

Independent Group Advising on the Release of Data (IGARD)

Minutes of meeting held 8 February 2018

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

In attendance: Dave Cronin, Arjun Dhillon, Jen Donald, Dan Goodwin (observer), Matilda Koroveshi (observer), Dickie Langley, Victoria May, Trish Thistlewood-Thomson (observer), Kimberley Watson, Vicki Williams.

Apologies: Sarah Baalham, Joanne Bailey, Anomika Bedi.

1	<p>Welcome and introduction</p> <p>The Chair welcomed Trish Thistlewood-Thomson, Dan Goodwin & Matilda Koroveshi to the meeting as observers.</p> <p>Declaration of interests</p> <p>Jon Fistein noted his professional links to University of Cambridge as a current employee (NIC-38314-C3P0Z) but noted no specific connection with the application or staff involved.</p> <p>Review of previous minutes and actions</p> <p>The minutes of the 1 February 2018 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>National Centre for Social Research (NatCen): MR579a - Research on Health and Ageing using English Longitudinal Study of Ageing (ELSA) data linked to NHS Digital data (Presenter: Jen Donald) NIC-311182-N0L1Y</u></p> <p>Application: This was a renewal and amendment Medical Research Information Service (MRIS) study application to continue to receive identifiable Hospital Episode Statistics (HES), cancer and mortality data to link to the ELSA study survey data. The amendment is to permit NatCen to onward share linked data in pseudonymised format with their collaborators within the ELSA research team, specifically the Institute of Fiscal Studies and University College London.</p> <p>IGARD were informed that the benefits for this application had been included in just one section and that at renewal further detail would be included in yielded benefits.</p> <p>Discussion: IGARD discussed the history of this application to its predecessor DAAG and the previous extensions given.</p> <p>IGARD queried the different waves outlined in the application and which consent materials had been used for each cohort, and queried if the same people were being consented each time. NHS Digital noted that the applicant was keeping numbers within the cohort consistent and that any new members to the cohort received the most up to date consent materials plus the applicant requested a download of their historical data from NHS Digital. IGARD asked that a special condition be included to ensure that the most recent patient information leaflet is sent to the participant cohort and that the cohort are given one month from the date the leaflet is sent to reply as to whether they wish to opt out of the study and before data can flow.</p> <p>IGARD queried the role of University of East Anglia and University of Manchester as outlined in supporting document 8 (contract between Economic & Social Research Council and University</p>

College London) provided and that it be explicit in section 5 of the application that the two universities will not receive data under this application.

IGARD noted that section five of the application would not be easily understood by a lay audience and suggested that the applicant endeavour to provide a clearer explanation of the Waves, using clearer language that could be understood by the general public when published as part of the data release register. IGARD also suggested that a reference to pseudonymised data flow within section 5 of the application be corrected. IGARD noted that a typo within supporting document 11 be corrected from customers to customs.

IGARD noted NHS Digital's suggestion and agreed that the renewal application would be expected to provide further evidence of the yielded benefits achieved for health and social care from their projects. IGARD also noted that a data flow diagram which clearly showed the flows to and from NHS Digital, legal basis for each flow and the full history of the flows (where appropriate) should be provided at renewal.

IGARD queried if the applicant's fair processing notice had been published and NHS Digital confirmed that it had not and that supporting document 7 provided would be sent to the participant cohort shortly. IGARD noted 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.

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

Outcome: recommendation to approve subject to the following conditions:

- Clarification within section 5 of the application that University of Manchester and University of East Anglia will not receive data under this application.
- A special condition be added to the application that the patient information leaflet (SD7) will be sent to the participant cohort and they will be given one month from the date sent to reply before data can flow.

The following amendments were requested:

- Providing a clearer explanation of the Waves within section 5 of the application.
- A typo within SD11 be updated to correctly reference customs not customers.
- To correct a reference to pseudonymised data within Section 5 of the application.
- A clear statement should be included in the application summary that NHS Digital have checked the privacy notice against NHS Digital's nine minimum criteria (to be known as NHS Digital's fair processing criteria) and have assured themselves that it meets current fair processing criteria.

The following advice was given:

- IGARD suggested that applicant update their DPA registration to more clearly state that data is processed about patients or healthcare users.
- IGARD advised when the application returns to IGARD for renewal, the applicant should provide a data flow diagram clarifying the flows to and from NHS Digital including legal basis and to clearly identify the full history of the flows, where appropriate.

