

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

### Minutes of meeting held 25 January 2018

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

**In attendance:** Jane Cleave (observer), Gaynor Dalton, Sharon Dempsey (observer) Arjun Dhillon, Kirsty Dormand (observer), Louise Dunn, Duncan Easton, James Humphries Hart, Stuart Richardson, Jonathan Smith (observer), Kimberley Watson, Vicki Williams.

**Apologies:** Sarah Baalham, Anomika Bedi.

1	<p><b>Welcome and introduction</b></p> <p>The Chair welcomed Sharon Dempsey and Jonathan Smith to the meeting as observers.</p> <p><b>Declaration of interests</b></p> <p>Nicola Fear noted her professional links to NIC-152414-W1M2Q University of Bristol, working on both the study and data, and would not be part of the discussion for that particular application.</p> <p><b>Review of previous minutes and actions</b></p> <p>The outcomes of the 18 January IGARD meeting were reviewed and were agreed as an accurate record of that aspect of the meeting.</p> <p>The minutes of the 18 January IGARD meeting were reviewed out of committee by IGARD following conclusion of the meeting, and subject to a number of minor changes were agreed as an accurate record of the meeting.</p> <p>Action updates were provided (see Appendix A).</p> <p><b>Out of committee recommendations</b></p> <p>An out of committee report was received (see Appendix B).</p>
2	<p><b>Data applications</b></p>
2.1	<p><u>University of Leicester – MR1275 The United Kingdom Aneurysm Growth Study (UKAGS) (Presenter: Dickie Langley) NIC-148437-C9YSC</u></p> <p><b>Application:</b> This was a renewal application for identifiable mortality data linked to the UKAGS cohort. The UKAGS aims to find out more about aortic aneurysms and started recruiting men who attended screening for abnormal aortic aneurysms in 2010/11 with the aim of the study to assess the outcomes from screening.</p> <p>Dickie Langley noted that the processing location on the application was incorrect and would be updated to correctly list the University of Leicester. Dickie Langley also noted that the applicant had requested date of death in addition to fact of death for research purposes, however for list cleaning the applicant needed only fact of death and NHS Digital would clarify with the applicant if date of death for patients was required.</p> <p><b>Discussion:</b> IGARD discussed the benefits of this work and recognised the applicant may wish to undertake a list cleaning exercise. The list cleaning exercise would ensure that the applicant had up to date addresses for all patients, however should they not wish to undertake list cleaning, IGARD asked what other steps had been undertaken to ensure the patient address details were up to date. IGARD noted that if a list cleaning exercise was undertaken then the applicant should inform patients of this and that it would be helpful to consider list cleaning on a regular basis.</p> <p>It was IGARD's view that the consent materials provided did not provide a clear legal basis for the list cleaning exercise. IGARD suggested that NHS Digital work with the applicant to bring the consent materials up to the current required standards and it was suggested that it would</p>

