

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

Thursday, 11<sup>th</sup> July 2024

09:00 – 14:15

*(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)
Dave Cronin (DC)	NHS England member (Data and Analytics Representative (Delegate for Michael Chapman))
Claire Delaney-Pope (CDP)	AGD independent member (Specialist Information Governance Adviser)
Andrew Martin (AM)	NHS England member (Data Protection Office Representative (Delegate for Jon Moore))
Dr. Phil Koczan (PK)	NHS England member (Caldicott Guardian Team Representative (Delegate for Dr. Jonathan Osborn))
Miranda Winram (MW)	AGD independent member (Lay Adviser)
<b>NHS ENGLAND STAFF IN ATTENDANCE:</b>	
<b>Name:</b>	<b>Role / Area:</b>
Garry Coleman (GC)	NHS England SIRO Representative
Dan Goodwin (DG)	Data Access and Partnerships, Data and Analytics ( <b>Observer:</b> items 6.5 to 6.6)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Delivery Directorate
Jodie Taylor-Brown (JTB)	Data Access and Partnerships, Data and Analytics ( <b>Observer:</b> items 6.1 to 6.4)
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Delivery Directorate
<b>AGD INDEPENDENT MEMBERS / NHS ENGLAND MEMBERS <u>NOT</u> IN ATTENDANCE:</b>	
<b>Name:</b>	<b>Role / Area:</b>

Michael Chapman (MC)	NHS England member (Data and Analytics Representative)
Prof. Nicola Fear (NF)	AGD independent member (Specialist Academic Adviser)
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)
Dr. Jonathan Osborn (JO)	NHS England member (Caldicott Guardian Team Representative)
Jenny Westaway (JW)	AGD independent member (Lay Adviser)

<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 the lack of availability of independent members, there was an even number of AGD independent members (three) and AGD NHS England members (three) in attendance for the meeting.</p> <p>The importance of the AGD independent member majority was acknowledged by those present, and it was suggested that an annual review / possible inclusion in the AGD annual report of the number of meetings where an independent majority had not been present would be useful, as this would allow consideration of whether any action needed to be taken to improve the proportion of meetings with an AGD independent member majority.</p> <p>The NHS England SIRO representative stated that should AGD members be required to vote on any issues in the meeting, then one AGD NHS England member would be asked to not participate, to ensure the appropriate balance of votes, i.e. that the majority was by AGD independent members. The Group noted and agreed with this proposal.</p> <p>Noting that the <a href="#">AGD Terms of Reference</a> state that “<i>The <b>majority</b> of the members of the Group or Sub-Group involved in any meeting <b>should</b> be independent members...</i>”, the Group agreed that 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 4<sup>th</sup> July 2024 were reviewed and, after several minor amendments, were agreed as an accurate record of the meeting.</p>
<b>3</b>	<p><b>Declaration of interests:</b></p>

	There were no declarations of interest.
4	<b>AGD Action Log:</b> <i>The action log was not discussed.</i>
<b>5 BRIEFING PAPER(S) / DIRECTIONS:</b>	
<i>There were no items discussed.</i>	
<b>6 EXTERNAL DATA DISSEMINATION REQUESTS:</b>	
6.1	<p><b>Reference Number:</b> NIC-484452-H8S1L-v6.5</p> <p><b>Applicant:</b> Department of Health and Social Care (DHSC)</p> <p><b>Application Title:</b> Department of Health and Social Care (DHSC) SDE access - Enabling Policy Analysis</p> <p><b>Observer:</b> Jodie Taylor-Brown</p> <p><b>Previous Reviews:</b> The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 25<sup>th</sup> January 2024 and the 14<sup>th</sup> December 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 8<sup>th</sup> September 2022, 19<sup>th</sup> May 2022, 7<sup>th</sup> April 2022, 21<sup>st</sup> October 2021 and the 16<sup>th</sup> September 2021.</p> <p>The application was previously presented at the GPES Data for Pandemic Planning and Research – Profession Advisory Group (PAG) on the 24<sup>th</sup> November 2021, 3<sup>rd</sup> November 2021, 15<sup>th</sup> September 2021 and the 25<sup>th</sup> August 2021.</p> <p><b>Application:</b> This was an amendment application.</p> <p>The amendments are to <b>1)</b> add National Disease Registration Service (NDRS) Cancer Consolidated Data Set, Packages 10,12,14 (Non-Sensitive Pseudo data will be supplied); <b>2)</b> to amend the dissemination legal basis to 261(2)(a); and <b>3)</b> to update section 5(b) (Processing Activities) of the application.</p> <p>NHS England were seeking advice on the following points:</p> <ol style="list-style-type: none"> <li>1. Confirmation that the criteria can be used as a reusable decision to add to the internal knowledgebase; and,</li> <li>2. Confirmation that the additional dataset can be added to the data sharing agreement (DSA).</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>

