

## Independent Group Advising on the Release of Data (IGARD)

### Minutes of meeting held 15 November 2018

**Members:** Joanne Bailey, Nicola Fear, Kirsty Irvine (Chair),

**In attendance:** Dave Cronin, Duncan Easton, Rachel Farrand, James Humphries-Hart, Dickie Langley, Karen Myers, Vicki Williams.

**Observers:** Maria Clark (2.1 - 2.6), Priscilla McGuire.

**Apologies:** Sarah Baalham, Anomika Bedi, Eve Sariyannidou

1	<p><b>Declaration of interests:</b></p> <p>Nicola Fear and Joanne Bailey noted professional links to the UK Biobank (NIC-08472-V9S6K) but noted no specific connections with the application or staff involved and it was agreed this was not a conflict of interest.</p> <p><b>Review of previous minutes and actions:</b></p> <p>The outcomes of the 8 November 2018 IGARD meeting were reviewed and were agreed as an accurate record of that aspect of the meeting.</p> <p>The minutes of the 8 November 2018 IGARD meeting were reviewed out of committee by IGARD following conclusion of the meeting, and subject to a number of minor changes were agreed as an accurate record of the meetings.</p> <p><b>Out of committee recommendations</b></p> <p>An out of committee report was received (see Appendix B).</p>
2	<b>Data applications</b>
2.1	<p><u>University of Nottingham: Evaluating protocols for identifying and managing patients with FH (Presenter: Rachel Farrand) NIC-115405-P6X6Q</u></p> <p><b>Application:</b> This was a new application for pseudonymised Hospital Episode Statistics (HES) data, which is a joint application with The University College London, The University of Nottingham and The University of York to link the data to the Simon-Broome Database of patients with familial hypercholesterolaemia (FH). This is a common inherited cause of raised cholesterol and the study is to evaluate treatment patterns and short / long-term cardiovascular outcomes and the cost to the NHS.</p> <p><b>Discussion:</b> IGARD queried and asked for further clarity as to whether any new identifiers will be flowing: NHS Digital confirmed that the cohort is already flagged and no new identifiers will be flowing.</p> <p>IGARD noted that the Data Sharing for Commissioners (DSfC) end date within section 1(a) (Abstract) of the application was showing as 2010 for the University of Nottingham and asked that this be updated with the correct date.</p> <p>IGARD queried the correct cohort numbers and noted that the application and supporting document 1, the Health Research Authority Confidentiality Advisory Group (HRA CAG) letter, were showing conflicting information. IGARD asked that the two documents be cross referenced, and the application be amended as necessary to reflect the current cohort number.</p> <p>IGARD agreed with NHS Digital's assessment that the applicant's privacy notice did not meet the ICO checklist including (not limited to) reference to the data controllers.</p>

