

Independent Group Advising on the Release of Data (IGARD)

Minutes of meeting held 31 January 2019

Members: Sarah Baalham, Maria Clark, Kirsty Irvine (Chair), Priscilla Maguire, Eve Sariyiannidou.

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

Apologies: Anomika Bedi, Joanne Bailey, Nicola Fear.

Observer: Gosia Bartkowska

1	<p>Declaration of interests:</p> <p>Maria Clarke noted professional links to North Derbyshire [NIC-142633-S5G3Q] but noted no specific connection with the application or staff involved and it was agreed this was not a conflict of interest.</p> <p>Priscilla McGuire noted professional links to NHS Barnsley CCG [NIC-90647-G3Q4S] but noted no specific connection with the application or staff involved and it was agreed this was not a conflict of interest.</p> <p>Review of previous minutes and actions:</p> <p>The outcomes of the 24th January 2019 IGARD meeting were reviewed and were agreed as an accurate record of that aspect of the meeting.</p> <p>The minutes of the 24th January 2019 IGARD meeting were reviewed out of committee by IGARD following conclusion of the meeting, and subject to a minor change were agreed as an accurate record of the meetings.</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>Use of cloud computing services for NHS data – Briefing Paper (Presenters: Stephen Elgar / James Humphries-Hart)</u></p> <p>The briefing paper was to inform IGARD of arrangements for approved use of cloud data storage services for a Digital Access Request Service (DARS) application.</p> <p>As defined by the National Institute of Standards and Technology: “Cloud computing is a model for enabling ubiquitous, convenient, on-demand network access to a shared pool of configurable computing resources (e.g. networks, servers, storage, applications, and services) that can be rapidly provisioned and released with minimal management effort or service provider interaction.”</p> <p>The briefing noted that all public sector and many private organisations are considering use of cloud data storage because of the lower costs and greater flexibility that this type of service offers. A care sector-wide policy has recently been developed and usage is increasing for the public sector, by NHS and Local Authorities and by Universities.</p> <p>Noting that this briefing is still a “work-in-progress”, IGARD welcomed the draft briefing paper and would provide written comments out of committee. IGARD also offered to support drafting an NHS Digital Standard on Cloud Storage.</p>

2.2	<p><u>NHS Sunderland CCG: DSfC - NHS Sunderland CCG - Comm (Presenter: James Humphries-Hart) NIC-250326-W3F1B</u></p> <p>Application: This was a new application for pseudonymised Secondary Uses Service (SUS) for Commissioners, Mental Health Services Data Set (MHSDS), Mental Health and Learning Disabilities Data Set (MHLDDS), Mental Health Minimum Data Set (MHMDS). The data required is to provide intelligence to support the commissioning of health services. The data is analysed so that health care provision can be planned to support the needs of the population within the CCG area.</p> <p>NHS Digital noted that supporting document 1, the data flow diagram needed updating to include the pseudonymised GP data as described in the application.</p> <p>Discussion: IGARD noted and supported the amendment that needed making to the data flow diagram.</p> <p>IGARD noted the applicant proposes using Cloud based storage for storing the data; and taking into account the briefing paper presented to IGARD earlier in the meeting on the 'Use of cloud computing services for NHS data' and noting that this was still work in progress, IGARD advised that they do not have a complete position from NHS Digital with regard to cloud storage in order to confidently acknowledge the risks involved and mitigation taking place.</p> <p>Outcome: Unable to recommend for approval</p> <ol style="list-style-type: none"> 1. IGARD did not have a complete position from NHS Digital with regard to cloud storage in order to confidently acknowledge the risks involved and mitigation taking place. 2. To update the data flow diagram provided with the pseudonymised GP data as described in the application.
2.3	<p><u>NHS Barnsley CCG: DSfC - NHS Barnsley CCG - Comm, RS & IV to add Outcomes based Healthcare as a Data Processor (Presenter: James Humphries-Hart) NIC-90647-G3Q4S</u></p> <p>Application: This was an amendment application for pseudonymised Secondary Use Service (SUS) for Commissioners data, 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). The data required is for Risk Stratification (RS) which is a tool for identifying and predicting which patients are at high risk or likely to be at high risk and prioritising the management of their care; Invoice Validation (IV) which is part of a process by which providers of care or services are paid for the work they do; and to provide intelligence to support the commissioning of health services.</p> <p>NHS Digital noted that supporting document 1, the data flow diagram needed updating to include the pseudonymised GP data as described in the application.</p> <p>NHS Digital noted that the application incorrectly referenced the Nexent Data Centre and that this would need amending with the new and correct name of Pulsant.</p> <p>Discussion: IGARD noted and supported the amendment that needed making to the application in respect of the amendment to the data flow diagram and the incorrect reference to Nexent Data Centre.</p> <p>IGARD queried if any other company within the Kier Group would have access to the data and asked that a special condition be included in section 6 stating that no other company within the</p>

