

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

## Minutes of meeting held 1 June 2017

**Members:** Sarah Baalham, Chris Carrigan, Jon Fistein, Kirsty Irvine, Eve Sariyannidou, James Wilson

**In attendance:** Dave Cronin, Gaynor Dalton, Arjun Dhillon, Frances Hancox, Kimberley Watson

**Apologies:** Joanne Bailey, Anomika Bedi, Nicola Fear, Debby Lennard

1	<p><b>Declaration of interests</b></p> <p>Jon Fistein and Chris Carrigan declared a potential interest in the University of Leeds application (NIC-378523-Y5Q9L) due to their work with that organisation, but noted no particular involvement with that application otherwise.</p> <p><b>Review of previous minutes and actions</b></p> <p>The minutes of the 25 May 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><b>Out of committee recommendations</b></p> <p>An out of committee report was received (see Appendix B).</p> <p>IGARD noted that the report indicated one instance where IGARD had agreed that the conditions for an application would be signed off out of committee by the IGARD Chair, but that in practice the Director of Data Dissemination had approved the conditions. It was agreed the IGARD Chair would query this with NHS Digital to determine the reasons for this.</p> <p><b>Action:</b> IGARD Chair to contact the Director of Data Dissemination regarding the out of committee sign-off for Monitor NIC-15814-C6W9R.</p>
2  2.1	<p><b>Data applications</b></p> <p><u>NHS Digital - National Oesophago-Gastric Cancer Audit (Presenter: Dave Cronin) NIC-376599-X4H8Y</u></p> <p><b>Application:</b> This application was to amend an existing agreement to include the flow of identifiers to NHS Wales Informatics Service (NWIS) for the purpose of linking to Patient Episode Database for Wales (PEDW) data, with HQIP acting as data controller. It was noted that this application was very similar to the NHS Digital – National Bowel Cancer Audit application (NIC-376603-K2J9R) that had been recommended for approval at the previous IGARD meeting, and that the two audits shared section 251 support documentation.</p> <p><b>Discussion:</b> IGARD briefly recapped the key points that had been raised regarding the section 251 support during the discussion at the previous meeting. It was agreed that the evidence provided was not ideal, but on balance there appeared to be a legal basis in place under section 251 based on the assumption made by NHS Digital IG staff to confirm this.</p> <p>IGARD noted that the commissioning letter, which was provided as evidence for the</p>

2.2	<p>applicant's legal basis to process ONS mortality data under Section 42(4) of the Statistics and Registration Service Act 2007, seemed to have expired and concerns were raised that the up to date documentation had not been provided as part of the application pack. It was agreed the IGARD Chair would raise this within NHS Digital. It was acknowledged that the current application was for an amendment relating to Welsh data flows, rather than to explicitly extend the use of ONS mortality data, but nevertheless IGARD considered that an up to date commissioning letter ought to be provided as evidence of current legal basis.</p> <p>There was a discussion about the use of jargon, acronyms and technical terms in section five of the application, given that this section would be published in the data release register and therefore IGARD considered that it should be comprehensible to a lay audience. IGARD acknowledged the difficulty in balancing the need for clear, plain English with the need to convey certain technical points for the purpose of the data sharing agreement. It was suggested that the IGARD Chair should contact the Wellcome Trust regarding their work around communicating with patients more clearly about the use of data.</p> <p>It was suggested that section five should be amended to reference some of the special conditions listed in section six.</p> <p>IGARD noted that this recommendation was based on the assumption made by NHS Digital IG staff to confirm that a legal basis was in place under section 251 support.</p> <p><b>Outcome:</b> Recommendation to approve, subject to conditions:</p> <ul style="list-style-type: none"> <li>• Providing an updated commissioning letter to ensure that an appropriate legal basis remains in place for the use of ONS mortality data.</li> </ul> <p>Section five of the application should be amended to include a statement around the restrictions on data sharing as currently set out within special conditions.</p> <p>IGARD advised that HQIP and the Royal College of Surgeons should update their DPA registration to include processing data about patients or health service users.</p> <p>It was agreed this condition would be reviewed out of committee by the IGARD Chair.</p> <p><b>Action:</b> IGARD Chair to feedback to NHS Digital about the need to ensure applications coming to IGARD include the appropriate, up to date documentation such as the most recent commissioning letter.</p> <p><b>Action:</b> IGARD Chair to contact the Wellcome Trust about their work around 'Understanding Patient Data' communications and how this could influence NHS Digital's applications.</p> <p><u>University of Oxford - Study of Cancer in Vegetarians (Presenter: Kimberley Watson) NIC-148267-W26RZ</u></p> <p><b>Application:</b> This application requested a renewal and amendment for the continued retention and future provision of Personal Demographics Service (PDS) data including cause of death and event notifications for a cohort. Previously identifiable data had been provided for this purpose but the applicant had now determined that future data processing could be carried out using pseudonymised data, and therefore while the identifiable data already received would be retained the only new data requested at this point was pseudonymised. The length of the study was noted, with data flowing since the 1980s.</p> <p>It was noted that the application at the time of submission had not shown the territory of use, but this had since been corrected to specify England/Wales. IGARD were informed that section three of the application did not correctly list the different data levels retained and requested, but it was confirmed that identifiable data would be retained and new pseudonymised data would be provided.</p>
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2.3	<p><b>Discussion:</b> IGARD noted the potential benefits of this study and welcomed the move from identifiable data to the use of pseudonymised data. It was suggested that section five of the application should be amended to include more information about how the two levels of data would be kept separate. IGARD agreed it would be helpful in general to have more information about the three options made available to applicants in terms of moving from the use of pseudonymised data, and what assurances were provided for how pseudonymised and identifiable data would be separated. For this application in particular, it was agreed a special condition should be added requiring the pseudonymised and identifiable data to be kept entirely separately and not linked.</p> <p>IGARD suggested that due to the technical error that had meant the data already held and its legal basis was not accurately reflected in section three, this should be specified within section five of the application to ensure transparency. It was agreed that the application should be amended to more clearly explain the potential benefits and how outputs would be disseminated in a way that would lead to those benefits. In addition it was agreed the study's Microdata Release Panel approval details should be included in section nine.</p> <p>There was a discussion of fair processing and IGARD noted that the information currently available online made use of technical terms and ideally should make better use of plain English, rather than describing data in potentially confusing terms such as 'pseudo-anonymised'. It was agreed that the applicant should commit to update this to use more appropriate language.</p> <p><b>Outcome:</b> Recommendation to approve.</p> <p>Section five should be amended to include more information about the anticipated health benefits of this study and how these will be shared with the general public, and to describe the data already held as this is not currently accurately reflected in section 3.</p> <p>Section seven of the application should be amended to include details of the study's Microdata Release Panel approval. A special condition should be added that the applicant must keep the pseudonymised data entirely separate from the identifiable data already held.</p> <p>The applicant should commit to update the fair processing information on their website to use plainer English with less use of jargon such as pseudo-anonymised, and this should take place within six weeks.</p> <p><b>Action:</b> Garry Coleman to provide information about the process for applicants moving from the use of identifiable to pseudonymised data and what standard steps are taken when they opt to retain identifiable data as well as receiving new pseudonymised data.</p> <p><u>London School of Hygiene and Tropical Medicine - Feasibility study of PROMs for emergency admissions (Presenter: Kimberley Watson) NIC-63345-L7D3D</u></p> <p><b>Application:</b> This was a new application for list cleaning, in order for the applicant to avoid contacting the families of recently deceased participants when a follow-up questionnaire was sent out by post.</p> <p><b>Discussion:</b> IGARD queried the involvement of the University College London in this application, as it was noted that a supporting document referred to the individual applicant as a Doctoral Student at the University College London. It was agreed that the roles of the two organisations in this application should be clarified, with confirmation of whether the individual applicant was substantive employee of the London School of Hygiene and Tropical Medicine.</p> <p>IGARD commented on the DPA registration wording for this applicant and emphasised that this should be checked as part of the pre-submission process.</p> <p>IGARD noted the potential benefits of carrying out list cleaning before initiating this type of contact with participants, and expressed their support for this approach. IGARD also noted the</p>
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<p>2.4</p>	<p>use of the term ‘vital status’ in information materials rather than describing this as mortality data or death data, as it was acknowledged that some individuals could find that type of description off-putting.</p> <p><b>Outcome:</b> Recommendation to approve, subject to conditions:</p> <ul style="list-style-type: none"> <li>• Confirmation of the employment status of the Doctoral Student referred to in this application and whether this individual is substantively employed by London School of Hygiene and Tropical Medicine or if not then what contractual arrangements are in place.</li> </ul> <p>Section five of the application should be updated to more clearly describe the roles of University College London and London School of Hygiene and Tropical Medicine in this work. IGARD advised that London School of Hygiene and Tropical Medicine should update their DPA registration wording to reflect the processing of data about patients or health service users.</p> <p>It was agreed this condition would be considered out of committee by the IGARD Chair.</p> <p><b>Action:</b> IGARD Secretariat to speak to Gaynor Dalton about the need for pre IGARD checks to include an applicant’s DPA registration wording.</p> <p><u>University of Leeds - Routinely collected hospital admissions data for care home residents (Presenter: Gaynor Dalton) NIC-378523-Y5Q9L</u></p> <p><b>Application:</b> This new application requested identifiable Hospital Episode Statistics (HES) data for a small consented cohort, as well as an aggregated tabulation with small numbers suppressed for a number of care homes. IGARD were informed that the applicant were aware and content that the tabulation would likely feature a large number of suppression, due to the likelihood of a large number of small numbers in this data. It was noted that Bradford Teaching Hospitals NHS Foundation Trust would act as joint data controllers but would not have access to the data.</p> <p><b>Discussion:</b> IGARD discussed the study consent materials and some concerns were raised that the consent materials did not more explicitly describe the proposed data sharing with NHS Digital, as although it was acknowledged that the resident consent form referred to using data from the HSCIC it was not stated that identifiers would need to be sent to NHS Digital to achieve this. In addition it was felt that the method to withdraw consent could have been made clearly, by explicitly stating that if anyone in future wished to withdraw consent then they could use the contact details provided. IGARD advised that if the applicant did scale up the study in future, they should first work with NHS Digital to update their consent materials appropriately.</p> <p>IGARD queried whether the newsletters referred to in the application had been sent directly to care home residents, or only provided to care home staff. It was agreed this should be clarified within the application.</p> <p>There was a brief discussion of the possible results from this feasibility study and how helpful they would be without carrying out a larger study; it was noted that a larger, scaled-up study would need to return to NHS Digital with an updated application for data.</p> <p><b>Outcome:</b> Recommendation to approve.</p> <p>The application should be amended to confirm that the newsletter has been provided to the study participants, rather than only being shared with care home staff.</p> <p>IGARD advised that before the applicant scaled up this study, they would need to update the consent materials to explicitly state that identifiers would be sent to NHS Digital to enable data sharing, and should more explicitly state that participants can withdraw consent via the contact details provided.</p> <p>It was suggested that if the study was in future scaled up, the applicant should consider sharing outputs with appropriate charities such as Age UK.</p>
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**Application:** This was a renewal and amendment application to include a new mental health dataset (MHSDS), add the historic K90 dataset which had previously been held by CQC under a separate agreement, and to reduce the amount of identifiable data shared under this agreement. IGARD were informed that some of the data requested, as listed within the abstract section of the application, was not currently shown in section three due to technical constraints.

**Discussion:** The role of ATOS as a data processor was noted and IGARD suggested that the application should be amended to more clearly describe the controls in place for data use within this organisation; specifically that data could only be used by individuals working to support the CQC statutory functions as set out within the application, and not for any other purpose. In addition IGARD discussed the CQC privacy notice and advised that this should be updated to reflect the involvement of ATOS as a data processor, as well as to clarify a statement that certain identifiers were 'deemed identifiable' by NHS Digital and clarify a statement that data would not be used to identify individuals, given the use of identifiable data in this application.

IGARD queried a description within the application of data being anonymised; it was suggested that this should be amended to explain how the data would be anonymised, or if more appropriate then to describe the data as pseudonymised instead. In addition it was suggested that the described legal basis should be amended to refer to the Health and Social Care Act 2012 schedule 12, part 9, subsection 11. IGARD also asked for section five to be amended to reflect the data that could not be included in section three due to technical constraints.

IGARD noted that DAAG had previously queried the amount of identifiable data required for this purpose. IGARD welcomed the steps taken to reduce the amount of identifiable data requested, and suggested that a special condition should be added that when a renewal application was next submitted this should include an update on the steps taken by CQC to review the use of identifiers and whether this amount of identifiable data continued to be necessary.

It was noted that the applicant's version 14 IG Toolkit score had been reviewed as satisfactory, and the application would be updated to reflect this. In addition IGARD queried a reference to Approved Researcher status and noted that the abstract stated that this was not relevant as the legal basis for ONS mortality data was under Section 42(4) of the Statistics and Registration Service Act 2007; it was suggested that this clarification should be included in section five. IGARD noted the use of a large number of acronyms in section five of the application and suggested these should be more clearly explained when first used.

**Outcome:** Recommendation to approve, subject to conditions:

- Confirmation that NHS Digital are content that the privacy notice for CQC meets the nine minimum criteria. In order to meet these nine point criteria IGARD noted that CQC should update their privacy notice to explain the role of ATOS in processing this data, to remove a statement that certain identifiers are 'deemed identifiable' by NHS Digital, and to clarify a statement that they will not identify individuals. IGARD requested sight of the updated privacy notice.

Section five should be amended to specify the datasets requested as these were not all listed in section three, and the legal basis should be specified as being under the Health and Social Care Act 2012 schedule 12, part 9, subsection 11. Section five should also include a commitment that only staff working on these specific purposes can access this data and only for the purpose specified.

The application should be amended to include the version 14 IG Toolkit details for CQC. A

	<p>reference to providing anonymised data should be amended to either clarify how the data is anonymised or to instead describe data as pseudonymised. A point of clarification from the abstract about the legal basis for ONS data under section 42(4) should be included in section five. A special condition should be added that as part of the future renewal process CQC should continue to review the use of identifiers and whether this amount of identifiable data continued to be necessary.</p> <p>IGARD advised that ATOS should update their DPA registration to include processing data about patients or health service users.</p> <p>It was agreed these conditions would be considered out of committee by IGARD.</p>
<b>3</b>	<p><b>Any other business</b></p> <p>The IGARD Secretariat gave a brief update on meeting rooms and members were reminded that the following meeting would take place in Leeds.</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>11/05/17: This action was not discussed due to time restrictions.</p> <p>18/05/17: IGARD received a verbal update on work underway to develop 'dummy data' for the purpose of developing tools and algorithms.</p> <p>01/06/17: Ongoing.</p>	Open
23/03/17	To provide additional information about the application checks made by the Pre-IGARD process	Gaynor Dalton	06/04/17: Ongoing. It was anticipated a response would be provided at the following IGARD meeting.	Open

	before applications are submitted to an IGARD meeting.		<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> <p>18/05/17: IGARD received a verbal update about the increased involvement of the IG Advisor in Pre-IGARD and about the role of Operational IG staff within DARS. There was a suggestion that the Deputy Caldicott Guardian could also attend Pre-IGARD. IGARD advised that it would still be helpful to have sight of a checklist to confirm what items should be checked prior to an application reaching an IGARD meeting.</p> <p>01/06/17: IGARD were given a brief update about the work underway, including involving the IG Advisor more actively in the Pre-IGARD process and it was hoped the Deputy Caldicott Guardian could also attend Pre-IGARD.</p>	
23/03/17	To provide a response to previously raised IGARD queries about indemnity.	IGARD Secretariat	<p>06/04/17: An update had been provided and the action remained open.</p> <p>13/04/17: This was ongoing within NHS Digital.</p> <p>01/06/17: The Caldicott Guardian had request a meeting with the IGARD Chair and others to discuss this.</p>	Open
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.	IGARD Chair	<p>06/04/17: This had been raised but a response had not yet been received.</p> <p>18/05/17: IGARD noted a verbal update provided about upcoming changes to the IG Toolkit and how this would be reviewed. It was agreed further clarity was still required about how this issue would be handled with existing applications until the IG Toolkit changes came into effect.</p>	Open



			01/06/17: Ongoing.	
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	01/06/17: 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.	IGARD Chair	18/05/17: Ongoing. It was agreed this would be discussed with the Deputy Caldicott Guardian. 01/06/17: 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	11/05/17: The IG Advisor gave a verbal update with confirmation that in October 2016 NHS Digital had confirmed a decision that type two objections would not be considered to apply to this flow of data due to the specific legal gateways around ONS data sharing. Further work was planned to agree the specific application wording to describe this. 18/05/17: IGARD were informed by the Secretariat that Robyn and Joanne had agreed new draft wording, and that this would be circulated to IGARD for discussion out of committee. 25/05/17: The new draft wording had been circulated out of committee and members were reminded to provide any comments by email if they wished to do so. 01/06/17: Ongoing.	Open
18/05/17	Garry Coleman to provide information about different arrangements for data storage and backup locations, for consideration of whether the organisations involved would be considered to be processing data.	Garry Coleman	01/06/17: Ongoing.	Open
25/05/17	Dave Cronin to provide information to IGARD regarding the NHS Digital policy on how different types of data sharing agreement breaches are classified and handled.	Dave Cronin	01/06/17: Ongoing.	Open
25/05/17	IGARD Chair to contact Garry Coleman regarding the special condition wording around version 14 IG Toolkit review, and the associated risk of requiring	IGARD Chair	01/06/17: The IGARD Chair had contacted Garry Coleman but had not yet had a response due to annual leave.	Open

	applicants to report back to NHS Digital.			
01/06/17	IGARD Chair to contact the Director of Data Dissemination regarding the out of committee sign-off for Monitor NIC-15814-C6W9R.	IGARD Chair		Open
01/06/17	IGARD Chair to feedback to NHS Digital about the need to ensure applications coming to IGARD include the appropriate, up to date documentation such as the most recent commissioning letter.	IGARD Chair		Open
01/06/17	IGARD Chair to contact the Wellcome Trust about their work around 'Understanding Patient Data' communications and how this could influence NHS Digital's applications.	IGARD Chair		Open
01/06/17	Garry Coleman to provide information about the process for applicants moving from the use of identifiable to pseudonymised data and what standard steps are taken when they opt to retain identifiable data as well as receiving new pseudonymised data.	Garry Coleman		Open
01/06/17	IGARD Secretariat to speak to Gaynor Dalton about the need for pre IGARD checks to include an applicant's DPA registration wording.	IGARD Secretariat		Open

## **Appendix B: Out of committee report (as of 26/05/17)**

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-70235 Met Office (*Considered at 27<sup>th</sup> April 2017 IGARD meeting*)

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

- NIC-15814 Monitor (*Considered at 18<sup>th</sup> May 2017 IGARD meeting – NB the minutes of this meeting recorded that conditions would be signed off by the IGARD Chair.*)