	<p>IGARD noted that supporting document 5, the data flow diagram, did not currently accurately show the data flow for each stage, and that up on renewal this should be amended.</p> <p><b>Outcome:</b> recommendation to approve</p> <p>The following amendments were requested:</p> <ol style="list-style-type: none"> <li>1. Further clarification within the application that no new identifiers will be flowing, as the cohort is already flagged by NHS Digital.</li> <li>2. To update the abstract with the correct DSfC date reference for the University of Nottingham.</li> <li>3. To cross reference the cohort numbers in the application and supporting document 1 and amend as necessary to reflect correct number in the application.</li> </ol> <p>The following advice was given:</p> <ol style="list-style-type: none"> <li>1. IGARD advised that on renewal the data flow diagram should be amended to accurately show the data flow for each stage.</li> </ol>
2.2	<p><u>Queen Mary University of London: IBIS-I The International Breast Cancer Intervention Study – MR710 (Presenter: Rachel Farrand) NIC-12629-B4N5K</u></p> <p><b>Application:</b> This was an amendment and renewal application for identifiable Medical Research Information Service (MRIS) and Hospital Episode Statistics (HES) data. The study which started in 1992 is investigating the efficacy of the hormonal drug tamoxifen versus a placebo drug in terms of reduction of breast cancer incidence in pre and post-menopausal women at high risk of developing breast cancer and whether tamoxifen continues to have a long-term beneficial impact in terms of breast cancer incidence, survival and side effects after the initial 5-year treatment period.</p> <p><b>Discussion:</b> IGARD noted that the section on Article 9(2)(j) in the abstract should be updated to reference the relevant public interest condition under the Data Protection Act 2018.</p> <p>IGARD queried information provided in the processing activities in 5(b) (Processing Activities) to clarify if users are able to download data; NHS Digital confirmed that users cannot download data and IGARD asked that this be expressly stated.</p> <p>IGARD noted that Indicative Data Retention Period date in section in 8(a) (Period and Funding) was 7<sup>th</sup> November 2018 and asked that this be updated with the correct date.</p> <p>IGARD noted that the study was international and asked that it be made explicitly clear within the application that there is to be no sharing of data with international partners.</p> <p>IGARD queried if the s251 support extends to the entire cohort, since it was potentially ambiguous in the application and supporting documents. NHS Digital advised that it did cover the entire cohort and IGARD asked that this be made clear in section 1(a) (Abstract).</p> <p><b>Outcome:</b> recommendation to approve</p> <p>The following amendments were requested:</p> <ol style="list-style-type: none"> <li>1. To update the section on Article 9(2)(j) of GDPR to reference the relevant public interest condition under the DPA 2018.</li> <li>2. To expressly state within section 5(b) that users cannot download the data.</li> <li>3. To update the data retention period within section 8(a).</li> <li>4. To explicitly state that the data will not be shared with international partners.</li> <li>5. To amend the abstract to make it clear the s251 support extends to the entire cohort.</li> </ol>

**Application:** This was an amendment, extension and renewal application for identifiable Medical Research Information Service (MRIS) for a long-running research study where the purpose is identification of disease susceptibility genes associated with development and clinical characteristics of primary inflammatory muscle diseases. The study aims to investigate the causes of death and understand if any subgroups of patient are more likely to develop cancers and if so the type of cancers.

**Discussion:** IGARD welcomed the application and noted the importance of the long-running study.

IGARD noted that NHS Digital had included within section 1(a) (Abstract) of the applicant's legal basis under the General Data Protection Regulation (GDPR) Article 6 and 9, however IGARD suggested that a clear justification for each choice indicated should be given in terms of how the specific criteria and additional requirements would be met since the applicant would need to satisfy the relevant tests associated with the legal basis suggested as per recent discussions between NHS Digital and IGARD.

IGARD noted that within section 1(a) (Abstract) information was provided under the heading 'Consent' and asked that this be updated to title the section 'Duty of Confidentiality'.

IGARD noted that there was some confusion over the cohort numbers noted in section 3(b) (Additional Data Access Requested) and asked for further clarity of this and for the data minimisation to be updated with the correct information.

IGARD noted the following in section 5(a) (Objective) "*Selected patients were consented between 2004 and 2010...*" and asked for further clarification on what is meant by "selected patients".

IGARD queried the current position with the funding in light of the original Chief Investigator no longer being in their role and asked that section 6 be updated to include a special condition stating that any incoming or new funder will not have any influence on the results nor suppress any results of the study.

IGARD queried if ethics approval was still in place, since it was not clear in the supporting documents provided and asked that evidence be provided of current approval which also reflected the significant changes that have been made to the study.

NHS Digital explained that, following an assessment of the historical consent material, there did not appear to be a legal basis, in respect of the common law duty of confidentiality, to hold the cancer registration data for approximately 100 members of the cohort recruited prior to 2009. Those members had not previously been identified to NHS Digital as having given consent using different versions of the consent materials which did not explicitly cover access to cancer registration data, unlike the participants who were subsequently recruited. NHS Digital advised that the applicant was already taking steps to determine whether cancer registration data had been supplied for any of those members and, if so, to destroy this data.

IGARD queried the lack of information around the expected benefits and yielded benefits and suggested on renewal that further information would be expected to be provided.

