

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

Thursday, 9<sup>th</sup> November 2023

09:30 – 15:15

*(In-person at Wellington Place, Leeds & via videoconference)*

<b>INDEPENDENT ADVISERS IN ATTENDANCE:</b>	
<b>Name:</b>	<b>Role:</b>
Paul Affleck (PA)	Specialist Ethics Adviser
Claire Delaney-Pope (CDP)	Specialist Information Governance Adviser
Prof. Nicola Fear (NF)	Specialist Academic Adviser (not in attendance for item 10)
Kirsty Irvine (KI)	Chair
Dr. Imran Khan (IK)	Specialist GP Adviser
Dr. Geoffrey Schrecker (GS)	Specialist GP Adviser
Dr. Maurice Smith (MS)	Specialist GP Adviser
Jenny Westaway (JW)	Lay Adviser
Miranda Winram (MW)	Lay Adviser
<b>NHS ENGLAND STAFF IN ATTENDANCE:</b>	
<b>Name:</b>	<b>Role / Area:</b>
Michael Chapman (MC)	Data and Analytics representative (not in attendance for part of item 10)
Garry Coleman (GC)	NHS England SIRO Representative (not in attendance for item 9.1)
Duncan Easton (DE)	Assurance Team, Data Access Request Service (DARS) ( <b>Observer:</b> items 4.1 to 5.2)
David Fitzgerald (DF)	Project Sponsor & Cancer Programme Director ( <b>Presenter:</b> 4.4)
Kate Fleming (KF)	NHS England Data & Analytics Representative (Delegate for Michael Chapman) (Item 10 only)
Charlotte Graham (CG)	CADEAS Lead Analyst, Cancer Alliance Data, Evidence & Analysis Service, NHS Cancer Programme ( <b>Presenter:</b> 4.4)

Dickie Langley (DL)	Assistant Director of Information Governance (Digital Operations), Privacy, Transparency and Trust (PTT) Delivery Directorate, ( <b>Presenter:</b> item 9)
Andrew Martin (AM)	NHS England Data Protection Office Representative (Delegate for Jon Moore)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT)
Jonathan Osborn (JO)	NHS England Caldicott Guardian Team Representative
Frances Perry (FP)	Applications Team, Data Access Request Service (DARS) ( <b>Observer:</b> item 5.2)
Denise Pine (DP)	Applications Team, Data Access Request Service (DARS) ( <b>Observer:</b> 5.1)
Emma Whale (EW)	Applications Teams, Data Access Request Service (DARS) ( <b>Observer:</b> item 5.1)
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT)
Tom Wright (TW)	Assurance Lead, Data Governance and Assurance, Data Access and Partnership Directorate ( <b>Observer:</b> item 4.1) ( <b>Presenter:</b> item 4.3)
<b>INDEPENDENT ADVISERS NOT IN ATTENDANCE:</b>	
Dr. Robert French (RF)	Specialist Academic / Statistician Adviser
<b>NHS ENGLAND STAFF NOT IN ATTENDANCE:</b>	
Jon Moore (JM)	NHS England Data Protection Office Representative

