

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

### Minutes of meeting held 7<sup>th</sup> December 2017

**Members:** Anomika Bedi, Joanne Bailey, Chris Carrigan (Chair), Nicola Fear, Jon Fistein, Kirsty Irvine,

**In attendance:** Dave Cronin, Jen Donald, Louise Dunn, Joseline Dzakpata, James Humphries, Dickie Langley, Stuart Richardson, Jan Spence, Vicki Williams.

**Apologies:** Sarah Baalham, Eve Sariyannidou.

1	<p><b>Declaration of interests</b></p> <p>Chris Carrigan noted his personal links with the University of Sheffield in relation to NIC-94749-Y1R8N but noted no specific connection with that project or the staff involved.</p> <p><b>Review of previous minutes and actions</b></p> <p>The minutes of the 16<sup>th</sup> November 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 received (see Appendix B).</p>
2	<p><b>Data applications</b></p>
2.1	<p><u>University of Oxford - Total hip arthroplasty versus hemiarthroplasty for independently mobile older adults with an intracapsular hip fracture (Presenter: Louise Dunn) NIC-61090-T9Y0G</u></p> <p><b>Application:</b> This was a new application for Hospital Episodes Statistics (HES) Admitted Patient Care and Office for National Statistics (ONS) mortality data (date of death) which will be linked to the National Hip Fracture Database (NHFD) to test two related hypotheses:</p> <ol style="list-style-type: none"><li>1. Total Hip Arthroplasty (joint replacement) (THA) is associated with better outcomes than hemiarthroplasty (HA) (partial replacement) for independently mobile older adults with hip fractures, i.e. patients satisfying the criteria proposed by NICE.</li><li>2. Patients that receive an operation that is non-compliant with NICE guidance (i.e. HA despite being eligible for THA or THA despite being ineligible) will have worse outcomes than those receiving NICE-compliant treatment.</li></ol> <p><b>Discussion:</b> IGARD queried the University of Oxford's relationship with HQIP and whether HQIP should be considered as a joint data controller and this be clarified as well as accurately reflected in the Data Sharing Agreement (DSA). IGARD queried how the data flowed between the applicant and HQIP and it was agreed the data flow diagram be updated to reflect the current flows.</p> <p>IGARD noted that fair processing information was not provided and that NHS Digital should be content that the University of Oxford's fair processing meets the nine minimum criteria for privacy notices before any data flowed and IGARD suggested the applicant may wish to work with NHS Digital to update their patient information leaflets.</p> <p>IGARD noted that reference to Crown Informatics in section 5b of the application was not clear and that for transparency should be updated to indicate Crown Informatics was being used as the processing organisation only.</p> <p>IGARD noted that the application was classed as not being commercial, however IGARD noted that it was important to specify for transparency why it had been classed as such and asked for clarification.</p> <p>It was suggested that reference to anonymised data should be updated to the correct terminology: pseudonymised data.</p>