**Outcome:** recommendation to approve subject to the following condition:

1. To provide evidence of the updated ethics approval to reflect significant changes made to the study.

The following amendments were requested:

	<ol style="list-style-type: none"> <li>1 To insert a special condition to state that any incoming or new funder will not have any influence on the results nor suppress any results.</li> <li>2 To update the abstract on Article 6 and 9 of GDPR to reflect recent discussions between NHS Digital and IGARD regarding the University of Manchester legal basis including (but not limited to) reference to public task.</li> <li>3 To update the abstract to title the section on “Consent” to “Duty of Confidentiality”.</li> <li>4 To clarify size of the cohort and update the data minimisation within section 3.</li> <li>5 To clarify within section 5(a) what “selected patients” means.</li> </ol> <p>The following advice was given:</p> <ol style="list-style-type: none"> <li>1 IGARD advised when the application returns for renewal, IGARD would expect to see further information with regard to expected benefits and yielded benefits.</li> </ol> <p>It was agreed the condition would be approved OOC by the IGARD Chair.</p>
2.4	<p><u>University of Oxford: Knee Arthroscopy and Knee Arthroplasty - Rates of Surgery, Outcomes, Complications (Presenter: Dave Cronin) NIC-68703-R4Y6C</u></p> <p><b>Application:</b> This was an amendment and renewal application for pseudonymised Hospital Episode Statistics (HES) and Civil Registrations data. The purpose is to study knee arthroscopies and knee arthroplasty surgery, investigating trends in surgery, variation in practice, and the outcomes, complications and service use of this type of surgery and factors that may be associated with these.</p> <p><b>Discussion:</b> NHS Digital advised that HES Opt-Out objections were never applied and will not be applied to the new HES data which is consistent with NHS Digital policy.</p> <p>IGARD noted that section 5(a) (Objective) should be updated to include clearer examples for processing and how the applicant has been using the data. IGARD also suggested that the applicant provide further details of pathways for disseminating the outputs of the study to patients and the public including specific examples of public / patient engagement, publications and open access.</p> <p><b>Outcome:</b> recommendation to approve</p> <p>The following advice was given:</p> <ol style="list-style-type: none"> <li>1. IGARD suggested on renewal that further details of pathways of dissemination of the outputs be provided, including examples of public / patient engagement, publications and open access.</li> </ol>
2.5	<p><u>UK Biobank: MR1109 – UK Biobank – Renewal / Extension (Presenter: Dave Cronin) NIC-08472-V9S6K</u></p> <p><b>Application:</b> This was an extension and renewal application for identifiable Mental Health and Learning Disabilities Data Set (MHLDDS), Medical Research Information Service (MRIS), Diagnostic Imaging Dataset (DIDs), bridge file Hospital Episode Statistics (HES) to Mental Health Minimum Data Set (MHMDS) and bridge file Hospital Episode Statistics (HES) to Diagnostic Imaging Dataset (DIDs). The purpose is to create a prospective epidemiological resource of the 500,000 people aged 45-69 and set up and manage a major international research resource for health-related research.</p> <p><b>Discussion:</b> IGARD queried the legal basis relied on for processing NHS Digital Data, as set out in the application, and clarification of how this aligns with the legal bases outlined in the applicant’s published privacy notice on their website and asked for further confirmation, since the applicant was relying on two legal bases and should expressly state their legal basis as outlined in the ICO guidance.</p>

