

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

## Minutes of meeting held 27 April 2017

**Members:** Joanne Bailey, Chris Carrigan, Jon Fistein, Kirsty Irvine, Debby Lennard, Eve Sariyiannidou,

**In attendance:** Gaynor Dalton, Jen Donald, Frances Hancox, Paul Niblett, Kirsty Oldroyd, Joanne Treddenick, Vicki Williams

**Apologies:** Sarah Baalham, Anomika Bedi, Nicola Fear, James Wilson

1	<p><b>Declaration of interests</b></p> <p>Chris Carrigan declared a potential conflict of interest with the NHS Digital – National Bowel Cancer Audit application (NIC-376603-K2J9R) due to an employment connection.</p> <p>Jon Fistein also noted a potential interest with this application due to an independent advisory role but it was agreed that this should not prevent him from participating in the discussion of the application.</p> <p><b>Review of previous minutes and actions</b></p> <p>The minutes of the 20 April 2017 IGARD meeting were reviewed and subject to a minor change were 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 Essex - National Child Measurement Programme (NCMP) School Level Results (Presenter: Paul Niblett) NIC-82493-P8Y3N</u></p> <p><b>Application:</b> This was a new application requesting aggregated, school-level NCMP data with small numbers unsuppressed. This data would be used as part of research into the impact of a government initiative around free school meals. IGARD were informed that Public Health England were joint data controllers for the NCMP data along with NHS Digital, and that Public Health England were supportive of this application.</p> <p><b>Discussion:</b> IGARD noted that the legal basis for this dissemination would be under the Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013, which stated that data could be disclosed for research only in a form in which no individual child could be identified. Confirmation was requested that NHS Digital were content that based on the controls in place, the data that would be disseminated would carry a very low chance of an individual child being re-identified and IGARD agreed that this confirmation should be reflected within section five of the application, with a clear explanation of why this was considered to be the case. In addition it was agreed the application should include a statement that the data would not be linked with any other record level data.</p> <p>IGARD discussed the possible benefits of this work and on balance agreed that it could provide healthcare benefits in line with the requirements of the Care Act 2014, for example via</p>

2.2	<p>influence on future policy decisions around child obesity.</p> <p>IGARD noted the potential value of this work and expressed their support, but also noted the importance of ensuring that individuals are sufficiently informed about the secondary uses of data about them.</p> <p>A query was raised about the possible involvement of the Nuffield Trust as a funder for this work. IGARD suggested the application should include confirmation that this organisation, or any similar organisation that funded the work, would not be able to influence or suppress the findings of the study and would not have access to any data other than aggregated data with small numbers suppressed. A clearer explanation was also requested for why the application was not considered to be commercial.</p> <p>NHS Digital's involvement in reviewing outputs prior to publication was noted, and IGARD queried whether this would include review by the Disclosure Control Panel. It was agreed the application wording should be amended to be clearer what this review by NHS Digital would involve, such as checking small number suppression.</p> <p>There was a discussion of the opt-out process for NCMP and it was noted that although parents were given the opportunity to opt out rather than children, if a child explicitly did not wish to take part then it was anticipated that they would not be required to participate. IGARD noted the current overlap between opting out of measurement and opting out of data sharing, and suggested that it would be more appropriate if opting out of data sharing for secondary uses could be separate from opting out of the NCMP entirely.</p> <p><b>Outcome:</b> Recommendation to approve, subject to conditions:</p> <ul style="list-style-type: none"> <li>• Confirmation that NHS Digital is content that based on the controls in place, there would be a very low chance of re-identifying an individual child from this data. Section five of the application should be updated to include an explanation of why this is the case as well as adding restrictions that the applicant must not attempt to link the data with other dataset.</li> <li>• Providing a justification for why this work is not considered commercial, with confirmation within the application that if the work is funded by the Nuffield Trust or similar organisation, then that organisation will not have access to any unsuppressed data and will not be able to influence or suppress the findings of the study.</li> </ul> <p>The wording around clearing outputs with NHS Digital should be amended to explain the purpose of this and what considerations will be taken into account, as well as whether outputs will be reviewed by the Disclosure Control Panel. The application should also be amended to include a clearer explanation of the expected healthcare benefits.</p> <p>IGARD advised that the University of Essex should consider updating their DPA registration wording to include processing data about patients or healthcare users.</p> <p>It was agreed the conditions for this application would be reviewed out of committee by the IGARD Chair.</p> <p><u>London School of Hygiene &amp; Tropical Medicine - Daily numbers of emergency hospital admissions and environmental exposures (Presenter: Gaynor Dalton) NIC-175251-DYDW4</u></p> <p><b>Application:</b> This was a renewal and amendment application for the applicant organisation to continue to retain pseudonymised Hospital Episode Statistics (HES) data and to also use this for an additional purpose, to support the review of the Department of Health Cold Weather Plan for England.</p> <p><b>Discussion:</b> IGARD noted the potential benefits of this use of data but suggested that in addition the applicant might wish to consider making outputs available to relevant charities or patient groups.</p>
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A reference in the application to 'the above named individuals' was queried and it was clarified the specific individual was named in a later section of the application.

