

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

### Minutes of meeting held 24 January 2019

**Members:** Sarah Baalham, Joanne Bailey, Kirsty Irvine (Chair), Priscilla Maguire, Eve Sariyiannidou.

**In attendance:** Dave Cronin, Louise Dunn, Rachel Farrand, James Humphries-Hart, Karen Myers, Vicki Williams.

**Apologies:** Anomika Bedi, Maria Clark, Nicola Fear.

**Observer:** Frances Hancox (Item 2.3 – 2.4), Frances Perry.

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| 1   | <p><b>Declaration of interests:</b></p> <p>Eve Sariyiannidou noted professional links to HQIP [NIC-238613-D3W0L – University of Oxford] but noted no specific connection 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 17<sup>th</sup> January 2019 IGARD meeting were reviewed and were agreed as an accurate record of that aspect of the meeting.</p> <p>The minutes of the 17<sup>th</sup> January 2019 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>NHS Bury CCG: DSfC – NHS Bury CCG; RS, Comm; IV (Presenter: James Humphries-Hart) NIC-47174-R9S4W</u></p> <p><b>Application:</b> This was an amendment and renewal application for pseudonymised Secondary Uses Service (SUS), Local Provider Flows, Mental Health Services Data Set (MHSDS), National Cancer Waiting Times Monitoring Data set (CWT), Mental Health and Learning Disabilities Data Set (MHLDDS), Mental Health Minimum Data Set (MHMDS), Children and Young People's Health Service (CYPHS), Diagnostic Imaging Dataset (DIDs), Improving Access to Psychological Therapies Data Set (IAPT), Maternity Services Data Set (MSDS), Community Services Data Set (CSDS). The data required is for Risk Stratification (RS) 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; Invoice Validation (IV) which is part of a process by which providers of care or services are paid for the work they do; and to provide intelligence to support the commissioning of health services.</p> <p>NHS Digital noted a number of amendments to the application including; removing NHS Arden and Greater East Midlands CSU in their capacity as Data Processor for the purpose of commissioning; updating the processing and storage addresses for NHS Arden and Greater East Midlands CSU; to change the storage address for Oldham CCG for Disaster Recovery; to remove Diagnostic Imaging Dataset, Community Services Data Set, Maternity Services Data Set and Cancer Waiting Times Data Set from the application as the remaining data processors do not process these data sets; to remove AQUA from the application as this is now covered by a regional DSA however Salford Royal NHS Foundation Trust will remain listed as a Data Processor since they host the Academic Health Science Network (AHSN).</p> |

**Discussion:** IGARD noted and supported the amendments outlined by the presenter and asked that, since they are substantial in number, these be reviewed Out of Committee (OOC) by the IGARD Chair.

IGARD noted that the standard geographical data minimisation wording was not included in section 5(b) (Processing Activities) and asked that this be updated clearly stating which CCG's are relevant to the application.

IGARD noted the special condition in section 6 (Special Conditions) clearly outlining when the identifiable data will be disclosed and asked that this, along with the seven points of criteria, were replicated within section 5 (Purpose / Methods / Outputs).

IGARD noted the standard wording in section 4 (Privacy Notice) reads "All data required by the Data Controller under this agreement..." and should be amended to read "Data processed under this agreement..." and to also remove "...but at the latest within one month" from the end of the sentence. It was also suggested that the applicant review the Article 6 lawful basis which was described within their privacy notice and that the applicant should consider amending their privacy notice to align these changes with their DPIA including, but not limited to, ensuring the appropriate subject rights are recorded.

IGARD noted that when searching through a search engine an out of date privacy notice could be accessed, and suggested that the applicant should remove any out of date privacy notices from their website and ensure they are not accessible.

IGARD queried the reference to India within section 1 (Abstract) and asked that a special condition be inserted in section 6 stating that no data shall be transferred outside the territory of use noted in this agreement (England and Wales), and to replicate this within section 5.

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

1. To update section 5(b) with the standard geographical data minimisation wording, clearly stating which CCG's are relevant to the application.
2. All amendments, since they are substantial in number, to be reviewed OOC by the IGARD Chair.

