

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

Thursday, 17<sup>th</sup> October 2024

09:00 – 14:20

*(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)
Claire Delaney-Pope (CDP)	AGD independent member (Specialist Information Governance Adviser)
Kirsty Irvine (KI)	AGD independent member (Chair)
Andrew Martin (AM)	NHS England member (Data Protection Office Representative (Delegate for Jon Moore))
Dr. Jonathan Osborn (JO)	NHS England member (Caldicott Guardian Team Representative)
Miranda Winram (MW)	AGD independent member (Lay Adviser)
Tom Wright (TW)	NHS England member (Data and Analytics Representative (Delegate for Michael Chapman))
<b>NHS ENGLAND STAFF IN ATTENDANCE:</b>	
<b>Name:</b>	<b>Role / Area:</b>
Dan Goodwin (DG)	Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> items 6.5 and 6.6)
Dickie Langley (DL)	NHS England SIRO Representative (Delegate for Garry Coleman)
Joe Lawson (JL)	Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> items 6.5)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Delivery Directorate
Jodie Taylor-Brown (JTB)	Data Access and Partnerships, Data and Analytics, Transformation Directorate ( <b>Observer:</b> items 6.1 to 6.3)
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Delivery Directorate

AGD INDEPENDENT MEMBERS / NHS ENGLAND MEMBERS <u>NOT</u> IN ATTENDANCE:	
Name:	Role / Area:
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)
Jon Moore (JM)	NHS England member (Data Protection Office Representative)
Jenny Westaway (JW)	AGD independent member (Lay Adviser)
NHS ENGLAND STAFF NOT IN ATTENDANCE	
Garry Coleman (GC)	NHS England SIRO Representative

1	<b>Welcome and Introductions:</b> The AGD Chair welcomed attendees to the meeting.	
2	<b>Review of previous AGD minutes:</b> The minutes of the AGD meeting on the 10 <sup>th</sup> October 2024 were reviewed and, after several minor amendments, were agreed as an accurate record of the meeting.	
3	<b>Declaration of interests:</b> Paul Affleck noted a previous link to the Chief Investigator of NIC-752432-W7V5T (University of Leicester) through his role at the University of Leeds but noted no specific connections with the application, and it was agreed that this was not a conflict of interest.	
4	<b>AGD Action Log:</b> The AGD Secretariat noted that the AGD Action Log would be discussed at the next AGD plenary meeting on the 5 <sup>th</sup> December 2024; and that this would be a standing item at the AGD plenary meetings going forward. It was also noted that the AGD Action Log would be accessible to AGD members via the internal AGD SharePoint site. The Group noted the update from the AGD Secretariat and advised that they were supportive of the AGD Action Log being discussed at future AGD plenary meetings. <b>ACTION:</b> The AGD Secretariat to update the internal AGD Forward Planner to add the AGD Action Log as a standing item at the AGD plenary meetings.	AGD Sec