	<p>IGARD noted that it was not clear within the application which team or department within University of Oxford were accessing the data and this should be referenced within section 5 of the application.</p> <p>IGARD noted that the legal basis for the Approved User listed in section 9 of the application should be updated and the expiry dates for approval considerations in section 7 should be clarified. IGARD asked that special condition 5.3 be updated to correct the legal basis under Statistics and Registrations Authority Act 2007.</p> <p>IGARD noted that University of Oxford's fair processing should be updated to include reference to 'researchers' because it did not reflect the staff accessing the data.</p> <p>IGARD noted that the DPA registration for the Crown Informatics did not reference patients and health service users and suggested that the applicant may wish to update.</p> <p><b>Outcome:</b> Recommendation to approve subject to the following conditions:</p> <ul style="list-style-type: none"> <li>• Clarification should be sought as to whether HQIP should be classed as a joint data controller and to ensure that the DSA correctly reflects this, along with updating the data flow diagram.</li> <li>• Providing evidence that NHS Digital is content that the fair processing information for University of Oxford meets the nine minimum criteria for privacy notices before data can flow.</li> </ul> <p>The following amendments were requested:</p> <ul style="list-style-type: none"> <li>• Section 5 of the application be updated to reference which team or department within Oxford University is accessing the data.</li> <li>• Section 5e be updated to clarify why NHS Digital have classed the application as not being commercial.</li> <li>• Section 5 of the application be updated as to why Crown Informatics are being used as the processing organisation.</li> <li>• The MRP expiry date should be noted in Section 7.</li> <li>• The special conditions para 5.3 within S6 be updated to correct the legal basis under the SRSA.</li> <li>• The privacy notice should be updated to include reference to 'researchers'.</li> <li>• Any reference to anonymised data should be updated to pseudonymised data.</li> </ul> <p>The following advice was given:</p> <ul style="list-style-type: none"> <li>• IGARD advised that Crown Informatics DPA registration be updated to include patients and healthcare users.</li> <li>• IGARD advised the applicant should work with the NHS Digital to update their patient information leaflets.</li> </ul> <p>It was agreed the above conditions would be reviewed out of committee by the IGARD Chair.</p>
2.2	<p><u>University of Birmingham - Cancer Research (Presenter: Dave Cronin) NIC 148286-3RWRG</u></p> <p><b>Application:</b> This application had been considered at the 20<sup>th</sup> July 2017 meeting when IGARD had deferred making a recommendation. The application had now been updated to address the previous points raised, including providing a clearer explanation of the legal basis to retain and use data provided as latest available demographics, confirming appropriate contractual arrangements between the applicant and the University of Oxford, providing a clearer explanation of how data will be minimised and updating fair processing materials.</p> <p>The application requested an extension to and renewal of a previous DSA to permit the retention and reuse of Personal Demographics data, Cancer Registration data and ONS mortality data that had been previously provided via NHS Digital's Medical Research</p>

	<p>Information Service (or predecessors) and the receipt of new identifiable data.</p> <p><b>Discussion:</b> IGARD were broadly content and acknowledged the updated information provided. IGARD noted that the privacy notice for the applicant had been uploaded to the website and that the applicant had worked with NHS Digital to meet the nine minimum criteria. IGARD requested that for future applications that supporting documentation with regard to privacy notices be consistent.</p> <p>It had been decided that honorary contract was not the way forward, but the applicant is putting in place a data processor agreement with University of Oxford and data will not be shared under this application because such a contract was not in place, and that section 5 of the application be updated to reference. IGARD noted that the researchers named in Section 9 of the application be clarified and corrected within the application.</p> <p>IGARD asked for clarification with regard to section 3 of the application and that to historical data fields which were supplied in both paper and electronic format be compared, and any previously unused data fields be destroyed.</p> <p><b>Outcome:</b> Recommendation to approve.</p> <p>The following amendments were requested:</p> <ul style="list-style-type: none"> <li>• Updated fair processing documentation should be provided.</li> <li>• Reference to information not being shared with Oxford University should be clarified within Section 5 of the application.</li> <li>• Clarifying in Section 3 of the application that the historical data fields which were supplied in paper and electronic reports be compared and any previously unused data fields destroyed.</li> <li>• Clarifying and confirming the named researchers and those that have access within section 9 of the application.</li> </ul>
2.3	<p><u>University of Sheffield, Collaborative European Neuro Trauma Effectiveness Research in Traumatic Brain Injury (CENTER-TBI) WP 17 (Presenter: Garry Coleman) NIC-62448-Z8K5T</u></p> <p><b>Application:</b> This application for pseudonymised HES data had previously been considered at the 16 November 2017 meeting, when IGARD had deferred making a recommendation. The application had now been updated to address the previous points raised including providing evidence that the applicant will not use NHS Digital data to populate the registries they are responsible for, to be clear that data from NHS Digital would be used solely to populate registry data and would only be shared in aggregated form as an output, and providing further evidence with regard to work package 17.</p> <p>This was a new application for pseudonymised HES data, to assist research into traumatic brain injury (TBI). The research is being run by a European collaboration, but the data from NHS Digital is to be used exclusively by the University of Sheffield (unless the data is aggregated, with small numbers suppressed).</p> <p><b>Discussion:</b> IGARD acknowledged the updated information provided however noted that references to the registries in section 5 were not clear and that section 5 be updated to clarify which register, UK TBI Registry or CENTER TBI Registry, were being referenced. IGARD noted that the application include the special conditions listed in section 6 and it was agreed this should also be reflected within section five of the application in the interests of transparency.</p> <p><b>Outcome:</b> Recommendation to approve.</p> <p>The following amendments were requested:</p> <ul style="list-style-type: none"> <li>• Section 5 of the application be updated to clearly identify which registry (CENTER TBI Registry or UK TBI Registry) is being referenced.</li> <li>• Section 5 within the application should be updated to appropriately reflect the special</li> </ul>

