

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

Thursday, 23<sup>rd</sup> November 2023

09:30 – 15:15

*(Remote meeting via videoconference)*

<b>INDEPENDENT ADVISERS IN ATTENDANCE:</b>	
<b>Name:</b>	<b>Role:</b>
Paul Affleck (PA)	Specialist Ethics Adviser (Items 7 and 9.1)
Claire Delaney-Pope (CDP)	Specialist Information Governance Adviser
Dr. Robert French (RF)	Specialist Academic / Statistician Adviser
Kirsty Irvine (KI)	Chair
Dr. Imran Khan (IK)	Specialist GP Adviser (Items 7 and 9.1)
Dr. Geoffrey Schrecker (GS)	Specialist GP Adviser
Dr. Maurice Smith (MS)	Specialist GP Adviser (Items 7 and 9.1)
Jenny Westaway (JW)	Lay Adviser
<b>NHS ENGLAND STAFF IN ATTENDANCE:</b>	
<b>Name:</b>	<b>Role / Area:</b>
Laura Bellingham (LB)	Deputy Director, Data Access and Partnerships, Data and Analytics ( <b>Presenter:</b> Item 5)
Garry Coleman (GC)	NHS England SIRO Representative (not in attendance for item 5)
Mujiba Ejaz (ME)	Applications Team, Data & Analytics ( <b>Presenter:</b> item 9.2)
Dan Goodwin (DG)	Applications Team, Data & Analytics ( <b>Observer:</b> item 4.1)
Andrew Martin (AM)	NHS England Data Protection Office Representative (Delegate for Jon Moore)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Delivery Directorate
Jonathan Osborn (JO)	NHS England Caldicott Guardian Team Representative

Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Delivery Directorate
Tom Wright (TW)	Data and Analytics Representative (Delegate for Michael Chapman)
<b>INDEPENDENT ADVISERS NOT IN ATTENDANCE:</b>	
Prof. Nicola Fear (NF)	Specialist Academic Adviser
Miranda Winram (MW)	Lay Adviser
<b>NHS ENGLAND STAFF NOT IN ATTENDANCE:</b>	
Michael Chapman (MC)	NHS England Data and Analytics Representative
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> <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>	<b>Review of previous AGD minutes:</b>

	The minutes of the 16 <sup>th</sup> November 2023 AGD meeting were reviewed and subject to a number of minor amendments were agreed as an accurate record of the meeting.
3	<b>Declaration of interests:</b> There were no declarations of interest.
<b>EXTERNAL DATA DISSEMINATION REQUESTS:</b>	
4.1	<p><b>Reference Number:</b> NIC-148321-ZPHJ3-v2.8</p> <p><b>Applicant:</b> Liverpool University Hospitals NHS Foundation Trust</p> <p><b>Application Title:</b> Evaluation of ocular and systemic outcomes after treatment of ocular melanoma and other ocular tumours</p> <p><b>Observer:</b> Dan Goodwin</p> <p><b>Application:</b> This was a new application.</p> <p>The purpose of the application is to request death notification data, about patients with ocular cancers treated at Liverpool University Hospitals NHS Foundation Trust, in order, to examine local treatment outcomes, prognosis and mortality from the disease or other causes.</p> <p>The data will be used for evaluation of patient outcomes following proton beam radiotherapy (including vision, retention of the eye, and mortality) and ruthenium plaque brachytherapy. It will also evaluate the success and complications of conservative treatments of conjunctival tumours with topical chemotherapy vs more aggressive treatments such as brachytherapy. This will enable a more accurate process of patient counselling and management of patient expectation. The service will then be audited against current international benchmarks regarding mortality outcomes and eye and vision retention.</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 application and wished to draw to the attention of the SIRO the following substantive comments:</p> <p><b>4.1.1</b> The independent advisers noted that the Health Research Authority Confidentiality Advisory Group (HRA CAG) application and letter of support provided, stated that the application was for the purpose of “<i>audit</i>” and “<i>service evaluation</i>” and the processing described in that HRA CAG application did <b>not</b> fully align with the processing described in the application. For example, the statement in section 5(a) (Objective for Processing) “<i>It will also evaluate the success and complications of conservative treatments of conjunctival tumours with topical chemotherapy vs more aggressive treatments such as brachytherapy</i>”, was not reflected in the HRA CAG application and could be argued to be “<i>research</i>” as opposed to “<i>audit</i>” or “<i>service evaluation</i>”.</p>

**4.1.2** Noting there would be a separate application submitted for the purpose of “research” in the future the independent advisers suggested that this application was reviewed and updated as appropriate, to ensure that **all** references / statements referring to any “*research*” aspects of the application were removed and added to a future research application; thus ensuring that this application fully aligned with the HRA CAG application and letter of support; and that this application refers to only being for the purpose of “*audit*” and “*service evaluation*”.

**4.1.3** Noting in the internal application assessment form that pathology data would be stored at the University of Liverpool; it was suggested that NHS England explore this further with the applicant, to determine if they are considered a Data Processor in line with [NHS England’s DARS Standard for Data Processors](#); and that the internal application assessment form **and** application were updated as may be necessary.

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

**4.1.4** The independent advisers suggested that section 5(b) (Processing Activities) was updated to clarify the flow of identifiers between the University of Liverpool and Liverpool University Hospitals NHS Foundation Trust, as per the information provided in the internal application assessment form.

**4.1.5** The group commended the applicant on the excellent patient and public involvement and engagement (PPIE) as outlined in the application.

**4.1.6** The independent advisers noted that ‘consent’ has been discussed with HRA CAG for future research, service evaluation and audit; and suggested that this should be considered more acutely and robustly, noting the applicant was in contact with individuals who would form the future cohort. The independent advisers noted the applicant’s concerns that taking consent for use of mortality data might be upsetting, but observed that the cohort are already made aware (via the patient notification leaflet) that mortality data will be obtained.

**4.1.7** In addition, it was suggested that the applicant work with their PPIE channels to seek advice on a suitable future consent model.

**4.1.8** The independent advisers noted that the internal application assessment form and the application made references to NHS England being the funder; and suggested that this information was reviewed, and either removed if NHS England were not providing **specific** funding for this work; or if specific funding was being provided, that this was made clear within the internal application assessment form and the application for transparency.

**4.1.9** The group noted that the transparency information, including the patient notification leaflet, poster and online information were broadly satisfactory, however suggested that further improvements could be made, including, but not limited to, providing further clarification of the distinction between the project specific opt-out,

	<p>which is required to comply with the HRA CAG support; <b>and</b> the National Data Opt-out (NDO), which should be accessible via a weblink provided, and should be clearly distinguished from the project specific opt-out.</p> <p><b>4.1.10</b> It was also suggested by the group that section 5(b) of the application was updated to provide further clarification of the distinction between the project specific opt-out, <b>and</b> the NDO and to state that both would be applied to the cohort by the applicant before flowing data to NHS England.</p> <p><b>4.1.11</b> It was suggested by the Data Protection Office (DPO) representative that the applicant should aim to publish a study-specific privacy notice; and that the current online 'generic' privacy notice could be updated in the meantime with a link to the patient notification leaflet, for further transparency.</p> <p><b>4.1.12</b> The DPO representative noted the information in the internal application assessment form that the applicant was having issues providing evidence of the deletion of data held previously and suggested that NHS England should seek assurance from the applicant that they would be able to provide evidence of any deleted data going forward in line with relevant policies and processes.</p> <p><b>4.1.13</b> Noting the information in section 5(d) (Benefits) in respect of the generic information relating to "<i>services to clients</i>", the independent advisers suggested that this was removed, as it was not relevant.</p> <p><b>4.1.14</b> The independent advisers noted and supported the information in section 5(d) (iii) (Yielded Benefits) in respect of previous activities aligned with the purpose of this application, however suggested that this was updated to make it clear that this was <b>not</b> achieved with data flowing under this data sharing agreement (DSA).</p>	
5	<p><b>Data Access and Partnerships sub-directorate and Data and Analytics directorate update, and Precedents and Standards (Presenter: Laura Bellingham)</b></p> <p>Laura attended the meeting to provide the group with an update on some recent internal changes within Data Access and Partnerships sub-directorate, which is part of the wider Data and Analytics directorate; and to outline the roles and responsibilities of the work area.</p> <p>In addition, Laura provided a brief overview of advice that they would be seeking from the group over the coming months, including, but not limited to, a discussion on NHS England Precedents and Standards at the AGD meeting on the 30<sup>th</sup> November 2023. Laura also referred to the development of a Risk Management Framework (see Section 6 below).</p> <p>The group noted and thanked Laura for the updates provided, and it was agreed that in addition to the NHS England Precedents and Standards discussion at the AGD meeting on the 30<sup>th</sup> November 2023; the group would have the opportunity to ask</p>	

