol; AGD noted the previous advice from the Director Privacy and Information Governance, Privacy, Transparency and Trust (PTT) made to the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) in early 2021, that the NHS Health Research Authority (HRA) guidance on 'Controllers and personal data in health and care research' states that study sponsors are automatically deemed data controllers and, if they are not, then NHS England should include a rebuttal statement in section 1 (Abstract) and section 5 (Purpose / Methods / Outputs) of the application detailing the analysis undertaken by NHS England that the study sponsor is not undertaking any data controllership activities, if supported by the facts.</p> <p>6.1.10 Noting the commercial nature of the applicant and the funder, it was suggested that more information was provided in section 5(a) (Objective for Processing) and section 5(d) (Benefits) of the application, as to the commercial benefits to both organisations, and whether there is a proportionate balance</p>	<p>D&A Rep</p> <p>D&A Rep</p>
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	<p>between public and commercial benefit, in line with NHS Digital DAS Standard for Expected Measurable Benefits and NHS England's DAS Standard for Commercial Purpose and the National Data Guardian (NDG) guidance on benefits.</p> <p>6.1.11 Separate to this application: AGD reiterated a point previously made at the AGD meeting on the 2nd May 2024, that there was an ongoing action initially raised at the AGD meeting on the 23rd March 2023, in respect of potential updates to the NHS England DAS Standard for Expected Measurable Benefits and NHS England DAS Standard for Commercial Purpose, to align with the NDG guidance on benefits, on enabling better public benefit evaluations when data is to be used in planning, research and innovation; and asked that a further update be provided on this.</p> <p>6.1.12 In addition, it was noted that any updates could feed into NHS England's internal Question and Answer (Q&A) document and the internal application assessment form.</p> <p>ACTION: AGD NHS England Data and Analytics representative to provide an update on the action raised at the 23rd March 2023 AGD meeting, in respect of updates to the NHS England DAS Standard for Expected Measurable Benefits and NHS England DAS Standard for Commercial Purpose, to align with the NDG guidance on benefits.</p> <p>6.1.13 AGD queried what, if any, data minimisation had been undertaken, for example by specific health conditions; and suggested that the application was updated with further clarity, in line with NHS England's DAS standard for data minimisation; or that a justification was provided if no data minimisation could be undertaken.</p> <p>6.1.14 Separate to the application: AGD noted that the points made for this application in relation to the pseudonymised data were not a reuseable decision for the NHS England Data Access Service (DAS).</p>	<p>D&A Rep</p> <p>To Note</p>
6.2	<p>Reference Number: NIC-05429-H7X6R-v11.3</p> <p>Applicant: Device Access UK Ltd</p> <p>Application Title: Device Access HES Application 2024</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 22nd February 2024 and the 12th October 2023.</p> <p>The application and relevant supporting documents were previously presented / discussed at the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) meetings on the 4th August 2022, 26th May 2022, 21st December 2017, 6th July 2017, 8th June 2017, 25th May 2017 and the 16th March 2017.</p> <p>Application: This was a renewal application.</p>	

