

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 24th October 2024

09:00 – 14:15

(Remote meeting via videoconference)

AGD INDEPENDENT / NHS ENGLAND MEMBERS IN ATTENDANCE:	
Name:	Role:
Paul Affleck (PA)	AGD independent member (Specialist Ethics Adviser) (Chair)
Claire Delaney-Pope (CDP)	AGD independent member (Specialist Information Governance Adviser)
Dr. Robert French (RF)	AGD independent member (Specialist Academic / Statistician Adviser)
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)
Tom Wright (TW)	NHS England member (Data and Analytics Representative (Delegate for Michael Chapman))
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	Role / Area:
Garry Coleman (GC)	NHS England SIRO Representative
Suzanne Hartley (SH)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.1)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Delivery Directorate
Jodie Taylor-Brown (JTB)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: items 5.2 to 5.4)
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)
Kirsty Irvine (KI)	AGD independent member (Chair)
Jon Moore (JM)	NHS England member (Data Protection Office Representative)
Miranda Winram (MW)	AGD independent member (Lay Adviser)

1	<p>Welcome and Introductions:</p> <p>The AGD meeting Chair welcomed attendees to the meeting.</p> <p>AGD noted that, due to a declaration of interest on item 5.3 (NIC-63347-R8J2M), there was an even number of AGD independent members (three) and AGD NHS England members (three) in attendance for that item.</p> <p>The importance of the AGD independent member majority was acknowledged by those present, and it was suggested that an annual review / possible inclusion in the AGD annual report of the number of meetings where an independent majority had not been present would be useful, as this would allow consideration of whether any action needed to be taken to improve the proportion of meetings with an AGD independent member majority.</p> <p>The NHS England SIRO Representative stated that should AGD members be required to vote on any issues in the meeting, then one AGD NHS England member would be asked to not participate, to ensure the appropriate balance of votes, i.e. that the majority was by AGD independent members. The Group noted and agreed with this proposal.</p> <p>Noting that the AGD Terms of Reference state that “<i>The majority of the members of the Group or Sub-Group involved in any meeting should be independent members...</i>”, the Group agreed that the meeting was still quorate for all agenda items and agreed to proceed on that basis.</p>
2	<p>Review of previous AGD minutes:</p> <p>The minutes of the AGD meeting on the 17th October 2024 were reviewed out of committee by the Group and, after several minor amendments, were agreed as an accurate record of the meeting by the Chair of the meeting, on behalf of the Group.</p>
3	<p>Declaration of interests:</p>

	Jenny Westaway noted a professional link to the Royal College of Anaesthetists (NIC-63347-R8J2M). It was agreed that Jenny would leave the virtual room for the discussion of this application.
4 BRIEFING PAPER(S) / DIRECTIONS:	
<i>There were no items discussed</i>	
5 EXTERNAL DATA DISSEMINATION REQUESTS:	
5.1	<p>Reference Number: NIC-748653-S9J4H-v0.3</p> <p>Applicant: Office for National Statistics (ONS)</p> <p>Application Title: Waiting List Minimum Data Set (WLMDS) - for the purposes of Statistics and Statistical Research, under section 45 of the Statistics and Registration Services Act 2007 as amended by the Digital Economy Act 2017</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 9th May 2024.</p> <p>Linked applications: This application is linked to NIC-748645-R5G3D.</p> <p>Application: This was a new application.</p> <p>The purpose of the application is for ONS to use the data for its health and labour market statistical work programme, which is currently sponsored by His Majesty's (HM) Treasury and potentially other funding bodies in the future. The statistics this will enable are in line with ONS's function to produce statistics for the public good.</p> <p>NHS England were seeking general advice on the application.</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 majority of the Group were not supportive of the application at this time, due to the concerns around the transparency and public engagement, and a minority (one member) of the Group was supportive of the application.</p> <p>AGD noted that they had been provided with a curated set of documentation and noted that they would be providing observations based on these documents.</p> <p>5.1.1 AGD noted and commended NHS England's Data Access Service (DAS), and the applicant, on the diligent work undertaken to address the previous points raised by the Group.</p> <p>5.1.2 AGD reiterated a previous point from the AGD meeting on the 9th May 2024, that the Group noted that patient objections do not apply; and noted the statement in the National Data Opt-out (NDO) policy (point 7.6) that "<i>The national data opt-out does not apply to data flowing into the Office for National Statistics (ONS) solely for the production of official statistics</i>"; and noting previous discussions on this point,</p>

the Group suggested consideration was given by NHS England as to whether all of the intended activities fall under the production of official statistics.