	<p>Kier Group would have access to the data other than the Kier entity listed within the data sharing agreement / application.</p> <p>IGARD noted that the consortium members are referred to differently throughout the application and the full and correct legal names would need to be used throughout the application.</p> <p>IGARD queried the reference to Yeadon Community Health Centre in section 5(b) (Processing Activities) of the application and asked if they should be part of the application / Data Sharing Agreement (DSA), and if so, to clarify if they should be listed as a processing and storage location address and to amend accordingly or to remove the reference to Yeadon Community Health Centre.</p> <p>IGARD noted the applicant proposes using Cloud based storage for storing the data; and taking into account the briefing paper presented to IGARD earlier in the meeting on the 'Use of cloud computing services for NHS data' and noting that this was still work in progress, IGARD advised that they do not have a complete position from NHS Digital with regard to cloud storage in order to confidently acknowledge the risks involved and mitigation taking place.</p> <p>Outcome: Unable to recommend for approval</p> <ol style="list-style-type: none"> 1. IGARD did not have a complete position from NHS Digital with regard to cloud storage in order to confidently acknowledge the risks involved and mitigation taking place. 2. To update the data flow diagram provided with the pseudonymised GP data as described in the application. 3. To include a special condition in section 6 that no other company within the Kier Group will have access to the data other than the Kier entity listed in the agreement. 4. To use the full and correct names for each of consortium members outlined throughout the application. 5. To clarify if Yeadon Community Health Centre should be part of the agreement, and if so, to clarify if they should be listed as a processing and storage location address and to amend accordingly or remove the reference. 6. To amend the incorrect reference to Nexent Data Centre to the correct name of Pulsant.
2.4	<p><u>NHS Erewash CCG: DSfC - NHS Erewash CCG, Comm (Presenter: James Humphries-Hart) NIC-142633-S5G3Q</u></p> <p>Application: This was an amendment application for pseudonymised Secondary Use Service (SUS) for Commissioners data, 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). The data required is to provide intelligence to support the commissioning of health services. The data is analysed so that health care provision can be planned to support the needs of the population within the CCG area.</p> <p>NHS Digital noted that the standard geographical data minimisation wording was not included in section 5(b) (Processing Activities).</p> <p>Discussion: IGARD noted and supported the amendment that needed making to the application in respect of the geographical data minimisation wording that needed including in section 5(b).</p>

