

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 23rd May 2024

09:00 – 13:05

(Remote meeting via videoconference)

AGD INDEPENDENT / NHS ENGLAND MEMBERS IN ATTENDANCE:	
Name:	Role:
Paul Affleck (PA)	AGD independent member (Specialist Ethics Adviser)
Dave Cronin (DC)	NHS England member (Data and Analytics Representative (Delegate for Michael Chapman))
Claire Delaney-Pope (CDP)	AGD independent member (Specialist Information Governance Adviser)
Dr. Robert French (RF)	AGD independent member (Specialist Academic / Statistician Adviser)
Kirsty Irvine (KI)	AGD independent member (Chair)
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)
Miranda Winram (MW)	AGD independent member (Lay Adviser)
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	Role / Area:
Garry Coleman (GC)	NHS England SIRO Representative
Nicki Maher (NM)	IG Risk and Assurance, Privacy, Transparency and Trust (PTT), Delivery Directorate (Observer: items 9.1 and 9.2)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Delivery Directorate (Presenter: item 11.2)
Jodie Taylor-Brown (JTB)	Data Access and Partnerships, Data and Analytics (Observer: items 6.1 and 6.2)
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)
Prof. Nicola Fear (NF)	AGD independent member (Specialist Academic Adviser)
Jon Moore (JM)	NHS England member (Data Protection Office Representative)
Jenny Westaway (JW)	AGD independent member (Lay Adviser)

1	Welcome and Introductions: <p>The AGD meeting Chair welcomed attendees to the meeting.</p>
2	Review of previous AGD minutes: <p>The minutes of the AGD meeting on the 16th May 2024 were reviewed and, after several minor amendments, were agreed as an accurate record of the meeting.</p>
3	Declaration of interests: <p>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-534549-M1N3P), noting the role of the PAG Chair was to receive the feedback from PAG members.</p> <p>Paul Affleck noted professional links to Arrow Business Communications Ltd as part of his role at the University of Leeds (NIC-708642-D2Z8T and NIC-341915-Z7J0Y) but no specific connection with the applications or staff involved. It was agreed this did not preclude Paul from taking part in the discussions about these applications.</p> <p>Paul Affleck noted a professional link to the Edinburgh Clinical Trials Unit (ECTU) (NIC-341915-Z7J0Y) but noted no specific connections with the application or the staff involved, and it was agreed that this was not a conflict of interest.</p> <p>Claire Delaney-Pope noted a professional link to NIC-708642-D2Z8T as part of her role at South London and Maudsley NHS Foundation Trust. It was agreed this did not preclude Claire from taking part in the discussion on this application.</p>
4	AGD Action Log: <p><i>The action log was not discussed.</i></p>
5 BRIEFING PAPER(S) / DIRECTIONS:	

