

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

## Minutes of meeting held 19 October 2017

**Members:** Joanne Bailey (agenda items 1-2 only), Anomika Bedi, Chris Carrigan (Chair), Jon Fistein, Kirsty Irvine, Eve Sariyannidou

**In attendance:** Garry Coleman, Louise Dunn, Rachel Farrand, Frances Hancox, Terry Hill, James Humphries-Hart, Stuart Richardson, Kimberley Watson, Vicki Williams

**Apologies:** Sarah Baalham, Nicola Fear

1	<p><b>Declaration of interests</b></p> <p>Jon Fistein noted a potential interest in the NHS Digital – National Bowel Cancer Audit application (NIC-376603-K2J9R) due to an advisory role with HQIP but it was agreed this was not a conflict of interests. Chris Carrigan noted his work with the University of Leeds and their use of audit data in relation to that application but it was agreed that was also not a conflict of interests.</p> <p><b>Review of previous minutes and actions</b></p> <p>The minutes of the 12 October 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 provided (see Appendix B). IGARD noted that two applications had not returned for out of committee review within the agreed three-month period and that these would be brought to an upcoming meeting.</p>
2	<p><b>Collective Changes presentation</b></p> <p>Terry Hill and Garry Coleman joined the meeting to provide IGARD with an update on anticipated changes to four areas: ONS data, which would soon be available for release by NHS Digital as Civil Registrations data; benefits, and how NHS Digital processes would be aligned with existing NIHR processes; the approach taken to applications relating to participant consent; and the proposed risk-based approach to the application review process.</p> <p>A query was raised about whether the proposed switch to Civil Registrations data required Directions to be issued or if this relied on a different legal basis.</p> <p>IGARD queried how the proposed benefits approach would be practically implemented; IGARD considered that while it was proposed that IGARD would not need to consider whether applications within scope met the requirements of the Care Act 2014 it would be impractical not to consider the benefits section of the application in other contexts (such as whether this aligned with the described dissemination of outputs). IGARD requested sight of the paper circulated to the Research Advisory Group on this topic.</p> <p>IGARD raised a number of queries about the proposed approach to consent and it was acknowledged that this was described in terms of the DPA rather than the upcoming GDPR. It was suggested that NHS Digital might wish to seek advice on specific points such as the upcoming requirements for clinical trials.</p>

	<p>It was noted that discussions were ongoing regarding the risk-based approach. IGARD agreed that the IGARD Chair would collate comments from members and provide a collective response back to NHS Digital on behalf of the members. It was also agreed that the Chair would feed back any further comments from members on the other three topics discussed.</p>
3	<p><b>Data applications</b></p>
3.1	<p><u>Beacon Consulting (Presenter: Rachel Farrand) NIC-14340-R7G1F</u></p> <p><b>Application:</b> This renewal application requested additional pseudonymised Hospital Episode Statistics (HES) data for two purposes, with the first purpose focusing on publishing results of analysis on disease management and the second purpose focusing on supporting the commissioning cycle and improving understanding of disease progression. It was noted that when DAAG had considered a previous version of this application, they had recommended approval for the first purpose but not for the second as further information was required. Following various discussions and escalation the applicant had provided the necessary information about purpose two and NHS Digital had approved the use of data for this second purpose. IGARD were now asked to consider the renewal application in light of other similar commercial applications, with the intention of improving consistency of approach.</p> <p><b>Discussion:</b> IGARD welcomed the information provided about the applicant's customers for the services offered under purpose one, but noted the lack of detail about the current customer base for purpose two. It was agreed that more information about this was needed to ensure that the data provided would be likely to result in benefits to the health and care system. In addition it was considered unclear why ten years of data would be required for purpose two; a clearer justification was requested for this amount of data.</p> <p>There was a discussion of how purpose two was described within the application and some concerns were raised that this could be interpreted as overly open-ended; IGARD agreed that the application should be updated to more clearly limit the reasons for which data could be used in line with the types of controls placed on the use of data for similar purposes by other commercial applicants.</p> <p>IGARD queried the distinction between Beacon Consulting, which was the organisation listed as data controller, and Meditrends Ltd which was the organisation named on the DPA registration details provided. It was thought that Beacon Consulting was a trading name of Meditrends, but that the two organisations had previously existed as separate legal entities. Clarification was requested of the legal status of Beacon Consulting with confirmation that if any data had previously been held by this organisation as a separate legal entity, appropriate steps had been taken to securely transfer or destroy this data.</p> <p><b>Outcome:</b> Recommendation deferred, pending:</p> <ul style="list-style-type: none"> <li>• Providing more information about the current customer base for purpose two.</li> <li>• Providing a more specific explanation of the purpose for which data can be used under Purpose 2 with this to be more clearly delineated in a way that is consistent of the requirements for other applicants with similar commercial uses of data.</li> <li>• Providing a clearer justification for the need for 10 years of data for purpose two.</li> <li>• Clarification regarding the legal status of Beacon Consulting as a trading name of Meditrends, with confirmation that the security assurances and DPA registration provided cover the relevant legal entity.</li> <li>• Confirmation that any data previously held by Beacon Consulting as a separate legal entity to Meditrends was securely destroyed.</li> </ul>
3.2	<p><u>Wilmington Healthcare (Presenter: Kimberley Watson) NIC-16016-Y9H1D</u></p>

**Application:** This renewal and amendment application had previously been considered at the 5 October 2017 meeting when IGARD had deferred making a recommendation. The application had now been updated to address the points raised including provided further detail of the applicant's customer base, clarification of the role of Rackspace Data Centre, clarity around the expected benefits and a clearer justification for the number of data years requested.

**Discussion:** IGARD acknowledged the updated information provided, which included the Terms of Reference for the applicant's internal advisory board that would assess the potential for each project to benefit health and social care prior to agreeing the use of this data. Some concerns were raised that this advisory board was described as consisting of 'business representatives' and did not include anyone external to the organisation such as patients or lay members. IGARD were informed that the applicant had endeavoured to recruit lay members but had not yet been successful, and it was suggested that they should consider approaching relevant patient charities for support in this area. In addition IGARD suggested that the applicant should consider including a data protection officer or other information governance specialist within the advisory group. IGARD also noted that the Terms of Reference referred to requiring a minimum of two advisory board members to consider requests, and asked that following recruitment of lay members the applicant should consider revising this process appropriately.

The updated website text was briefly discussed and IGARD asked for a statement that 'individuals cannot be identified' to be corrected to instead state that individuals cannot be directly identified. The role of Rackspace was also briefly discussed and IGARD noted the assurances that this organisation would not have access to any data other than aggregated outputs. IGARD discussed the importance of data minimisation and requested a clearer justification for the amount of data requested, particularly in light of references to rare diseases.

IGARD noted that the applicant's previous data sharing agreement had come to an end and in light of the updates provided and further questions raised, agreed it would be appropriate to issue a short-term extension that would permit the applicant to continue to hold data but not otherwise process it while appropriate steps were taken to address these queries.

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

- The data sharing agreement end date should be limited to only last for three months, with an updated application to be submitted to IGARD at the end of that period, and the agreement should be limited to permit the applicant to continue to store data but not otherwise process it.

The following amendments were requested:

- IGARD noted that the extension, amendment or renewal application submitted within three months should include clarification of what specific criteria are used by the advisory board to determine whether a use of data is compliant with the DSA, with confirmation of what other steps the applicant will take to expand the membership of this advisory board such as including a data protection officer or information governance specialist, as well as recruiting one or more lay members potentially via engagement with relevant charities.
- The application in three months' time should also provide further information about the amount of data required with a clear justification for why this is necessary.
- The proposed website text should be amended to clarify a reference to data that cannot identify an individual as this was considered misleading.

3.3

Imperial College London (Presenter: Louise Dunn) NIC-366210-V2H5M

**Application:** This application requested an extension to permit the applicant to continue to

	<p>hold pseudonymised HES data for a further three years for the previously agreed programme of research into UK health reform policy. It was noted that an earlier version of the application had been considered and recommended for approval by DAAG on 21 July 2015, and that the agreement had subsequently been extended by IAO and Director approval. The application had been updated to incorporate additional detail about how data had been used to date and what future outputs and benefits were expected.</p> <p><b>Discussion:</b> IGARD queried a statement within the application that ‘access has not been granted to PROMs data’. It was confirmed that PROMs data was not requested under the current application, and that NHS Digital did not anticipate a separate application to request this data. IGARD asked for this to be more clearly explained within the application.</p> <p>It was noted that the application referred to conference presentations as a way to disseminate findings to the general public and IGARD queried whether the general public would be likely to attend healthcare-related conference. However it was noted that the applicant had also made efforts to communicate findings through other additional methods.</p> <p><b>Outcome:</b> Recommendation to approve. The following amendments were requested:</p> <ul style="list-style-type: none"> <li>• Section five should be amended to clarify references to PROMs data as this is not requested under the current application.</li> </ul>
3.4	<p><u>NHS Digital - National Bowel Cancer Audit (Presenter: Kimberley Watson) NIC-376603-K2J9R</u></p> <p><b>Application:</b> This application was to renew and amend an existing data sharing agreement, which had previously been recommended for approval by IGARD on 25 May 2017. The updated application requested more HES and Office for National Statistics (ONS) mortality data, and also requested linkage with data from the Cancer Outcomes and Services Dataset (COSD) and from the Cancer Registration process.</p> <p><b>Discussion:</b> IGARD queried a statement within the application that the request of ONS data was a renewal, as it was thought that under the previous application version no new ONS data had been requested. Given the request for new ONS data IGARD requested up-to-date evidence of legal basis under section 42(4) of the Statistics and Registration Service Act 2007, and it was agreed the application should be amended to more clearly reflect that the addition of new ONS data was considered an amendment.</p> <p>In addition IGARD noted that the applicant’s section 251 support referred to a need to update the statement of use provided to CPES respondents and confirmation was requested of whether this update had yet taken place.</p> <p><b>Outcome:</b> Recommendation deferred, pending:</p> <ul style="list-style-type: none"> <li>• Providing evidence that appropriate approvals are in place for the use of data under section 42(4) of the SRSA 2007.</li> <li>• Confirmation of whether the applicant has acted on advice from HRA CAG to update the statement of use provided to CPES respondents.</li> </ul> <p>The following amendments were requested:</p> <ul style="list-style-type: none"> <li>• Amending the abstract to state that the request for ONS data is an amendment rather than a renewal.</li> </ul>
3.5	<p><u>NHS England – Temporary National Repository (Presenter: James Humphries-Hart) NIC-92346-T4Z0F</u></p> <p><b>Application:</b> This application was to consolidate the existing Temporary National Repository applications and to request additional data from Improving Access to Psychological Therapies</p>

(IAPT) additional payment data, IAPT pilot wave 2, Emergency Care dataset, Children and Young People's Health Service (CYPHs). Community Services Dataset (CDS), Maternity Services Dataset (MSDS), Diagnostic Imaging Dataset (DIDs), and National Hip Fracture Database (NHFD). It was noted that the application had also been updated to include additional data processors as NHS England had requested the ability to use any CSU as a data processor.

IGARD were asked in particular to consider the described linkage to the Master Patient Index and what impact this might have on the identifiability of data within the Temporary National Repository; the description of permitted additional linkage; and how existing data sharing agreements with CCGs might need to be amended to provide equivalent cover to that already in place for 111 data as referred to within the outputs section.

**Discussion:** IGARD expressed concern regarding the three points raised above and agreed that these would all need further clarification. In general it was agreed that the application should more clearly explain what linkages would and would not be permitted, and explain the roles of different organisations involved.

IGARD queried a statement within the application that any outputs to third parties 'must be anonymous in nature'; it was suggested this should be amended to include the standard wording that outputs would only contain aggregated data with small numbers suppressed in line with relevant NHS Digital analysis guidance. IGARD also queried statements within the application that for some of the additional datasets there would be 'no additional benefits' in addition to those already outlined; it was agreed a clearer explanation was needed, such as whether the additional data would be used to enhance the outputs already described.

The role of multiple CSUs as data processors was queried and IGARD asked for the application to more clearly explain that potentially any CSU could be asked by NHS England to process data for this purpose.

There was a brief discussion of the purpose of the Temporary National Repository infrastructure and IGARD requested a briefing on this at a future meeting.

**Outcome:** Not recommended for approval.

- Clarification is needed of references to the Master Patient Index and how this will affect the identifiability of the data held in the Temporary National Repository.
- Point 23 in the list of outputs should be amended to clarify references to CCG DSAs and how this will be arranged to provide equivalent cover as is in place for 111 data.
- Section five should be updated to more clearly explain what data will not be linked, and to more clearly explain the roles of the different organisations involved.
- Clarifying the description of how CSUs will be included as data processors.
- A reference to additional linkage would be amended to be clear this only refers to linkage with the data already held on this agreement.
- References to outputs being 'anonymous' should be amended to use the standard wording that outputs must be aggregated with small numbers suppressed in line with relevant NHS Digital requirements.
- Statements that the use of some additional datasets will not lead to additional benefits should be clarified.

**Action:** Stuart Richardson to provide a briefing on the Temporary National Repository infrastructure.

4	<b>Any other business</b>  No other business was raised.
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## 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	14/09/17: Ongoing. It was agreed this would be discussed during the educational session. 05/10/17: It was agreed that the first draft would be discussed at December's education session. 19/10/17: 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.	Arjun Dhillon	18/05/17: Ongoing. It was agreed this would be discussed with the Deputy Caldicott Guardian. 22/06/17: Ongoing; it was suggested the Deputy Caldicott Guardian should discuss this in more detail with Joanne Bailey. 29/06/17: It was noted this action would be taken forward by the Deputy Caldicott Guardian, and the action owner was updated. 20/07/17: It was agreed the Deputy Caldicott Guardian would provide an update on the current status of this. 10/08/17: An update from NHS England had been requested. 19/10/17: 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	15/06/17: IGARD had been advised by email that a paper about this would be submitted to an upcoming IGARD meeting. 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. 27/07/17: An email had been circulated requesting further information from IGARD members. 03/08/17: Two IGARD members had responded by email and the action remained ongoing. 10/08/17: It was anticipated that a paper on this would be brought to IGARD within the following two weeks. 24/08/17: The paper was in the process of being updated based on	Open

			<p>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 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>19/10/17: Ongoing</p>	
15/06/17	Data Services for Commissioners to work with NHS Digital IG staff to check the privacy notices for these 4 CCGs (South Kent Coast CCG; Ashford CCG; Thanet CCG; Canterbury & Coastal CCG) as part of the ongoing training, and provide a copy of the outcome of this check to IGARD for information.	Stuart Richardson	<p>29/06/17: Ongoing. It was suggested it would be helpful to discuss this at an upcoming educational session.</p> <p>05/10/17: It was confirmed this would be discussed at the October education session</p> <p>12/10/17: Stuart Richardson attended IGARD</p>	Open
06/07/17	Stuart Richardson to ensure that privacy notice checklists are provided for all DSfC applications for a trial period of three months from 13 July IGARD meeting.	Stuart Richardson	<p>05/10/17: It was confirmed this would be discussed at the October education session</p> <p>12/10/17: Stuart Richardson attended IGARD</p>	Open
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> <p>19/10/17: Ongoing</p>	Open
20/07/17	Garry Coleman to categorise different standard lengths of indicative data retention periods for	Garry Coleman	19/10/17: Ongoing	Open



	general research and clinical trials, with appropriate justification.			
27/07/17	Arjun Dhillon to provide information for IGARD about the robustness of different funding processes and how this might affect the level of scrutiny applied to or information included in applications provided to IGARD.	Arjun Dhillon	10/08/17: Ongoing. It was thought that this action might be addressed within the context of a forthcoming paper on a risk-based approach to application, which it was anticipated would be brought to IGARD for discussion soon. 24/08/17: Ongoing, pending wider work on a risk-based approach. 19/10/17: 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	19/10/17: Ongoing	Open
14/09/17	Stuart Richardson to provide IGARD with a copy of the Directions relating to the Emergency Care Data Set (ECDS) with confirmation of the date this was approved by the NHS Digital Board.	Stuart Richardson	21/09/17: The Directions had been provided by email. IGARD members were asked to provide any comments by email, ahead of potentially closing the action at the next meeting. It was noted that confirmation would still be required of NHS Digital Board approval. 19/10/17: Ongoing	Open
14/09/17	Stuart Richardson to provide IGARD with a copy of the Directions relating to Social Care Data with confirmation of the date this was approved by the NHS Digital Board.	Stuart Richardson	21/09/17: The Directions had been provided by email. IGARD members were asked to provide any comments by email, ahead of potentially closing the action at the next meeting. It was noted that confirmation would still be required of NHS Digital Board approval. 19/10/17: Ongoing	Open
21/09/17	Dickie Langley to provide a briefing paper (with relevant supporting documents) regarding the legal basis for receipt of data from Department for Education, and for this to be reviewed by the IG Advisor prior to circulation to IGARD.	Dickie Langley	19/10/17: Ongoing	Open
21/09/17	Dickie Langley to provide IGARD with a copy of the new standard DSA terms and conditions.	Dickie Langley	19/10/17: Ongoing	Open
19/10/17	Stuart Richardson to provide a briefing on the	Stuart		Open

	Temporary National Repository infrastructure.	Richardson		
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## Appendix B: Out of committee report (as of 13/10/17)

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)
NIC-41543 NIC-41537	NHS Shropshire CCG NHS Telford & Wrekin CCG	13/07/17	<ul style="list-style-type: none"><li>The CCGs must update their privacy notices in order to meet the NHS Digital nine point criteria. In particular IGARD advised that the notices should be updated to reflect the involvement of PI Health and Care Ltd, and to describe the particular use of data set out in this application</li></ul>	IGARD	IGARD Quorum	N/A
NIC-36767	NHS North Cumbria CCG	13/07/17	<ul style="list-style-type: none"><li>The CCG must update their privacy notice in order to meet the NHS Digital nine point criteria. In particular IGARD advised that the notice should be updated to remove a statement that health data would not be shared without a patient's explicit consent, and to clarify a statement that data within a safe haven cannot be identified.</li></ul>	IGARD	IGARD Quorum	N/A

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

- None