

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

### Minutes of meeting held 1 February 2018

**Members:** Chris Carrigan (Chair), Nicola Fear, Jon Fistein, Kirsty Irvine.

**In attendance:** Rachel Farrand, Dickie Langley, Joanne Treddenick, Kimberley Watson, Aaron White (Observer), Vicki Williams.

**Apologies:** Sarah Baalham, Joanne Bailey Anomika Bedi, Eve Sariyannidou.

1	<p><b>Welcome and introduction</b></p> <p>The Chair welcomed Aaron White to the meeting as an observer.</p> <p><b>Declaration of interests</b></p> <p>There were no declarations of interest.</p> <p><b>Review of previous minutes and actions</b></p> <p>The minutes of the 25 January IGARD meeting were reviewed and, subject to a number of minor changes, 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	<p><b>Data applications</b></p>
2.1	<p><u>University of Sheffield – the Invasive Dentistry Endocarditis Association (IDEA) Study: a study of the link between invasive dental procedures and critical medical events including infective endocarditis, myocardial infarction, stroke, pulmonary embolus and spontaneous pre-term birth (Presenter: Dickie Langley) NIC-116377-L5J9M</u></p> <p><b>Application:</b> This was an application to request Hospital Episode Statistics (HES) and patient identifiable linking data to investigate the link between invasive dental procedures and a variety of medical events (infective endocarditis, myocardial infarction, pulmonary embolus and spontaneous pre-term birth).</p> <p>Dickie Langley noted the incorrect legal basis sub section had been used within the application and would be updated.</p> <p><b>Discussion:</b> IGARD noted the importance of the study and the potential far-reaching impact of the research, (noting a proportion of the public used private dentists and this data would not form part of this research).</p> <p>IGARD suggested the application be updated to clearly reflect and identify the legal basis for the dissemination of data.</p> <p>IGARD queried re-identification when linkage occurred and if a patient could be easily identified from the data. NHS Digital noted identifiers were provided and appropriate steps taken, including standard wording within the data sharing agreement, so that patients could not be easily re-identified.</p> <p>IGARD noted that a clear statement should be added to the application summary that NHS Digital was satisfied that the applicant's fair processing meets the NHS Digital nine minimum criteria for privacy notices (to be known as NHS Digital's fair processing criteria) before data can flow.</p> <p><b>Action:</b> Dickie Langley to ensure the application summary clearly states that NHS Digital have assured themselves that an applicant's privacy notice meets NHS Digital's fair processing criteria.</p> <p><b>Outcome:</b> recommendation to approve.</p> <p>The following amendments were requested:</p>

	<ul style="list-style-type: none"> <li>NHS Digital should satisfy itself that the correct legal basis for data releases is listed in the application.</li> <li>A clear statement should be included in the application summary that NHS Digital have checked the privacy notice against NHS Digital's nine minimum criteria (to be known as NHS Digital's fair processing criteria) and have assured themselves that it meets current fair processing criteria.</li> </ul>
2.2	<p><u>Competitions &amp; Markets Authority – for National HES Data for investigation of mergers (Presenter: Dickie Langley) NIC-32833-M3M9V</u></p> <p><b>Application:</b> This was an application for Hospital Episode Statistics (HES) Admitted Patient Care, Outpatients and Accident &amp; Emergency data to monitor, investigate and decide whether Trust mergers may be expected to give rise to a substantial lessening of competition within any market(s) in the UK for good or services.</p> <p><b>Discussion:</b> IGARD suggested that section 5a of the application be updated to enable a lay reader to clearly understand the content.</p> <p>IGARD queried if the legal basis within the application (s261(1) and s261(2)(b)(ii)) was correct, and the IG Advisor to IGARD confirmed that data could be disseminated under either provision listed.</p> <p>IGARD suggested that the applicant should review their fair processing against the ICO's Privacy Notices Code of Practice to ensure it reflects best practice standards and update their privacy notice as soon as possible. IGARD noted that a clear statement should be added to the application summary that NHS Digital was satisfied that the applicant's fair processing meets the NHS Digital nine minimum criteria for privacy notices (to be known as NHS Digital's fair processing criteria) before data can flow.</p> <p>IGARD noted that an amendment should be made to the application to insert the standard NHS Digital wording with regard to clarifying that outputs will be suppressed in line with the HES Analysis Guide.</p> <p>IGARD noted that information within section 5c outputs would be better placed in section 5d yielded benefits and to ensure all links within the published section 5 link to the appropriate webpage(s).</p> <p><b>Outcome:</b> recommendation to approve.</p> <p>The following amendments were requested:</p> <ul style="list-style-type: none"> <li>A clear statement should be included in the application summary that NHS Digital have checked the privacy notice against NHS Digital's nine minimum criteria (to be known as NHS Digital's fair processing criteria) and have assured themselves that it meets current fair processing criteria.</li> <li>Section 5d yielded benefits be updated to include text from section 5c outputs.</li> <li>Section 5a of the application to be clarified to enable a lay reader to understand more clearly.</li> </ul> <p>The following advice was given:</p> <ul style="list-style-type: none"> <li>IGARD advised the applicant should review their fair processing against the ICO's Privacy Notices Code of Practice to ensure it reflects best practice standards, and in the interests of transparency, update their privacy notice as soon as possible. The EU General Data Protection Regulation recognises that pseudonymised data should be considered as information on an identifiable natural person and also places a greater focus on the need to demonstrate transparency of data processing in the information provided to data subjects.</li> </ul> <p>It was the view of IGARD that this application would not be appropriate for renewal by IAO and Director delegated authority.</p>

