

Independent Group Advising on the Release of Data (IGARD)

Minutes of meeting held 9 February 2017

Members: Sarah Baalham, Joanne Bailey, Chris Carrigan (Chair), Nicola Fear, Jon Fistein, Kirsty Irvine, Debby Lennard, Eve Sariyiannidou

In attendance: Dave Cronin, Jen Donald, Dawn Foster, Frances Hancox, Vicki Williams, Robyn Wilson

Apologies: Anomika Bedi, James Wilson

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Welcome and introductions

The IGARD Chair welcomed all members and other attendees to the inaugural IGARD meeting. It was noted that Dawn Foster was in attendance as the Deputy Caldicott Guardian was not available.

Declaration of interests

Kirsty Irvine declared a potential conflict of interest with the Guy's and St Thomas' NHS Foundation Trust application (NIC-44383-L6C0X) due to a volunteer role, but it was not thought that this should prevent her from participating in the discussion. Nicola Fear noted that the applicant for that application was affiliated with King's College London, her employer.

Jon Fistein and Chris Carrigan declared a conflict of interest in the University of Leeds application (NIC-17649-G0X4B) due to their employment by that organisation.

Debby Lennard noted a personal relationship with the named contact for one of the applicant Local Authorities for the group application for two Local Authorities (PCMD).

Review of previous minutes and actions

The minutes of the 31 January 2017 DAAG meeting were reviewed and agreed as an accurate record.

Action updates were provided (see Appendix A). It was agreed that the open DAAG actions would be included in the new IGARD action log.

Out of committee recommendations

An out of committee report was received (see Appendix B).

IGARD noted on the report that the DAAG caveats for NIC-69707 KPMG had been agreed out of committee by the Director for Data Dissemination, whereas the DAAG minutes had indicated that the caveats would be agreed by the DAAG Chair. IGARD therefore requested an update from NHS Digital on this application and what actions had been taken.

Action: To provide an update on the out of committee sign-off of NIC-69707 KPMG.

There was a brief discussion of the transition process between DAAG and IGARD with respect to applications with outstanding caveats. It was suggested that the IGARD dashboard or management report should include how many applications currently had outstanding caveats.

<p>2</p> <p>2.1</p> <p>2.2</p>	<p>Data applications</p> <p><u>Group application for 2 Local Authorities¹ - PCMD (Presenter: Robyn Wilson)</u></p> <p>Application: This was an application for access to Office for National Statistics (ONS) births and deaths data via the Primary Care Mortality Database (PCMD). The application was based on a previously agreed template, which had most recently been considered at the 17 January 2017 DAAG meeting as part of a group application for two Local Authorities. It was confirmed that this application contained the standard special condition wording around privacy notice updates.</p> <p>Discussion: IGARD noted a lack of clarity in the summary section of this application, partially due to the lengthy review process that the template had undergone. It was suggested that it might be helpful to hold a future joint training session to discuss the content and formatting of applications' summary or abstract section.</p> <p>The proposed agreement end date was queried and it was clarified that PCMD applications would all be due for renewal from June 2017. IGARD also queried the amount of data requested and it was noted that while applicants may only require a subset of the data for their purposes, the PCMD system could only currently grant access to the full dataset rather than to a specific subset for each applicant. IGARD requested further information about planned improvements to the PCMD system and it was agreed that the IGARD Chair would raise this with NHS Digital. There was a suggestion that for future renewal applications, one option would be for applicants to indicate what subset of data they intended to make use of while acknowledging that the system would provide access to the full dataset.</p> <p>The definition of data as 'sensitive' was queried and it was agreed that information about this would be circulated. IGARD discussed the application wording regarding advice to regularly review privacy notices, and a query was raised about how 'regularly' was defined; it was clarified that this could vary from organisation to organisation, and that for example the privacy notice should be reviewed whenever there was a significant change to how the organisation processed any data. IGARD noted that this wording was not phrased as a requirement but that instead organisations were advised to ensure that they were in accordance with the ICO privacy notices code of practice.</p> <p>IGARD discussed the DPA registration wording for both applicants and noted that these should be updated to refer to processing data for the purpose of public health. IGARD asked for future applications to include an indication of whether applicants' DPA registration wording was appropriate. In addition IGARD suggested that NHS Digital should amend a reference in the application summary template to the patient objections approach being 'agreed by Information Governance' to be clear that this referred to NHS Digital's Information Governance.</p> <p>Outcome: Recommendation to approve IGARD noted that the DPA registrations for both organisations should be updated to include processing data for public health purposes. A template reference to agreement by Information Governance should be amended to be clear this refers to NHS Digital Information Governance.</p> <p>Action: To circulate information about how NHS Digital currently defines data as 'sensitive'.</p> <p><u>NIC-86054-Q4Y8W Brent CCG</u></p>
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¹ NIC-47574-X5R3X Warrington Borough Council, NIC-52166-B4R8P Bury Metropolitan Borough Council

This application was withdrawn by the applicant prior to the meeting.

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Guy's and St Thomas' NHS Foundation Trust - HES data for the analysis of alcohol related frequent attenders to hospitals (Presenter: Jen Donald) NIC-44383-L6C0X

Application: This was a new application for pseudonymised Hospital Episode Statistics (HES) data for use in a research study and the production of a risk stratification model for the South London area. The researcher was substantively employed by Guy's and St Thomas' NHS Foundation Trust, but held a research passport as part of Kings' Health Partners and would carry out this work on behalf of South London and Maudsley NHS Foundation Trust with that organisation acting as both data controller and data processor.

IGARD were informed of an error in the application where King's College London had been listed as a processing location. It was confirmed that this processing address had now been removed from the application. In addition it was confirmed that although the study protocol referred to linking to ONS data, that linkage was not requested as part of the current application and if this was required in future then the applicant would be required to submit an amendment application.

Discussion: IGARD noted that the abstract of this application was particularly helpful and suggested that this should be used as an example of good practice. The planned outputs and potentially significant benefits from this study were acknowledged.

There was a discussion of the amount of data requested; IGARD were assured that NHS Digital had discussed data minimisation with the applicant and were content that appropriate measures had been taken. A query was raised about the funding for this work and it was confirmed that there were no external funding sources involved.

The use of a research passport was discussed and some concerns were raised that unlike similar applications that made use of honorary contracts, in this instance there did not seem to be appropriate assurances that if the individual working under a research passport misused data then the substantive employer would take appropriate disciplinary action. Confirmation was requested that the substantive employer would be bound by the terms of the data sharing agreement and would take action in the event of a data breach.

It was noted that only pseudonymised data would be used but IGARD suggested that in the interests of openness and transparency, South London and Maudsley NHS Foundation Trust should consider making information available to the general public about this study and its use of healthcare data.

IGARD discussed data controllership and it was considered unclear whether Guy's and St Thomas' NHS Foundation Trust should also be considered a data controller as a substantive employee of that trust would determine how the data would be processed. It was agreed that this point should be clarified.

IGARD noted that section five of the application included a commitment not to link with other record level data. It was suggested that a standard special condition along these lines should be included in all applications that did not require data linkage.

Outcome: Recommendation deferred, pending:

- A commitment from the substantive employer that they will be bound by the terms of this DSA and would take action in the event of a data breach.
- Clarification of whether Guy's and St Thomas' Hospital Trust should also be considered a data controller for this application.

IGARD advised that in the interests of openness and transparency, the applicant might wish to

2.4	<p>consider making information about this study and its use of data available to the general public. In addition IGARD advised that the application should be amended to include a special condition that data will not be linked with other record level data.</p> <p>Action: To consider the use of a standard special condition for applications that do not require data linkage.</p> <p><u>Oliver Wyman – New Models of Care Analytics (Presenter: Jen Donald) NIC-291736-N6J7Z</u></p> <p>Application: This renewal application for pseudonymised HES and mental health (MHMDS) data in addition to Secondary Uses Service (SUS) data had previously been considered by DAAG at the 17 January 2017 meeting, when DAAG had deferred making a recommendation. The updated application now provided more information about the applicant's past, current and expected future customer base. The application included confirmation that data would only be used to support NHS customers and only for the purposes of this application, and the data requested had been minimised to five years.</p> <p>Discussion: IGARD discussed the request for national data given the small number of client organisations listed. Assurances were given that NHS Digital was content that based on the geographical spread of these organisations it would not be practical to limit the data geographically in this instance. IGARD agreed that when the applicant next submitted a renewal, extension or amendment to this application this would be expected to provide more information about the outputs that had been created and the benefits achieved using this data, to help justify the continued need to provide this amount of data.</p> <p>A query was raised about the wording of a special condition stating that data cannot be used for sales or marketing purposes, as it was suggested that the definition of these purposes was unclear. It was noted that this was standard wording that had been used for multiple applications in the past, but that IGARD might wish to suggest alternative wording in future.</p> <p>IGARD raised some concerns that the objectives and outputs of the application were not more well defined. It was suggested that a special condition should be added that the applicant could not use the data for any additional purposes in order to support new clients, unless an amendment application was first submitted and agreed. In addition it was agreed that a clearer explanation of the objective and outputs would be expected when a renewal application was next submitted.</p> <p>IGARD queried whether this application should include a special condition to restrict the linkage of this data, but it was confirmed that this wording was already included in the special conditions section. It was noted that the applicant should review their DPA registration.</p> <p>It was noted that only section five of applications would be included on the data release register, and the special conditions attached to applications would therefore not be published online in the same way. IGARD queried whether NHS Digital could consider also making the special conditions of applications publicly available to provide further context about how applicant organisations' use of data had been limited, and it was noted this information could be helpful to future applicants.</p> <p>Outcome: Recommendation to approve IGARD advised that NHS Digital should amend the purpose section to be clear that data can only be used for these specific purposes with any new clients, and use of data for any other purpose would be subject to an amendment application. In addition IGARD advised that when a renewal, amendment or extension application was next submitted the applicant would be expected to provide more information about the outputs created and what benefits had been achieved to date particularly in relation to the continued need for this amount of national data.</p>
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2.5	<p>IGARD also advised that the applicant should consider updating their DPA registration to more clearly reflect this use of data.</p> <p>Action: To provide an update on whether special conditions could be reflected on the data release register or otherwise made publicly available.</p> <p><u>University of Leeds - Hospitalisation and Mortality after Acute Myocardial Infarction (Presenter: Dave Cronin) NIC-17649-G0X4B</u></p> <p>Application: An earlier version of this application had been recommended for approval by DAAG at the 10 January 2017 meeting, subject to caveats which had been met following the meeting. The applicant had noted that the application did not correctly list all the data required for their study, and an updated application had therefore been submitted which also included pseudonymised national HES data for comparison with the study cohort.</p> <p>Discussion: IGARD discussed the amount of data now requested and the data minimisation options that had been considered, and initially some concerns were raised about the large amount of data now requested. It was agreed that the applicant could have more clearly justified the requirement for this data within the application, but on balance IGARD agreed that based on the information provided in both the application and the study protocol the amount of data requested was appropriate to the study requirements and there did not appear to be any other minimisation efforts that could reasonably be undertaken without disproportionate impact on the study outputs.</p> <p>A query was raised about the statement within the application that patients aged less than 18 in 2009 would be excluded; it was clarified that this also excluded any individuals born since 2009.</p> <p>Outcome: Recommendation to approve</p>
3	<p>Any other business</p> <p>IGARD expressed their thanks to Dawn Foster for attending the meeting in place of the Deputy Caldicott Guardian, and noted that it had been helpful to have an NHS Digital information governance presence at the meeting to answer queries.</p> <p><u>Dashboard / Management information</u></p> <p>IGARD were asked to consider what type of reporting would be helpful to include in the monthly dashboard or other management information. There was a suggestion that it would be helpful to provide more narrative around the reasons for applications being deferred, to highlight any recurring issues and hence help improve future application quality. It was agreed the final DAAG dashboard would be circulated for comments and further suggestions.</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 / Alan Hassey	<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>09/02/17: 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> <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</p>	Open

			week. 09/02/17: Ongoing. It was agreed this action would be taken forward by the IGARD Chair.	
10/01/17	To speak to NHS Digital colleagues regarding security assurance for HQIP.	Chris Carrigan	24/01/17: This had been raised with NHS Digital. 31/01/17: This had been raised with HQIP and it was thought that work was underway to provide assurances. 09/02/17: Ongoing.	Open
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. 09/02/17: Ongoing.	Open
24/01/17	To clarify the Local Authority Public Health application template wording regarding the Licensing Act.	Garry Coleman	09/02/17: Ongoing. It was thought the template would be updated for renewal applications from March onwards.	Open
31/01/17	To consider the NHS Digital process for new applicant organisations, such as due diligence and data availability for new start-ups.	Alan Hassey / Gaynor Dalton	09/02/17: Ongoing.	Open
09/02/17	To provide an update on the out of committee sign-off of NIC-69707 KPMG.	Garry Coleman		Open
09/02/17	To circulate information about how NHS Digital currently defines data as 'sensitive'.	Gaynor Dalton		Open
09/02/17	To consider the use of a standard special condition for applications that do not require data linkage.	Garry Coleman		Open
09/02/17	To provide an update on whether special conditions could be reflected on the data release register or otherwise made publicly available.	Garry Coleman		Open

Appendix B: Out of committee report (as of 03/02/17)

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

The following application caveats have been signed off by DAAG:

- NIC-25051-V0K1X Kings College London (*considered at 17/01/17 DAAG meeting*)
- NIC-19237 University of Liverpool (*considered at 13/12/16 DAAG meeting*)

The following application caveats have been signed off by the DAAG Chair:

- NIC-30645 University of Bristol (*considered at 10/01/17 DAAG meeting*)

The following application caveats have been signed off by the Director for Data Dissemination:

- NIC-67398 Imperial College London (*considered at 31/01/17 DAAG meeting*)
- NIC-15814 Monitor (*considered at 31/01/17 DAAG meeting*)
- NIC-51342 Centre for Longitudinal Studies (UCL) (*considered at 31/01/17 DAAG meeting*)
- NIC-79018 Halton Borough Council (*considered at 31/01/17 DAAG meeting*)
- NIC 324220 Queen Mary University of London (*considered at 24/01/17 DAAG meeting*)
- NIC-69707 KPMG – *please note the DAAG minutes indicated that the caveats for this application should be signed off by the DAAG Chair. (Considered at 31/01/17 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-376603-K2J9R NHS Digital (National Bowel Cancer Audit)
- NIC-355855-R4G6G Royal College of Anaesthetists (National Emergency Laparotomy Audit)
- NIC-291981 Imperial College London
- NIC-30560 University of Bristol
- NIC-381984 University Hospitals Birmingham
- NIC-09046 London Borough of Wandsworth