Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 22nd January 2026

09:00 – 16:00

(Remote meeting via videoconference)

AGD INDEPENDENT / NHS ENGLAND MEMBERS IN ATTENDANCE:	
Name:	**Role:**
Noela Almeida (NA)	NHS England member (Data Protection Office Representative (Delegate for Jon Moore)) (not in attendance for items 8 to 10.1)
Paul Affleck (PA)	AGD independent member (Specialist Ethics Adviser) (In attendance for item 9.1 only)
Mr Christopher Barben (CB)	AGD independent member (Specialist Clinician 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. Jon Fistein (JF)	AGD independent member (Chair) (**Presenter**: item 9.1)
Dr. Robert French (RF)	AGD independent member (Specialist Academic / Statistician Adviser) (In attendance for item 9.1 only)
Kirsty Irvine (KI)	AGD independent member (Lay Adviser) (In attendance for items 8 and 9.1)
Prof. Jo Knight (JK)	AGD independent member (Specialist Academic / Researcher Adviser) (In attendance for item 9.1 only)
Dr. Mark McCartney (MM)	AGD independent member (Specialist GP / Clinician Adviser)
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:**
Laura Bellingham (LB)	Deputy Director, Data Access and Partnerships, Data and Analytics (In attendance for item 9.1 only)

Garry Coleman (GC)	NHS England SIRO Representative
Dr. Kevin Dunbar (KD)	Deputy Director of Public Health, Vaccination and Screening Directorate (**Presenter**: item 4.1)
Dickie Langley (DL)	Assistant Director of IG (Digital Operations), Privacy, Transparency, and Trust (PTT), Technology, Digital and Data (In attendance for item 9.1 only)
Maddie Laughton (ML)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer:** item 5.6)
Joe Lawson (JL)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer:** item 5.1)
Andrew Martin (AM)	Senior Information Governance Manager, Data Protection Office and Trust, Privacy Transparency, and Trust (PTT), Technology, Digital and Data (In attendance for item 9.1 only)
Karen Myers (KM)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Technology, Digital and Data
Narinda (Nin) Sandhu (NS)	Head of Programme Delivery, Data Access & Partnerships, Data and Analytics, Transformation Directorate (**Observer**: items 1 to 10)
Jodie Taylor Brown (JTB)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer:** item 5.4)
Ellie Ward (EW)	Assistant Director, Deputy Data Protection Officer, Data Protection Office and Trust, Privacy, Transparency, and Trust (PTT), Technology, Digital and Data (In attendance for item 9.1 only)
Emma Whale (EW)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer:** items 5.4 and 5.5)
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Technology, Digital and Data
AGD INDEPENDENT MEMBERS / NHS ENGLAND MEMBERS NOT IN ATTENDANCE:	
Michael Chapman (MC)	NHS England member (Data and Analytics Representative)
Jon Moore (JM)	NHS England member (Data Protection Office Representative)

1	**Welcome and Introductions:** The AGD Chair welcomed attendees to the meeting.

	AGD noted that, due to unforeseen circumstances, only two AGD NHS England members were in attendance for items 8 to 10.1. Noting that the AGD Terms of Reference state that *"The quorum for meetings of the Group or a Sub-Group is five members, including at least three independent members, one of whom may be the Chair, Deputy Chair or Acting Chair and* ***two of the three NHSE Members****…",* the Group agreed that, as there were two AGD NHS England members present, the meeting was still quorate for agenda items 8 to 10.1, and agreed to proceed on that basis.	
2	**Review of previous AGD minutes:** The minutes of the AGD meeting on the 15th January 2026 were reviewed and, after minor amendments, were agreed as an accurate record of the meeting.	
3	**Declaration of interests:** Claire Delaney-Pope noted a professional link to NIC-791166-Q7K5H (King's College London) and the applicant as part of her role within the South London and Maudsley NHS Foundation Trust. It was agreed this did not preclude Claire from taking part in the discussion on this application. Dr. Jon Fistein noted a professional link to the University of Oxford but noted no specific connections with the application (NIC-144057-G4S0Q), or staff involved, and it was agreed that this was not a conflict of interest.	
4 BRIEFING PAPER(S) / DIRECTIONS:		
4.1	**Title:** National Breast Screening Programme effectiveness audit data (limited to cases of non-invasive screen detected tumours) – Briefing Paper **Presenter:** Dr. Kevin Dunbar The national breast screening programme holds a legacy data asset which is a national data collection of cases of breast cancer screening detected tumours that were non-invasive on biopsy. The Sloane Project Breast screening: the Sloane Project - GOV.UK was initially established in 2003 as a large-scale audit to provide data to inform the breast screening programme in response to awareness of the potential harms from overdiagnosis, a topic of significant concern at the time. The audit data was used to establish the benefit and disbenefit of relevant care pathways used to manage non-invasive tumours. This data is no longer used for the screening programme quality assurance function but should be retained in an identifiable format due to the research value of the data. NHS England were seeking advice on the following points: 1. To support the proposal to retain data in an identifiable format under the existing legal basis of the cancer registry, to be held as an NHS England Data Access Request Service (DARS) asset for sharing with researchers. Alternative options are to either fully anonymise all data in line with the Information Commissioner's Office (ICO) anonymisation guidance; or to delete all data. **Outcome of discussion:** AGD welcomed the briefing paper and made the following observations / comments:	