	<p>be helpful to update the consent materials at the same time to explain any planned list cleaning and the involvement of NHS Digital.</p> <p>IGARD asked for clarification with regard to the consent process for the control group since it was not clear which consent materials had been provided to this group and two documents provided had been referenced as SD11. IGARD also noted that it was not clear which consent forms had been provided to each of the recruitment waves of the cohort group and suggested that clarification be sought as to which consent materials were provided to each group and what percentage of the cohort group each of these represented.</p> <p>IGARD noted that it was not clear which patient information sheet and consent form the applicant was currently using as part of their ongoing recruitment, and suggested that the applicant suspend recruitment, if recruitment was ongoing, until list cleaning had been undertaken and the consent materials updated to current standards.</p> <p>IGARD suggested that Section 3 of the application be updated to include the relevant sections of the Health &amp; Social Care Act 2012 and Statistics &amp; Registration Service Act 2007, along with updating the governance path within the application summary.</p> <p><b>Outcome:</b> recommendation deferred, pending:</p> <ul style="list-style-type: none"> <li>• Confirmation of whether the applicant will be undertaking list cleaning to ensure they have up to date address details for all patients or what other steps had been taken to ensure address details were up to date. If list cleaning is undertaken, information about this should be included in the applicant's patient information leaflets and consent materials and to explicitly state that they were sending identifiers to NHS Digital.</li> <li>• Clarification whether the applicant required date of death for research purposes in addition to fact of death for patients.</li> <li>• Clarification of the consent process for the control group and evidence of any consent materials provided to the control group.</li> <li>• To clarify which consent materials were used for each recruitment wave of the cohort group and what percentage of the cohort group each of these represent.</li> <li>• To clarify which patient information sheet and consent form the applicant is currently using as part of ongoing recruitment.</li> <li>• The legal basis within section 3 of the application be updated to include the relevant sections of the Health &amp; Social Care Act 2012 and Statistics &amp; Registration Service Act 2007.</li> <li>• The processing location be updated to correctly list the University of Leicester.</li> <li>• The governance path within the summary be corrected to "for independent review"</li> </ul> <p>The following advice was given:</p> <ul style="list-style-type: none"> <li>• IGARD advised that the applicant should suspend recruitment, if recruitment was ongoing, until list cleaning had been undertaken and the consent materials updated to current standards.</li> <li>• The consent materials do not provide a clear legal basis for the list-cleaning exercise as they do not create a reasonable expectation for the flow of identifiers to NHS Digital. However, in order to bring the consent materials up to the current required standard, NHS Digital might consider it appropriate to work with the applicant to undertake such a list cleaning exercise.</li> </ul>
2.2	<p><u>London Borough of Tower Hamlets – Vanguard application (Presenters: Stuart Richardson / James Humphries Hart) NIC-150201-T3G7X</u></p> <p><b>Application:</b> This was a new vanguard application to receive identifiable Secondary User Services (SUS), Mental Health Data and Local Provider data flows to support the development of an integrated pseudonymised whole system dataset which includes health, social care and</p>

	<p>local authority providers and will inform a one-off report to support new care model planning and commissioning.</p> <p>Stuart Richardson noted that an error within the data flow diagram would be corrected to accurately reflect that zone 1 is for linkage and as outlined in Section 5 of the application.</p> <p><b>Discussion:</b> IGARD queried why Queen Mary University Hospital was listed as a Data Processor due to the application stating that it was Local Authority staff that accessed the data and that clarity should be sought from the applicant.</p> <p>The role and identity of the entity subcontracted to carry out the Whole Systems Data Project (WSDP) was queried. It was noted that WSDP were based at Queen Mary but that their identity and their role should be clearly stated in the application.</p> <p>IGARD noted that the application and data flow diagram did not clearly state the legal basis for the flow of National Health Application and Infrastructure Services (NHAIS) data from NHS England to NHS Digital and that this should be clarified within Section 5 of the application.</p> <p>IGARD noted that the applicant's fair processing information did not meet NHS Digital nine minimum criteria and NHS Digital should be content that the Local Authority's fair processing meets the NHS Digital nine minimum criteria for privacy notices before data can flow.</p> <p><b>Outcome:</b> recommendation deferred, pending:</p> <ul style="list-style-type: none"> <li>• Clarification of the legal basis for the flow of NHAIS data from NHS England to NHS Digital.</li> <li>• Clarifying why Queen Mary University Hospital London is listed as the Data Processor.</li> <li>• The fair processing notice for London Borough of Tower Hamlets be updated to meet NHS Digital's nine minimum criteria for privacy notices, before data can flow.</li> <li>• The role of the sub-contacted entity carrying out the Whole Systems Data Project (WSDP) be more clearly described in section 5 of the application and ideally named.</li> <li>• The data flow diagram be updated to accurately reflect that zone 1 is for linkage as outlined in section 5 of the application.</li> </ul>
2.3	<p><u>Group application for 3 CCG's<sup>1</sup> (Presenter: Stuart Richardson) GA10a-NW-AMD</u></p> <p><b>Application:</b> This was a new application for 3 CCG's to move data processors through a period of dual running for invoice validation and general commissioning and continue to use pseudonymised data Secondary User Services (SUS), Mental Health Minimum Data Set (MHMDS), Mental Health Services Data Set (MHSDS), Mental Health Disability Data Set (MHDDS), Improving Access to Psychological Therapies (IAPT), Maternity Services Data Set, Children &amp; Young People's Health (CYPH), Community Services Data Set, Diagnostic Imaging Data Set (DIDS) and local provider flows data to provide intelligence to support commissioning of health services. The data sharing agreements (DSA) will be agreed for a period no longer than 6 months and once expired the data will be destroyed with only this data sharing agreement in place.</p> <p><b>Discussion:</b> IGARD were not clear what differentiated the two data processors outlined in the application, since both were undertaking population health management. IGARD suggested that further clarity be provided for MedeAnalytics International Ltd and Optum Health Solutions (UK) Ltd with regard to what each Data Processor did in order to address any concerns around excessive data processing. IGARD noted that it was not clear which data processors were being referred to within the application in reference to dual running and it should be explicit within Section 5 which Data Processor is being referred to.</p> <p>IGARD noted that a reference to 2017 within the application summary be updated to 2018 and that reference to invoice validation be removed from the application.</p>

