

Independent Group Advising on the Release of Data (IGARD)

Minutes of meeting held 4 July 2019

In attendance (IGARD Members): Maria Clark, Nicola Fear, Kirsty Irvine (Chair), Priscilla McGuire, Maurice Smith.

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

Not in attendance (IGARD Members): Sarah Baalham, Anomika Bedi, Eve Sariyiannidou, Geoffrey Schrecker.

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 4th July 2019 IGARD meeting were reviewed and subject to a number of minor amendments were agreed as an accurate record of 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>NHS Coventry & Rugby CCG: DSfC - NHS Coventry and Rugby - STP - Comm, including GP data (Presenter: James Humphries-Hart) NIC-238282-X0B6H</u></p> <p>Application: This was an amendment and 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 Sets (CRD), Patient Reported Outcome Measures Data Set (PROMs) and National Diabetes Audit Data Set (NDA). The data is required to ensure that analysis of health care provision can be completed to support the needs of the health profile of the population within the CCG area based on the full analysis of multiple pseudonymised datasets.</p> <p>NHS Digital advised that section 5(a) (Objective for Processing) required a further update to reflect recently agreed GP standard wording.</p> <p>Discussion: IGARD noted the update from NHS Digital on the inclusion of the GP standard wording and supported the update to section 5(a) to reflect this.</p> <p>IGARD noted the seven Data Processors listed in the application and that when previously presented to IGARD consideration was given as to whether it met the necessity test and asked that the application was amended to provide further justification on the number of Data Processors outlined, for example by noting which Data Processors relate to which Data Controllers and the different tasks carried out.</p> <p>IGARD noted the reference in section 5(a) (Objective for Processing) to 'pseudo at source' and asked that this was removed as it was not relevant.</p> <p>IGARD queried information that appeared to be missing from supporting document 4, the data flow diagram, specifically the GP data that flows into NHS Arden and Gem Commissioning</p>

	<p>Support Unit; and asked that the diagram was updated to reflect the flows of data as described in the agreement.</p> <p>IGARD noted that section 4 (Privacy Notice) referred to 'privacy notice' (singular) and asked that this was updated to 'privacy notices' (plural) to correctly reflect the three Clinical Commissioning Group's (CCG's) that form the STP.</p> <p>IGARD queried the contractual arrangement for the Sustainability Transformation Partnership (STP) and asked that section 1 (Abstract) was updated to provide additional information on this arrangement.</p> <p>IGARD noted that the 'Request Title' in section 1 was incorrect and asked that this was updated to note the correct title.</p> <p>Outcome Summary: recommendation to approve</p> <p>The following amendments were requested:</p> <ol style="list-style-type: none"> 1. To amend the application to provide justification on the number of Data Processors listed (for example by noting which Data Processors relate to which Controllers and the different tasks carried out). 2. To update section 5(a) with the latest agreed GP standard wording. 3. To update section 5(a) to remove the reference to 'pseudo at source'. 4. To update supporting document 4, the Data Flow Diagram to reflect the flows of data described in the agreement. 5. To amend section 4 to refer to 'privacy notices' (plural). 6. To update section 1 to provide additional detail about the STP contractual arrangements. 7. To update section 1 to reflect the correct 'Request Title'.
2.2	<p><u>National Institute for Cardiovascular Outcomes Research: Barts Health NICOR NCAP (Previously known as CCAD - Central Cardiac Audit Database - MR1233) (Presenter: James Humphries-Hart) NIC-359940-W1R7B</u></p> <p>Application: This was a renewal, extension and amendment application for identifiable Medical Research Information Service (MRIS), Hospital Episode Statistics (HES) and Civil Registrations data for six national cardiovascular audits. The aim of the audits is to measure and report delivery of care against defined guidance standards and to enable the improvement of the quality of care and outcomes of patients with a range of cardiac conditions.</p> <p>The application was been previously considered on the 20th June 2019 when IGARD had deferred pending: To provide adequate evidence to substantiate that public task is the appropriate legal basis for HQIP; to clarify why NHS England is not considered joint data controller as the narrative around the GDPR legal basis provided by the applicant clearly describes how the work undertaken is in fulfilment of NHS England's statutory functions; to update section 5(a) and 5(b) to clearly identify the three purposes and their objectives; to update section 1 and section 5(b) to ensure that for each of the 3 purposes outlined, the legal gateway is in place along with the relevant supporting documents to support the flow of data; to insert in section 5 a clear narrative explaining that data disseminated under this application can only be used for different purposes after those different purposes have been approved by NHS Digital under separate applications and a live DSA is in place; to update section 1 to clearly explain the purpose(s) of this application.</p> <p>Discussion: IGARD noted that the application had been updated to reflect most of the comments previously made with the exception of the previous request that adequate evidence was provided to substantiate that public task is the appropriate legal basis for HQIP. IGARD had a lengthy discussion on the ongoing matter with the legal basis for the Healthcare Quality</p>