	<p>IGARD noted that they would welcome the General Data Protection Regulation (GDPR) legal bases for the processing of data provided from other sources, since it was not clear within the application, but this additional information may explain why there were multiple legal bases in the applicant's privacy notice.</p> <p>IGARD noted that the application had previously been presented to its predecessor the Data Access Advisory Group (DAAG) in 2015 and an action had been raised and noted in the published minutes, to provide a case study and asked for clarity on how this action had been addressed.</p> <p>IGARD noted information provided in supporting document 7.1, funding letter, and queried if discussions were still ongoing on the funding and asked for the application to be updated to confirm that funding is continuing or now in place and provide the relevant evidence. IGARD asked that the application be updated to state that any funders were not involved in the study, other than providing funding, nor will they have any influence on the results nor suppress any results.</p> <p>IGARD noted that the applicant's fair processing notice did not meet NHS Digital's fair processing criteria for privacy notices and suggested that section 4 (Privacy Notice) be updated to clearly state that the application privacy notice 'does not' meet the criteria.</p> <p><b>Outcome:</b> Recommendation to defer, pending:</p> <ol style="list-style-type: none"> <li>1 To provide further confirmation of the legal basis relied on for processing NHS Digital Data, as set out in the application, and clarification of how this aligns with the legal bases outlined in the applicant's published privacy notice.</li> <li>2 Clarification of the GDPR legal bases for the processing of data provided from other sources would be welcomed.</li> <li>3 To clarify how the action raised by DAAG in 2015 with regard to providing a case study has been addressed.</li> <li>4 The application should be updated to confirm that funding is continuing or now in place and provide the relevant evidence.</li> <li>5 To confirm that any funder will not have influence on the outcomes nor suppress any outcomes of research.</li> <li>6 To update section 4 to clearly state the applicant's fair processing notice "does not" meet NHS Digital's fair processing criteria for privacy notices.</li> </ol>
2.6	<p><u>NHS Eastern Cheshire CCG: DSfC – NHS Eastern Cheshire CCG – IV (Presenter: James Humphries-Hart) NIC-35107-B1P1X</u></p> <p><b>Application:</b> This was a new application for identifiable Secondary Uses Service (SUS) data for Commissioners data covering invoice validation (IV) which is part of a process by which providers of care or services are paid for the work they do.</p> <p>NHS Digital noted that reference to s251 support should be included in section 7 (Ethics Approval) and section 5(b) (processing activities) be updated.</p> <p><b>Discussion:</b> IGARD noted that there was reference within section 5(b) (Processing Activities) of the application to "data held in section 3(a)" and asked that this be removed due to this being a new application and therefore no data is held.</p> <p>IGARD noted that within section 3(a) (Common Law Duty of Confidentiality) it states "<i>Does not include the flow of Confidential data</i>" and asked that this reference be removed and s251 Health Research Authority Confidentiality Advisory Group (HRA CAG) support be referenced.</p> <p>IGARD also noted that section 7 (Ethics Approval) be updated to include reference to s251 HRA CAG support.</p>

	<p>IGARD noted that there was a reference to 'clear data' within supporting document 1 - the data flow diagram and asked that this be removed.</p> <p><b>Outcome:</b> recommendation to approve</p> <p>The following amendments were requested:</p> <ol style="list-style-type: none"> <li>1 To remove reference within section 5 to "data held in section 3(a)" since this is a new application and no data is held.</li> <li>2 To remove reference to 'no flow of confidential data' from Section 3 and include reference to s251 HRA CAG support.</li> <li>3 To remove reference to 'clear data' from the data flow diagram.</li> <li>4 To update section 7 to include reference to s251 HRA CAG support under "approval considerations".</li> </ol>
2.7	<p><u>NHS South Norfolk CCG: DSfC – NHS South Norfolk CCG (Presenter: James Humphries-Hart) NIC-215114-S6J7P</u></p> <p><b>Application:</b> This was a new application for identifiable Secondary Uses Service (SUS) data for risk stratification which is a tool for identifying and predicting which patients are at high risk or likely to be at high risk and prioritising the management of their care.</p> <p>NHS Digital that the GDPR Article 6 and 9 wording within section 1 (Abstract) should be updated and that the section 8 (data retention) should be updated to correct the date</p> <p><b>Discussion:</b> IGARD noted that NHS Digital had included within the abstract the applicant's legal basis under the General Data Protection Regulation (GDPR) Article 6 and 9, however IGARD suggested that a clear justification for each choice indicated should be given in terms of how the specific criteria and additional requirements would be met since the applicant would need to satisfy the relevant tests associated with the legal basis suggested and as per recent discussions between NHS Digital and IGARD, including to 'no less intrusive to the data subject' wording under Article 9(2)(h) in the Public Task section of the abstract.</p> <p>IGARD noted that section 8(a) (Data Retention) currently states "...3 years to enable trend analysis' and needed updating with the relevant wording.</p> <p><b>Outcome:</b> recommendation to approve</p> <p>The following amendments were requested:</p> <ol style="list-style-type: none"> <li>1 To update the abstract sections on Article 6 and 9 of GDPR to reflect recent discussions between NHS Digital and IGARD including (but not limited to) reference to 'no less intrusive to the data subject' wording under Article 9(2)(h).</li> <li>2 To update the data retention table in section 8.</li> </ol>
2.8	<p><u>NHS Lincolnshire East CCG: DSfC – Lincolnshire East CCG – STP commissioning – 4 CCGs (Presenter: James Humphries-Hart) NIC-224512-Z9W0B</u></p> <p><b>Application:</b> This was a new application for pseudonymised Secondary Uses Service (SUS), Mental Health Minimum Data Set (MHMDS), Mental Health Learning Disability Data Set (MHLDDS), Mental Health Services Data Set (MHSDS), Maternity Services Data Set (MSDS), Improving Access to Psychological Therapy (IAPT), Children and Young People Health Service (CYPHS), Community Services Data Set (CSDS), Diagnostic Imaging Data Set (DIDS), National Cancer Waiting Times Monitoring Data Set (CWT). The purpose is for 4 Clinical Commissioning Group's to commission as a Sustainable Transformation Partnership, which is responsible for implementing large parts the 5 Year Forward View set out by NHS England.</p>