<sup>1</sup> NHS Dartford, Gravesham and Swanley CCG - NIC-154880-M7G5Z; NHS Medway CCG - NIC-155188-V0V7L; NHS Swale CCG - NIC-155197-S3L3V

	<p>IGARD noted that Interxion were listed as a storage location and stated in their view that it would be more appropriate to also list this organisation as an additional data processor. It was acknowledged that there was currently an open action with NHS Digital regarding storage locations and how to reflect their role as data processors</p> <p><b>Outcome:</b> recommendation to approve</p> <p>The following amendments were requested:</p> <ul style="list-style-type: none"> <li>• Reference to population health management processing activities for the two Data Processors (MedeAnalytics International Ltd and Optum Health Solutions (UK) Ltd) be differentiated to provide clarity on what each Data Processor provides.</li> <li>• Reference to dual running be clarified within the application and to be clarified to be explicit about to which Data Processor this refers.</li> <li>• Reference to invoice validation within the application be removed.</li> <li>• The date within the abstract to be updated to 2018.</li> </ul>
2.4	<p><u>Group application for 3 CCG's <sup>2</sup>(Presenter: Stuart Richardson) GA10b-NW-AMD</u></p> <p><b>Application:</b> This was a new application for 3 CCG's to move data processors through a period of dual running for invoice validation and continue to use Secondary User Services (SUS) data to provide intelligence to support commissioning of health services. The data sharing agreements (DSA) will be agreed for a period no longer than 6 months and once expired the identifiable SUS data will be destroyed with only this DSA in place.</p> <p>Stuart Richardson noted that a review of the CCG's fair processing materials had not taken place prior to submission to IGARD.</p> <p><b>Discussion:</b> IGARD noted that fair processing information was not provided for review and NHS Digital should be content that the CCG's fair processing meets the NHS Digital nine minimum criteria for privacy notices before data can flow.</p> <p>IGARD noted that a reference to 2017 within the application summary be updated to 2018 and that reference to MedeAnalytics International Ltd be removed from the application. IGARD noted a number of typos within Section 5 of the application and that a number reference to the Data Processor be corrected within the data flow diagram.</p> <p>IGARD noted that Interxion were listed as a storage location and stated in their view that it would be more appropriate to also list this organisation as an additional data processor. It was acknowledged that there was currently an open action with NHS Digital regarding storage locations and how to reflect their role as data processors</p> <p><b>Outcome:</b> recommendation to approve subject to the following condition:</p> <ul style="list-style-type: none"> <li>• The fair processing information for CCG's NHS Dartford Gravesham &amp; Swanley CCG, NHS Medway CCG and NHS Swale CCG is updated to meet NHS Digital's 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>• Reference to MedeAnalytics International Ltd should be removed from the application.</li> <li>• To correct erroneous typos within the application and correct a numbering reference to the Data Processor within the data flow diagram.</li> <li>• The date within the abstract to be updated to 2018</li> </ul>

<sup>2</sup> NHS Dartford, Gravesham and Swanley CCG NIC-170580-K3W3H; NHS Medway CCG NIC-170585-V9Q4L; NHS Swale CCG NIC-170593-N0R4N