5.1.3 AGD noted the firm opposition from the representatives of the Royal College of General Practitioners (RCGP) and British Medical Association (BMA) (via the General Practice Extraction Service (GPES) Data for Pandemic Planning and Research (GDPPR) – Profession Advisory Group (PAG)) against data from the GP practice (in this case ethnicity data alone) being linked by ONS with Department for Work and Pensions (DWP) data (please see **Appendix A**). AGD noted that the dataflows may be underpinned by a legal requirement for a flow for the purposes of official statistics, and the NDO is **not** upheld in such circumstances. AGD considered that this may come as a surprise to patients, and whilst the benefits of sharing were clearly stated within the application, there was a risk of unintended consequences in relation to patient(s) acting on concerns. AGD advised that NHS England should review its transparency pages to make clear that it may be required to flow data in such circumstances where the benefits are much broader than health and social care, and ensure that the application is reviewed to ensure that it is clear as to why the NDO is **not** being applied, and that any constraints on use of data by ONS as a result of the legal basis are clearly spelt out.

5.1.4 The AGD NHS England Data Protection Office Team Representative highlighted the first data protection principle of the UK General Data Protection Regulation (UK GDPR), that personal data shall be “*processed lawfully, fairly and in a transparent manner....*”; and whilst they welcomed the update to the applicant’s privacy notice, the Group suggested that transparency should be undertaken **prior** to the data flowing.

5.1.5 The AGD NHS England Caldicott Guardian Team Representative noted that whilst [The Caldicott Principles](#) would not necessarily apply to ONS, they did highlight to NHS England, the eighth principle “*A range of steps should be taken to ensure no surprises for patients and service users...*”, which underlines the importance of transparency.

5.1.6 AGD noted the special condition in section 6 (Special Conditions) of the application, in respect of the applicant producing a patient and public involvement and engagement (PPIE) plan; and, whilst they welcomed this, there may be a risk that if the PPIE highlighted public concern, then it would be too late for anything to be done about this because data had already flowed. The Group suggested that the special condition was updated to be more time specific.

5.1.7 The Group also suggested that, as part of the PPIE, the applicant should seek input / feedback from relevant parts of the population, for example national mental health groups, as also recommended by the National Statistician’s Data Ethics Advisory Committee (NSDEC).

5.1.8 In addition, the Group noted that there may be ethical issues in the future, in that this work could underpin prioritisation of healthcare, based on, for example,

	<p>employability rather than health need; and suggested that the applicant explore this as part of the PPIE.</p> <p>5.1.9 AGD noted the work undertaken on the Data Protection Impact Assessment; (DPIA) however, noted that the transparency risk was not addressed, and suggested that this, along with the outcomes of any PPIE work, were also included in the DPIA.</p> <p>5.1.10 AGD queried whether any of the parties named in section 5(a) (Objective for Processing) should also be considered a Data Controller, for example, His Majesty's Treasury; and suggested that this was reviewed in line with NHS England DAS Standard for Data Controllers, and that the application was updated as may be necessary.</p> <p>5.1.11 AGD suggested that for the purpose of transparency, section 5(a) of the application was updated, to be clearer on the purpose of processing, including, but not limited to, the five specific projects approved by NSDEC.</p> <p>5.1.12 In addition, it was suggested that section 5(c) (Specific Outputs Expected) was updated to reflect the expected outcomes of the five specific projects noted in point 5.1.11.</p> <p>5.1.13 Noting employees are referred to as "<i>substantive</i>" in section 5(a), AGD noted the statement in section 5(b) (Processing Activities) "<i>Access is restricted to employees of ONS...</i>"; and suggested that NHS England clarify that they were substantive employees of ONS; and, if not, that the NHS England's DAS Standard for Honorary Contracts was applied as appropriate.</p> <p>5.1.14 AGD noted in section 7 (Ethics Approval) of the application that ethical approval was not required; however, suggested that this was updated to reflect that work was taking place under the oversight of NSDEC.</p>	
5.2	<p>Reference Number: NIC-616019-B4C8W-v5.5</p> <p>Applicant: NHS West Yorkshire Integrated Care Board (ICB)</p> <p>Application Title: DSfC - NHS WEST YORKSHIRE INTEGRATED CARE BOARD - IV, RS and Comm</p> <p>Observer: Jodie Taylor-Brown</p> <p>Previous Reviews: A briefing paper linked to this application was presented / discussed at the AGD meeting on the 14th December 2023.</p> <p>Application: This was an amendment application.</p> <p>The amendments are:</p> <ol style="list-style-type: none"> 1. to permit linkage of NHS England data to several external datasets, submitted by local providers, for the purposes of Commissioning; 2. to add Catalyst IT Solutions as a Data Processor; 	