There were no items discussed

6 EXTERNAL DATA DISSEMINATION REQUESTS:

6.1	<p>Reference Number: NIC-708642-D2Z8T-v0.4</p> <p>Applicant: University of Hull</p> <p>Application Title: The effect of alcohol care teams on hospital admissions in England: interrupted times series and health economic analysis using routine collected NHS hospital episodes statistics</p> <p>Observer: Jodie Taylor-Brown</p> <p>Application: This was a new application.</p> <p>The purpose of the application is for a study, which hopes to identify the impact, value and effectiveness of alcohol care teams in England. Synthesis of study outcomes should inform future commissioning of these services by NHS England.</p> <p>NHS England were seeking advice on the following point:</p> <ol style="list-style-type: none">1. Whether the use of Honorary Contracts is suitable for individuals from the University of Kent who will be analysing the data via the University of Hull Trusted Research Environment (TRE). <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>In response to point 1:</p> <p>6.1.1 AGD discussed the honorary contracts for the individuals from the University of Kent, and noted that, based on the information provided, they were content that the use of honorary contracts was appropriate.</p> <p>6.1.2 The Group suggested that that the honorary contracts were updated to ensure that the honorary contract holders know their responsibilities as outlined in the University of Hull data sharing agreement (DSA) and the University of Hull Data Security and Protection Toolkit (DSPT).</p> <p>6.1.3 In addition, the Group also suggested that it may be appropriate for the University of Hull to furnish those individuals on honorary contracts from the University of Kent, with IT equipment from the University of Hull to ensure the devices met the adequate security controls outlined in the DSPT.</p> <p>6.1.4 Noting the information in section 5(b) (Processing Activities) in respect of how the data will be accessed, it was suggested by AGD that NHS England consider / address how this will be enforced for individuals from the University of Kent on honorary contracts, noting that it was currently unclear.</p>
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<p>6.1.5 AGD queried whether any publications from the study would be published under the University of Hull or the University of Kent; and whether it would be transparent that those individuals from the University of Kent were on honorary contracts.</p> <p>6.1.6 AGD noted that whilst the DSA was transparent on the individuals from the University of Kent accessing the data; it was suggested that the draft privacy notice, provided as a supporting document, was updated to also clarify the role of the individuals from the University of Kent and that they were on honorary contracts.</p> <p>In addition, AGD made the following observations on the application and / or supporting documentation as part of the review:</p> <p>6.1.7 In addition to the suggested amendment to the draft privacy notice outlined in point 6.1.6, AGD also noted that a Professor from the University of Southampton was referenced in the draft privacy notice; and noting that the University of Southampton was not referred to in the application, suggested that this was reviewed and the draft privacy notice or the application were updated as may be necessary to reflect the correct information.</p> <p>6.1.8 AGD noted the reference in the draft privacy notice for individuals to contact NHS England for specific queries; and suggested that this was removed.</p> <p>6.1.9 AGD noted the reference in the draft privacy notice in respect of the deletion of the data at the end of the study; and suggested that NHS England keep this under review, and to consider adding a special condition in section 6 (Special Conditions) of the application in respect of this, as may be appropriate.</p> <p>6.1.10 AGD queried what, if any, data minimisation had been undertaken for the control group; and suggested that the application was updated, to provide further information about how the cohort had been identified, noting that this would be done by the University of Hull and not NHS England.</p> <p>6.1.11 In addition, it was noted by the NHS England SIRO representative, that section 3(b) (Additional Data Access Requested) stated that the tabulation will include data for all adult patients aged over the age 18; and asked that it was clarified in the application that the cohort would include those individuals who were aged 18 or over at the time of admittance, and that no data would flow prior to that date.</p> <p>6.1.12 AGD noted the inconsistent references in the application to who is accessing the data, for example, section 5(a) (Objective for Processing) refers to the University of Kent, and section 5(b) refers to the University of Hull and the University of Sheffield. It was suggested by the Group, that the application was reviewed / aligned as appropriate to ensure that the facts were reflected.</p> <p>6.1.13 In addition, AGD queried the statement in section 5(a) “...agent of the <i>University of Hull</i>...”; and suggested that either further information was provided as to who would be covered by “<i>agents</i>”, and whether this aligned with the Data</p>	
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	<p>Sharing Framework Contract (DSFC); or that this was amended / removed as may be necessary to reflect the correct / factual information.</p> <p>6.1.14 AGD noted the extensive expected benefits in section 5(d) (Benefits) of the application; and suggested that these were also reviewed and updated as may be necessary in line with NHS England DAS Standard for Expected Measurable Benefits; and to also ensure that the inclusion of the templated wording in its entirety in this section was correct and appropriate (including because any Annual Confirmation Report or revised DSA would need to update progress against all of the expected benefits).</p> <p>6.1.15 The Group commended the applicant on the excellent patient and public involvement and engagement (PPIE) undertaken / ongoing as outlined in the application; in particular the recruitment of the individual with lived experience to co-ordinate the patient advisory and stakeholder groups.</p> <p>6.1.16 AGD noted and commended the work undertaken by NHS England's Data Access Service (DAS) on the content of the DAS internal application assessment form, which supported the review of the application.</p> <p>6.1.17 Separate to the application: AGD suggested that as part of the DAS triage process, consideration was given to the Contributor Roles Taxonomy when determining the roles of different parties.</p>	To Note
6.2	<p>Reference Number: NIC-341915-Z7J0Y-v0.7</p> <p>Applicant: University of Edinburgh</p> <p>Application Title: Duration of Dual Anti-Platelet Therapy in Acute Coronary Syndrome: The DUAL-ACS Trial</p> <p>Observer: Jodie Taylor-Brown</p> <p>Application: This was a new application.</p> <p>The purpose of the application is for a research project, to answer the following principal question: should the default strategy for the duration of dual antiplatelet therapy be 3 or 12 months after type 1 myocardial infarction.</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 In respect of transparency, AGD noted and strongly endorsed the advice provided by NHS England to the applicant, as outlined in the Data Access Service (DAS) internal application assessment form that the applicant should have a study specific webpage to provide further information on the data sharing, including, but not limited to, what data is flowing, the time period, and the options available for withdrawing consent.</p>	

