

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

Thursday, 5<sup>th</sup> June 2025

09:00 – 15:30

*(Remote meeting via videoconference)*

<b>AGD INDEPENDENT / NHS ENGLAND MEMBERS IN ATTENDANCE:</b>	
<b>Name:</b>	<b>Role:</b>
Paul Affleck (PA)	AGD independent member (Specialist Ethics Adviser) (Chair)
Eleanor Berg (EB)	NHS England member (Data Protection Office Representative (Delegate for Jon Moore))
Michael Chapman (MC)	NHS England member (Data and Analytics Representative) ( <b>Presenter:</b> item 10.1)
Claire Delaney-Pope (CDP)	AGD independent member (Specialist Information Governance Adviser)
Dr. Jonathan Osborn (JO)	NHS England member (Caldicott Guardian Team Representative) not in attendance for item 5.1 and part of item 5.2)
Jenny Westaway (JW)	AGD independent member (Lay Adviser)
Miranda Winram (MW)	AGD independent member (Lay Adviser)
Tom Wright (TW)	NHS England member (Data and Analytics Representative (Delegate for Michael Chapman))
<b>NHS ENGLAND STAFF IN ATTENDANCE:</b>	
<b>Name:</b>	<b>Role / Area:</b>
Garry Coleman (GC)	NHS England SIRO Representative
Claire Corney (CC)	Senior Information Governance Manager, Privacy, Transparency and Trust (PTT), Delivery Directorate ( <b>Presenter:</b> item 4.1)
Dave Cronin (DC)	Applications Service Owner, Data Access and Partnerships, Transformation Directorate ( <b>Observer:</b> items 4.2 and 5.1)
Louise Garnham (LG)	Service Delivery Manager, NHS DigiTrials, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 5.2)
Martin Grund (MG)	Data Product Manager, 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> item 5.2)

Caroline Keef (CK)	Senior Analytical Lead, Pharmacy, Optom and Dental Analysis, Strategy Analysis, Transformation Directorate ( <b>Presenter:</b> item 4.1)
Joe Lawson (JL)	Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 5.5)
Sara Lubbock (SL)	Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 5.3)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Delivery Directorate
Frances Perry (FP)	Data Portfolio Management Team, Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 5.5)
Suzanne Shallcross (SS)	Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 5.3)
Emma Whale (EW)	Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> item 5.4)
<b>AGD INDEPENDENT MEMBERS / NHS ENGLAND MEMBERS <u>NOT</u> IN ATTENDANCE:</b>	
<b>Name:</b>	<b>Role / Area:</b>
Dr. Robert French (RF)	AGD independent member (Specialist Academic / Statistician Adviser)
Kirsty Irvine (KI)	AGD independent member (Chair)
Jon Moore (JM)	NHS England member (Data Protection Office Representative)

<b>1</b>	<p><b>Welcome and Introductions:</b></p> <p>The AGD meeting 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 item 5.1 and part of item 5.2.</p> <p>Noting that the <a href="#">AGD Terms of Reference</a> state that “<i>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 <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.</p>
<b>2</b>	<p><b>Review of previous AGD minutes:</b></p> <p>The minutes of the AGD meeting on the 15<sup>th</sup> May 2025 were reviewed out of committee by the Group and, after several minor amendments, were agreed as an accurate record of the meeting by the AGD meeting Chair, on behalf of the Group.</p>

3	<p><b>Declaration of interests:</b></p> <p>Jenny Westaway noted that she had undertaken some paid contract work for Templar Executives to provide training courses for Our Future Health. It was agreed this did not preclude the Jenny from taking part in the discussions about the Our Future Health application (NIC-414067-K8R6J).</p> <p>Paul Affleck noted a previous professional link to the Leeds Teaching Hospitals NHS Trust, but noted no specific connections with the application (NIC-748215-Z7K2V) or staff involved, and it was agreed that this was not a conflict of interest.</p> <p>Paul Affleck noted a previous professional link to the University of Leeds but noted no specific connections with the application (NIC-751713-S7J7R), or staff involved, and it was agreed that this was not a conflict of interest.</p> <p>Claire Delaney-Pope noted a professional link to King's Health Partners (NIC-774351-T6M3Q-v0.4 University of East Anglia) as part of her role at South London and Maudsley NHS Foundation Trust (SLAM). It was agreed this did not preclude Claire from taking part in the discussion on this application.</p> <p>Claire Delaney-Pope noted that she had some involvement with the subject matter of item 10.1 (Foresight AI Project), as part of her role at South London and Maudsley NHS Foundation Trust (SLAM). It was agreed this did not preclude Claire from taking part in the discussion.</p> <p>A number of AGD members noted they would be part of the cohort of the University of Leeds research programme (NIC-751713-S7J7R). It was agreed this did not preclude the AGD members from taking part in the discussions about this application.</p>
4 BRIEFING PAPER(S) / DIRECTIONS:	
4.1	<p><b>Title:</b> Delegation of NHS England Direct Commissioning Functions – Evaluation and Monitoring of Services Directions 2025</p> <p><b>Presenters:</b> Caroline Keef and Claire Corney</p> <p><b>Observer:</b> Martin Grund</p> <p>The framework Direction is to require NHS England to collect and analyse information from health and care bodies relating to services commissioned by Integrated Care Boards (ICBs) by virtue of NHS England's delegation of its direct commissioning functions to ICBs under section 65Z5 of the NHS Act 2006. This will enable NHS England to: monitor and evaluate national and local service performance against relevant service specifications to understand whether the commissioned services are achieving the desired aims and patient benefits; understand the impact these services have on the wider NHS; understand patient pathways and care outcomes to improve the quality and safety of services and reduce health inequalities; inform priority setting for the development of new clinical services; support an integrated approach to population health management and facilitating health and care partnerships to design new models of care; and, enable partnership working with ICBs and support them to monitor delivery within their region, conduct benchmarking, inform decision making and target inefficiencies.</p> <p>This will be achieved via a framework Direction which enables multiple collections to be established under this one Direction over a phased period, subject to NHS England information governance advice and governance processes.</p>

