

Independent Group Advising on the Release of Data (IGARD)

Minutes of meeting held 15 February 2018

Members: Sarah Baalham, Anomika Bedi, Chris Carrigan (Chair), Jon Fistein, Eve Sariyiannidou.

In attendance: Louise Dunn, Duncan Easton, Kimberley Watson, Vicki Williams.

Apologies: Joanne Bailey, Nicola Fear, Kirsty Irvine.

1	<p>Welcome and introduction</p> <p>The Chair welcomed Sarah Baalham back to IGARD after a period of absence.</p> <p>Declaration of interests</p> <p>Both Jon Fistein and Chris Carrigan declared conflicts of interest in relation to NIC-352291 University of Leeds due to their work with the University of Leeds and professional relationships with the particular applicants. It was agreed they would leave the meeting for the discussion of that application, and that agenda item would be chaired by Sarah Baalham.</p> <p>Review of previous minutes and actions</p> <p>The outcomes of the 8 February IGARD meeting were reviewed and were agreed as an accurate record of that aspect of the meeting.</p> <p>The minutes of the 8 February 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>Out of committee recommendations</p> <p>An out of committee report was received (see Appendix B).</p>
2	<p>Data applications</p>
2.1	<p><u>London North West Healthcare NHS Trust - National Clinical Audit of Specialist Rehabilitation following major Injury (NCASRI) (Presenter: Kimberley Watson) NIC-131964-Q6L1J</u></p> <p>Application: This was a new application for Hospital Episode Statistics (HES) Admitted Patient Care and Office for National Statistics (ONS) Mortality Data. NCASRI, commissioned by the Health Quality Improvement Partnership (HQIP) and led by the UK Rehabilitation Outcomes Collaborative (UKROC) at London North West Healthcare NHS Trust is three-year audit programme (2015-18) which determines the scope, provision, quality and efficiency of specialist rehabilitation services across England and improves the quality of care for adults with complex rehabilitation needs following major trauma.</p> <p>Discussion: IGARD noted that this was a valuable three-year study involving three organisations at different points throughout the trial, however IGARD were not clear of each organisation's role and asked for further clarification on the roles of HQIP and Kings College London. IGARD also queried whether Kings College London should be a Data Controller, however NHS Digital noted that this was a clinical audit with deliverables determined by HQIP in their role as sole Data Controller. IGARD asked if Kings College London would be processing the data, and it was confirmed they were not.</p> <p>IGARD suggested that it be explicit within the application that the applicant would not use the data for re-identification purposes and will not link the data in this application to any other data, apart from those outlined within the application. IGARD queried who would be accessing the data and NHS Digital confirmed that only those substantive employees listed in the application would access the data. IGARD also suggested that a statement be added stating that outputs would be suppressed in line with the HES Analysis Guide.</p>

IGARD noted that the applicant's fair processing did not meet NHS Digital's nine minimum criteria for privacy notices, specifically references to anonymous and anonymised data to be described as pseudonymised, to clarify that the opt out process applies to the processing of all data and the fair processing notice to be published. IGARD noted that a clear statement should then be added to the application summary that NHS Digital was satisfied that the applicant's fair processing meets the NHS Digital nine minimum criteria for privacy notices (to be known as NHS Digital's fair processing criteria) before data can flow.

IGARD queried the different usages of the term 'TARN' (The Trauma Audit and Research Network) and that in some instances it was used to reference the database but also used to reference the network and asked for clarity within the application. IGARD also noted that TARN terminology was used to reference Salford Royal NHS Foundation Trust and asked that this be clear and consistent throughout the application.

IGARD queried what HRA data was and requested clarification of the acronym and further information be provided within section 5 of the application.

IGARD suggested that the first two sentences of HQIP's security assurance information be removed from section 1b 'security assurances for the Data Controller' as it was not relevant to this application and that HQIP's DPA number be corrected within the application.