IGARD noted that this agreement would enable the applicant to use the data they already held for a different purpose from the reason that data had previously been held. It was agreed the application should be updated to be clear that if the applicant wished to use data for any further additional purposes then this would need to be subject to a further application. A reference to previous data sharing with an EU project was noted and IGARD asked for the application to more clearly state that only aggregated outputs with small numbers suppressed could be shared with third parties, and that this included any further sharing with the EU project in question.

**Outcome:** Recommendation to approve.

Section five of the application should be amended to state that only aggregated data with small numbers suppressed can be shared with third parties, and that this includes any data sharing with EU Projects. In addition the application should be amended to be clear that if the applicant wishes to use data for any additional purposes then this would need to be subject to a further application.

IGARD suggested that the applicant should consider further disseminating outputs to relevant charities.

## 2.3

### NHS Digital - National Bowel Cancer Audit (Presenter: Louise Dunn) NIC-376603-K2J9R

**Application:** This application requested an amendment to permit the linkage of HES and audit data to Intensive Care National Audit and Research Centre (ICNARC) data, and to permit the flow of identifiers to NHS Wales Informatics Service (NWIS) for the purpose of linking to Patient Episode Database for Wales (PEDW) data. It was acknowledged that two supporting documents evidencing the legal basis had been circulated late.

**Discussion:** IGARD queried whether NHS Digital had sought recent assurances regarding the legal basis for the organisations to process Office for National Statistics (ONS) mortality data as part of this application. IGARD were informed that an updated review of this legal basis had not been sought as part of this amendment application, as no further data was requested at this point in time, but that the legal basis for the use of ONS mortality data had been confirmed by both ONS and NHS Digital when the previous application was submitted in 2016.

There was a discussion about the flow of patient identifiers to NWIS and IGARD noted that while the application indicated these identifiers would only flow for those 'identified as being welsh patients', it was unclear whether this meant patients resident in Wales, those registered at a Welsh general practice or some other definition. A reference to Welsh NHS number was queried. IGARD considered the supporting documents provided to be insufficiently clear about which application version had been reviewed by HRA CAG at what point in time, and therefore whether the Welsh data flow was included as part of the current section 251 support. It was agreed that further evidence was required that the application version cited was the one that had been reviewed by HRA CAG, and IGARD noted that this might be reflected on the applicant's section 251 outcome letter.

IGARD noted that the application stated an updated patient information leaflet would be published in May 2017, and suggested that the application should be updated to include a special condition that this publication should happen within the expected timeframe.

The potential benefits of this work were acknowledged and IGARD suggested the organisations involved might wish to further consider how to make more information about the results of the audit available to the audit cohort as well as the general public.

	<p>IGARD noted the various data linkages referred to in the application and stated that it was currently unclear which data flows were requested as part of the current application, which flows had previously been approved under earlier applications, or if any of the linkages described did not involve NHS Digital data. There was a suggestion that future data flow diagrams could possibly highlight the flows that related to a particular application, to be clearer which data flows were included for background information only. A particular query was raised about the linkage to Patient Reported Outcome Measures (PROMs) data and it was agreed the application should state the legal basis for this linkage more clearly.</p> <p><b>Outcome:</b> Recommendation deferred, pending:</p> <ul style="list-style-type: none"> <li>Confirmation of which section 251 application version has most recently been reviewed by HRA CAG, with appropriate evidence of this.</li> </ul> <p>The application should be amended to include a clearer definition of which patients will be included in data sharing with Wales, such as whether this will be defined by patients registered with a GP in Wales.</p> <p>A special condition should be added to the application that the updated patient information leaflet must be published online in May 2017. Section five should be updated to more clearly state what data processing is requested as part of the current amendment application, as opposed to what has already been approved. The legal basis for PROMs data should also be stated more clearly within the application.</p> <p>IGARD advised that HQIP should update their DPA registration to reflect the use of data about patients or healthcare users. In addition IGARD advised that the applicant should consider how best to disseminate information about the audit outputs to the audit cohort as well as the general public.</p>
2.4	<p><u>Royal College of Obstetricians and Gynaecologists - National Maternity and Perinatal Audit NIC-44356-Y8N6R</u></p> <p>This application was withdrawn prior to the meeting at the request of the presenter.</p>
2.5	<p><u>Met Office - Health Research Programme (Presenter: Jen Donald) NIC-70235-T6P9F</u></p> <p><b>Application:</b> This was a renewal and amendment application to retain the pseudonymised HES data already held, receive newer HES data and combine three previous data sharing agreements into a single agreement. Data would be used to support the work of the Health Research Programme, particularly around the impact of weather on health and improving areas such as cold weather and heat wave plans. It was noted that a large number of data years were requested and IGARD were told that this was due to the long period needed to establish a climate baseline as well as the need to monitor low frequency, high impact events such as extreme heat waves.</p> <p>IGARD were informed that the data sharing framework contract with this organisation was currently undergoing renewal process, and that data would not be shared until this had been completed.</p> <p><b>Discussion:</b> IGARD noted some similarities between the purpose of this application and the work described in application 2.2 (NIC-175251-DYDW4 London School of Hygiene and Tropical Medicine). There was a suggestion that in future the IGARD annual report could potentially consider an example of instances where two applications had resulted in dissemination of the same data to two different organisations for very similar purposes. In addition IGARD suggested that some of the points raised in relation to that previous application, such as the restriction around sharing data with third parties, should also be applied to this application along with confirmation that there will be no requirement or attempt made to re-identify individuals within the data.</p>

	<p>There was a discussion of the amount of data requested, and IGARD noted that while an explanation was provided for the number of years required it was unclear whether any other data minimisation efforts had been considered. It was agreed that a clearer justification should be given for why this amount of data was needed for the full population.</p> <p>IGARD queried some references in the application to researchers reviewing ‘research outputs’ or ‘results from analyses’. It was agreed the application wording should be amended to clarify whether these researchers were substantive employees of the Met Office, or if not employees then the application should state that they would only have access to aggregated data with small numbers appropriately suppressed.</p> <p><b>Outcome:</b> Recommendation to approve, subject to a condition:</p> <ul style="list-style-type: none"> <li>• Providing more information about what data minimisation efforts have been considered, with a clearer justification of the need to use record level data for the full population for this number of data years.</li> </ul> <p>References in the application to results of analyses being reviewed by researchers should be amended to be clear either that these are substantive employees of the Met Office, or that if these are external researchers then only aggregated data with small numbers suppressed will be shared with the researchers.</p> <p>Section five of the application should be amended to state that only aggregated data with small numbers suppressed can be shared with third parties. In addition the application should be amended to be clear that there will be no requirement or attempt to reidentify individuals, that data will not be linked to other record level data, and that if the applicant wishes to use data for any additional purposes then this would need to be subject to a further application.</p> <p>It was agreed the conditions for this application would be reviewed out of committee by the IGARD Chair.</p>
<p><b>3</b></p>	<p><b>Any other business</b></p> <p>There was a brief discussion about GPs’ role as data controllers for the primary care data that was typically linked with SUS data for use in risk stratification, and the importance of having appropriate fair processing information in place for patients.</p> <p><b>Action:</b> IGARD Chair to contact the NHS Digital Caldicott Guardian regarding GPs’ data controller responsibilities for fair processing around risk stratification.</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>27/04/17: 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>27/04/17: 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>27/04/17: 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>	Open
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>	Open

			27/04/17: 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. 27/04/17: 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	27/04/17: 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	27/04/17: 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		Open



## **Appendix B: Out of committee report (as of 21/04/17)**

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 IGARD:

- NIC-86183 London Borough of Hackney Council (*Considered at 23<sup>rd</sup> March 2017 IGARD meeting*)
- NIC-36767 Cumbria CCG (*Considered at 14<sup>th</sup> October 2016 DAAG meeting*)
- NIC-47180 Bolton CCG (*Considered at 18<sup>th</sup> October 2016 DAAG meeting*)
- NIC-147978 Cambridge University Hospitals NHS Foundation Trust (*Considered at 2<sup>nd</sup> March 2017 IGARD meeting*)
- NIC-86202 Tameside Council (*Considered at 23<sup>rd</sup> March 2017 IGARD meeting*)
- NIC-09519 Methods Analytics Ltd (*Considered at 23<sup>rd</sup> March 2017 IGARD meeting*)
- NIC-33318 University of Manchester (*Considered at 6<sup>th</sup> April 2017 IGARD meeting*)
- NIC 60624 IMS Health Limited (*Considered at 13<sup>th</sup> April 2017 IGARD meeting*)