	<p>It is proposed that the first two datasets which NHS England will collect from NHS Business Services Authority (NHS BSA) under this Direction (at the date of signing) are <b>1)</b> Community Pharmacy Clinical Services Dataset; and <b>2)</b> Dental and Orthodontic Activity Dataset.</p> <p>NHS England were seeking advice on the following points:</p> <ol style="list-style-type: none"> <li>1. The draft Direction</li> <li>2. The adequacy of the transparency information / information provided to patients</li> </ol> <p><b>Outcome of discussion:</b> AGD welcomed the draft Direction and made the following observations / comments:</p> <p><b>In response to point 1 above:</b></p> <p><b>4.1.1</b> AGD noted the content of the framework Direction, and advised that they were supportive of the proposal outlined and had no specific comments on this document.</p> <p><b>In response to point 2 above:</b></p> <p><b>4.1.2</b> AGD suggested that the 'community pharmacy England template privacy notice', be updated to be clearer on <b>1)</b> the data that would be processed; <b>2)</b> the data linkage; <b>3)</b> the scope of the / purpose of processing; and <b>4)</b> to remove the description of the information to be collected about patients as "<i>limited</i>".</p> <p><b>4.1.3</b> AGD noted in the transparency materials that the data would be retained by NHS England for "<i>a minimum of six years after the date by which the information is no longer required</i>"; and suggested that this was updated to state that data would be held for as long as there was a legal basis and purpose to retain the data.</p> <p><b>4.1.4</b> AGD noted the references in the transparency materials to "...such as..." when referring to various points; and noting that this was quite a general term, suggested that these references were reviewed and updated where appropriate to be more specific about what has / will be done.</p> <p><b>4.1.5</b> AGD suggested that the transparency materials were reviewed and updated to be clearer on the status of the data, for example, at what point(s) the data would / would not be pseudonymised.</p> <p><b>4.1.6</b> The Group noted the information in the data protection impact assessment (DPIA) in relation to the role of AGD, and the process that would be undertaken if AGD were not supportive of data flowing; and suggested that this was reviewed and updated to reflect current practice.</p> <p><b>4.1.7</b> AGD suggested that the information within the DPIA in respect of cyber-attacks was reviewed and updated to be clear that the safeguards in place would minimise the risk of a cyber-attack but may not prevent it.</p> <p><b>4.1.8</b> AGD noted and commended the consultation with patient representative groups outlined in the DPIA.</p> <p><b>4.1.9 Separate to this Direction and for NHS England to consider:</b> AGD noted the content of the 'NHS Practice Record – Patient Declaration form (FP17PR)' provided as a supporting document, and suggested that NHS England feedback to the relevant team that the form would need updating to <b>1)</b> update references to "<i>NHS Digital</i>"; and <b>2)</b> to amend the</p>	<p>CK / CC / MG</p>
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	statement “Your personal data will be deleted within 8 years of receipt into our systems” to reflect data that has been onwardly shared may not be deleted.	
4.2	<p><b>Title:</b> National Institute for Cardiovascular Outcomes Research (NICOR) Data – Briefing Paper</p> <p><b>Observer:</b> Dave Cronin</p> <p><b>Linked Application:</b> This briefing paper was linked to NIC-748215-Z7K2V Leeds Teaching Hospitals NHS Trust (NIC-748215-Z7K2V Leeds Teaching Hospitals NHS Trust).</p> <p>The purpose of the briefing paper was to make AGD aware that external applicants requesting NICOR data will now apply through NHS England’s Data Access Service (DAS) process, and will receive the NICOR data along with any other linked NHS England datasets, under a single data sharing agreement (DSA).</p> <p>Historically NICOR was hosted initially at University College London and then by Barts Health NHS Trust as a Data Processor and commissioned by the Healthcare Quality Improvement Programme (HQIP). During 2022 the commissioning and location of this work was changed to NHS England and a migration exercise undertaken.</p> <p>In 2022, NICOR were requested to operate an independent application and data access process to the NHS England DAS process. NHS England are now combining them.</p> <p><b>Outcome of discussion:</b> AGD welcomed the briefing paper and made the following observations / comments:</p> <p><b>4.2.1</b> AGD noted the content of the briefing paper and advised that they were supportive of the proposal outlined.</p> <p><b>4.2.2</b> AGD noted that they welcomed the scientific engagement and expertise via the NICOR Research Access Committee (RAC).</p> <p><b>4.2.3</b> AGD queried the opt-out arrangements for this data, and were advised by NHS England, that work would be undertaken to ensure the National Data Opt-out policy was adhered to where appropriate.</p> <p><b>4.2.4</b> AGD noted and commended colleagues in NHS England’s Data and Analytics on the ongoing work on this area of work; and noted that a further update would be provided in due course.</p>	
<b>5 EXTERNAL DATA DISSEMINATION REQUESTS:</b>		
5.1	<p><b>Reference Number:</b> NIC-748215-Z7K2V-v0.7</p> <p><b>Applicant and Data Controller:</b> Leeds Teaching Hospitals NHS Trust</p> <p><b>Application Title:</b> “The Association Between Right Bundle Branch Block and Long-term Mortality Post-TAVI – Data from the UK TAVI Registry”</p> <p><b>Observer:</b> Dave Cronin</p> <p><b>Linked Briefing Paper:</b> This application is linked to the ‘National Institute for Cardiovascular Outcomes Research (NICOR) Data – Briefing Paper’ (item 4.2).</p> <p><b>Application:</b> This was a new application.</p>	