2.5	<p><u>Group application for 5 CCG's<sup>3</sup> (Presenter: Stuart Richardson) GA11a-NW-AMD</u></p> <p><b>Application:</b> This was an amendment application for 5 CCG's to change data processor and continue to use pseudonymised data Secondary User Services (SUS), Mental Health Minimum Data Set (MHMDS), Mental Health Services Data Set (MHSDS), Mental Health Disability Data Set (MHDDS), Improving Access to Psychological Therapies (IAPT), Maternity Services Data Set, Children &amp; Young People's Health (CYPH), Community Services Data Set, Diagnostic Imaging Data Set (DIDS) and local provider flows to provide intelligence to support the commissioning of health services.</p> <p><b>Discussion:</b> IGARD were not clear what differentiated the two data processors outlined in the application, since both were undertaking population health management. IGARD suggested that further clarity be provided for MedeAnalytics International Ltd and Optum Health Solutions (UK) Ltd with regard to what each Data Processor did in order to address any concerns around excessive data processing. IGARD noted that it was not clear which data processors were being referred to within the application in reference to dual running and it should be explicit within Section 5 which Data Processor is being referred to.</p> <p>IGARD noted that a reference to 2017 within the application summary be updated to 2018 and that reference to invoice validation be removed from the application.</p> <p>IGARD noted that Interxion were listed as a storage location and stated in their view that it would be more appropriate to also list this organisation as an additional data processor. It was acknowledged that there was currently an open action with NHS Digital regarding storage locations and how to reflect their role as data processors</p> <p><b>Outcome:</b> recommendation to approve</p> <p>The following amendments were requested</p> <ul style="list-style-type: none"> <li>• Reference to population health management processing activities for the two Data Processors (MedeAnalytics International Ltd and Optum Health Solutions (UK) Ltd) be differentiated to provide clarity on what each Data Processor provides.</li> <li>• Reference to invoice validation within the application be removed.</li> <li>• The date within the abstract to be updated to 2018.</li> </ul>
2.6	<p><u>Group application for 5 CCG's<sup>4</sup> (Presenter: Stuart Richardson) GA11b-NW-AMD</u></p> <p><b>Application:</b> This was a new application for the purpose of invoice validation to receive identifiable Secondary User Services (SUS) data. Invoices are submitted to the CCG so they are able to ensure that the activity claimed for each patient is their responsibility and 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 is only used to confirm the accuracy of the backing-data sets and will not be used further.</p> <p><b>Discussion:</b> IGARD noted that fair processing information provided for review for NHS Canterbury &amp; Coastal CCG, NHS South Kent Coast CCG, NHS Thanet CCG did not meet NHS Digital's nine minimum criteria for privacy notices and should be updated before data can flow.</p> <p>IGARD noted that reference to MedeAnalytics International Ltd be removed from the application.</p> <p><b>Outcome:</b> recommendation to approve subject to the following condition:</p>

<sup>3</sup> NHS Ashford CCG - NIC-153720-N8K6X; NHS Canterbury and Coastal CCG - NIC-155278-D1D1J; NHS South Kent Coast CCG - NIC-155254-Y1H0S; NHS Thanet CCG - NIC-155287-C4K4G; NHS West Kent CCG - NIC-154892-N5F9Z

<sup>4</sup> NHS Ashford CCG - NIC-153720-N8K6X; NHS Canterbury and Coastal CCG - NIC-155278-D1D1J; NHS South Kent Coast CCG - NIC-155254-Y1H0S; NHS Thanet CCG - NIC-155287-C4K4G; NHS West Kent CCG - NIC-154892-N5F9Z