	conditions listed in section 6.
2.4	<p><u>University College London, 'Usual Care' versus 'Specialist Integrated Care': A Study of Hospital Discharge Arrangements for Homeless People in England (Presenter: Louise Dunn) NIC 86666-V7Z1L</u></p> <p><b>Application:</b> This was a new application to evaluate the impact of specialist hospital discharge services for homeless people and compare the outcomes to those for homeless people admitted to hospitals without specialist services. Outcomes will also be compared to hospitalised non-homeless people in the most deprived quintile. The study will compare patient's hospitalisation history before and after engagement with specialist services. The study will undertake to understand whether the outcomes are a factor of homelessness specifically or are tied to deprivation. It was noted that there was an error in section 9 of the application and that the legal basis for one approved user had not been provided.</p> <p><b>Discussion:</b> IGARD noted that the applicant had met the nine minimum criteria however this was not accurately reflected in the application summary, which should be updated. IGARD noted that a statement in the application summary should be updated to accurately reflect section 5 of the application that patients will not be identified and IGARD suggested the duplicate paragraph within section 5 benefits should be deleted.</p> <p>IGARD queried why the CAG letters had been sent to a Kings College address and sought clarification on this relationship and if the address was correct. IGARD noted that section 5 of the application should be clear that no data would be shared with Kings College London. IGARD also noted that the application did not accurately reflect the CAG letter and protocol and that reference to the cohort and data sets should be clearly stated in section 5.</p> <p>IGARD referred to reports being sent to National Institute for Health Research (NIHR) and that these should be mentioned in the application if applicable and routinely published.</p> <p>IGARD queried reference to NHS partner hospitals in the DPA registration for the University College of London and suggested the applicant may wish to update and remove the reference.</p> <p><b>Outcome:</b> Recommendation to approve.</p> <p>The following amendments were requested:</p> <ul style="list-style-type: none"> <li>• Section 9 of the application should be amended to include the legal basis for the specified user.</li> <li>• The statement in the summary section that patients will not be identified should be amended to accurately reflect section 5 of the application.</li> <li>• The summary section be updated to be clear that the fair processing had met NHS Digital's 9 minimum criteria for privacy notices.</li> <li>• Clarification in Section 5 of the application be clarified that data will not be shared with Kings College London.</li> <li>• Clarification that the address referenced in the CAG letter is correct.</li> <li>• Section 5 of the application should be updated to clearly reflect the wording within the CAG letter and protocol, and to include reference to the cohort and data sets.</li> <li>• The duplicate paragraph in the benefits of section 5 of the application should be removed – process / benefits.</li> <li>• Section 5 of the application should be updated to clarify if the NHIR report is routinely published.</li> </ul> <p>The following advice was given:</p> <ul style="list-style-type: none"> <li>• IGARD advised that the DPA registration for University College London should be updated</li> </ul>