## 5 BRIEFING PAPER(S) / DIRECTIONS:

*There were no items discussed*

## 6 EXTERNAL DATA DISSEMINATION REQUESTS:

6.1	<p><b>Reference Number:</b> NIC-727732-M8C2N-v0.11</p> <p><b>Applicant:</b> Norfolk and Norwich University Hospital</p> <p><b>Application Title:</b> A national retrospective cohort review of the epidemiology of lentigo maligna in England from 2004 to 2020</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 programme, which aims to examine the epidemiological trends of Lentigo Maligna (LM), a type of melanoma in situ, within the English population from 2004 to 2020.</p> <p>NHS England were seeking general advice on the application.</p> <p>Should an application be approved by NHS England, further details would be made available within the <a href="#">Data Uses Register</a>.</p> <p><b>Outcome of discussion:</b> AGD were supportive of the application and wished to draw to the attention of the SIRO the following comments:</p> <p><b>6.1.1</b> AGD noted the information in the NHS England Data Access Service (DAS) internal application assessment form in respect of data controllership, and the responses received from the applicant; acknowledging the difficulty in providing complete assurance in situations where researchers have multiple affiliations. The Group suggested that NHS England had a further discussion with regard to data controllership with the applicant, to specifically ask <b>1)</b> how the researcher would identify themselves when information on this research is published; <b>2)</b> and who pays for their time when working on the research. It was suggested that any further update to the data controllership arrangements following any further discussions were reflected in the application, in line with <a href="#">NHS England DAS Standard for Data Controllers</a>.</p> <p><b>6.1.2</b> AGD noted that in addition to the data sharing agreement (DSA), there was also a 'User Agreement' for those individuals accessing data in NHS England's Secure Data Environment (SDE), that covers off key points, including, but not limited to, specific user access and restrictions on exporting data; and suggested that this was referred to in section 5(b) (Processing Activities) of the application.</p> <p><b>6.1.3 Separate to the application:</b> AGD suggested that the AGD NHS England Data and Analytics Representative ensure that where an applicant is accessing data in NHS England's SDE, that DAS colleagues ensure that the 'User Agreement' is</p>
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	<p>referred to in section 5 (Purpose / Methods / Outputs) of the application for transparency, as part of <a href="#">NHS England's data uses register</a>.</p> <p><b>6.1.4</b> AGD noted the potential shortcoming of the ethnicity fields in the National Disease Registration Service (NDRS) dataset; and suggested that NHS England ensure that the applicant is aware of this; and ensures that this is reflected in any outputs and / or recommendations from the research.</p> <p><b>6.1.5 Separate to this application:</b> The AGD NHS England Caldicott Guardian Team Representative noted that research using datasets with incomplete ethnicity data may introduce bias into the results; and advised that further discussions would be held internally on this point to discuss possible solutions, such as a dedicated dataset. AGD noted that they were supportive of this, noting that this was an issue they had discussed previously.</p> <p><b>ACTION:</b> The AGD NHS England Caldicott Guardian Team Representative to discuss with NHS England colleagues, options for improving access to reliable ethnicity data.</p> <p><b>6.1.6</b> AGD noted the information in section 4.7 (Transparency) of the DAS internal application assessment form in respect of patient and public involvement and engagement (PPIE); and suggested that there was ongoing PPIE throughout the lifecycle of the work. The <a href="#">HRA guidance on Public Involvement</a> is a useful guide.</p> <p><b>6.1.7</b> In addition, it was suggested that the PPIE, could include specific melanoma charities, which may be beneficial, noting that the research programme was still at an early stage.</p> <p><b>6.1.8</b> AGD noted that section 7 (Ethics Approval) of the application states that <i>"Ethics approval is not required..."</i>; and suggested that this was updated to be clear that the applicant had sought and received ethical approval.</p> <p><b>6.1.9 Separate to this application:</b> The AGD NHS England Data Protection Office Representative noted the mismatch between the data requested by the applicant, which is calendar year; and the data processed in NHS England's Secure Data Environment (SDE), which is financial year. It was noted that whilst this was not material in this instance, suggested that this could be incorporated into the NHS England Data Protection Impact Assessment (DPIA) for the NHS England SDE, to consider the risks, checks and balances for the various modes of data access.</p> <p><b>ACTION:</b> The AGD NHS England Data and Analytics Representative to consider addressing the potential mismatch of data requested by an applicant versus what is available, in the NHS England SDE DPIA, for example, to consider the risks, checks and balances for the various modes of data access.</p> <p><b>6.1.10</b> AGD noted that the NHS England citation special condition in section 6 (Special Conditions) of the application referred to NHS England's <i>"Data Access Request Service"</i> and suggested that the application should be updated to correctly refer to <i>"Data Access Service"</i>.</p>	<p>JO</p> <p>D&amp;A Rep</p>
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**6.2**

**Reference Number:** NIC-483357-P5L8F-v0.11

**Applicant:** National Centre for Social Research (NatCen) Social Research

**Application Title:** A Better Start Evaluation (ABS) - Identifying the contribution made by the ABS programme to the life chances of children who have received ABS interventions

**Observer:** Jodie Taylor-Brown

**Application:** This was a new application.

A Better Start Evaluation (ABS) is a ten-year (2015-2025), £215 million programme set up by The National Lottery Community Fund; and aims to improve the life chances of children under 4. There are five ABS partnerships in Blackpool, Bradford, Lambeth, Nottingham, and Southend-on-Sea. NatCen is part of a consortium engaged to evaluate the contribution made by ABS to the life chances of children.