6.2.2 AGD suggested that the study specific webpage requirement could be addressed by NHS England in a number of ways, including, but not limited to, adding a special condition to section 6 (Special Conditions) of the application, that addresses the requirement for this, and a timeframe.

6.2.3 Noting that the study outlined in the application was much smaller than originally envisaged, and as outlined in the protocol provided as a supporting document, AGD suggested that this was communicated to the cohort for transparency.

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

6.2.4 AGD noted the content of the DAS internal consent review; and advised that they were satisfied that there was a legal gateway for the data to flow; and that there was a clear benefit to health and care.

6.2.5 AGD noted concern that the objectives for processing outlined in section 5(a) (Objective for Processing) and the anticipated outputs outlined in section 5(c) (Specific Outputs Expected) of the application, have **not** been updated to reflect the smaller scale of the study; and suggested that these were reviewed and updated as may be appropriate, in line with [NHS England DAS Standard for Objective for Processing](#) and [NHS England DAS Standard for Expected Outcomes](#).

6.2.6 In addition, AGD noted the extensive expected benefits in section 5(d) (Benefits) of the application; and suggested that these were also reviewed and updated as may be necessary in line with [NHS England DAS Standard for Expected Measurable Benefits](#), to reflect the smaller scale of the study; and to also ensure that the inclusion of the templated wording in its entirety in this section was correct and appropriate (including because any Annual Confirmation Report or revised DSA would need to update progress against all of the expected benefits).

6.2.7 In respect of data minimisation, AGD noted the dates of the Hospital Episode Statistics (HES) Accident & Emergency (A&E) and the Emergency Care Data Set (ECDS) data required; and suggested that this was reviewed to ensure there was not an excessive amount of data flowing unnecessarily for cohort members, in line with [NHS England DAS standard for data minimisation](#); and that the application was updated as may be necessary.

6.2.8 AGD noted that the use of the terms "*Acute Coronary Syndrome*" and "*Type I myocardial infarction*" was discussed / referenced in the ethical support provided as a supporting document, dated the 29th January 2018; and suggested that this was reviewed and updated as may be necessary, to ensure consistency of language.

6.2.9 AGD queried the statement in section 5(b) (Processing Activities) "*There will be no requirement and no attempt to reidentify individuals when using the pseudonymised dataset*"; and suggested that this was removed, noting that there may be occasions where reidentification would be appropriate / necessary, and that

	<p>this would be covered by the consent provided, noting the statement within the consent form that <i>“I agree to you telling my GP I’m taking part in the study”</i>.</p> <p>6.2.10 Separate to the application: AGD suggested that the AGD NHS England Data and Analytics representative advise colleagues in DAS that standard wording relating to reidentification, should be on a case by case basis and not automatically added to applications.</p> <p>ACTION: The AGD NHS England Data and Analytics representative to advise colleagues in DAS, that standard wording in an application relating to reidentification, should be done on a case by case basis and not automatically added to the application as standard wording.</p> <p>6.2.11 Noting that Medicines dispensed in Primary Care (NHSBSA) data had been requested as part of this application, it was suggested by AGD that NHS England satisfies itself that the use outlined in the application was in scope of the NHSBSA medicines data Direction.</p> <p>6.2.12 AGD noted that whilst the NHSBSA would not provide information on compliance with medication prescribed to participants in the trial; it would provide useful information in terms of whether a prescription had been dispensed or not.</p> <p>6.2.13 Separate to the application: The Group noted the discussions at the AGD meeting on the 18th April 2024 (as part of the discussion for NIC-482394-D4Q4R Imperial College London), 18th January 2024 (as part of the discussion for NIC-480151-B0M5Q University of East Anglia), 2nd November 2023 (as part of the discussion for NIC-08472-V9S6K UK Biobank), 16th November 2023 (as part of the discussion for NIC-568980-P9W7B University of Edinburgh) and the 7th December 2023 (as part of the discussion for NIC-302994-C2Q2Y University of Oxford), where the SIRO representative had advised that although the NHSBSA medicines data Direction did set out constraints on the use of data, it was not the only legal gateway that NHS England had to share data. For the purpose of transparency and public trust, the Group suggested that NHS England should explore how this could be explained, since the public may take at face value the constraints as set out in a Direction and as published on the website, and may not envisage NHS England using other legal powers to set aside restrictions in a Direction.</p> <p>6.2.14 Separate to the application: Noting the NHSBSA presentation to the Group on the 20th July 2023, and that the SIRO representative at AGD on the 24th August 2023 had noted that the Direction was being reviewed and would be presented back to the Group in due course; the Group also reiterated a request made at the AGD meeting on the 18th April 2024, 18th January 2024, 7th December 2023, 16th November 2023, and the 2nd November 2023, for a note setting out the work undertaken to reach the position set out in 6.2.13 above, alongside the work to review the Direction be presented to AGD as soon as practicable. In addition to the transparency and public trust points raised in 6.2.13 above, the Group queried whether this view would have retrospective or prospective impact on other</p>	D&A Rep
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	<p>applications using this dataset, or indeed any other applications where there were restrictions on use or dissemination of data due to wording in Directions.</p> <p>ACTION: NHS England SIRO representative to provide a note outlining the work undertaken to allow the applicant to use the data as outlined in the data sharing agreement (DSA), and to provide a copy of the work undertaken to review the Direction.</p> <p>6.2.15 AGD noted that this was a one year data sharing agreement (DSA), and queried whether this was sufficient to meet all the aims and objectives of the research project; and advised that they would be supportive of a longer DSA if required / appropriate, if this was appropriately justified within the application. AGD noted that if a longer DSA was required, then they would not need to review this application again for this amendment unless a further review was required by NHS England.</p> <p>6.2.16 AGD noted that the Data Security and Protection Toolkit (DSPT) was still outstanding for the University of Edinburgh; and supported the statement in the DAS internal application assessment form, that no data would flow until this had been completed.</p>	SIRO Rep
6.3	<p>Reference Number: NIC-534549-M1N3P-v1.2</p> <p>Applicant: University of Bristol</p> <p>Application Title: ELUCIDate: ELUcidate long-term consequences of Childhood Infections using administrative and research Data</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 18th May 2023.</p> <p>The application was previously presented at the GPES Data for Pandemic Planning and Research – Profession Advisory Group (PAG) out of committee on the 26th March 2024.</p> <p>Application: This was an amendment application.</p> <p>The purpose of the application amendment is the addition of the General Practice Extraction Service (GPES) Data for Pandemic Planning & Research (COVID-19) (GDPPR) dataset.</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 deferred the application as not all the necessary information was available to make a full assessment. AGD wished to draw to the attention of the SIRO the following substantive points; and suggested that the application be brought back to a future meeting once the previous AGD points had been sufficiently addressed (or it was clearly highlighted / justified where points were no longer applicable).</p>	

<p>6.3.1 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>6.3.2 AGD noted that the consent materials had not been provided as part of the limited documentation provided by NHS England, and the Group noted that the inclusion of these was essential to support the review of the application / amendment, especially because AGD had not provided a consent review when the application had been reviewed on 18th May 2023.</p> <p>6.3.3 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>6.3.4 AGD queried if NHS England had provided a copy of the AGD minutes from the 18th May 2023 to PAG as part of their review; noting that it was unclear if they had been made aware of the previous AGD comments / queries when reviewing the application.</p> <p>6.3.5 Separate to this application: AGD suggested to the AGD NHS England Data and Analytics representative that as part of the process when submitting applications / papers to PAG, the minutes from the previous AGD (or IGARD) review, were provided to PAG as part of the documentation pack.</p> <p>ACTION: The AGD NHS England Data and Analytics representative to liaise with Data Access Service (DAS) colleagues to ensure that as part of the process when submitting applications / papers to PAG, the minutes from the last AGD review, were provided to PAG as part of the documentation pack.</p> <p>6.3.6 AGD noted the PAG condition of support, that NHS England provides assurance that the initial consent material has been reviewed and deemed as meeting the standard for informed consent; and noting that the consent materials and / or the DAS internal consent review had been provided; and that they had not received any information as to whether this point had been addressed; the Group were unable to determine whether this PAG condition of support had been met by NHS England.</p> <p>6.3.7 AGD noted the statement in the DAS internal application assessment form, that the consent materials had been reviewed by the Group in July 2023; and advised that 1) the date of the AGD review was the 18th May 2023 (not July); and 2) no consent materials had been provided as part of the review on the 18th May 2023, so they had not reviewed the consent materials. The Group suggested that for audit purposes, this incorrect information was reviewed and updated to reflect the correct information.</p> <p>6.3.8 AGD noted that it was not clear how the points raised at the AGD meeting on the 18th May 2023 had been addressed, noting that this had not been outlined in section 11 (independent review history) of the DAS internal application assessment</p>	<p>D&A Rep</p>
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	<p>form, as per the usual process. It was therefore suggested, that prior to the application returning to AGD, it was made clear as to how all of the previous points outlined in the AGD minutes from the 18th May 2023 had been addressed.</p> <p>6.3.9 AGD queried whether there was consent for the linkage outlined in the application and suggested that this was addressed within the DAS internal consent review / consent review form.</p> <p>6.3.10 The SIRO representative queried why the legal basis had changed from s251 to consent and asked that this was made clear within the application / meeting papers, when this returns to AGD. If there had been no change in the legal basis, the SIRO Representative suggested the relevant errors be updated within the papers.</p>	
7 INTERNAL DATA DISSEMINATION REQUESTS:		
<i>There were no items discussed</i>		
8 EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL		
8.1	<p>Reference Number: NIC-736310-S6T1Z v0.2</p> <p>Applicant: NHS Counter Fraud</p> <p>Application Title: For the purposes of the prevention and detection of crime</p> <p>This application has not had a previous independent review.</p> <p>The SIRO approval was for a period of four months, to permit the access to be provided whilst a longer-term agreement is considered; with a request for the application to be brought back to a future AGD meeting.</p> <p>Outcome of discussion: AGD noted that the NHS England SIRO had already provided SIRO approval and confirmed that they were supportive of this.</p> <p>AGD thanked NHS England for the written update and made the following observations on the documentation provided:</p> <p>8.2.1 AGD queried the meaning of "<i>pre-empting</i>" in relation to the application, and following discussion suggested that this may be reworded for greater clarity when the subsequent longer-term application is submitted.</p> <p>8.2.2 AGD, including the AGD NHS England Data Protection Office representative queried why the applicant required ethnicity data; and were advised by the SIRO representative that this appeared to have been an error in the supporting Data Protection Impact Assessment (DPIA) and that ethnicity data was not required.</p> <p>8.2.3 AGD noted that the UK General Data Protection Regulation (UK GDPR) Article 9 legal basis cited, differed between the application and the DPIA; and suggested that this was reviewed and updated to reflect the correct information.</p>	

	The NHS England SIRO representative thanked AGD for their time.	
9 OVERSIGHT AND ASSURANCE		
9.1	<p>Oversight and Assurance Process</p> <p>The Statutory Guidance states that the data advisory group (AGD) should be able to provide NHS England with advice on: <i>“Precedents for internal and external access, including advising in accordance with an agreed audit framework whether processes for the use of precedents are operating appropriately, to provide ongoing assurance of access processes”</i>.</p> <p>In advance of the meeting, the AGD independent members were provided with 1) eight applications (selected by the AGD Secretariat); 2) internal application assessment forms for each of the eight applications; and 3) an oversight and assurance template to complete.</p> <p>Following review of the applications by the AGD independent members out of committee, the completed oversight and assurance templates were sent to the AGD Secretariat prior to the meeting.</p> <p>It was noted that only high-level points would be discussed in meeting (and noted in the minutes); however, the full suite of comments and feedback from AGD independent members on the oversight and assurance templates would be collated by the AGD Secretariat and shared with the SIRO representative and relevant NHS England colleagues as may be appropriate.</p> <p>Please see appendix A for high-level points raised in-meeting on the nine applications.</p>	
9.2	<p>Oversight and Assurance Conclusion / Review</p> <p>AGD noted that the SIRO representative and colleagues would be providing an overview at the AGD meeting on the 20th June 2024 plenary meeting, as to progress on the oversight and assurance feedback received to date; and how this was being addressed.</p> <p>The AGD NHS England Data and Analytics representative was invited to join the bi-weekly call with the AGD Secretariat and colleagues from the SIRO Representative Team, to discuss the applications chosen by the AGD Secretariat for oversight and assurance; and whether these were appropriate in terms of Precedents applied and what information was available to support the review. This is to ensure the best value for money / time of AGD members.</p>	<p>To Note</p> <p>To Note</p>
10 AGD OPERATIONS		
10.1	<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>	

	It was noted that a further update would be provided to the Group in due course.
10.2	AGD Stakeholder Engagement <i>There were no items discussed</i>
10.3	AGD Project Work <i>There were no items discussed</i>
11 Any Other Business	
11.1	Receive final AGD Terms of Reference (ToR) The Group noted that following approval of the AGD ToR at the Data, Digital and Technology Committee (DDAT) of the NHS England Board, on Thursday 14 th March 2024 (as noted in the 21 st March 2024 minutes), they would move from being the 'interim advisory group for data' to the 'Advisory Group for Data' in line with the approved AGD ToR (as noted in the 11 th April 2024 minutes). The Group noted that the AGD Secretariat had now received / shared a copy of the final ToR; and that a copy of the final ToR would be published on the new AGD webpages, that were due to be published following the meeting (see item 11.2).
11.2	AGD Webpage (Presenter: Karen Myers) The Group noted that prior to the meeting, a link to the draft AGD webpage, had been shared by the AGD Secretariat; and made a number of minor suggested changes to the draft website. The Group were advised that subject to the relevant approvals, the AGD webpage would go live following the meeting. The Group noted and thanked Karen for the update on this and the work undertaken on the new website, working with the NHS England communications and web teams.
Meeting Closure As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.	

Appendix A

General Practice Extraction Service (GPES) Data for Pandemic Planning & Research (COVID-19) (GDPPR) Profession Advisory Group (PAG)
Feedback Form
(Out of Committee)

APPLICATION DETAILS:		
PAG advice sought out of committee on (date):	26/03/2024	
NIC Number:	DARS-NIC-534549-M1N3P-v1.1	
Applicant:	University of Bristol	
Application Title:	ELUCIDate: "ELUCidate long-term consequences of Childhood Infections using administrative and research Data	
Application version number reviewed:	V1.1	
REVIEWERS / CHAIR:		
NAME:	ROLE / ORGANISATION REPRESENTING:	DATE FEEDBACK RECEIVED:
Dr. Mark Coley	Co-Chair of Joint GP IT committee (Representing the British Medical Association (BMA))	26/03/2024
Dr. Amir Mehrkar	BMA Representative and Health Informatics Group member (Representing the Royal College of General Practitioners (RCGP))	26/03/2024
Dr. Jonathan Osborn	PAG Chair, Associate Caldicott Guardian (NHS England) (receiving advice)	26/03/2024
DECLARATIONS OF INTEREST:		
There were no declarations of interest.		

SUMMARY OF PAG FEEDBACK TO THE PAG CHAIR:
<p>PAG understands the children and young persons information from the Schools Infection Survey (SIS) were consented, and that CAG has confirmed that direct re-consenting is not required for this linkage to GDPR.</p> <p>All the conditions of the PAG checklist have been met for this COVID-19 related research, which also has HRA favourable ethical approval, and is conducted in a TRE supported by the profession (the ONS SRS).</p> <p>PAG understands that the dissemination of GDPR data back to the ONS TRE is for only the cohort's data.</p>
CONCLUSION / OUTCOME:
<p>PAG support is provided, on the condition that:</p> <ol style="list-style-type: none">1. NHS England provides assurance that the initial consent material has been reviewed and deemed as meeting the standard for informed consent.2. The applicant identifies exactly which other ONS datasets will be used in this study, in addition to the SIS.
<i>Date Form Completed: 23/5/24</i>

Appendix B

Oversight and Assurance Review – 23rd May 2024

Ref:	NIC Number:	Organisation:	Areas to consider:
240523a	NIC-06587-S1Q6N-v7.5	Wiltshire Council	<ul style="list-style-type: none"> No SDA had been provided as a supporting document, so unclear if any exclusion criteria applied No update to the yielded benefits since they had been accrued in 2019/20. Noting the large volume of data flowing, it is unclear whether national data is justified, especially because the yielded benefits do not reference this point.
240523b	NIC-185179-V0B0T-v2.3	London School of Hygiene and Tropical Medicine	<ul style="list-style-type: none"> Unclear whether the remote access had been added, and whether adding remote access is a simple amendment (Precedent 12) or needs a separate precedent. The legal basis for dissemination appeared to have been changed, noting the data has already flowed and it can't be retrospectively changed. Privacy Notice informs data subjects that they can opt out of 'research of this kind', however no opt-outs are applied because it's pseudonymised data.
240523c	NIC-136916-B7D5C-v3.6	University College London (UCL)	<ul style="list-style-type: none"> Precedent assessed against not available to AGD

			<ul style="list-style-type: none"> • The legal basis for dissemination appeared to have been changed, noting the data has already flowed and it can't be retrospectively changed. • IGARD previously asked to see the yielded benefits so they could be given an independent review.
240523d	NIC-44356-Y8N6R-v8.4	Royal College of Obstetricians and Gynaecologists (RCOG)	<ul style="list-style-type: none"> • The cumulative changes made over a series of simple amendments means the application is substantially different to the version seen by IGARD, so it is not clear if the correct Precedent had been used / applied correctly (subjective). • CAG decision to disapply National Data Opt Out was challenging and sensitive and NHS England may have wished to seek independent advice.
240523e	NIC-199726-F4V3C-v3.14	King's College London	<ul style="list-style-type: none"> • Do not support the access to the data, serious concerns that there has not been careful rigour of the previous issues raised by IGARD when it had been unable to recommend for approval (7/3/19) and request by IGARD (3/11/22) to see the next iteration of the application, the fact that the DAS ethics standard has been recently updated and the SDA is not clear what HRA CAG are supporting. • Precedent assessed against not available to AGD (precedent 16).

			<ul style="list-style-type: none"> • It was not clear when the yielded benefits were updated, as they had not been date stamped.
240502f	NIC-06759-X5V7P-v6.4	University of York	<ul style="list-style-type: none"> • Unable to confirm if supportive due to insufficient information provided. • Precedent assessed against not available to AGD (precedent 16). • No SDA / escalation form provided as a supporting document. • Unclear what HRA CAG have supported or if it is still in place.
240523g	NIC-170100-T1Q8C-v3.3	Cambridgeshire and Peterborough NHS Foundation Trust	<ul style="list-style-type: none"> • Unable to confirm if supportive since the SDA / escalation form had not been provided • Precedent assessed against not available to AGD (precedent 16). • HRA CAG s251 support appears to be in place, but it is unclear.
240523h	NIC-61864-C6X2R-v6.2	South Tyneside Council	<ul style="list-style-type: none"> • Unable to confirm if supportive because the Local Authority template is just for HES data and doesn't cover the other amendments made. • Yielded benefits are insufficient and refer to a dataset not used in this application.