	to remove reference to NHS partner hospitals.
2.5	<p><u>University of Sheffield, Survival outcomes and HES-based Charlson Comorbidity Scores for women recruited to the Bridging the Age Gap in Breast Cancer study – for advice on consent, (Presenter: Garry Coleman) NIC-94749-Y1R8N</u></p> <p><b>Application:</b> This application was presented to IGARD for advice only. IGARD were asked to consider whether the consent materials provided a legal basis for participant identifiers to flow to NHS Digital, whether the consent materials provided a legal basis for the mortality data to flow to the University, whether the consent materials provided a legal basis for HES data to flow to the University and whether any fair processing actions were required before (or after) any of the flows. The University of Sheffield are running a study called “Bridging the Age Gap in Breast Cancer”. The cohort being studied are women over the age of 70. For this cohort, the university wants certain hospital records (episodes in HES where there is a related diagnosis/treatment, such as cancer recurrence and chemotherapy-related). In addition, the university wants an update on mortality (date and cause of death).</p> <p><b>Discussion:</b> IGARD welcomed the application and noted the importance of the medical and social issues raised and complexities surrounding the study.</p> <p>IGARD queried whether internal advice from NHS Digital’s Information Governance staff had been sought and IGARD suggested that this be done in addition to obtaining IGARD advice.</p> <p>IGARD discussed the application documents and felt that although there were a number of issues that would need to be resolved, the first step would be to work with the applicant on their consent materials. IGARD raised a concern over applications where vulnerable patients were asked to give consent, since this was a complex area involving the Mental Capacity Act and intrusive research and IGARD noted that NHS Digital should prepare a briefing note on legal basis for cohorts that do not have capacity.</p> <p><b>Outcome:</b> The following advice was given.</p> <p>IGARD welcomed the application which came for advice and without prejudice. IGARD advised that NHS Digital should consult with senior NHS Digital IG staff and work with the customer on their current consent materials.</p> <p><b>ACTION:</b> IGARD noted that a briefing note should be provided with applications for any first of type applications or first of type data flows.</p>
2.6	<p><u>University of Leeds, Total hip arthroplasty versus hemiarthroplasty for independently mobile older adults with an intracapsular hip fracture (Presenter: Louise Dunn) NIC-40493-G5Y6K</u></p> <p><b>Application:</b> This was a new application from Joint Data Controllers University of Leeds and Bradford Teaching Hospitals with a request for HES and ONS data for a small cohort of people recruited into the ISCOMAT (Improving the safety and continuity of medicines management at care transitions) Study.</p> <p>The programme is a series of interlinked projects which will design and test a complex intervention (a Medicines at Transitions Toolkit) to make best use of medicines and reduce harm through effective medicines management for heart failure patients from hospital discharge and into primary care.</p> <p><b>Discussion:</b> IGARD queried the consent material provided to the participants and the presenter noted that the applicant had been working with NHS Digital since initial consent materials were disseminated. Although the applicant had made considerable progress to update their consent and patient information material, IGARD suggested that current wording needed to be updated and suggested the applicant continue to work with NHS Digital.</p> <p>IGARD suggested that the website links within the application and on the patient information leaflets should be checked to ensure that participants could access the website via the leaflets provided.</p>

	<p>IGARD noted that Bradford Teaching Hospitals Trust's DPA registration should refer to 'patients' and not 'our patients' and suggested the applicant may wish to update. IGARD noted that NHS Digital intended to continue to work with the applicant to ensure that their privacy notice met the nine minimum criteria.</p> <p><b>Outcome:</b> Recommendation to approve.</p> <p>The following amendment was requested:</p> <ul style="list-style-type: none"> <li>The website links within the application and on the patient information leaflets should be updated and corrected to ensure that participants can access the website.</li> </ul> <p>The following advice was given:</p> <ul style="list-style-type: none"> <li>IGARD advised that Bradford Teaching Hospitals Trust should update their DPA registration to list patients.</li> <li>IGARD advised that the fair processing for Leeds University should be updated to be in line with NHS Digital's nine minimum criteria for privacy notices and that the information on the University of Bradford webpages is reflected on the University of Leeds and Bradford Teaching Hospital Trust.</li> <li>IGARD advised that the applicant work with NHS Digital to update the current wording within their patient information leaflets.</li> </ul>
2.7	<p><u>NHS Midlands and Lancashire Commissioning Support Unit - Contractual and strategic benchmarking across Midlands and Lancashire (Presenter: Garry Coleman), NIC-05206-L1V6D</u></p> <p><b>Application:</b> This application had been previously considered by DAAG at the 13<sup>th</sup> August 2015 meeting. The CSU supports contractual and strategic benchmarking across Midlands and Lancashire, for programmes such as planning commissioning and productivity, service quality and performance improvement, and activity and outcomes monitoring for local populations. For this they require a variety of datasets, covering a considerable period of data. The CSU's customer base consists of: CCGs, Trusts, Local Authorities for the purposes of public health and social care, CQC, Sustainability and Transformation Partnerships, Public Health England, Department of Health, Clinical senates, Strategic clinical networks, NHS England, NHS Improvement, and health charities.</p> <p><b>Discussion:</b> IGARD queried the request for national data and whether smaller local samples could be used, however NHS Digital were satisfied this was consistent with other applications. IGARD noted that the reference to the role of NHS England should be removed from section 5b of the application and noted that although the CSU and DSCRO were different legal entities the same staff were employed across both organisations. IGARD queried the title of the application and thought that the NHS Midlands and Lancashire CSU may wish to amend the title to adequately reflect the application summary.</p> <p><b>Outcome:</b> Recommendation to approve</p> <p>The following amendment was requested:</p> <ul style="list-style-type: none"> <li>Section 5b of the application be updated to remove the erroneous sentence with regard the role of NHS England.</li> </ul> <p>The following advice was given:</p> <ul style="list-style-type: none"> <li>IGARD advised that the applicant consider reviewing the title of the application.</li> </ul>
2.8	<p><u>Group of 207 CCGs - Emergency Care Data Set (ECDS) (Presenter: Stuart Richardson) NIC: NIC-164062-K2G8J</u></p> <p><b>Application:</b> This was an amendment application for 207 CCGs to receive additional fields of data when providers move from the submission of Accident &amp; Emergency (A&amp;E) Commissioning Data Set to Emergency Care Data Set (ECDS). NHS England (NHSE) issued a Direction (The Health and Social Care Information Centre (<i>Establishment of Information</i></p>