	In response to point 1 above: **4.1.1** AGD noted that they were supportive of the proposal outlined, to retain data in an identifiable format under the existing legal basis of the cancer registry, to be held as an NHS England's DARS asset for secondary use, in line with the relevant Directions. **4.1.2** AGD noted the importance of ensuring the organisational memory of the dataset is preserved to ensure the value of the dataset is maximised. **4.1.3** AGD noted that work was ongoing to ensure that the proposed storage of the dataset, is in line with the usual NHS England policies and procedures. **4.1.4** AGD noted that work was ongoing within NHS England in respect of how the data will be stored, including, but not limited to, the status of the data in devolved nations, in line with the scope of the Directions; and suggested that the briefing paper was updated with further clarification of the outcome of this. **4.1.5** AGD discussed whether the data should be identifiable, anonymised or pseudonymised; however, noted that anonymising the data would prevent long-term follow-up. The Group did query whether there was an option to minimise the data in anyway, for example, pseudonymising the data, if this did not cause any issues with further linkage etc; and suggested that further information on this point was addressed in the briefing paper for clarify / future reference. **4.1.6** AGD noted the information that would be published on the Sloane Project website in respect of the proposed use of the dataset; however, suggested that some communications activities aimed at relevant patient and public audiences, should be undertaken, in respect of how information relating to the proposed use of the dataset could be communicated to data subjects and researchers. **4.1.7** AGD suggested that NHS England seek further clarity on whether the National Data Opt-out should be applied or not; and that this was done in line with the relevant legal basis / policy. In addition, **AGD made the following observations separate to the briefing paper**: **4.1.8** AGD suggested that NHS England ensure that any future briefing papers submitted to the Group for information / review, follow due agreed process, including but not limited to **1)** ensuring NHS England IG advice in respect of the legal basis relied on has been sought and updated within the briefing paper; and **2)** clarification as to any issues in respect of anonymising the data (or similar) are noted within the briefing paper.	
4.2	**Title:** OpenSAFELY Pilot – Briefing Paper **Previous Reviews:** OpenSAFELY briefing papers / applications were previously presented / discussed at the AGD meetings on the 25th September 2025 and the 18th September 2025. The purpose of the briefing paper, was to provide an update to the Group, on the points previously raised at the AGD meetings on the 18th September 2025 where the 'OpenSAFELY Draft Application Process' was discussed; and the 25th September 2025 where two OpenSAFELY applications were reviewed by the Group (NIC-791166-Q7K5H - King's College London (KCL) and NIC-791168-N2D1Z - London School of Hygiene and Tropical Medicine).	

	The briefing paper was submitted to AGD for information; and to support the review of NIC-791166-Q7K5H (item 5.2) and NIC-791168-N2D1Z (item 5.3). **Outcome of discussion:** AGD welcomed the briefing paper and made the following observations / comments: **4.2.1** AGD noted the and thanked NHS England for the information / updates provided in the briefing paper. **4.2.2** AGD noted that previous discussions had taken place on the National Data Opt-out (NDO) and whether this should be applied for individual studies in OpenSAFELY; and also noted that there were ongoing discussions and work to align the Data Provision Notice (DPN), the Data Protection Impact Assessment (DPIA) and the transparency materials, to ensure any process to consider the application of the NDO to individual studies took those documents into account. AGD noted that they would welcome an update on this once this work on this has been progressed. **4.2.3** NHS England advised the Group that following submission of the briefing paper to the Group, the 'Profession Advisory Group (PAG)' Terms of Reference (ToR) had now been updated. The Group noted and thanked NHS England for the update and advised that they would welcome an update on the PAG ToR at a future meeting.	
5 EXTERNAL DATA DISSEMINATION REQUESTS:		
5.1	**Reference Number:** NIC-338864-B3Z3J-v6.2 **Applicant:** Barts and the London School of Medicine and Dentistry **Data Controller:** Queen Mary University of London **Application Title:** "Genes and Health" **Observer:** Joe Lawson **Previous Reviews:** The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 3rd April 2025 and the 18th May 2023. 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 15th July 2021. 6th May 2021 and the 29th October 2020. **Application:** This was an amendment application. NHS England were seeking advice on the following points only: 1. The amendment to expand the territory of use from European Economic Area (EEA) to Worldwide. 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 amendment to the application **if** the substantive comments were addressed and were providing comments in response to NHS England's request for advice on specific points **only**, rather than all aspects of the application. AGD wished to draw to the attention of the SIRO the following observations in relation to the advice points:	