The purpose of the application is to identify the contribution made by the ABS programme to the life chances of children who have received ABS interventions.

NHS England were seeking general advice on the application.

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 substantive comments:

**6.2.1** AGD welcomed the application and noted the potential importance of the evaluation.

**6.2.2** AGD noted concerns that the 'Big Lottery Fund' were the sole Data Controllers of the application; and suggested that NHS England discuss this further with the applicant, in line with [NHS England DAS Standard for Data Controllers](#). The Group noted that, based on the information provided, NatCen were determining the means of processing and were therefore carrying out data controllership activities. In addition, the Group noted that NatCen were named in the privacy notice. The Group suggested that this would therefore suggest NatCen were joint data controllers. It was suggested that any further update to the data controllership arrangements following any further discussions were reflected in the application, in line with [NHS England DAS Standard for Data Controllers](#).

**6.2.3** The AGD Specialist Information Governance Adviser noted that the consent materials stated that data would be received on individuals for the period June 2022 to June 2024; however, this did not align with the data that NHS England was able to flow (and in line with the data destruction required see point 6.2.9). The Group suggested that NHS England explore with the applicant whether there was a legal gateway for data to flow outside of the time period stated in the consent materials.

<p><b>6.2.4</b> In addition, it was advised that the applicant should consider undertaking some patient and public involvement and engagement (PPIE) to determine whether participants would be surprised that data was flowing outside of the time period stated in the consent materials.</p> <p><b>6.2.5</b> AGD noted that the consent / transparency materials state that participants can withdraw consent up to June 2024; however, advised that as the data has not yet been linked, this was incorrect. It was suggested that the consent / transparency materials were updated to reflect the correct time periods for withdrawing consent.</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>6.2.6</b> AGD suggested that section 3(c) (Patient Objections) of the application was updated to reflect whether the National Data Opt-out was applied, for the data flowing under consent and the pseudonymised data.</p> <p><b>6.2.7</b> AGD suggested that given the significant volume of data flowing and the nature of the data flowing, i.e. children's data, this would require a Data Protection Impact Assessment (DPIA); and suggested that NHS England discuss this further with the applicant, in line with the Information Commissioner's Office (ICO) <a href="#">guidance</a> on DPIAs.</p> <p><b>6.2.8</b> AGD noted, in the Data Access Service (DAS) internal application assessment form, that the applicant would be 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 special condition in section 6 (Special Conditions), the applicant was required to carry out additional minimisation work and destroy the excess data. The Group suggested that a specific timeframe was added to the special condition confirming when the excess data should be destroyed by.</p> <p><b>6.2.9</b> In addition, it was suggested that the data destruction being undertaken by the applicant should be noted in section 5(b) (Processing Activities) of the application for transparency.</p> <p><b>6.2.10 Separate to this application:</b> AGD noted the risks involved with excess data flowing and the reliance on the applicant to destroy data; and suggested that this could be incorporated into the NHS England consideration of the risks, checks and balances for the various modes of data access.</p> <p><b>ACTION:</b> The AGD NHS England Data and Analytics Representative to consider addressing the risks involved with excess data flowing and the reliance on the applicant to destroy the data; and to consider the risks, checks and balances for the various modes of data access.</p> <p><b>6.2.11</b> Some of the AGD members noted that there may be ethical issues with the nature of the funding provided, i.e. from gambling which can itself damage families and therefore the life chances of children; however, it was noted that <a href="#">NHS England DAS Standard for Ethical Approval</a> had been followed, and that they have ethical</p>	<p>D&amp;A Rep</p>
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	approval. It was noted that other AGD members did not have any ethical concerns with the source of the funding.	
6.3	<p><b>Reference Number:</b> NIC-752432-W7V5T-v0.3</p> <p><b>Applicant:</b> University of Leicester</p> <p><b>Application Title:</b> Policy Research Unit on Awareness, Early Detection and Screening</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, with a number of aims, including tracking trends over time in various early cancer diagnosis markers; tracking trends in stage-specific net survival among cancer cases overall and by specific population groups; to develop and apply causal inference methodologies to assess relationships between diagnostic stages, routes, and survival outcomes; quantify potential survival gains from targeted improvements in early diagnosis markers and reducing related inequalities; and to collaborate with NHS England to build public health data science capacity and create a toolkit for monitoring early diagnosis trends, integrating it into routine NHS surveillance.</p> <p>NHS England were seeking general advice on the application.</p> <p>Should an application be approved by NHS England, further details would be made available within the <a href="#">Data Uses Register</a>.</p> <p><b>Outcome of discussion:</b> The majority of the Group were supportive of the application, and a minority (one member) of the Group was <b>not</b> supportive of the application <b>at this time</b> due to the concerns in respect of how the data was being accessed.</p> <p>The Group wished to draw to the attention of the SIRO the following substantive comments:</p> <p><b>6.3.1</b> Noting the large volume of data requested under this application, and that this would be flowing as a data extract; AGD queried why the extract could not be placed in NHS England's Secure Data Environment (SDE), in line with the Department of Health and Social Care (DHSC) Data Access Policy that states "<i>Secure Data Environments (SDEs) will become the primary route for accessing NHS data for research</i>". It was suggested that this was given further consideration by NHS England.</p> <p><b>6.3.2 Separate to this application:</b> AGD asked that NHS England provide an update to the Group as to how they are complying with the DHSC Data Access <a href="#">Policy</a> in respect of the SDEs becoming the primary route for accessing NHS data for research.</p>	