	<p><i>Systems for NHS Services: Emergency Care Data Set Collection</i>) Directions 2017) to support the ECDS. Implementing ECDS will facilitate better and more timely access to data on Emergency Department activity. The Direction covers transmission of ECDS data to NHS Digital and the subsequent dissemination of the data.</p> <p><b>Discussion:</b> IGARD noted that a number of CCG's DPA and Data Sharing Framework Contract's had expired and advised that data should not flow until these had been renewed. IGARD noted that for those CCG's assessed as satisfactory with improvement plans on V13 of the IGT, that NHS Digital IG staff should review those improvement plans for any areas of concern.</p> <p><b>Outcome:</b> Recommendation to approve</p> <p>The following advice was given:</p> <ul style="list-style-type: none"> <li>• IGARD advised that until the DPA and DSFC's had been renewed, that data should not flow for those relevant CCGs.</li> <li>• IGARD advised that senior IG staff within NHS Digital should review those CCG's with an improvement plan for any areas of concern.</li> </ul>
2.9	<p><u>Group application for 3 CCGs - Social Care, (Presenter: Stuart Richardson) SA12-NW-AMD<sup>1</sup></u></p> <p><b>Application:</b> This was a new application from a group of 3 CCGs to use pseudonymised data to provide intelligence to support the commissioning of health services. The data (containing both clinical and financial information) is analysed so that health care provision can be planned to support the needs of the population within the CCG area. The CCGs commission services from a range of providers covering a wide array of services. Each of the data flow categories requested supports the commissioned activity of one or more providers.</p> <p><b>Discussion:</b> IGARD noted that section 5 (purposes) of the application should be clear that the social care data will only be used for the purposes specified in the relevant Direction, and for transparency and audit that these should be separated out from the generic list of purposes listed.</p> <p>IGARD noted that the privacy notices for the 3 CCG's should be in line with the ICO's Privacy Notice Code of Practice to ensure they reflect best practice standards including plain English and IGARD suggested that the CCG's update their fair processing in line with NHS Digital's nine minimum criteria for privacy notices.</p> <p><b>Outcome:</b> Recommendation to approve</p> <p>The following amendment was requested:</p> <ul style="list-style-type: none"> <li>• Section 5 of the application should be updated to clearly state that the adult social care data can only be used for the specific purposes outlined with the purpose section and in line with Directions.</li> </ul> <p>The following advice was given:</p> <ul style="list-style-type: none"> <li>• IGARD advised that the CCG's should update their privacy notice in line with NHS Digital's minimum criteria for privacy notices.</li> </ul>

<sup>1</sup> NIC-139074-D9N2C NHS Heywood, Middleton and Rochdale CCG; NIC-113980-R8Z8K NHS Liverpool CCG; NIC-139079-M6P7X NHS Manchester CCG

