

Independent Group Advising on the Release of Data (IGARD)

Minutes of meeting held 6 April 2017

Members: Chris Carrigan (Chair), Jon Fistein, Kirsty Irvine, Debby Lennard, Eve Sariyannidou, James Wilson

In attendance: Diane Clark, Garry Coleman, Dave Cronin, Arjun Dhillon (observer), Frances Hancox, Stuart Richardson, Andrea Shires, Vicki Williams

Apologies: Sarah Baalham, Joanne Bailey, Anomika Bedi, Nicola Fear

1	<p>Declaration of interests</p> <p>James Wilson declared a potential interest in the group of three applications from University College London (NIC-99077-Q0K6Z, NIC-91374-Z5V6Y, NIC-148407-LRP3M) due to his employment by that organisation but noted no particular connection with the study or applicants in question.</p> <p>Review of previous minutes and actions</p> <p>The minutes of the 30 March 2017 IGARD meeting were reviewed and agreed as an accurate record of the meeting, subject to a minor change.</p> <p>Action updates were provided (see Appendix A).</p> <p>Out of committee recommendations</p> <p>An out of committee report was received (see Appendix B).</p>
2 2.1	<p>Data applications</p> <p><u>NHS England – Temporary National Repository (Presenter: Stuart Richardson) NIC-92346-T4Z0F</u></p> <p>Application: This application for the receipt and use of local provider 111 data within the Temporary National Repository (TNR) had previously been discussed at the 16 March 2017 meeting, when IGARD had not recommended approval. A briefing paper had been provided to support the application, describing the proposed data flows and explaining the legal bases under the Data Services for Commissioners Directions 2015 as well as the Health and Social Care Act 2012. The briefing paper also set out how NHS England considered the data to be compliant with the ICO Code of Practice for anonymisation.</p> <p>Discussion: IGARD acknowledged the potential benefits of this work and expressed their support for efforts to better monitor the use of and to improve 111 services.</p> <p>There was a broad discussion of the approach taken by NHS England in considering whether the data could be considered anonymised in line with the ICO Code of Practice; the difficulties in determining this were acknowledged, but some queries were raised about whether the analysis had taken into account the amount of data linkage that would take place as well as factors such as a recent data sharing agreement breach involving one of the organisations processing data. IGARD noted the inherent risk of this amount of data being re-identified, but also noted the steps taken to mitigate this risk and to control access to the data appropriately. IGARD asked for the application to be amended to clearly state that NHS Digital consider the data to be anonymised in context, and to include the explanation for why this is considered to</p>

be the case.

IGARD suggested that one of the previously raised queries did not seem to have been fully answered, as the use of a consistent pseudonym that would allow the different datasets to be linked still did not seem to be clearly explained and justified in the application. In addition it was not clearly stated that this was a change from the previous application that had been considered by DAAG at the 22 November 2016 meeting, as IGARD noted that the linkage between datasets had not been explicitly described as part of that previous application. It was agreed the application should be updated to include this information and to provide a justification for why this linkage was required.

Outcome: Recommendation to approve

The application should be amended to describe the data as anonymised in context with a detailed explanation of why this is considered to be the case given the use of a consistent pseudonym.

The application should also be amended to note a clearer justification for why there is a requirement to link data, with an explanation of whether this requirement was contained in the previous TNR application as it had not previously been made explicit.

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Greater Huddersfield CCG (Presenter: Stuart Richardson) NIC-90661-W2S5Q

Application: This application was to consolidate and renew the applicant's existing data sharing agreements to use pseudonymised Secondary Uses Service (SUS) data, local provider flows, mental health (MHMDS, MHLDDS, MHSDS), Maternity Services Dataset (MSDS), Improving Access to Psychological Therapies (IAPT), Children and Young People's Health Dataset (CYPHs), and Diagnostic Imaging Dataset (DIDs) data for commissioning purposes as well as using SUS data identifiable at the level of NHS number for risk stratification and invoice validation. North of England CSU, eMBED Health Consortium (Kier Business Services Limited and Dr Foster Limited), The Health Informatics Service hosted by Calderdale & Huddersfield NHS Foundation Trust, and PI Limited would act as data processors on behalf of the CCG. IGARD were informed that two data processors would process data for risk stratification until mid-July, at which point one data processor would be told to cease processing and asked to destroy the data held for this purpose.