Outcome: recommendation to approve subject to the following condition:

- The fair processing notice for the applicant be updated to meet NHS Digital's nine minimum criteria (to be known as NHS Digital's fair processing criteria) for privacy notices, specifically, references to anonymous and anonymised data to be described as pseudonymised, to clarify that the opt out process applies to the processing of all data, and the fair processing notice to be published, before data can flow

The following amendments were requested

- Giving a clear explanation within section 5 of the application the roles of both HQIP and Kings College London.
- Clarification within section 5b of the application that the applicant will not use the data for re-identification purposes and clearly state that the applicant will not link the data in this application to any other data apart from linkages permitted under this application / DSA.
- Clarifying within section 5 of the application that outputs will be suppressed in line with the HES Analysis Guide
- Clarifying the terminology used within section 5 of the application referencing TARN database and TARN network and ensuring there is a clear distinction between both.
- Clarifying the terminology used when referencing Salford Royal Trust or TARN and ensuring consistency throughout the application.
- Clarifying in section 5 of the application what is HRG data.
- The two first sentences of HQIP's security assurance information be removed from section 1b 'security assurances for the Data Controller'.
- The application should clearly reference the DPA number for HQIP

It was agreed that the condition be approved OOC by the IGARD Chair.

Rod Gibson Associates Ltd - Inpatient HES for the provision of maternity and general health indicators for the consumer organisation Which (Presenter: Kimberley Watson) NIC-15402-M9L6Z

Application: This was a renewal application to continue to hold Hospital Episode Statistics (HES) previously disseminated under NIC-15402 and to request two additional years for 2015/16 and 2016/17, and an amendment to restrict the data disseminated to females with the purpose restricted to providing aggregated maternity indicators for the “Which? Birth Choice” website and to continue to provide maternity indicators for the BirthChoiceUK website.

NHS Digital noted that the BirthChoiceUK website was currently offline and those wishing to access the website were being directed to the Which? BirthChoice website.

Discussion: IGARD noted their concern over the amount of data being requested which currently had no filters applied and queried why the applicant wanted the full HES dataset for all females of all ages since this did not reflect the outputs for the application. NHS Digital noted they had discussed with the applicant and that the data was being used to provide information on the BirthChoiceUK and Which? Birth Choice websites. IGARD noted the good work being undertaken, however the purpose within the application was too narrow to justify the amount of data requested and that a clear justification be included within section 5 as to why the full HES dataset of all females of all ages was required.

IGARD noted that it was not clear within the application if data would be linked to other data sets held by the applicant and asked that it be explicitly stated that the applicant could not link the data requested with any other data, apart from linkages under the application. IGARD queried if those accessing the website could access any of the ‘raw’ data and it was confirmed that they could not and that the HES output restrictions applied.

IGARD noted that a statement that the applicant would ‘trawl back through a woman’s obstetric history to estimate the number of previous pregnancies a woman has had’ should be clarified with the process clearly explained for the lay reader and that this would not include any direct identifiers.

IGARD suggested that the applicant update their DPA registration to more clearly state that data is processed about patients or healthcare users.

IGARD noted that the applicant’s DSA with NHS Digital had expired and that NHS Digital should progress as per due process and that NHS Digital may wish to audit the organisation in relation to this application.

Outcome: recommendation deferred, pending:

- A clearer justification within the application why the full HES dataset for all females of all ages was required and why a filter could not be applied that more accurately reflects the outputs of the application.
- Section 5 of the application should be updated to more clearly state that Rod Gilbert Associates Ltd will not link the data requested in this application to any other data, apart from the linkages permitted under this application / DSA.
- Clarifying the terminology within section 5 of the application with reference to ‘trawling through medical history’ with a clear explanation of the process involved.
- IGARD suggested that applicant update their DPA registration to more clearly state that data is processed about patients or healthcare users.