	<p><b>ACTION:</b> The AGD NHS England Data and Analytics Representative to provide an update to AGD, to provide further information as to how NHS England are complying with the DHSC Data Access <a href="#">Policy</a> in respect of the SDEs becoming the primary route for accessing NHS data for research.</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>6.3.3</b> AGD queried whether, given the significant volume of data flowing, this would fall into the remit of requiring a mandatory Data Protection Impact Assessment (DPIA); and suggested that NHS England discuss this further with the applicant, in line with the Information Commissioner's Office (ICO) <a href="#">guidance</a> on DPIAs.</p> <p><b>6.3.4</b> AGD noted in section 5(a) (Objective for Processing) of the application, that that University of Leicester had engaged with their patient and public involvement and engagement (PPIE) panel, and that there was also planned PPIE engagement going forward. The Group suggested that the application was updated with further clarification as to what the outcome was of the PPIE engagement to date, for example, had views been sought on the volume of data flowing, and what feedback had been received.</p> <p><b>6.3.5</b> AGD noted in section 5(a) of the application, that the breast cancer data would be minimised to females only; and noting the potential importance of the male breast cancer data, suggested that NHS England discuss this further with the applicant to determine whether or not requesting this data was to support data minimisation efforts, or whether it was because the data was not required.</p> <p><b>6.3.6</b> AGD noted the references in section 5(c) (Specific Outputs Expected) and section 5(d) (Benefits) of the application, in respect of a “<i>collaboration</i>” with NHS England; and suggested that this was reviewed and either clarified that this was correct; or that the application was amended as may be necessary to reflect the correct / factual scenario.</p> <p><b>6.3.7</b> AGD noted that the NHS England citation special condition in section 6 (Special Conditions) of the application referred to NHS England’s “<i>Data Access Request Service</i>”, and suggested that the application should be updated to correctly refer to “<i>Data Access Service</i>”.</p>	D&A Rep
6.4	<p><b>Reference Number:</b> NIC-734202-N9F7P</p> <p><b>Applicant:</b> Cardiff University</p> <p><b>Application Title:</b> Post-operative adjuvant treatment for HPV-positive tumours (PATHOS) - Request for Civil Registrations of Death</p> <p><b>Application:</b> This was a new application.</p> <p>The purpose of the application is for an international randomised phase III study, with the objectives to <b>1)</b> demonstrate if swallowing function can be improved and toxicities reduced following transoral surgery for Human papillomavirus (HPV) -</p>	



positive oropharyngeal cancer, by reducing the intensity of adjuvant treatment protocols; and **2)** to demonstrate the non-inferiority of reducing the intensity of adjuvant treatment protocols in terms of overall survival.

NHS England were seeking general advice on the application.