In addition Kirklees Council would provide pseudonymised social care to PI Limited to be linked with pseudonymised SUS data, with the linked data being used to generate reports for the CCG. IGARD were informed that in future Kirklees Council wished to apply for access to the linked data, but that this was not part of the current application.

Discussion: IGARD noted that some of the points raised regarding CCG applications at the previous meeting also applied to this application. It was noted that section five would be updated to incorporate more information about the planned outputs and expected benefits of the different data processors involved in this application. It was also noted that the DPA registration expiry date for the CCG seemed to have passed and IGARD suggested the application should be updated to show the updated expiry date.

The data flow diagram was discussed and it was suggested that the acronym RBAC (role based access control) should be explained.

IGARD queried the data destruction process for the organisation that would be asked to cease processing data for risk stratification in July. It was agreed the application wording should be updated to reflect NHS Digital's involvement in this process.

Outcome: Recommendation to approve

The application should be amended to correct a reference to pseudonymised non-sensitive data, and to amend the table of data already held to be clearer what data has previously been

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recommended for approval by DAAG or IGARD. The application should also be amended to reflect NHS Digital's responsibility to request a data destruction certificate for the data processor ceasing risk stratification, and to include the updated wording about substantive employees.

It was noted section five would be updated to include the specific work undertaken by and benefits around the involvement of PI Benchmarking, and to add an explanation of the benefits to the work carried out by THIS. The data flow diagram should be updated to spell out the acronym RBAC.

IGARD advised that Dr Foster and Kier should review their DPA registrations to ensure they reflect the use of data for this purpose and for these data subjects in order to comply with the Data Protection Act 1998.

It was noted that the DPA registration for the CCG appeared to have expired and would need to be renewed in order for data to be disseminated. IGARD advised that Kirklees Council should consider updating their DPA registration to reflect the use of data for public health. IGARD advised that a special condition should be included within the DSA to state that: "As a result of your application IGARD would like to draw your attention to the importance of the accessibility and clarity of your Privacy Notice. In the interests of transparency, you are advised to regularly review your notice against the ICO's Privacy Notices Code of Practice to ensure it reflects best practice. You will be expected to demonstrate progress against this recommendation in any audit undertaken and for any renewal or new application for data."

North Kirklees CCG (Presenter: Stuart Richardson) NIC-90698-W7X6Y

Application: This application was to consolidate and renew the applicant's existing data sharing agreements to use pseudonymised SUS data, local provider flows, mental health (MHMDS, MHLDDS, MHSDS), MSDS, IAPT, CYPHs and DIDs data for commissioning purposes as well as using SUS data identifiable at the level of NHS number for risk stratification and invoice validation. North of England CSU, eMBED Health Consortium (Kier Business Services Limited and Dr Foster Limited), The Health Informatics Service hosted by Calderdale & Huddersfield NHS Foundation Trust, and PI Limited would act as data processors, and Kirklees Council would provide pseudonymised social care data to PI Limited for linkage with SUS data.

Discussion: IGARD acknowledged the similarities between this and the previous application (NIC-90661-W2S5Q Greater Huddersfield CCG) and reiterated the comments raised for that application.

Outcome: Recommendation to approve

The application should be amended to correct a reference to pseudonymised non-sensitive data, and to amend the table of data already held to be clearer what data has previously been recommended for approval by DAAG or IGARD. The application should also be amended to reflect NHS Digital's responsibility to request a data destruction certificate for the data processor ceasing risk stratification.