	further questions in respect of the internal changes within Data Access and Partnerships sub-directorate and Data and Analytics directorate.	
<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. Laura Bellingham attended the meeting and noted that plans for this work were in train (see section 5 above).</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 six months had passed since the <a href="#">Statutory Guidance</a> had been published, requiring a ToR to be agreed and published.</p> <p>Following the update by Jackie Gray, Director of Privacy, Transparency and Trust (PTT) (formally Privacy, Transparency, Ethics and Legal) at the AGD meeting on the 16<sup>th</sup> November 2023, it was noted that the group had received the updated draft ToR on Wednesday 22<sup>nd</sup> November 2023.</p> <p>Noting that a stakeholder workshop, that would include representatives from AGD and AGD Secretariat, would be taking place on Monday 27<sup>th</sup> November to discuss this document and any further suggested updates and amendments to the draft ToR,</p>	

	<p>the independent advisers discussed initial thoughts / feedback on the updated draft ToR received, to feed into the workshop.</p> <p>In addition, the group reiterated that they looked forward to further information on the timeline for progressing the ToR, including when this would be considered by the NHS England Board / subcommittee of the Board.</p> <p><b>ACTION:</b> The SIRO representative to provide further information to the group on the timeline for progressing the draft ToR, including when this would be considered by the NHS England Board / subcommittee of the Board, following the workshop on the 27<sup>th</sup> November 2023.</p>	GC
8	<p><b>Standard operating procedures</b></p> <p>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.</p>	To note
<b>Any Other Business</b>		
9.1	<p><b>Reviewing The Health Service (Control of Patient Information) Regulations 2002</b></p> <p>Following the discussion at the AGD meeting on the 16<sup>th</sup> November 2023, the independent advisers had a further discussion on the updated COPI proposal document, which had been initially shared with them on the 30<sup>th</sup> October 2023 for comments, from the Department of Health and Social Care (DHSC) in respect of the '<i>Responsible use of information to support the delivery of health and care: reviewing The Health Service (Control of Patient Information) Regulations 2002</i>'.</p> <p>It was noted that comments / feedback on this document would be shared with DHSC on the 24<sup>th</sup> November 2023 as requested; and that the Director of Privacy, Transparency and Trust (PTT) (formally Privacy, Transparency, Ethics and Legal) would be copied in for information.</p>	
9.2	<p><b>NIC-561357-X0F3N Evidera Ltd</b></p> <p>Mujiba Ejaz attended the meeting to provide the group with a verbal update on NIC-561357-X0F3N Evidera Ltd, that had been discussed at the AGD meeting on the 16<sup>th</sup> November 2023; where the group had <b>not</b> been supportive of the application, due to unresolved issues with transparency.</p> <p>The group were advised that further discussions had taken place following the meeting between NHS England and the applicant; and that the applicant had advised NHS England that a draft copy of their privacy notice would be shared with NHS England week commencing the 27<sup>th</sup> November 2023; with the expectation that this would be published by mid-January 2024. In addition, the SIRO representative noted that there would be a clause in the data sharing agreement (DSA) that the privacy notice would need to be published by mid-January 2024.</p>	

	<p>The group noted and thanked NHS England for the update, and advised that based on the verbal update, they would be supportive of a renewal <b>only</b>; and that they would expect a UK General Data Protection Regulation (UK GDPR) compliant, privacy notice to be published mid-January 2024, as advised.</p>
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	<p>The group commended the work that had been undertaken rapidly by NHS England to work with the applicant to address the advice given the previous week.</p>
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<b>Meeting Closure</b>
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<p>As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.</p>
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