	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:** **5.1.1** AGD noted that based on the information provided, the proposed amendment, to expand the territory of use from European Economic Area (EEA) to Worldwide was in line with the consent, and there was a legal basis for this data to flow. **5.1.2** AGD suggested that, whilst noting the reference to worldwide access in the consent materials provided to participants, the applicant should **1)** undertake some patient and public involvement and engagement (PPIE) specifically on this amendment, to ensure that there is increased transparency; and **2)** ensure that **all** consent and transparency materials are updated to reflect the amended territory of use. In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review: **5.1.3** AGD noted that there were a number of substantive points raised at the AGD meeting on the 18th May 2023, that had not been reviewed by the Group as part of this review; and advised that they would welcome the opportunity to review these as part of the AGD oversight and assurance programme of work. **5.1.4** AGD noted that there **was** a commercial aspect to the application. In addition, **AGD made the following observations separate to the application**: **5.1.5** AGD noted that where data access is being expanded to worldwide access, there are internal processes that need to be followed, including, but not limited to seeking advice from NHS England's Privacy, Transparency, and Trust. **5.1.6** The NHS England SIRO Representation confirmed that there was no precedent in place to amend territory of use to being worldwide, and AGD suggested that it should therefore continue to provide advice on applications where the territory of use is being amended to 'worldwide' given such cases might be impactful on public trust.	
5.2	**Reference Number:** NIC-791166-Q7K5H **Applicant:** King's College London (KCL) **Data Controller:** Unknown **Application Title:** "Evaluating the implementation of NICE gout guidance within the NHS" **Previous Reviews:** The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 25th September 2025. The application and relevant supporting documents were previously presented / discussed at the 'Profession Advisory Group' (PAG) meetings on the 5th January 2026. **Application:** This was a new application. NHS England were seeking general advice on the application. 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. AGD noted that as part of an NHS England Data Access Request Service (DARS) pilot (discussed at the AGD meeting on the 7th August 2025), the Group had been asked **not** to review the application for this item, and had instead been provided with a new NHS England DARS internal application form that contained summary information that, once finalised, would be transferred into the usual data sharing agreement (DSA) template. **5.2.1** AGD noted that 'Profession Advisory Group' (PAG) had reviewed the application as per process (please see **Appendix A**). **5.2.2** AGD noted that a briefing paper had been provided to support the discussion of this application (see item 4.2). **5.2.3** AGD noted that at the meeting on the 25th September 2025, it had been noted that the stated purpose of the application was for 'service evaluation', and suggested further clarification as to how it was distinguished from research. The Group noted that the purpose of the application had been amended to state that this was for the purpose of 'research'; and that ethical approval (with provisos) had been obtained as per the usual process. **5.2.4** AGD noted some minor amendments to the form, including, but not limited to **1)** the removal of the suggestion that NHS England's Data Access Request Service (DARS) would be updating the National Data Opt-out policy in response to a previous point (11.1.6) raised by the Group on the 25th September 2025; and **2)** an update to the response to the previous point (11.1.7) raised by the Group on the 25th September 2025 in respect of Type 1 objections, noting that the response as currently noted was too generic. **5.2.5** No AGD member noted a commercial aspect to the application.	
5.3	**Reference Number:** NIC-791168-N2D1Z **Applicant:** London School of Hygiene and Tropical Medicine (LSHTM) **Data Controller:** Unknown **Application Title:** "Harmonised Assessment of Risk Groups for Vaccine Prioritisation" **Previous Reviews:** The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 25th September 2025. 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 January 2026. **Application:** This was a new application. NHS England were seeking general advice on the application. 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 **if** the following substantive comments were addressed, and wished to draw to the attention of the SIRO the following substantive 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. AGD noted that as part of an NHS England Data Access Request Service (DARS) pilot (discussed at the AGD meeting on the 7th August 2025), the Group had been asked **not** to review the application for this item, and had instead been provided with a new NHS England DARS internal application form that contained summary information that, once finalised, would be transferred into the usual data sharing agreement (DSA) template. **5.3.1** AGD noted that 'Profession Advisory Group' (PAG) had reviewed the application as per process (please see **Appendix B**). **5.3.2** AGD noted that a briefing paper had been provided to support the discussion of this application (see item 4.2). **5.3.3** AGD noted that at the meeting on the on the 25th September 2025, it had been noted that the stated purpose of the application was for 'service evaluation', and suggested further clarification as to how it was distinguished from research. The Group noted that the purpose of the application had been amended to state that this was for the purpose of 'research'; however, noted that ethical opinion had **not** been sought / obtained as per the usual process. AGD suggested that the applicant obtain ethical opinion, in line with NHS England DAS Standard for Ethical Approval and that this was done prior to the data sharing agreement being signed. In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review: **5.3.4** AGD noted some minor amendments to the form, including, but not limited to **1)** the removal of the suggestion that NHS England's Data Access Request Service (DARS) would be updating the National Data Opt-out policy in response to a previous point (11.2.7) raised by the Group on the 25th September 2025; and **2)** an update to the response to the previous point (11.2.8) raised by the Group on the 25th September 2025 in respect of Type 1 objections, noting that the response as currently noted was too generic. **5.3.5** No AGD member noted a commercial aspect to the application.	
5.4	**Reference Number:** NIC-776600-D8P6R-v0.3 **Applicant and Data Controller:** Observational and Pragmatic Research International Limited **Application Title:** "Pragmatic evaluation of a quality improvement programme for people living with modifiable high-risk COPD (PREVAIL)" **Observer:** Jodie Taylor Brown and Emma Whale **Previous Reviews:** The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 11th December 2025. **Application:** This was a new application.	

	NHS England were seeking general advice on the application. 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 **if** the following substantive comments were addressed, and wished to draw to the attention of the SIRO the following substantive comments: AGD noted that as part of an NHS England Data Access Request Service (DARS) pilot (discussed at the AGD meeting on the 7th August 2025), the Group had been asked **not** to review the application for this item, and had instead been provided with a new NHS England DARS internal application form that contained summary information that, once finalised, would be transferred into the usual data sharing agreement (DSA) template. **5.4.1** In respect of the point (5.3.1) raised previously on the existing Data Sharing Framework Contract (DSFC), which had been signed incorrectly by the customer; the Group noted that this had now been resolved and that a new DSFC had been signed by the Observational and Pragmatic Research International Limited (OPRI UK). AGD welcomed the update on this issue, however suggested that NHS England continued to satisfy itself that any location of data is accessed in an appropriate location and is **only** accessed by those permitted in the data sharing agreement (DSA). **5.4.2** AGD noted that they had previously noted concerns (5.3.3) in respect to the additional work that this study may put on GPs; and separately had suggested (5.3.6) that NHS England explore with the applicant that there is an appropriate equity in the demographic coverage across the GP practices, to ensure that different populations are not disadvantaged in terms of the access to the benefits of the study. The Group noted that the responses to both of these points did **not** fully address the issues raised, for example, it was still unclear how the burden to GP's would be minimised; and how it would be ensured that any limitations to findings due to any lack of diversity in the population studied would be accounted for in the research. The Group suggested that NHS England satisfy itself that any results of this work has considered a representative sample. **5.4.3** AGD noted that they had previously (5.3.4) suggested that in line with NHS England DARS Standard for Commercial Purpose, NHS England discuss the commercial aspects further with the applicant. The Group noted the response on this point, however, suggested that NHS England explore this further with the applicant, noting that it was still unclear if the applicant would receive a direct commercial benefit for carrying out the study, for example, whether they were being paid for the work; and that any relevant updates should be made to **1)** section 5(a) (Objective for Processing); and **2)** the legitimate interest statement in the form. **5.4.4** In order to ensure that the commercial benefit remains secondary to the public benefit, AGD advised that NHS England assure itself that **all** significant findings will be made public, and that the funders will not receive more information or prior information than that which is publicised. **5.4.5** AGD noted that they had previously (5.3.5) queried the purpose of the study, noting the inconsistencies in the documents provided, for example, is this a **1)** quality improvement activity; **2)** screening activity; and / or **3)** for the purpose of broader research. AGD noted the response provided which confirmed that it was a quality improvement activity; however,	

	suggested that NHS England explore this further with the applicant, noting that it was still unclear how much this work blurs into screening activity, for example, noting that there may be identification of individuals who may not have previously had contact with COPD services. **5.4.6** AGD noted that they had previously queried (5.3.7) what opt-outs would / would not be applied and the mechanisms for applying opt-outs; and that notwithstanding the s251 support in place, that any opt-outs would not add any undue burden on GPs. In addition, AGD also noted that there would be an additional opportunity for patients to opt-out before the data is refreshed and would encourage the applicant to give this further consideration. **5.4.7** AGD noted the point raised previously on patient and public involvement and engagement (PPIE), and noted as part of the response that there were some future actions as part of the PPIE work. The Group advised that they would encourage some PPIE was undertaken prior to the linkage and that any negative outcomes were addressed as may be appropriate. 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 and commended the work undertaken by NHS England's Data Access Request Service (DARS) and the applicant on the work undertaken on this application and the responses to the previous advice provided by the Group. **5.4.9** AGD noted that they would be supportive of providing further advice on any aspect of this application, as may be required by NHS England. **5.4.10** Given the points raised by the Group, the NHS England SIRO representative noted this application could **not** progress via delegated authority until such time as the NHS England SIRO Representative had reviewed the updated application. **5.4.11** AGD noted that there **was** a commercial aspect to the application.	
5.5	**Reference Number:** NIC-144057-G4S0Q-v5.11 **Applicant and Data Controller:** University of Oxford **Application Title:** "pre-DIRECT - All cause mortality following hip fracture" **Observer:** Emma Whale **Previous Reviews:** The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 18th April 2024. **Application:** This was an amendment application. NHS England were seeking advice on the following points only: 1. The amendment not covered by existing reusable (Precedent) decision (change of purpose). 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 amendment to the application **if** the following comments were addressed, and were providing comments in response to NHS England's request for advice on specific points **only**, rather than all aspects of the	