3. the addition of wording to permit Leeds Beckett University staff to access the data under honorary contract with West Yorkshire Integrated Care Board for a quantitative evaluation of the 'Enhance intervention'; and
4. the removal of wording to permit Health Innovation Yorkshire and Humber staff to access the data under honorary contract with West Yorkshire Integrated Care Board as their work has now been completed.

NHS England were seeking advice on the following points, including general advice on any other aspect of the application:

1. The amendment to permit linkage to the four additional datasets.

Should an application be approved by NHS England, further details would be made available within the [Data Uses Register](#).

Outcome of discussion: AGD were supportive of the application and wished to draw to the attention of the SIRO the following significant comments:

AGD noted that they had been provided with a curated set of documentation and noted that they would be providing observations based on these documents.

In response to point 1:

5.2.1 AGD discussed the request for the linkage to the new datasets, and noted concerns on the sensitivity of the data, for example, housing and children's data; however, it was noted that, based on the information provided, there was a valid legal basis / purpose for the linkage and use of this data.

5.2.2 AGD noted that the National Data Opt-out (NDO) would **not** be applied, but that the data would be pseudonymised when processed. Noting the sensitivity of the data linkage, the Group highlighted the need for transparency, noting that individuals may be surprised. AGD noted that this also emphasised the need for having a robust re-identification process.

5.2.3 AGD noted that section 5(a) (Objective for Processing) of the application contained inconsistent information in respect of who could request re-identification of data for direct care; and suggested that this was reviewed and updated, for example, to state that **only** those in an appropriate position can make this request and receive this data. It was also suggested that this was updated to be clearer on the role of the ICB Caldicott Guardian within the re-identification process, as referred to in section 10 (Sub-licensing) of the application.

5.2.4 AGD recalled that at the AGD meeting on the 14th December 2023, the Group had noted that the NDO was **not** applied to pseudonymised data released for the purpose of commissioning. The Group and SIRO Representative had also 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 had also noted their concerns around individuals possibly withdrawing from services to prevent their data being shared. In response to these points, AGD noted the internal

	<p>Data Access Service (DAS) Escalation Form stated that this would be explored further with the ICB. The Group suggested that further clarification was provided on the outcome of this.</p> <p>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.2.5 AGD noted that part of the work under this application would be with a consented cohort; and suggested that NHS England's DAS undertake a consent review to ensure that the processing activities were compatible with the consent, as per the usual process.</p> <p>5.2.6 AGD noted that an employee from Leeds Beckett University would have an honorary contract with the NHS West Yorkshire ICB. The Group agreed that, based on the information provided, an honorary contract seemed to be appropriate, rather than via a Data Processing Agreement.</p> <p>5.2.7 The Group also suggested that NHS England clarify with the applicant if Leeds Beckett University had any other further role / responsibilities with the work outlined in this application and in line with the NHS England DAS Standard for Data Controllers / NHS England DAS Standard for Data Processors; and if so, that the application was updated accordingly.</p> <p>5.2.8 AGD noted the reference in the internal NHS England DAS Escalation Form and application to "<i>honorary contracts</i>" (plural); and noting that there only appeared to be one individual on an honorary contract, suggested that this was reviewed and updated to reflect the correct / factual information.</p> <p>5.2.9 AGD noted that the address for NHS England in section 1(c) (Data Processor(s)) was incorrect; and suggested that this was updated to reflect the correct address.</p> <p>ACTION: NHS England Data & Analytics Representative to ensure that the address for NHS England is updated across all relevant applications.</p> <p>5.2.10 AGD suggested that the yielded benefits in section 5(d) (Benefits) (iii) (Yielded Benefits) of the application were updated to reflect the Health Innovation Yorkshire and Humberside work that is now complete.</p>	D&A Rep
5.3	<p>Reference Number: NIC-63347-R8J2M-v7.2</p> <p>Applicant: Royal College of Anaesthetists</p> <p>Application Title: Perioperative Quality Improvement Programme (PQIP)</p> <p>Observer: Jodie Taylor-Brown</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 12th September 2024 and the 30th November 2023.</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 17th February 2022, 12th October 2017, 28th September 2017 and the 14th September 2017.