	<p>IGARD noted the special condition in section 6 (Special Conditions) clarifying the position with Pulsant and asked that this be replicated in section 5(b).</p> <p>Outcome: recommendation to approve</p> <p>The following amendments were requested:</p> <ol style="list-style-type: none"> 1. To update section 5(b) with the standard geographical data minimisation wording, clearly stating which CCG's are relevant to the application. 2. To replicate the last special condition in section 6 within section 5(b).
2.5	<p><u>NHS Midlands and Lancashire CSU: DSfC - STP - NHS Staffordshire and Stoke on Trent CCGs – Comm NIC-234915-J3K4V (Presenter: James Humphries-Hart)</u></p> <p>Application: This was a new application for pseudonymised Secondary Use Service (SUS) for Commissioners data, 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) and Civil Registrations Births and Deaths Data (CRD). The data required is to provide intelligence to support the commissioning of health services. The data is analysed so that health care provision can be planned to support the needs of the population within the CCG area.</p> <p>NHS Digital noted that supporting document 1, the data flow diagram, needed amending to remove reference to Health Navigator Ltd and to correctly align with the processing outlined in the application.</p> <p>Discussion: IGARD noted and supported the amendment that needed making to the data flow diagram.</p> <p>Outcome: recommendation to approve</p> <p>The following amendment was requested:</p> <ol style="list-style-type: none"> 1. To update the data flow diagram to align with the processing outlined in the application.
2.6	<p><u>Institute of Fiscal Studies: Work on Healthcare at the Institute for Fiscal Studies (Presenter: Rachel Farrand) NIC-17824-V9F2B</u></p> <p>Application: This was an amendment and renewal application for pseudonymised Patient Reported Outcome Measures (PROMs), Hospital Episode Statistics (HES) and Civil Registrations data for a number of existing and new projects aiming to better inform policy makers, practitioners and the general public into the effects of economics on health and the health system.</p> <p>Discussion: IGARD queried if PROMS data was requested when the application was previously submitted and recommended for approval by IGARD on the 8th June 2017 and NHS Digital confirmed that PROMS data was part of the previous application and should have been reflected in the published minutes.</p> <p>IGARD noted the potential political sensitivity of the Junior doctor's strike project outlined in the application and asked for a more sensitive description of the project and to include a clear and compelling case outlining the benefits to health and social care accruing from this study.</p> <p>IGARD queried the amount of data and years of data that needed to be processed for each project and asked for the applicant to provide further justification for this along with a clear description of the data requested and the data minimisation efforts that have been undertaken.</p>

	<p>IGARD noted the clear outputs for the Sure Start Programme and the Waiting Time Projects and asked that the applicant describes the outputs and route to dissemination for each of the other projects, also outlining how the data requested benefits health and social care.</p> <p>IGARD noted that the Sure Start Programme referred to a report “being published in 2017” and asked that for all the projects outlined, the application should be updated to reflect their current status.</p> <p>IGARD noted that the application be updated to use the correct name for the Royal College of Gynaecologists and Obstetricians (RCOG).</p> <p>Outcome: recommendation to approve subject to the following conditions:</p> <ol style="list-style-type: none"> 1. In respect of the Junior Doctor’s strike project, to provide a more sensitive description of the project and include a clear and compelling case outlining the benefits to health and social care accruing from this study. 2. The applicant to justify the amount of data and years of data that needs to be processed for each project and to include a clear description of the data requested and the data minimisation efforts undertaken. 3. The applicant to describe the outputs and route to dissemination for each project (with the exception of the Sure Start Programme and the Waiting Time Projects) outlining how the data requested benefits health and social care. <p>The following amendment was requested:</p> <ol style="list-style-type: none"> 1. For all the projects outlined, the application should be updated to reflect their current status (for example the Sure Start Programme referring to a report being published in 2017). <p>It was agreed the conditions be approved OOC by IGARD Members.</p>
2.7	<p><u>Imperial College London: MR1108: CT colonography, colonoscopy, or barium enema for diagnosis of colorectal cancer in older symptomatic patients: SIGGAR1 (Special Interest Group in Gastrointestinal and Abdominal radiology). Plus SOCCER (Symptoms of Colorectal Cancer Evaluation Research). (Presenter: Louise Dunn) NIC-291981-Y7J2F</u></p> <p>Application: This was an extension application for identifiable Medical Research Information Service (MRIS) data to complete the outstanding SIGGAR study work and to enable further analysis of the SOCCER data in order to respond to questions from the scientific community post-publication.</p> <p>NHS Digital advised that due to the historical complexities of this application, that this application is being brought to IGARD for advice on the consent materials.</p> <p>NHS Digital noted that the applicant’s current Data Sharing Agreement (DSA) was due to expire on the 31st January 2019.</p> <p>Discussion: The application had previously been unable to be recommended for approval by IGARD’s predecessor DAAG (Data Access Advisory Group) on the 10th November 2015 and again on 1st December 2015. NHS Digital subsequently took the decision to disseminate the data.</p> <p>IGARD noted that because the application had not previously been approved by DAAG, the historical issues raised, including providing a legal basis to support the flow of data, still needed to be addressed and for clarity outlined within the application confirming how these had been met.</p> <p>IGARD queried who the Cancer Screening Prevention Research Group were, as referred to in the application, and asked for further information about the role of this group. IGARD further</p>