	<p>Improvement Partnership (HQIP) (<i>which is detailed further under section 4 of the minutes</i>) and asked that section 1 (Abstract) was amended to clarify that NHS Digital had carefully reviewed the application and to provide an assurance to IGARD that they had satisfied themselves there was a legal basis in place in respect of HQIP data.</p> <p>IGARD also noted that deferral point 2 raised previously had been met because NHS England does not have a statutory obligation to carry out an audit but does have a generic obligation to carry out the action for the health system</p> <p>IGARD noted the reference in section 5(d) (Benefits) to <i>“Outcomes of treatment are measured by mortality data”</i> and asked that this was rephrased.</p> <p>Action: NHS Digital to provide assurance in writing to IGARD with regard the ongoing unresolved issue re HQIP legal basis with an aim to resolve by the first meeting in October, or sooner.</p> <p>Outcome Summary: The application was recommended for approval on all aspects presented, save for HQIP’s legal basis, in respect of which IGARD did not receive sufficient evidence to enable it to concur with the position put forward by HQIP.</p> <p>The following amendments were requested:</p> <ol style="list-style-type: none"> 1. To rephrase the reference in section 5(d) to ‘Outcomes of treatment are measured by mortality data’. 2. To amend section 1 to clarify that NHS Digital have carefully reviewed the application and provide an assurance to IGARD that they have satisfied themselves there is a legal basis in place in respect of HQIP data.
2.3	<p><u>McKinsey & Company, Inc. United Kingdom: Standard Extract Subscription (Presenter: Dave Cronin) NIC-368233-L2N0W</u></p> <p>Application: This was an amendment application to store and process data using a Cloud facility for the purpose of providing fact-based answers to NHS clients regarding identification, assessment and quantification of opportunities to improve the quality and efficiency of the NHS services that they deliver or are responsible for overseeing and regulating.</p> <p>NHS Digital noted that they had sought advice from NHS Digital Security Advisors on Cloud storage and that section 1 (Abstract) would be updated to reference this.</p> <p>Discussion: IGARD noted the update provided by NHS Digital that they had sought advice from their Security Advisors on Cloud storage and supported the update to section 1 of the application to reflect this.</p> <p>IGARD noted and endorsed NHS Digital’s review that the applicant’s privacy notice did not meet NHS Digital’s fair processing criteria for privacy notices. IGARD suggested, given the time that had elapsed, that the applicant work with NHS Digital to revise its privacy notice, including, addressing the points previously raised by IGARD.</p> <p>IGARD noted that section 5(a) (Objective for Processing) did not clearly state that McKinsey & Company, Inc. United Kingdom was a UK branch of a USA company; and asked that for transparency this was clarified.</p> <p>IGARD queried the reference in section 2(a) (Processing Locations) that listed ‘England and Wales’ as the ‘location area’ and asked that NHS Digital consult with its Security Advisors given that the applicant was a branch of a USA company and, as such, subject to a foreign jurisdiction, and that the location was amended as may be appropriate.</p>