<b>1</b>	<p><b>Welcome and Introductions</b></p> <p>The NHS England Senior Information Risk Owner (SIRO) Representative, noting the Advisory Group for Data (AGD) Terms of Reference (ToR) had not yet been agreed, proposed that:</p> <ul style="list-style-type: none"> <li>• Kirsty Irvine (as an independent adviser) will be asked to Chair the AGD meetings;</li> <li>• The meeting will be minuted, with advice and minutes published;</li> <li>• Attendees will include both independent advisers from outside NHS England and representatives from within NHS England. Attendees from NHS England include representatives covering the offices of the Data Protection Officer (DPO); the Caldicott Guardian; Data and Analytics; and the SIRO.</li> </ul>
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	<ul style="list-style-type: none"> <li>Attendees would not be listed as “members” in minutes during the transitional period;</li> <li>NHS England representatives would not, during the transitional period, be formally part of any consensus that is reached, but would be active participants in the meeting;</li> <li>It was agreed to use the Data Access Request Service (DARS) Standards / Precedents in relation to applications for external data sharing.</li> </ul> <p>The attendees present at the meeting considered the proposal put forward by the NHS England SIRO Representative and, as no objections were raised, it was agreed that the meeting would proceed on this basis.</p> <p>Kirsty Irvine noted and accepted the request from the NHS England SIRO Representative to chair; and welcomed attendees to the meeting.</p>
<b>2</b>	<p><b>Review of previous AGD minutes:</b></p> <p>The minutes of the 2<sup>nd</sup> November 2023 AGD meeting were reviewed out of committee and subject to a number of amendments were agreed as an accurate record of the meeting.</p>
<b>3</b>	<p><b>Declaration of interests:</b></p> <p>Miranda Winram noted a personal connection to the cohort study in NIC-389134-S8L1C (University of Oxford). It was agreed that Miranda would remain in the room, but would not be part of the discussion of this application.</p> <p>Prof. Nicola Fear noted a personal and professional link to the applicant and Principal Investigator of NIC-389134-S8L1C (University of Oxford) as part of her role at King’s College London. It was agreed that Prof. Fear would remain in the room, but would not be part of the discussion of this application.</p> <p>Prof. Nicola Fear noted a professional link to NIC-604847-S4B5L Grail Bio UK Ltd as part of her role at King’s College London, but no specific connection with the application or staff involved. It was agreed this did not preclude Prof. Fear from taking part in the discussion about this application.</p> <p>Dr. Maurice Smith noted professional links to AIMES Management Service (NIC-604847-S4B5L Grail Bio UK Ltd) but no specific connection with the application or staff involved. It was agreed this did not preclude Dr. Smith from taking part in the discussion about this application.</p> <p>Dr. Imran Khan noted that he had previously been consulted on the National Obesity Audit and Directions in his role as Deputy Chair of the Health Informatics Group RCGP. It was agreed this did not preclude Dr. Khan from taking part in the discussion about this application.</p> <p>Claire Delaney-Pope noted a professional link to King’s College London (NIC-604847-S4B5L Grail Bio UK Ltd) as part of her role at South London and Maudsley NHS Foundation Trust. It was agreed this did not preclude Claire from taking part in the discussion on this application.</p>

	Michael Chapman noted a professional link to the study in NIC-604847-S4B5L (Grail Bio UK Ltd) as a member of the Trial Steering Group. It was agreed that Michael would remain in the room, but would not be part of the discussion of this application.
<b>BRIEFING PAPER(S):</b>	
<b>4.1</b>	<p><b>Title:</b> NHS Wayfinder Services Direction</p> <p><b>Assurance Team Observer:</b> Duncan Easton</p> <p><b>Observer:</b> Tom Wright</p> <p><b>Previous Reviews:</b> The draft Direction was previously presented / discussed at the AGD meeting on the 25<sup>th</sup> May 2023.</p> <p>The purpose of the Direction is to require NHS England to develop and operate the NHS Wayfinder programme and related services (collectively the NHS Wayfinder Services). These services will enable patients in England to access details of appointments and additional information about NHS Trust referrals and their elective care via the NHS App. They will also generate anonymous statistical data which may be used by NHSE to better understand health issues and challenges, and to support strategies which may improve health outcomes for the population and reduce inequalities in health.</p> <p>These Directions will replace the Wayfinder (NHS App) Services Directions 2022 issued by NHS England to NHS Digital.</p> <p><b>Outcome of discussion:</b> The group welcomed the updated briefing paper addressing the points raised on the 25<sup>th</sup> May 2023, and made the following observations / comments:</p> <p><b>4.1.1</b> Noting that the transparency point raised at the 25<sup>th</sup> May 2023 meeting (4.3.1) had not been sufficiently addressed; they reiterated the point that there were concerns on providing information for NHS app users (not just the readers of the briefing paper) about how data will be used both for their appointments and to manage the health service. The independent advisers suggested that the purpose was clarified as primarily for direct care, but also specific secondary care uses, so patients can understand what is happening with data.</p> <p><b>4.1.2</b> The independent advisers advised that all the pertinent information needed to be easily accessible on the NHS app.</p> <p><b>4.1.3</b> The group noted the content of the draft privacy notice provided as a supporting document and suggested that this was updated further, including, but not limited to, ensuring that acronyms be correctly defined upon first use; to ensure that statistical terms of art or technical terms were used only where necessary and explained in a manner suitable for a lay audience; and that the correct contact point for participants was referenced.</p> <p><b>4.1.4</b> The independent advisers queried the reference to Article 6(1)(a) of UK General Data Protection Regulation (UK GDPR) in the draft privacy notice; and were advised by the Data Protection Office Representative that this should be updated to make clear that this legal basis was for the purpose of delivering cookies only. The group were not supportive of any further / other use of Article 6(1)(a), other than for the purpose of delivering cookies.</p>