Application: This was a renewal application.

The purpose of the application is for a research project, with the primary objective of measuring the rate of postoperative complications and other adverse outcomes after major inpatient surgery in England and Wales.

NHS England were seeking advice on the following points, including general advice on any other aspect of the application:

1. Whether the information made available to the participants is sufficient to allow Royal College of Anaesthetists to receive additional linked data.

Should an application be approved by NHS England, further details would be made available within the [Data Uses Register](#).

Outcome of discussion: AGD were supportive of the application and wished to draw to the attention of the SIRO the following comments:

AGD noted that they had been provided with a curated set of documentation and noted that they would be providing observations based on these documents.

In response to point 1:

5.3.1 AGD noted and commended NHS England's Data Access Service (DAS) and the applicant on the work undertaken to address the previous points raised by the Group, including, but not limited to, the letter from the patient representatives on the Study Management Team, confirming that as part of the consent provided they were aware of the continuing flow / retention of follow up data; and the update to the privacy notice.

5.3.2 AGD noted that the participation information sheet (PIS) has been provided as a supporting document, and made a number of comments on this, including, but not limited to, adding the date and a version number to the document; to remove references to "*NHS Digital*" and replace with "*NHS England*"; and to review and amend the references to "*anonymised*" data. In addition, the AGD Specialist Academic / Statistician Adviser noted a number of other minor amendments and would share their comments with DAS colleagues separately.

5.3.3 AGD noted that two Article 6 UK General Data Protection Regulation (UK GDPR) limbs had been cited in the application, Article 6(1)(e) (*Public Task*) and 6(1)(f) (*Legitimate Interests*); and that the privacy notice only referred to one Article 6 legal basis. The Group suggested that the application and privacy notice were reviewed and updated to reflect the correct Article 6 limb(s), in line with the Information Commissioner's (ICO) [Guidance](#).

5.4	<p>Reference Number: NIC-561357-X0F3N-v2.2</p> <p>Applicant: Evidera Ltd</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>Observer: Jodie Taylor-Brown</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 14th December 2023, 23rd November 2023 and the 16th November 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 16th June 2022 and the 20th October 2022.</p> <p>The application and relevant supporting documents were previously presented / discussed at the General Practice Extraction Service (GPES) Data for Pandemic Planning and Research (GDPPR) – Profession Advisory Group (PAG) meetings on the 5th October 2022 and the 9th February 2022.</p> <p>Application: This was an amendment application.</p> <p>The amendments are to 1) increase the cohort size from 25% to 50% of the population of England; and 2) to add the National Disease Registration Service (NDRS) Cancer Consolidated dataset and the Electronic Prescribing and Medicines Administration (ePMA) dataset.</p> <p>NHS England were seeking general advice on the application.</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 if the following substantive comments were addressed, and wished to draw to the attention of the SIRO the following substantive comments.</p> <p>AGD noted that they had been provided with a curated set of documentation and noted that they would be providing observations based on these documents.</p> <p>5.4.1 AGD noted the amendment to the application to increase the cohort size from 25% to 50% of the population of England. The AGD Specialist Academic / Statistician Adviser noted that the ‘masking’ argument would only be relevant to the descriptive outputs and not the analysis, and would therefore not be a reason in itself to increase the cohort size. The ‘power’ argument required more detail on which aspects of the stated purposes could not be completed with the current, large sample. The Group therefore suggested that section 5(a) (Objective for Processing) of the application, was updated to provide a clear and robust justification for the increase of the cohort size from circa 11 million to circa 22 million.</p>	
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5.4.2 AGD suggested that NHS England could consider increasing the cohort size for particular segments of the population, such as patients with COVID-19, specific rare conditions, and other vulnerable groups, as opposed to increasing the entire cohort size. Given the applicant currently has access to a 25% sample of the population, they should be able to use that data to make robust calculations of the potential benefit of any additional cases requested.