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

**Outcome of discussion:** The majority of the Group were supportive of the application, and a minority (one member) of the Group were **not** supportive of the application **at this time** due to the outstanding query on the follow-up and whether there had been patient and public involvement and engagement (PPIE).

**6.4.1** AGD noted that one of the Co-Chief Investigators was based at the University of Liverpool, however, noted that the University of Liverpool were **not** referenced within the application. The Group noted, that based on the information within the NHS England Data Access Service (DAS) internal application assessment form, the applicant had not been asked about this; and suggested that NHS England satisfies itself that the correct parties had been noted within the application in line with [NHS England DAS Standard for Data Controllers](#) and [NHS England DAS Standard for Data Processors](#); and that the application was updated to reflect the correct / factual information.

**6.4.2** AGD noted that prior to the meeting, a query had been raised with NHS England's DAS, in respect of a statement in the patient information sheet, provided as a supporting document (SD2b) *"If we lose contact with you during the study, we would like to try to find out what has happened to you for the purpose of following your health status through the National Health Service Information Centre..."*. A query was raised as to whether it is the contention that contact has been lost with all the participants; and whether this had been discussed with the PPIE group, for example, whether the participants understand the Patient Information Sheet (PIS) and consent form to mean everyone will be followed up in this way. The Group noted that the query remained outstanding and suggested that NHS England discussed this further with the applicant.

**6.4.3** AGD noted that the PIS stated that individuals can still take part in the study, even if they do not consent to follow-up; and suggested that NHS England satisfies itself, that either this option was not selected by any of the participants of the cohort; or, if this was selected, confirmation that no data would flow for these individuals, noting that there would be no legal gateway.

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

**6.4.4** AGD noted that section 7 (Ethics Approval) of the application states that *"Ethics approval is not required because already granted"*; and suggested that this was updated to be clear that the applicant had sought and received ethical approval.