**Outcome of discussion:** AGD were supportive of the application and wished to draw to the attention of the SIRO the following comments:

AGD noted that they had been provided with a curated set of documentation and noted that they would be providing observations based on these documents.

**In response to point 1:**

**6.1.1** AGD discussed the request from NHS England for advice on a reusable decision, and noted that they were supportive of this, on the basis that the data will be accessed in NHS England's Secure Data Environment (SDE).

**6.1.2** The Group did however suggest that the criteria for the reusable decision was updated to be clear that this is restricted to the existing purposes **only**; the applicant provides evidence of any patient and public involvement and engagement (PPIE) undertaken; and also provides evidence of any ethics reviews undertaken / rationale for not requiring ethics review

**6.1.3 Separate to the application:** AGD queried whether NHS England should consider restricting the number of datasets that can be used under a reusable decision; however, it was noted by NHS England colleagues that this would **not** be necessary due to other processes already in place. The Group thanked NHS England for the verbal confirmation.

**In response to point 2:**

**6.1.4** On the basis that the applicant will be accessing the data via the SDE, the Group were supportive of the inclusion of the additional datasets.

**6.1.5** The NHS England SIRO representative noted that if sensitive data items were requested, the justification for these should be specifically stated within section 5(a) (Objective for Processing) of the application.

**6.1.6** The NHS England SIRO representative requested that any specific special conditions relating to the additional datasets should be included in section 6 (Special Conditions) of the application.

**6.1.7** AGD noted the statement in section 5(a) *"DHSC have also worked with the Data Policy Unit (DPU) on a **DHSC Data Access policy document** which involved consulting with patients on DHSC use of the SDE - this document includes case studies of how the SDE is used and **how the patient panel was engaged**. This document will be published in **January**..."*; and suggested that this was updated in line with the facts and whether any PPIE plans had progressed. It was also suggested that the reference to *"January"* was updated with a year.

**6.1.8** Assuming that the reference to *"January"* was relating to January **2025**, it was suggested that NHS England add a special condition to section 6 (Special Conditions) of the application, requesting that a copy of the DHSC Data Access policy document, which outlined the applicant's PPIE, was provided to NHS England by February 2025.

	<p><b>6.1.9</b> AGD stressed / reiterated the previous advice made, that there was ongoing patient and public involvement and engagement (PPIE) throughout the lifecycle of the work. The <a href="#">HRA guidance on Public Involvement</a> is a useful guide.</p> <p><b>6.1.10</b> AGD noted that Article 9(2)(j) (<i>processing is necessary for archiving purposes in the public interest, scientific or historical <b>research purposes</b> or statistical purpose</i>) had been cited in the application; however noted the statement in section 7 (Ethics Approval) of the application, that stated the data would be used “...<i>exclusively for <b>non-research purposes</b></i>”. It was therefore suggested that NHS England explore this further with the applicant, and that the application and DAS internal application assessment form were updated to reflect the correct / factual information.</p> <p><b>6.1.11</b> Noting that section 7 (Approval Considerations) stated that ethical approval was <b>not</b> required; AGD noted that as part of the review of NIC-463165-H3R4K (DHSC) on the 5th October 2023, the “<i>DHSC Ethics Team</i>” had been referred to. The Group queried whether the DHSC ethics team had been approached to review this application; and if not, suggested that the applicant engage with them, in line with <a href="#">NHS England’s DAS Standard for Ethical Approval</a>.</p> <p><b>6.1.12</b> AGD noted in section 8.1 (Security Assurance) of the internal Data Access Service (DAS) Escalation Form, that the DHSC security assurances expired on the 30<sup>th</sup> June 2024; and suggested that this was reviewed and updated with the most up to date information. The Group noted the verbal update by NHS England that access to the data would <b>not</b> be permitted unless the security assurances were in place.</p> <p><b>6.1.13</b> AGD noted and commended the work undertaken by NHS England’s DAS on the content of the DAS internal application assessment form, which supported the review of the application.</p>	
<b>6.2</b>	<p><b>Reference Number:</b> NIC-167794-K1P8H-v4.3</p> <p><b>Applicant:</b> University of Newcastle Upon Tyne</p> <p><b>Application Title:</b> Examining inequalities in the provision of elective surgical and diagnostic procedures</p> <p><b>Observer:</b> Jodie Taylor-Brown</p> <p><b>Previous Reviews:</b> The application and relevant supporting documents were previously presented / discussed at the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) meetings on the 5<sup>th</sup> December 2019, 11<sup>th</sup> April 2019 and the 28<sup>th</sup> February 2019.</p> <p><b>Application:</b> This was an amendment application.</p> <p>The amendments are <b>1)</b> the addition of STARTAGE Fields under Hospital Episode Statistics Admitted Patient Care (HES APC) product; <b>2)</b> the addition of the latest data years for HES APC; <b>3)</b> to add an additional objective (analysing comorbidity) to the</p>	