<p><b>2.3</b></p>	<p><u>3M United Kingdom Plc – data extract to support the continued accuracy of 3M developed quality and performance indicators for commissioners and providers (Presenter: Dickie Langley) NIC-91972-S9W9T</u></p> <p><b>Application:</b> This was an application to request 5 years of Hospital Episode Statistics (HES) data to anglicise a new 3M tool which provides software for clinical coding and analytical ‘grouping’. 3M solutions are used in approximately 80% of NHS Acute sector and this is typically in the form of clinical coding software such as Medicores Encoder or as part of the offering of a larger service provider.</p> <p><b>Discussion:</b> IGARD noted that they were supportive of new initiatives or organisations coming into the marketplace which may lead to improvements and innovations within the NHS, however, IGARD noted the lack of NHS clients for this tool and suggested that the applicant be given appropriate time to anglicise their tool. IGARD suggested that the applicant should work with an NHS partner and endeavour to detail explicit demonstrable benefits when the application returns for review.</p> <p>IGARD queried if the applicant already received NHS Digital data and it was confirmed that they did not access NHS Digital data but had worked with NHS clients, using locally provided data, on other tools. NHS Digital advised that it was not possible to provide the applicant with “dummy data” to anglicise this tool.</p> <p>IGARD noted that an amendment should be made to the application to insert the standard NHS Digital paragraph with regard to clarifying that outputs will be suppressed in line with the HES Analysis Guide.</p> <p>IGARD suggested that applicant update their DPA registration date which was due to expire and that a number of typos be corrected within section 5 of the application.</p> <p>IGARD suggested that a period of 7 months be given to enable the applicant 4 months to develop the tool and a further 3 months for benefits to be generated.</p> <p><b>Outcome:</b> recommendation to approve for 7 months.</p> <p>The following amendments were requested:</p> <ul style="list-style-type: none"> <li>• IGARD noted that the applicant’s DPA registration was shortly due to expire and would need to be renewed in order for data to be disseminated.</li> <li>• Clarifying within section 5 of the application that outputs will be suppressed in line with the HES Analysis Guide.</li> </ul> <p>It was the view of IGARD that this application would not be appropriate for renewal by IAO and Director delegated authority.</p>
<p><b>2.4</b></p>	<p><u>Meditrends Ltd – information intermediary specialising to produce outputs for use in health and social care (Presenter: Rachel Farrand) NIC-14340-R7G1F</u></p> <p><b>Application:</b> The renewal application had previously been presented at the 2 November 2017 IGARD meeting when IGARD had deferred making a recommendation pending; explaining the purposes for which data can be used under purpose two; clarifying how the applicant will seek to evidence that work is taking place; providing more information about the due diligence undertaken by NHS Digital; amending a statement that the applicant will only work with six customers at a time; clarifying reference to purpose two using historical data; clarifying who will apply scrutiny to the purposes for which data can be used; clarifying reference to the requirement for potential customers to undertake governance training and; updating section five to include a special condition that refers to data destruction.</p> <p><b>Discussion:</b> IGARD noted that this complex application had been updated to reflect comments previously raised. IGARD also noted that NHS Digital had issued a three month renewal and a one month short-term extension agreement to permit the applicant to continue to process data.</p> <p>IGARD noted that an amendment should be made to the application to insert the standard NHS Digital paragraph with regard to clarifying that outputs will be suppressed in line with the HES Analysis Guide.</p>

	<p>IGARD noted that further clarity had been given regarding the legal status of Meditrends Ltd and Beacon Consulting, however IGARD were still not clear about the due diligence procedures undertaken by NHS Digital, but were assured that it had taken place. IGARD suggested that NHS Digital may wish to undertake an audit of the applicant.</p> <p><b>Outcome:</b> recommendation to approve.</p> <p>The following amendment was requested:</p> <ul style="list-style-type: none"> <li>Clarifying within section 5 of the application that outputs will be suppressed in line with the HES Analysis Guide.</li> </ul> <p>The following advice was given:</p> <ul style="list-style-type: none"> <li>IGARD suggested that NHS Digital might wish to consider auditing the organisation.</li> </ul> <p>It was the view of IGARD that this application would not be appropriate for renewal by IAO and Director delegated authority</p>
2.5	<p><u>University College London – National Child Development Study (NCDS) (Presenter: Kimberley Watson) NIC-137864-T1P9B</u></p> <p><b>Application:</b> This was a new application for an MRIS list cleaning report for new addresses for the individuals lost to follow up. The list clean will also return fact of death and this is used to ensure that no contact is made with any individuals who have died. The NCDS is a national longitudinal birth cohort study following all those born in one week in 1958 through the course of their lives, charting the effects of experiences in early life on outcomes and achievements in later life. The next NCDS survey will take place in 2019 when study members will be aged 61.</p> <p><b>Discussion:</b> IGARD noted that the MRIS list clean will return ‘fact of death’ data, however IGARD noted that ‘fact of death’, although not identifiable, was not detailed within the application as a set of data being requested. NHS Digital noted that for pseudonymised data ‘fact of death’ data would not normally be listed within section 3, however IGARD queried whether this was not transparent.</p> <p>IGARD also queried whether exit and embarkation data was within the ‘MRIS – list cleaning report’ dataset, noting that the applicant had requested and had been granted this data in their s251 application to HRA CAG.</p> <p>IGARD requested that information be provided within the section 3 table and that if the data was not to be listed to clear why ‘fact of death’ data would not be listed. The IG Advisor to IGARD noted that the NHS Digital Data Protection Officer was currently undertaking a review of all datasets which contained death data fields and NHS Digital would feed back to IGARD once the review had concluded how this data will be represented on applications.</p> <p>IGARD suggested that the applicant update their DPA registration to more clearly state that data is processed about patients or healthcare users.</p> <p>IGARD noted that a clear statement should be added to the application summary and that NHS Digital was satisfied that the applicant’s fair processing meets the NHS Digital nine minimum criteria for privacy notices (to be known as NHS Digital’s fair processing criteria) before data can flow.</p> <p><b>Outcome:</b> recommendation to approve.</p> <p>The following amendments were requested:</p> <ul style="list-style-type: none"> <li>A clear statement should be included in the application summary that NHS Digital have checked the privacy notice against NHS Digital’s nine minimum criteria (to be known as NHS Digital’s fair processing criteria) and have assured themselves that it meets current fair processing criteria</li> <li>Clarification within section 5 of the application if the applicant requires entry and exit embarkation data as requested and granted in their s251 application to HRA CAG.</li> </ul>

	<ul style="list-style-type: none"> <li>Clarification within section 3 of the application that fact of death data was requested, and if the data is not to be listed within the table, NHS Digital to clarify why it is not to be listed, for transparency purposes.</li> </ul> <p>The following advice was given:</p> <ul style="list-style-type: none"> <li>IGARD advised the applicant they should update their DPA registration wording to reflect the use of data about patients or health service users.</li> </ul>
<b>3</b>	<p><b>Any Other Business</b></p> <p>No AOB items were raised.</p>

## Appendix A: Summary of Open Actions

Date raised	Action	Owner	Updates	Status
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	<p>14/09/17: Ongoing. It was agreed this would be discussed during the educational session.</p> <p>07/12/17: Ongoing. It was agreed to bring the first draft to January's education session.</p> <p>01/02/18: Ongoing.</p>	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	<p>15/06/17: IGARD had been advised by email that a paper about this would be submitted to an upcoming IGARD meeting.</p> <p>22/06/17: It was anticipated that this would be discussed at the 6 July 2017 IGARD meeting. IGARD asked for some information to be circulated by email prior to the meeting in order to inform members who would not be present at that particular meeting.</p> <p>27/07/17: An email had been circulated requesting further information from IGARD members.</p> <p>03/08/17: Two IGARD members had responded by email and the action remained ongoing.</p> <p>10/08/17: It was anticipated that a paper on this would be brought to IGARD within the following two weeks.</p> <p>24/08/17: The paper was in the process of being updated based on recently published ICO guidance.</p> <p>14/09/17: Ongoing. IGARD noted that given the amount of time that had passed, they would consider starting to note this on relevant</p>	Open

			<p>applications where a data storage location was not listed as a data processor.</p> <p>21/09/17: Ongoing. IGARD asked for Dickie Langley to provide an update on Garry Coleman's open actions at the next meeting to help ensure timely progression.</p> <p>02/11/17: IGARD discussed this action with Garry Coleman and requested a written update in response to the points previously raised by IGARD. Some difficulties were acknowledged as this specific scenario did not seem to be addressed in existing ICO guidance; IGARD suggested that NHS Digital should seek legal advice and if necessary then contact the ICO directly.</p> <p>16/11/17: Ongoing. IGARD queried the progress made regarding this action and there was a suggestion that this should be discussed at an education session; however it was suggested that it would be necessary to receive an updated response from NHS Digital before this.</p> <p>01/02/18: Ongoing</p>	
20/07/17	Garry Coleman to provide an update within two weeks on how NHS Digital manage the risk involved in CCGs using South Central and West CSU as a data processor in light of data sharing breaches and recent audits.	Garry Coleman	<p>10/08/17: It was anticipated that a paper on this would be brought to IGARD within the following two weeks.</p> <p>24/08/17: IGARD received a verbal update on the work that had taken place following both audits and verbal assurances that NHS Digital were content with the level of risk involved in this organisation continuing to act as a data processor. IGARD welcomed this update and requested written confirmation.</p> <p>31/08/17: IGARD were notified that the requested written confirmation should be provided within one day.</p> <p>14/09/17: An email response had been circulated on 31 August, and IGARD noted that they were awaiting receipt of the post-audit report.</p>	Open

			01/02/18: Ongoing	
20/07/17	Garry Coleman to categorise different standard lengths of indicative data retention periods for general research and clinical trials, with appropriate justification.	Garry Coleman	01/02/18: Ongoing	Open
31/08/17	Garry Coleman to report back on how cancer registration data was previously described as pseudonymised PDS data within older versions of applications, and present to a future education session on changes to how MRIS reports are now shown within applications.	Garry Coleman	01/02/18: Ongoing	Open
19/10/17	Stuart Richardson to provide a briefing on the Temporary National Repository infrastructure.	Stuart Richardson	16/11/17: Stuart Richardson noted discussions were ongoing. 01/02/18: Ongoing.	Open
02/11/17	NHS Digital to consider the responses provided by an applicant (Imperial College London NIC-27085) in relation to the language and terminology used in patient information materials.	Louise Dunn	01/02/18: Ongoing.	Open
07/12/17	Dickie Langley to provide a briefing note on NHS Digital's due diligence policy and process	Arjun Dhillon	01/02/18: IGARD suggested that the action owner be changed to Arjun Dhillon	Open
07/12/17	Stuart Richardson to provide a briefing note outlining NHS Digital's work with STP's to clarify the legal / access arrangements in place between CCG's to ensure responsibilities are clearly defined	Stuart Richardson	01/02/18: Ongoing.	Open



21/12/17	NHS Digital / IGARD to discuss at a future meeting the issue of consistency across applications presented.	IGARD Chair / Garry Coleman	01/02/18: Ongoing.	Open
25/01/18	Arjun Dhillon, Deputy Caldicott Guardian, was tasked to check with NHS Digital whether templates which had not been approved by IGARD but where NHS Digital had taken the decision to disseminate data would come back to IGARD for consideration or was the template now class as an approved template by NHS Digital	Arjun Dhillon	01/02/18: Ongoing	

## Appendix B: Out of committee report

### Independent Group Advising on Releases of Data (IGARD): Out of committee report 26/01/18

These applications were previously recommended for approval with conditions by IGARD, and since the previous Out of Committee Report the conditions have been agreed as met out of committee.

NIC reference	Applicant	IGARD meeting date	Recommendation conditions as set at IGARD meeting	IGARD minutes stated that conditions should be agreed by:	Conditions agreed as being met in the updated application by:	Notes of out of committee review (inc. any changes)
None			•			

In addition the following applications were not considered by IGARD but have been progressed for IAO and Director extension/renewal:

- None notified to IGARD