	<p>NHS England were seeking general advice on the application.</p> <p>Should an application be approved by NHS England, further details would be made available within the <a href="#">Data Uses Register</a>.</p> <p><b>Outcome of discussion:</b> The Group were broadly supportive of the purpose outlined in the application, but were <b>not</b> 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:</p> <p><b>5.1.1</b> AGD noted that the application referred to the work being undertaken was “<i>research</i>”, however the NHS England internal application assessment form referred to the work being “<i>service evaluation</i>”. The Group suggested that NHS England clarify this point with the applicant, and the application / NHS England internal application assessment form were updated to reflect the correct / factual information, in line with <a href="#">NHS England’s DAS Standards</a>.</p> <p><b>5.1.2</b> AGD suggested that once it had been determined whether the work being undertaken was research or service evaluation, that the Article 9 UK General Data Protection Regulation (UK GDPR) legal basis cited was reviewed and updated as may be appropriate.</p> <p><b>5.1.3</b> AGD noted in the NHS England internal application assessment form that an ethical review had not been sought, and no patient and public involvement and engagement (PPIE) had been undertaken, due to it being service evaluation. The Group suggested that, dependent on the outcome of point 5.1.1, if the work was deemed to be research and not service evaluation, that <b>1)</b> the applicant seek ethical review; and <b>2)</b> suggested there was ongoing PPIE throughout the lifecycle of the work. The <a href="#">HRA guidance on Public Involvement</a> is a useful guide.</p> <p><b>5.1.4</b> AGD noted that section 3(c) (Patient Objections) stated opt-outs would not be applied; however, noting the NICOR <a href="#">privacy notice</a> refers to an exemption of opt outs for audit purposes but not for research where there is a s251 legal basis, it was suggested that this was reviewed and updated as appropriate, noting that opt-outs may need applying.</p> <p><b>5.1.5</b> AGD noted that section 3(b) (Additional Data Access Requested) stated that the NICOR Transcatheter Aortic Valve Implantation (TAVI) dataset was “<i>identifiable</i>”; and suggested that this was amended to align with section 5(a) (Objective for Processing) and section 5(b) (Processing Activities) that states the datasets would be “<i>pseudonymised</i>”, if this was the correct information.</p> <p><b>5.1.6</b> AGD noted the NICOR privacy notice, however, suggested that this was reviewed and updated as may be appropriate to ensure the correct information was available in respect of opt-outs / objections.</p> <p><b>5.1.7</b> AGD noted that this application had been reviewed / supported by the NICOR Research Access Committee (RAC); however, suggested that this was clarified in section 5(a) for transparency.</p> <p><b>5.1.8 Separate to this application and for NHS England to consider:</b> AGD suggested that NHS England’s DAS provide NICOR RAC feedback as a supporting document for future NICOR applications submitted to AGD for review.</p>	<p>D&amp;S Rep DAS</p>
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	<p><b>5.1.9</b> AGD noted the two statements at the beginning / end of section 5(b) in respect of linkage; and suggested that these statements were sat next to each other, to avoid any confusion as to what linkage was / was not permitted.</p> <p><b>5.1.10</b> AGD queried the statement in section 5(b) “<i>Access is restricted to employees or agents of...</i>” and suggested that either further information was provided as to who would be covered by “<i>agents</i>”; or that this word was removed, as may be necessary to reflect the facts.</p> <p><b>5.1.11</b> No AGD member noted a commercial aspect to the application.</p>	
<b>5.2</b>	<p><b>Reference Number:</b> NIC-414067-K8R6J-v8.3</p> <p><b>Applicant and Data Controller:</b> Our Future Health</p> <p><b>Application Title:</b> “Our Future Health Recruitment Programme”</p> <p><b>Observers:</b> Louise Garnham and Suzanne Hartley</p> <p><b>Previous Reviews:</b> The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 30<sup>th</sup> January 2025, 11<sup>th</sup> April 2024, 14<sup>th</sup> March 2024, 18<sup>th</sup> January 2024, 2<sup>nd</sup> November 2023, 28<sup>th</sup> September 2023, 10<sup>th</sup> August 2023, 13<sup>th</sup> July 2023, 29<sup>th</sup> June 2023, 11<sup>th</sup> May 2023, 30<sup>th</sup> March 2023 and the 2<sup>nd</sup> March 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 1<sup>st</sup> December 2022, 17<sup>th</sup> November 2022, 26<sup>th</sup> May 2022 and the 5<sup>th</sup> May 2022.</p> <p><b>Linked applications:</b> This application is linked to NIC-411795-X5N2V.</p> <p><b>Application:</b> This was an amendment application.</p> <p>NHS England were seeking general advice on the application.</p> <p>Should an application be approved by NHS England, further details would be made available within the <a href="#">Data Uses Register</a>.</p> <p><b>Outcome of discussion:</b> AGD were supportive of the application and wished to draw to the attention of the SIRO the following comments:</p> <p>AGD noted that they had been provided with a curated set of documentation and noted that they would be providing observations based on these documents.</p> <p><b>5.2.1</b> AGD noted that the majority of points raised from the last AGD review on the 30<sup>th</sup> January 2025 had been addressed.</p> <p><b>5.2.2</b> AGD noted that at the AGD meeting on the 30<sup>th</sup> January 2025, the Group had noted the process outlined in section 5(a) (Objective for Processing) for the letters / envelopes that are returned to NHS England, to support the Personal Demographic Service (PDS); and had suggested that NHS England assure itself that there is a legal basis for this data to be used in this way. AGD suggested that this point was reviewed further noting that the response provided in the NHS England DAS internal Escalation Form did not address the issue raised.</p>	