study with the help of re-admissions data; and **4)** to remove a special condition relating to amendment point 3 from section 6 (Special Conditions) of the application. NHS England were seeking advice on the following points:

1. The additional use of the data.

Should an application be approved by NHS England, further details would be made available within the [Data Uses Register](#).

**Outcome of discussion:** AGD were supportive of the application and wished to draw to the attention of the SIRO the following comments:

AGD noted that they had been provided with a curated set of documentation and noted that they would be providing observations based on these documents.

**In response to point 1:**

**6.2.1** AGD noted, in the internal Data Access Service (DAS) Escalation Form, that the applicant had initially been provided with more data than was requested, due to NHS England being unable to further minimise prior to dissemination. It was noted that as per the data sharing agreement (DSA), the applicant had **not** met the special condition in section 6 (Special Conditions) to carry out additional minimisation work and destroy the excess data by a certain date. NHS England noted that the applicant had engaged with and discussed this with NHS England, who advised the Group that the minimisation and data destruction work had not been completed within the expected period due to resource issues within the University of Newcastle Upon Tyne.

**6.2.2** AGD were disappointed that the data had **not** been destroyed in line with the DSA special condition but on this occasion AGD noted and accepted the explanation as to why, and the assurances given to NHS England by the applicant. AGD suggested that NHS England audit the Controller against the commitments set out within the DSA to confirm that the data was destroyed as set out in the new DSA. In addition, it was suggested that NHS England should make clear to the applicant that failure to meet that condition would be a clear breach of the DSA, irrespective of any mitigating circumstances.

**6.2.3** AGD noted in the internal DAS Escalation Form that NHS England had taken decisions about the extent of bespoke minimisation it could offer as a sustainable service taking account of capacity, demand and cost to the end user and, consequently, further filtering / data minimisation of some of the data was not possible within the scope of the service offering, and the applicant had been provided with the full dataset. The Group suggested that NHS England satisfy itself that sufficient data minimisation had been undertaken, in line with [NHS England DAS standard for data minimisation](#) and the UK General Data Protection Regulation (UK GDPR).

**6.2.4** AGD noted that if it was not possible for NHS England to undertake any further data minimisation, then a robust justification should be provided in the internal DAS Escalation Form and section 5 (Purpose / Methods / Outputs) of the application for transparency; and that if it is the responsibility of the applicant to undertake data