	<p><b>4.1.5</b> The independent advisers queried whether the data collected was just relating to the users of the NHS app, or whether there was a wider collection of data; and suggested that this was made clear within the briefing paper / transparency materials.</p> <p><b>4.1.6</b> The group looked forward to receiving the finalised briefing paper, either out of committee (OOC) or tabled at a future meeting.</p>
<b>4.2</b>	<p><b>Title:</b> Wayfinder internal transfer and use by NHS England Briefing Paper</p> <p>The item was withdrawn by NHS England.</p>
<b>4.3</b>	<p><b>Title:</b> National Obesity Audit internal transfer and use by NHS England</p> <p><b>Presenter:</b> Tom Wright</p> <p><b>Assurance Team Observer:</b> Duncan Easton</p> <p><b>Previous Reviews:</b> The National Obesity Audit Directions 2023 including new use of Cardiovascular Disease Prevention (CVDP) audit was previously presented / discussed at the AGD meeting on the 25<sup>th</sup> May 2023, 18<sup>th</sup> May 2023 and the 20<sup>th</sup> April 2023. It was also previously discussed at the IGARD BAU Meeting on the 10<sup>th</sup> December 2020; and at the COVID-19 Response Meeting on the 8<sup>th</sup> December 2020.</p> <p>The purpose of the briefing paper was to inform AGD that the <a href="#">National Obesity Audit Directions 2023</a>, will permit NHS England to collect certain data items from the Cardiovascular Disease Prevention (CVDP) data flow for these new NOA purposes, creating a separate NOA CVDP Asset. Therefore whilst there is one practical flow from GP systems the National Obesity Audit (NOA) will provide a new legal basis for collection of these data items, which also permits analysis and linkage of data named below for NOA purposes.</p> <p>The NOA cohort/asset will not collect any new data but make use of data collected through other data assets. For each data source NHS England will also access all relevant and available historical data.</p> <p>NHS England were seeking advice on the following points:</p> <ol style="list-style-type: none"> <li>1. The transfer to, and use of, NOA data by NHS England.</li> </ol> <p><b>Outcome of discussion:</b> The group welcomed the briefing paper and made the following observations / comments:</p> <p>In response to point 1 above:</p> <p><b>4.3.1</b> NHS England advised the group that following submission of the paper for review, the <a href="#">National Obesity Audit Directions 2023</a> had been published.</p> <p><b>4.3.2</b> NHS England noted that as part of this package of work, they would be seeking advice on a class action application. A class action application template had been provided to the group as part of the meeting pack, but it was agreed that the use of the data would instead be discussed at a future AGD meeting (as per 4.3.9 below).</p> <p><b>4.3.3</b> The independent advisers queried the information within the transparency materials, that seemed to imply that the National Data Opt-out (NDO) would be applied, however, noting</p>