The following amendments were either noted by the presenter and agreed by IGARD, or requested by IGARD:

1. To remove NHS Arden and Greater East Midlands CSU in their capacity as Data Processor for the purpose of commissioning.
2. To update the processing and storage addresses for NHS Arden and Greater East Midlands CSU as these have changed.
3. To change the storage address for Oldham CCG for Disaster Recovery.
4. To remove Diagnostic Imaging Dataset, Community Services Data Set, Maternity Services Data Set and Cancer Waiting Times Data Set from the application as the remaining data processors do not process these data.
5. To remove Advancing Quality Alliance (AQuA) from the application as this is now covered by a regional DSA.
6. To replicate the Special Condition in section 6 relating to 'identifiable data' (including the 7 points of criteria) within section 5.
7. To amend the standard wording within section 4 to read: "Data processed under this agreement..." and to also remove "...but at the latest within one month" from the end of the sentence.
8. To insert a special condition that no data shall be transferred outside the territory of use noted in this agreement which is England and Wales, and to replicate this within section 5.

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|     | <p>The following advice was given:</p> <ol style="list-style-type: none"> <li>1. In reviewing Article 6 the lawful basis described in the privacy notice, if the applicant needs to make amendments they should consider also aligning these changes with the DPIA and ensure the appropriate subject rights are recorded.</li> <li>2. To remove any out of date privacy notices from their website and ensure they are not accessible.</li> </ol> <p>It was agreed the conditions would be approved OOC by the IGARD Chair</p>   |
| 2.2 | <p><u>NHS East Riding of Yorkshire CCG: DSfC – NHS East Riding of Yorkshire CCG, IV RS Comm with GP/social/consent linkage (Presenter: James Humphries-Hart) NIC-90658-F0W4R</u></p> <p><b>Application:</b> This was an amendment application for pseudonymised Secondary Uses Service (SUS), Local Provider Flows, Mental Health Services Data Set (MHSDS), National Cancer Waiting Times Monitoring Data set (CWT), Mental Health and Learning Disabilities Data Set (MHLDDS), Mental Health Minimum Data Set (MHMDS), Children and Young People's Health Service (CYPHS), Diagnostic Imaging Dataset (DIDs), Improving Access to Psychological Therapies Data Set (IAPT), Maternity Services Data Set (MSDS), Community Services Data Set (CSDS). The data required is for Risk Stratification (RS) 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; Invoice Validation (IV) which is part of a process by which providers of care or services are paid for the work they do; and to provide intelligence to support the commissioning of health services.</p> <p>NHS Digital noted that the standard geographical data minimisation wording was not included in section 5(b) (Processing Activities).</p> <p>NHS Digital noted that unless listed as a Data Processor or Data Controller, that other eMBED consortium members will not have access the data under this application or Data Sharing Agreement.</p> <p>NHS Digital noted that the eMBED consortium members are referred to differently throughout the application and the full and correct legal names would need to be used throughout the application.</p> <p><b>Discussion:</b> IGARD noted and supported the amendments that needed making to the application including adding the standard geographical data minimisation wording within 5(b) (Processing Activities) stating which CCG's are relevant to the application, that unless listed as a Data Processor or Data Controller, that other eMBED consortium members would not have access the data under this application or Data Sharing Agreement and that a special condition be included within section 6 (Special Conditions) stating this and for this to be also replicated in section 5 (Purpose / Methods / Outputs) and that the eMBED consortium members referred to differently throughout the application that for consistency the full and correct names would be used throughout the application.</p> <p>IGARD queried if any other company within the Kier Group would have access to the data and asked that a special condition be included in section 6 stating that no other company within the Kier Group would have access to the data other than the Kier entity listed within the data sharing agreement / application.</p> <p>IGARD queried the roles undertaken by Kier Business Service Limited and Dr Foster Limited in their role as data processors and asked that be differentiated this in section 5(b), along with clarity on how this differentiates from the CCG's role as a data processor; and to provide further clarity on what service each data processor provides.</p> |

