

Independent Group Advising on the Release of Data (IGARD)

Minutes of meeting held 23 February 2017

Members: Joanne Bailey, Debby Lennard, Eve Sariyannidou, James Wilson

In attendance: Jen Donald, Louise Dunn, Frances Hancox, Alan Hassey (observer), Terry Hill (observer), Kimberley Watson (observer), Vicki Williams

Apologies: Sarah Baalham, Anomika Bedi, Chris Carrigan (Chair), Nicola Fear, Jon Fistein, Kirsty Irvine

1	<p>Welcome and introductions</p> <p>It was noted that due to unforeseen circumstances the IGARD Chair was unable to attend the meeting, and it was agreed Joanne Bailey would act as chair for this meeting.</p> <p>Declaration of interests</p> <p>James Wilson declared a potential interest in the University College London application (NIC-28051-Q3K7L) due to his employment by that organisation. However it was confirmed that he did not have any direct involvement with the applicant or the particular research in question, and it was agreed this should not prevent him from participating in the discussion.</p> <p>Review of previous minutes and actions</p> <p>The minutes of the 16 February IGARD meeting were reviewed. Due to the limited number of attendees who had been present at that meeting, it was agreed the draft minutes would be reviewed and ratified out of committee.</p> <p>Action updates were provided (see Appendix A).</p> <p>Out of committee recommendations</p> <p>An out of committee report was received (see Appendix B).</p> <p>Terry Hill provided a verbal operational update and suggested that in future, applicants should confirm that all organisations party to an agreement were aware of the content of the application and understood their obligations with regard to the data sharing agreement.</p>
2 2.1	<p>Data applications</p> <p><u>Aggregated Management Information for General Practice Workload Data (Presenter: Dave Roberts)</u></p> <p>Application: IGARD were presented with a briefing paper on the proposed collection and publication of aggregated data on general practice workload and appointment availability. It was confirmed that small numbers would be suppressed in all published outputs and this was therefore brought to IGARD for information only. It was confirmed that a direction was in place from NHS England to collect this data, and that the proposed collection had been reviewed by SCCI.</p> <p>Discussion: The briefing paper was noted and there was a brief discussion about ways in which this data could be used in future.</p>

	<p>IGARD noted the importance of not disproportionately burdening general practice, for example through requiring manual data submissions, and it was anticipated that the proposed data collection would have a minimal impact in this area. In addition IGARD noted the potential difficulties in accurately monitoring appointment numbers, given different processes within different practices and the fact that appointment numbers could greatly fluctuate over a single day. It was acknowledged that there would likely need to be significant data quality undertaken for the initial collections.</p> <p>Outcome: IGARD noted the information provided.</p>
2.2	<p><u>Group application for 5 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 9 February 2017 IGARD 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, and that all applicant Local Authorities had provided a privacy notice link. In addition it was confirmed that the template had been slightly updated in two places to address previous IGARD comments.</p> <p>Discussion: IGARD requested an update on progress regarding privacy notices for the Local Authorities who had previously committed to make improvements within twelve weeks. It was agreed an update would be provided.</p> <p>A query was raised about the version 13 IG Toolkit review date for Cumbria County Council, as this was listed as October 2015 rather than 2016; however it was confirmed that this was correct.</p> <p>It was suggested that in future, applications should indicate whether or not the applicant's DPA Registration wording appropriately reflected the requested use of data and the relevant data subjects.</p> <p>Outcome: Recommendation to approve. IGARD advised that the applicants should ensure their DPA registrations cover processing data for public health purposes about patients or health service users.</p>
2.3	<p><u>University College London - Small area geodemographic profiling of health needs (Presenter: Jen Donald) NIC-28051-Q3K7L</u></p> <p>Application: This application requested pseudonymised Hospital Episode Statistics (HES) data link to name/ethnicity classification. The application had previously been considered by DAAG at the 18 October 2016 meeting, when DAAG had deferred making a recommendation and requested more information about data minimisation efforts and health or social care benefits.</p> <p>IGARD were informed of some errors within the application as an incorrect contract expiry date was listed, a reference to 2013 should instead state 2014, and the funding information was now out of date as this referred to PhD funding. It was confirmed that the application had been amended to correct these errors after the meeting papers had been circulated.</p>

¹ NIC-46116-N5L4J Cumbria County Council; NIC-51979-B8X2V Staffordshire County Council; NIC-52237-B6W3B London Borough of Kingston upon Thames; NIC-61265-Q4L9V Wirral Borough Council; NIC-40319-H0N3V London Borough of Newham Council.

	<p>Discussion: IGARD noted the updated information provided and agreed that this seemed to have adequately addressed the previously raised questions regarding data minimisation. A query was raised about the linkage carried out by NHS Digital and it was confirmed that the name classification provided to the applicant should not enable any individuals to be identified. IGARD asked for section five of the application to be updated that the applicant would not link with any other record level data. A further query was raised regarding the need for a data destruction certificate and it was confirmed that this had been reflected within the application's special conditions. It was confirmed that the research would not produce any commercial products.</p> <p>IGARD noted that at one point the application referred to 'a specified user' processing data but that the application elsewhere suggested that more than one individual would have access to data. It was suggested the application should be amended to more consistently describe the number of individuals accessing data. In addition a typographical error in the application was noted.</p> <p>Outcome: Recommendation to approve. IGARD advised that section five should be amended to state that the applicant will not link the data with any other record level data. It was also advised the application should be amended to clarify a reference to the number of individuals accessing data. IGARD noted that application would be updated to correct errors before a DSA was issued.</p> <p>2.4 <u>Sheffield City Council – Local Authority Public Health HDIS (Presenter: Louise Dunn) NIC-77633-Y4X1L</u></p> <p>Application: This application requested access to pseudonymised data through the HES Data Interrogation Service (HDIS), including the ability to download record level data, for public health purposes. It was noted that the applicant organisation did not currently hold any HES data but had been granted access to PCMD data. In addition it was noted the applicant organisation had not yet published a privacy notice of the expected standard, and the application therefore included the previously agreed special condition wording regarding privacy notice updates.</p> <p>Discussion: IGARD asked for section five of the application to be updated to reflect the verbal assurances that the applicant organisation did not currently hold any HES data.</p> <p>Outcome: Recommendation to approve. IGARD advised the application should be amended to indicate in section five that the applicant does not currently hold any other HES data. IGARD noted that the applicant's DPA registration was shortly due to expire, and advised that the applicant should update this wording to include processing data for public health purposes about patients or health service users</p>
<p>3</p>	<p>IGARD Standard Operating Procedures</p> <p>There was a brief discussion about the ongoing process to update and finalise the IGARD Standard Operating Procedures. It was agreed that updated versions incorporating members' comments would be brought to the March educational session, and it was noted that a query had been raised regarding indemnity.</p>
<p>4</p>	<p>Any other business</p> <p>No other business was raised.</p>

Appendix A: Summary of Open Actions

Date raised	Action	Owner	Updates	Status
15/11/16	To update DAAG on the feasibility of providing random samples of data to applicants, and to ask the Production Team to provide DAAG with further information about the options for data minimisation	Garry Coleman / 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>23/02/17: 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

			<p>week.</p> <p>09/02/17: Ongoing. It was agreed this action would be taken forward by the IGARD Chair.</p> <p>16/02/17: It was noted that a meeting with the NHS Digital Caldicott Guardian was scheduled to discuss this.</p> <p>23/02/17: Ongoing.</p>	
10/01/17	To speak to NHS Digital colleagues regarding security assurance for HQIP.	Chris Carrigan	<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>23/02/17: Ongoing.</p>	Open
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>23/02/17: Ongoing.</p>	Open
24/01/17	To clarify the Local Authority Public Health application template wording regarding the Licensing Act.	Garry Coleman	<p>09/02/17: Ongoing. It was thought the template would be updated for renewal applications from March onwards.</p> <p>23/02/17: An update was provided with a commitment that this change would be made for the upcoming renewal applications.</p>	Closed
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	<p>23/02/17: Information about this had been provided via email and it was noted that NHS Digital had begun work to review this process to ensure it could adequately address the queries raised by IGARD. It was agreed IGARD members would be asked to provide comments by a certain date.</p>	Open
09/02/17	To provide an update on the out of committee sign-off of NIC-69707 KPMG.	Garry Coleman	<p>23/02/17: A brief update was provided by email and IGARD requested sight of the final application.</p>	Open
09/02/17	To circulate information about how NHS Digital currently defines data as 'sensitive'.	Gaynor Dalton	<p>23/02/17: IGARD were informed that a significant piece of work was taking place within NHS Digital to review the definition of 'sensitive' data. It was agreed an update would be provided in future once this work had progressed further.</p>	Closed
09/02/17	To consider the use of a standard special condition for applications that do not require data linkage.	Garry Coleman	<p>23/02/17: It was agreed there would be a discussion at an upcoming educational session about special conditions versus the</p>	Open

			standard conditions included in data sharing agreements.	
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	23/02/17: It was confirmed that special conditions were not typically reflected on the release register and that any key clarifications should be included in section five of the application. In addition IGARD noted that special conditions were usually intended to be time-limited rather than ongoing.	Closed
16/02/17	To contact the NHS Digital Caldicott Guardian about terminology and the use of terms such as 'anonymised' or 'pseudonymised' to describe data, particularly in relation to Data Services for Commissioners applications.	Chris Carrigan	23/02/17: Ongoing. It was noted that wider work was taking place within NHS Digital to agree standard terminology that could be used consistently, but IGARD noted the need to address this specific query regarding terminology in Data Services for Commissioners applications and data flow diagrams.	Open

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

No application caveats had been signed off out of committee since the previous report.

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-277499 Optum
- NIC-368543 CHKS
- NIC-08472 UK Biobank
- NIC-05217 Woodward Associates