6.5	<p><b>Reference Number:</b> NIC-767681-R8J9N-v0.2</p> <p><b>Applicant:</b> University of Bristol</p> <p><b>Application Title:</b> Evaluating Clinical Outcomes in Hip, Knee, Foot, and Ankle Surgery</p> <p><b>Observers:</b> Dan Goodwin and Joe Lawson</p> <p><b>Previous Reviews:</b> The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 23<sup>rd</sup> March 2023.</p> <p><b>Linked applications:</b> This application is linked to NIC-667559-J3L9G.</p> <p><b>Application:</b> This was a new application.</p> <p>The purpose of the application is for a project, to analyse national hospital episode data to determine the rate of adverse events associated with commonly performed orthopaedic procedures of the lower limbs, investigate the impact of surgeon and unit volume on outcomes, and benchmark proposed thresholds for care outcomes (rate of adverse events or outcomes) that could permit the monitoring of the quality of care and outcomes in the future.</p> <p>This application is a request to access data previously disseminated to the University of Oxford under NIC-667559-J3L9G, due to the Chief Investigator's substantive employment transferring from the University of Oxford to the University of Bristol.</p> <p>NHS England were seeking advice on the following points only:</p> <ol style="list-style-type: none"> <li>1. Data Controllershship; and,</li> <li>2. The proposed plan for simultaneous processing of the same dataset.</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 <b>not</b> supportive of the application until the following substantive comments were addressed, and wished to draw to the attention of the SIRO the following substantive points:</p> <p><b>In response to points 1 and 2:</b></p> <p><b>6.5.1</b> AGD noted that this application was a duplicate request of data, due to the Chief Investigator changing organisations; however, queried why this work required two separate data sharing agreements (DSA) and why the original DSA (NIC-667559-J3L9G) could not be amended to address the changes outlined in this application.</p> <p><b>6.5.2</b> AGD queried if remote access was the purpose of the dual running DSAs; and suggested that NHS England explored this further, for example, to determine whether the original DSA (NIC-667559-J3L9G) could be amended to address the</p>	
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<p>change of processing and location; and remove the University of Oxford as a joint Data Controller once their involvement had concluded.</p> <p><b>6.5.3</b> If this was not practicable, and NHS England proceeded with the dual running of the two DSAs, the Group suggested that the original DSA (NIC-667559-J3L9G) should have the University of Bristol named as a joint Data Controller; and the University of Bristol should be named as the sole Data Controller in NIC-767681-R8J9N.</p> <p><b>6.5.4</b> AGD suggested that if there was a dual running of the two DSAs, that NIC-667559-J3L9G should be time and purpose limited; and the application should be amended to reflect this.</p> <p><b>6.5.5</b> AGD considered the evidence to support the dual running of the two DSAs, including, but not limited to, both applications would be under the direction of the same Chief Investigator based at the University of Bristol and both applications were working from the same protocol. AGD did however query whether both organisations would be collaborating on any publications together and suggested that NHS England explore this further with the applicant.</p> <p><b>6.5.6</b> Noting that under the dual DSAs there would be duplicate data flowing, AGD discussed data minimisation; and suggested that NHS England explore whether it would be an option for both organisations to work from one set of data, for example, via remote access or a secure portal, and in line with the <a href="#">NHS England Standard for Data Minimisation</a>.</p> <p><b>6.5.7</b> AGD queried whether any patient and public involvement and engagement (PPIE) had been undertaken in respect of the dual DSAs; and suggested that further clarification was provided in section 5(a) (Objective for Processing) of the application; or, suggested that the view of the PPIE group were sought if this had not been done already.</p> <p><b>6.5.8</b> AGD also suggested that ethical support was sought and obtained for the dual DSAs.</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>6.5.9</b> AGD noted in the application that individuals would be brought into the University of Bristol on honorary contracts; and suggested that further information was provided in section 5 (Purpose / Methods / Outputs) of the application as to the substantive employer of those on honorary contracts, noting that this was unclear.</p> <p><b>6.5.10</b> AGD noted that as part of the review of NIC-667559-J3L9G on the 23<sup>rd</sup> March 2023, AGD had raised a query in respect of the consultant code field requested as part of the Hospital Episode Statistics Admitted Patient Care (HES APC) dataset, which is identifiable via the publicly available General Medical Council (GMC) register. AGD noted that the consultant code field had been removed from this application and had been replaced with the Pseudonymised consultant code</p>	
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	<p>(PConsult field). The Group advised that the points raised previously on this issue still remain outstanding in respect of the ethical issues, and suggested that NHS England explore these points further if the PConsult field is requested; or that the impact on the outcomes were clarified if this data did not flow under this agreement.</p>	
6.6	<p><b>Reference Number:</b> NIC-359692-Q4X1C-v11.5</p> <p><b>Applicant:</b> Lightfoot Solutions UK Ltd</p> <p><b>Application Title:</b> HES data through Signals From Noise (sfn) Business Intelligence Platform</p> <p><b>Observer:</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 27<sup>th</sup> August 2020, 23<sup>rd</sup> July 2020, 21<sup>st</sup> May 2020 and the 9<sup>th</sup> November 2017.</p> <p>The application and relevant supporting documents were previously presented / discussed at the Data Access Advisory Group (DAAG) meetings on the 15<sup>th</sup> September 2015 and the 1<sup>st</sup> September 2015.</p> <p><b>Application:</b> This was an amendment application.</p> <p>Lightfoot Solutions UK Ltd (Lightfoot) are an organisation who work to help healthcare organisations transition from a traditional silo-based structure to a flow-based system-wide management approach. By incorporating data from different healthcare providers, Lightfoot can measure patient outcomes across the whole pathway, linking all the services in each patient's journey.</p> <p>NHS England were seeking general advice on the application.</p> <p>Should an application be approved by NHS England, further details would be made available within the <a href="#">Data Uses Register</a>.</p> <p><b>Outcome of discussion:</b> AGD were <b>not</b> supportive of the application until the following substantive comments were addressed, and wished to draw to the attention of the SIRO the following substantive points:</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 concern that this application had <b>not</b> had an independent review since 2020; and noted that there was a period of approximately four months in 2023 where the DSA had expired. The Group noted that a SIRO approval had been obtained however this did not appear to have been notified to AGD, as per the usual process, for noting in published minutes.</p> <p><b>6.6.2</b> AGD noted the reference in section 5(a) (Objective for Processing) of the application, to the 'Lightfoot HES Group', which is responsible for the oversight of the governance for approving and on-boarding new clients. The Group noted that</p>	