	<p>The purpose of the application is for a programme of work, which identifies where medical and diagnostic technologies can best be used by healthcare providers worldwide, including NHS providers in NHS patient care pathways to improve patient outcomes, reduce lengths of stay, elective and diagnostic waiting times.</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: AGD were supportive of the application and wished to draw to the attention of the SIRO the following substantive comments:</p> <p>6.2.1 AGD noted that they had only been provided with limited documentation and noted that they would be providing observations based on these documents only.</p> <p>6.2.2 AGD noted and commended the applicant on their response to points previously made by the Group at the interim AGD meeting on the 12th October 2023 and the way in which they had been addressed.</p> <p>6.2.3 AGD reiterated the point raised at the meeting on the 12th October 2023, (and previously raised by the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) on the 26th May 2022), in respect of transparency to the public, for example, public information available about the Device Access UK Limited (DAUK) Data Access Review Group (DADARG), for instance whether minutes from DADARG meetings were available to the public. It was noted that the applicant had previously advised that they would be able to implement this by the end of the calendar year and retrospectively publish previous years' reviews and approval numbers. The Group noted that they had been supportive of this approach suggested by the applicant, however, had also suggested that NHS England request quarterly updates in arrears, noting that this was consistent with other commercial organisations who were also subject to non-disclosure agreements with clients. It was noted by the Group that whilst some effort had been made to address this point, the information available was very high-level and the information was not easy to locate. AGD reiterated their previous advice that further, granular detail should be included in the information available, noting that this was a process followed by other commercial organisations, including, but not limited to, Clinical Practice Research Datalink (CPRD) (NIC-15625-T8K6L).</p> <p>6.2.4 AGD reiterated the point raised at the interim AGD meeting on the 12th October 2023, in respect of the DADARG application of the *PICO formula; and that it had been suggested by the Group that the formula was further developed to include consideration of the National Data Guardian (NDG) guidance on benefits. It was noted that this was important to support the applicant in assessing applications; and highlighted the importance of having a public record of this, i.e. published minutes, to support NHS England in assessing and identifying that users of NHS England data are applying the NDG guidance on benefits. AGD noted that some publicly available information on this was available, however, reiterated the point to have this information in a more prominent place, i.e. within the published minutes.</p>	
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6.3	<p>Reference Number: NIC-736352-N5H7X-v0.2</p> <p>Applicant: University of Oxford</p> <p>Application Title: UK Biobank – Use of NHS DigiTrials Patient List Update Service</p> <p>Observer: Frances Perry</p> <p>Linked applications: This application is linked to NIC-08472-V9S6K.</p> <p>Application: This was a new application.</p> <p>The purpose of the application is for UK Biobank to use the NHS DigiTrials Patient List Update Service, to obtain both the current status of the UK Biobank cohort, and their current email address on an annual basis.</p> <p>Should an application be approved by NHS England, further details would be made available within the Data Uses Register.</p>	

Outcome of discussion: AGD were **not** supportive of the application and wished to draw to the attention of the SIRO the following substantive comments:

6.3.1 AGD noted and thanked NHS England DigiTrials colleagues, for the thoughtful and detailed information provided as part of the meeting papers pack, which outlined the questions raised by NHS England with the applicant, and the responses received.

6.3.2 AGD discussed the legal basis for UK Biobank to request the e-mail addresses of cohort members. One member of the Group was of the view that this may **not** be covered as part of the consent, as it was their view that it was unclear if research participants would have regarded contact details flowing from NHS England to enable communications as “health data”. However, other members of the Group were of the view that obtaining e-mail addresses for this purpose would be covered under the consent obtained.

6.3.3 The AGD Chair noted that it was possible to flow e-mail addresses for the purpose of non-direct care, in line with the information on the NHS England Personal Demographics Service (PDS) [webpage](#), that states “PDS is normally used for [direct care](#). **However, there are non-direct care uses - these are supported by appropriate information governance and data sharing arrangements**”.

6.3.4 Noting that there may be a basis in consent to flow the e-mail addresses, it was, however, noted by the Group that the applicant had requested, via various communications to participants over the years, for e-mail addresses to be provided. It was therefore suggested by AGD and the AGD NHS England Data Protection Officer (DPO) representative that it may be a surprise to some cohort members if they receive communication via e-mail, when they had chosen not to provide their e-mail address directly as a method of receiving communications. It was noted that this would support the view that there was not consent for the e-mail addresses to flow and be used for this purpose.

6.3.5 AGD noted that the applicant had undertaken some patient and public involvement and engagement (PPIE) with a small number of the cohort, but given the nature of the questions and the number of non-responses, it was unclear what participants understood they had consented to in regard to obtaining email addresses.

6.3.6 The Group discussed a number of scenarios where an individual may not want to be contacted by e-mail, including, but not limited to, individuals preferring / needing a hard copy of any correspondence.

6.3.7 For those cohort members who had already provided an e-mail address, some members of the Group were supportive of the PDS data being used to correct any pre-identified incorrect e-mail addresses (i.e. where an email address has bounced back, or there is clearly a typo.). For clarity, the majority view was that data minimisation required that only data for incorrect email addresses should be requested. However, some members of the Group, including the AGD NHS England