	<p><b>5.2.3 Separate to this application and for NHS England to consider:</b> The Group suggested that once point 5.2.2 had been resolved, that an update was provided at a future AGD meeting under 'AOB'.</p> <p><b>5.2.4</b> AGD noted the Health Research Authority Confidentiality Advisory Group (HRA CAG) condition for this application in respect of the update on ongoing patient involvement, and noted that a report on this was due to be submitted to HRA CAG by the 11<sup>th</sup> June 2025. The Group noted the request to extend this application to the 11<sup>th</sup> January 2026, to allow sufficient time for HRA CAG to review and feedback on the report. Noting that AGD may have some valuable reflections on the report, a request was made for the Group to receive a copy of the report at the same time as HRA CAG, and suggested that this was done via a special condition in section 6 (Special Conditions), or other similar mechanism.</p> <p><b>5.2.5</b> AGD noted the amendment to the application to add NHS Notify as a mailout provider; however, advised that the current transparency information for NHS Notify did not fully encompass research and use of the system for commercial purposes; and <b>1)</b> suggested that the transparency information was updated to reflect this; and <b>2)</b> the NHS Notify data protection impact assessment (DPIA) was fully up to date with all the relevant / correct information.</p> <p><b>5.2.6</b> In addition, AGD noted in the application, that NHS Notify was referred to as a “<i>sub-processor</i>” and a “<i>processor</i>”; and suggested that these were reviewed and updated to reflect the correct information, noting that NHS Notify is part of NHS England.</p> <p><b>5.2.7</b> AGD noted and commended the applicant on <b>1)</b> the work undertaken to clarify the commercial aspects with the cohort; and <b>2)</b> the patient and public involvement and engagement (PPIE) undertaken on worldwide sharing of data.</p> <p><b>5.2.8</b> AGD noted and commended NHS DigiTrials on the work undertaken to monitor opt-outs and complaints.</p> <p><b>5.2.9 Separate to this application and for NHS England to consider:</b> AGD suggested that NHS England should consider using the work undertaken by the applicant on the engagement with the cohort and the PPIE as an example for other large cohort studies.</p> <p><b>5.2.10</b> AGD noted and commended the work undertaken by NHS England’s DAS on the application.</p> <p><b>5.2.11</b> AGD noted that there <b>was</b> a commercial aspect to the application.</p>	<p>D&amp;A Rep / DAS</p> <p>D&amp;A Rep / DAS</p>
5.3	<p><b>Reference Number:</b> NIC-734273-H8R3Q-v0.11</p> <p><b>Applicant and Data Controller:</b> Institute of Occupational Medicine (IOM)</p> <p><b>Application Title:</b> “MORSE (MORTality Study of former professional footballers in England and Wales) Study”</p> <p><b>Observers:</b> Suzanne Shallcross and Sara Lubbock</p> <p><b>Application:</b> This was a new application.</p> <p>NHS England were seeking general advice on the application.</p> <p>Should an application be approved by NHS England, further details would be made available within the <a href="#">Data Uses Register</a>.</p>	



**Outcome of discussion:** AGD could see the potential value in the work outlined in the document provided, but were **not** supportive of the application at this time and wished to draw to the attention of the SIRO the following substantive comments, and suggested the application be brought back to a future meeting:

**5.3.1** AGD advised that they would be supportive of a two-stage approach, to **1)** the applicant to flow data to NHS England for the latter to perform linkage; and **2)** for NHS England to flow statistical information on the linkage to the applicant, but **not** the actual linked data, to determine next steps.