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|     | <p>IGARD noted the standard wording in section 4 (Privacy Notice) reads “All data required by the Data Controller under this agreement...” and should be amended to read “Data processed under this agreement...” and to also remove “...but at the latest within one month” from the end of the sentence.</p> <p>IGARD queried the information provided in supporting document 1, the data flow diagram and asked that this be correctly aligned with the description of activities described within the application.</p> <p>IGARD queried the reference to India within section 1 (Abstract) and asked that a special condition be inserted in section 6 stating that no data shall be transferred outside the territory of use noted in this agreement (England and Wales), and to replicate this within section 5.</p> <p><b>Outcome:</b> recommendation to approve subject to the following conditions:</p> <ol style="list-style-type: none"> <li>1. To update section 5(b) with the standard geographical data minimisation wording, clearly stating which CCG’s are relevant to the application.</li> <li>2. To include a special condition in section 6 that no other company within the Kier Group will have access to the data other than the Kier entity listed in the agreement.</li> <li>3. To differentiate within section 5(b) the different roles undertaken by Kier Business Service Limited and Dr Foster Limited in their role as data processors, and in addition, how this also differentiates from the CCG’s role as a data processor to provide clarity on what services each data processor provides.</li> </ol> <p>The following amendments were requested:</p> <ol style="list-style-type: none"> <li>1. To use the full and correct names for each of the eMBED consortium members outlined throughout the application.</li> <li>2. To amend the standard wording within section 4 to read: “Data processed under this agreement...” and to also remove “...but at the latest within one month” from the end of the sentence.</li> <li>3. To align the description of activities described within the application with the data flow diagram provided.</li> <li>4. To include a special condition within section 6, clearly stating that unless listed as a Data Processor or Data Controller, other eMBED consortium members will not have access the data under this application / Data Sharing Agreement, and to replicate this statement in section 5.</li> <li>5. To insert a special condition that no data shall be transferred outside the territory of use noted in this agreement which is England and Wales, and to replicate this within section 5.</li> </ol> <p>It was agreed the condition would be approved OOC by the IGARD Chair.</p> |
| 2.3 | <p><u>Newcastle University: Impact of a community based social prescribing intervention in an ethnically diverse area of high socio-economic deprivation. Exploiting a natural experiment to evaluate effects on health and health care utilisation with economic assessment and ethnographic observation. (Presenter: Rachel Farrand) NIC-204646-B9G2N</u></p> <p><b>Application:</b> This was a new application for pseudonymised Secondary Use Service (SUS) for Commissioners data which will be used to evaluate a study into Social Prescribing, focusing specifically on the Ways to Wellness programme, which is a service for people with certain long-term health conditions to provide support with activities such as becoming more active, healthy eating and benefits support.</p> <p><b>Discussion:</b> IGARD welcomed the application and noted the potential national importance of the study, in addition to the outputs and benefits provided in section 5 (Purpose / Methods /</p>  |

Outputs).

IGARD noted that the application referenced the data requested as 'identifiable' and asked that this be updated to correctly reference the data as 'identifying' or otherwise change to 'pseudonymised'.

IGARD noted that section 1 (Abstract) should be updated to ensure that Article 6 and 9 of the GDPR reflects recent discussions between NHS Digital and IGARD regarding the legal basis including (but not limited to) reference to public task.

IGARD noted that the abstract should be updated to ensure that sections on Article 9(2)(j) of General Data Protection Regulation (GDPR) were updated to reflect recent discussions between NHS Digital and IGARD, including (but not limited to) reference to research purposes in the public interest condition under the Data Protection Act (DPA) 2018.

IGARD queried the references to 'evaluation' in section 5 and the presenter explained that the applicant was clear that this was research and not a service evaluation. IGARD asked that where possible references to "evaluation" be removed to avoid confusion with the purpose of the application and to ensure a coherent theme of that of a research study.

IGARD noted and endorsed NHS Digital's review that the applicant's privacy notice does not meet NHS Digital's fair processing criteria for privacy notices. IGARD suggested that the applicant work with NHS Digital to revise the privacy notice, including to ensure that it reflects all aspects of the study, not just diabetes, and that identifying GP data will be flowing into the Commissioning Support Unit (CSU).

IGARD advised that the applicant should ensure that GP data controllers are aware of and content with data flows to the CSU for research purposes in this application, and that information is made available to patients and the public about the data flows from GP practices and Ways to Wellness in this application for research purposes, including the ability to opt out.

**Outcome:** recommendation to approve

The following amendments were requested:

1. To update the application to correctly reference the data within the application as being 'identifying' not 'identifiable', or otherwise change to 'pseudonymised'.
2. To update the abstract on Article 6 and 9 of GDPR to reflect recent discussions between NHS Digital and IGARD regarding the legal basis including (but not limited to) reference to public task.
3. To update the abstract sections on Article 9(2)(j) of GDPR to reflect recent discussions between NHS Digital and IGARD, including (but not limited to) reference to research purposes in the public interest condition under the DPA 2018.
4. To remove reference to 'evaluation', where possible, from section 5.

The following advice was given:

1. IGARD endorsed NHS Digital's review that the applicant's privacy notice does not meet NHS Digital's fair processing criteria for privacy notices and suggested that the applicant works with NHS Digital to ensure this reflects all aspects of the study, not just diabetes, and that identifying GP data will be flowing into CSU.
2. IGARD advises the applicant ensures that GP data controllers are aware of and content with data flows to the CSU for research purposes in this application, and that information is available to patients and the public about the data flows from GP practices and Ways to Wellness in this application for research purposes including the ability to opt out.

