

## **Advisory Group for Data (AGD) – Meeting Minutes**

Thursday, 2<sup>nd</sup> July 2026

09:00 – 14:50

*(Remote meeting via videoconference)*

| <b>AGD INDEPENDENT / NHS ENGLAND MEMBERS IN ATTENDANCE:</b> |                                                                                                                                                  |
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| <b>Name:</b>                                                | <b>Role:</b>                                                                                                                                     |
| Paul Affleck (PA)                                           | AGD independent member (Specialist Ethics Adviser)                                                                                               |
| Noela Almeida (NA)                                          | NHS England member (Data Protection Office Representative (Delegate for Jon Moore))                                                              |
| Mr Christopher Barben (CB)                                  | AGD independent member (Specialist Clinician Adviser)                                                                                            |
| Claire Delaney-Pope (CDP)                                   | AGD independent member (Specialist Information Governance Adviser)                                                                               |
| Dr. Jon Fistein (JF)                                        | AGD independent member (Chair)                                                                                                                   |
| Prof. Matthew Sydes (MS)                                    | NHS England member (Data and Analytics Representative (Delegate for Michael Chapman))                                                            |
| Jenny Westaway (JW)                                         | AGD independent member (Lay Adviser)                                                                                                             |
| <b>NHS ENGLAND STAFF IN ATTENDANCE:</b>                     |                                                                                                                                                  |
| <b>Name:</b>                                                | <b>Role / Area:</b>                                                                                                                              |
| Garry Coleman (GC)                                          | NHS England SIRO Representative                                                                                                                  |
| Cath Day (CD)                                               | Data Portfolio Management, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 4.1)                                           |
| Dan Goodwin (DG)                                            | Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 4.1)                                        |
| Suzanne Hartley (SH)                                        | Data Applications Service (DAS) - Senior Manager, Data Access and Partnerships, Transformation Directorate ( <b>Observer:</b> items 4.1 and 5.3) |
| Maddie Laughton (ML)                                        | Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 5.4)                                        |
| Joe Lawson (JL)                                             | Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 5.1)                                        |
| Karen Myers (KM)                                            | AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Technology, Digital and Data                                                     |

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| Suzanne Shallcross (SS)                                                          | Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 5.3)                       |
| Jodie Taylor-Brown (JTB)                                                         | Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> items 5.1 and 5.2)              |
| Emma Whale (EW)                                                                  | Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 5.2)                       |
| <b>AGD INDEPENDENT MEMBERS / NHS ENGLAND MEMBERS <u>NOT</u> IN ATTENDANCE:</b>   |                                                                                                                                 |
| <b>Name:</b>                                                                     | <b>Role / Area:</b>                                                                                                             |
| Michael Chapman (MC)                                                             | NHS England member (Data and Analytics Representative)                                                                          |
| Dr. Robert French (RF)                                                           | AGD independent member (Specialist Academic / Statistician Adviser)                                                             |