	<p>that the data would be pseudonymised, it was suggested that the transparency materials were updated to be clear that the NDO would <b>not</b> be applied.</p> <p><b>4.3.4</b> The independent advisers noted that the transparency materials implied that anyone who had submitted a Type 1 Opt-out would not have their data shared with NHS England for this collection; and suggested that this was reviewed and updated as may be necessary, noting that their data may be collected via another method other than via their GP.</p> <p><b>4.3.5</b> The independent advisers queried the statement that the NAO audit would be made up of <i>“Anyone in the agreed GP data set (CVDPREVENT Audit) with a BMI or BMI/weight and height/ centile recorded or who have been referred to a weight management service or attended a weight management intervention...”</i>; and suggested that the briefing paper was updated to clarify whether those whose BMI was classed as healthy (under 25) and those who were classed as underweight according to their BMI would also form part of the data flow; or whether it was only overweight and obese individuals living with overweight and obesity (BMI 25 and over), and if so to clarify what data was being collected from the CVDPREVENT audit and update the transparency materials to make this explicitly clear.</p> <p><b>4.3.6</b> The independent advisers noted the statement in the published <a href="#">privacy notice</a> that <i>“We treat the data we hold with great care”</i>; and suggested that for further transparency to the cohort, this was updated to also reflect that NHS England have a <i>“legal obligation”</i> to treat the data they hold with care, or similar.</p> <p><b>4.3.7</b> Noting the references to <i>“Clinical Commissioning Groups”</i> in the class action template, the independent advisers suggested that these references were removed or updated as may be necessary to refer to <i>“Integrated Care Boards”</i>.</p> <p><b>4.3.8 Separate to this briefing paper:</b> it was suggested by the group that there were further discussions at a future AGD in respect of Integrated Care Board’s (ICBs) transparency and how this aligned with NHS England’s transparency.</p> <p><b>4.3.9</b> The group advised that they would only be supportive of a class action template, once the points above had been adequately addressed. The SIRO representative noted the feedback from the group and advised that the points raised would need to be addressed prior to any data flowing.</p> <p><b>4.3.10</b> The group looked forward to receiving the finalised briefing paper, either out of committee (OOC) or tabled at a future meeting.</p>
<p><b>4.4</b></p>	<p><b>Title:</b> Cancer Programme Pilots Evaluation Directions 2023 Briefing Paper</p> <p><b>Presenters:</b> Charlotte Graham, David Fitzgerald</p> <p><b>Assurance Team Observer:</b> Duncan Easton</p> <p>The purpose of the briefing paper was to inform AGD that the Cancer Programme is requesting a Direction to cover establishing and operating a system for collecting, linking and analysing information from Cancer Programme pilots. It is anticipated that there will be</p>



multiple data collections (one for each pilot) within the scope of these Directions. Each collection will have a requirements specification published alongside these Directions.

There are two initial specifications being drafted for these Directions, these cover the data collection for **1) The Targeted Lung Health Check Pilot Evaluation**; and **2) The Community Pharmacy Pilot Evaluation**.

NHS England were seeking advice on the following points:

1. Does the processing raise any risks for NHS England which have not been adequately addressed within the documents provided?
2. Do you feel that patient transparency has been adequately addressed in relation to Targeted Lung Health Check Pilot?
3. Are there any elements of the proposed data collection or processing which the group feel may result in harm to patients?

**Outcome of discussion:** The group welcomed the briefing paper and confirmed they had no comments / observations to make on the briefing paper provided. The briefing paper was therefore finalised as an artefact to be included as a supporting document, as and when required: The group provided the following observations / comments, separate to the briefing paper:

In response to point 1 above:

**4.4.1** The group noted that they were very supportive and noted the importance of the programme of work outlined in the briefing paper.

**4.4.2** The group noted the (draft) Cancer Programme Pilots Evaluation Directions 2023 provide a legal basis for the collection of data outlined in the briefing paper.

In response to point 2 above:

**4.4.3** The independent advisers noted that there was an opportunity for the cohort to be provided with a hard copy of transparency materials when attending a health check; in addition to this information also being available online.

**4.4.4** The independent advisers noted the content of the draft privacy notice provided as a supporting document, and suggested that this could be updated further, in line with the (draft) Cancer Programme Pilots Evaluation Directions 2023, to include a clearer description of the community pharmacy pilot, in language suitable for a lay reader.