	<p>NHS Digital noted that the DPA expiry date for Optum Health Solutions UK Ltd was incorrect and section 5(b) (processing activities) be updated to remove reference to it being a new application.</p> <p><b>Discussion:</b> IGARD noticed that in section 1(c) (Data Processor(s)) the Data Protection Act expiry date for Optum Health Solutions UK Limited is showing as 6<sup>th</sup> November 2018 and asked that this be updated with the correct date of 2019.</p> <p>IGARD noted that there was a typo in section 2(a) (Processing Location(s)) when referring to 'NHS Arden and Greater East Midlands Commissioning Support Unit' and asked that this be amended.</p> <p>IGARD noted that section 5(b) (Processing Activities) states <i>"Data can only be stored at the addresses listed under storage addresses"</i> and asked that this be updated to correctly list data processors addresses within the 'storage location' section.</p> <p>IGARD noted that there was reference within section 5(b) (Processing Activities) of the application to "data held in section 3(a)" and asked that this be removed due to this being a new application and therefore no data is held.</p> <p><b>Outcome:</b> recommendation to approve</p> <p>The following amendments were requested:</p> <ol style="list-style-type: none"> <li>1 To update the DPA expiry date for Optum Health Solutions UK Ltd.</li> <li>2 To correct the spelling of NHS Arden and Greater East Midlands Commissioning Support Unit in section 2(a).</li> <li>3 To update section 5(b) to correctly list data processors addresses within the 'storage location' section.</li> <li>4 To remove reference within section 5(b) the application to "data held in section 3(a)" since this is a new application and no data is held.</li> </ol>
2.9	<p><u>University of Sheffield: MR1452 - The Invasive Dentistry – Endocarditis Association (IDEA) Study: A study of the link between invasive dental procedures and critical medical events including infective endocarditis, myocardial infarction, stroke, pulmonary embolus and spontaneous pre-term birth. (Presenter: Dickie Langley) NIC-116377-L5J9M</u></p> <p><b>Application:</b> This was a new application for pseudonymised Hospital Episode Statistics (HES) and identifiable Medical Research Information Service (MRIS) data for the purpose of a study looking at the link between invasive dental procedures and critical medical events; including infective endocarditis, myocardial, stroke, pulmonary embolus and spontaneous pre-term birth. There are concerns that bacteria entering the circulation during invasive dental procedures could precipitate these critical medical conditions.</p> <p>The application was previously recommended for approval on the 1<sup>st</sup> February 2018, subsequently the applicant has updated the application to include MRIS Bespoke product, and an additional Data Processor.</p> <p><b>Discussion:</b> IGARD queried if the s251 support extends to Capita as the Data Processor as there was no reference to them in either the Health Research Authority Confidentiality Advisory Group (HRA CAG) support letter or the HRA CAG application, or in the data flow diagram provided with the application.</p> <p>IGARD queried if the s251 support is in the process of being renewed or has been renewed as this was not clear and asked that confirmation be provided, noting that s251 support does not expire.</p> <p><b>Outcome:</b> recommendation to approve subject to the following conditions:</p>