	<p>IGARD noted reference to a number of technical phrases and words within section 5 (Purpose / Methods / Outputs) and suggested that it be updated to ensure the use of technical jargon was used only where necessary and that it was written in a language suitable for a lay reader.</p> <p>IGARD suggested that NHS Digital may wish to consider auditing large organisations handling significant amounts of data, with a particular focus in this instance on the mandatory training required by the Data Security Protection Toolkit (DSPT).</p> <p>IGARD advised NHS Digital that they would wish to review this application again when it comes up for renewal; and that on renewal they would expect the application to contain further specific detail in section 5 to reflect recent developments with regard to NHS Digital's developing Programme Level Standard, to ensure ongoing consistency across all such applications of this nature.</p> <p>Outcome Summary: recommendation to approve subject to the following condition:</p> <ol style="list-style-type: none"> 1. The applicant should work with NHS Digital on a fair processing notice that is GDPR compliant, particularly addressing the points previously raised by IGARD. <p>The following amendments were requested:</p> <ol style="list-style-type: none"> 1. NHS Digital to consult with its Security Advisors and to amend the location noted in section 2(a) as may be appropriate. 2. For transparency, to update section 5(a) to clarify that McKinsey & Company, Inc. United Kingdom is a UK branch of a USA company. 3. To update section 5(b) 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. 4. To amend section 1 to reference NHS Digital's Security Advisors advice on Cloud storage. <p>The following advice was given:</p> <ol style="list-style-type: none"> 1. As a general point of advice, IGARD suggested that NHS Digital may wish to consider auditing large organisations handling a significant amounts of data with a particular focus on the mandatory training required by the DSPT. 2. IGARD advised that they would wish to review this application again when it comes up for renewal. 3. IGARD suggested on renewal they would expect the application to contain further specific detail in section 5 to reflect recent developments with regard to NHS Digital's developing Programme Level Standard, to ensure ongoing consistency across all such applications of this nature. <p>It was agreed the conditions be approved Out of Committee (OOC) by the IGARD Chair.</p>
2.4	<p><u>Care Quality Commission: CQC agreement for HES, MHSDS, MSDS, CSDS and ECDS and associated datasets (Presenter: Dave Cronin) NIC-359603-D2Q6M</u></p> <p>Application: This was an extension, renewal and amendment application for identifiable Civil Registration data, Hospital Episode Statistics (HES), Mental Health and Learning Disabilities Data Set (MHLDDS), Mental Health Services Data Set (MHSDS), Mental Health Minimum Data Set (MHMDS), Maternity Services Data Set (MSDS), Community Services Data Set (CSDS) and Emergency Care Data Set (ECDS). CQC's remit is to make sure health and social care services provide people with safe, effective, compassionate, high-quality care and CQC encourages them to improve. It does that through effective monitoring and inspection activity underpinned by an Intelligence insight programme that draws together risk and bench marking metrics at core service level. The data directly influence the risk and benchmarking models</p>

and help determine both when inspections take place and where they should focus. They also help with CQC's statutory responsibility to monitor the use of the Mental Health Act.

Discussion: IGARD noted that when this application was previously reviewed by IGARD on the 1st June 2017, IGARD had asked that on renewal an update should be included on the steps taken by CQC to review the use of identifiers and whether this amount of identifiable data continued to be necessary; IGARD noted that this information had not been provided and asked that an update be provided in the application.

IGARD noted that section 5(a) (Objective for Processing) states *"The data contain patient identifying details although CQC have worked with IGARD in previous iterations to reduce the number of identifying fields..."* and asked that that this was removed and updated with the steps actually taken to review the use of identifiers.

IGARD queried the reference in section 5(a) (paragraph 4) to an 'internal Caldicott Guardian review' and a 'Data Protection Impact Assessment' (DPIA) that was currently under review; and asked that this was revised with confirmation, including dates, of the most recent Caldicott review and confirmation that the DPIA assessment had been completed.