| Prof. Jo Knight (JK)                                                             | AGD independent member (Specialist Academic / Researcher Adviser)                                                               |
| Dr. Mark McCartney (MM)                                                          | AGD independent member (Specialist GP / Clinician Adviser)                                                                      |
| Jon Moore (JM)                                                                   | NHS England member (Data Protection Office Representative)                                                                      |
| Dr. Jonathan Osborn (JO)                                                         | NHS England member (Caldicott Guardian Team Representative)                                                                     |
| Miranda Winram (MW)                                                              | AGD independent member (Lay Adviser)                                                                                            |
| <b>CLINICAL PRACTICE RESEARCH DATALINK (CPRD) STAFF IN ATTENDANCE (ITEM 4.1)</b> |                                                                                                                                 |
| Nadia Azimikorf (NA)                                                             | Information Governance Manager, Clinical Practice Research Datalink (CPRD) ( <b>Presenter / Observer:</b> item 4.1)             |
| Dr. Jennifer Campbell (JC)                                                       | Interim Observational Research Team Leader, Clinical Practice Research Datalink (CPRD) ( <b>Presenter / Observer:</b> item 4.1) |
| Dr Susan Hodgson (SH)                                                            | Head of Observational Research, Clinical Practice Research Datalink (CPRD) ( <b>Presenter / Observer:</b> item 4.1)             |
| Peter Wright (PW)                                                                | Head of Information Governance, Clinical Practice Research Datalink (CPRD) ( <b>Presenter / Observer:</b> item 4.1)             |

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| <b>1</b> | <p><b>Welcome and Introductions:</b></p> <p>The AGD Chair welcomed attendees to the meeting.</p> <p>AGD noted that, due to unforeseen circumstances, only two AGD NHS England members were in attendance for the meeting. Noting that the <a href="#">AGD Terms of Reference</a> state that “<i>The quorum for</i></p> |
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|                                   | <i>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 <b>two of the three NHSE Members...</b></i> ”, the Group agreed that, as there were two AGD NHS England members present, the meeting was still quorate for <b>all</b> agenda items and agreed to proceed on that basis.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| 2                                 | <b>Review of previous AGD minutes:</b><br><br>The minutes of the AGD meeting on the 25 <sup>th</sup> June 2026 were reviewed and were agreed as an accurate record of the meeting.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
| 3                                 | <b>Declaration of interests:</b><br><br>Paul Affleck noted a potential professional link to Clinical Practice Research Datalink (CPRD) (item 4.1) as part of his role at the University of Leeds, but noted no specific connections with the application (NIC-15625-T8K6L), or staff involved, and it was agreed that this was not a conflict of interest.<br><br>Paul Affleck noted a personal link to Clinical Practice Research Datalink (CPRD) (item 4.1), as part of his role on a GP practice Patient Participation Group, but noted no specific connections with the application (NIC-15625-T8K6L), or staff involved, and it was agreed that this was not a conflict of interest.<br><br>Claire Delaney-Pope noted a professional link to NIC-797405-H6S8S Northumbria University, as part of her role at South London and Maudsley NHS Foundation Trust. It was agreed this did not preclude Claire from taking part in the discussion on this application.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
| 4 BRIEFING PAPER(S) / DIRECTIONS: |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| 4.1                               | <b>Title:</b> Clinical Practice Research Datalink (CPRD) proposed “processing activities” updates in relation to NIC-15625-T8K6L<br><br><b>CPRD Presenters / Observers:</b> Dr. Susan Hodgson, Dr. Jennifer Campbell, Peter Wright and Nadia Azimikorf<br><br><b>NHS England Observers:</b> Dan Goodwin, Suzanne Hartley and Cath Day<br><br>CPRD is currently transitioning from a data sharing model to a data access model, and has developed a Trusted Research Environment (TRE), CPRD Safe, for this purpose. As CPRD move towards onboarding all research organisations who hold a current study licence onto CPRD Safe, they have been examining the provisioning data for approved researchers involved in public health research and the safety and surveillance of medicines. The proposals outlined below are to enable CPRD users to better carry out their public health research, in line with their statutory roles where applicable.