**4.4.5** The independent advisers queried if the National Cancer Registration and Analysis Service (NCRAS) specific opt-out would be applied to the datasets; and suggested that this was made clear within the relevant briefing paper and transparency materials.

**4.4.6** The group noted that access to the data would be via NHS England's [Data Access Request Service](#) and it is expected that this access would be via a Secure Data Environment (SDE); and suggested that this was reflected in the transparent materials in a consistent manner.

In response to point 3 above:

	<p><b>4.4.7</b> The group advised that data linkage was key in checking the efficacy of the programme and early detection of cancer.</p> <p><b>4.4.8</b> The group noted the importance of being transparent with the cohort in respect of the early detection of lung cancer as part of the lung health checks.</p> <p><b>4.4.9</b> Some of the group did not support the use of the (draft) Cancer Programme Pilots Evaluation Directions as a legal basis because it appeared that the possibility of taking consent for data linkage, which would be preferable in terms of patient autonomy, had not been adequately considered (and consent was already being taken for some of the evaluation work). Also, whether other routes, such as Section 251 of the NHS Act 2006, should be explored that would mean the application of the NDO</p> <p><b>4.4.10 Separate to this briefing paper:</b> Notwithstanding that NHS England had a legal basis to collect the data via the (draft) Cancer Programme Pilots Evaluation Directions 2023, the group were concerned about the Direction approach and suggested that the SIRO representative raise this concern with NHS England's Information Governance team, as to whether a Direction was the most appropriate legal basis for this / other similar types of processing; or, would an alternative be more suitable, for example, consent or s251 in terms of giving maximum patient autonomy, and of maintaining public trust.</p> <p><b>4.4.11</b> The group looked forward to receiving an update on the relevant points noted above in due course.</p>
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#### EXTERNAL DATA DISSEMINATION REQUESTS:

5.1	<p><b>Reference Number:</b> NIC-389134-S8L1C-v15.7</p> <p><b>Applicant:</b> University of Oxford</p> <p><b>Application Title:</b> The Million Women Study</p> <p><b>SAT Observer:</b> Duncan Easton</p> <p><b>Observers:</b> Denise Pine, Emma Whale</p> <p><b>Previous Reviews:</b> The application and relevant supporting documents were previously presented / discussed at the IGARD meetings on the 11<sup>th</sup> February 2021 and the 7<sup>th</sup> June 2018.</p> <p>The application and relevant supporting documents were previously presented / discussed at the DAAG meetings on the 19<sup>th</sup> January 2016 and the 12<sup>th</sup> January 2016.</p> <p><b>Application:</b> This was an extension, renewal and amendment application.</p> <p>The purpose of the application is for a study, with the primary aim of investigating common, largely modifiable, risk factors for serious and common diseases in women.</p> <p>The amendments are <b>1)</b> the addition of mental health data sets; and <b>2)</b> the incorporation of worldwide sub-licencing.</p>	
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Should an application be approved by NHS England, further details would be made available within the [Data Uses Register](#).

**Outcome of discussion:** The group were supportive of the extension and renewal of the application; but were **not** supportive of the amendments until the following substantive comments were addressed, and wished to draw to the attention of the SIRO the following substantive points:

**5.1.1** The independent advisers queried whether there was sufficient transparency to the cohort for the proposed amendments to the processing, in particular for sublicensing. Noting that a newsletter mentioning sublicensing had been created for the cohort, the independent advisers advised that it was unclear on the reach of this newsletter and advised that this should be clarified by the applicant, for example if it was circulated by email or post (to how many participants?) or via collection points.

**5.1.2** In addition, it was suggested by the independent advisers that a communication plan was produced by the applicant, to illustrate how they were communicating with the cohort about the sublicensing development, with clear timescales of what will be done, and when; and that a copy be provided and uploaded to NHS England's customer relationships management (CRM) system

**5.1.3** The independent advisers also suggested that the applicant take proactive steps, such as engaging with the Participant Panel, to check their understanding of the amendments to the proposed processing, including, but not limited to, potential commercial sublicensees.

**5.1.4** The independent advisers queried the information in some of the supporting documents provided, including the primary study questionnaire (SD3), that states the information provided from the questionnaire will be treated “...with *absolute confidentiality and used for medical research only*...” and follow-up questionnaires SD3.2 and SD3.3 that state “...no personal details will be passed on to any commercial organisation.”; and queried whether this was compatible with the proposed worldwide sub-licencing, including potential commercial recipients of personal data.

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

**5.1.5** Noting the information in section 5(a) (Objective for Processing) in respect of sub-licensing, the independent advisers suggested that this was updated to ensure it aligned with the advice from NHS England's Privacy, Trust and Transparency (formally Privacy, Transparency, Ethics and Legal (PTEL)) and that this links to the UK General Data Protection Regulation (UK GDPR).

**5.1.6** It was also suggested that the reference to “*America*” in the sub-licensing information in section 5(a) was updated to refer to the “*United States of America*”.

**5.1.7** The independent advisers suggested that special conditions were added to section 6 (Special Conditions) in line with [NHS England's DARS Standard for](#)

[Special Conditions](#) and section 10 (Sub-licensing) in line with [NHS Digital DARS Standard for Sub-licencing and Onward Sharing of Data](#), to clearly outline the countries that the worldwide sub-licensing could take place in.

**5.1.8** The independent advisers queried the statement in section 3.2 of the internal application assessment form, where it stated that the applicant would negotiate contracts with third party researchers to allow linkage to other cohorts where “CAG approval is in place for this linkage”; and suggested that this was reviewed and updated as may be necessary, noting it was unclear which flows of data it related to.

**5.1.9** Noting that the follow-up period for some of the cohort would be 27 years, the independent advisers suggested that the applicant engage with the Participant Panel, to determine whether the cohort may be surprised at the length of the follow-up.

**5.1.10** The independent advisers noted in the internal application assessment form, that approximately 3,000 participants have lost mental capacity, and that the study had not been able to obtain a consultee for 2,500 these participants, and that the study had been advised by their sponsor that they can only obtain data up to the date they lost mental capacity for the participants who do not have a consultee. The independent advisers noted the potential loss of a number of valuable cohort members; and advised that it was their view that this data **could** flow without the need for a consultee to become involved, noting consent had been provided by participants before they lost mental capacity. Also, if it is judged consent ended when the person lost capacity there is no consent to flow any data for that person, including data for the period before they lost capacity. It was acknowledged that consent, capacity, and long-term research is an area under discussion as covered by a recent Health Research Authority blog: <https://www.hra.nhs.uk/about-us/news-updates/blog-consent-capacity-and-long-term-research/>

**5.1.11** The independent advisers noted the statement in section 3(c) (Patient Objections) that “*The national data opt-out will apply where participants have lost the mental capacity to consent and where the University of Oxford is relying on the Consultee to permit the flow of confidential data*”; and suggested that this was reviewed, for example, in respect of the logic for relying on consultees, noting that the scope of the processing should be within the bounds of the original consent provided by the participant.

**5.1.12** The independent advisers queried if the National Cancer Registration and Analysis Service (NCRAS) specific opt-out would be applied to the datasets; and suggested that this was made clear within section 3(c) and / or section 5 (Purpose / Methods / Outputs) of the application.

**5.1.13** Noting the reference in section 5(a) to linkage of the data to Clinical Practice Research Datalink (CPRD), it was suggested by the independent advisers that this was updated to clarify the legal basis to undertake this, and to clarify whether it aligned with the original consent provided.

	<p><b>5.1.14</b> The independent advisers noted the information / process in section 5(a) for the “<i>visiting collaborators</i>”, in that they would be given access to the data under “a <i>standard Collaborative Agreements</i>”; and suggested that this was reviewed, for example, should this access be given via an honorary contract, appropriately countersigned by the collaborators home institution. In addition, it was queried whether there were any data controllership implications from such collaboration, and that this was reviewed in line with <a href="#">NHS England’s DARS Standard for Data Controllers</a>.</p> <p><b>5.1.15</b> The group commended the applicant on the excellent yielded benefits and suggested this be used by NHS England as an exemplar.</p>	
<b>5.2</b>	<p><b>Reference Number:</b> NIC-604847-S4B5L-v5.2</p> <p><b>Applicant:</b> Grail Bio UK Ltd</p> <p><b>Application Title:</b> NHS Galleri Clinical Trial Outcomes Data Request</p> <p><b>Assurance Team Observer:</b> Duncan Easton</p> <p><b>Observer:</b> Frances Perry</p> <p><b>Previous Reviews:</b> The application and relevant supporting documents were previously presented / discussed at the IGARD meetings on the 18<sup>th</sup> August 2022, 19<sup>th</sup> May 2022, 10<sup>th</sup> February 2022, 13<sup>th</sup> January 2022, 16<sup>th</sup> December 2021 and the 25<sup>th</sup> November 2021.</p> <p><b>Linked applications:</b> This application is linked to NIC-604851-W0M3S, NIC-661736-Y2Q9R, NIC-456778-J0G3H and NIC-651660-J5T6C.</p> <p><b>Application:</b> This was an amendment application.</p> <p>The amendments are for the following additions <b>1)</b> the ‘REFERRAL_ASSESSMENT_DATE’ field to the ECDS dataset; <b>2)</b> five data fields relating to Faster Diagnosis Standard data which has been added to the NDRS Linked Cancer Waiting Times data; <b>3)</b> Queen Mary, University of London (QMUL) as a Data Processor; <b>4)</b> a Secondary Objective Analysis of NDRS data.</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 supportive of the amendments, and wished to draw to the attention of the SIRO the following comments:</p> <p><b>5.2.1</b> The group noted that due to time restrictions in the meeting, the feedback was restricted to high-level points only and they were not providing comments on the application and / or supporting documents.</p> <p><b>5.2.2</b> The group noted that the Annual Confirmation Report had <b>not</b> been completed correctly including, but not limited to, the section of progress toward achieving outputs and benefits and suggested this was remedied as a matter of urgency.</p>	

	<p><b>5.2.3</b> The independent advisers queried the role of the Data Processors, and whether any of them should be considered Data Controllers, for example, noting that one of the Data Processors appeared to be directing a Data Controller. It was suggested that this was reviewed in line with <a href="#">NHS England's DARS Standard for Data Controllers</a>, and the application was updated as may be appropriate.</p>	
<b>AGD Operations</b>		
<b>6</b>	<p><b>Statutory Guidance</b></p> <p>The independent advisers again noted the reference to reviewing materials in accordance with “<i>a clearly understood risk management framework</i>” within the published <a href="#">Statutory Guidance</a> and advised that they were <b>not</b> aware of an agreed risk management framework, and requested that NHS England provide further information/ clarity on this, noting this topic had been raised by Lord Hunt in the House of Lords on the 26<sup>th</sup> June 2023, and was answered by Lord Markham on the 5<sup>th</sup> July 2023: <a href="#">Written questions, answers and statements – UK Parliament</a>.</p> <p>The NHS England SIRO Representative had provided further clarity on the risk management framework via email to the group, which confirmed that NHS England were asking the interim data advisory group to use the NHS England DARS Standards and Precedents model to assess the risk factors in relation to items presented to the interim data advisory group for advice; however the independent advisers noted that the wording in the in the statutory guidance “...<i>using a clearly understood risk management framework, precedent approaches and standards that requests must meet...</i>”, suggested that the risk management framework is <b>separate</b> to the DARS Standards and Precedents, and asked that this be clarified by NHS England.</p> <p>It had been noted previously that an Oversight and Assurance Programme of applications that had not be subject to AGD review could form part of this Risk Management Framework.</p> <p><b>ACTION:</b> NHS England SIRO representative to provide a written response addressed to AGD with further clarity on the risk management framework.</p>	GC
<b>7</b>	<p><b>AGD Terms of Reference (ToR)</b></p> <p>The independent advisers noted that over five months had passed since the <a href="#">Statutory Guidance</a> had been published, requiring a ToR to be agreed and published, and queried whether there was any further update on the progress of the AGD ToR.</p> <p>The SIRO representative noted that NHS England were still considering comments from stakeholders on the AGD ToR.</p> <p><b>ACTION:</b> The NHS England SIRO representative noted a previous action to clarify when a revised draft of the AGD ToR would be presented to AGD and when the</p>	GC

	AGD ToR was scheduled to be considered by the NHS England Board / subcommittee of the Board.	
<b>8</b>	<b>Standard operating procedures</b> The ongoing forward plan of work for creating Standard Operating Procedures was discussed and noted that this could not progress further without sight of the final ToR.	To note
<b>Any Other Business</b>		
<b>9.1</b>	<b>Federated Data Platform (FDP) Information Governance (IG) Group</b> <p>Dickie Langley attended the meeting, to provide a brief update to the group on the FDP IG Group, which currently includes representation from the National Data Guardian (NDG), Information Commissioner's Office (ICO), Health Research Authority (HRA), Faculty of Clinical Informatics (FCI) and AGD.</p> <p>Dickie advised the group on the ongoing work of the FDP IG Group, which meets approximately once a month; and noted that the next meeting of this group was the week commencing the 13<sup>th</sup> November 2023, where the draft IG framework for FDP would be discussed.</p> <p>Dickie advised that further information in respect of the FDP and the FDP IG Group would be provided to the group in due course.</p>	
<b>9.2</b>	<b>OpenSAFELY</b> <p>Dickie Langley attended the meeting, to provide a brief update to the group on OpenSAFELY, and advised that an announcement was expected in the coming weeks, in respect of the contract.</p> <p>Dickie also advised that work had <b>not</b> yet started on expansion of OpenSAFELY beyond COVID-19 research, however, noted that it was hoped this work would be started within the coming months; and that any further updates would be provided in due course to the group.</p>	
<b>9.3</b>	<b>How to support large-scale consented cohort studies to get GP data</b> <p>Dickie Langley attended the meeting, to provide a brief update to the group on a high-priority request for a Direction, that enabled support for large-scale consented cohort studies; and advised that this was not limited to specific organisations.</p> <p>Dickie noted that there were discussions about the technology solution for this, and noted that there was also some consolidation work required; and that NHS England were looking at this.</p> <p>Dickie noted that a further update would be provided to the group in due course.</p>	

9.4	<p><b>Sub-national Secure Data Environments (for research)</b></p> <p>Dickie Langley attended the meeting, to provide a brief update to the group on Sub-national Secure Data Environments (for research) and the advice that they will be requesting national Hospital Episode Statistics (HES) data at some point in the near future. Dickie noted that this was a complex issue, noting, for example that one of the Sub-national Secure Data Environments (for research) has 880 Data Controllers providing data, some models are joint Data Controllers, some rely on s251 for linkages, and others rely on linkage of pseudonymised data via a “black-box” solution.</p> <p>Dickie noted that a further update would be provided to the group in due course.</p> <p>The group thanked Dickie for attending the meeting, and noted the content of the updates provided; and looked forward to receiving further updates on the topics discussed in due course.</p>
9.5	<p><b>Independent adviser recruitment / day rate</b></p> <p>The independent advisers noted that a number of recruitment / day rate issues remained outstanding following the move from the Independent Group Advising on the Release of Data (IGARD) (NHS Digital) to the interim data advisory group (NHS England); and wished to note to NHS England the frustration for current independent advisers; and that this may be a risk to NHS England for future recruitment to the independent adviser roles.</p> <p>The SIRO representative on behalf of NHS England, noted the concerns raised, and advised that work was ongoing and that an update would be provided as soon as possible.</p>
10	<p><b>Confidential AGD Workshop</b></p>
<p><b>Meeting Closure</b></p> <p>As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.</p>	