IGARD noted reference to a number of technical phrases and words within section 5(b) (Processing Activities) and suggested that it be updated to ensure the use of technical jargon was used only where necessary and that it was written in a language suitable for a lay reader.

IGARD queried the references in section 5(b) and 5(c) (Specific Outputs Expected) to "internal family" and asked these references were updated to further define this term.

IGARD queried if any recent yielded benefits had been generated given the amount of data received, and asked that section 5(d) (Benefits) was updated with a more specifically detailed summary; in particular to consider if reference to an already existing annual report or similar could be provided with a brief explanation of how NHS Digital data had supported this work.

IGARD suggested that NHS Digital may wish to consider auditing large organisations handling significant amounts of data, with a particular focus in this instance on the mandatory training required by the Data Security Protection Toolkit (DSPT).

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

1. To update the application setting out the steps taken by CQC to review the use of identifiers and an analysis of whether the amount of identifiable data held and requested continues to be necessary.

The following amendments were requested:

1. To revise paragraph 4 of section 5(a) with confirmation (dates) of the most recent Caldicott review and confirmation that the DPIA assessment has been completed.
2. To update section 5(b) 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.
3. To update section 5(b) and 5(c) to define the reference to "internal family".
4. Remove reference to "working with IGARD" from section 5(a) and include the steps actually taken to review the use of identifiers (linked to condition 1 above).
5. To update section 5(d) with a more specifically detailed summary of the most recent benefits yielded; in particular to consider if reference to an already existing annual report or similar could be provided with a brief explanation of how NHS Digital data has supported this work.

The following advice was given:

	<p>1. As a general point of advice, IGARD suggested that NHS Digital may wish to consider auditing large organisations handling a significant amounts of data with a particular focus on the mandatory training required by the DSPT.</p> <p>It was agreed the conditions be approved Out of Committee (OOC) by the IGARD Chair.</p>
3	<p><u>Life Sciences (Presenter: Garry Coleman)</u></p> <p>The update from NHS Digital was to inform IGARD of the '<i>Life Sciences: Sector Deal between the government and the life sciences industry</i>'.</p> <p>The agreement follows on from, and starts to implement, the Life Sciences Industrial Strategy published in August 2017; and brings together the Government with Universities, charities and more than 25 businesses to make a joint commitment to invest in all parts of the United Kingdom. These investments produce real benefits for patients, such as through allowing earlier diagnosis of conditions and speeding up access to new treatments.</p> <p>IGARD noted the information on the Life Sciences Sector Deal and thanked NHS Digital for the update.</p>
4	<p>AOB:</p>
4.1	<p>HQIP Legal Basis</p> <p>IGARD and NHS Digital discussed the ongoing matter with regard to the legal basis for the Healthcare Quality Improvement Partnership (HQIP) and it was agreed that going forward section 1 of applications (Abstract) would be updated clarifying that NHS Digital had carefully reviewed the application and provided an assurance to IGARD that they had satisfied themselves there was a legal basis in place in respect of HQIP. It was also agreed that appropriate standard wording be development in respect of any future recommendation.</p> <p>There was no further business raised, the IGARD Deputy Chair thanked members and NHS Digital colleagues for their time and closed the application section of the meeting.</p>
4.2	<p>As part of their oversight role, IGARD discussed the following matters and it was agreed that NHS Digital would discuss any updates internally before bringing back to a future IGARD meeting:</p> <ul style="list-style-type: none"> • Review: Standard 1b Controllers • Review: Standard 1c Processors

Independent Group Advising on Releases of Data (IGARD): Out of committee report 28/06/19

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-156409-F4P2D	King's College London	13/06/19	<ol style="list-style-type: none"> 1. To update the application throughout to remove reference to General Practices learning and improving from this research and ensure the focus of the output is on Commissioners, CCGs and NHS England. 2. To update the reference in section 5(c) to disseminating to General Practices and provide explicit detail on which General Practices will be in receipt of the information (for example to those practices for whom the research is particularly relevant) and how the dissemination will take place 	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