	<ol style="list-style-type: none"> <li>1. To clarify that the s251 support extends to Capita as the Data Processor since they are not referenced within the HRA CAG support letter or HRA CAG application.</li> <li>2. To confirm that s251 support is in the process of being renewed or has been renewed.</li> </ol> <p>It was agreed the conditions would be approved OOC by the IGARD Chair.</p>
2.10	<p><u>Dr Foster Ltd: Summary Hospital-level Mortality Indicator (SHMI) data (Presenter: Dickie Langley) NIC-368020-R5L2K</u></p> <p><b>Application:</b> This was a renewal application for pseudonymised Civil Registrations data, Hospital Episode Statistics (HES) data and a summary Hospital-level Mortality Indicator (SHMI) report. NHS customers are provided with a free of charge dashboard that allows for them to analyse and benchmark their performance and produce / analyse statistics to help the NHS perform its duties.</p> <p>NHS Digital advised that supporting documents 2 and 3 that were provided to IGARD were not relevant to this application and should be removed from the Customer Relationship Management (CRM) system.</p> <p><b>Discussion:</b> IGARD noted that sections 1(b) (Data Controller(s)) and 1(c) (Data Processor(s)) incorrectly reference to data processors address as being in Scotland and asked that this be removed.</p> <p>IGARD queried whether the HES SHMI data extract contains any data relating to living individuals as this was not clear and asked that the application be updated to clarify this information.</p> <p>IGARD noted the difficulties for customers who produce business intelligence tools to provide yielded benefits, even where data had been flowing for some time, however IGARD suggested on renewal further information would be expected to be provided, which could also include a representative case study from a user of the tool.</p> <p>IGARD endorsed NHS Digital's review of the applicant's privacy notice and that it should include reference to mortality data, for transparency.</p> <p><b>Outcome:</b> recommendation to approve</p> <p>The following amendments were requested:</p> <ol style="list-style-type: none"> <li>1. To remove supporting documents 2 and 3 from the holder on CRM since they are not relevant to this application.</li> <li>2. To remove the incorrect reference to 'Scotland' from the data processors addresses in section 1(b) and 1(c).</li> <li>3. To clarify whether the HES SHMI data extract contains any data relating to living individuals and for the application to be updated accordingly.</li> </ol> <p>The following advice was given:</p> <ol style="list-style-type: none"> <li>1 IGARD suggested on renewal that the applicant provide further details of the benefits which could include a representative case study from a user of the tool.</li> <li>2 IGARD endorsed NHS Digital's review of the applicant's privacy notice and that it should include reference to mortality data, for transparency.</li> </ol>
2.11	<p><u>The University of Manchester: Investigation of the association between different forms of healthcare support for care home residents and both hospital admissions and place of death (Presenter: Dickie Langley) NIC-186860-T7H5K</u></p> <p><b>Application:</b> This was a new application for Hospital Episode Statistics (HES) Civil Registration (Deaths) Bridge data, Civil Registrations (Deaths) Second Care Cut data and</p>