<br><br><b>Proposal 1:</b> CPRD will continue to develop versions of the linked data mapped to the Observational Medical Outcomes Partnership (OMOP) Common Data Model (CDM) and permit whole-database access for analysis via OMOP analytics tooling within the CPRD Safe environment. To leverage maximum research benefit, the full OMOP-mapped CPRD Aurum and linked data would be made available to approved researchers, via CPRD Safe, to be queried using the Atlas or other standard OMOP analytics packages, specifically to ensure efficient and consistent analysis of data in the OMOP model.<br><br><b>Proposal 2:</b> CPRD will make linked data available to regulatory bodies and national public health bodies to perform their statutory, regulatory or government obligations relating to |

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| <p>public health, including functions/activities relating to pharmacovigilance and public health surveillance. For these purposes, data access will not require, or be limited to, study-specific protocols.</p> <p><b>Previous Reviews:</b> The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 5<sup>th</sup> June 2025, 20<sup>th</sup> March 2025, 13<sup>th</sup> March 2025 and the 12<sup>th</sup> September 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 15<sup>th</sup> December 2022, 27<sup>th</sup> October 2022, 10<sup>th</sup> October 2022, 28<sup>th</sup> April 2022, 27<sup>th</sup> January 2022, 27<sup>th</sup> August 2020, 16<sup>th</sup> July 2020, 9<sup>th</sup> April 2020, 19<sup>th</sup> March 2020, 27<sup>th</sup> February 2020, 6<sup>th</sup> February 2020, 7<sup>th</sup> November 2019, 31<sup>st</sup> October 2019, 17<sup>th</sup> October 2019, 8<sup>th</sup> November 2018, 20<sup>th</sup> September 2018, 27<sup>th</sup> July 2017 and the 22<sup>nd</sup> June 2017.</p> <p>The application and relevant supporting documents were previously presented / discussed at the IGARD COVID-19 response meetings on the 13<sup>th</sup> October 2020, 6<sup>th</sup> October 2020, 26<sup>th</sup> May 2020, 19<sup>th</sup> May 2020 and the 12<sup>th</sup> May 2020.</p> <p>The application and relevant supporting documents were previously presented / discussed at the Data Access Advisory Group (DAAG) meeting on the 24<sup>th</sup> January 2017.</p> <p>NHS England were seeking general advice on the briefing paper.</p> <p><b>Outcome of discussion:</b> The AGD Chair welcomed colleagues from CPRD, who were in attendance with NHS England colleagues to observe the discussion on item 4.1 and to answer any questions on the information provided.</p> <p>The Group thanked CPRD colleagues for attending the meeting, and for the information provided.</p> <p>Following the departure from the meeting by CPRD colleagues, the Group made the following observations / comments:</p> <p><b>4.1.1</b> AGD advised that they could see the value in the proposals outlined, however, noted that there needed to be additional, specific governance arrangement in place.</p> <p><b>4.1.2</b> AGD queried whether the data accessed via CPRD Safe, will be minimised by dataset, and advised that NHS England clarify this with CPRD.</p> <p><b>4.1.3</b> AGD noted that further information would need to be provided on access and use, and advised that there should be a gateway at the start of the process, to determine that this was the most appropriate route / access to the data, or, whether there was a more suitable alternative to CPRD, such as the national NHS Secure Data Environment or OpenSAFELY.</p> <p><b>In respect of Proposal 1:</b></p> <p><b>4.1.4</b> AGD recognised that this mode of access did appear to align with access elsewhere, which the Group commended; however, advised that there risks from providing access to large and complex datasets of this type, including, but not limited to, the potential identifiability of the data; and the risk of re-identification.</p> <p><b>4.1.5</b> AGD noted that applicants for data in CPRD Safe may use the data for purposes beyond what has been agreed, and advised that CPRD have robust processes in place for:</p> <p><b>4.1.5.1</b> clarifying the purpose at the outset;</p> |  |
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|                                                | <p><b>4.1.5.2</b> clarifying that the datasets requested can support the outlined purpose;</p> <p><b>4.1.5.3</b> oversight and assurance; and</p> <p><b>4.1.5.4</b> an audit to ensure that the data is being used for the purpose outlined.</p> <p><b>In respect of Proposal 2:</b></p> <p><b>4.1.6</b> AGD noted that there may be worldwide access to the data, and advised NHS England to engage with CPRD on this point, noting that there must be a clear <i>potential</i> benefit to health and social care in England and Wales.</p> <p><b>4.1.7</b> In respect of transparency, AGD noted the materials available, however advised that CPRD should:</p> <p><b>4.1.7.1</b> update their privacy notice; and</p> <p><b>4.1.7.2</b> clarify how they will continuously demonstrate that the benefits to health and care outweigh any potential risks.</p> <p><b>4.1.8</b> AGD advised that NHS England and CPRD work together, to ensure that there is no broader access to data provided via CPRD Safe, than would be provide via systems under NHS England; and noted that this may result in changes to NHS England's processes.</p> <p><b>4.1.9</b> AGD advised that they were not considering use of data to support clinical trials, noting that a separate proposal would be submitted to the Group for consideration at a future AGD meeting.</p> <p><b>4.1.10</b> AGD advised that they would welcome the opportunity to provide further advice on this application and / or any other aspect of the advice provided above, as may be required by NHS England.</p> |  |