2.10	<p><u>Group application for 3 CCGs (Presenter: Stuart Richardson) GA01-YO-AMD<sup>2</sup></u></p> <p><b>Application:</b> This was a consolidated application from a group of 3 CCG'S for the purpose of Invoice Validation, Risk Stratification and Commissioning. The amendment request is due to Leeds CCG partnership (Leeds North CCG, Leeds West CCG and Leeds South and East CCG) merging to become one in January 2018. The pseudonymised data is required to ensure that analysis of health care provision can be completed to support the needs of the health profile of the population within the CCG area based on the full analysis of multiple pseudonymised datasets.</p> <p><b>Discussion:</b> IGARD queried the legal personality of data processor 4 listed in the application summary and noted that the Health and Care Hub was not a legal entity and should be corrected to Leeds City Council. IGARD queried which staff were accessing the data and what controls were in place to restrict access and sought clarification on the role based controls in place for those staff accessing the data. IGARD noted that data processor 5, Leeds City West CCG, was missing from section 5 of the application and this should be correctly referenced.</p> <p>IGARD noted that the application stated that patient level care would not be shared outside the CCG unless for the purpose of direct care, and that this should be updated to accurately reflect that data would be shared outside the CCG, if that was the case.</p> <p>IGARD suggested that the applicant consider the levels of repeated data processing and whether this processing could be considered as excessive.</p> <p><b>Outcome:</b> Recommendation to approve, subject to the following condition:</p> <ul style="list-style-type: none"> <li>• Clarification that appropriate role based access controls are in place for those staff accessing the data.</li> </ul> <p>The following amendments were requested:</p> <ul style="list-style-type: none"> <li>• Data processor 5, Leeds City West CCG, should be correctly referenced within Section 5 of the application.</li> <li>• Reference to LCC Health and Care Hub as a Data Processor 4 within the application should be updated to Leeds City Council.</li> <li>• Reference within Section 5 of the application that patient level data will not be shared outside the CCG unless it is for the purpose of direct care should be corrected that it will be shared.</li> </ul> <p>The following advice was given:</p> <ul style="list-style-type: none"> <li>• IGARD advised that the CCG's should update their privacy notice in line with NHS Digital's nine minimum criteria for privacy notices.</li> </ul> <p>It was agreed the above condition would be reviewed out of committee by the IGARD Chair.</p>
2.11	<p><u>NHS Cambridge and Peterborough CCG (Presenter: Stuart Richardson) NIC141755-M8J2J</u></p> <p><b>Application:</b> This was a new application for Invoice Validation which is part of a process by which providers of care or services get paid for the work they do. Invoices are submitted to the Clinical Commissioning Group (CCG), so they are able to ensure that the activity claimed for each patient is their responsibility. This is done by processing and analysing Secondary User Services (SUS) data, which is received into a secure Controlled Environment for Finance (CEff). The SUS data is identifiable at the level of NHS number and the NHS number is only used to confirm the accuracy of backing-data sets and will not be used further.</p> <p><b>Discussion:</b> IGARD noted that any historic data should be destroyed before further data flowed.</p> <p><b>Outcome:</b> Recommendation to approve.</p>

<sup>2</sup> Leeds North, Leeds South and East and Leeds West CCGs NIC-30034-N7D1F, NIC-129953-Y2H5J, NIC-129961-P7T9Z