this had been discussed at the IGARD meeting on the 21<sup>st</sup> May 2020, where it had been suggested that a satisfactory explanation was provided of the operation of the Lightfoot HES Group, including Terms of Reference or guiding principles, composition of the group and other internal arrangements, for example minutes. Noting that this application had not had an independent review since 2020, AGD suggested that NHS England undertake a review of the Lightfoot HES Group's governance documents, including, but not limited to, ensuring that these reflect current practice; that they have been updated to reflect the proposed extension of the datasets, including Emergency Care Data Set (ECDS); and the use of the tool by non-NHS organisations (solution providers) working on behalf of the NHS Trusts was addressed.

**6.6.3** AGD noted that the application does **not** currently cover the flow of data to non-NHS organisations (solution providers) working on behalf of the NHS Trusts who were the primary recipient of the reports; and suggested that section 5 (Purpose / Methods / Outputs) was updated as appropriate to reflect this information.

**6.6.4** AGD noted that the privacy notice was missing key information, including, but not limited to, the ECDS data requested; the Lightfoot HES Group; the Article 6 UK General Data Protection Regulation (UK GDPR) legal basis; and the relevant limb of the Article 9 UK GDPR legal basis; and suggested that this was reviewed and updated to reflect this information, and in line with the [NHS England Standard for Transparency \(fair processing\)](#).

**6.6.5** AGD noted that the internal Data Access Service (DAS) Escalation Form and the application made reference to outputs and benefits to primary care and a GP Practice based in Kent using the data. Noting that there was limited primary care related data flowing, the Group queried whether the outputs and benefits to primary care could be achieved with the data requested or if there are any potential risks using the data for this purpose, and suggested that NHS England discuss this further with the applicant.

**6.6.6** In addition, it was queried whether the tool was digesting other datasets from other sources that have not been disclosed; and suggested that NHS England explored this further with the applicant, noting that the application was silent on this point.

**6.6.7** AGD queried whether views should be sought from the General Practice Extraction Service (GPES) Data for Pandemic Planning and Research (GDPPR) – Profession Advisory Group (PAG), on the use of NHS England data, that would allow comparison of GP practices; and suggested that NHS England gave this further consideration and action as appropriate.

**6.6.8** AGD noted in section 1(b) (Data Controller(s)) of the application, that the Data Sharing Framework Contract (DSFC) for Lightfoot Solutions UK Ltd was due to expire on the 19<sup>th</sup> October 2024; and asked that this was updated with the latest information.

	<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 it was difficult to ascertain the new outputs and benefits in section 5(c) (Specific Outputs Expected) and section 5(d) (Benefits) of the application; and suggested that the application was updated to be clearer on this point, in line with the <a href="#">NHS England DAS Standard for Expected Outcomes</a> and the <a href="#">NHS Digital DAS Standard for Expected Measurable Benefits</a>.</p> <p><b>6.6.10</b> In addition, noting the commercial nature of the applicant, it was suggested that more information was provided in section 5(a) and section 5(d) of the application, as to the commercial benefits, and whether there is a proportionate balance between public and commercial benefit, in line with the <a href="#">NHS Digital DAS Standard for Expected Measurable Benefits</a> and the <a href="#">NHS England's DAS Standard for Commercial Purpose</a> and the National Data Guardian (NDG) <a href="#">guidance on benefits</a>.</p> <p><b>6.6.11</b> AGD noted in the DAS Escalation Form, that DAS had requested clarification of whether the change could be approved under an existing reusable (precedent) decision, however the NHS England SIRO Representative had not agreed it was a reusable decision and asked that AGD advice was sought. AGD advised that they would <b>not</b> be supportive of this application proceeding under an existing reusable decision.</p> <p><b>6.6.12 Separate to this application:</b> The SIRO Representative noted that, whilst not noted in the documentation provided, this application had been subject to an NHS England audit in 2016. As suggested at the AGD meeting on the 10<sup>th</sup> October 2024, for ease of reference, the DAS internal application assessment form template and the DAS Escalation Form templates should be updated, to include a section specifically related to audits, which would support reviews by both AGD and NHS England colleagues.</p> <p><b>ACTION:</b> The AGD NHS England Data and Analytics Representative to discuss with colleagues whether the DAS internal application assessment form template and the DAS Escalation Form templates could be updated, to include a section specifically related to audits.</p>	D&A Rep
<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>		