**Application:** This was an extension application for pseudonymised Medical Research Information Service (MRIS) data for a study of White and South Asian individuals aiming to explore the relationship between risk factors for cardiovascular disease (CVD) and diabetes in these two populations; and to examine if differences in the relationship between the risk factors and CVD and diabetes between the populations were apparent.

**Discussion:** IGARD noted that section 1 (Abstract) should be updated to include specific reference to Article 9(2)(j) General Data Protection Regulation (GDPR) and the Data Protection Act (DPA) 2018 and clearly describe how the schedule conditions are met.

IGARD noted that under the heading 'Common Law Duty of Confidentiality' in section 3 (Datasets Held / Requested) it incorrectly referenced consent as being the legal basis and asked that this be removed due to the data being pseudonymised.

IGARD queried if a number of ethnic groups or just two ethnic groups were part of the study and if just two ethnic groups were part of this study that clarification be sought and made clear within section 5(d) (Benefits).

IGARD noted the applicant should provide a fair processing notice that it is compliant with the notice requirements under the GDPR and suggested that they work with NHS Digital to amend their current privacy notice including (but not limited to) contact details for a Data Protection Officer, removing reference to anonymised data and to also consider a cohort-appropriate local communication strategy for the fair processing material.

IGARD noted that section 5(a) (Objective for Processing) 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 plans, particularly since this is a long running study.

IGARD noted that should the applicant require future identifiable data in the future that NHS Digital and the applicant should consider the legal basis for the processing of data for flagged individuals for any future application.

**Outcome:** recommendation to approve

The following amendments were requested:

1. The abstract should be updated to make specific reference to Article 9(2)(j) GDPR and the DPA 2018 and clearly describe how the schedule conditions are met.
2. To remove reference to the legal basis as being consent in section 3 due to the data being pseudonymised.
3. To make it clear within section 5(d) that there are just two ethnic groups that are being studied.

The following advice was given:

1. IGARD suggested that the applicant should work with NHS Digital on a fair processing notice that is GDPR compliant including (not limited to) contact details for a Data Protection Officer, removing reference to anonymised data and to consider a cohort-appropriate local communication strategy for this fair processing material.
2. IGARD advised when the application returns to IGARD for renewal, IGARD would expect to see further information with regard to benefits and outputs including examples of public / patient engagement plans, particularly since this is a long running study.

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|     | <p>3. IGARD suggested that NHS Digital and the applicant should consider the legal basis for the processing of data for flagged individuals for any future application.</p>  |
| 2.5 | <p><u>University of Leeds: UK GRACE Risk Score Intervention Study (UKGRIS) (Presenter: Louise Dunn) NIC-112910-R4X9X</u></p> <p><b>Application:</b> This was a new application for identifiable Hospital Episode Statistics (HES) and Civil Registrations data for a prospectively studied scoring system to risk stratify patients with diagnosed Acute Coronary Syndrome (ACS) to estimate their in-hospital and 6-month to 3-year mortality.</p> <p>NHS Digital advised that a request had been submitted for an audit on the organisation in relation to this application / data sharing agreement.</p> <p><b>Discussion:</b> IGARD noted this was both a useful and important study and queried why the data was required now if the analysis was not due to start until 2020. NHS Digital advised that the main analysis will start at a later date and that preliminary work exploring the methodology will start now. IGARD asked that section 5(a) (Objective for Processing) be updated to reflect this information with a clear narrative.</p> <p>IGARD queried the reference to 'identifiers' in section 1 (Abstract) and section 5(a) and asked that it be made clear that the research data set is without "direct" identifiers.</p> <p>IGARD noted that the common law duty of confidentiality section within section 1 was incomplete and asked that this be completed and updated with the standard wording.</p> <p>IGARD noted that section 5(a) contained a lot of relevant technical information and suggested that the beginning of section 5(a) should be updated to include a brief summary for the lay audience.</p> <p>IGARD queried the wider dissemination strategy and asked that a detailed assessment was provided as background to the strategy or details provided about routes to wider dissemination.</p> <p>IGARD queried what data will be downloaded and asked that section 5(c) (Specific Outputs Expected) be amended to clarify what it will be used for. IGARD also noted the reference to the independent Data Monitoring Committee and asked that the application include further information on this, including clarifying the nature of the data they will receive or be presented with.</p> <p>IGARD noted the reference to 'binding stopping rules' in section 5(c) and asked for clarity on what this meant by this.</p> <p>IGARD noted and endorsed NHS Digital's review that the applicant's privacy notice does not meet NHS Digital's fair processing criteria for privacy notices including (but not limited to) is not easily accessible or in language suitable for a lay reader.</p> <p>IGARD noted and endorsed NHS Digital's request for an audit on the organisation in relation to this application / data sharing agreement.</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 section 5(a) to explain that the main analysis will commence at a later date and that preliminary work exploring methodology will start now.</li> <li>2. Where there is reference in the abstract and section 5(a) to 'identifiers' to be clear that the research data set is without "direct" identifiers.</li> <li>3. To complete the sentence and add the standard wording to the common law duty of confidentiality section within the abstract.</li> </ol> |