	<ul style="list-style-type: none"> <li>The fair processing information for CCG's NHS Canterbury &amp; Coastal CCG, NHS South Kent Coast CCG, NHS Thanet CCG is updated to meet NHS Digital's nine minimum criteria for privacy notices before data can flow.</li> </ul> <p>The following amendment was requested:</p> <ul style="list-style-type: none"> <li>Reference to MedeAnalytics International Ltd should be removed from the section 7 of the application.</li> </ul>
2.7	<p><u>Group application for 3 CCG's<sup>5</sup> (Presenter: Stuart Richardson) GA13-SCW-AMD</u></p> <p><b>Application:</b> This was a new application for the 3 CCG's to act as joint Data Controllers to receive pseudonymised data based on Sustainable Transformation Partnership Footprint (STPF) to allow collaborative working and support the commissioning of health services</p> <p><b>Discussion:</b> IGARD noted the helpful explanation of the black box process in the abstract and suggested that the publishable Section 5 of the application be updated, using this explanation, to provide a clearer explanation of the black box arrangements in place.</p> <p>IGARD noted a typo within the special conditions and suggested that singular references to CCG's be updated, where appropriate, to plural.</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 provide further brief explanation for a lay reader of the black box arrangements in place.</li> <li>A typo within the special conditions be corrected and the singular references to CCG's within the application be corrected to plural where appropriate.</li> </ul>
2.8	<p><u>Group application for 5 CCG's<sup>6</sup> (Presenter: Stuart Richardson) GA14-SCW-AMD</u></p> <p><b>Application:</b> This was a new application for 5 CCG's to act as joint Data Controller to receive pseudonymised data based on the Sustainable Transformation Partnership Footprint (STPF) collaborative working and support the commissioning of health services.</p> <p><b>Discussion:</b> IGARD noted the helpful explanation of the black box process in the abstract and suggested that the publishable Section 5 of the application be updated, using this explanation, to provide a clearer explanation of the black box arrangements in place.</p> <p>IGARD noted a typo within the special conditions and suggested that singular references to CCG's be updated, where appropriate, to plural.</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 provide further brief explanation for a lay reader of the black box arrangements in place.</li> <li>A typo within the special conditions be corrected and the singular references to CCG's within the application be corrected to plural where appropriate.</li> </ul>
2.9	<p><u>Neil Wilson Associates – financial benchmarking service (Presenter Louise Dunn) NIC-07233-W1M2Q</u></p> <p><b>Application:</b> This was an extension application to continue to hold Hospital Episode Statistics (HES) Admitted Patient Care (APC) and HES Critical Care (CC) which has already been disseminated to support NHS organisations during financial turnaround; to support NHS organisations plan and implement service change for the benefit of patients; and to assure</p>

<sup>5</sup> NHS Bath & North East Somerset CCG NIC-116524-S2N2H; NHS Swindon CCG NIC-49725-M7Y0M; NHS Wilshire CCG NIC-49745-X5P6X

<sup>6</sup> NHS Bracknell and Ascot CCG NIC-169866-G4Z6F; NHS North East Hampshire and Farnham CCG NIC-169885-G1C4F; NHS Slough CCG NIC-169894-P6B1T; NHS Surrey Heath CCG NIC-169890-N5T9S; NHS Windsor, Ascot and Maidenhead CCG NIC-169901-Z0S4X

	<p>NHS organisations within a healthcare economy that financial transactions are fair, transparent and compliant with national guidance.</p> <p>Louise Dunn noted that an amendment should be made to the application to insert the standard NHS Digital paragraph with regard to clarifying that outputs will be suppressed in line with the HES Analysis Guide.</p> <p><b>Discussion:</b> IGARD noted the suggestion to clarify within Section 5 that outputs will be suppressed in line with the HES Analysis Guide. IGARD also noted that it was not clear within Section 5 which new CCG's had been included and that for transparency these be clearly identified and that the yielded benefits section be further updated for clarity and transparency.</p> <p>IGARD asked that it be explicit that appropriate levels of controls were in place for Neil Wilson Associate staff accessing data and that standard wording be included to ensure compliance with the ICO Anonymisation Code.</p> <p>IGARD suggested that applicant update their DPA registration to more clearly state that data is processed about patients or healthcare users.</p> <p><b>Outcome:</b> recommendation to approve</p> <p>The following amendments were requested.</p> <ul style="list-style-type: none"> <li>• Clarifying within section 5 of the application that outputs will be suppressed in line with the HES Analysis Guide.</li> <li>• Clarification within section 5 of the application that appropriate controls are in place for access of data by Neil Wilson and Associates staff to ensure compliance with the ICO Anonymisation Code.</li> <li>• That wording within section 5 yielded benefits be updated for clarity and transparency.</li> <li>• Clearly identifying the new CCG's added within section 5 of the application for transparency.</li> </ul> <p>The following advice was given:</p> <ul style="list-style-type: none"> <li>• IGARD suggested the UKFast update their DPA registration to more clearly state that data is processed about patients or healthcare users.</li> </ul>
2.10	<p><u>University of Bristol – continuation of Avon Longitudinal Study of Parents and Children (ALSPAC) with the children aspect only (Presenter: Duncan Easton) NIC-152414-W1M2Q</u></p> <p>Nicola Fear was an observer for this discussion.</p> <p><b>Application:</b></p> <p>This was an application to renew and amend for bespoke extracts of Hospital Episode Statistics (HES) Admitted Patient Care, Critical Care, Outpatient and Accident &amp; Emergency data as well as Mental Health Services Data. ALSPAC is a transgenerational prospective birth cohort study that recruited women during pregnancy during the 1990's. ALSPAC is designed to investigate influences on health, wellbeing and development across the life course. The seven purposes for the use of data requested cover various factors of mental and physiological health, including the connection between drug use and mental health outcomes, various aspects of self harm and sexual health.</p> <p>Duncan Easton noted that a previous linked application, NIC-13133 University of Bristol had previously been considered by IGARD on the 21 December 2017.</p> <p><b>Discussion:</b> IGARD were unclear what the application was requesting noting the wording in Section 5 of the application was ambiguous and suggested that it be updated in plain English to be clear to the reader, including ensuring that for each project a numbering convention be applied and used consistently across the application, particularly in regard to the table of supporting documents.</p> <p>IGARD noted it was not clear whether the s251 general approval provided by HRA CAG covered projects 3 and 7 as outlined in the application. Although IGARD noted that this application was the second of two applications to IGARD, it was suggested that further detail</p>