2.12	<p><u>The Christie NHS Foundation Trust - Cancer Intelligence Service (Presenter: Stuart Richardson), NIC-154978-N9X9M</u></p> <p><b>Application:</b> This application for The Christie NHS Foundation trust (as host of the Greater Manchester (GM) and East Cheshire (EC) Cancer Intelligence Service) was to receive pseudonymised Local Provider Flows for cancer datasets relating to the 11 CCGs covering the GM &amp; EC region for commissioning purposes</p> <p>The Cancer Vanguard is responsible for ensuring that the delivery of cancer services for the GM &amp; EC population meet national standards and that all patients have equal access to care. To ensure this happens, data are needed for ongoing evaluation of care and outcomes at regional and local levels and local flows have been established by the CCGs both for their own purposes and also to specifically support the cancer vanguard in their work. The local datasets required are listed below. They are based on national returns submitted by the trusts, but the local flow enables the Cancer Intelligence Service to gain much more timely access to the data in a form that can be linked to produce useful reports.</p> <p><b>Discussion:</b> IGARD noted that the applicant was requesting data for the period 01/12/17-30/11/18 and queried why the applicant was also requesting an extract of historical data for the period 01/04/11-30/11/17 and it was agreed a clearer explanation be provided in section 5. IGARD were unclear why data was being sourced locally rather than nationally and it was agreed that further clarification be provided. IGARD requested to know how the data would be kept separately and it was suggested that a clearer explanation of this in the application would be helpful. IGARD also noted that there should be no attempt to re-identify data stored and that this should be updated in the application.</p> <p>IGARD queried the nature of the datasets requested and asked that the application be updated to clarify the detail. IGARD suggested that the Trust's update their DPA to remove reference to 'our patients'.</p> <p><b>Outcome:</b> Recommendation to approve subject to the following conditions.</p> <ul style="list-style-type: none"> <li>• A clearer explanation in Section 5 of the application as to why the CCG need an historic extract from 01/04/11-30/11/17 alongside data period 01/12/17-30/11/17, a clearer explanation how the data will be kept separately and clarification that there will be no attempt to re-identify the data stored.</li> <li>• Clarification within Section 5 of the application with regard to why data is sourced locally rather than nationally.</li> </ul> <p>The following amendments were requested.</p> <ul style="list-style-type: none"> <li>• Section 5 of the application should be amended to clarify the detail of the data sets.</li> </ul> <p>The following advice was given.</p> <ul style="list-style-type: none"> <li>• IGARD advised that The Christie NHS Foundation Trust should update their DPA registration to remove reference to our patients.</li> </ul> <p>It was agreed the above conditions would be reviewed out of committee by a quorum of IGARD members.</p> <p><b>ACTION:</b> IGARD noted that a briefing note should be provided with applications for any first of type applications or first of type data flows.</p>
3	<p><b>Any other business</b></p> <p>No other business was 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	14/09/17: Ongoing. It was agreed this would be discussed during the educational session.  07/12/17: Ongoing. It was agreed to bring the first draft to January's education session.	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.  09/11/17: A response from NHS England had been received and this would be circulated to IGARD by email.  07/12/17: Ongoing – draft response to IGARD with Deputy Caldicott Guardian for sign off.	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	Open

			<p>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 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>	
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			07/12/17: Ongoing.	
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>07/12/17: ongoing.</p>	Open
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	07/12/17: 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	07/12/17: 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	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	Closed

	approved by the NHS Digital Board.		confirmation would still be required of NHS Digital Board approval. 07/12/17: NHS Digital Board received the Direction at 31/05/17 board meeting.	
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. 07/12/17: NHS Digital Board received the Direction at 06/09/17 board meeting.	Closed
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	07/12/17: Dickie Langley noted that a briefing paper would be presented to IGARD in December / January.	Open
21/09/17	Dickie Langley to provide IGARD with a copy of the new standard DSA terms and conditions.	Dickie Langley	07/12/17: Documentation provided to members on 06/11/17.	Closed
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.	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	07/12/17: Ongoing.	Open

**Appendix B: Out of committee report (as of 1<sup>st</sup> December 2017)****Independent Group Advising on Releases of Data (IGARD): Out of committee report 01/12/17**

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.

<b>NIC reference</b>	<b>Applicant</b>	<b>IGARD meeting date</b>	<b>Recommendation conditions as set at IGARD meeting</b>	<b>IGARD minutes stated that conditions should be agreed by:</b>	<b>Conditions agreed as being met in the updated application by:</b>	<b>Notes of out of committee review (inc. any changes)</b>
NIC-147863-CCGZN	Royal Devon & Exeter NHS Foundation Trust	16/11/17	<ul style="list-style-type: none"><li>• Providing a copy of the applicant's latest research ethics approval letter.</li></ul>	IGARD Chair	Director Data Dissemination	
NIC-392669-T1F8B	University of Oxford	16/11/17	<ul style="list-style-type: none"><li>• Confirmation of whether the applicant has sought updated ethics review based on the updated protocol, or whether the changes made were only considered minor amendments</li></ul>	IGARD Chair	Director Data Dissemination	
NIC-91808-P5Z1F	NHS Brighton & Hove CCG	24/08/17	<ul style="list-style-type: none"><li>• The CCG should update their privacy notice in line with NHS Digital's nine criteria.</li><li>• Providing evidence that the South Central and West CSU's action plan relating to the second data sharing audit has been completed, particularly in relation to any points around governance and the management of</li></ul>	IGARD Chair	IGARD Chair	

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

- None notified to IGARD