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|     | <ol style="list-style-type: none"> <li>4. To add a brief summary for the lay audience at the beginning of section 5(a).</li> <li>5. To provide a detailed assessment of the wider dissemination strategy or the routes to wider dissemination.</li> <li>6. To amend section 5(c) to explain what data will be downloaded and what it will be used for; and explain what the independent Data Monitoring Committee is, and to also clarify nature of data they will receive or be presented with.</li> <li>7. To clarify what is meant by 'binding stopping rules' as referenced in section 5(c).</li> </ol> <p>The following advice was given:</p> <ol style="list-style-type: none"> <li>1. IGARD endorsed NHS Digital's review that the applicant's privacy notice does not meet NHS Digital's fair processing criteria for privacy notices including (but not limited to) is not easily accessible or in language suitable for a lay reader.</li> <li>2. IGARD noted and endorsed NHS Digital's request for an audit on the organisation in relation to this application / agreement.</li> </ol>   |
| 2.6 | <p><u>University of York: English Indices of Deprivation 2019 - Health Deprivation and Disability Domain indicators (Presenter: Louise Dunn) NIC-219055-K4F8R</u></p> <p><b>Application:</b> This was a new application for pseudonymised Hospital Episode Statistics (HES) data for the purpose of calculating and validating indicators of health deprivation for each lower-layer super output area (LSOA) in England. The resulting health deprivation indicators will form part of the English Indices for Deprivation 2019 and will be published as official statistics by the Ministry of Housing, Communities and Local Government.</p> <p><b>Discussion:</b> IGARD queried the Data Controller(s) and the Data Processor(s) outlined in the application given the parties involved in the research as outlined in the supporting documents provided. IGARD asked that the applicant and NHS Digital give further consideration to these roles. IGARD also asked that the appropriate General Data Protection Regulation (GDPR) legal basis for each party be included within section 1 (Abstract). IGARD also asked that, when clarifying the appropriate Data Controller(s) / Data Processor(s), it should be clearly explained within section 5 (Purpose / Methods / Outputs) of the application the roles and responsibilities of those parties including their role in the design of and the responsibility for the project, with a clear narrative for the lay reader.</p> <p>IGARD noted the reference to the Higher Education and Research Act 2017 in section 1 and asked that this be removed since it is not relevant to this application.</p> <p>IGARD noted that the abstract should be amended to update the abstract on Article 6 and 9 of GDPR to reflect recent discussions between NHS Digital and IGARD regarding the legal basis including (but not limited to) reference to public task to clearly pinpoint the statutory function for the Ministry of Housing, Communities and Local Government and clearly linking this to the purpose set out in the application.</p> <p>IGARD noted that the applicant was relying on Article 9(2)(g) and asked that section 1 (Abstract) be updated to describe how the schedule conditions are met under the Data Protection Act (DPA) 2018, and that reference to Article 89(1) be removed since it was not relevant to this application.</p> <p>IGARD noted that the University of York's DPA had expired and asked that this be updated to reflect the correct expiry date.</p> <p>IGARD noted the technical information included within section 5(a) (Objectives for Processing) and suggested that this be revised in terms suitable for a lay reader or a brief lay summary provided at the beginning of section 5(a).</p> |