5.4.3 In addition, it was queried whether there would be any further processing of the data once this had been exported from NHS England's Secure Data Environment (SDE), and suggested that NHS England explored this further with the applicant, noting The [Lancet Regional Health Europe article](#) which outlined the work in this application.

5.4.4 AGD also suggested that NHS England satisfy itself that all relevant NHS England procedures had been followed with regard to authors of The Lancet Regional Health Europe article having full access to **all** study data.

5.4.5 The Group noted that following the publication of an article in The Lancet Regional Health Europe, this may provide further information / support an increase to the cohort size; for example, that work under this application would be looking at stem cell transplants and high-dose corticosteroid treatment; and suggested that, if this was correct, that this information was added to section 5(a) of the application.

5.4.6 In addition, AGD queried if the published article in The Lancet Regional Health Europe had included the NHS citation statement, as per the special condition in section 6 (Special Conditions) of the application; and suggested that NHS England clarified this with the applicant.

5.4.7 Noting that the PAG advice had been previously sought / obtained on this application, it was suggested by AGD that NHS England consider seeking a further view from PAG, and in line with their current [published Terms of Reference](#), noting the substantive updates to the application, i.e. in respect of the increase to the cohort size.

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

5.4.8 AGD noted that following the last review of this application, the applicant had produced a privacy notice, and noting this was not easy to locate and access, unless via the link provided by the application, suggested that NHS England discuss this further with the applicant, in line with the Information Commissioner's (ICO) [Guidance](#), and [NHS England DAS Standard for Transparency \(Fair Processing\)](#).

5.4.9 AGD noted that the published privacy notice referred to the ability for individuals to opt-out via the National Data Opt-out (NDO); and noting that this was incorrect, it was suggested that NHS England discuss this further with the applicant, and that the privacy notice was updated as necessary to reflect the correct / factual information.

<p>5.4.10 AGD queried whether the information in section 3 (Datasets Held / Requested) of the application reflected the correct information, including but not limited to, the datasets that would continue to be made available to the applicant and the volume of data required, i.e. would the data flowing for existing datasets be increased to reflect the increase in cohort size; and suggested that NHS England reviewed and updated this as may be required, to ensure that the correct information was reflected.</p> <p>5.4.11 AGD noted the information in section 5(a) of the application, in respect of the support that was being provided by the Professor from the University of Oxford. Noting that the University of Oxford were not mentioned elsewhere in the application, the Group suggested that NHS England explored this further with the applicant; and that the application was updated accordingly for example, whether they would be considered a Data Controller in line with NHS England DAS Standard for Data Controllers or a Data Processor in line with NHS England DAS Standard for Data Processors.</p> <p>5.4.12 AGD noted that in addition to the data sharing agreement (DSA), there was also a 'User Agreement' for those individuals accessing data in NHS England's Secure Data Environment (SDE), that covers off key points, including, but not limited to, specific user access and restrictions on exporting data; and suggested that this was referred to in section 5(b) (Processing Activities) of the application.</p> <p>5.4.13 Separate to the application: AGD suggested that the AGD NHS England Data and Analytics Representative ensure that where an applicant is accessing data in NHS England's SDE, that DAS colleagues ensure that the 'User Agreement' is referred to in section 5 (Purpose / Methods / Outputs) of the application for transparency, as part of NHS England's data uses register.</p> <p>ACTION: NHS England Data and Analytics Representative to ensure that DAS colleagues refer to the 'User Agreement' in section 5 of the application for transparency.</p> <p>5.4.14 AGD noted the reference in section(c) (Specific Outputs Expected) of the application to patient and public involvement and engagement (PPIE); and suggested that the outcome of this PPIE was included in section 5(a) of the application, in line with NHS England DAS Standard for Objective for Processing.</p> <p>5.4.15 AGD suggested that the commercial aspect of the application in section 5(e) (Is the Purpose of this Application in Anyway Commercial), particularly the information in respect of the balance between public and commercial benefit, was replicated for transparency in (the published) section 5(a), in line with NHS England's DAS Standard for Objective for Processing and NHS England's DAS Standard for Commercial Purpose</p> <p>5.4.16 AGD queried the statement in section 5(e) (Is the Purpose of this Application in Anyway Commercial) of the application "<i>AstraZeneca UK Ltd will not suppress findings or receive exclusive access to findings</i>"; and noting that AstraZeneca UK</p>	<p>D&A Rep</p>
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	<p>Ltd were the sole Data Controller, it was suggested that this statement was reviewed and updated to ensure that it was factually correct, for example, to reflect that they would not suppress findings. In addition, it was suggested that the updated statement was replicated for transparency in section 5(a).</p>	
5.5	<p>Reference Number: NIC-616039-L2R9G-v1.2</p> <p>Applicant: NHS Nottingham and Nottinghamshire Integrated Care Board (ICB)</p> <p>Application Title: DSfC - NHS Nottingham and Nottinghamshire Integrated Care Board - Comm/IV/RS</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 12th September 2024.</p> <p>Application: This was an amendment application.</p> <p>The amendments are 1) the addition of linkage to Acute data, Community data, Out of hours Care and Mental health data; and 2) the addition of the s251 linkage method.</p> <p>NHS England were seeking general advice on the application.</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>AGD noted that they had been provided with a curated set of documentation and noted that they would be providing observations based on these documents.</p> <p>5.5.1 AGD discussed the method for applying the National Data Opt-out (NDO) for linkages with the ICBs flowing pseudonymised data, with a pseudo key, to the Data Services for Commissioners Regional Offices (DSCRO); and queried whether this was in line with the NDO policy, and whether the ICBs should apply the NDO before flowing the data; and suggested that NHS England gave this further consideration.</p> <p>5.5.2 AGD discussed the s251 support, and whether this aligned with the application in respect of the application of the NDO, and agreed, that this did align; noting that the NDO policy was owned by NHS England.</p> <p>5.5.3 AGD noted that NHS England were acting as a Data Processor for the ICB and were applying the NDO for this part of the processing.</p> <p>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.5.4 AGD noted that section 5(a) (Objective for Processing) of the application contained inconsistent information in respect of who could request re-identification of data for direct care; and suggested that this was reviewed and updated, for example, to state that only those in an appropriate position can make this request and receive</p>	

	<p>this data. It was also suggested that this was updated to be clearer on the role of the ICB Caldicott Guardian with the re-identified data, as referred to in section 10 (Sub-licensing) of the application.</p> <p>5.5.5 AGD noted and commended the applicant on their efforts to inform the local population in respect of the data processing and the ability to opt-out; and suggested that this was used as an exemplar to other ICBs, for example, via the Integrated Care System (ICS) Steering Group.</p> <p>5.5.6 Separate to this application: AGD noted that NIC-616019-B4C8W NHS West Yorkshire ICB (item 5.2) was not applying opt-outs, and that there appeared to be a discrepancy and inconsistency between the two applications considered at the AGD meeting. The Group suggested that NHS England's Data Access Service (DAS) reviewed this, to determine if this was justified based on the facts.</p> <p>ACTION: NHS England's DAS to review NIC-616019-B4C8W NHS West Yorkshire ICB to determine whether not applying opt-outs was justified, based on the facts available.</p>	DAS
5.6	<p>Reference Number: NIC-690385-R5D4B-v0.5</p> <p>Applicant: Lancaster University</p> <p>Application Title: Mental healthcare use and longer-term outcomes in people with co-occurring mental health conditions and alcohol use disorder</p> <p>Application: This was a new application.</p> <p>The purpose of the application is for a research project, investigating how the prevalence of co-occurring mental health problems and alcohol use disorder (AUD) (with a focus on co-occurring Bipolar disorder (BD) and AUD) across people using secondary mental health services in England differs by geographical region, demographic information (e.g. age, ethnicity), and by level of deprivation.</p> <p>NHS England were seeking general advice on the application.</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 if the following substantive comments were addressed, and wished to draw to the attention of the SIRO the following substantive comments.</p> <p>5.6.1 Noting that the data requested was linked to alcohol dependence, AGD noted that it was unclear what the justification was for the data requested prior to 2020; and suggested that NHS England discussed this further with the applicant, and that the application was updated with further clarity.</p> <p>5.6.2 AGD noted that, prior to the meeting, the SIRO Representative had raised a query with NHS England's Data Access Service (DAS) in respect of the data minimisation; and noted that there were ongoing internal discussions on this point.</p>	