	application. AGD wished to draw to the attention of the SIRO the following observations in relation to the advice points: 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:** **5.5.1** AGD noted that they were supportive of the proposed amendment to the application to amend the objective for processing; noting that this could potentially provide further insight into the long-term implications of hip fractures. **5.5.2** AGD queried the data destruction arrangements for the data held previously; and suggested that NHS England satisfy itself that the appropriate data destruction had been undertaken, for any data not covered by the revised agreement, and appropriate evidence of this had been received. **5.5.3** AGD suggested that any new data sharing agreement issues reflects **1)** a full history of the application / data; **2)** any new data; and **3)** the opt-out arrangements for any new data flowing. **5.5.4** AGD suggested that the applicant provide further clarity on the expected benefits of any further studies, stemming from long-terms outcomes of hip fractures, noting that this was not captured as part of the original time limited study. In addition, AGD made the following observation on the application and / or supporting documentation provided as part of the review: **5.5.5** No AGD member noted a commercial aspect to the application.	
5.6	**Reference Number:** NIC-762279-Q6S6T-v0.12 **Applicant:** University of Newcastle Upon Tyne **Data Controllers:** Sheffield Teaching Hospitals NHS Foundation Trust, University of Aberdeen and London School of Hygiene and Tropical Medicine **Application Title:** "Assessing the long-term effectiveness of urethroplasty and urethrotomy as treatments for recurrent urethral strictures in men: Long-term follow-up of the OPEN Trial" **Observer:** Maddie Laughton **Previous Reviews:** The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 23rd January 2025. **Application:** This was a new application. NHS England were seeking general advice on the application. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** The Group were broadly supportive of the purpose outlined in the application, but were **not** supportive of the application **at this time** and wished to draw to the attention of the SIRO the following significant comments, and suggested that the application be brought back to a future meeting:	

	AGD noted that as part of an NHS England Data Access Request Service (DARS) pilot (discussed at the AGD meeting on the 7th August 2025), the Group had been asked **not** to review the application for this item, and had instead been provided with a new NHS England DARS internal application form that contained summary information that, once finalised, would be transferred into the usual data sharing agreement (DSA) template. **5.6.1** AGD welcomed the application and noted the potential clinical results that could flow from this study. **5.6.2** AGD noted that as part of the meeting pack a draft letter had been provided that the applicant had committed to issue to the original cohort as part of NHS England's consent review, which outlined details of the proposed long-term follow-up. NHS England advised that following circulation of the papers to the Group, Sheffield Teaching Hospitals NHS Foundation Trust had advised that this letter would now **not** be issued, due to their concerns about conflicts with the ethical support. AGD noted and thanked NHS England for the verbal update, and advised that based on this new information, they could **not** support the progression of the application based on this verbal update. **5.6.3** AGD noted that whilst the letter outlining details of the proposed long-term follow-up would now not be sent, the Group made some suggested amendments to the draft letter, should the position on this change in the future, including, but not limited to **1)** providing some historical information on the original study; and **2)** adding a link to the website. **5.6.4** In addition, AGD suggested that **1)** the applicant review clause 8 of the original consent, to ensure that communications are **only** shared with those who specifically consented to being contacted in the future for long-term follow-up; and **2)** NHS England consider / discuss with the applicant, any support they are able to provide in respect of ensuring the letters are sent to the correct address for those participants who may have moved; or not sent to those who are deceased to avoid any distress. **5.6.5** AGD noted that the consent for the original study was taken by the University of Newcastle Upon Tyne, and queried how this could then transfer to Sheffield Teaching Hospitals NHS Foundation Trust, University of Aberdeen and London School of Hygiene and Tropical Medicine; noting that without this information there appeared to be no legal basis for this study to proceed in this way. **5.6.6** AGD advised that if there was a legal basis for the consent to transfer from the University of Newcastle Upon Tyne, the Group suggested that **1)** patient and public involvement and engagement (PPIE) was undertaken; **2)** there is appropriate transparency on the proposal outlined and the change of Data Controllers; and that this is in line with the ethical support. **5.6.7** In addition, AGD noted that the PPIE undertaken so far had involved only four participants; and suggested that the applicant review this to ensure they are getting feedback from a wide range of participants, noting the sensitivity of some of the issues that may need discussing, for example, a change of data controllership. **5.6.8** No AGD member noted a commercial aspect to the application.	

6 INTERNAL DATA DISSEMINATION REQUESTS:
There were no items discussed

7 EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL	
There were no items discussed	
8 OVERSIGHT AND ASSURANCE	
8.1	**Oversight and Assurance Process** (**Workstream 2:** Internal and external applications that have had an independent review in the last 6 months and been approved internally) The Statutory Guidance states that the data advisory group (AGD) should be able to provide NHS England with advice on: *"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"*. In advance of the meeting, the AGD independent members were provided with **1)** seven applications (selected by the AGD Secretariat); **2)** internal application assessment forms for each of the seven applications; and **3)** an oversight and assurance template to complete for each of the applications that each individual member had been asked to review. 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. 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 NHS England SIRO representative and relevant NHS England colleagues as may be appropriate. Please see **appendix C** for high-level points raised in-meeting on the seven applications.
8.2	**Oversight and Assurance Conclusion / Review** AGD noted that the last oversight and assurance for workstream 2 review had taken place on the 13th November 2025, and that as agreed, workstream 2 would be a monthly agenda item. The Group noted that whilst the majority of applications clearly communicated how the previous IGARD / AGD comments had been addressed, a few applications fell into the following categories **1)** previous AGD comments had not been adequately addressed; **2)** it was unclear if / how previous AGD comments had been addressed; and **3)** the response to the previous AGD comments could have been clearer. The Group provided some feedback for future reviews including, but not limited to **1)** the preparation time of 10 minutes per application was sufficient if it was clear how AGD comments had been addressed; **2)** reviewing fewer applications per independent members was more effective. The NHS England SIRO Representative noted that it was important for NHS England Data Access Request Service (DARS) to clearly articulate how the AGD advice had been considered across all points. The NHS England SIRO Representative noted that there was still room for improvement and thanked AGD and NHS England colleagues for the work undertaken to date
9 AGD OPERATIONS	

9.1	**AGD ways of working (Presenter: Jon Fistein)** AGD noted that at the AGD plenary meeting on the 4th December 2025, the Group had discussed new ways of working (under items 5 and 6), and how it supports / provides advice to NHS England, both now and in the future. The AGD Chair provided an overview of potential areas for change and discussed with the Group a number of potential new ways of working going forward, including, but not limited to, **1)** reviewing the advice that is sought from AGD on applications, i.e. being asked to give more focussed advice; **2)** how the expertise within the Group can be better utilised by NHS England; **3)** ensuring value for money; **4)** the role of AGD NHS England members at the meetings, noting the imminent reduction in staff and resources and future merger with the Department for Health & Social Care (DHSC); and **5)** any engagement that could be undertaken across NHS England in respect of AGD and the service / support it can offer. The Group felt that AGD could continue to add value by providing robust expert advice and learning from a mix of expertise and perspectives, complementing those acting in their professional roles within NHS England; that it does this by identifying pertinent issues and relevant actions relating to data access; by enhancing corporate memory; by capturing outcomes at a point in time explaining why the outcome is so, helping to maintain consistency across data applications; and by helping to inform the data access processes, to ensure they are reasonable, robust and repeatable. The AGD Chair asked the Group to think about some specific points, and that these would form part of a further discussion at a future AGD meeting, including, but not limited to, **1)** specific risks that AGD look for; **2)** what helps AGD members form their advice; **3)** an example of where AGD advice could have been sought earlier; and **4)** anything that AGD should be aware of or protect. The Group thanked the AGD Chair for the update on this evolving area of work and noted that a further discussion would take place at a future AGD meeting.	AGD
9.2	**Risk Management Framework** The NHS England SIRO Representative noted the recent discussions at the AGD plenary meeting on the 4th December 2025, on a number of different scenarios that may influence the content of a Risk Management Framework; and it was noted that further work / discussions on this will take place out of committee with some of the AGD members; and that further information would be provided / discussed with the Group at a future AGD meeting. **ACTION:** The NHS England SIRO Representative, AGD Chair and AGD Secretariat to discuss out of committee work on the Risk Management Framework.	SIRO Rep
9.3	**AGD Stakeholder Engagement** The AGD Chair noted he had met with Dr. Tony Calland, the outgoing Chair of the Health Research Authority Confidentiality Advisory Group (HRA CAG), Prof, Lorna Fraser, the Chair of the HRA CAG, and Dr. Nicola Byrne, the National Data Guardian for health and adult social care in England, on Wednesday 21st January 2026, as part of their regular engagement.	
9.4	**AGD Project Work**	

	There were no items discussed
10 Any Other Business	
10.1	**NHS England meeting with Health Research Authority Confidentiality Advisory Group (HRA CAG)** The NHS England SIRO Representative advised the Group that he had recently met with HRA CAG colleagues to discuss a number of issues, including, but not limited to, date of death data, and whether this is identifiable or not; and advised the Group that further information would be provided on this at a future AGD meeting.
Meeting Closure As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.	

Appendix A

Profession Advisory Group (PAG) Feedback Form - OpenSAFELY Pilot

(Out of Committee)

Meeting Details	
PAG advice sought by NHSE (via email) out of committee on:	09/12/25
Date of PAG advice	05/01/2026

Application Details			
NIC Reference:	DARS-NIC-791166-Q7K5H OpenSAFELY Ref: 0279	**Application version Number:**	V0
Applicant Organisation:	King's College London (KCL)		
Application Title:	Evaluating the implementation of NICE gout guidance within the NHS		

Attendees		
Representing Organisation	**Name**	**Role**
British Medical Association (BMA)	Mark Coley	BMA Representative
Royal College of General Practitioners (RCGP)	Tom Nichols	RCGP Representative

Declarations of Interest
PAG Members did not confirm

Advice Required

OpenSAFELY Application

The OpenSAFELY Data Analytics Service Pilot Direction 2025 states:

The purpose of accessing the data is to establish a secure analytics service using the OpenSAFELY platform, for users approved by or on behalf of NHS England, to run queries on GP and NHS England pseudonymised patient data.

1a. Does this application meet the requirements of the OpenSAFELY Direction?
Yes
1b. Is this request in line with the following purposes as specified in the OpenSAFELY Requirement Specification? NHS OpenSAFELY Data Analytics Service Pilot Directions 2025 - NHS England Digital
☐ Clinical audit ☐**X Service evaluation** ☐ Health surveillance ☐ Research ☐ Evaluation of the service ☐ Health & social care policy, planning & commissioning & public health
1c. Advice from the Profession
This is an important health condition because it is treatable with a good evidence base, and mature guidelines. The authors constrain the scope to the NICE guideline, and to specific, readily easy-to-measure outcomes. The stated aims of the study are appropriate to the data requested. In the absence of good machine-readable dose syntax, colchicine and naproxen are often prescribed with bespoke dose and timing labelling, which may make interpretation of prescribed doses from extracted Quantities of medication. Many patients advise us of their over-the-counter self-treatment which will not be captured though the GP record. PAG would expect that the applicant consider whether patients with an NDOO should have their data excluded, having due regard to the details of their study. The decision should be documented, with its rationale. This should be handled in a procedurally neutral way so that the applicant is not influenced either way. At present the language stating that NDOOs "can be applied at the discretion of the applicant" and as a "preference" is loaded language, and prejudices towards a decision that those with an NDOO should have their data included by default unless a justification is given, not least as this will form part of the public record. We agree that the decision should be an informed one. Supportively, we also invite consideration of the following: 1 - the paradigm shift away from face to face consulting can be predicted to result in compromise to 1.1.6 "In people with suspected gout, take a detailed history and carry out a physical examination to assess the symptoms and signs" in particular the 'just pop your shoe off' examinations. This effect might be demonstrable relatively easily, and document the lasting effects of the pandemic. On 1st October 2025, it became mandatory for GP surgeries to offer increased availability of 'online consultations'. Assessing these metrics including consultation mode may help document the climate of general practice, and in so doing, draw attention to the resource implications, and the impact of the reported crisis in general practice workload and difficulties and give necessary context to any gaps in care.

2 - Gout disproportionately affects those from groups who suffer health inequity such as those with socio-economic deprivation, ethnic minorities, and those with reduced access to healthcare such as the homeless and refugees so studying this may help advance health equity by providing good data. It is not entirely clear whether variables in the demographics could help enrich the outputs.

3 - as this is a data driven study, some assessment of data quality would be valuable - as urate levels and drugs are being reviewed, even high level data considering how many patients may reasonably be suspected as having undiagnosed gout through the presence of urate lowering treatments on repeat without a diagnosis or persistent hyperuricaemia may be helpful. The decision support available to GPs is data driven, and so any gaps in data quality identified could give rise to new or improved decision support tooling

4 - “1.4.2 Advise people with gout that excess body weight or obesity, or excessive alcohol consumption, may exacerbate gout flares and symptoms.” by investigating this as a variable, the study could approach patient experience as a recommended part of pastoral care

5 - the study is clearly equipped to approach two of the Quintuple Aims (improving health, advancing health equity) but with relatively minor broadening of scope, could also touch on workforce wellbeing, and improving the patient experience, which may add value. As the components are re-usable, the impact of doing so could be more broad reaching than the biomedical components.

PAG is supportive of this proposal.

Appendix B

Profession Advisory Group (PAG) Feedback Form - OpenSAFELY Pilot

(Out of Committee)

Meeting Details	
PAG advice sought by NHSE (via email) out of committee on:	09/12/25
Date of PAG advice	05/01/2026

Application Details			
NIC Reference:	DARS-NIC-791168-N2D1Z OpenSAFELY Ref: 2156	**Application version Number:**	V0
Applicant Organisation:	London School of Hygiene and Tropical Medicine (LSHTM)		
Application Title:	Harmonised Assessment of Risk Groups for Vaccine Prioritisation		

Attendees		
Representing Organisation	**Name**	**Role**
British Medical Association (BMA)	Mark Coley	BMA Representative
Royal College of General Practitioners (RCGP)	Tom Nichols	RCGP Representative

Declarations of Interest
PAG did not confirm

Advice Required
OpenSAFELY Application
The OpenSAFELY Data Analytics Service Pilot Direction 2025 states: The purpose of accessing the data is to establish a secure analytics service using the OpenSAFELY platform, for users approved by or on behalf of NHS England, to run queries on GP and NHS England pseudonymised patient data.

1a. Does this application meet the requirements of the OpenSAFELY Direction?
Yes
1b. Is this request in line with the following purposes as specified in the OpenSAFELY Requirement Specification? NHS OpenSAFELY Data Analytics Service Pilot Directions 2025 - NHS England Digital
☐ Clinical audit ☐ Service evaluation ☐ Health surveillance ☐**X** Research ☐ Evaluation of the service ☐ Health & social care policy, planning & commissioning & public health
1c. Advice from the Profession
This is clinically valuable work with potential far reaching benefits. We note the overlapping interests of Bennett Institute being part of the study team, but also the context - that this application is also being used to establish business as usual processes, and there are considerable (short-term) advantages to Bennett Institute using its own service. The expected benefits are listed, and clearly connect with three of the Quintuple Aims (population health, and patient experience, and advancing health equity). It does not focus directly on cost economics, or caring for the workforce. In 4.7 “The outputs will not contain NHS England Data” requires clarification given that NHSE will become the data controller of the queried outputs from the GP data. If the study is not to use SUS or NHS Civil Registration Data in England and Wales then it should state so explicitly (cf. Appendix 1 of the Requirements Specification for The NHS OpenSAFELY Data Analytics Service Pilot). https://digital.nhs.uk/about-nhs-digital/corporate-information-and-documents/directions-and-data-provision-notices/secretary-of-state-directions/nhs-opensafely-data-analytics-service-pilot-directions-2025 PAG would expect that the applicant consider whether patients with an NDOO should have their data excluded, having due regard to the details of their study. The decision should be documented, with its rationale. This should be handled in a procedurally neutral way so that the applicant is not influenced either way. At present the language stating that NDOOs “can be applied at the discretion of the applicant” and as a “preference” is loaded language, and prejudices towards a decision that those with an NDOO should have their data included by default unless a justification is given, not least as this will form part of the public record. We agree that the decision should be an informed one. PAG is supportive of this proposal.