	<p>HES Admitted Patient Care (APC) data to explore the forms, content and impacts of healthcare support to care homes, investigating the association between the different forms of healthcare support provided for long term care home residents and both emergency hospital admissions and locus of death by being provided with a list of postcodes that relate to the care homes within the Greater Manchester area enabling the linkage to HES APC and fact and place of death.</p> <p>The application was been previously considered on the 13<sup>th</sup> September 2018 when IGARD had deferred making a recommendation pending; the applicant should work with NHS Digital on a fair processing notice which is GDPR compliant including (but not limited to) being in appropriate language for the participants (having regard to both age and potential capacity issues) and to consider the most suitable methods for disseminating the transparency information; to consider how to carry out fair processing for any non-care home residents who may be captured by the care home postcode; to update the application to correctly reference the data within the application as being ‘identifying’ not ‘identifiable’; to explain the consideration that has been given to minimising capture of data of non-care home residents and to build a narrative to support how the proposed processing will meet the necessity test under GDPR; to clearly state within section 5 the number of care homes to be included within the research; to give consideration to running a small pilot to establish how many non-care home residences may be captured by a care home postcode and to updating the application with this information; to update the application to use the correct terminology of ‘care home’ rather than ‘nursing home’; to remove reference to the ‘latest release available’ referenced in section 3(b); to remove the special condition referencing the Data Protection Act 1998 since it is not relevant to this application</p> <p><b>Discussion:</b> IGARD noted that application had been updated to reflect most of the comments previously raised and commended the innovative approach to data production to avoid processing the data of non-care home residents.</p> <p>IGARD noted that there were inconsistencies within section 1(a) (Abstract) and section 5(b) (Processing Activities) of the number of care homes involved as part of the study and asked for clarification across the application.</p> <p>IGARD noted that there was a mis-match of information relating to the funding in the application and supporting document 1, evidence of the funding, provided and asked for further clarity in section 8 (Funding Sources).</p> <p>IGARD suggested that the applicant may wish to update their privacy notice to (but not limited to) use language suitable for its potentially vulnerable audience for example by avoiding using technical terms like “pseudonymised”</p> <p><b>Outcome:</b> recommendation to approve</p> <p>The following amendments were requested:</p> <ol style="list-style-type: none"> <li>1 Clarification, for consistency across the application, of the number of care homes involved.</li> <li>2 To clarify within section 8 the funding in place, since there was a mismatch between the application and supporting document 1 (the evidence of funding that was provided).</li> </ol> <p>The following advice was given:</p> <ol style="list-style-type: none"> <li>1. IGARD suggested that the applicant update their privacy notice to (but not limited to) use language suitable for its potentially vulnerable audience (for example by avoiding using technical terms like “pseudonymised”).</li> </ol>
2.12	<u>Birmingham City Council: LAPH HES (Presenter: Duncan Easton) NIC-25007-J9M9P</u>

**Application:** This was an amendment application for pseudonymised Hospital Episode Statistics (HES) data to be used to support the Local Authority's fulfilment of its public health and commissioning functions.

**Discussion:** IGARD noted that the applicant was requesting national data and queried whether for commissioning purposes the applicant should have access to a smaller subset of the national data. Depending on the outcome of this analysis, IGARD requested the applicant set out the access controls in place or provide justification of the provision of national data for commissioning purposes and address how the necessity test has been met, specifically for commissioning purposes.

IGARD queried what the outputs and benefits were for receiving national data and what the justification was for the use of national data in relation to the various processing that is being undertaken and asked for further clarification in section 5 (Purpose / Methods / Outputs).

IGARD queried the information in section 5(b) (Processing Activities) and asked that it be clearly stated that NHS Digital will not be transferred out of England and Wales.

IGARD queried if the necessity of the processing for the performance of the task has been assessed by NHS Digital to ensure that only the minimum amount of data required is processed and that consideration has been given to whether the volume of data being requested is proportionate to the expected benefits and whether the task itself is necessary and asked that it be expressly stated with the application.

IGARD noted that NHS Digital had included within the abstract the applicant's legal basis under the General Data Protection Regulation (GDPR) Article 6 and 9, however IGARD suggested that a clear justification for each choice indicated should be given in terms of how the specific criteria and additional requirements would be met since the applicant would need to satisfy the relevant tests associated with the legal basis suggested and as per recent discussions between NHS Digital and IGARD, including to 'no less intrusive to the data subject' wording under Article 9(2)(h) in the Public Task section of the abstract.

IGARD noted that the abstract should be updated to make specific reference to the Article 9(2)(h) of the GDPR and the Data Protection Act (DPA) 2018 and provide a clear description of how the schedule conditions are met.

IGARD suggested the abstract be updated with reference to 9(2)(h) to expand the activities in addition to 'service evaluation', for example including "public health" or similar.

IGARD noted that NHS Digital had included within the abstract the applicant's legal basis under the General Data Protection Regulation (GDPR) Article 9, however IGARD suggested that a clear justification for each choice indicated should be given in terms of how the specific criteria and additional requirements would be met since the applicant would need to satisfy the relevant tests associated with the legal basis suggested and as per recent discussions between NHS Digital and IGARD, including the processing being undertaken.

