

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

### Minutes of meeting held 11 October 2018

**Members:** Sarah Baalham, Joanne Bailey, Kirsty Irvine (Chair), Eve Sariyannidou.

**In attendance:** Louise Dunn, Duncan Easton, Rachel Farrand, Dickie Langley, Karen Myers, Kimberley Watson, Vicki Williams.

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

1	<p><b>Declaration of interests:</b></p> <p>There were no declarations of interest.</p> <p><b>Review of previous minutes and actions:</b></p> <p>The outcomes of the 4 October 2018 IGARD meeting were reviewed and were agreed as an accurate record of that aspect of the meeting.</p> <p>The minutes of the 4 October 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	<p><b>Data applications</b></p>
2.1	<p><u>NHS North Norfolk CCG: DSfC – NHS Norwich CCG - RS (Presenter: Dickie Langley) NIC-215080-Y5K7C</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><b>Discussion:</b> IGARD noted that no information was provided within the table in section 3(b) to outline the data minimisation undertaken and asked the abstract was amended to provide further information and that this be cross referenced with section 3(b).</p> <p>IGARD queried the reference to 'clear data' in the data flow diagram in supporting document 1 and asked for this term to be removed from the diagram.</p> <p>IGARD suggested that, as per recent discussions between NHS Digital and IGARD, the wording 'no less intrusive to the data subject' wording under Article 9(2)(h) in the Public Task section of the abstract be revised.</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 amend the abstract to provide further information on the data minimisation efforts undertaken by the applicant and cross reference this with section 3(b).</li><li>2. To amend the data flow diagram to remove reference to "clear data".</li><li>3. 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></ol>
2.2	<p><u>NHS Norwich CCG: DSfC – NHS Norwich CCG - RS (Presenter: Dickie Langley) NIC-215003-F6L3H JHH</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><b>Discussion:</b> IGARD noted that no information was provided within the table in section 3(b) to outline the data minimisation undertaken and asked the abstract was amended to provide further information and that this be cross referenced with section 3(b). IGARD queried what the correct legal basis was for the flow of data and asked for the table in section 3(b) be updated to accurately reflect this.</p> <p>IGARD queried the reference to 'clear data' in the data flow diagram in supporting document 1 and asked for this term to be removed from the diagram.</p> <p>IGARD suggested that, as per recent discussions between NHS Digital and IGARD, the wording 'no less intrusive to the data subject' wording under Article 9(2)(h) in the Public Task section of the abstract be revised.</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 amend the abstract to provide further information on the data minimisation efforts undertaken by the applicant and cross reference this with section 3(b).</li> <li>2. To amend the data flow diagram to remove reference to "clear data".</li> <li>3. 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>4. To amend the table in section 3(b) to accurately reflect the legal basis for the flow of data.</li> </ol>
2.3	<p><u>NHS West Norfolk CCG: DSfC – NHS Norwich CCG Comm STP (Presenter: Dickie Langley) NIC-211082-P5V9W</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 (MSDS), Improving Access to Psychological Therapy (IAPT), Children and Young People Health Service (CYPHS), Community Services Data Set (CSDS), Diagnostic Imaging Data Set (DIDS) and National Cancer Waiting Times Monitoring Data Set (CWT). This application requests approval for five CCG's to collaboratively share data with each other to support collaborative commissioning requirements.</p> <p><b>Discussion:</b> IGARD noted that no information was provided within the table in section 3(b) to outline the data minimisation undertaken and asked the abstract was amended to provide further information and that this be cross referenced with section 3(b). IGARD noted that section 3(c), patient objections, refers to the table in section 3(b) and asked for this reference to be removed as it was not relevant.</p> <p>IGARD suggested that, as per recent discussions between NHS Digital and IGARD, the wording 'no less intrusive to the data subject' wording under Article 9(2)(h) in the Public Task section of the abstract be revised.</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 amend the abstract to provide further information on the data minimisation efforts undertaken by the applicant and cross reference this with section 3(b).</li> <li>2) 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>3) To amend the patient objection section to remove reference to table 3(b).</li> </ol>
2.4	<p><u>NHS Lincolnshire West CCG: DSfC – NHS Lincolnshire West CCG – IV (Presenter: Dickie Langley) NIC-148038-Y7M6H</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><b>Discussion:</b> IGARD noted that no information was provided within the table in section 3(b) to outline the data minimisation undertaken and asked the abstract was amended to provide further information and that this be cross referenced with section 3(b).</p> <p>IGARD queried the reference to 'clear data' in the data flow diagram in supporting document 1 and asked for this term to be removed from the diagram.</p> <p>IGARD suggested that, as per recent discussions between NHS Digital and IGARD, the wording 'no less intrusive to the data subject' wording under Article 9(2)(h) in the Public Task section of the abstract be revised.</p> <p>IGARD noted that the abstract section of the application refers to 'commissioning' and asked that this be removed as it was for risk stratification and therefore not relevant to this application.</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 amend the abstract to provide further information on the data minimisation efforts undertaken by the applicant and cross reference this with section 3(b).</li> <li>2. To amend the data flow diagram to remove or update reference to "clear data"</li> <li>3. 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>4. To remove reference to commissioning from the abstract since it is not relevant to this application.</li> </ol>
2.5	<p><u>NHS Mid Essex CCG: DSfC – NHS Mid Essex CCG – RS (Presenter: Dickie Langley) NIC-226296-S7T2Y</u></p> <p><b>Application:</b> This was a new application for identifiable Secondary Uses Service (SUS) data for Commissioners data covering risk stratification (RS) which provides focus for future demands by enabling commissioners to prepare plans for patients who may require high levels of care.</p> <p><b>Discussion:</b> IGARD noted that no information was provided within the table in section 3(b) to outline the data minimisation undertaken and asked the abstract was amended to provide further information and that this be cross referenced with section 3(b).</p> <p>IGARD queried the reference to 'clear data' in the data flow diagram in supporting document 1 and asked for this term to be removed from the diagram.</p>

	<p>IGARD suggested that, as per recent discussions between NHS Digital and IGARD, the wording ‘no less intrusive to the data subject’ wording under Article 9(2)(h) in the Public Task section of the abstract be revised.</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 amend the abstract to provide further information on the data minimisation efforts undertaken by the applicant and cross reference this with section 3(b).</li> <li>2. To amend the data flow diagram to remove or update reference to “clear data”</li> <li>3. 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> </ol>
2.6	<p><u>University of Bristol: MR1332: The Cleft Collective Project (Presenter: Louise Dunn) NIC-207953-Q9H2M</u></p> <p><b>Application:</b> This was a renewal application for identifiable Medical Research Information Service (MRIS) data. The Cleft Collective project's aim is to create the infrastructure, capacity and resources necessary to gain important new knowledge that will advance the projects understanding of the causes of cleft lip and/or palate, inform treatment and ultimately improve the lives of children, adolescents and adults with the condition.</p> <p><b>Discussion:</b> IGARD noted the importance of the proposed research but queried why the applicant required access to cancer data. It was not clear what aspects were for research purposes and which were to avoid contacting those families with a cancer diagnosis. IGARD asked for further clarity on the exact proposed uses of the cancer data and further details of any data linkages and an expanded reference to research into “genetic predisposition”. IGARD also asked for further justification as to why the applicant continues to hold cancer data.</p> <p>In addition to the lack of clarity in the application around the proposed use of the cancer data, IGARD queried why the protocol does not address research with cancer data at all and asked for an explanation in the application or an update to supporting document 9 to align the protocol with the proposed research to be undertaken with the cancer data.</p> <p>IGARD noted the following statement in section 5(a) <i>“The Cleft Collective project do not wish to burden the participants regarding the study and are aware of a member of the family who has cancer and will treat this family with extra caution.”</i> and asked for further clarity on this statement and to be clear within the application that a specific family has not been identified or contacted.</p> <p>IGARD noted that that certain statements in section 5(b) were contradictory and asked for further clarity of the processing activities, what data is held and who has access to the data, in order to align with the protocol provided in supporting document 9 (for example the apparently contradictory statements about access to personal data).</p> <p>IGARD queried if any additional data linkages would be undertaken and that it be explicit within section 5(b) of the application that the applicant will not link data in this application except those permitted under this application / data sharing agreement (including further details of any linkage to pupil data).</p> <p>IGARD noted that the information within section 5(d)(iii) was quite vague and aspirational and asked for that further explicit examples of yielded benefits and further expected benefits be included.</p>

IGARD queried what the legal basis for dissemination and legislative references were, following advice from the IG Advisor to IGARD and asked for section 3(b) to be updated to clarify this information.

IGARD noted that it was not clear which cohorts have been consented on which materials and asked for a clear description of this including an explanation of the numbers of patients using which combination of Patient Information leaflet and consent form.

IGARD noted that historic phrasing was being used in section 4 Fair Processing and it was suggested that the following standard wording be used: "All Data controllers are expected to provide a privacy notice that is compliant with the General Data Protection Regulation (GDPR) notice requirements within a reasonable period after obtaining the personal data, but at the latest within one month of the data being disseminated."

IGARD noted that there is reference in the application to Research and Ethics Committee (REC) approval being sought and asked for clarification.

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

1. To provide further clarification on why access to cancer data is required (both the research element and the concern with contacting families with a cancer diagnosis), any data linkages (for example whether the linkage to the National Pupil Database will be with data obtained under this application) and the reference to research into genetic predisposition.
2. To provide clear justification why the applicant is continuing to hold cancer data.
3. Clarify the statement in section 5(a) "aware of a member of a family who has cancer" and be clear, as necessary, that a specific family has not been identified or contacted.
4. To clarify in section 5(b) the processing activities, what data is held and who has access to the data to align with the protocol provided in supporting document 9 (for example the apparently contradictory statements about access to personal data).
5. To provide confirmation within section 5(b) that the applicant will not link the data further and the only data linkages are those permitted under this application (including further details of any linkage to pupil data as mentioned in 1 above).
6. To provide explicit examples of yielded benefits within section 5(d)(iii) of the application.
7. To update section 3(b) in relation to the legal basis for dissemination and legislative references as advised by the IG Advisor to IGARD.
8. To provide a clear description of which cohorts have consented and on which materials with a clear explanation of the numbers of patients using which combination of Patient Information leaflet and consent form.
9. To clarify that there is current REC approval.
10. To provide an explanation why the protocol does not address research with cancer data or to update the protocol (SD9) to align with the proposed research to be undertaken with the cancer data.
11. To update section 4 with the standard wording "All data required by the Data Controller under this application is pseudonymised and therefore is considered as personal data under the GDPR. All Data controllers are expected to provide a privacy notice that is compliant with the GDPR notice requirements within a reasonable period after obtaining the personal data, but at the latest within one month".

IGARD noted the importance of the research undertaken and the need for the applicant to continue to hold data. IGARD noted that the applicant's Data Sharing Agreement with NHS Digital had expired, and in light of this it was suggested that NHS Digital might wish to

	consider a short-term extension to permit the applicant to hold but not in any other way process the data while work was undertaken to address the queries raised by IGARD.
2.7	<p><u>CRAB Clinical Informatics: HES re-supply CRAB Clinical Informatics (Presenter: Rachel Farrand) NIC-351722-W7D4N</u></p> <p><b>Application:</b> This was a renewal application for pseudonymised Hospital Episode Statistics (HES) data. Copeland Risk Adjusted Barometer (CRAB) is a web-based tool to evaluate quality and outcomes in a way which accurately reflects the clinical profile of patients treated. This is designed to provide a granular local dashboard to support NHS Trusts and appropriate National Authorities to interpret mortality analysis and understand safety in relation to avoidable harm, morbidity and areas for improvement.</p> <p>The application was been previously considered on the 5<sup>th</sup> July 2018 when IGARD had deferred making a recommendation pending; update of the abstract sections on Article 6 and 9 of General Data Protection Regulation (GDPR) to reflect recent discussions between NHS Digital and IGARD and the processing being undertaken; confirmation in the abstract or a supporting document that NHS Digital have assessed the LIA and deemed it satisfactory; CRAB Clinical Informatics to provide a fair processing notice and to ensure that it is compliant with the notice requirements under the GDPR; confirmation within section 5b of the application that the applicant will not link the data further and the only data linkages are those permitted under this application; to remove reference to other 'national bodies' since they are not relevant to this application; to clarify why the CQC are not listed as a Data Processor; to clarify that only the Data Processor, L2S2 Limited, will have access to the raw data and that CRAB Clinical Informatics who own the server cannot access this raw data; to clarify why the data fields outlined in section 3b cannot be limited further to align to the project outlined in the application; the following advice was given, IGARD suggested that NHS Digital work with the applicant to narrow the application to their current sole customer: CQC.</p> <p><b>Discussion:</b> IGARD noted the involvement of the Care Quality Commission (CQC) and asked for further clarification as to why they were not also considered as a Data Controller.</p> <p>IGARD noted that there were references in the application to 'pseudo-anonymised' and asked that this be replaced with '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. To update section 5 to clarify why Care Quality Commission are not considered as joint data controllers.</li> <li>2. To remove any reference in the application to 'pseudo-anonymised' and replace with 'pseudonymised'.</li> </ol>
2.8	<p><u>University College London (UCL): MR1396 - GALA-5: An Evaluation of the Tolerability and Feasibility of combining 5-Amino-Levulinic Acid (5-ALA) with Carmustine Wafers (Gliadel) in the Surgical Management of Primary Glioblastoma. (Presenter: Kimberley Watson) 03422-Y7Y0Z</u></p> <p><b>Application:</b> This was an extension application for identifiable Medical Research Information Service (MRIS) for a pilot trial to look at two treatments for a type of brain tumour called a glioblastoma, the most common form of brain tumour in adults. The trial will also be looking at whether patients receiving the combination of the two trial treatments do better than expected as to the control of the tumour and their neurological symptoms, and whether they have a better quality of life.</p>

	<p><b>Discussion:</b> IGARD queried what the background and nature of the “Cancer Research UK and University College London Cancer Trials Centre” at UCL and asked that the application be updated to reflect this information and to state that the funder Cancer Research UK (the charity) 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 queried the entity of the “Cancer Research UK and University College London Cancer Trials Centre” and noted there was potential for some confusion with Cancer Research UK (the charity). IGARD suggested that when reference was made to the “Cancer Research UK and University College London Cancer Trials Centre” in the application, this should be clearly identified with quotation marks to avoid any confusion with the charity.</p> <p>IGARD queried whether employees of Cancer Research UK (the charity) were involved with the project outlined in the application and asked for further clarity on this and to provide details of any data they may have access to.</p> <p>IGARD noted that historic phrasing was being used in section 4 Fair Processing and it was suggested that the following standard wording be used: “All Data controllers are expected to provide a privacy notice that is compliant with the General Data Protection Regulation (GDPR) notice requirements within a reasonable period after obtaining the personal data, but at the latest within one month of the data being disseminated.”</p> <p><b>Outcome:</b> recommendation to approve subject to the following condition:</p> <ol style="list-style-type: none"> <li>1. The application be updated to reflect the background and nature of the “Cancer Research UK and University College London Cancer Trials Centre” and to state that the funder Cancer Research UK (the charity) are not involved in the study, other than providing funding, nor will they have any influence on the results nor suppress any results.</li> </ol> <p>The following amendments were requested:</p> <ol style="list-style-type: none"> <li>2. The “Cancer Research UK and University College London Cancer Trials Centre” entity to be clearly identified within quotation marks throughout the application to avoid any confusion with Cancer Research UK, the charity.</li> <li>3. To provide clarity in the application if any employees of Cancer Research UK (the charity) are involved with the project outlined in the application and provide details of any data they may access.</li> <li>4. To update section 4 with the standard wording “All data required by the Data Controller under this application is pseudonymised and therefore is considered as personal data under the GDPR. All Data controllers are expected to provide a privacy notice that is compliant with the GDPR notice requirements within a reasonable period after obtaining the personal data, but at the latest within one month”.</li> </ol> <p>To be approved OOC by a quorum of IGARD members</p>
2.9	<p><u>University of Oxford: MR1471 (MR865 &amp; MR850) – Health of Civil Servants (Presenter: Rachel Farrand) NIC-148044-RGS7W</u></p> <p><b>Application:</b> This was a new application for identifiable Medical Research Information Service (MRIS) data for a study following the health of a number of male civil servants who worked in London between 1967 and 1970 to determine the combined influence on cause-specific mortality in old age of lifestyle, socioeconomic circumstances and cardiovascular risk factors.</p> <p><b>Discussion:</b> IGARD queried whether the London School of Hygiene and Tropical Medicine has retained a copy of the data after they disseminated to the University of Oxford and asked</p>

	<p>for further clarity on this along with confirmation that they have been issued a data destruction certificate.</p> <p>IGARD also queried whether University College London held any data previously received and asked for further clarity on this along with confirmation that they have been issued a data destruction certificate.</p> <p>IGARD noted that the abstract needed updating to revise the GDPR public task legal basis for each of the University of Oxford, London School of Hygiene and Tropical Medicine and University College London in accordance with IGARD advice.</p> <p>IGARD noted that schedule 1 part 1 had been referenced within the abstract, however suggested that NHS Digital work with the IG Advisor to IGARD to correctly list the DPA 2018 (reference Article 9(2)(j)) schedule 1 Part 1 references against each of the Article 9 legal basis cited and clearly describe how the schedule conditions are met.</p> <p>IGARD noted that section 5 should be updated to include clearer examples of 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.</p> <p><b>Outcome:</b> recommendation to approve subject to the following conditions:</p> <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> <p>The following amendments were requested:</p> <ol style="list-style-type: none"> <li>1. 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 the public interest condition under the DPA 2018.</li> </ol> <p>The following advice was given:</p> <ol style="list-style-type: none"> <li>1. IGARD suggested that, on renewal, further details of pathways of dissemination of the outputs be provided, including examples of the wider public / patient engagement.</li> </ol> <p>To be approved OOC by a quorum of IGARD members</p>
2.10	<p><u>University of Warwick: Modelling the Frailty Patient Pathway (Presenter: Rachel Farrand) NIC-32537-Y2H2L</u></p> <p><b>Application:</b> This was a new application for pseudonymised Hospital Episode Statistics (HES) data for a research project to understand the variation in the care of older patients attending hospital and the support the modelling of in-hospital patient pathways for older patients with complex needs.</p> <p><b>Discussion:</b> IGARD queried what contractual clauses were in place to make the University of Warwick fully and solely responsible for any breaches of the Data Sharing Agreement (DSA) by the PhD student and suggested that an undertaking by NHS Digital be included stating that it will report any data breaches to the Information Commissioner's Office (ICO).</p>



<p>IGARD queried if Shrewsbury and Telford Hospital Trust (SaTH) were joint Data Controllers and asked for this to be clarified in the application and for any contradictory statements that suggest otherwise to be removed.</p> <p>IGARD noted that the application references the University of Warwick as the “sole Data Processor” and asked that this be removed from the application.</p> <p>IGARD queried what the justification was for receiving national data and asked for further clarity within section 5 of the application. NHS Digital advised that efforts had been taken to minimise the data by regions, but preferred not to do this could impact on the validity of the results of the research.</p> <p>IGARD noted that the abstract 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 the suitable wording for public task undertaken by a Foundation Trust</p> <p>IGARD noted that there was reference to cancer waiting time in the abstract and asked that this be removed as it is not relevant to this application.</p> <p>IGARD suggested that standard wording be included in section 5 with regard to access controls to access the data and to specifically state that only the PhD student and supervisor would access the data.</p> <p>IGARD noted that within supporting document 4 it indicates that the PhD is quite advanced and asked for confirmation of the start date of the students PhD and also what stage of the PhD they were at and further justification as to why the data is being requested now.</p> <p>IGARD 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.</p> <p>IGARD asked for further clarification on the Acute Frailty Network and asked for a further brief explanation in section 5 of the application.</p> <p>IGARD noted that section 7, the ethics approval states the following ‘Ethics approval is required and in place’ and suggested this was removed as it is not required for this application.</p> <p>IGARD noted that the abstract should be updated with a fair processing notice review for all data controllers.</p> <p><b>Outcome:</b> Recommendation to defer, pending:</p> <ol style="list-style-type: none"> <li>1. Appropriate additional contractual clauses which are effective to make the University of Warwick fully and solely responsible for any breaches of the DSA by the PhD student and include an undertaking that NHS Digital will report any data breaches to the ICO.</li> <li>2. To clarify that SaTH are joint DC and remove reference to contradictory statements that suggest otherwise.</li> <li>3. To remove reference to a “sole Data Controller” within the application.</li> <li>4. To provide further justification within section 5 for the receipt of national data.</li> <li>5. 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 the public interest condition under the DPA 2018 and public task for Foundation Trusts.</li> <li>6. To remove reference to cancer waiting time in the abstract, since it is not relevant to the application.</li> <li>7. To specifically state within section 5 that the individuals accessing the data are the PhD student and supervisor.</li> </ol>
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	<ol style="list-style-type: none"> <li>8. To confirm the start date of the student's PhD and at what stage of the PhD they are at and why they are requiring the data now.</li> <li>9. To provide further details of pathways of dissemination of the outputs including any specific examples of public / patient engagement and dissemination plans.</li> <li>10. To briefly explain what the Acute Frailty Network is within section 5 of the application.</li> <li>11. To remove the sentence in Section 7 stating that ethics approval is required, since it is not required for the application.</li> <li>12. To update the abstract with a fair processing notice review for all data controllers.</li> </ol>
2.11	<p><u>Kingston Hospital NHS Foundation Trust: Continued access to NHS Digital Portal (Presenter: Duncan Easton) NIC-09949-T4N3W</u></p> <p><b>Application:</b> This was a renewal application for pseudonymised Hospital Episode Statistics (HES) data to support the understanding of the healthcare needs of the local population, the services the Trust needs to provide and what they should look like to best support the local catchment.</p> <p><b>Discussion:</b> IGARD queried what the planned outputs were from the work outlined in the application and for a clear demarcation between what is planned and what has already taken place and asked that this be clearly articulated in sections 5(a) and 5(c).</p> <p>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.</p> <p>IGARD noted that as the applicant is a Foundation Trust, the abstract should be amended to make clear that the relevant Article 6 and 9 of the General Data Protection Regulation (GDPR) be updated to reflect the suitable wording for a public task undertaken by a Foundation Trust</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 provide further details of future planned outputs and clearly articulate the difference between what is planned and what has already taken place within section 5(a) and 5(c).</li> <li>2. IGARD noted that the abstract should make specific reference to Article 9(2)(h) GDPR and the DPA 2018 and clearly describe how the schedule conditions are met.</li> <li>3. 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) the justification of public task for Foundation Trusts.</li> </ol> <p>The following observation was made:</p> <ol style="list-style-type: none"> <li>1. IGARD noted that a briefing paper on the new online portal was forthcoming, it was IGARD's understanding that this application would be a continuation of the same level of access as previously received on the old system and that the outcome was not necessarily an endorsement of the new system.</li> </ol>
2.12	<p><u>Imperial College London: Estimating the Impact of Patient Safety Incidents on Quality of Life using Patient Reported Outcome Measures (Presenter: Louise Dunn) NIC-209174-W2H3G UCL</u></p> <p><b>Application:</b> This was a new application for pseudonymised Hospital Episode Statistics (HES) data and Patient Reported Outcome Measures (PROM) data to support the study that is attempting to estimate the impact of patient safety events on quality of life in elective surgery patients and the monetary value of quality of life loss due to patient safety events.</p>

	<p><b>Discussion:</b> IGARD noted that historic phrasing was being used in section 4 Fair Processing and it was suggested that the following standard wording be used: “All Data controllers are expected to provide a privacy notice that is compliant with the General Data Protection Regulation (GDPR) notice requirements within a reasonable period after obtaining the personal data, but at the latest within one month of the data being disseminated.”</p> <p>IGARD noted that the following was noted within section 6, the special conditions section of the application “<i>All Data Controllers are expected to provide a privacy notice that is compliant with NHS Digital’s standards on transparency/lawful basis within a reasonable period after obtaining the personal data, but at the latest within one month.</i>” and asked that this be removed as it is not relevant to this application.</p> <p>IGARD noted that the abstract required a further update to ensure that Article 6 and 9 of the GDPR reflects recent discussions between NHS Digital and IGARD including (but not limited to) reference to the Royal Charter and public interest condition under the DPA 2018.</p> <p>NHS Digital noted that there was a reference to supporting document 1 in the application and advised this reference should be removed as it is not relevant to this application.</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 4 with the standard wording “All data required by the Data Controller under this application is pseudonymised and therefore is considered as personal data under the GDPR. All Data controllers are expected to provide a privacy notice that is compliant with the GDPR notice requirements within a reasonable period after obtaining the personal data, but at the latest within one month”.</li> <li>2. To remove the special condition in section 6 with reference to the fair processing notice, since it is not relevant to this application.</li> <li>3. To update the abstract of Article 6 and 9 of GDPR to reflect recent discussions between NHS Digital and IGARD including (but not limited to) reference to the Royal Charter and public interest condition under the DPA 2018.</li> <li>4. To amend the application to remove reference to supporting document 1, data flow diagram, since it is not relevant to this application.</li> </ol>
2.13	<p><u>Imperial College London: Bespoke Extract – HES / Civil Registration Mortality Extract (Presenter: Louise Dunn) NIC-383203-Q8B9L</u></p> <p><b>Application:</b> This was a renewal application for pseudonymised Hospital Episode Statistics (HES) data and Civil Registrations data to measure the quality of healthcare delivery by healthcare providers, this work also includes comparing hospital mortality rates, calculate total post-operative mortality rates and assess potential quality of care issues by comparing the cause of death with the reason(s) for admission.</p> <p><b>Discussion:</b> IGARD welcomed the application and noted the importance of the project.</p> <p>IGARD queried how the datasets would be kept separate noting in particular that the mortality data will not be linked to any identifiable data and asked for further clarification on this within section 5 including a further description of the security measures in place.</p> <p>IGARD queried the process NHS Digital had undertaken in assessing and confirming that the data is not identifying and asked for section 5 and the abstract to be amended to reflect this information, and to make consequential amendments throughout the document, where necessary, to reference data as being either “identifying” or identifiable.</p> <p>IGARD queried what the intention was for the future of the project and asked for a brief statement at the start of sections 5(c) and 5(d) outlining this and to clarify if the future projects</p>

	<p>outputs / benefits are the same outputs / benefits as existing projects and if so to clearly state that the projects and work previously described are ongoing.</p> <p>IGARD noted that the abstract required a further update to ensure that Article 6 and 9 of the General Data Protection Regulation (GDPR) reflects recent discussions between NHS Digital and IGARD including (but not limited to) reference to the Royal Charter and public interest condition under the DPA 2018.</p> <p><b>Outcome:</b> Recommendation to defer, pending:</p> <ol style="list-style-type: none"> <li>1. Further explanation be given within Section 5 of how the datasets will be kept separate, in particular that the mortality data will not be linked to identifiable data, and to include a further description of security measures in place.</li> <li>2. To amend section 5 and the abstract, to clarify the process undertaken by NHS Digital in assessing and confirming that the data is not identifying and to make consequential amendments throughout the document, where necessary, to reference data as being either “identifying” or identifiable.</li> <li>3. To update the abstract of Article 6 and 9 of GDPR to reflect recent discussions between NHS Digital and IGARD including (but not limited to) reference to the Royal Charter and the correct subsection reference under the DPA 2018.</li> <li>4. To include a brief statement at start of sections 5(c) and 5(d) outlining the intentions for the future of the project and if they are the same outputs / benefits as existing projects and to clearly state that the projects and work previously described are ongoing.</li> </ol> <p>IGARD noted the importance of the research undertaken and the need for the applicant to continue to hold data. IGARD noted that the applicant’s Data Sharing Agreement with NHS Digital had expired, and in light of this it was suggested that NHS Digital might wish to consider a short-term extension to permit the applicant to hold but not in any other way process the data while work was undertaken to address the queries raised by IGARD.</p>
2.14	<p><u>University College London: Mixed methods evaluation of the Getting it Right First Time (GIRFT) Programme - improvements to NHS orthopaedic care in England (Presenter: Kimberley Watson) NIC-112374-X0T4S</u></p> <p><b>Application:</b> This was a new application for identifiable Hospital Episode Statistics (HES) data and Patient Reported Outcome Measures (PROMS) data to enhance patient safety by addressing the complex issues of unwarranted variation in elective orthopaedic surgery. The GIRFT programme seeks to change practice in order to improve patient outcomes.</p> <p><b>Discussion:</b> IGARD noted that Healthcare Quality Improvement Partnership (HQIP) had not provided evidence in law that public task is the appropriate legal basis particularly in light of documents available in the public domain that state that charities (not covered by the FoI Act) providing public services under contract should be treated in the same way as private contractors.</p> <p>IGARD noted that section 5(d) of the application should be updated to include clearer examples of specific and actual benefits, for transparency.</p> <p>IGARD 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 within section 5(c) of the application.</p> <p>It was noted that there were inconsistencies with the application and some of the supporting documents provided (Fair Processing Notice and Protocol) with the references to the “other parties involved in the project” which suggest that joint Data Controllership may be more appropriate and asked for further clarity on this.</p>

	<p>IGARD noted that historic phrasing was being used in section 4 Fair Processing and it was suggested that the following standard wording be used: "All Data controllers are expected to provide a privacy notice that is compliant with the General Data Protection Regulation (GDPR) notice requirements within a reasonable period after obtaining the personal data, but at the latest within one month of the data being disseminated."</p> <p>IGARD noted that schedule 1 part 1 had been referenced within the abstract, however suggested that NHS Digital work with the IG Advisor to IGARD to correctly list the DPA 2018 (reference Article 9(2)(j)) schedule 1 Part 1 references against each of the Article 9 legal basis cited and clearly describe how the schedule conditions are met.</p> <p><b>Outcome:</b> Unable to recommend for approval</p> <ol style="list-style-type: none"> <li>1. HQIP have not provided evidence in law that public task is the appropriate legal basis, particularly in light of documents available in the public domain that state that charities (not covered by the FoI Act) providing public services under contract should be treated in the same way as private contractors.</li> <li>2. To provide further details of pathways of dissemination of the outputs including any specific examples of public / patient engagement within section 5c.</li> <li>3. To provide more examples of specific and actual benefits within section 5d of the application.</li> <li>4. Clarification, due to the apparent inconsistencies between the supporting documents provided (Fair Processing Notice and Protocol) and application with regard to the "other parties involved in the project" which suggest joint Data Controllership may be more appropriate.</li> <li>5. To update section 4 with the standard wording "All data required by the Data Controller under this application is pseudonymised and therefore is considered as personal data under the GDPR. All Data controllers are expected to provide a privacy notice that is compliant with the GDPR notice requirements within a reasonable period after obtaining the personal data, but at but at the latest within one month".</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 the public interest condition under the DPA 2018 (reference Article 9(2)(j)).</li> </ol>
3	<p><b>AOB</b></p> <p>None</p>

### Independent Group Advising on Releases of Data (IGARD): Out of committee report 05/10/18

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-148096-PT589	Institute of Cancer Research	13/09/18	<ol style="list-style-type: none"> <li>1. To provide more examples of measurable and yielded benefits within section 5 of the application with a focus on outputs from the perspective of the cohort and wider community.</li> <li>2. To explicitly state within section 5 that no new participants from 2015, (following guidance on consent issued by NHS Digital at that time), can be flagged for inclusion within the scope of the project.</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