The following advice was given:

	<ul style="list-style-type: none"> IGARD suggested that NHS Digital might wish to consider auditing the organisation in relation to this application/agreement <p>IGARD noted the importance of this study and the need for the applicant to continue to hold data. IGARD noted that the applicant's Data Sharing Agreement with NHS Digital had expired, and in light of this it was suggested that NHS Digital might wish to consider a short-term extension to permit the continued retention of data while work was undertaken to address the queries raised by IGARD.</p>
2.3	<p><u>Nottinghamshire Healthcare NHS Foundation Trust - Arnold Lodge Admission Cohort Reconvictions and Intervening Treatment (ALACRITY) study: 1983-2013 (Presenter: Kimberley Watson NIC-69751-COM8P)</u></p> <p>Application: This was a new application for identifiable Office for National Statistic (ONS) mortality data, death of death and Hospital Episode Statistics (HES) Admitted Patient Care data which will be linked to a cohort of approximately 850 patients. The cohort consists of patients submitted to Arnold Lodge between 1983 and 2013 and the retrospective study is to examine the outcomes (mortality and readmission) of the cohort of first admission discharged from Arnold Lodge Medium Security Unit. The study will also form part of a PhD at the University of Leicester.</p> <p>NHS Digital noted that the application did not refer to 'date of death' data nor did it feel that it met the NHS Digital nine minimum criteria for fair processing notices.</p> <p>Discussion: NHS Digital noted that the fair processing notice did not reference the word 'death' and although IGARD agreed, they stated that any privacy notice should have language appropriate to the audience. However, IGARD noted that the applicant's fair processing notice was not easily accessible and should be updated to be truthful and clear and that a clear statement should be added to the application summary that NHS Digital was satisfied that the applicant's fair processing meets the NHS Digital nine minimum criteria for privacy notices (to be known as NHS Digital's fair processing criteria) before data can flow.</p> <p>A query was raised about whether the applicant would take any steps to make outputs available to the general public. IGARD suggested that more information be included how the outputs will be disseminated to help inform commissioning of services that could be understood by the lay reader when published as part of the data release register.</p> <p>IGARD noted that ONS and HES data would be linked to outcome data from the Ministry of Justice (MoJ) to provide a single follow-up record for each patient, however it was not clear how the linkage of the NHS Digital data to the MoJ data was compatible with the Care Act 2014 and how it served a healthcare purpose and asked for further clarity to better understand how it will improve any health outcomes, including any conditions from the MoJ which may need to be included in the Data Sharing Agreement to restrict how NHS Digital data is used. IGARD noted that any data linkage should be explicit referenced within section 5 of the application plus any prohibitions to linkage and that standard wording be included with regard to limited access controls to access the data.</p> <p>IGARD noted that a special condition within the abstract that 'no data will be requested from outside of Arnold Lodge as originally attended' should be referenced within section 6 of the application.</p> <p>IGARD suggested that the University of Leicester update their DPA registration to more clearly state that data is processed about patients or healthcare users. IGARD suggested that the standard ONS wording be including within section 5b of the application.</p> <p>Outcome: recommendation to approve subject to the following conditions:</p>

	<ul style="list-style-type: none"> • The fair processing notice for the applicant be updated to meet NHS Digital's nine minimum criteria (to be known as NHS Digital's fair processing criteria) for privacy notices including ensuring the privacy notice is accessible, the language is appropriate to the audience and not misleading, before data can flow. • Clearly describe in section 5 of the application how the linkage of the NHSD data to the MoJ data serves a healthcare purpose in a way that is compatible with the Care Act 2014. • Clarify in section 5 of the application that no further linkages are permitted, except from those described in the application. <p>The following amendments were requested</p> <ul style="list-style-type: none"> • Section 5b be updated with ONS standard wording: all processing of ONS data will be in line with the ONS standard conditions. • The special condition referenced in the abstract be included in the special conditions section of the application. • More information was requested about the planned outputs and how these will be disseminated in a way that will help ensure health benefits and influence commissioning of services. <p>The following advice was given:</p> <ul style="list-style-type: none"> • IGARD suggested that University of Leicester update their DPA registration to more clearly state that data is processed about patients or healthcare users. <p>It was agreed that the conditions be approved OOC by IGARD Members.</p>
2.4	<p><u>Intensive Care National Audit & Research Centre (ICNARC) - The 65 Trial: Evaluating the clinical and cost-effectiveness of permissive hypotension in critically ill patients aged 65 years or over with vasodilatory hypotension (Presenter: Kimberley Watson) NIC-96444-N2B7K – Advice on consent</u></p> <p>Application: This was an application for advice on patient consent and patient information sheet to ascertain if the documents provided would be acceptable to provide legal basis to flow patient identifiers to NHS Digital to link to Hospital Episode Statistics (HES) and Office for National Statistics (ONS) Mortality Data.</p> <p>The 65 Trial is a pragmatic, multi-parallel group randomised clinical trial aiming to evaluate the clinical and cost-effectiveness of permissive hypotension in critically ill patients aged 64 and over with vasodilatory hypotension.</p> <p>Discussion: NHS Digital noted they had been working with the applicant, IGARD noted that the applicant should proactively check their consent materials to ensure they met current and future GDPR standards. IGARD noted that consent issues could not be addressed via fair processing and suggested that consent material should have language appropriate to the audience.</p> <p>IGARD suggested that a way forward would be for the applicant to update their consent material to ensure they meet the GDPR standard of consent since this was a clinical trial. The applicant should set out a clear process for how they intend to re-consent the cohort and ensure that a clear process was put in place for recording and monitoring consent.</p> <p>IGARD suggested that the applicant may wish to seek an alternate legal basis and should consult with relevant guidance recently issued by the Information Commissioner's Office (ICO) but noted that significant progress should have been made by the 25 May 2018.</p>