	<p>minimisation following receipt of the full dataset, then NHS England should undertake the relevant balances and checks, in a timely manner, to ensure that this had been completed.</p> <p><b>6.2.5</b> AGD noted concerns that <b>no</b> patient and public involvement and engagement (PPIE) had been undertaken; and suggested that there was ongoing PPIE throughout the lifecycle of the project. The <a href="#">HRA guidance on Public Involvement</a> is a useful guide.</p> <p><b>6.2.6</b> AGD queried the statement in section 5(b) (Processing Activities) “Access is restricted to employees or <b>agents</b> of...” and suggested that either further information was provided as to who would be covered by “agents”, and whether this aligned with the Data Sharing Framework Contract (DSFC); or that this was removed as may be necessary to reflect the facts.</p> <p><b>6.2.7</b> AGD noted the benefit in section 5(d) (Benefits) in relation to funding, and suggested that the 18<sup>th</sup> January 2024 date referred to, was updated, as may be necessary, noting that this date had now passed.</p> <p><b>6.2.8</b> AGD noted the benefits outlined in section 5(d), however suggested that this section was reviewed and any ‘outputs’ were moved to section 5(c) (Specific Outputs Expected) in line with <a href="#">NHS England’s DAS Standard for Expected Outcomes</a>.</p>	
<b>6.3</b>	<p><b>Reference Number:</b> NIC-692254-N3J5W-v0.8</p> <p><b>Applicant:</b> University College London (UCL)</p> <p><b>Application Title:</b> General Health Outcomes in Subfertile Men: a UK register-based cohort study</p> <p><b>Observer:</b> Jodie Taylor-Brown</p> <p><b>Application:</b> This was a new application.</p> <p>The purpose of the application is for a research project to investigate the risks of long-term malignant and non-malignant health outcomes, as well as early death, in men with known subfertility in the UK.</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 significant comments:</p> <p><b>6.3.1</b> AGD noted that the Data Security and Protection Toolkit (DSPT) information needed updating in section 1(b) (Data Controller(s)) and section 1(c) (Data Processor(s)) of the application, and the Data Access Service (DAS) internal application assessment form, to include the output of the 2023/24 submission. It was recognised that data would <b>not</b> flow unless DSPT was in place, but AGD stressed the importance of this, in particular ensuring that the safe haven had robust security in place (including for example multi-factor authentication).</p>	