	<p>suggested that the application clarify which cohort the application related to (to be clear if it was one or the other or both). The aged ethics approval was discussed and IGARD suggested that this was either refreshed or an explanation provided as to why a more recent ethical approval was not needed. IGARD also suggested that further information was provided about the security issues previously raised.</p> <p>Outcome: IGARD welcomed the application which came for advice on the consent materials and without prejudice to any additional issues that may arise when the application is fully reviewed.</p> <p>IGARD noted the need for the applicant to continue to hold data. IGARD noted that the applicant's Data Sharing Agreement with NHS Digital was due to expire on the 31st January 2019, 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>
2.8	<p><u>*NHS Digital Information Governance Alliance: Cancer Alliance access to National Cancer Waiting Times Monitoring Data Set (NCWTMDS) from the Cancer Wait Times (CWT) System (Presenter: Dave Cronin) NIC-204544-H5L0S</u></p> <p>Application: This was a new application for pseudonymised National Cancer Waiting Times Monitoring Dataset (CWT) to both monitor and improve performance against the Cancer Waiting Time standards and to inform wider Cancer pathways improvements.</p> <p>NHS Digital noted that the application followed a template application that was previously brought to IGARD and advised that the section 1 (Abstract) needed updating to note this and to make it clear that this is not a 'template application'.</p> <p>NHS Digital noted that section 5(b) (Processing Activities) needed updating to clearly describe in the actual outputs that will be shared including the level of data.</p> <p>Discussion: IGARD noted and supported the amendment that needed making to the application in respect of noting that the application followed a template application and also the update to the outputs.</p> <p>IGARD queried the information in section 14 (Applicant Details) and the reference to NHS Digital Information Governance Alliance (IGA) and asked that this be amended to correctly reference the correct applicant information to reflect the appropriate NHS body.</p> <p>Outcome: recommendation to approve subject to the following condition:</p> <ol style="list-style-type: none"> 1. To amend the applicant information to reflect the appropriate NHS body. <p>The following amendments were requested:</p> <ol style="list-style-type: none"> 1. To update the abstract to be clear that this application follows a template and that it is not a "template application". 2. To clearly describe in section 5(b) the actual outputs that will be shared including the level of data. <p>It was agreed the condition would be approved OOC by the IGARD Chair.</p> <p>*Following the meeting it was confirmed by NHS Digital that the incorrect organisation was listed on the application form and that this should be listed as NHS England (Quarry House) not NHS Digital Information Governance Alliance.</p>
3	<p>AOB</p> <p>None.</p>

Independent Group Advising on Releases of Data (IGARD): Out of committee report 25/01/19

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

NIC Reference	Applicant	IGARD meeting date	Recommendation conditions as set at IGARD meeting	IGARD minutes stated that conditions should be agreed by:	Conditions agreed as being met in the updated application by:	Notes of out of committee review (inc. any changes)
NIC-125783-W2W3P	NHS Wakefield CCG	17/01/19	1. To update section 5(b) with the standard geographical data minimisation wording, clearly stating which CCG's are relevant to the application.	OOC by the IGARD Chair	OOC by the IGARD Chair	
NIC-174337-X0N1L	Kent County Council	17/01/19	1. To clarify how the applicant meets the requirements under Article 9(3) GDPR and section 11 of DPA 2018.	OOC by the IGARD Chair	OOC by the IGARD Chair	
NIC-241634-Z3F2L	NHS North Kirklees CCG	17/01/19	1. To update the geographical data minimisation wording in section 5(b) to specify which CCG's are relevant to this application. 2. To differentiate within section 5(b) the different roles undertaken by Kier Business Service Limited and Dr Foster Limited in their role as data processors, and in addition, how this also differentiates from the CCG's role as a data processor to provide clarity on what services each data processor provides.	OOC by the IGARD Chair	OOC by the IGARD Chair	

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

- None