	<p>Caldicott Guardian Team representative, expressed concern at this approach and suggested that an alternate form of communication should be used if an e-mail bounced back, for example, via a letter.</p> <p>6.3.8 AGD noted that a majority of the Group did not think a blank e-mail field should be populated via a flow of PDS data, if this information had not been provided by participants.</p> <p>6.3.9 AGD including the AGD NHS England Caldicott Guardian Team representative, noted concerns that cohort members may have provided specific e-mail address for the purpose of direct care, and may be distressed if this was used for communication from UK Biobank for non-direct care purposes.</p> <p>6.3.10 AGD including the AGD NHS England Caldicott Guardian Team representative discussed a number of options for the applicant, including, but not limited, a specific communication to the cohort on the intention to source email addresses from the NHS where these are missing, with an 'opt-in' model; or more robust engagement with some of the cohort, to further ascertain if they would be surprised that their consent was being used to obtain their e-mail address.</p> <p>6.3.11 AGD advised NHS England that they would welcome further discussions on this application as may be required.</p>	
7	Confidential Advice Session	
8 INTERNAL DATA DISSEMINATION REQUESTS:		
There were no items discussed		
9 EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL		
There were no items discussed		
10 OVERSIGHT AND ASSURANCE		
There were no items discussed		
11 AGD OPERATIONS		
11.1	<p>AGD Standard Operating Procedures (SOPs) (Presenter: Vicki Williams)</p> <p>The ongoing forward plan of work for creating the AGD Standard Operating Procedures was discussed; and noting that the AGD Terms of Reference (ToR) had now been approved, it was noted that work was progressing in order to finalise the AGD SOPs in line with the approved AGD ToR.</p> <p>It was noted that a further update would be provided to the Group in due course.</p>	
11.2	AGD Stakeholder Engagement	

	<i>There were no items discussed</i>
11.3	<p>AGD Project Work</p> <p>The Group noted that Miranda Winram had attended the NHS England OpenSAFELY Direction - Working Group meetings; and that the last meeting had taken place on the 11th March 2024; noting that a final discussion (separate to the Working Group) had taken place between Miranda and Narissa Leyland on the 10th May 2024 in respect of transparency relating to which data sources contributed to OpenSAFELY.</p> <p>The Group were advised that as part of the wider stakeholder engagement on the OpenSAFELY Direction, AGD's views would be sought around September 2024.</p> <p>The Group noted the update and looked forward to further engagement in due course.</p>
12 Any Other Business	
12.1	<p>AGD independent members recruitment (Presenter: Garry Coleman)</p> <p>The NHS England SIRO Representative advised that there were ongoing discussions on the recruitment of AGD independent members; and that a further update would be provided in due course.</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>	

Appendix A

GPES Data for Pandemic Planning and Research - Profession Advisory Group

Record of feedback: 25/03/2024

Application & application version number:

Avon Community Acquired Pneumonia Surveillance Study: A Pan-pandemic Acute Lower Respiratory Tract Disease Surveillance Study - Denominator by risk group only

DARS-NIC-596002-V3N9J-v0.14

Due to challenges in arranging timely attendance at a PAG meeting of all necessary members, and to avoid further delay, this item was discussed by BMA and RCGP representatives on 25th March 2024, and submitted via email to PAG Chair as feedback on the above application. This is consistent with the guidelines which form part of the PAG Terms of Reference [GPES data for pandemic planning and research - Profession Advisory Group terms of reference - NHS England Digital](#)

With the pandemic period long past, PAG would only support the use of GP Data for appropriate COVID-19 related studies in one of the four national TREs: the NHS England TRE; the Genomics England TRE; the ONS TRE; the OpenSAFELY TRE (which is another NHS England controlled environment).

PAG has used their template for assessing the application.

As background, by April 2022, essentially all UK covid restrictions were lifted (<https://www.gov.uk/government/news/prime-minister-sets-out-plan-for-living-with-covid>); PAG last convened Dec 2022; in May 2023, the WHO declared an end to the COVID-19 public health emergency of international concern.

During the pandemic, it is true that PAG supported, on a case by case basis, dissemination of GP data to other (TRE) environments.

However, a considerable period of time has now passed since the height of the international and national COVID-19 emergency response.

PAG considers that limiting the dissemination of GP data is an appropriate privacy enhancing principle, especially outside of national or international emergencies. Many of the other PAG template criteria are also used to enhance public and professional trust and privacy, for example through the promotion of transparency (such as publication of analysis code).

In summary, PAG would only support the use of GP Data for this application in one of the current four aforementioned TREs, and encourages NHS England to prioritise making these TREs scalable for appropriate COVID-19 related applications.

Members	Role	Organisation
Jonathan Osborn	PAG Chair, Associate Caldicott Guardian (not present at call between BMA and RCGP representatives)	NHS England
Amir Mehrkar	BMA Representative and Health Informatics Group member	RCGP
Mark Coley	Co-Chair of Joint GP IT committee	BMA