	<p><b>6.3.2</b> Given the number of applications using the safe haven, AGD supported NHS England SIRO representative's suggestion that NHS England audit the Data Controller against the commitments set out within the data sharing agreement (DSA) to provide assurance on this. The size and nature of the data was noted, and it was suggested that ensuring appropriate cyber security was essential, especially around multi factor authentication. It was noted that data sharing audits are focussed appropriately on areas of risk, depending on the application.</p> <p><b>6.3.3 Separate to this application:</b> AGD sought reassurance that existing data DSAs would still have a valid DSPT in place. The NHS England SIRO representative confirmed that work is underway to assess and take appropriate action in relation to organisations using DSPT as their security.</p> <p><b>ACTION:</b> The NHS England SIRO representative to provide a briefing on organisations using DSPT as their security; as well as DSPT requirements and security standards more generally.</p> <p><b>6.3.4</b> AGD noted that some patient and public involvement and engagement (PPIE) had been undertaken in the form of a survey, however, suggested that further information was added to the application, for example, the outcomes of the survey and the response rate.</p> <p><b>6.3.5</b> Noting the potential importance of the project, the Group suggested that there was ongoing PPIE throughout the lifecycle of the project. The <a href="#">HRA guidance on Public Involvement</a> is a useful guide.</p> <p><b>6.3.6</b> AGD noted and commended the work undertaken by NHS England's DAS on the content of the DAS internal application assessment form, which supported the review of the application.</p>	SIRO Rep
6.4	<p><b>Reference Number:</b> NIC-361955-F6S9W-v0.5</p> <p><b>Applicant:</b> University College London (UCL)</p> <p><b>Application Title:</b> Long-term risk of cancer and general health outcomes in women who underwent assisted reproductive technology in Great Britain, 1991-2010: a data linkage study</p> <p><b>Observer:</b> Jodie Taylor-Brown</p> <p><b>Application:</b> This was a new application.</p> <p>The purpose of the application is for a research project to investigate the risks of long-term malignant and non-malignant health outcomes in women who have undergone assisted reproductive therapy (ART) between 1991 and 2009 in the UK.</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 processing outlined in the application, but were <b>not</b> supportive of the application <b>at this time</b> and wished to draw to the attention of the SIRO the following significant comment:</p> <p><b>6.4.1</b> AGD queried if the local opt-outs had been observed; and suggested that further information was provided in section 5(a) (Objective for Processing) of the application, including, but not limited to, a justification as to whether the local opt-out had / had not been observed and the process for this at all stages, given that NHS England already hold the cohort and local opt outs may have been made since the data was transferred.</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>6.4.2</b> AGD welcomed the application and noted the importance of the research.</p> <p><b>6.4.3</b> AGD noted that the Data Security and Protection Toolkit (DSPT) information needed updating in section 1(b) (Data Controller(s)) and section 1(c) (Data Processor(s)) of the application, and the DAS internal application assessment form, to include the output of the 2023/24 submission. It was recognised that data would <b>not</b> flow unless DSPT was in place, but AGD stressed the importance of this, in particular ensuring that the safe haven had robust security in place (including for example multi-factor authentication).</p> <p><b>6.4.4</b> Given the number of applications using the safe haven, AGD supported NHS England SIRO representative's suggestion that NHS England audit the Data Controller against the commitments set out within the data sharing agreement (DSA) to provide assurance on this. The size and nature of the data was noted, and it was suggested that ensuring appropriate cyber security was essential, especially around multi factor authentication. It was noted that data sharing audits are focussed appropriately on areas of risk, depending on the application.</p> <p><b>6.4.5 Separate to this application:</b> AGD sought reassurance that existing DSAs would still have a valid DSPT in place. The NHS England SIRO representative confirmed that work is underway to assess and take appropriate action in relation to organisations using DSPT as their security.</p> <p><b>ACTION:</b> The NHS England SIRO representative to provide a briefing on organisations using DSPT as their security; as well as DSPT requirements and security standards more generally.</p> <p><b>6.4.6</b> AGD noted that some patient and public involvement and engagement (PPIE) had been undertaken in the form of a survey, however, suggested that further information was added to the application, for example, the outcomes of the survey and the response rate.</p> <p><b>6.4.7</b> Noting the potential importance of the project, the Group suggested that there was ongoing PPIE throughout the lifecycle of the project. The <a href="#">HRA guidance on Public Involvement</a> is a useful guide.</p>	<p>SIRO Rep</p>
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	<p><b>6.4.8</b> AGD noted and commended the work undertaken by NHS England's DAS on the content of the DAS internal application assessment form, which supported the review of the application.</p>	
6.5	<p><b>Reference Number:</b> NIC-743987-M7B3P-v0.2</p> <p><b>Applicant:</b> Medicines and Healthcare Products Regulatory Agency (MHRA)</p> <p><b>Application Title:</b> Monitoring the Safety of Breast Implants using BCIR Data</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 for a research project to <b>1)</b> conduct exploratory data analyses for the purposes of assessing the value in the safety vigilance of breast implants of different textures; <b>2)</b> explore the feasibility of using Breast and Cosmetic Implant Registry (BCIR) data to support MHRA's vigilance and surveillance of breast implant products; and <b>3)</b> to use results of this project to provide insights into the strengths and limitations of the data within the BCIR for the purposes of supporting device vigilance.</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 high-level comments:</p> <p><b>6.5.1</b> AGD noted that two Article 9 UK General Data Protection Regulation (UK GDPR) limbs had been cited, Article 9(2)(i) (<i>processing is necessary for reasons of public interest in the area of public health</i>) and 9(2)(j) (<i>processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purpose</i>); and suggested that section 5(a) (Objective for Processing) of the application was updated to clarify what processing was being carried out under each Article 9 limb; or to amend the application if only one Article 9 limb was relevant.</p> <p><b>6.5.2</b> AGD noted the legal basis for collecting / disseminating the data was under the <a href="#">Breast and Cosmetic Implant Registry Direction 2018</a>; and had a lengthy discussion on the conflicting wording in the Direction and its Appendix A, and how this aligned with the proposed access and sharing of the data in the Breast and Cosmetic Implant Registry (BCIR). It was noted that advice had been sought from NHS England's Privacy, Transparency and Trust (PTT), but the Group had <b>not</b> been provided with a copy of the advice. It was suggested that NHS England's DAS seek an updated review from PTT on the advice previously received, and that a copy of this was uploaded to NHS England's customer relationships management (CRM) system for future reference.</p> <p><b>6.5.3</b> AGD also expressed concern in respect of the transparency to those individuals in the BCIR and the conflicting information in the Direction / Appendix A, that may</p>	

	<p>cause some confusion; noting the online information and the patient information leaflet provided clear information on how the data will be shared.</p> <p><b>6.5.4</b> AGD queried whether the concerns raised on the conflicting information within the Direction / Appendix A could be addressed within the relevant Data Protection Impact Assessment (DPIA); and suggested that NHS England explore this further.</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>6.5.5</b> AGD noted that the Data Security and Protection Toolkit (DSPT) for the Department of Health and Social Care (DHSC) for 2022/23 had not been fully met and a plan had been agreed, and that there was an ongoing NHS England review on this; and suggested that this was updated with the most recent information.</p> <p><b>6.5.6</b> AGD noted that the cohort would only include those individuals that had breast implants within England; and queried why data was not included for individuals from Scotland and Northern Ireland, noting that they were in the BCIR. It was suggested that NHS England explore this further, noting the value it may bring to the research including these individuals in the cohort.</p> <p><b>6.5.7</b> AGD noted in the DAS internal application assessment form, that a special condition would need adding to the application in relation to suppression; and suggested that section 6 (Special Conditions) was updated to reflect this additional special condition, in line with the <a href="#">NHS England DAS Standard for Special Conditions</a>.</p> <p><b>6.5.8</b> AGD noted concerns that <b>no</b> patient and public involvement and engagement (PPIE) had been undertaken; and suggested that there was ongoing PPIE throughout the lifecycle of the project, for example, with women in the cohort regarding the research elements. The <a href="#">HRA guidance on Public Involvement</a> is a useful guide.</p>	
<b>6.6</b>	<p><b>Reference Number:</b> NIC-17824-V9F2B-v7.2</p> <p><b>Applicant:</b> Institute for Fiscal Studies</p> <p><b>Application Title:</b> Work on Healthcare at the Institute for Fiscal Studies</p> <p><b>Observers:</b> Dan Goodwin</p> <p><b>Previous Reviews:</b> The application and relevant supporting documents were previously presented / discussed at the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) meetings on the 25<sup>th</sup> May 2019, 31<sup>st</sup> January 2019, 10<sup>th</sup> August 2017 and the 8<sup>th</sup> June 2017.</p> <p>The application and relevant supporting documents were previously presented / discussed at the Data Access Advisory Group (DAAG) meeting on the 26<sup>th</sup> April 2016.</p> <p><b>Application:</b> This was an amendment application.</p> <p>The amendments are to <b>1)</b> receive a renewal of Deaths and Hospital Episode Statistics (HES) and Emergency Care Data Set (ECDS) data up until 2022/23; and <b>2)</b></p>	

<p>to update section 5 (Purpose / Methods / Outputs) to account for further processing activities for five new projects.</p> <p>NHS England were seeking advice on the following points:</p> <ol style="list-style-type: none"> <li>1. The requested reuse of the data for the five new projects described.</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 were supportive of the application and wished to draw to the attention of the SIRO the following substantive 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>6.6.1</b> AGD noted their concern that the applicant had submitted the amendment application to NHS England's Data Access Service (DAS) on the 19<sup>th</sup> December 2023 after the data sharing agreement (DSA) had expired on the 30<sup>th</sup> November 2023; and that there had been delays within DAS at progressing the amendment request and getting an updated DSA in place.</p> <p><b>6.6.2</b> AGD queried whether, following the expiry of the DSA, the data had been used, including for the five new projects outlined in this version of the application, noting that this amendment had <b>not</b> yet been approved by NHS England and suggested that this was followed up.</p> <p><b>6.6.3</b> AGD suggested that NHS England audit the controller(s) against the commitments set out within the past data sharing agreement (DSA) to provide assurance, and ensure that the data had not been used for any new purpose (including the 5 new purposes in this DSA) / projects prior to this amendment application being approved.</p> <p><b>6.6.4</b> Given the failure to apply for an extension / amendment prior to the DSA expiring, the AGD Lay member recommended that the audit be completed before new data requested under this amendment application flowed, to give further public reassurance, but the AGD NHS England Data and Analytics representative explained the practical difficulties of taking such an approach.</p> <p><b>6.6.5 Separate to the application:</b> The NHS England SIRO representative noted that information would be provided to the Group at a future AGD meeting, in respect of the process / actions taken by NHS England when DSAs are due to expire and when they have expired.</p> <p><b>ACTION:</b> The NHS England SIRO representative to provide an update to the Group at a future AGD meeting, in respect of the process / actions taken by NHS England when DSAs are due to expire and when they have expired.</p> <p><b>In response to point 1:</b></p> <p><b>6.6.6</b> AGD noted that whilst they were supportive of the five new projects outlined, they noted the challenging subjects of the projects, and queried whether the</p>	<p>SIRO Rep</p>
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	<p>appropriate patient and public involvement and engagement (PPIE) and peer reviews had been / or were in the process of being undertaken; and suggested that section 5(a) (Objective for Processing) was updated with the most recent information.</p> <p><b>6.6.7</b> It was also noted by AGD that there should also be engagement with the health and social care workforce, noting the purpose of project which aims to analyse how changes to the health and social care workforce impact the health outcomes of hospital patients. The <a href="#">HRA guidance on Public Involvement</a> is a useful guide.</p> <p><b>6.6.8</b> AGD suggested that the Data Protection Impact Assessment (DPIA) could be updated to address relevant points on each of the five new projects, and suggested that a copy of the DPIA was provided to support the review of papers, where appropriate.</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>6.6.9</b> AGD noted that section 5.6 (honorary contractors) of the internal DAS Escalation Form had not been completed, however queried whether they were any non-employees accessing the data, noting information on the website that referred to collaborating UK academics and overseas academics. It was suggested that NHS England explore this further, in line with <a href="#">NHS England's DAS Standard for Honorary Contracts</a>.</p> <p><b>6.6.10</b> AGD queried the statement in section 5(b) (Processing Activities) “Access is restricted to employees or <b>agents</b> of...” and suggested that either further information was provided as to who would be covered by “agents”, and whether this aligned with the Data Sharing Framework Contract (DSFC); or that this was removed as may be necessary to reflect the facts.</p> <p><b>6.6.11</b> The NHS England SIRO representative noted that 5(b) referred to “remote access”; and asked that this was reviewed to ensure the correct text was in the application relating to this.</p> <p><b>6.6.12</b> AGD noted the valuable outputs in section 5(c) (Specific Outputs Expected) from the work undertaken to date.</p>	
<b>7 INTERNAL DATA DISSEMINATION REQUESTS:</b>		
<i>There were no items discussed</i>		
<b>8 EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL</b>		
<i>There were no items discussed</i>		
<b>9 OVERSIGHT AND ASSURANCE</b>		
<i>There were no items discussed</i>		

## 10 AGD OPERATIONS

### 10.1 Risk Management Framework

As last noted in the AGD minutes from the 21<sup>st</sup> March 2024, the independent members noted the reference to reviewing materials in accordance with “a *clearly understood risk management framework*” within the published [Statutory Guidance](#) and advised that they were not aware of an agreed risk management framework, and reiterated a previous request that NHS England provide further information/ clarity on this to the Group, 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: [Written questions, answers and statements – UK Parliament](#).

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 AGD (and previously the interim data advisory group) to use the NHS England DAS Standards and Precedents model to assess the risk factors in relation to items presented to AGD for advice; however the independent members noted that the wording in the statutory guidance “...using a *clearly understood risk management framework, precedent approaches and standards that requests must meet...*”, suggested that the risk management framework is separate to the DAS Standards and Precedents, and asked that this be clarified by NHS England. The Group noted that plans for this work were in train.

It had been noted previously by the interim data advisory group that the Oversight and Assurance Programme of applications that had not be subject to AGD review could form part of this Risk Management Framework.

The NHS England SIRO representative noted an outstanding action in respect of providing a written response to AGD on the risk management framework; and noted that this was progressing under the NHS England Precedents and Standards work.

**ACTION:** The NHS England SIRO Representative to provide a written response to AGD on the risk management framework

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### 10.2 AGD Standard Operating Procedures (SOPs) (Presenter: Vicki Williams)

The ongoing forward plan of work for creating the AGD Standard Operating Procedures was discussed; and noting that the AGD Terms of Reference (ToR) had now been approved, it was noted that work was progressing in order to finalise relevant AGD SOPs in line with the approved AGD ToR.

Vicki Williams noted that most of the SOPs were in fact operating processes and procedures for the running of AGD and had been badged accordingly, and noted she would engage with members over the coming weeks and provide an update in due course.

### 10.3 AGD Stakeholder Engagement



	<i>There were no items discussed</i>
<b>10.4</b>	<b>AGD Project Work</b> <i>There were no items discussed</i>
<b>11 Any Other Business</b>	
<i>There were no items discussed</i>	
<b>Meeting Closure</b> As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.	