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|     | <p>IGARD queried whether the application was commercial and asked that this be considered dependant on the parties involved with this project.</p> <p><b>Outcome:</b> Recommendation to defer, pending:</p> <ol style="list-style-type: none"> <li>1. The applicant and NHS Digital to consider the appropriate Data Controller(s) / Data Processor(s) in light of the parties involved in the research as outlined in the supporting documents provided and to include the appropriate GDPR legal basis for each party.</li> <li>2. When clarifying the appropriate Data Controller(s) / Data Processor(s) it should be clearly explained within section 5 of the application the roles and responsibilities of those parties including their role in the design of and the responsibility of the project.</li> <li>3. To delete the paragraph referencing the Higher Education and Research Act 2017 since it is not relevant to this application.</li> <li>4. To update the abstract on Article 6 and 9 of GDPR to reflect recent discussions between NHS Digital and IGARD regarding the legal basis including (but not limited to) reference to public task to clearly pinpoint the statutory function for the Ministry of Housing, Communities and Local Government and clearly linking this to the purpose set out in the application.</li> <li>5. If the applicant is relying on Article 9(2)(g) the abstract should be updated to clearly describe how the schedule conditions are met under DPA 2018, and reference to Article 89(1) should be removed.</li> <li>6. To correctly update the University of York DPA expiry date.</li> <li>7. To revise section 5(a) in terms suitable for a lay reader.</li> <li>8. Dependant on the parties involved with this project, consideration should be given to whether this application is commercial or not.</li> </ol> |
| 2.7 | <p><u>Moorfields Eye Hospital NHS Foundation Trust: Detecting Dementia in the Retina: a Big Data Machine Learning Approach (Presenter: Dave Cronin) NIC-116883-L8W9Q</u></p> <p><b>Application:</b> This was a new application for pseudonymised Hospital Episode Statistics (HES) data to investigate the association between changes of the retina, as measured using retinal photography and scans, with the onset of dementia and will focus on how retinal morphology evolves with time.</p> <p>NHS Digital noted that the reference to the common law duty of confidentiality within section 1 (Abstract) required a heading.</p> <p>NHS Digital noted that where s251 support is outlined in section 1, that the bracketed “in this case NHS Digital” should be removed.</p> <p>NHS Digital noted that that there were two Data Controllers and that section 1 should be updated to pluralise the reference to Data Controller.</p> <p>NHS Digital noted that the data minimisation wording within section 3 (Datasets Held / Requested) needed updating to clearly state that NHS Digital are only providing the HES episodes relating to ICD10 codes.</p> <p>NHS Digital noted that the application needed updating to correctly reference the data within the application as being ‘identifying’ not ‘identifiable’.</p> <p>NHS Digital noted that section 5 (Purpose / Methods / Outputs) refers to “...our analysis” and that this would need removing.</p> <p><b>Discussion:</b> IGARD welcomed the application and noted the importance of the research being undertaken.</p>  |

IGARD praised the applicant's efforts in explaining the risk assessment they had undertaken and the mitigating steps taken to address any risks identified. IGARD were also impressed with how the applicant differentiated their research from other similar studies. IGARD suggested that these aspects of the application could be used as an exemplar by NHS Digital to help other researchers with their applications to the Data Access Request Service (DARS).

IGARD noted and supported the application amendments outlined by NHS Digital.

IGARD noted that section 1 (Abstract) referred to Moorfields Eye Hospital NHS Foundation Trust (MEH) sharing "confidential patient information" and asked that NHS Digital confirm that this was confidential personal information.

IGARD queried what 'direct data processors' were within section 1 and suggested that the word "direct" in front of Data Processors be removed.

IGARD noted that section 1 should be amended to make clear that the applicant is a Foundation Trust and the relevant Article 6 and 9 of the General Data Protection Regulation (GDPR) be updated to reflect recent discussions between NHS Digital and IGARD including, but not limited to, reference to section 43(5) NHS Act 2006 in relation to the legal basis for Foundation Trusts and to remove reference to the Care Act 2014.

IGARD queried the legal bases for each of the Data Controllers and asked that section 1 be updated to clearly delineate this.

IGARD queried if any additional data linkages would be undertaken and that it be explicit within section 5(b) (Processing Activities) of the application that the applicant will not link data in this application except those permitted under this application / data sharing agreement.

IGARD queried supporting document 3.1, the HRA and Health and Care Research Wales Approval Letter and asked that NHS Digital's Customer Relationship Management (CRM) system be updated to remove this document since it is not relevant to this application.

IGARD noted that section 5(b) states that "Moorfields Eye Hospital will send a cohort of patients..." and asked that this be amended to make it clear that it will send 'identifiers of the cohort'.

IGARD noted the applicant should provide a fair processing notice that it is compliant with the notice requirements under the GDPR and suggested that they work with NHS Digital to amend their current privacy notice since this study is likely to be of high public interest and it is therefore important that they are accurate and up to date.