	<p>be added to Section 5 of the application to more accurately reflect the legal basis for each project.</p> <p>IGARD were not clear of the filtering processing outlined in Section 5 and suggested that a clearer description be given for transparency.</p> <p>IGARD queried the applicant's retention of the full HES data set and it was noted that a full refresh had been requested due to the increase in the cohort size. IGARD noted that the legal basis to retain the HES dataset may have been outlined in the previous application (NIC 13133) however the legal basis for the retention of the original copy of the HES data should be clearly stated and cross referenced in this application summary for transparency. IGARD queried if data would be linked to any other data and that it be explicit in Section 5 of the application that data will not be linked and there should be no attempt to reidentify the previous extract for consenting index children.</p> <p>IGARD noted that the cohort should also be more clearly described in Section 5 of the application, including the increase in the cohort size.</p> <p>IGARD suggested that the retention period agreed for each project by HRA CAG be cross referenced with Section 8a of the application.</p> <p><b>Outcome:</b> recommendation deferred, pending:</p> <ul style="list-style-type: none"> <li>• The application be updated to be more accessible to the reader.</li> <li>• Confirmation whether the s.251 general approval provided by HRA CAG covers projects 3 and 7 listed within the application, and that the retention period agreed for each project by HRA CAG are cross referenced to section 8a of the application.</li> <li>• The legal basis for the retention of the original copy HES data be clearly stated within the application summary.</li> <li>• To provide a clearer description of the filtering process outlined in section 5 of the application.</li> <li>• To clearly describe the cohort in section 5 of the application.</li> <li>• Section five of the application should be updated to more clearly state that University of Bristol will not link data requested in this application to any other data, apart from the linkages permitted under this application, and that there should be no attempt to re-identify previous extract for consenting index children.</li> <li>• The numbering convention for each project be applied across the entire application.</li> </ul>
2.11	<p><u>Barts Health NHS Trust – NICOR Commissioning through Evaluation (CtE) Registries / Audits: left Atrial Appendage Occlusion (LAAO), Mitral valve repair (Mitraclip) and Patent Foramen Ovale Closure (PFOC) (Presenter: Kimberley Walsh) NIC-151212-B5Z3R</u></p> <p><b>Application:</b> This was a renewal and amendment application for bespoke extract of Hospital Episode Statistics (HES) Admitted Patient Care (APC), Critical Care (CC), Outpatient (OP) and Accident &amp; Emergency (A&amp;E) data as well as Mental Health Services (MHLDDS) and had previously been considered by IGARD on the 21<sup>st</sup> December 2017 when IGARD had deferred making a recommendation pending the application being redrafted to more accurately reflect the cohorts, the processing activities and the projects that are covered by consent as a legal basis; the applicant to provide a copy of all previous earlier consent materials from when the cohort consented at age of 16.</p> <p><b>Discussion:</b> IGARD noted the application had been updated to reflect comments previously raised.</p> <p>IGARD noted that fair processing for the applicant did not meet the nine minimum criteria. In particular that the privacy notice was not published, and that NHS Digital should work with the applicant before data can flow to ensure it had been both updated in line with previous comments made and published.</p>