**5.3.2** AGD welcomed the application and noted that this was a potentially valuable study that may have wider implications for contact sport more generally.

**5.3.3** AGD noted that, prior to the meeting, a query had been raised by an AGD independent member in respect of the data within the Barry Hugman's Footballer database; and noted that the applicant had advised that they were not aware of any UK General Data Protection Regulation (UK GDPR) issues relating to the data within this database. AGD suggested that NHS England advise the applicant that **1)** a legal basis is required for obtaining and transferring the data to NHS England, noting that whilst this may have come from a public source, it is still personal information and subject to UK GDPR; **2)** there is sufficient transparency on the legal basis for the applicant to obtain and transfer this data to NHS England.

**5.3.4** AGD queried why some of the data being sought from the Barry Hugman's Footballer database could not be obtained from the Professional Footballers' Association (PFA), and noting that this was unclear, suggested that NHS England explore this further with the applicant.

**5.3.5** AGD noted the statement in the Legitimate Interest Assessment (LIA) provided as a supporting document that "*...we will respect the wishes of family members if they get in touch and wish their relative's details not included in the study*". The Group suggested that the applicant gave further consideration to **1)** how awareness of the study could be raised in general, for instance in relevant media outlets including social media; and **2)** how families could be made aware of the study, so that they had the option of removing their relative's details from the study.

**5.3.6** AGD noted that there was a leaflet to raise awareness of the study, however, suggested that if this was updated at any point in the future, this was updated to **1)** provide further clarity on the s251 support; and **2)** be clear as to the point in the analysis where it would not be possible to opt out of the analysis dataset.

**5.3.7** AGD noted that the leaflet gave individuals the opportunity to opt out, however, noted that it was unclear if the Professional Footballers' Association (PFA) had circulated this to its members and / or publicised this. AGD suggested that a special condition was added to section 6 (Special Conditions), that no data would flow until this leaflet had been circulated to the cohort and individuals had been given the opportunity to opt out.

**5.3.8** AGD noted that there had been **no** patient and public involvement and engagement (PPIE) undertaken to date, and suggested that there was ongoing PPIE throughout the lifecycle of the work. The [HRA guidance on Public Involvement](#) is a useful guide.

**5.3.9** AGD noted that the Barry Hugman website was no longer live, and suggested that **1)** the reference to this in section 5(a) (Objective for Processing) was updated; and **2)** any

	<p>other online sources used to obtain information / data were added to section 5(a) for transparency.</p> <p><b>5.3.10</b> AGD noted that there may be issues with the linkage of this data, and how valid inferences would be, and whilst the Group recognised that this was research, suggested that NHS England discuss this further with the applicant, including, but not limited to, <b>1)</b> how the linkage would be carried out; and <b>2)</b> whether data would flow for individuals that were incorrectly matched, noting that this would not be covered by the s251 support.</p> <p><b>5.3.11</b> AGD noted that it was proposed that 'date of death' data would be used to match individuals, and queried if this was possible, and if it was possible, noted they were unclear why this data would flow back to the applicant as it would only flow on those individuals matched. The Group suggested that NHS England explored this further, to refine the process and gauge the likelihood of false matches.</p> <p><b>5.3.12</b> AGD noted that section 5(c) (Specific Outputs Expected) stated <i>"The outputs will not contain NHS England Data and will only contain aggregated information with small numbers suppressed..."</i>; and suggested that section 5(b) (Processing Activities) was updated to also make this clear.</p> <p><b>5.3.13</b> AGD noted the multiple 'cause of death lines' in section 3(b) (Additional Data Access Requested), and suggested that NHS England explore this further to see if this information was required or could be amended to only reflect the information once, however, noted that this may be a reflection of how this information is recorded.</p> <p><b>5.3.14</b> AGD noted and commended the work undertaken by NHS England's DAS on the application.</p> <p><b>5.3.15</b> No AGD member noted a commercial aspect to the application.</p>	
<b>5.4</b>	<p><b>Reference Number:</b> NIC-736873-X9F8V-v0.7</p> <p><b>Applicant and Data Controller:</b> Imperial College London</p> <p><b>Application Title:</b> "Periprosthetic femoral fractures: data, management and outcomes"</p> <p><b>Observer:</b> Emma Whale</p> <p><b>Application:</b> This was a new application.</p> <p>NHS England were seeking general advice on the application.</p> <p>Should an application be approved by NHS England, further details would be made available within the <a href="#">Data Uses Register</a>.</p> <p><b>Outcome of discussion:</b> AGD were supportive of the application <b>if</b> the following substantive comments were addressed, and wished to draw to the attention of the SIRO the following substantive comments</p> <p><b>5.4.1</b> AGD noted that the applicant's Data Security and Protection Toolkit (DSPT) was for 2022/23, and suggested that <b>1)</b> NHS England satisfy themselves that the appropriate DSPT is in place; and <b>2)</b> if there is not an appropriate DSPT in place, NHS England determine the impact this may have on other applications where Imperial College London is cited as a Data Controller.</p>	

	<p>In addition, AGD made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p><b>5.4.2</b> AGD queried at what point the national data opt-out (NDO) would be applied, and by whom; and suggested that section 5 (Purpose / Methods / Outputs) was updated with further clarity on this point.</p> <p><b>5.4.3</b> AGD discussed the role of VIRTUS data centre, and whilst it was determined that they were not a Data Processor, the Group suggested that section 5 was updated to be clear that they were providing the facilities (building) to store the data only.</p> <p><b>5.4.4</b> AGD queried the reference in section 5(a) (Objective for Processing) to “<i>ONS Civil Registration</i>”; and suggested that this was reviewed and updated as may be necessary, for example, by removing the reference to “<i>ONS</i>” if this was appropriate / correct.</p> <p><b>5.4.5</b> AGD noted that the privacy notice weblink on the National Major Trauma Registry (NMTR) <a href="#">webpage</a> did not link to the privacy notice; and suggested that this was reviewed and updated with the correct information.</p> <p><b>5.4.6</b> AGD noted and commended the work undertaken by NHS England’s DAS on the application.</p> <p><b>5.4.7</b> No AGD member noted a commercial aspect to the application.</p>	
<b>5.5</b>	<p><b>Reference Number:</b> NIC-751713-S7J7R</p> <p><b>Applicant and Data Controller:</b> University of Leeds</p> <p><b>Application Title:</b> “Segregated careers in the NHS: A intersectional study of occupational access, progression, and turnover”</p> <p><b>Observers:</b> Frances Perry and Joseph Lawson</p> <p><b>Application:</b> This was a new application.</p> <p>NHS England were seeking advice on the following points only:</p> <ol style="list-style-type: none"> <li>1) Does AGD support the provision of access to the requested data to the named organisation for the stated purpose?</li> <li>2) Would AGD recommend any actions or points of clarification which must be resolved before the provision of access to the data?</li> <li>3) Noting that the application will meet NHS England DARS standards and will use the relevant template for Section 5, do AGD think there is any reason not to proceed to a DSA, without returning to AGD?</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 provided preliminary advice only on the briefing paper and documentation provided <b>only</b>, and suggested that any application be brought back to a future meeting.</p> <p>AGD noted that they had been provided with a curated set of documentation, including, but not limited to, a briefing paper instead of an application, and noted that they would be providing observations based on these documents.</p>	

	<p>AGD noted that this was a first of type review under the 'AGD first' concept.</p> <p><b>In response to point 1:</b></p> <p><b>5.5.1</b> AGD noted the potential importance of the research project outlined, however, advised that they would <b>not</b> be supportive of the provision of access to the requested data for the stated purpose at this time due to the points raised below.</p> <p><b>In response to point 2:</b></p> <p><b>5.5.2</b> AGD noted the volume of sensitive data requested, and noted concerns that this was being accessed via a data extract and not in NHS England's Secure Data Environment (SDE); and noting that there should be a strong justification for the data to be accessed via a data extract, suggested that this was explored further.</p> <p><b>5.5.3</b> AGD noted the sensitive data fields requested, and queried why all of the data fields were required, and queried <b>1)</b> where data minimisation could be applied in line with <a href="#">NHS England DAS standard for data minimisation</a>; or <b>2)</b> what the justification was for all of the data fields requested.</p> <p><b>5.5.4</b> AGD queried how this research differed from other similar research being undertaken by other organisations already, including, but not limited to, the Institute for Fiscal Studies; and what, if any engagement / collaboration had been discussed with any other organisations. AGD suggested seeking further input from relevant parts of NHS England.</p> <p><b>5.5.5</b> Noting this was a PhD research project, AGD queried what the potential / realistic benefits of this study were to the health and care; and noted that further clarity should be provided on this point, in line with <a href="#">NHS England DAS Standard for Expected Measurable Benefits</a>.</p> <p><b>5.5.6</b> AGD queried what engagement had / would be undertaken with <b>1)</b> workforce groups <b>2)</b> NHS Trusts; and / or <b>3)</b> NHS Trade Unions, to seek their views on the research project outlined; and what impact the feedback from the engagement would have on the research project if there was a lack of support for it.</p> <p><b>In response to point 3:</b></p> <p><b>5.5.7</b> AGD suggested that if this work progressed further, an application should be submitted for review at a future AGD meeting, due to the issues raised as part of this initial review.</p> <p><b>5.5.8</b> Noting AGD was only asked to advise on specific points reviewed, no AGD member noted any substantive commercial aspects.</p>	
<b>5.6</b>	<p><b>Reference Number:</b> NIC-774351-T6M3Q-v0.4</p> <p><b>Applicant:</b> University of East Anglia</p> <p><b>Data Controller(s):</b> University of Leicester</p> <p><b>Application Title:</b> "Comprehensive Geriatrician Led Medication Review (CHARMER) Definitive Study"</p> <p><b>Application:</b> This was a new application.</p> <p>NHS England were seeking general advice on the application.</p>	

