

# Independent Group Advising on the Release of Data (IGARD)

## Minutes of meeting held 4 May 2017

**Members:** Anomika Bedi, Chris Carrigan, Nicola Fear, Kirsty Irvine, Debby Lennard, Eve Sariyiannidou, James Wilson

**In attendance:** Jen Donald, Frances Hancox, Louise Hill, Bernard Horan, Dickie Langley, Stuart Richardson, Vicki Williams, Robyn Wilson

**Apologies:** Sarah Baalham, Joanne Bailey, Jon Fistein

1	<p><b>Declaration of interests</b></p> <p>No interests were declared.</p> <p><b>Review of previous minutes and actions</b></p> <p>The minutes of the 27 April 2017 IGARD meeting were reviewed and agreed as an accurate record of the meeting.</p> <p>Action updates were provided (see Appendix A).</p> <p><b>Out of committee recommendations</b></p> <p>An out of committee report was received (see Appendix B).</p>
2  2.1	<p><b>Data applications</b></p> <p><u>University of Dundee - Data linkage request for 'Allopurinol and cardiovascular outcomes in patients with ischaemic heart disease ALL-HEART' study (Presenter: Dickie Langley) NIC-369348-H6H8B</u></p> <p><b>Application:</b> This was a new application for identifiable Hospital Episode Statistics (HES), cancer registration and cause of death data for a consented study cohort. The University of Glasgow would act as data processor on behalf of the University of Dundee. IGARD were notified that the proposed agreement end date would be updated to run for one year.</p> <p><b>Discussion:</b> The potential benefits of this work were noted and IGARD expressed their support for the aims of the study.</p> <p>IGARD queried the legal basis for the dissemination of cause of death data, as it was unclear from the application whether this was Office for National Statistics (ONS) mortality data or data for which NHS Digital was the data controller.</p> <p>There was a discussion of the study consent materials, and while some concerns were raised that the actual consent form did not refer to the use of mortality data the patient information leaflet did include this. IGARD noted that the consent materials had not been very clear about the involvement of NHS Digital and had not referred to HES data by name, but on balance it was felt that sufficient information was provided for informed consent and the proposed fair processing updates were appropriate. However it was agreed that for any future studies or any continuation of this study, clearer consent materials should be used.</p> <p>A query was raised about whether study recruitment was ongoing, as the cohort numbers listed within the application appeared inconsistent. Confirmation of the current cohort size was</p>

requested. IGARD agreed that if recruitment was still taking place then the study consent materials ought to be updated in line with the proposed updates to fair processing information, and should include an email and postal address for any individuals who might wish to withdraw consent at a later date.

IGARD queried the role of the University of Nottingham in this study, given that one of the patient information sheets provided was for this organisation. It was explained that Nottingham had taken part in recruiting participants but would not have access to the data provided by NHS Digital, and similarly the University of Dundee carried out recruitment but would not process data. IGARD requested a clearer explanation of the involvement of the three different organisations and an explanation of why the University of Dundee was considered sole data controller, with further information about whether the other two organisations would have any role in determining how the data should be analysed or otherwise processed.

IGARD noted that the study was funded by the Department of Health, and that one of the supporting documents provided indicated that the funder would have access to data and sight of the study findings prior to publication. It was noted that the NHS Digital – University of Dundee agreement would not allow any data to be shared with third party organisations (including the Department of Health) except for aggregated data with small numbers suppressed; IGARD asked for this to be more explicitly stated within the application and for this point to be discussed with the Department of Health. In addition it was agreed the application should be updated to include a commitment that the funder would not have the ability to influence or suppress the outputs of the study.

IGARD suggested that a reference in the application to ‘the research team’ should be clarified to be clear which organisation’s employees this referred to. In addition it was suggested that the application should more clearly describe what record level linkage would take place.

**Outcome:** Recommendation deferred, pending:

- Providing a clearer justification for the University of Dundee being considered a sole data controller, and what the involvement of the University of Nottingham and University of Glasgow will be.
- Stating the current cohort size and what number of individuals data will be provided for, with an explanation of the inconsistent numbers stated within the application.
- Confirmation of whether recruitment is still ongoing, as if so the applicant should update the consent materials in line with the additional information provided in fair processing materials, and to include an email and postal address for individuals wishing to withdraw consent at a later date.
- Including a statement within the application that no record level data will be shared with any organisations other than the specified data controller and processors, and that therefore only aggregated outputs with small numbers suppressed can be shared with the Department of Health.
- Including confirmation in the application that the Department of Health as funding organisation will not have the ability to influence or suppress the outputs of this work, with confirmation that the Department of Health are aware of and content with this restriction.
- Confirmation of whether the mortality data is considered to be NHS Digital data or whether this is ONS data, and therefore confirmation of the relevant legal basis.

The application should be amended to clarify a reference to ‘the research team’ to state which University this team is employed by, and a description of ‘the only record linkage permitted’ should also be amended for clarity.

It was noted the application would be amended to update the DSA start and end date to run for one year.

**2.2****Group application for 3 Local Authorities<sup>1</sup> – PCMD (Presenter: Robyn Wilson)**

**Application:** This was an application for access to Office for National Statistics (ONS) births and deaths data via the Primary Care Mortality Database (PCMD) based on a previously agreed template application.

**Discussion:** A reference to listing names in section 8 of the application was queried and it was agreed this wording should be removed. It was noted that the privacy notice link for Wakefield Council did not work and IGARD asked for the correct link to be provided.

IGARD queried the date by which these organisations would need to update their privacy notices, as it was noted this had changed compared to previous applications. It was confirmed that as these data sharing agreements would only be issued for a very short period of time, a specific date had been set for privacy notice amendments to ensure this would be taken note of for any renewal applications.

A query was raised about the reason that type two objections would not be applied to this release of data. The application stated that this was because data disseminated on behalf of ONS was not considered to be personal confidential data and IGARD queried whether this description was technically accurate and asked for clarification of the rationale upon which such a statement was made. It was noted that this standard text had previously been agreed by DAAG but IGARD asked for the IG Advisor to IGARD to work with the application presenter to ensure that the wording around type two objections could be checked for accuracy and any changes applied to future PCMD applications. In particular IGARD noted that the NHS Digital's website description of type two objections indicated that objections would be upheld after a patient's death.

**Outcome:** Recommendation to approve.

The application template should be amended to remove a reference to names being listed in section 8 of the application, and should include the correct link for the Wakefield Council privacy notice.

IGARD advised that the Local Authorities should ensure their DPA registrations accurately reflect the processing of data for public health purposes.

**Action:** Robyn Wilson and Joanne Treddenick to agree updated wording for the PCMD application template on type two objections, ensuring that this is consistent with published NHS Digital information about exceptions to type two objections.

**2.3****Workforce Statistics Data – For advice (Presenter: Bernard Horan) 106434-G2P0X**

**Application:** This item was presented for advice only on the possibility of disseminating NHS workforce data, including pay bands, under the Freedom of Information Act and then publishing the aggregate data online.

**Discussion:** IGARD noted that if data was released under the Freedom of Information Act, this would amount to a publication of data by NHS Digital (as opposed to provision of confidential data between two parties) and therefore NHS Digital would need to be satisfied that the data was appropriate for publication prior to release. It was noted that in this instance the data would include aggregated fields such as gender and age bands, in line with other workforce statistics already publicly available, but would also contain aggregated pay bandings.

<sup>1</sup> NIC-40296-L3N1D Cornwall Council; NIC-41730-G3J5W Wakefield Council; NIC-47842-Z4R7D London Borough of Waltham Forest Council

	<p>IGARD requested more information about any review of this request already undertaken by NHS Digital's Information Governance staff to confirm whether the data should be considered confidential personal data as per the Data Protection Act, and therefore whether it would be appropriate to publish. It was agreed that it would not be appropriate for IGARD to advise on this without receiving this information, as well as further background information about the data in question, how it would be processed and aggregated, and the legal basis for dissemination. IGARD welcomed the information provided so far and noted the potential complexities in determining whether or not to release data under this legal basis, as it was acknowledged that making a Freedom of Information request would not always result in data being disseminated.</p> <p><b>Outcome:</b> IGARD suggested that in order to advise on this possible release of data they would wish to see additional background information on the data collection, processing, and what assessment had already been made of whether NHS Digital's Information Governance staff considered the data to be personal data as defined by the Data Protection Act.</p> <p><b>2.4</b> <u>NHS England – Temporary National Repository (Presenter: Stuart Richardson) NIC-92346-T4Z0F</u></p> <p><b>Application:</b> This was an amendment application to receive additional Improving Access to Psychological Therapies (IAPT) data for Early Implementer pilot sites, and to add Imperial College London as a data processor for this additional data. In addition South Central and West CSU were added as a data processor for the use of Secondary Uses Service (SUS) and NHS 111 data.</p> <p><b>Discussion:</b> IGARD acknowledged the potential benefits from this use of data.</p> <p>It was noted that the application described this data as 'anonymised in accordance with the ICO Anonymisation Code of Practice' and IGARD had previously queried this description given the data linkage involved. IGARD asked for this wording to be amended and to instead describe the data as pseudonymised.</p> <p>There was a brief discussion of the additional data requested, and it was clarified that additional fields within the existing IAPT dataset were requested for the pilot sites rather than an entirely new dataset being requested. IGARD asked for the table of data requested to be updated to state the additional fields in the relevant place more clearly.</p> <p>IGARD noted that the application referred to disclosure controls for each dataset without specifying these in more detail; confirmation was requested that NHS Digital's Disclosure Control Panel were content with the controls in place for each dataset.</p> <p><b>Outcome:</b> Recommendation to approve, subject to conditions:</p> <ul style="list-style-type: none"> <li>• Confirmation that the Disclosure Control Panel are content with the disclosure controls specified within this application.</li> </ul> <p>The application wording should be amended so that references to the data as anonymised in context make clear that the data is considered pseudonymised, and remove references to de-identification in line with the ICO code of practice. In addition in the table of data requested, the description of 14 additional fields should be included in the column of data requested rather than within the data minimisation efforts.</p> <p>It was agreed the conditions for this application would be reviewed out of committee by the IGARD Chair.</p> <p><b>2.5</b> <u>IMS Health Ltd - THIN-HES IMS Health Information Solutions / IMS World Publications Ltd (Presenter: Louise Dunn) NIC-24629-X6B6N</u></p>
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2.6	<p><b>Application:</b> This application requested an amendment to an agreement that had previously been considered at the 13 December 2016 DAAG meeting, with the requested amendment being to use the data already held for an additional purpose and to add IMS World Publications Ltd as a joint data controller. IGARD were informed that this would not change the agreement end date, and that a renewal application was still expected in June 2017.</p> <p><b>Discussion:</b> IGARD noted that NHS Digital had issued a letter to the applicant in March 2017 renewing the existing data sharing agreement until the end of June 2017. The timing for this amendment submission was queried, as it was noted that there were a number of outstanding queries raised at the DAAG review in December 2016, such as around data minimisation, that would need to be addressed in time for the renewal application in June 2017. In addition IGARD noted that as a result of the discussion at the 13 December 2016 meeting, a special condition had been added to the agreement that the applicant cannot approve the use of this data for any additional purposes at this point in time; some concerns were therefore raised about this request to use data for an additional purpose before the previously raised points had been fully addressed.</p> <p>IGARD did not feel it was appropriate to consider recommending this amendment application for approval before those outstanding points had been addressed as part of the upcoming renewal application.</p> <p><b>Outcome:</b> Not recommended for approval.</p> <p>IGARD noted that there were a number of outstanding points raised by DAAG in relation to the upcoming renewal application, and it was not considered appropriate to recommend this amendment for approval before these had been addressed.</p> <p><u>Nuffield Trust - Retrospective analysis of the impact of Royal Voluntary Service Home from Hospital scheme on NHS hospital use (Presenter: Jen Donald) NIC-86623-P4F4D</u></p> <p><b>Application:</b> This was a new application for HESIDs along with Lower Super Output Area, age, year of birth and gender for a cohort that would be supplied by the Royal Voluntary Service (RVS). The Nuffield Trust would then link this data to the pseudonymised HES data already held for other research projects, and use the linked data as well as a control cohort to provide an independent evaluation of the Home From Hospital scheme.</p> <p><b>Discussion:</b> There was a brief discussion around what data the applicant already held and what new data would be provided as part of this agreement. It was agreed the table of data requested within the application should be updated to more clearly explain what new data would be disseminated.</p> <p>Some concerns were raised about the consent materials, as these referred to the use of 'anonymised' data without making clear that data would be linked with other data without making clear that the data could be considered potentially identifiable. IGARD suggested that it would have been preferable to state that individuals could not be "directly identified" from the data. It was agreed that the applicant should make appropriate fair processing materials available online, within a reasonable timeframe, to help clarify this for individuals who had already given their consent as it was noted that recruitment to the study had ended.</p> <p>It was noted that the Nuffield Trust had committed to update their template consent form and IGARD advised that this should amend references to 'anonymised' data and should explain whether there would be any intention to link with other data. IGARD observed that they would welcome sight of the updated template form in advance of any further applications for data, and noted that they would expect the template to have been updated and be in use for any studies that had so far not begun recruitment.</p>
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	<p>IGARD queried a statement in the application that data would be transferred using ‘our own’ system; it was thought that this referred to the RVS secure file transfer system and IGARD asked for this wording to be clarified. Some minor typographical errors were noted, and IGARD asked for the application to be updated to correctly state the reason that patient objections would not be applied.</p> <p>The roles of WaveX and Data Protect UK were queried; it was explained that these two organisations provided IT services to the Nuffield Trust, but that neither organisation would have access to the HES data. It was noted that the data sharing agreement would contain special conditions confirming this. IGARD suggested that in future it would be helpful to discuss security assurances for this type of organisation at an educational session, including what considerations were taken into account to confirm an organisation should not be considered a data processor.</p> <p><b>Outcome:</b> Recommendation to approve, subject to conditions:</p> <ul style="list-style-type: none"> <li>• A commitment from the applicant to publish appropriate fair processing information online for this study within one month, including an appropriate description of data from which individuals cannot be directly identified rather than describing this as anonymised data, and a description of the planned data linkage.</li> </ul> <p>The table of data requested should be amended to be clear what new data will be provided to the applicant, and the explanation of why patient objections will not be applied should also be amended. A reference to “our own secure file transfer (SFTP) system” should be amended to clarify which organisation’s system this refers to, and a reference to seven service providers should be clarified.</p> <p>IGARD advised that the template consent form should be updated as soon as possible to correct references to ‘anonymised’ data to instead state that individuals cannot be directly identified and an explanation of any intention to link data. This would expect to be completed for any future applications that had not started recruitment at this point in time, and IGARD noted that they would welcome sight of the updated consent materials in advance of any further application submissions.</p> <p>It was agreed the conditions for this application would be reviewed out of committee by the IGARD Chair.</p>
3	<p><b>Any other business</b></p> <p><u>University of Bristol (Presenter: Jen Donald) NIC-30645-Z2Z2K</u></p> <p>This application had previously been reviewed at the 10 January 2017 DAAG meeting a recommended for approval. IGARD were notified that due to a technical error, the application at that time stated non-sensitive data was requested whereas in fact three specific sensitive fields were requested. IGARD acknowledged the change to the application and no concerns were raised.</p> <p><b>Outcome:</b> Recommendation to approve.</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>04/05/17: Ongoing.</p>	Open
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</p>	Open

			<p>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> <p>16/03/17: NHS Digital had received a System Level Security Policy (SLSP) from HQIP and this was currently under review.</p> <p>20/04/17: It was confirmed that the HQIP SLSP had been reviewed and approved. IGARD requested sight of this for information.</p> <p>04/05/17: Ongoing.</p>	
17/01/17	To provide an update on the security assurances that NHS Digital would seek for applicants using contractors.	Garry Coleman	<p>24/01/17: It was anticipated this update would be provided to a meeting within the next few weeks.</p> <p>09/03/17: Ongoing. It was agreed that the IGARD chair would contact Garry Coleman.</p> <p>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.</p> <p>23/03/17: It was confirmed one query had been addressed by email; confirmation was requested if any queries remained outstanding.</p> <p>04/05/17: Ongoing.</p>	Open
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	<p>06/04/17: Ongoing. It was anticipated a response would be provided at the following IGARD meeting.</p> <p>13/04/17: A verbal update was given on the Pre-IGARD process and it was agreed that it would be helpful on both sides to develop a Pre-IGARD checklist to define what checks would be carried out as standard for each application before reaching IGARD.</p> <p>27/04/17: Gaynor offered to provide a marked up application to demonstrate the types of comments raised at Pre-IGARD, but IGARD felt that this could be potentially prejudicial to the consideration of that application.</p> <p>04/05/17: Ongoing. This had been discussed as part of the morning educational session.</p>	Open
23/03/17	To provide a response to previously raised IGARD	IGARD	06/04/17: An update had been provided and the action remained	Open



	queries about indemnity.	Secretariat	open. 13/04/17: This was ongoing within NHS Digital. 04/05/17: Ongoing.	
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. 04/05/17: Ongoing.	Open
20/04/17	IGARD Chair to contact key stakeholder organisations regarding the benefits of uses of data to feed into the IGARD annual report.	IGARD Chair	04/05/17: Ongoing.	Open
20/04/17	Louise Dunn to request an update from Garry Coleman about possible future improvements to the data release register, and whether this might include publishing data flow diagrams to add clarity.	Louise Dunn	04/05/17: Ongoing.	Open
27/04/17	IGARD Chair to contact the NHS Digital Caldicott Guardian regarding GPs' data controller responsibilities for fair processing around risk stratification.	Chris Carrigan	04/05/17: Ongoing.	Open
04/05/17	Robyn Wilson and Joanne Treddenick to agree updated wording for the PCMD application template on type two objections, ensuring that this is consistent with published NHS Digital information about exceptions to type two objections.	Robyn Wilson		Open

## **Appendix B: Out of committee report (as of 28/04/17)**

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 application conditions have been signed off by the IGARD Chair:

- NIC-86349-M3B9V NHS Nottingham City CCG (*Considered at 20<sup>th</sup> April 2017 IGARD meeting*)
- NIC-86244-P6Y1N NHS Nottingham North & East CCG (*Considered at 20<sup>th</sup> April 2017 IGARD meeting*)
- NIC-86409-C4S9S NHS Nottingham West CCG (*Considered at 20<sup>th</sup> April 2017 IGARD meeting*)
- NIC-86250-T2M6F NHS Rushcliffe CCG (*Considered at 20<sup>th</sup> April 2017 IGARD meeting*)