	<p>IGARD noted the data retention period for the applicant and suggested that justification be given as to why the data should be retained until 2031.</p> <p>IGARD suggested that the table within the summary section of the application be updated to clearly reflect and identify the legal basis for both the receipt of and dissemination of data.</p> <p><b>Outcome:</b> recommendation to approve subject to the following condition:</p> <ul style="list-style-type: none"> <li>• In line with NHS Digital's nine minimum criteria, the fair processing information be published before data can flow.</li> </ul> <p>The following amendments were requested:</p> <ul style="list-style-type: none"> <li>• The table within the application summary be updated to clearly identify the legal basis for both receipt and dissemination.</li> <li>• To provide clearer justification for the retention period of 2031.</li> <li>• To correct an erroneous typo within section 5 of the application.</li> </ul>
<p><b>3</b></p> <p><b>3.1</b></p>	<p><b>AOB</b></p> <p><b>NIC-159399 National Centre for Social Research</b></p> <p>IGARD noted that following the 18<sup>th</sup> January 2018 meeting, when IGARD had been unable to make a recommendation. The relevant extract is as follows:</p> <p><b>“Outcome:</b> Unable to recommend for approval</p> <p>IGARD believe there is an authority to collect the data outlined within the application, however evidence of the legal basis was not available for IGARD to consider. IGARD recognised the importance of the work involved and that NHS Digital may choose to continue to flow data. IGARD found itself in difficult position of not being able to make a recommendation for approval.”</p> <p>NHS Digital had taken the decision to disseminate the data. The IGARD Chair and IGARD Deputy Chair had been informed of this out of committee.</p> <p><b>Action:</b> Arjun Dhillon, Deputy Caldicott Guardian, was tasked to check with NHS Digital whether templates which had not been approved by IGARD but where NHS Digital had taken the decision to disseminate data would come back to IGARD for consideration or was the template now classed as an approved template by NHS Digital.</p>
<p><b>3.2</b></p>	<p><b>Principles re review of applications to IGARD</b></p> <p>IGARD noted that although a number of principles had already been adopted by DAAG and then IGARD, it was important to note the following which would be revisited periodically:</p> <ul style="list-style-type: none"> <li>• Consistency is important, but this does not mean that points raised in previous applications cannot be debated in the context of another application to IGARD.</li> <li>• IGARD is entitled to ask for and consider information pertinent to an application, even if it may have been provided the information on a previous occasion.</li> <li>• Each application will be considered on its merits and with a view to providing a recommendation to NHS Digital as to how to address the risks associated with that application.</li> <li>• IGARD's input to NHS Digital extends to the different aspects of data processing covered by the Data Protection legislation.</li> </ul>

## Appendix A: Summary of Open Actions

Date raised	Action	Owner	Updates	Status
20/04/17	IGARD Chair to contact key stakeholder organisations regarding the benefits of uses of data to feed into the IGARD annual report.	IGARD Chair	<p>14/09/17: Ongoing. It was agreed this would be discussed during the educational session.</p> <p>07/12/17: Ongoing. It was agreed to bring the first draft to January's education session.</p> <p>25/01/18: Ongoing.</p>	Open
18/05/17	Garry Coleman to provide information about different arrangements for data storage and backup locations, for consideration of whether the organisations involved would be considered to be processing data.	Garry Coleman	<p>15/06/17: IGARD had been advised by email that a paper about this would be submitted to an upcoming IGARD meeting.</p> <p>22/06/17: It was anticipated that this would be discussed at the 6 July 2017 IGARD meeting. IGARD asked for some information to be circulated by email prior to the meeting in order to inform members who would not be present at that particular meeting.</p> <p>27/07/17: An email had been circulated requesting further information from IGARD members.</p> <p>03/08/17: Two IGARD members had responded by email and the action remained ongoing.</p> <p>10/08/17: It was anticipated that a paper on this would be brought to IGARD within the following two weeks.</p> <p>24/08/17: The paper was in the process of being updated based on recently published ICO guidance.</p> <p>14/09/17: Ongoing. IGARD noted that given the amount of time that had passed, they would consider starting to note this on relevant</p>	Open