**Outcome:** recommendation to approve

The following amendments were requested:

1. To include a heading in the abstract when outlining the common law duty of confidentiality.
2. To remove the bracketed "in this case NHS Digital" from the paragraph referencing section 251 support.
3. To update the abstract to pluralise the reference to Data Controller.
4. To update the data minimisation wording within section 3 to clearly state that NHS Digital are only providing the HES episodes relating to ICD10 codes.
5. To update the application to correctly reference the data within the application as being 'identifying' not 'identifiable'.
6. To remove reference to "our" from section 5.
7. To clarify within the abstract MEH sharing "confidential patient information" and to confirm this is confidential personal information.
8. To remove from the abstract "direct" when referencing Data Processors.

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|     | <p>9. 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 section 43(5) NHS Act 2006 in relation to the legal basis for Foundation Trusts and remove reference to the Care Act 2014.</p> <p>10. To update the abstract to clearly delineate the legal bases for each Data Controller.</p> <p>11. Confirmation within section 5(b) of the application that the applicant will not link the data further and the only data linkages are those permitted under this application.</p> <p>12. To update the CRM holder to remove the supporting document relating to Wales, since it is not relevant to this application.</p> <p>13. To amend section 5(b) to be clear that Moorfields Eye Hospital NHS Foundation Trust will send 'identifiers of the cohort' rather than the current "cohort of patient".</p> <p>The following advice was given:</p> <ol style="list-style-type: none"> <li>1. The Data Controllers should work with NHS Digital on fair processing notices which are GDPR compliant since this study is likely to be of high public interest and it is therefore important that they are accurate and up to date.</li> </ol>   |
| 2.8 | <p><u>NHS England North (Cumbria and North East): Cancer Alliance access to National Cancer Waiting Times Monitoring Data Set (NCWTMDS) from the Cancer Wait Times (CWT) System (Presenter: Dave Cronin) NIC-204512-H4R8C</u></p> <p><b>Application:</b> This was a new application for pseudonymised National Cancer Waiting Times Monitoring Dataset (CWT) to both monitor and improve performance against the Cancer Waiting Time standards and to inform wider Cancer pathways improvements.</p> <p><b>Discussion:</b> IGARD noted that the application followed a template application that was previously brought to IGARD and asked that the abstract be updated to note this and to make it clear that this is not a 'template application'.</p> <p>IGARD queried the actual outputs that will be shared and asked that this be clearly described in section 5(b) (Processing Activities) including the level of data.</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 to be clear that this application follows a template and that it is not a "template application".</li> <li>2. To clearly describe in section 5(b) the actual outputs that will be shared including the level of data.</li> </ol> |
| 2.9 | <p><u>University of Oxford: Associations between frailty, implant and outcomes after primary knee replacement (Presenter: Dave Cronin) NIC-238613-D3W0L</u></p> <p><b>Application:</b> This was a new application for pseudonymised Patient Reported Outcome Measures (PROMs), Civil Registrations (mortality) and Hospital Episode Statistics (HES) data for the purpose of an investigation to determine associations between surgical and patient factors on outcome following primary knee replacement. The work will investigate factors relevant in the delivery of knee arthroplasty care and consists of two work packages; Package 1 addresses surgical factors (implant choice and surgical strategy) important in knee arthroplasty outcomes; and Package 2 will investigate the role of patient frailty in knee arthroplasty outcomes.</p> <p><b>Discussion:</b> IGARD noted that the Healthcare Quality Improvement Partnership (HQIP) had not provided adequate evidence to substantiate that public task is the appropriate legal basis.</p>   |