	<p>ACTION: NHS Digital to update questions submitted for IGARD consideration on advice for consent applications and that questions 1 and 2 asked within the abstract summary should not be included on future advice for consent applications since they were not for IGARD to consider.</p> <p>Outcome: IGARD suggested that NHS Digital work with the applicant to ensure their consent materials are re-drafted to meet the GDPR standard of consent, including a clear process for re-consenting the cohort, as well as setting up a process for recording and monitoring consent. IGARD noted that should an alternative legal basis be explored, the applicant should consult the guidance recently issued by the ICO. IGARD offered their advice and further support without prejudice to the consideration of this application and any future applications.</p>
2.5	<p><u>University of Bristol - MR1048b Continuation of Avon Longitudinal Study of Parents and Children (ALSPACT) with for the Children aspect only (Presenter: Duncan Easton) NIC-152414-W3P6Q</u></p> <p>Application: This was an application to renew and amend for a bespoke extract of Hospital Episode Statistics (HES) Admitted Patient Care, Critical Care, Outpatients and Accident & Emergency data as well as Mental Health Services Data and had been previously considered by IGARD on the 25 January 2018 when IGARD had deferred making a recommendation pending the application being redrafted to be more accessible to the reader; confirmation whether s251 general support covered projects 3 and 7; the retention period in the application cross referenced to HRA CAG approval; the legal basis for the retention of the original copy HES data to be stated; a clearer description of the filtering process; clearly describe the cohort; clearly state that University of Bristol will not link data requested unless permitted under this application; and the numbering convention to be clear throughout the application.</p> <p>NHS Digital noted that a further three purposes had been included within the application for consideration and that further clarity had been given to the naming convention of supporting documentation.</p> <p>Discussion: IGARD noted the application had been updated to reflect some of the comments previously raised, however IGARD noted the wording in Section 5a of the application was still not clear and suggested that it be updated in plain English in order to be accessible to the lay reader. IGARD also noted that the cohort was still not clearly described, including the increase in cohort size and this should be cross referenced with the HRA CAG application summary and updated within section 5. IGARD were also still not clear of the filtering process outlined in section 5 and suggested that a clearer description of how the filtering process was conducted for transparency.</p> <p>IGARD noted it did not appear that the s251 general support provided by HRA CAG covered projects 9 and 10 as outlined in the application, agreeing that project 8 was covered by s251 general support, and that the applicant should identify the relevant s251 support for projects 9 and 10.</p> <p>IGARD queried if data under this application could be linked to other data and NHS Digital confirmed that it could not be linked and relevant wording was within section 5. IGARD suggested for transparency that standard wording within section 5 be updated from 'the agreement' to 'the Data Sharing Agreement' (DSA).</p> <p>IGARD queried the data retention period in section 8a and suggested that NHS Digital cross reference with the various s251 support letters submitted to ensure consistency, with appropriate standard wording including in section 5b.</p>