			<p>applications where a data storage location was not listed as a data processor.</p> <p>21/09/17: Ongoing. IGARD asked for Dickie Langley to provide an update on Garry Coleman's open actions at the next meeting to help ensure timely progression.</p> <p>02/11/17: IGARD discussed this action with Garry Coleman and requested a written update in response to the points previously raised by IGARD. Some difficulties were acknowledged as this specific scenario did not seem to be addressed in existing ICO guidance; IGARD suggested that NHS Digital should seek legal advice and if necessary then contact the ICO directly.</p> <p>16/11/17: Ongoing. IGARD queried the progress made regarding this action and there was a suggestion that this should be discussed at an education session; however it was suggested that it would be necessary to receive an updated response from NHS Digital before this.</p> <p>25/01/18: Ongoing</p>	
20/07/17	Garry Coleman to provide an update within two weeks on how NHS Digital manage the risk involved in CCGs using South Central and West CSU as a data processor in light of data sharing breaches and recent audits.	Garry Coleman	<p>10/08/17: It was anticipated that a paper on this would be brought to IGARD within the following two weeks.</p> <p>24/08/17: IGARD received a verbal update on the work that had taken place following both audits and verbal assurances that NHS Digital were content with the level of risk involved in this organisation continuing to act as a data processor. IGARD welcomed this update and requested written confirmation.</p> <p>31/08/17: IGARD were notified that the requested written confirmation should be provided within one day.</p> <p>14/09/17: An email response had been circulated on 31 August, and IGARD noted that they were awaiting receipt of the post-audit report.</p>	Open

			25/01/18: Ongoing	
20/07/17	Garry Coleman to categorise different standard lengths of indicative data retention periods for general research and clinical trials, with appropriate justification.	Garry Coleman	25/01/18: Ongoing	Open
31/08/17	Garry Coleman to report back on how cancer registration data was previously described as pseudonymised PDS data within older versions of applications, and present to a future education session on changes to how MRIS reports are now shown within applications.	Garry Coleman	25/01/18: Ongoing	Open
19/10/17	Stuart Richardson to provide a briefing on the Temporary National Repository infrastructure.	Stuart Richardson	16/11/17: Stuart Richardson noted discussions were ongoing. 25/01/18: Ongoing.	Open
02/11/17	NHS Digital to consider the responses provided by an applicant (Imperial College London NIC-27085) in relation to the language and terminology used in patient information materials.	Louise Dunn	25/01/18: Ongoing.	Open
07/12/17	Dickie Langley to provide a briefing note on NHS Digital's due diligence policy and process	Dickie Langley	25/01/18: Ongoing.	Open
07/12/17	Stuart Richardson to provide a briefing note outlining NHS Digital's work with STP's to clarify the legal / access arrangements in place between CCG's to ensure responsibilities are clearly defined	Stuart Richardson	25/01/18: Ongoing.	Open

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

## Appendix B: Out of committee report

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-10343	Royal College of Physicians	11/01/18	<ul style="list-style-type: none"> <li>Confirmation that the three data items listed in Section 5 of the application will be destroyed after use.</li> <li>Providing a copy of the NHS England commissioning letter (a) detailing that the project is funded beyond March 2017 and (b) listing all the Data Processors.</li> </ul>	IGARD Chair	IGARD Chair	N/A
NIC 147755	Nuffield Dept of Surgical Sciences	14/12/17	<ul style="list-style-type: none"> <li>Confirmation that the fair processing information is easily accessible on the study website and is amended to include the information contained in the current newsletter.</li> </ul>	IGARD Chair	IGARD Chair	N/A
NIC-123200	London School of Hygiene & Tropical Medicine	21/12/17	<ul style="list-style-type: none"> <li>The fair processing information for LSHTM is updated to meet the nine minimum criteria for privacy notices before data can flow, in particular that identifiers will be sent to NHS Digital and the fair processing information consolidated into one place</li> </ul>	IGARD Chair	IGARD Chair	N/A

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

- None notified to IGARD