	<p>Should an application be approved by NHS England, further details would be made available within the <a href="#">Data Uses Register</a>.</p> <p><b>Outcome of discussion:</b> AGD were supportive of the application and wished to draw to the attention of the SIRO the following comments:</p> <p><b>5.6.1</b> AGD welcomed the application and noted the importance of the study for the welfare of patients.</p> <p><b>5.6.2</b> AGD discussed that there may be multiple cohorts in the study, depending on how the common law duty of confidentiality was being met; and were advised by NHS England that there may be multiple applications as a result of the various ways in which opt-outs would / would not be applied, and that comments on this application would also feed into any linked applications. AGD noted the verbal update and agreed to proceed on this basis, noting that the consent review had been provided that covered all of the data subjects included under consent and consultee advice.</p> <p><b>5.6.3</b> AGD noted that section 3(b) (Additional Data Access Requested) and section 5 (Purpose / Methods / Outputs) referred to the data as being “<i>pseudonymised</i>”, and queried if this was correct, noting the flow of identifiers into NHS England; and suggested that this information was reviewed and updated to correctly refer to the data as being “<i>identifiable</i>”.</p> <p><b>5.6.4</b> AGD queried the timeframe for the data and how this was being determined, and suggested that the application was updated to be clear that the data would flow from one month prior to the date an individual entered into the study, and not a single date for all.</p> <p><b>5.6.5</b> AGD suggested that the Medicines dispensed in Primary Care (NHSBSA data) special condition in section 6 (Special Conditions) was reviewed and updated by NHS England, to remove any restrictive wording that is no longer relevant; but suggested that the ‘suppression methodology’ remained.</p> <p><b>5.6.6</b> AGD noted that whilst the applicant did have a privacy notice, suggested that this could be updated further to be clear on how individuals can withdraw from the study.</p> <p><b>5.6.7</b> AGD noted and commended the PPIE undertaken by the applicant to date.</p> <p><b>5.6.8</b> No AGD member noted a commercial aspect to the application.</p>	
<b>6 INTERNAL DATA DISSEMINATION REQUESTS:</b>		
<i>There were no items discussed</i>		
<b>7 EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL</b>		
<b>7.1</b>	<p><b>Reference Number:</b> NIC-737333-K2F1T-v1.3</p> <p><b>Applicant and Data Controller:</b> Queen Mary University of London</p> <p><b>Application Title:</b> “Investigating the impact of London’s Ultra Low Emission Zone on children’s respiratory health: evidence from NHS health records CHILL-HR: Children’s Health in London and Luton: Health Records Study. NIHR Public Health Research Programme, Project Reference Number: 16/139/01”</p> <p><b>Previous Reviews:</b> The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 12<sup>th</sup> December 2024.</p>	

	<p>The SIRO approval was for an amendment to add to Medicines dispensed in Primary Care (NHSBSA data) data.</p> <p><b>Outcome of discussion:</b> AGD noted that the NHS England SIRO had already provided SIRO approval and confirmed that they were supportive of this.</p> <p>AGD thanked NHS England for the written update and made the following observations on the documentation provided:</p> <p><b>7.1.1</b> AGD suggested that the rationale/evidence for concluding that the addition of the NHSBSA dataset was in line with the consent was more clearly documented.</p> <p><b>7.1.2</b> AGD noted and commended the applicant on the ongoing communication with the cohort.</p> <p>The NHS England SIRO representative thanked AGD for their time.</p>	
<b>7.2</b>	<p><b>Reference Number:</b> NIC-15625-T8K6L-v14.2</p> <p><b>Applicant:</b> Medicines and Healthcare Products Regulatory Agency (MHRA) (Clinical Practice Research Datalink (CPRD))</p> <p><b>Data Controller:</b> Department of Health and Social Care</p> <p><b>Application Title:</b> “R23 - Clinical Practice Research Datalink (CPRD) Routine Linkages Application”</p> <p><b>Previous Reviews:</b> The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 20<sup>th</sup> May 2025, 13<sup>th</sup> March 2025 and the 14<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, 10<sup>th</sup> November 2022, 27<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 2019 and the 20<sup>th</sup> September 2018.</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) on the 27<sup>th</sup> July 2017, 22<sup>nd</sup> June 2017 and the 24<sup>th</sup> January 2017.</p> <p>The SIRO approval was for a number of amendments to the application, including, but not limited to, an update to the special conditions in section 6 (Special Conditions); and the ability for CPRD to provide NHS England data to third parties for the purpose of clinical trials.</p> <p><b>Outcome of discussion:</b> AGD noted that the NHS England SIRO had already provided SIRO approval and confirmed that they were supportive of this.</p> <p>AGD thanked NHS England for the written update and made the following observations on the documentation provided:</p>	