| <b>5 EXTERNAL DATA DISSEMINATION REQUESTS:</b> |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |  |
| <b>5.1</b>                                     | <p><b>Reference Number:</b> NIC-370843-R6V8T-v7.1</p> <p><b>Applicant and Data Controller:</b> Imperial College London</p> <p><b>Application Title:</b> "COSMOS: Cohort Study of mobile phone use and health (MR1367)"</p> <p><b>Observers:</b> Jodie Taylor-Brown and Joe Lawson</p> <p><b>Previous Reviews:</b> 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 28<sup>th</sup> April 2022, 11<sup>th</sup> November 2021, 1<sup>st</sup> July 2021, 20<sup>th</sup> May 2021 and the 5<sup>th</sup> March 2020.</p> <p>The application and relevant supporting documents were previously presented / discussed at the Data Access Advisory Group (DAAG) meetings on the 1<sup>st</sup> September 2015 and the 13<sup>th</sup> August 2015.</p> <p>The application and relevant supporting documents were previously presented / discussed at the IGARD COVID-19 response meeting on the 15<sup>th</sup> June 2021.</p> <p><b>Application:</b> This was an amendment application.</p> <p>NHS England were seeking advice on the following points:</p>                                                                                                                                                                                                                                                                                                                                                                                     |  |

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|  | <ol style="list-style-type: none"> <li>1. Is the existing consent and transparency sufficient to cover the inclusion of offspring data and birth outcomes; if the consent is sufficient: <ol style="list-style-type: none"> <li>a) is the use of infant date of death (0–28 days) justified and appropriately minimised.</li> <li>b) is the inclusion of birth outcomes (including neonatal mortality) appropriate and sufficiently justified.</li> <li>c) are the additional datasets necessary and proportionate.</li> </ol> </li> <li>2. The governance controls around delegated decision making are sufficient to ensure appropriate oversight and mitigate risks.</li> <li>3. The transparency materials adequately inform participants about the use of offspring data and birth outcome analysis.</li> </ol> <p>Should an application be approved by NHS England, further details would be made available within the <a href="#">Data Uses Register</a>.</p> <p><b>Outcome of discussion:</b> AGD advised that major concerns had been identified and advised NHS England against providing access to additional types of data until the following had been addressed; and advised NHS England to confirm that the current data flows are being used within the expected scope:</p> <p><b>In response to point 1:</b></p> <p><b>5.1.1</b> AGD advised that the existing consent and transparency was <b>not</b> sufficient to cover the inclusion of offspring data and birth outcomes, noting that the original protocol and the patient facing materials did not reflect this information. The Group advised that this issue could not be addressed via extra transparency and patient and public involvement and engagement (PPIE), and it may require consent being sought from potential participants.</p> <p><b>In response to point 2:</b></p> <p><b>5.1.2</b> AGD noted and supported the concerns raised by NHS England, that a clear justification for the use of honorary contracts has not been provided; and advised that NHS England engage with the applicant on this point, and either:</p> <ol style="list-style-type: none"> <li><b>5.1.2.1</b> permission to allow access to personnel under honorary contracts is removed; or</li> <li><b>5.1.2.2</b> a clear justification is made for access to data for people with only honorary contracts, and the appropriate controls are added to the internal form / application as appropriate in line with <a href="#">NHS England's DARS Standard for Honorary Contracts</a>.</li> </ol> <p><b>In response to point 3:</b></p> <p><b>5.1.3</b> AGD noted that the study appears to have evolved significantly since its initial inception, based on the original protocol; and advised that:</p> <ol style="list-style-type: none"> <li><b>5.1.3.1</b> the applicant provides NHS England with clear information on exactly what has changed from the initial protocol; and</li> <li><b>5.1.3.2</b> how updates to transparency have been made.</li> </ol> |  |