**Outcome:** Recommendation to defer, pending:

1. To address whether for commissioning purposes the applicant should have access to a smaller subset of the national data provided and to set out the access controls in place OR to provide a justification of the provision of national data for commissioning purposes and address how the necessity test has been met, specifically for commissioning purposes.
2. To update section 5 to clearly define how the outputs and benefits listed justify and reflect the use of national data.
3. To update section 5 to justify the use of national data in relation to all the various processing being undertaken.

	<ol style="list-style-type: none"> <li>4. To update section 5(b) to clearly state that NHS Digital data will not be transferred outside of England and Wales.</li> <li>5. To expressly state with the application that the necessity for the processing for the performance of task has been assessed by NHS Digital to ensure that only the minimum amount of data required is processed and consideration has been given to the whether the volume of data being requested is proportionate to the expected benefits and whether the task is itself necessary.</li> <li>6. To update the abstract sections on Article 6 and 9 of GDPR to reflect recent discussions between NHS Digital and IGARD including (but not limited to) reference to ‘no less intrusive to the data subject’ wording under Article 9(2)(h) and justification of public task.</li> <li>7. The abstract should be updated to make specific reference to Article 9(2)(h) GDPR and the DPA 2018 and clearly describe how the schedule conditions are met.</li> <li>8. To update the abstract with reference to 9(2)(h) to expand the activities in addition to ‘service evaluation’, for example including “public health” or similar.</li> <li>9. To update the abstract section on Article 9 to expressly refer to Article 9(3) GDPR and section 11(1) DPA 2018, to the conditions found therein and how these are met (for example naming the role of the relevant healthcare professional).</li> <li>10. To expressly state with in section 5(b) that the data held will be segregated from any identifiable data already held by the applicant.</li> </ol>
<b>3.</b>  <b>3.1</b>	<p><b>AOB</b></p> <p>Chair’s action</p> <p>The Chair of IGARD drew the members’ attention to the published minutes of the 1 November 2018 meeting noting that the outcome for NIC-140981-R5W6Z University College London had been amended following the meeting via Chair’s action (following discussion with NHS Digital and taking advice from a specialist member). Members present noted their contentment with the Chair’s action.</p>

### Independent Group Advising on Releases of Data (IGARD): Out of committee report 09/11/18

These applications were previously recommended for approval with conditions by IGARD, and since the previous Out of Committee Report the conditions have been agreed as met out of committee.

NIC Reference	Applicant	IGARD meeting date	Recommendation conditions as set at IGARD meeting	IGARD minutes stated that conditions should be agreed by:	Conditions agreed as being met in the updated application by:	Notes of out of committee review (inc. any changes)
NIC-79728-X2C2X	Lancashire Care NHS FT	20/09/18	1. To obtain confirmation from the substantive employer (by way of a letter of assurance or similar) of those on honorary contracts that they agree to be bound by and take action in line with the terms of the relevant honorary contract.	Quorum of IGARD Members	Quorum of IGARD Members	N/A
NIC-192032-K0J3X	NHS Calderdale CCG	18/10/18	1. To provide further information within section 5 of the data minimisation efforts undertaken by the applicant and cross reference this within section 3(b). 2. Giving a clear explanation within section 5 of the application the relationship of Kier Business Services Limited and Dr Foster Limited with the other Data Processors outlined within the application, including	Quorum of IGARD Members	Quorum of IGARD Members	N/A

			any data they may have access to.			
NIC-148044-RGS7W	University of Oxford	11/10/18	<ol style="list-style-type: none"> <li>1. To clarify whether London School of Hygiene and Tropical Medicine has retained a copy of the data after they disseminated to the University of Oxford and to confirm if they have been issued a data destruction certificate.</li> <li>2. To clarify whether University College London hold any data previously received and if so, to confirm they have been issued a data destruction certificate.</li> <li>3. To revise the GDPR public task legal basis in the abstract for each of the Universities in accordance with IGARD advice.</li> </ol>	Quorum of IGARD Members	Quorum of IGARD Members	N/A

In addition, the following applications were not considered by IGARD but have been progressed for IAO and Director extension/renewal:

- None notified to IGARD