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|   | <p>IGARD noted the reference to Article 9(2)(i) within the application and asked that it also be noted how the relevant schedule condition of the Data Protection Act (DPA) 2018 was met.</p> <p>IGARD noted that section 5(a) (Objective for Processing) referred to the data being linked to the National Joint Registry (NJR) “which is owned by HQIP” and asked that this to be amended to refer to it being ‘controlled’ by HQIP, since data cannot be owned.</p> <p>IGARD queried what the difference was between this study and other evaluation studies that use NJR data and asked for this to be clearly delineated within section 5 (Purpose / Methods / Outputs) and to outline for clarification how this study will offer new analyses or outputs.</p> <p>IGARD queried what the public and patient outputs were as requested in the Health Research Authority Confidentiality Advisory Group (HRA CAG) letter of support provided as a supporting document and asked that section 5(c) (Specific Outputs Expected) be updated to provide further consideration of this.</p> <p><b>Outcome:</b> Unable to recommend for approval</p> <ol style="list-style-type: none"> <li>1. HQIP have not provided adequate evidence to substantiate that public task is the appropriate legal basis.</li> </ol> <p>The following amendments were requested:</p> <ol style="list-style-type: none"> <li>1. IGARD noted that where there is reference to Article 9(2)(i) GDPR, it should also be noted how the relevant schedule condition of DPA 2018 is met.</li> <li>2. To clarify within the abstract the legal basis for the flow of data from HQIP to NHS Digital.</li> <li>3. To remove reference to the data being “owned” from section 5(a) and instead refer to it being controlled by HQIP.</li> <li>4. To clearly delineate within section 5 the points of difference between this study and other evaluation studies using NJR data and how this study will offer new analysis or outputs.</li> <li>5. To update section 5(c) to provide further consideration of public and patient outputs and in line with the HRA CAG condition of support.</li> </ol> |
| 3 | <p><b>AOB</b></p> <p>None</p>   |

### Independent Group Advising on Releases of Data (IGARD): Out of committee report 18/01/19

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-141410-W6H4Y | University College London                | 13/12/18           | <ol style="list-style-type: none"> <li>1. To clarify that the cohort encompasses individuals who died under the age of 25 and also accessed secondary care prior to their death.</li> <li>2. To clearly explain how the PhD study differs from the wider study, how the two studies fit together and to clarify that PhD student is substantive employee of the University College London.</li> <li>3. To include helpful extra detail from the data flow diagram provided (supporting document 6) in the narrative of section 5(b).</li> </ol> | OOO by quorum of IGARD Members                            | OOO by quorum of IGARD Members                                |   |
| NIC-116377-L5J9M | University of Sheffield                  | 15/11/18           | <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>  | OOO by quorum of IGARD Members                            | OOO by quorum of IGARD Members                                |   |
| NIC-148331-5F2FS | Wolfson Institute of Preventive Medicine | 13/12/18           | <ol style="list-style-type: none"> <li>1. To provide evidence that the original ethics approval is still ongoing or confirmation that it is no longer required.</li> </ol>  | OOO by quorum of IGARD Members                            | OOO by quorum of IGARD Members                                | <i>"The new SD3C has been dated 18 Dec 2019 instead of 2018. Perhaps there could be a manual note inserted to note the correct date."</i> |

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|                  |  |          | <ol style="list-style-type: none"> <li>To provide further examples of measurable and yielded benefits to health and social care within section 5(d).</li> <li>To update section 5(d) to explicitly state what collaborative working is being undertaken as referenced in section 5(d).</li> <li>To obtain confirmation from the substantive employer (by way of a letter of assurance or similar) of the honorary professor confirming that they agree to be bound by and take action in line with the terms of the relevant honorary contract in the event of a breach.</li> </ol> |                                |                                       | <i>"Given how long this study has been running I would like to see further details of the measurable and yielded benefits when the application comes for renewal."</i> |
| NIC-354497-V2J9P | London School of Economics and Political Science | 22/11/18 | <ol style="list-style-type: none"> <li>To clarify how the Health Foundation funding for testing new technology fits into the 4 components of work outlined in the application.</li> <li>To provide a more detailed justification in section 5(a) for the request of data for the period 1996 to 2006 including reference to the information provided in the data minimisation table in section 3(b) explaining the data production process.</li> <li>Provision of suitable honorary contracts for use with the Honorary Research Associates.</li> </ol>                             | OOO by quorum of IGARD Members | OOO by IGARD Chair and 1 IGARD member | The additional text for condition 1 should be more reader friendly.  |
| NIC-14230-X7P9J  | University of Sheffield                          | 13/12/18 | <ol style="list-style-type: none"> <li>To provide further clarity on the expected measurable benefits, especially when the evidence briefing will take place, and in what form and clarify the reference to 2016/17 in section 5(d).</li> <li>To update the assessment in the abstract and section 4 to state that the Fair Processing Notice 'does not' meet the criteria, including (but not limited to) that individuals can contact the ICO at any time, refer to automated decision making, and update the legal basis (since a different basis</li> </ol>                     | OOO by quorum of IGARD Members | OOO by quorum of IGARD Members        | <i>"I would like to see further details of the measurable and yielded benefits when the application comes back for renewal."</i>                                       |

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|  |  |  | is noted in the application and the Fair Processing Notice). |  |  |  |
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In addition, the following applications were not considered by IGARD but have been progressed for IAO and Director extension/renewal: