

Independent Group Advising on the Release of Data (IGARD)

Minutes of meeting held 16 March 2017

Members: Joanne Bailey, Chris Carrigan (Chair), Kirsty Irvine, Eve Sariyiannidou, James Wilson

In attendance: Jen Donald, Louise Dunn, Frances Hancox, Julia King, Stuart Richardson, Kimberley Watson (observer), Vicki Williams

Apologies: Sarah Baalham, Anomika Bedi, Nicola Fear, Debby Lennard, Jon Fistein

1	<p>Declaration of interests</p> <p>James Wilson noted a potential interest in the University College London application (NIC-18646-P0R3M) due to his employment by that organisation, but no particular knowledge of the applicants or the study in question.</p> <p>Review of previous minutes and actions</p> <p>The minutes of the 9 March IGARD meeting were reviewed and subject to minor changes were agreed as an accurate record of the meeting.</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>
2 2.1	<p>Data applications</p> <p><u>Device Access UK Ltd (Presenter: Jen Donald) NIC-05429-H7X6R</u></p> <p>Application: This application was a renewal and amendment for an existing data sharing agreement, with the applicant requesting additional pseudonymised Hospital Episode Statistics (HES) data in addition to what they had already received. Data would be used to produce bespoke analysis for NHS and non-NHS clients relating to the evaluation of medical devices.</p> <p>IGARD were informed of some minor errors within the application, particularly that the correct DPA registration expiry date had not been listed and that a sentence was missing from section five of the application restricting access to the data to only substantive employees of Device Access. It was confirmed these points had been corrected since the meeting papers were issued.</p> <p>Discussion: There was a discussion of the information provided about how the applicant had used this data previously, and the examples of benefits that had been achieved. IGARD expressed their support for this work and encouraged applicants to continue providing this type of update information on how data had been used effectively.</p> <p>IGARD noted that there appeared to be a disconnect between the way the applicant organisation described itself within this application compared to on its website; in particular the website listed a large number of commercial clients and only two NHS organisations, and it was unclear whether this proportion of clients was reflective of this particular use of data. IGARD requested clearer information about what proportion of the previous data uses, current data uses or anticipated future uses would revolve around commercial clients as opposed to NHS organisations. Confirmation was also requested that this use of data was not considered</p>

to be a solely commercial purpose, in line with the requirements of the Care Act 2014. IGARD noted the importance of clearly describing any commercial uses of data, both for the data sharing agreement itself and also in the interests of transparency in terms of what information would be made available in the data release register.

In addition it was felt that the application should be updated to more clearly describe how data would be used, as IGARD considered that the current description was overly vague in places with phrases such as 'working through' the Department for International Trade.

Outcome: Not recommended for approval.

- A clearer, more specific description is needed of the purposes for which data will be used.
- Clarification of what proportion of the applicant's work will relate to commercial organisations rather than public sector bodies.
- A clearer justification for the use of data with confirmation that this is not a solely commercial purpose, in line with the requirements of the Care Act 2014.

2.2

Imperial College London – Airwave Health Monitoring Study (Presenter: Jen Donald) NIC-148056-T6T5Z

Application: This was a renewal application for identifiable Office for National Statistics (ONS) mortality and cancer data for a consented cohort. IGARD were informed that due to concerns around the original consent materials, the study had not been in receipt of data since 2015. The applicant had subsequently undertaken a list cleaning exercise to enable them to provide updated fair processing information to participants and offer them the opportunity to withdraw from the study; it was also noted that the study website explained how participants could withdraw.

Discussion: IGARD queried whether any further recruitment was planned, as if so it was agreed that the study consent materials would need to be updated. It was confirmed that no further recruitment was currently planned.

Some concerns were raised about the current fair processing materials as IGARD considered that more information should be made available to participants about the proposed data processing. It was noted that the applicant had committed to further improve their website fair processing information, in line with advice from NHS Digital IG staff, by the end of March 2017. IGARD suggested that the application should be amended to include a special condition for this information to be updated within the agreed timescales.

IGARD also raised some concerns that the withdrawal form available on the study website did not seem to include any commitments that withdrawing from the study would not affect an individual's employment or other rights. It was suggested that if the withdrawal form was no longer in use then this should be removed from the website to avoid confusion, or if the form was still used then this should be updated to include this commitment.

It was noted that the special conditions section of the application included the standard ONS terms and conditions; IGARD suggested that section five should include a statement that these standard conditions would apply, so that this would be visible on the data release register.

The potential benefits of this study were noted and IGARD agreed that this was in the public interest. It was suggested that the applicant might wish to consider disseminating information about the study and its outputs more widely.

Outcome: Recommendation to approve.

The application should be amended to include a special condition for the applicant to appropriately update their fair processing information by the end of March 2017, and to either publish an updated withdrawal form with confirmation that withdrawing from the study will not

	<p>affect an individual's rights, or if the withdrawal form is no longer in use then to remove from the study website, within the same timescale.</p> <p>IGARD advised that section five should be amended to include a statement that the standard ONS terms and conditions will be adhered to.</p> <p>IGARD also advised that in the interests of transparency, the applicant should consider making information about the study and its outcomes more widely available to potentially interested groups.</p>
2.3	<p><u>University of Oxford – Knee Arthroscopy rates of surgery and complications (Presenter: Louise Dunn) NIC-68703-R4Y6C</u></p> <p>Application: This was a new application for HES data linked to Patient Reported Outcome Measures (PROMs) data and ONS mortality data including date of death. It was confirmed that the applicant held Approved Researcher accreditation as well as Microdata Release Panel approval for the use of ONS data.</p> <p>Discussion: There was a discussion about the process for patient objections, as the application had stated that the applicant of objections for this application was 'mixed'. IGARD were informed that as PROMs data did not consistently contain NHS number, type two patient objections could not be directly applied to that data; however objections would be applied to the HES and ONS data, and only the remaining HES records would be linked to PROMs data meaning that PROMs data on any individuals who had objected would not be shared. IGARD suggested that the application wording should be amended to more clearly state that objections would be applied prior to dissemination.</p> <p>IGARD queried a statement within the application that 'all identifiers will be removed by NHS Digital' as it was noted that date of death, which was considered an identifier, would be disseminated. It was agreed this wording should be corrected.</p> <p>A query was raised about whether one named individual held Approved Researcher accreditation, as the email evidence provided did not seem to state that this had been renewed.</p> <p>Some concerns were raised about the amount of data requested and IGARD queried whether the applicant had considered particular ways to limit the amount of historical data needed, such as NHS Digital providing ten years of data but excluding individuals with a particular event or diagnosis within twenty years. It was agreed the application should be updated to provide a clearer justification for why this amount of data was required, or alternatively to state what further data minimisation efforts would be made.</p> <p>Outcome: Recommendation deferred, pending:</p> <ul style="list-style-type: none"> • Providing a clearer justification for the number of data years requested, or an explanation of what further data minimisation efforts could be made. • Providing evidence that one of the named individuals has Approved Researcher accreditation. <p>The application should be amended to state that patient objections will be applied, and to clarify a reference to the data provided to the applicant being anonymised in conformance with the ICO code of practice to be clear that date of death is included in the data disseminated.</p>
2.4	<p><u>NHS Digital - National Diabetes Footcare Audit (Presenter: Louise Dunn) NIC-59915-R9T8P</u></p> <p>Application: This was a new application for pseudonymised HES data and fact of death for a consented cohort, to support the audit commissioned by HQIP. It was noted that as raised during the action updates, NHS Digital was currently reviewing the SLSP provided by HQIP.</p> <p>Discussion: IGARD noted that the applicant intended to update their consent materials so that in future they could also request date of death data, and a query was raised about how</p>

those who had consented using the updated materials would be differentiated so that this data was only provided for certain individuals. It was clarified that the audits ran on an annual cycle, with the individuals consenting each year forming distinct cohorts, and that date of death would only be provided in future for those who had given their consent for that.

IGARD queried the information materials provided as supporting documents and it was noted that the updated versions had been provided. It was agreed that the applicant should be asked to update the patient information leaflet wording to correct a reference to 'anonymous' data, and to publish the updated leaflet online within six weeks.

Outcome: Recommendation to approve.

The application special conditions should be amended to include that the applicant should update their patient information leaflet to correct a description of the data as 'anonymous' and that this should be published online within six weeks.

The application should be amended to correct a statement that HQIP are not the data controller.

IGARD advised that the applicant should consider updating their DPA registration wording to reflect this use of data.

2.5

University College London - Clinical Relevance of Microbleeds In Stroke CROMIS-2
(Presenter: Louise Dunn) NIC-18646-P0R3M

Application: This application was to amend and renew a previous data sharing agreement for ONS mortality data and NHS registration for the flagged cohort, with the requested amendment being to additionally receive identifiable HES data. It was noted that participant consent was in place, and that the applicant had worked with NHS Digital IG staff to develop further fair processing information for their patient newsletter that had now been published online. IGARD were informed that the applicant had previously been approved to receive HES data in 2012, but the data had not been disseminated for reasons including technical limitations. Following discussions of data minimisation the applicant had agreed to destroy some data fields they no longer required.

Discussion: IGARD discussed the potential clinical impact and benefits of this work. It was suggested the applicant should consider disseminating the outputs more widely, such as to relevant patient groups or professional bodies. There was a discussion of the patient information and IGARD suggested that the applicant should consider updating this to be clearer that the contact details provided could be used by individuals wishing to withdraw from the study.

The commitment to destroy historical data fields that were no longer required was noted, and IGARD suggested that the special conditions section should include a requirement for the applicant to provide a data destruction certificate for this. In addition IGARD asked for the processing activities section to be updated to more clearly state who would have access to the data and how it would be processed.

IGARD asked what identifiers would be provided to NHS Digital to enable patient flagging; it was agreed the application should be amended to state what identifiers would be provided or had previously been provided for the cohort.

Outcome: Recommendation to approve.

The application special conditions should be amended to include a requirement for the applicant to provide a data destruction certificate for the historic data items that are no longer required. The processing activities section should be amended to be more specific about who will have access to the data and how it will be processed. In addition section five should be amended to state what patient identifiers will be provided to NHS Digital or have already been provided.

IGARD advised that the applicant should consider updating their patient information to be clear that the contact details provided can be used to withdraw from the study. In addition IGARD

advised that the applicant should consider disseminating the outputs of this work more widely to relevant professional and patient groups.

2.6

NHS England - Temporary National Repository (Presenter: Stuart Richardson) NIC-92346-T4Z0F

Application: This amendment application requested the receipt and use of local provider 111 data within the temporary national repository. IGARD were informed that a further application would be submitted to request the use of this data by CCGs but that this was not part of the current application. The repository was hosted at Arden and GEM CSU on behalf of the data controller.

Discussion: There was a discussion about the legal basis for the proposed data processing, including input from the IG Advisor to IGARD. IGARD noted a lack of clarity within the application and from the information provided verbally about which Directions applied to the flows of data and how the various sections of the Health and Social Care Act 2012 that were quoted were relevant. It was suggested that this application should have been considered a first of type and therefore been submitted along with a briefing paper setting out the particular details of this data flow and its legal basis or bases. In addition to this it was agreed the application should be updated to more clearly specify the relevant legal basis, and references to 'Directions' should be clear which Directions this referred to.

There was a discussion of fair processing and IGARD acknowledged that while only pseudonymised data would be disseminated, NHS Digital would process identifiable data for the purpose of this application. IGARD suggested that NHS Digital should consider whether their fair processing information covered the processing of identifiable 111 data for this purpose. In addition IGARD noted the amount of data requested and the proposed linkage to multiple datasets and it was agreed that a clearer explanation would be needed for how the linked data would still be considered to be anonymised in line with the ICO code of practice.

A query was raised about the different organisations involved in this application and the applicable legal bases for each organisation to act. It was agreed that this should be made clearer as part of a briefing note. IGARD had shared some suggestions prior to the meeting about what topics a briefing note should cover and it was agreed these suggestions would be circulated after the meeting.

IGARD noted that NHS Digital had recently undertaken an audit of Arden and GEM CSU; they were informed that an audit report had not yet been finalised and published, but it was not thought that any issues had been raised that would be of concern in relation to this application. It was agreed that the application should be amended to include standard wording regarding the requirements for arrangements between the data controller and processor.

IGARD also noted the use of some technical terms, jargon and abbreviations within the application and suggested that better use should be made of Plain English to help the information be more easily understandable by a lay audience when published as part of the release register.

Outcome: Not recommended for approval.

- A briefing note should be provided for this type of application including the nature and type of data requested, data flows, the context for the request, the legal bases for the requirement, the parties involved, the relevant Directions for this requirement and a justification for why the data is considered compliant with the ICO anonymisation code of practice.
- Clarification of whether NHS Digital's fair processing information covers the processing of identifiable 111 data for this purpose.
- A clearer justification that the amount of linked data that will be disseminated is still considered to be compliant with the ICO anonymisation code of practice.
- Confirmation that this application includes the new standard wording regarding

	<p>arrangements between the data controller and the data processor.</p> <p>The application should be amended to more clearly state which Directions provide a legal basis for this use of data. In addition IGARD advised the application should make better use of Plain English.</p>
2.7	<p><u>Group application for 3 CCGs¹ (Presenter: Stuart Richardson)</u></p> <p>Application: This renewal and amendment application requested pseudonymised SUS data for the purpose of risk stratification, in addition to the pseudonymised SUS, local flows, mental health (MHMDS, MHSDS, MHLDDS), Maternity Services Dataset (MSDS), Improving Access to Psychological Therapies (IAPT), Children and Young People's Health Services (CYPHS) and Diagnostic Imaging Dataset (DIDs) data already requested under previous applications. IGARD were informed that for purposes of direct care, GPs would be able to request that the risk stratification data for their patients be re-identified by the DSCRO. It was noted that the CCG privacy notices had passed a full review.</p> <p>Discussion: IGARD queried the re-identification process as set out on the data flow diagram, and it was confirmed that the DSCRO would hold the re-identification key but that this information would not be accessible by the CSU. A further query was raised about the amount of data held by the CCG and IGARD suggested that in the future, NHS Digital should consider asking CCGs as part of the renewal process whether some older data years were still required or if these could be securely destroyed.</p> <p>It was noted that a previous application had removed the request for risk stratification, as the re-identification model proposed at that time had not been appropriate. IGARD suggested that a special condition should be included in the data sharing agreement that any earlier versions of the re-identification lookup table held by the CSU or CCG should be destroyed.</p> <p>Outcome: Recommendation to approve.</p> <p>The special conditions section of the data sharing agreement should include a statement that the applicant is required to destroy any earlier versions of lookup table that contained NHS number.</p> <p>IGARD advised that a special condition should be included within the DSA to state that: "As a result of your application IGARD would like to draw your attention to the importance of the accessibility and clarity of your Privacy Notice. In the interests of transparency, you are advised to regularly review your notice against the ICO's Privacy Notices Code of Practice to ensure it reflects best practice. You will be expected to demonstrate progress against this recommendation in any audit undertaken and for any renewal or new application for data."</p>
2.8	<p><u>Group application for 3 CCGs² (Presenter: Stuart Richardson)</u></p> <p>Application: This renewal and amendment application requested pseudonymised SUS data for the purpose of risk stratification, in addition to the pseudonymised SUS, local flows, mental health (MHMDS, MHSDS, MHLDDS), MSDS, IAPT, CYPHS and DIDs data already requested under previous applications. IGARD were informed that this application was largely identical to the previously discussed group application for 3 CCGs, with the addition of Queen Mary University of London who would act as an additional data processor on behalf of the CCGs.</p> <p>Discussion: IGARD noted that the application listed a DPA registration expiry date that had already passed and it was agreed this should be corrected to list the new expiry date. In addition IGARD noted that although the application summary section indicated that only pseudonymised data was requested, in fact SUS data identifiable by NHS number was also</p>

¹ NHS Islington CCG NIC-95815-C3W0W; NHS Haringey CCG NIC-95817-Q6V9N; NHS Norwich CCG NIC-95820-K4K6V

² NHS Tower Hamlets CCG NIC-95867-F5F0L; NHS Newham CCG NIC-95884-F9J1V; NHS City & Hackney CCG NIC-95909-K7G6V

	<p>requested and the table should be updated to reflect this.</p> <p>Outcome: Recommendation to approve.</p> <p>The table of data requested in the summary section should be amended to correctly show the level of data requested, and the table of differences should be amended to list the correct DPA registration expiry date for City & Hackney CCG.</p> <p>The special conditions section of the data sharing agreement should include a statement that the applicant is required to destroy any earlier versions of lookup table that contained NHS number.</p> <p>IGARD advised that a special condition should be included within the DSA to state that: “As a result of your application IGARD would like to draw your attention to the importance of the accessibility and clarity of your Privacy Notice. In the interests of transparency, you are advised to regularly review your notice against the ICO’s Privacy Notices Code of Practice to ensure it reflects best practice. You will be expected to demonstrate progress against this recommendation in any audit undertaken and for any renewal or new application for data.”</p>
3	<p>Any other business</p> <p>There was a discussion about first-of-type applications and IGARD reiterated that a briefing paper should be provided alongside significantly different or new types of applications.</p> <p>There was also a discussion about the role of the IG Advisor to IGARD and IGARD expressed their support for the IG Advisor attending meetings to assist in mutual learning and building relationships.</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>16/03/17: 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>	Open

			<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 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>02/03/17: This had been discussed at the educational session and it was agreed the IGARD Chair would contact the Caldicott Guardian following that discussion.</p> <p>16/03/17: IGARD's comments had been shared with the Caldicott Guardian, particularly regarding an unclear table, and the IGARD Chair had requested sight of the updated paper.</p>	
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 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>	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>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>	Open

09/03/17	NHS Digital to ensure that for all future DSfC applications, data flow diagrams should be provided and where appropriate the applications should be split in order to aid transparency of the process.	Stuart Richardson		Open
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Appendix B: Out of committee report (as of 10/03/17)

These applications were previously recommended for approval with conditions by 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-28602 Private Healthcare Information Network (PHIN)

The following two application caveats had been signed off by DAAG and the Director for Data Dissemination on 22 December 2016, but had been omitted from the out of committee report at the time:

- NIC-43358-L8W2Q NHS Bristol CCG (*considered at DAAG meeting on 19 July 2016 as part of a group application for 4 CCGs*)
- NIC-43355-Q4R2Y NHS South Gloucestershire CCG (*considered at DAAG meeting on 19 July 2016 as part of a group application for 4 CCGs*)