Appendix C

Oversight and Assurance Review – 22nd January 2026

Ref:	NIC Number:	Organisation:	Areas to consider:
260122a	NIC-748004-M6G9X-v0.5	Evidera Ltd	The application had last been seen by AGD on the 7th August 2025 where the Group had been supportive with comments. **Feedback on the application:** • The Group felt that there were adequate responses to the majority of the points raised by AGD, except: ○ Point 5.2.6 where an interim response had been provided, however this had not been followed up by DARS and evidence provided as to whether the ethical review had taken place. **Feedback on the process:** • **Process point: Action for D&A Representative** when the response to a point raised by AGD is a commitment by the applicant to commit a future action, **1)** consider whether the action(s) should be completed *before* the DSA is issued; **2)** if not, add a special condition requiring confirmation of completion of the action(s) by a specific date; and **3)** clearly explain in response to the AGD point, how completion of the action will be followed up.
260122b	NIC-749150-S0M7G-v0.5	Evidera Ltd	The application had last been seen by AGD on the 7th August 2025, where the Group had been supportive with comments

			Feedback on the application: • The Group felt that there were adequate responses to the majority of the points raised by AGD, except: ○ Point 5.1.1 advice had been given based on the application being in an SDE, which was changed to an extract and the special condition suggested had been rejected with a rationale that was not satisfactory to the reviewers. The reviewers felt it would have been helpful for the change in approach to have been discussed with the NHSE SIRO Representative. **Feedback on the process:** • **Process point: Action for D&A Representative** to consider discussing with the NHSE SIRO Representative any decision taken which is contrary to AGD advice that sets out a clear action (for example the use of a special condition).
260122c	NIC-615980-P3Y7N-v6.2	NHS Cheshire and Merseyside Integrated Care Board (ICB)	The application had last been seen by AGD on the 4th September 2025 where the majority of the Group had been supportive "if" the substantive comments had been addressed and the minority of the Group had been supportive with comments. **Feedback on the application:** • No issues were raised on the application. **Feedback on the process:** • No issues were raised on the application.

260122d	NIC-661742-Y2K8L-v1.5	University of Leicester	The application had last been seen by AGD on the 4th September 2025 when the Group had been supportive "if" the points had been addressed. **Feedback on the application:** • No issues were raised on the application. **Feedback on the process:** • No issues were raised on the application.
260122e	NIC-782158-W5V8C-v0.3	Synapsys IQ	The application had last been seen by AGD on the 11th September 2025 where the majority of the Group had been supportive "if" the substantive comments had been addressed and a minority of the Group had been supportive of the application as is. **Feedback on the application:** • The Group felt that there were adequate responses to the majority of the points raised by AGD, except: ○ Point 5.2.4 narrative indicated that the applicant felt their "head of legal" was a suitable substitute for a "lay member" but offered to explore bringing in external lay representation if NHSE disagreed. It was unclear from the narrative what NHSE's view on this had been. **Feedback on the process:** • **Process point: Action for the D&A Representative** that the extra check detailing what the applicant had said verse an assessment of that response, with a view to any risks was an exemplar for good practice to share with the wider team

260122f	NIC-784100-W4B7T-v0.4	The University of Manchester	The application had last been seen by AGD on the 11th September 2025 where the Group had been supportive "if" the substantive comments had been addressed. **Feedback on the application:** • The Group felt that there were adequate responses to the majority of the points raised by AGD, except: ○ Point 5.4.3 – a response to point 2 had not been followed up, or the evidence had not been provided. **Feedback on the process:** • **Process point: Action for the D&A Representative** to ensure that the minutes from the independent group are dated within the SDA or S1a of the application summary • **Process point: Action for D&A Representative** to ensure that there is a clear narrative as to how each point of advice is being addressed • **Process point: Action for the AGD Secretariat** to note the responses to the minutes and ensure all relevant SD's are provided in the agenda pack
260122g	NIC-759203-S1P1T-v0.6	ST George's University Hospitals NHS Foundation Trust	The application had last been seen by AGD on the 18th September 2025 where the Group had been supportive of the application with comments. **Feedback on the application:** • No issues were raised on the application. **Feedback on the process:**

			• No issues were raised on the application.