<p>AGD suggested that this was clarified, and the application was updated accordingly, in line with NHS England DAS standard for Data Minimisation.</p> <p>5.6.3 AGD queried whether Lancaster University would be involved with the data minimisation, noting the information in section 5 (Purpose / Methods / Outputs) of the application that suggests they would; and advised that NHS England explored this further with the applicant, and that the application was updated with further clarification.</p> <p>5.6.4 Separate to the application: AGD queried what data minimisation could be undertaken in NHS England's Secure Data Environment (SDE) and at what point the data was minimised; and asked that an update was provided to the Group on this point.</p> <p>ACTION: The AGD Data and Analytics Representative, to provide confirmation to AGD, as to what data minimisation would be undertaken in NHS England's SDE and at what point the data was minimised.</p> <p>5.6.5 AGD noted that the PhD student was also an employee of Lancaster University; and that only this individual would have access to the data. The Group suggested that NHS England discussed this further with the applicant, for example, to ensure that at least one supervisor of the individual also had access to the data, to provide support with the output creation and checking of the analysis; noting the complexity and the type of data being processed and the potential sensitivity of any findings.</p> <p>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.6.6 AGD noted and commended the work undertaken by NHS England's Data Access Service (DAS) on this application, in particular the questions determining the PhD student access to the SDE.</p> <p>5.6.7 AGD noted there are ethical issues with the work being undertaken noting the sensitivity of the subject being researched; and suggested that the application was updated to be clearer on this, and in line with the NHS England DAS Standard for Ethical Approval.</p> <p>5.6.8 AGD noted that section 7 (Approval Considerations) stated that ethical approval was not required, however, suggested that this was updated to reflect that institutional ethical support had been obtained.</p> <p>5.6.9 AGD suggested that the language in the application was reviewed and updated, for example to remove the reference to mental health "<i>problem</i>" and replace with a more sensitive term, to avoid stigmatisation.</p> <p>5.6.10 AGD noted that in addition to the data sharing agreement (DSA), there was also a 'User Agreement' for those individuals accessing data in NHS England's Secure Data Environment (SDE), that covers off key points, including, but not limited</p>	<p>D&A Rep</p>
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	<p>to, specific user access and restrictions on exporting data; and suggested that this was referred to in section 5(b) (Processing Activities) of the application.</p> <p>5.6.11 Separate to the application: AGD suggested that the AGD NHS England Data and Analytics Representative ensure that where an applicant is accessing data in NHS England's SDE, that DAS colleagues ensure that the 'User Agreement' is referred to in section 5 of the application for transparency, as part of NHS England's data uses register.</p> <p>ACTION: NHS England Data and Analytics Representative to ensure that DAS colleagues refer to the 'User Agreement' in section 5 of the application for transparency.</p> <p>5.6.12 AGD noted and commended the applicant on the patient and public involvement and engagement (PPIE) in section 5(a) (Objective for Processing) of the application; and suggested that there was ongoing PPIE throughout the lifecycle of the work. The HRA guidance on Public Involvement is a useful guide.</p>	D&A Rep
6 INTERNAL DATA DISSEMINATION REQUESTS:		
<i>There were no items discussed</i>		
7 EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL		
<i>There were no items discussed</i>		
8 OVERSIGHT AND ASSURANCE		
<i>There were no items discussed</i>		
9 AGD OPERATIONS		
9.1	<p>Risk Management Framework</p> <p>AGD has been previously informed that a risk management framework is being developed by Data Access. However, AGD noted that the Group's Terms of Reference have been in place since March 2024 and charge the Group with operating in line with NHS England's risk management framework, and it is therefore of concern that there is still not a Risk Management Framework in place.</p> <p>ACTION: The NHS England SIRO Representative to provide a written response to AGD on the progress, and expected time frame for implementation, of the risk management framework.</p>	SIRO Rep
9.2	<p>Standard Operating Procedures (SOPs)</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</p>	

	was noted that work was progressing in order to finalise relevant AGD SOPs in line with the approved AGD ToR.	
9.3	AGD Stakeholder Engagement <i>There were no items discussed</i>	
9.4	AGD Project Work It was noted that Kirsty Irvine, Paul Affleck and Claire Delaney-Pope would be attending NHS England Data Access Service (DAS) Standards Working Groups with regard to the NHS England DAS Standards from November 2024 to January 2025.	
10 Any Other Business		
10.1	AGD Minutes AGD and the SIRO Representative discussed whether it would be more transparent to the public to include the name of the Data Controller(s) rather than the Applicant, noting that the AGD minutes only currently include the name of the Applicant when discussing external data dissemination requests. The Group agreed that this would feed into the proposal being drafted by the AGD Secretariat in respect of updating the format of the AGD minutes, as discussed at the AGD meeting on the 17 th October 2024. ACTION: The AGD Secretariat to include options for adding the name of the Data Controller(s) rather than the Applicant / as well as the Applicant in the draft AGD minutes proposal for consideration by the NHS England's SIRO Representative and the AGD Chair.	AGD Sec
Meeting Closure As there was no further business raised, the Deputy Chair of meeting 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 by NHSE out of committee on (date):	15 th March 2024	
NIC Number:	DARS-NIC-748653-S9J4H	
Applicant:	Office of National Statistics	
Application Title:	Waiting List Minimum Data Set (WLMDs) - for the purposes of Statistics and Statistical Research, under section 45 of the Statistics and Registration Services Act 2007 as amended by the Digital Economy Act 2017	
Application version number reviewed:	Briefing Paper and NIC-400304-S1P1B-v6.2	
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. Jonthan Osborn	PAG Chair, Associate Caldicott Guardian (NHS England) (<i>receiving advice via email on behalf of NHSE</i>)	26/03/2024
DECLARATIONS OF INTEREST:		

There were no declarations of interest.

SUMMARY OF BMA and RCGP FEEDBACK TO NHS England via PAG route:

As of this time, PAG does not support any linkage of health data from GDPRR with DWP data (such as, but not limited to income and benefits data). PAG cannot consider supporting such work until consultation has occurred with:

1. The wider public
2. The executives and leaders of the BMA and RCGP.
3. The National Data Guardian for Health and Social Care
4. Privacy campaigners

We point to significant parliamentary select committee discussions around such type of linkage and the concerns raised:

<https://publications.parliament.uk/pa/cm201719/cmselect/cmhealth/677/67707.htm>

Also, has ONS approached PHE regarding the findings for this call for evidence work: <https://www.gov.uk/government/calls-for-evidence/data-sharing-mou-between-nhs-digital-and-home-office-call-for-evidence>

Finally, we point to this publication,

<https://bmjopen.bmj.com/content/10/2/e033202>: “The patient data-sharing agreement was considered a threat to some of the core principles of the NHS and its implementation as adversely affecting healthcare access and patient safety. Future policy development should involve a range of stakeholders including civil society, healthcare professionals and ethicists, and include more meaningful assessments of the impact on healthcare and public health”.

Requests

- 1 Before any further work on processing GDPRR, and in part due to the delay in restarting PAG, PAG requests clarification from ONS as to which datasets GDPRR has been linked to; we need to assure ourselves that this is in keeping to how we had assumed the GDPRR data would be used.
- 2 Please can ONS provide a timeline of when different datasets were linked, and when linkages did occur, and clarify if any of the linkages were actually processed for publication / policy use.
- 3 PAG is keen to understand what the outcome was from the NSDEC recommendations:
 - *The Committee requested that the research team provide additional assurance that the public engagement work undertaken to support this project is sufficient. The NSDEC recommends that the research team further considers public attitudes towards the linkage to benefits and tax data to Census more generally.*

- *NSDEC recommends that further public acceptability work is undertaken to ensure that such groups are comfortable with the use of such data and understand how analysis may feed into policy interventions that impact them.*

PAG is committed to ensuring that there is no real or perceived erosion to public trust in the profession, nor unintended patient safety effects which might transpire if any DWP data is linked to health data.

CONCLUSION / OUTCOME:

See text from BMA and RCGP representatives' email above.

Date Form Completed: 22/10/24