	<p>IGARD noted that outputs would not be disseminated to patients, patient groups or the public and suggested that the applicant provide more information how the outputs would be made more accessible to the general public.</p> <p>Outcome: recommended for approval subject to the following conditions:</p> <ul style="list-style-type: none"> • Confirmation which s.251 support documents cover the additional projects 9 and 10 listed within the application. • To clearly describe the cohort in section 5 of the application. <p>The following amendments were requested:</p> <ul style="list-style-type: none"> • The application be updated to be more accessible to the reader. • To provide a clearer description of the filtering process outlined in section 5 of the application. • More information was requested about the planned outputs and how these will be made more accessible to patients. • To update the planned data retention period section in line with the various s.251 support letters and update standard wording in section 5b. • References in section 5b relating to “the agreement” should refer to “the DSA”. <p>It was agreed that conditions be approved OOC by IGARD members.</p>
2.6	<p><u>Cardiff University - Building Blocks:2-6 - Evaluating the long-term effectiveness, and the cost and consequences of the Family Nurse Partnership parenting support programme in reducing maltreatment in young children (Presenter: Louise Dunn) NIC-333498-D1K7G</u></p> <p>Application: This was an amendment application to update Office for National Statistic (ONS) users and linking to Abortion Data provided by the Department of Health to Hospital Episode Statistics (HES) data up to 2016/17 and full refresh of the historical data for participants. The Building Blocks randomised controlled trial is to provide independent evidence on the effectiveness of the Family Nurse Partnership programme improving short term outcomes for young parents and their babies, an early intervention programme for reducing risk of child maltreatment in a targeted vulnerable population.</p> <p>NHS Digital noted that the legal basis was incorrectly referenced within the application and should be s261(7) and that reference to ‘we’ within section 5 would be removed.</p> <p>Discussion: IGARD noted that the applicant’s fair processing did not meet NHS Digital’s nine minimum criteria for privacy notices, specifically references to linkages to abortion data and that various webpages be consolidated and accessible. IGARD noted that a clear statement should then be added to the application summary that NHS Digital was satisfied that the applicant’s fair processing meets the NHS Digital nine minimum criteria for privacy notices (to be known as NHS Digital’s fair processing criteria) before data can flow.</p> <p>IGARD noted that reference to ‘name’ as an identifier was included within the s251 support for the first wave, however for the second wave the s251 support did not reference ‘name’ as an identifier to flow data to NHS Digital and suggested that the incorrect reference to ‘name’ being used as an identifier be removed from section 5 of the application.</p> <p>IGARD noted that information relating to the first Wave of data requested had been incorrectly removed from the application and that the language was confusing and suggested that information be provided for both Waves of data requested and be clearly described within section 5.</p>

	<p>IGARD noted that s251 support had expired and asked for clarity as to whether s251 support was in place for the project and that a copy of the most recent HRA CAG support letter be provided as evidence.</p> <p>IGARD noted that data retention for Department of Education data was in place until 2018 and asked if the applicant had applied for an extension to retain the education data, and if so that evidence be provided to confirm if a licence was in place for the applicant to retain Department of Education data beyond January 2018.</p> <p>IGARD queried reference to the legal basis for ONS data and suggested that the table in Section 9 be updated to s42(4). IGARD also suggested that the standard ONS wording be including within section 5b of the application.</p> <p>IGARD suggested that the applicant update their DPA registration to more clearly state that data is processed about patients or healthcare users.</p> <p>Outcome: recommendation to approve subject to the following conditions:</p> <ul style="list-style-type: none"> • The fair processing notice for the applicant be updated to meet NHS Digital's nine minimum criteria (to be known as NHS Digital's fair processing criteria) for privacy notices including ensuring information is consolidated and accessible, as well as referencing linkage to abortion data, before data can flow. • An incorrect reference to 'name' being used as an identifier for data linkage be removed from the application. • Providing evidence that s.251 support is still in place for the project. • Providing evidence that there is a license in place to retain the Department of Education data beyond January 2018. <p>The following amendments were requested:</p> <ul style="list-style-type: none"> • The legal basis within section 3 of the application be updated s261(7). • Reference to S42(4) be updated within section 9 of the application. • Providing a clearer explanation of the two waves of data requested within section 5 of the application. • Section 5b be updated with ONS standard wording: all processing of ONS data will be in line with the ONS standard conditions <p>The following advice was given:</p> <ul style="list-style-type: none"> • IGARD suggested that applicant update their DPA registration to more clearly state that data is processed about patients or healthcare users. <p>It was agreed the condition would be approved OOC by IGARD Members.</p>
2.7	<p><u>University of Leeds - Bariatric surgery and colorectal cancer risk – Bespoke Data Linkage (Presenter: Louise Dunn) NIC-352291-Y7B1S</u></p> <p>Sarah Baalham acted as chair for this agenda item only. It was noted that due to a conflict of interests Chris Carrigan and Jon Fistein were not present for the discussion of this application and that IGARD would therefore not be quorate for this item.</p> <p>Application: This was an application to extend an agreement for non-sensitive Hospital Episode Statistics (HES) Admitted Patient Care data. Previously NHS Digital had linked bariatric / obesity HES cohort to a cancer cohort which flowed from Public Health England under s251 approval (NIC-352291-Y7B1S) and this application was to link this cohort to the</p>