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|            | <p><b>5.1.3.3</b> the applicant undertake some PPIE work with a small subset of the cohort to establish the scope of their original consent and whether it extends beyond the health implications of mobile phone use.</p> <p><b>5.1.3.4</b> NHS England satisfy themselves that the processing being undertaken is in line with the original consent taken.</p> <p><b>5.1.4</b> AGD advised that the applicant provides confirmation as to:</p> <p><b>5.1.4.1</b> how they are considering the changing patterns to mobile phone usage; and</p> <p><b>5.1.4.2</b> how this may affect the analysis / data requirements.</p> <p>In addition to their advice on the specific points raised by NHS England, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p><b>5.1.5</b> AGD noted the role of the UK Longitudinal Linkage Collaboration in the patient information sheet, and:</p> <p><b>5.1.5.1</b> queried whether they were determining the purpose and means of processing; and advised that NHS England engage with the applicant further on this, in line with <a href="#">NHS England DARS Standard for Data Controller(s)</a>; and</p> <p><b>5.1.5.2</b> advised that any onward sharing of data should be clarified in the internal form / application.</p>             |  |
| <b>5.2</b> | <p><b>Reference Number:</b> NIC-70235-T6P9F-v8</p> <p><b>Applicant and Data Controller:</b> Met Office</p> <p><b>Application Title:</b> “Met Office Health Research Programme”</p> <p><b>Observers:</b> Jodie Taylor-Brown and Emma Whale</p> <p><b>Previous Reviews:</b> The application and relevant supporting documents were previously presented and discussed at the AGD meeting on the 17<sup>th</sup> August 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) meeting on the 31<sup>st</sup> March 2022.</p> <p>The application and relevant supporting documents were previously presented / discussed at the Data Access Advisory Group (DAAG) meetings on the 1<sup>st</sup> June 2017 and the 27<sup>th</sup> April 2017.</p> <p><b>Application:</b> This was an amendment application.</p> <p>NHS England were seeking advice on the following points:</p> <ol style="list-style-type: none"> <li>1. The purpose provides sufficient clarity on the permitted uses of the data.</li> <li>2. The level of delegated decision-making is appropriate.</li> <li>3. The inclusion of ‘visiting scientists’ as users of the data at the Met Office is appropriate noting the governance controls in place.</li> </ol> |  |

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|  | <p>4. Whether NHS England should seek greater clarity on the controls in place around permitted downloads of data (specifically whether they are technical or contractual controls).</p> <p>5. The approach to data minimisation remains justified.</p> <p>6. There are any ethical considerations that remain unaddressed, noting that this is a renewal.</p> <p>Should an application be approved by NHS England, further details would be made available within the <a href="#">Data Uses Register</a>.</p> <p><b>Outcome of discussion:</b> AGD advised that major concerns had been identified and advised NHS England against providing further data access until the following had been addressed:</p> <p><b>In response to point 1:</b></p> <p><b>5.2.1</b> AGD noted that the purpose and exclusion criteria etc had been outlined in the internal form / application; however, advised that this was updated further:</p> <p style="padding-left: 40px;"><b>5.2.1.1</b> to be clear that data can only be used for purposes connected with health and social care; and</p> <p style="padding-left: 40px;"><b>5.2.1.2</b> to be clear that the purpose must require weather data.</p> <p><b>In response to point 2:</b></p> <p><b>5.2.2</b> AGD noted that the proposal outlined in the internal form / application in respect of delegated decision-making, represents existing practices; however, advised that this was no longer in line with best practice. The Group advised that the applicant should consider:</p> <p style="padding-left: 40px;"><b>5.2.2.1</b> reviewing the history of delegated decision-making in the organisation and the criteria used; and</p> <p style="padding-left: 40px;"><b>5.2.2.2</b> reviewing the list of projects received and the process to approve / not approve.</p> <p><b>5.2.3</b> AGD advised that an update should be provided to NHS England on this point as part of any renewal submitted.</p> <p><b>In response to point 3:</b></p> <p><b>5.2.4</b> AGD advised that the inclusion of 'visiting scientists' as users of the data at the Met Office was appropriate subject to sufficient governance controls being in place, including but not limited to:</p> <p style="padding-left: 40px;"><b>5.2.4.1</b> access is time limited with a clear route to removal at the end of any visiting period;</p> <p style="padding-left: 40px;"><b>5.2.4.2</b> ensuring appropriate supervision was in place; and</p> <p style="padding-left: 40px;"><b>5.2.4.3</b> ensuring that anyone with access was contractually bound to the same restrictions as substantive staff under the DSA.</p> <p><b>5.2.5</b> AGD noted that the applicant was encouraging this [collaboration], and advised that the applicant should be clear whether as part of this, the 'visiting scientists' are:</p> <p style="padding-left: 40px;"><b>5.2.5.1</b> working solely on behalf of the applicant; or</p> |  |
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|            | <p><b>5.2.5.2</b> working for another organisation.</p> <p><b>5.2.6</b> AGD also noted that if the 'visiting scientists' are working for another organisation, or initiating a project, this would imply joint data controllership arrangements, which is not permitted under this application; and advised NHS England to explore this further with the applicant, in line with <a href="#">NHS England DARS Standard for Data Controller(s)</a>.</p> <p><b>In response to point 4:</b></p> <p><b>5.2.7</b> AGD noted a concern that, notwithstanding statements regarding technical controls on downloads, there appeared to be only contractual controls, which was a risk. The Group advised that NHS England engage with the applicant:</p> <p><b>5.2.7.1</b> to clarify what technical controls are in place; or</p> <p><b>5.2.7.2</b> if there are no technical controls in place, to establish these, in line with current expectations, for example, the NHS secure data environment (SDE) policy / processes.</p> <p><b>In response to point 5:</b></p> <p><b>5.2.8</b> AGD noted that there was a lack of details in the internal form / application on why access to all fields for all years was required; and noting that the applicant has been using this data for a period of time on a number of projects, the Group advised that NHS England should seek clarification how and why different data fields and datasets have been used. AGD advised that an update should be provided to NHS England on this point as part of any renewal submitted.</p> <p><b>In response to point 6:</b></p> <p><b>5.2.9</b> AGD noted the information in the internal form / application that ethical review had not been sought as the processing is part of the Met Offices public task as a government agency; and advised that they should ensure the <a href="#">NHS England DARS Standard for Ethical Approval is followed</a>.</p> <p>In addition to their advice on the specific points raised by NHS England, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p><b>5.2.10</b> AGD noted that a System Level Security Policy (SLSP) was being relied upon for security assurance; and queried why the Data Security and Protection Toolkit (DSPT) was not being relied on. The Group advised that NHS England engage with the applicant on this, and that the data sharing agreement (DSA) was limited to a period of approximately 15 months, to allow sufficient time to move across to DSPT, in line with the NHS England DSPT <a href="#">guidance</a>, that <i>"All organisations that have access to NHS patient data and systems must use this toolkit to provide assurance that they are practising good data security and that personal information is handled correctly"</i>.</p> <p><b>5.2.11</b> AGD noted the use of a Public Involvement and Engagement Group, and would encourage the applicant to increase their involvement, for example, by advising on which projects are suitable, and on the priority of suitable projects.</p> |  |
| <b>5.3</b> | <p><b>Reference Number:</b> NIC-797405-H6S8S-v0.2</p> <p><b>Applicant:</b> Northumbria University</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |  |

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| <p><b>Data Controller:</b> Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust NHS Foundation Trust</p> <p><b>Application Title:</b> “Police Involvement In Interagency Crisis Mental Health First Response Pathways In England: A Realist And Cost Consequence Analysis (PIONEER-MH)”</p> <p><b>Observers:</b> Suzanne Shallcross and Suzanne Hartley</p> <p><b>Application:</b> This was a new application.</p> <p>NHS England were seeking advice on the following points:</p> <ol style="list-style-type: none"> <li>1. The application is sufficiently clear on the role of Northumbria University.</li> <li>2. The current ethics position, particularly the distinction between overall Research Ethics Committee (REC) approval and the SDE workstream, provides sufficient assurance, or requires further clarification.</li> <li>3. The data minimisation approach is clear as to how to handle age, and mental health linkage.</li> </ol> <p>Should an application be approved by NHS England, further details would be made available within the <a href="#">Data Uses Register</a>.</p> <p><b>Outcome of discussion:</b> AGD advised that significant concerns had been identified and advised NHS England against providing data access (dissemination / release) until the following had been addressed:</p> <p><b>In response to point 1:</b></p> <p><b>5.3.1</b> NHS England advised the Group that prior to the meeting, Northumbria University had confirmed that they are a Data Processor. AGD noted the update, however, if this was correct, noting the information in the internal form / application that indicates that they may be a Data Controller, for example, the information in the outputs that note Northumbria University will be undertaking work from their press office; and they appear in the funding letter. The Group advised that NHS England explore this further with the applicant, in line with <a href="#">NHS England DARS Standard for Data Controller(s)</a>.</p> <p><b>In response to point 2:</b></p> <p><b>5.3.2</b> NHS England advised the Group that, prior to the meeting, the applicant had confirmed that REC approval had been obtained on the 25<sup>th</sup> June 2026, for the latest version of the protocol, which provides sufficient ethical assurance. AGD thanked NHS England for the update.</p> <p><b>In response to point 3:</b></p> <p><b>5.3.3</b> AGD noted that the data would be accessed in the NHS secure data environment (SDE) and advised that the data minimisation was appropriate, noting the information provided in the meeting, in respect of pre-determined packages and the pseudonymisation arrangements. The Group advised that the applicant ensure that this information was reflected in the application and transparency materials.</p> <p>In addition to their advice on the specific points raised by NHS England, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> |  |
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|            | <p><b>5.3.4</b> AGD noted the potential importance of the study, and recognised that this may attract a lot of visibility, and advised that the applicant ensures that:</p> <p><b>5.3.4.1</b> they have a robust set of transparency materials in line with the <a href="#">NHS England DARS Standard for Transparency</a>, including but not limited to, a UK General Data Protection Regulation (UK GDPR) compliant privacy notice.</p> <p><b>5.3.4.2</b> have undertaken appropriate patient and public involvement and engagement (PPIE).</p> <p><b>5.3.5</b> AGD advised that the applicant may wish to consider applying to NHS England for further datasets to support the work outlined if required at a later date.</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |  |
| <b>5.4</b> | <p><b>Reference Number:</b> NIC-715053-T6B8C-v0.4</p> <p><b>Applicant and Data Controller:</b> Queen Mary University of London</p> <p><b>Application Title:</b> “Exploring differences in oesophageal cancer burden between England and Israel”</p> <p><b>Observer:</b> Maddie Laughton</p> <p><b>Application:</b> This was a new application.</p> <p>NHS England were seeking advice on the following points:</p> <ol style="list-style-type: none"> <li>1. AGD considers that the PPIE undertaken is sufficient to address the specific ethical sensitivities associated with analysing and comparing outcomes across religious or ethnically identifiable populations, or whether further engagement is required.</li> </ol> <p>Should an application be approved by NHS England, further details would be made available within the <a href="#">Data Uses Register</a>.</p> <p><b>Outcome of discussion:</b> AGD advised that major concerns had been identified and advised NHS England against providing data access until the following had been addressed:</p> <p><b>In response to point 1:</b></p> <p><b>5.4.1</b> AGD noted that the applicant will require data on the general population, and therefore patient and public involvement and engagement (PPIE) needed to be broader.</p> <p><b>5.4.2</b> In addition, when undertaking PPIE with the Jewish population in England, this should include more than one individual. The <a href="#">HRA guidance on Public Involvement</a> is a useful guide.</p> <p>In addition to their advice on the specific points raised by NHS England, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p><b>5.4.3</b> AGD queried why the applicant was requesting 20 years of data, and advised that NHS England discuss this further with the applicant, in line with <a href="#">NHS England DARS standard for Data Minimisation</a>.</p> <p><b>5.4.4</b> AGD advised that, noting the sensitive nature of the study, this study would benefit from a review by an appropriate Research Ethics Committee (REC); and advised that the applicant seek ethical review, in line with the <a href="#">NHS England DARS Standard for Ethical Approval</a>.</p> |  |

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|                                                                       | <p><b>5.4.5</b> AGD advised that, as expected for any studies of this type, the applicant would need to demonstrate that the approach taken with this study has undergone an independent scientific peer review, to ensure that the data they are requesting would be sufficient to answer the research question and to determine the scientific value of the research. The Group advised that NHS England discuss this further with the applicant.</p> <p><b>5.4.6</b> Noting the purpose of the study, AGD advised that NHS England satisfy themselves that there are clear benefits from this research to health and social care in England and Wales.</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |  |
| 6 INTERNAL DATA DISSEMINATION REQUESTS:                               |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |  |
| There were no items discussed                                         |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |  |
| 7 EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |  |
| 7.1                                                                   | <p><b>Reference Number:</b> NIC-71603-T8C0Q-v7.2</p> <p><b>Applicant and Data Controller:</b> London Borough of Islington</p> <p><b>Application Title:</b> “LAPH Standard Extract”</p> <p><b>Previous Reviews:</b> The application and relevant supporting documents were previously presented / discussed at the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) meeting on the 16<sup>th</sup> February 2017.</p> <p>The SIRO approval was for a renewal.</p> <p><b>Outcome of discussion:</b> AGD noted that the NHS England SIRO had already provided SIRO approval on the 12<sup>th</sup> June 2026 and confirmed that they were supportive of this.</p> <p>AGD thanked NHS England for the written update and made the following observations on the documentation provided:</p> <p><b>7.1.1</b> AGD noted that the applicant had not submitted all relevant Annual Confirmation Reports (ACRs) as per the usual process, and supported the NHS England SIRO Representative’s position, that failure to submit any further ACR’s would be a breach of the data sharing agreement (DSA).</p> <p><b>7.1.2</b> AGD queried whether the applicant had provided a data destruction certificate for data held prior to April 2016, and advised that NHS England explore this further with the applicant.</p> <p>The NHS England SIRO representative thanked AGD for their time.</p> |  |
| 8 OVERSIGHT AND ASSURANCE                                             |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |  |
| There were no items discussed                                         |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |  |
| 9 AGD OPERATIONS                                                      |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |  |
| 9.1                                                                   | <p><b>AGD ways of working</b></p> <p>There were no items discussed.</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |  |
| 9.2                                                                   | <p><b>AGD Stakeholder Engagement</b></p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |  |

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|                                                                                                                                              | <b>Federated Data Platform</b><br><p>The Group's representative on the Federated Data Platform Data Governance Group provided a brief update.</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
| <b>9.3</b>                                                                                                                                   | <b>AGD Project Work</b><br><p>AGD noted that, following the meeting, some project work would be undertaken with the majority of AGD independent members in attendance and NHS England, to discuss 'delegated decision-making'.</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| <b>10 Any Other Business</b>                                                                                                                 |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>10.1</b>                                                                                                                                  | <b>Calming Minds Study</b><br><p>AGD noted that at the AGD meeting on the 30<sup>th</sup> April 2026, the Group had discussed the NHS DigiTrials invitation letter for the 'Calming Minds Study'; and, as part of this review, had raised significant concerns in respect of a telephone number not being included in the letter templates.</p> <p>The NHS England SIRO Representative advised the Group, that an update would be provided on this point at a future AGD meeting, noting that the applicant was in the process of providing NHS England with a position on this.</p> <p>The Group noted the update and looked forward to receiving further information in due course.</p> |
| <b>10.2</b>                                                                                                                                  | <b>Internal Data Dissemination Requests</b><br><p>An AGD independent member queried what the latest position was with internal data disseminations, noting that the Group had been asked to review very few since its inception. The NHS England SIRO Representative advised the Group that an update would be provided on this due course. An AGD member suggested that internal data disseminations should have their own oversight and assurance strand.</p>                                                                                                                                                                                                                           |
| <b>10.3</b>                                                                                                                                  | <b>AGD Chair Blog</b><br><p>The Group noted that the AGD Chair's blog had now been published on the NHS England webpage: <a href="#">A new chapter for the Advisory Group for Data - NHS England Digital</a></p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| <b>Meeting Closure</b><br><p>As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.</p> |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |