

Independent Group Advising on the Release of Data (IGARD)

Minutes of meeting held 14 November 2019

In attendance (IGARD Members): Maria Clark, Kirsty Irvine (Chair), Eve Sariyannidou, Geoffrey Schrecker, Maurice Smith.

In attendance (NHS Digital): Stuart Blake, Garry Coleman, Dave Cronin, James Humphries-Hart, Dickie Langley, Karen Myers, Kimberley Watson, Vicki Williams.

Not in attendance (IGARD Members): Sarah Baalham, Anomika Bedi, Nicola Fear.

1	<p>Declaration of interests:</p> <p>There were no declarations of interest.</p> <p>Review of previous minutes and actions:</p> <p>The minutes of the 7th November 2019 IGARD meeting were reviewed and subject to a number of minor amendments were agreed as an accurate record the meeting.</p> <p>Out of committee recommendations:</p> <p>An out of committee report was received (see Appendix B).</p>
2	Data applications
2.1	<p><u>University of Oxford: The role of patient factors, surgical factors and hospital factors upon patient outcomes and NHS costs in the treatment of upper limb musculoskeletal injuries and infections: spatial and longitudinal analysis of routine data (Presenter: Dave Cronin) NIC-295342-W3Z6L</u></p> <p>Application: This was a new application for pseudonymised Hospital Episode Statistics (HES) Admitted Patient Care, HES: Civil Registration (Deaths) bridge and Civil Registration (Deaths) Secondary Care Cut. The purpose is to investigate the trends in surgery undertaken for the treatment of upper limb injuries and infections, and the complications that follow surgery. By understanding the burden of surgery needed to treat upper limb injuries and infections on the National Health Service (NHS) and observing temporal and geographic trends, services can be better planned. In addition, understanding injury patterns and risk factors for infections allows targeted preventative strategies to be considered. Lastly, analysis of upper limb injury and infection burden allows clinical research to be directed towards better understanding and managing the most prevalent and impactful conditions.</p> <p>The application was been previously considered on the 10th October 2019 when IGARD had been unable to recommended pending: To provide clarification if there is any further data filtering or data production steps that NHS Digital could undertake before the data reaches the applicant to address the data set size and ensure all possible data minimisation has taken place in accordance with Art 5(1)(c) GDPR (and if not, an explanation of why those steps cannot be taken by NHS Digital; paragraphs 1, 3, 4, 5, 6, 11 and 12, NHS Digital's Data Minimisation Standard refers); to provide an explanation on the inconsistencies between the application and the protocol in respect of the reference / request for children's data and if children's data is included, to specifically justify the need for child data (as stipulated in the introductory paragraph of NHS Digital's Data Minimisation Standard); If the cohort does <i>not</i> include children under 16, to update the data minimisation column in section 3(b) and production specification to make clear that they are not included in the data set; since this research supports fulfilment of two DPhils, to provide further information on how the significant size of the cohort outlined will be processed and to clarify if the data provided is proportionate to the academic endeavour and whether there are sufficient</p>

	<p>resources available to ensure the project is carried out to completion; to explain the link between the volume of data required and how it is necessary to meet the research aims stated in section 5; to amend section 5 to make it clear that this is a retrospective study; IGARD suggested that all acronyms upon first used in the application be defined and further explained, as may be necessary for a lay reader.</p> <p>NHS Digital advised IGARD that they had worked with the applicant in-line with the General Data Protection Regulation (GDPR) and NHS Digital's Data Minimisation Standard (Standard 3) to establish that data minimisation had been considered and that the data requested was justified.</p> <p>Discussion: IGARD noted that the application had been updated to reflect most of the comments previously made.</p> <p>IGARD queried information provided in the application that outlined the stated research aims and noted that this did not align with the information stated in the revised study protocol which contained a number of key research questions which did not align with the benefits and outputs outlined in section 5; and asked that the application was revised throughout to correctly align to the revised study protocol, and to also include the purpose, outputs and benefits. If such a revision was not possible, IGARD offered their support to NHS Digital on this application via the IGARD medical specialist members in order to reach a workable solution with the applicant.</p> <p>IGARD queried the reference in section 5(c) (Specific Outputs Expected) to <i>"The target date is 120-months following receipt of the data"</i> and asked that this was updated to provide further clarity on this statement.</p> <p>IGARD noted reference to a number of technical phrases and words within section 5 (Purpose / Methods / Outputs), for example: <i>"Multilevel regression modelling"</i> and suggested that it be updated to ensure that technical language was used only where necessary; and where necessary, that it also had an explanation in language suitable for a lay reader.</p> <p>Outcome Summary: recommendation to approve subject to the following condition:</p> <ol style="list-style-type: none"> 1. To revise the application throughout to align with the stated research aims outlined in the study protocol, including the purpose, outputs and benefits. <p>The following amendments were requested:</p> <ol style="list-style-type: none"> 1. To update section 5(c) to provide further clarity on the reference <i>"The target date is 120-months following receipt of the data"</i>. 2. To update section 5 to ensure the use of technical jargon is used only where necessary; and where it is necessary, to be also written in language suitable for a lay reader (for example: <i>"Multilevel regression modelling"</i>). <p>It was agreed the condition would be approved OOC by the IGARD Chair and two IGARD medical Specialist members.</p>
2.2	<p><u>Guy's and St Thomas' NHS Foundation Trust: Transforming Cancer Services Team for London access to National Cancer Waiting Times Monitoring Data Set (NCWTMDS) from the Cancer Wait Times (CWT) System (Presenter: James Humphries-Hart) NIC-228903-Z0F4V</u></p> <p>Application: This was a new application for pseudonymised National Cancer Waiting Times Monitoring Dataset (CWT) for the Transforming Cancer Service Team London, hosted by the applicant, to access data (previously supplied by NHS England) to provide London-wide support for improving cancer services and in terms of cancer waiting times, provide all the pan-London analysis across London, working with the Cancer Alliances to improve waiting times.</p>

The application was been previously considered on the 14th March 2019 when IGARD had deferred pending: to clarify how the processing in this application aligns with the processing carried out by the same parties under various Cancer Waiting Times (CWT) applications; how the proposed processing meets the necessity test in light of the data controller having access to CWT data via their role in the relevant Cancer Alliance (and other Cancer Alliances having access to the full geographical spread covered by the Transforming Cancer Services Team for London); and to clarify for each section how the processing, outputs and benefits differ from the activities carried out by this (and other) data controller(s) for various Cancer Alliances covering the same geographical area of the Transforming Cancer Services Team for London; to amend the data minimisation column within section 3(b) to include West Essex; to clarify whether the remit of the application covers just London or London and West Essex and amend the application accordingly; to provide further clarity on who the 'Healthy London Partnership' are and the relationship with the Transforming Cancer Services Team; to update the abstract sections on Article 6 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.

Discussion: IGARD noted that the application had been updated to reflect most of the comments previously made.

IGARD had a lengthy discussion with regard to who would have access to the data requested under this application, noting that section 5(b) (Processing Activities) inferred throughout that CCG's and others may have access to the pseudonymised record level data. IGARD asked that the application was redrafted to reflect that only Guy's and St Thomas' NHS Foundation Trust on behalf of the Transforming Cancer Services Team (TCST) London would have access to the data and that any reference to the CCG's or other organisations accessing the data was removed.

IGARD queried if Guy's and St Thomas' NHS Foundation Trust held any other extracts of the same data that replicated the data that was also held on the I-View Plus Tool. It was suggested that if the applicant did hold extracts for the same data that a clear written justification was provided for the retention of the data extract(s); or that written confirmation was provided confirming destruction of the data extract(s).

IGARD noted that the stated outcomes and project benefits that were outlined in the application and queried how realistic they were and asked that further clarity was provided clearly linking to the data accessed, including, but not limited to, how "*equity of access*" would be achieved by accessing CWT data.

IGARD queried the legal basis noted in section 1 (Abstract) under Article 9 and asked that this was reviewed and amended to ensure the correct legal basis was referenced.

IGARD also asked that Article 9 in section 1 was updated to make specific reference to section 11 of the Data Protection Act (DPA) 2018.

Outcome Summary: Recommendation to defer, pending:

1. To redraft the application throughout to reflect that only Guy's and St Thomas' NHS Foundation Trust on behalf of the Transforming Cancer Services Team (TCST) London will have access to the data; and to remove any reference to CCG's accessing the data.
2. To confirm if Guy's and St Thomas' NHS Foundation Trust hold any extracts of data that replicate data held on the I-View Plus Tool and if so to provide clear written justification for the retention of the data extract or to provide written confirmation of destruction.

	<ol style="list-style-type: none"> 3. To ensure that the stated outcomes and project benefits outlined in the application are realistic for example, but not limited to, providing further clarification of how “equity of access” will be achieved. 4. To amend section 1 to ensure the correct legal basis is referenced. 5. To update section 1 on Article 9 to make reference to section 11 of the DPA.
2.3	<p><u>NHS North Durham CCG: DSfC - NHS North Durham CCG; RS, IV, Comm (Presenter: James Humphries-Hart) NIC-134666-G5H1F</u></p> <p>Application: This was an amendment application to add Liaison Financial Services as a Data Processor for the purpose of Invoice Validation; to add Microsoft UK as a Data Processor; to update the North of England Commissioning Support Units processing and storage locations; and to change the address of NHS North Durham CCG. It was also a renewal application for pseudonymised Secondary Uses Service (SUS+), Local Provider Flows, Mental Health Minimum Data Set (MHMDS), Mental Health Learning Disability Data Set (MHLDDS), Mental Health Services Data Set (MHSDS), Maternity Services Data Set (MSDS), Improving Access to Psychological Therapy (IAPT), Child and Young People Health Service (CYPHS), Community Services Data Set (CSDS), Diagnostic Imaging Data Set (DIDS), National Cancer Waiting Times, Monitoring Data Set (CWT), Civil Registries Data (CRD) (Births), Civil Registries Data (CRD) (Deaths), National Diabetes Audit (NDA), Patient Reported Outcome Measures (PROMs).</p> <p>The purpose is for Invoice Validation (IV) which is part of a process by which providers of care or services are paid for the work they do, 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; and to provide intelligence to support the commissioning of health services.</p> <p>Discussion: IGARD queried the reference in section 5(a) (Objective for Processing) to Liaison Financial Services Ltd and asked that this was updated to include a clear statement outlining what function they would be undertaking. IGARD also noted the amendment to the application to add Liaison Financial Services Ltd as a Data Processor, and asked that further information was provided outlining how their role differed from the other Data Processors listed in section 1.</p> <p>IGARD noted inconsistencies within the application when referring to ‘Cloud’ and ‘Liaison’ and asked that the application was amended throughout to ensure that the correct full terms were used to correctly refer to “<i>Cloud storage</i>” and “<i>Liaison Financial Services</i>”.</p> <p>IGARD noted the language used in section 5(c) (Specific Outputs Expected) and asked that this was reviewed, for example removing the reference to “<i>high flyers</i>”. IGARD also suggested that within this section, the term “<i>most expensive patients</i>” was replaced with “<i>use of high cost activity</i>”.</p> <p>IGARD discussed NHS Digital's Cloud Standard that was still in draft form and was currently with NHS Digital for review. It was noted that the wording in the application abstract from the NHS Digital security adviser regarding Cloud Storage had been agreed as a temporary measure whilst the Cloud Standard was finalised. IGARD agreed that they would continue to review Cloud-related applications (with the temporary NHS Digital security adviser assurance in the application abstracts) until the 1st March 2020, by which time IGARD would anticipate that the Cloud Standard would be finalised.</p> <p>Outcome Summary: recommendation to approve</p> <p>The following amendments were requested:</p>

	<ol style="list-style-type: none"> 1. To update section 5(a) to include a clear statement outlining what function Liaison Financial Services are undertaking and how this differs from the other Data Processors listed. 2. To update the application throughout to ensure that full terms are used when referring to Cloud 'storage' and Liaison 'Financial Services'. 3. To review the language used in section 5(c) and remove for example, reference to <i>"high flyers"</i>. 4. To review the language used in section 5(c) and amend to replace the term <i>"most expensive patients"</i> with <i>"use of high cost activity"</i>.
2.4	<p><u>NHS Darlington CCG: DSfC - NHS Darlington CCG - Comm, RS & IV (Presenter: James Humphries-Hart) NIC-36794-M9N3S</u></p> <p>Application: This was an amendment application to add Liaison Financial Services as a Data Processor for the purpose of Invoice Validation; to add Microsoft UK as a Data Processor; to change the processing and storage address of NHS Darlington CCG. It was also a renewal application for pseudonymised Secondary Uses Service (SUS+), Local Provider Flows, Mental Health Minimum Data Set (MHMDS), Mental Health Learning Disability Data Set (MHLDDS), Mental Health Services Data Set (MHSDS), Maternity Services Data Set (MSDS), Improving Access to Psychological Therapy (IAPT), Child and Young People Health Service (CYPHS), Community Services Data Set (CSDS), Diagnostic Imaging Data Set (DIDS), National Cancer Waiting Times, Monitoring Data Set (CWT), Civil Registries Data (CRD) (Births), Civil Registries Data (CRD) (Deaths), National Diabetes Audit (NDA), Patient Reported Outcome Measures (PROMs).</p> <p>The purpose is for Invoice Validation (IV) which is part of a process by which providers of care or services are paid for the work they do, 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; and to provide intelligence to support the commissioning of health services.</p> <p>Discussion: IGARD queried the reference in section 5(a) (Objective for Processing) to Liaison Financial Services Ltd and asked that this was updated to include a clear statement outlining what function they would be undertaking. IGARD also noted the amendment to the application to add Liaison Financial Services Ltd as a Data Processor, and asked that further information was provided outlining how their role differed from the other Data Processors listed in section 1.</p> <p>IGARD noted inconsistencies within the application when referring to 'Cloud' and 'Liaison' and asked that the application was amended throughout to ensure that the correct full terms were used to correctly refer to <i>"Cloud storage"</i> and <i>"Liaison Financial Services"</i>.</p> <p>IGARD noted the language used in section 5(c) (Specific Outputs Expected) and asked that this was reviewed, for example removing the reference to <i>"high flyers"</i>. IGARD also suggested that within this section, the term <i>"most expensive patients"</i> was replaced with <i>"use of high cost activity"</i>.</p> <p>IGARD discussed NHS Digital's Cloud Standard that was still in draft form and was currently with NHS Digital for review. It was noted that the wording in the application abstract from the NHS Digital security adviser regarding Cloud Storage had been agreed as a temporary measure whilst the Cloud Standard was finalised. IGARD agreed that they would continue to review Cloud-related applications (with the temporary NHS Digital security adviser assurance in the application abstracts) until the 1st March 2020, by which time IGARD would anticipate that the Cloud Standard would be finalised.</p> <p>Outcome Summary: recommendation to approve</p>

	<p>The following amendments were requested:</p> <ol style="list-style-type: none"> 1. To update section 5(a) to include a clear statement outlining what function Liaison Financial Services are undertaking and how this differs from the other Data Processors listed. 2. To update the application throughout to ensure that full terms are used when referring to Cloud 'storage' and Liaison 'Financial Services'. 3. To review the language used in section 5(c) and remove for example, reference to <i>"high flyers"</i>. 4. To review the language used in section 5(c) and amend to replace the term <i>"most expensive patients"</i> with <i>"use of high cost activity"</i>.
2.5	<p><u>NHS Durham Dales, Easington and Sedgefield CCG: DSfC - NHS Durham Dales, Easington and Sedgefield CCG; IV, RS & Comm. (Presenter: James Humphries-Hart) NIC-36808-C2G1F</u></p> <p>Application: This was an amendment application to add Liaison Financial Services as a Data Processor for the purpose of Invoice Validation and to add Microsoft UK as a Data Processor. It was also a renewal application for pseudonymised Secondary Uses Service (SUS+), Local Provider Flows, Mental Health Minimum Data Set (MHMDS), Mental Health Learning Disability Data Set (MHLDDS), Mental Health Services Data Set (MHSDS), Maternity Services Data Set (MSDS), Improving Access to Psychological Therapy (IAPT), Child and Young People Health Service (CYPHS), Community Services Data Set (CSDS), Diagnostic Imaging Data Set (DIDS), National Cancer Waiting Times, Monitoring Data Set (CWT), Civil Registries Data (CRD) (Births), Civil Registries Data (CRD) (Deaths), National Diabetes Audit (NDA), Patient Reported Outcome Measures (PROMs).</p> <p>The purpose is for Invoice Validation (IV) which is part of a process by which providers of care or services are paid for the work they do, 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; and to provide intelligence to support the commissioning of health services.</p> <p>Discussion: IGARD queried the reference in section 5(a) (Objective for Processing) to Liaison Financial Services Ltd and asked that this was updated to include a clear statement outlining what function they would be undertaking. IGARD also noted the amendment to the application to add Liaison Financial Services Ltd as a Data Processor, and asked that further information was provided outlining how their role differed from the other Data Processors listed in section 1.</p> <p>IGARD noted inconsistencies within the application when referring to 'Cloud' and 'Liaison' and asked that the application was amended throughout to ensure that the correct full terms were used to correctly refer to <i>"Cloud storage"</i> and <i>"Liaison Financial Services"</i>.</p> <p>IGARD noted the language used in section 5(c) (Specific Outputs Expected) and asked that this was reviewed, for example removing the reference to <i>"high flyers"</i>. IGARD also suggested that within this section, the term <i>"most expensive patients"</i> was replaced with <i>"use of high cost activity"</i>.</p> <p>IGARD discussed NHS Digital's Cloud Standard that was still in draft form and was currently with NHS Digital for review. It was noted that the wording in the application abstract from the NHS Digital security adviser regarding Cloud Storage had been agreed as a temporary measure whilst the Cloud Standard was finalised. IGARD agreed that they would continue to review Cloud-related applications (with the temporary NHS Digital security adviser assurance in the application abstracts) until the 1st March 2020, by which time IGARD would anticipate that the Cloud Standard would be finalised.</p> <p>Outcome Summary: recommendation to approve</p>

	<p>The following amendments were requested:</p> <ol style="list-style-type: none"> 1. To update section 5(a) to include a clear statement outlining what function Liaison Financial Services are undertaking and how this differs from the other Data Processors listed. 2. To update the application throughout to ensure that full terms are used when referring to Cloud 'storage' and Liaison 'Financial Services'. 3. To review the language used in section 5(c) and remove for example, reference to <i>"high flyers"</i>. 4. To review the language used in section 5(c) and amend to replace the term <i>"most expensive patients"</i> with <i>"use of high cost activity"</i>.
2.6	<p><u>NHS Greenwich CCG: DSfC - NHS Greenwich CCG - IV (Presenter: James Humphries-Hart) NIC-43418-W0V0N</u></p> <p>Application: This was an amendment application to add Liaison Financial Services as a Data Processor for the purpose of Invoice Validation; to add Microsoft UK as a Data Processor; to remove commissioning and Risk Stratification; and to change the processing and storage address of the Data Controller. It was also a renewal application for identifiable Secondary Uses Service (SUS) data for the purpose of 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>Discussion: IGARD noted the reference in section 5(a) (Objective for Processing) to "Liaison Financial Services" and asked that this was updated to clarify the purpose of their involvement with the work outlined in the application.</p> <p>IGARD queried the information provided in section 1 (Abstract) under the heading "Article 9(2)(h)" that referred to <i>"risk stratification"</i> and asked that this removed as this did not form part of this application and was therefore not relevant.</p> <p>Outcome Summary: recommendation to approve</p> <p>The following amendments were requested:</p> <ol style="list-style-type: none"> 1. To update section 5(a) to clarify the purpose of Liaison Financial Services' involvement. 2. To amend section 1 under Article 9(2)(h) to remove reference to 'Risk Stratification', since it is not relevant to this application
3	<p><u>Oversight and Assurance: 5a Objective for Processing and 5e Commercial Purpose Standard and Commercial Applications</u></p> <p>The Associate Director Data Dissemination, Garry Coleman, attended IGARD to discuss with members the Objective for Processing (5a) Standard.</p> <p>It was agreed that the Objective for Processing Standard 5a would be updated to reflect discussions with NHS Digital; trialed on an application by NHS Digital, before being brought to a future IGARD meeting for further discussion, feedback and comments.</p>
4	<p><u>AOB:</u></p> <p>There was no further business raised, the IGARD Chair thanked members and NHS Digital colleagues for their time and closed the application section of the meeting.</p>

Independent Group Advising on Releases of Data (IGARD): Out of committee report 08/11/19

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)
None						

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

- None