It was noted section five would be updated to include the specific work undertaken by and benefits around the involvement of PI Benchmarking, and to add an explanation of the benefits to the work carried out by THIS. The data flow diagram should be updated to spell out the acronym RBAC.

IGARD advised that Dr Foster and Kier should review their DPA registrations to ensure they reflect the use of data for this purpose and for these data subjects in order to comply with the Data Protection Act 1998.

IGARD advised that Kirklees Council should consider updating their DPA registration to reflect the use of data for public health.

IGARD advised that a special condition should be included within the DSA to state that: "As a result of your application IGARD would like to draw your attention to the importance of the accessibility and clarity of your Privacy Notice. In the interests of transparency, you are advised to regularly review your notice against the ICO's Privacy Notices Code of Practice to

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Application: This new application requested filtered and pseudonymised Hospital Episode Statistics (HES) data for the purpose of service evaluation.

IGARD queried the amount of data requested and whether it would be feasible to instead provide a smaller sample to generate the matched controls, and in particular why HES APC data was requested from 2005-6 while later years were requested for the other HES datasets. A possible explanation was suggested but it was agreed that the applicant should be asked to clarify and that the application should be updated to include a clearer justification for the amount of data.

Outcome: Recommendation to approve, subject to conditions:

- The application should be amended to reduce the use of acronyms in section five. IGARD suggested that the applicant should consider how the outputs of this work could be more widely disseminated to help increase the potential benefits.

2.5

Application: IGARD noted the briefing paper provided to explain the format of this group of applications; data was requested for three different but related cohorts, for use to support the same study and purpose. It was suggested that future briefing papers should include clearer version control.

Discussion: IGARD queried why updated consent had only been sought from a small proportion of the cohort; it was noted that this approach had been taken following discussions with HRA CAG, and as a high percentage of those invited to update consent had not responded but only a small number of respondents declined consent it had been determined

¹ NIC-99077-Q0K6Z, NIC-91374-Z5V6Y, NIC-148407-LRP3M

that section 251 support would be more appropriate than seeking updated consent from the full cohort. IGARD asked for the application to be updated to include this explanation.

IGARD asked for clarification of which version consent materials had been used by the cohort that re-consented, and it was confirmed that a mix of the 2013, 2014 and 2016 versions would have been used depending on what point in time an individual re-consented. Some concerns were raised regarding the 2016 version consent form, as this did not include the statement from earlier versions that an individual could withdraw their right to consent at any time without needing to state a reason. IGARD asked whether recruitment to the study was still ongoing, as if this was the case it would be advisable to update the consent form to correct this; it was noted that some recruitment had not yet closed but that the consent materials had already been issued, and no further mail-outs of consent materials were currently planned. On balance IGARD agreed that the updated consent materials seemed generally acceptable, if not ideal, but that given the concerns raised about the 2016 version consent form the study should contact participants to remind them of the option to withdraw consent. It was suggested that given the average age of participants, the study should consider providing a telephone number to withdraw consent in addition to an email address. IGARD asked for the application to be updated to include a special condition requiring the study to contact participants about this within three months.

A reference to list cleaning was queried and it was agreed the applications would be amended to be clear that although the applicant had received list cleaning services in the past, this was not part of the current application. In addition IGARD noted that the processing activities section of each of the three applications did not currently explain the applicable subset and the legal basis for that particular processing.

IGARD noted that section five of NIC-99077-Q0K6Z still contained a reference to cancer registration data, despite the confirmation elsewhere that this data would not be provided for that particular cohort. It was agreed the application would be amended to clarify this.

Further information was requested about what updates about the study had been provided to participants and IGARD encouraged the applicant to consider making information about study outputs more easily available to participants.

Outcome:

For NIC-148407:

Recommendation to approve.

The application should be amended to include a special condition that the applicant must provide evidence for review by NHS Digital that they have contacted the consented cohort, potentially as part of any planned newsletters or other contact, by the end of July 2017 to remind them of their right to withdraw consent at any time without giving a reason. The application should also be amended to include an explanation of why updated consent was not sought for the entire cohort.

A reference to list cleaning should be amended to be clear this is not part of the current application, and the processing activities section should be amended to include the explanation wording from the abstract about which of the three subsets each particular application relates to and specifying the relevant legal basis for each.

IGARD requested sight of the information previously provided to participants about the outputs of this study, and encouraged the applicant to consider making more information available to participants.

IGARD advised that if any further recruitment was planned then the applicant ought to update their consent form to include a clear statement that individuals are free to withdraw their consent at any time without giving a reason.

For NIC-91374:

Recommendation to approve.

	<p>A reference to list cleaning should be amended to be clear this is not part of the current application, and the processing activities section should be amended to include the explanation wording from the abstract about which of the three subsets each particular application relates to and specifying the relevant legal basis for each.</p> <p>IGARD requested sight of the information previously provided to participants about the outputs of this study, and encouraged the applicant to consider making more information available to participants.</p> <p>For NIC-99077: Recommendation to approve.</p> <p>A reference to list cleaning should be amended to be clear this is not part of the current application, and the processing activities section should be amended to include the explanation wording from the abstract about which of the three subsets each particular application relates to and specifying the relevant legal basis for each. The objective section for this application should be amended to remove a reference to cancer registration data.</p> <p>IGARD requested sight of the information previously provided to participants about the outputs of this study, and encouraged the applicant to consider making more information available to participants.</p>
3	<p>Any other business</p> <p>No other business was raised.</p>

Appendix A: Summary of Open Actions

Date raised	Action	Owner	Updates	Status
15/11/16	To update DAAG on the feasibility of providing random samples of data to applicants, and to ask the Production Team to provide DAAG with further information about the options for data minimisation	Garry Coleman	<p>06/12/16: This action was ongoing and it was anticipated an update would be available in mid-January. There had also been a discussion during the training session about data minimisation, with a suggestion for Peter Short to contact the Production Team for further information, and it was agreed that would be incorporated into this action.</p> <p>20/12/16: It was anticipated an update would be available in mid-January.</p> <p>10/01/17: Ongoing. It was agreed that this action would be taken forward by Alan Hassey rather than Peter Short.</p> <p>17/01/17: A number of internal discussions had taken place and it was anticipated an update would be brought to DAAG within the next few weeks.</p> <p>31/01/17: Ongoing. It was agreed the IGARD Chair would request an update on progress of this action.</p> <p>09/03/17: Ongoing. A number of internal discussions continued to take place and it was agreed the action would be taken forward by Garry Colman.</p> <p>23/03/17: Ongoing. There was a suggestion it might be helpful to discuss the type of sampling used by the Department for Work and Pensions.</p> <p>06/04/17: Ongoing.</p>	Open
06/12/16	To query the privacy notice review process within NHS Digital.	Chris Carrigan	<p>13/12/16: This had been discussed with the Caldicott Guardian but further clarification was needed.</p> <p>20/12/16: This action was ongoing in light of developments in other areas, including the drafting of minimum criteria. It was agreed that the action would be taken forward by Dawn Foster and Noela Almeida.</p>	Open

			<p>10/01/17: Ongoing, pending updated criteria.</p> <p>17/01/17: DAAG were given a brief verbal update on the work taking place.</p> <p>24/01/17: Work was ongoing following receipt of the final DAAG comments on the minimum review criteria.</p> <p>31/01/17: A meeting was scheduled to discuss this later in the week.</p> <p>09/02/17: Ongoing. It was agreed this action would be taken forward by the IGARD Chair.</p> <p>16/02/17: It was noted that a meeting with the NHS Digital Caldicott Guardian was scheduled to discuss this.</p> <p>02/03/17: This had been discussed at the educational session and it was agreed the IGARD Chair would contact the Caldicott Guardian following that discussion.</p> <p>16/03/17: IGARD's comments had been shared with the Caldicott Guardian, particularly regarding an unclear table, and the IGARD Chair had requested sight of the updated paper.</p> <p>23/03/17: Ongoing, pending sight of the updated paper.</p> <p>06/04/17: An updated paper had been agreed within NHS Digital and was now circulated to IGARD members. It was agreed IGARD members would review the updated paper and share any comments at the following week's meeting so that the action could be closed.</p>	
10/01/17	To speak to NHS Digital colleagues regarding security assurance for HQIP.	Garry Coleman	<p>24/01/17: This had been raised with NHS Digital.</p> <p>31/01/17: This had been raised with HQIP and it was thought that work was underway to provide assurances.</p> <p>16/02/17: Ongoing. It was suggested that Jon Fistein could support this work.</p> <p>02/03/17: It was agreed the action should be taken forward by Garry Coleman.</p> <p>09/03/17: Security assurance discussions with HQIP and NHS Digital had taken place and it was hoped to be resolved by the end of the month.</p>	Open

			16/03/17: NHS Digital had received a System Level Security Policy (SLSP) from HQIP and this was currently under review. 06/04/17: Ongoing.	
17/01/17	To provide an update on the security assurances that NHS Digital would seek for applicants using contractors.	Garry Coleman	24/01/17: It was anticipated this update would be provided to a meeting within the next few weeks. 09/03/17: Ongoing. It was agreed that the IGARD chair would contact Garry Coleman. 16/03/17: An update had been provided by email; it was agreed this would be circulated to confirm whether this had addressed IGARD's query. 23/03/17: It was confirmed one query had been addressed by email; confirmation was requested if any queries remained outstanding. 06/04/17: Ongoing.	Open
09/03/17	NHS Digital to ensure that for all future DSfC applications, data flow diagrams should be provided and where appropriate the applications should be split in order to aid transparency of the process.	Stuart Richardson	06/04/17: Stuart Richardson had confirmed that data flow diagrams would be provided for future applications.	Closed
23/03/17	To provide additional information about the application checks made by the Pre-IGARD process before applications are submitted to an IGARD meeting.	Gaynor Dalton	06/04/17: Ongoing. It was anticipated a response would be provided at the following IGARD meeting.	Open
23/03/17	To provide a response to previously raised IGARD queries about indemnity.	IGARD Secretariat	06/04/17: An update had been provided and the action remained open.	Open
30/03/17	To provide assurances for IGARD about how data destruction is managed under BAU processes when data processors change	Garry Coleman	06/04/17: IGARD were informed that applications should usually contain standard special condition wording about the requirement to provide a data destruction certificate.	Closed
30/03/17	To contact the NHS Digital Caldicott Guardian regarding how NHS Digital handles applications from organisations whose IG Toolkit has been reviewed as satisfactory with an improvement plan.	Chris Carrigan	06/04/17: This had been raised but a response had not yet been received.	Open

Appendix B: Out of committee report (as of 31/03/17)

These applications were previously recommended for approval with conditions by DAAG or IGARD, and the conditions have subsequently been agreed as met out of committee.

The following applications had the non-privacy notice caveats signed off by DAAG or IGARD, and then the privacy notice caveats signed off by the Director for Data

Dissemination:

- NIC-43358-L8W2A NHS Bristol CCG (*considered at 19/07/16 DAAG meeting*)
- NIC-43537-C6R8Q NHS Dartford, Gravesham and Swanley CCG (*considered at 06/09/16 DAAG meeting*)
- NIC-43454-T1L8KJ NHS Horsham & Mid Sussex CCG (*considered at 19/07/16 DAAG meeting*)
- NIC-47124-X5C9X NHS West Leicestershire CCG (*considered at 28/07/16 DAAG meeting*)

IAO and Director approvals

The following applications were not considered by DAAG or IGARD but have been progressed for IAO and Director extension/renewal only:

- NIC-07289 Northgate Public Services (UK) Limited
- NIC-10328-S0H5J Northumberland, Tyne and Wear NHS Foundation Trust