*There were no items discussed*

## 10 AGD OPERATIONS

10.1	<b>Risk Management Framework</b>  AGD has been previously informed that a risk management framework is being developed by Data Access. However, AGD noted that the Group's <a href="#">Terms of Reference</a> have been in place since March 2024 and charge the Group with operating in line with NHS England's risk management framework, and it is therefore of concern that there is still <b>not</b> a Risk Management Framework in place.  <b>ACTION:</b> The NHS England SIRO Representative to provide a written response to AGD on the progress, and expected time frame for implementation, of the risk management framework	SIRO Rep
10.2	<b>Standard Operating Procedures (SOPs)</b> 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.	
10.3	<b>AGD Stakeholder Engagement</b>  <i>There were no items discussed</i>	
10.4	<b>AGD Project Work</b>  A brief update was given by the Group's Representative on the Federated Data Platform Information Governance Group.	

## 11 Any Other Business

11.1	<b>NHS England Data Access Service (DAS) Standards</b>  Following on from the NHS England Data Access Service (DAS) Standards Working Group meetings, attended by some of the AGD independent members; and the discussion on NHS England Standards at the AGD plenary meeting on the 26 <sup>th</sup> September 2024; the Group were advised by the AGD Secretariat, that NHS England DAS colleagues were in the process of setting up further workshops.  The Group were advised that, where possible, these discussions would take place at the AGD meetings; however, if this was not possible, then these workshops would be held on alternate dates; and as per process would be noted in the 'AGD Project Work' section of the AGD minutes for transparency.	
11.2	<b>Quantifying volumes of data</b>	

	<p>AGD discussed whether there was a way that NHS England would be able to quantify the volume of data requested in applications, to give a clearer picture of the volume and breadth of the data requested; whilst noting that not all datasets are equal in terms of sensitivity and fields available.</p> <p>The Group noted that this would support the information in Data Protection Impact Assessments (DPIA).</p> <p>The AGD NHS England Data and Analytics Representative advised that he would discuss this further internally and provide feedback to the Group at a future AGD meeting.</p> <p><b>ACTION:</b> The AGD NHS England Data and Analytics Representative to explore whether there is a way that NHS England would be able to quantify the volume of data requested in applications, to give a clearer picture of the volume and breadth of the data requested.</p> <p>AGD requested that NHS England provide a training session on the NHS England datasets, as part of their ongoing learning and development. The AGD Secretariat noted that this would be added to the internal AGD Forward Planner for discussion at a future AGD plenary meeting.</p> <p><b>ACTION:</b> AGD Secretariat to update the internal AGD Forward Planner to add a discussion about NHS England datasets at a future AGD plenary meeting.</p> <p><b>ACTION:</b> the AGD NHS England Data &amp; Analytics Representative to provide a training session at a future AGD plenary meeting with regard to NHS England datasets.</p>	<p>D&amp;A Rep</p> <p>AGD Sec</p> <p>D&amp;A Rep</p>
11.3	<p><b>AGD Minutes</b></p> <p>The AGD Secretariat advised the Group that a proposal was being put together in respect of updating the format of the AGD minutes and following on from a discussion with the Executive Director Privacy, Information and Governance at the last plenary meeting on the 26<sup>th</sup> September 2024.</p> <p>The Group were advised that further information on this would be shared at a future AGD meeting.</p> <p><b>ACTION:</b> The AGD Secretariat to share the draft AGD minutes proposal with NHS England's SIRO Representative and the AGD Chair for consideration.</p> <p><b>ACTION:</b> The AGD Secretariat to update the internal AGD Forward Planner to add a future discussion on the AGD minutes.</p> <p>AGD suggested that as part of any new process for the AGD minutes, NHS England's Data Access Service (DAS) should ensure that an observer is in attendance for all relevant agenda items, to ensure the discussion is heard first hand by those working on the application; and to support the progression of the applications prior to the ratified minutes being shared / published.</p>	<p>AGD Sec</p> <p>AGD Sec</p>

**Meeting Closure**

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