	<p><b>7.2.1</b> Prior to the meeting, a number of points had been raised by an AGD independent member with the NHS England SIRO Representative, in respect of <b>1)</b> whether the long and complex special conditions in section 6 may be overlooked in this lengthy data sharing agreement; <b>2)</b> the reference in section 5(a) (Objective for Processing) 2024 patient and public involvement and engagement (PPIE) meeting, which needs updating / removing; <b>3)</b> the reference in section 5(b) (Processing Activities) to the “ICO Code on Anonymisation” which needs updating; and <b>4)</b> section 5(e) (Is the Purpose of this Application in Anyway Commercial) that states there are no commercial aspects to the application, that needs reviewing / updating.</p> <p><b>7.2.2</b> In addition, the AGD independent member noted that national data opt out (NDO) and Type 1 objections are applied, however, noted that the Health Research Authority Confidentiality Advisory Group (HRA CAG) register states, “<i>The CAG requested that the website should clearly describe the study specific Opt-Out process and make it easily accessible to patients</i>”. A query was raised as to whether this was an error and whether HRA CAG have agreed a study specific opt-out is not needed.</p> <p><b>7.2.3</b> AGD queried whether restricting data access to a Trusted Research Environment (TRE) had been considered for this application to avoid onward disseminations.</p> <p>The NHS England SIRO representative thanked AGD for their time.</p>	
<b>8 OVERSIGHT AND ASSURANCE</b>		
<i>There were no items discussed</i>		
<b>9 AGD OPERATIONS</b>		
<b>9.1</b>	<p><b>Risk Management Framework</b></p> <p>AGD has been previously informed that a risk management framework is being developed by Data Access and had commented on early thinking about such a Framework. Nonetheless, presently AGD were still operating using the precedent and standard framework as an interim arrangement since February 2023 and AGD were concerned that the permanent Risk Management Framework was not in place. The Group discussed the NHS England corporate risk management framework (see minutes of 14<sup>th</sup> November 2024) and the AGD Chair subsequently formally asked via email if the NHS England corporate risk management framework could be used. The NHS England SIRO Representative updated the Group that NHS England was still considering the request, including how the NHS England corporate risk management framework could be adapted for AGD.</p> <p><b>ACTION:</b> The NHS England SIRO Representative to provide a written response to AGD on the progress, and expected time frame for implementation, of the risk management framework.</p>	SIRO Rep
<b>9.2</b>	<p><b>Standard Operating Procedures (SOPs)</b></p> <p>The Group noted that the ‘AGD member Declaration of Interest’ SOP was in the process of being finalised and published on the AGD webpage.</p>	



	<p>AGD queried if the review of the AGD Terms of Reference, forwarded to the Director of Privacy and Information Governance on the 14<sup>th</sup> March 2025 had been considered and asked that an update be provided as to next steps.</p> <p><b>ACTION:</b> NHS England SIRO Representative to update the Group at a future AGD Meeting.</p>	SIRO Rep
9.3	<p><b>AGD Stakeholder Engagement</b></p> <p><b>Federated Data Platform</b></p> <p>A brief update was given by the Group’s Representative on the Federated Data Platform Data Governance Group.</p>	
9.4	<p><b>AGD Project Work</b></p> <p><i>There were no items discussed</i></p>	
10 Any Other Business		
10.1	<p><b>Foresight AI Project (Update from Michael Chapman)</b></p> <p>Following the update at the AGD meeting on the 15<sup>th</sup> May 2025, the AGD NHS England Data and Analytics Representative provided a further update on the Foresight AI Project.</p> <p>The Group were advised that, since the last update, the Joint GP IT Committee have raised concerns with NHS England about the inclusion of GP data in the Foresight model.</p> <p>Following a request from the Joint GP IT Committee, NHS England have paused the Foresight AI Project and NHS England's Data Protection Office (DPO) is conducting a review in relation to the data sharing within the SDE. NHS England have welcomed the Joint GP IT Committee's feedback, and are committed to working with them to improve the approach to, and visibility of, such projects in future.</p> <p>The Foresight project is part of a broader research programme - COVID-IMPACT-UK - which accesses data in NHS England's Secure Data Environment under data sharing agreement NIC-381078-Y9C5K-v11.3. NHS England had already informed the research team that no new projects may be initiated under this agreement. A final set of projects was already in review by the COVID-IMPACT-UK consortium. NHS England will bring details of the these to AGD for advice at the AGD meeting on the 12<sup>th</sup> June 2025.</p> <p>The Group noted and thanked the AGD NHS England Data and Analytics Representative for the update.</p>	
10.2	<p><b>AGD Recruitment (update from Garry Coleman)</b></p> <p>The NHS England SIRO Representative advised the Group that interviews for the Chair, Researcher / Academic and Clinician posts had been completed and that candidates had been advised of the outcome of those interviews.</p> <p>The NHS England SIRO Representative advised that further information would be shared with the Group at a future AGD meeting.</p>	
Meeting Closure		

As there was no further business raised, the Chair of meeting thanked attendees for their time and closed the meeting.