	<p>HES Admitted Patient Care and Linked HES / ONS Mortality Datasets and extracts of the study dataset.</p> <p>Discussion: IGARD noted that the HRA CAG evidence of support provided within the supporting documentation was dated 2015 and suggested that evidence be provided that s251 support was still in place to enable access to identifiable extracts of bariatric and obesity HES data which would be linked to cancer incidence data. IGARD were not clear if the ONS cancer registration data would be linked to mortality information and suggested that further clarity be included in section 5 with regard to the use of ONS data. IGARD also suggested that it be explicit within the application that the applicant would not link the data in this application to any other data, apart from those outlined within the application.</p> <p>Although it was noted that the Data Sharing Agreement included some data encryption, IGARD suggested that a special condition be included within the application that all data should be encrypted.</p> <p>IGARD queried the history of the application and NHS Digital provided an update to the ongoing work with the applicant and IGARD suggested that NHS Digital may wish to audit the organisation in relation to this application / agreement.</p> <p>Outcome: IGARD were unable to make a recommendation as there was not a quorum of members present. The following comments were made:</p> <ul style="list-style-type: none"> • Providing evidence that the s.251 support is still in place to enable access to identifiable extracts of bariatric and obesity HES data which was to be linked with cancer incidence data. • To provide further clarity of the use of ONS data within section 5b of the application. • Section 5 of the application should be updated to more clearly state that the University of Leeds will not link data requested in this application to any other data, apart from the linkages permitted under this application and DSA. • That a special condition be added to the application that all data should be encrypted.
<p>3</p> <p>3.1</p>	<p>AOB</p> <p>Local Authority Hospital Episode Statistic (HES) Template</p> <p>NHS Digital noted that a number of renewals for HES access were being received by NHS Digital and whilst it was noted that the Local Authority was still within the 'template and 2 year renewal period' approach it was confirmed that no alterations to the purpose were being undertaken, but that NHS Digital were taking the opportunity to reconfirm processing / storage locations, ensuring security was updated and to make explicit the critical care and maternity data (both part of the HES datasets) were included within the template. IGARD noted the update to the agreed LA HES template.</p>

Appendix A: Summary of Open Actions

Date raised	Action	Owner	Updates	Status
20/04/17	IGARD Chair to contact key stakeholder organisations regarding the benefits of uses of data to feed into the IGARD annual report.	IGARD Chair	<p>14/09/17: Ongoing. It was agreed this would be discussed during the educational session.</p> <p>07/12/17: Ongoing. It was agreed to bring the first draft to January's education session.</p> <p>08/02/18: it was agreed the updated draft be brought to the March education session</p> <p>15/02/18: Ongoing.</p>	Open
18/05/17	Garry Coleman to provide information about different arrangements for data storage and backup locations, for consideration of whether the organisations involved would be considered to be processing data.	Garry Coleman	<p>15/06/17: IGARD had been advised by email that a paper about this would be submitted to an upcoming IGARD meeting.</p> <p>22/06/17: It was anticipated that this would be discussed at the 6 July 2017 IGARD meeting. IGARD asked for some information to be circulated by email prior to the meeting in order to inform members who would not be present at that particular meeting.</p> <p>27/07/17: An email had been circulated requesting further information from IGARD members.</p> <p>03/08/17: Two IGARD members had responded by email and the action remained ongoing.</p> <p>10/08/17: It was anticipated that a paper on this would be brought to IGARD within the following two weeks.</p> <p>24/08/17: The paper was in the process of being updated based on recently published ICO guidance.</p>	Open

			<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> <p>15/02/18: Ongoing</p>	
20/07/17	Garry Coleman to provide an update within two weeks on how NHS Digital manage the risk involved in CCGs using South Central and West CSU as a data processor in light of data sharing breaches and recent audits.	Garry Coleman	<p>10/08/17: It was anticipated that a paper on this would be brought to IGARD within the following two weeks.</p> <p>24/08/17: IGARD received a verbal update on the work that had taken place following both audits and verbal assurances that NHS Digital were content with the level of risk involved in this organisation continuing to act as a data processor. IGARD welcomed this update and requested written confirmation.</p> <p>31/08/17: IGARD were notified that the requested written confirmation should be provided within one day.</p>	Open

			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. 15/02/18: Ongoing	
20/07/17	Garry Coleman to categorise different standard lengths of indicative data retention periods for general research and clinical trials, with appropriate justification.	Garry Coleman	15/02/18: Ongoing	Open
31/08/17	Garry Coleman to report back on how cancer registration data was previously described as pseudonymised PDS data within older versions of applications, and present to a future education session on changes to how Medical Research Information Service (MRIS) reports are now shown within applications.	Garry Coleman	15/02/18: Ongoing	Open
19/10/17	Stuart Richardson to provide a briefing on the Temporary National Repository infrastructure.	Stuart Richardson	16/11/17: Stuart Richardson noted discussions were ongoing. 15/02/18: Ongoing.	Open
02/11/17	NHS Digital to consider the responses provided by an applicant (Imperial College London NIC-27085) in relation to the language and terminology used in patient information materials.	Louise Dunn	15/02/18: Ongoing.	Open
07/12/17	Dickie Langley to provide a briefing note on NHS Digital's due diligence policy and process	Garry Coleman	08/02/18: It was agreed that the action owner be changed from Dickie Langley to Garry Coleman. 15/02/18: 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	15/02/18: Ongoing.	Open
21/12/17	NHS Digital / IGARD to discuss at a future meeting the issue of consistency across applications presented.	IGARD Chair / Garry Coleman	15/02/18: Ongoing.	Open
25/01/18	Arjun Dhillon, Deputy Caldicott Guardian, was tasked to check with NHS Digital whether templates which had not been approved by IGARD but where NHS Digital had taken the decision to disseminate data would come back to IGARD for consideration or was the template now class as an approved template by NHS Digital	Arjun Dhillon	01/02/18: Arjun Dhillon noted that a template not recommended for approval by IGARD should be flagged on CRM and would speak with the Director Data Dissemination if such templates could be flagged as 'not recommended by IGARD'. 15/02/18: Ongoing,	Open

Appendix B: Out of committee report

Independent Group Advising on Releases of Data (IGARD): Out of committee report 09/02/18

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

NIC reference	Applicant	IGARD meeting date	Recommendation conditions as set at IGARD meeting	IGARD minutes stated that conditions should be agreed by:	Conditions agreed as being met in the updated application by:	Notes of out of committee review (inc. any changes)
NIC-154978	The Christie NHS Foundation Trust	07/12/17	<ul style="list-style-type: none">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.Clarification within Section 5 of the application with regard to why data is sourced locally rather than nationally.	IGARD Quorum	IGARD Quorum	N/A
NIC-149923	Public Health England	18/01/18	<ul style="list-style-type: none">Clarifying in section five of the application that small numbers will be suppressed before inclusion in the Microsoft Excel spreadsheet	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