It was agreed the conditions be approved OOC by the IGARD Chair

	IGARD noted that on renewal, IGARD would expect to see further information with regard to yielded benefits.
2.2	<p><u>Institute for Fiscal Studies (IFS): MR1404 - Research on Health and Ageing using English Longitudinal Study of Ageing (ELSA) data linked to NHS Digital data (Presenter: Jen Donald) NIC-32854-Y8P8B</u></p> <p>Application: This was a new application to receive pseudonymised Hospital Episode Statistics (HES), cancer and mortality data for work in the ELSA study from the National Centre for Social Research (NatCen). The study, since 2002, has tracked over 10,000 people aged 50 and over, with participants invited to take part in interviews every two years collecting information about their lives, biometric data, health, finances, relationships and interests to build a detailed picture and understand complex interrelationships between these factors.</p> <p>IGARD were informed that this was a first of type data sharing model and also noted that following discussion with DARS IG it was not clear which part of the Health & Social Care Act should apply for the legal basis to flow data.</p> <p>Discussion: IGARD discussed the history of this application to its predecessor DAAG and the previous extensions given.</p> <p>IGARD queried the different waves outlined in the application and which consent materials had been used for each cohort and queried if the same people were being consented each time. NHS Digital noted that the applicant was keeping numbers within the cohort consistent and that any new members to the cohort received the most up to date consent materials plus the applicant requested a download of their historical data from NHS Digital. IGARD asked that a special condition be included to ensure that the most recent patient information leaflet is sent to the participant cohort and that the cohort are given one month from the date the leaflet is sent to reply as to whether they wish to opt out of the study and before data can flow.</p> <p>IGARD queried the role of NatCen as sole data controller and it was agreed that since both NatCen and the collaborators made decisions it was suggested that IFS were joint data controllers along with NatCen and that the application be updated to reflect.</p> <p>IGARD suggested that the applicant work with DARS IG to ensure the correct legal basis for dissemination of data is listed within the application and before any data can flow.</p> <p>IGARD queried the information contained within the data minimisation table and it was agreed that the “identifiable” additional wording contained within section 3 should be removed.</p> <p>IGARD noted NHS Digital’s suggestion and agreed that the renewal application would be expected to provide further evidence of the yielded benefits achieved for health and social care from their projects. IGARD also noted that a data flow diagram which clearly showed the flows to and from NHS Digital, legal basis for each flow and the full history of the flows (where appropriate) should be provided at renewal.</p> <p>IGARD noted that section five of the application would not be easily understood by a lay audience and suggested that the applicant endeavour to provide a clearer explanation of the Waves, using clearer language that could be understood by the general public when published as part of the data release register.</p> <p>Outcome: recommendation to approve subject to the following conditions:</p> <ul style="list-style-type: none"> • The applicant should work with DARS IG to ensure the correct legal basis for dissemination is listed before data can flow. • Confirmation that the Institute of Fiscal Studies and National Centre for Social Research are shown as joint Data Controllers.

	<ul style="list-style-type: none"> • Removing current data minimisation identifiable wording within section 3 of the application. • A special condition be added to the application that the patient information leaflet (SD7) will be sent to the participant cohort and they will be given one month from the date sent to reply before data can flow. <p>The following amendments were requested:</p> <ul style="list-style-type: none"> • Providing a clearer explanation of the Waves within section 5 of the application. <p>The following advice was given:</p> <ul style="list-style-type: none"> • IGARD advised when the application returns to IGARD for renewal, the applicant should provide a data flow diagram clarifying the flows to and from NHS Digital including legal basis and to clearly identify the full history of the flows, where appropriate <p>It was agreed that the conditions be approved OOC by the IGARD Chair.</p> <p>IGARD noted that on renewal, IGARD would expect to see further information with regard to yielded benefits.</p>
2.3	<p><u>University College London (UCL): Research on Health and Ageing using English Longitudinal Study of Ageing (ELSA) (Presenter: Jen Donald) NIC-30493-Y0C0K</u></p> <p>Application: This was a new application to receive pseudonymised Hospital Episode Statistics (HES), cancer and mortality data for work in the ELSA study from the National Centre for Social Research (NatCen). The study, since 2002, has tracked over 10,000 people aged 50 and over, with participants invited to take part in interviews every two years collecting information about their lives, biometric data, health, finances, relationships and interests to build a detailed picture and understand complex interrelationships between these factors.</p> <p>IGARD were informed that this was a first of type data sharing model and also noted that following discussion with DARS IG it was not clear which part of the Health & Social Care Act should apply for the legal basis to flow data.</p> <p>Discussion: IGARD discussed the history of this application to its predecessor DAAG and the previous extensions given.</p> <p>IGARD queried the different waves outlined in the application and which consent materials had been used for each cohort and queried if the same people were being consented each time. NHS Digital noted that the applicant was keeping numbers within the cohort consistent and that any new members to the cohort received the most up to date consent materials plus the applicant requested a download of their historical data from NHS Digital. IGARD asked that a special condition be included to ensure that the most recent patient information leaflet is sent to the participant cohort and that the cohort are given one month from the date the leaflet is sent to reply as to whether they wish to opt out of the study and before data can flow.</p> <p>IGARD queried the role of NatCen as sole data controller and it was agreed that since both NatCen and the collaborators made decisions it was suggested that UCL were joint data controllers along with NatCen and that the application be updated to reflect.</p> <p>IGARD suggested that the applicant work with DARS IG to ensure the correct legal basis for dissemination of data is listed within the application and before any data can flow.</p> <p>IGARD queried the data minimisation table and it was agreed that the identifiable wording contained within section 3 should be removed. IGARD also queried reference to 'death' as a health outcome and suggested that this be clarified within section 5 of the application.</p>

	<p>IGARD noted that section five of the application would not be easily understood by a lay audience and suggested that the applicant endeavour to provide a clearer explanation of the Waves, using clearer language that could be understood by the general public when published as part of the data release register.</p> <p>Outcome: recommendation to approve subject to the following conditions:</p> <ul style="list-style-type: none"> • The applicant should work with DARS IG to ensure the correct legal basis for dissemination is listed before data can flow. • Confirmation that University College London and National Centre for Social Research are shown as joint Data Controllers. • Removing current data minimisation identifiable wording within section 3 of the application. • A special condition be added to the application that the patient information leaflet (SD7) will be sent to the participant cohort and they will be given one month from the date sent to reply before data can flow. <p>The following amendments were requested:</p> <ul style="list-style-type: none"> • Providing a clearer explanation of the Waves within section 5 of the application. • To clarify 'death' as a health outcome within section 5 of the application. <p>The following advice was given:</p> <ul style="list-style-type: none"> • IGARD advised when the application returns to IGARD for renewal, the applicant should provide a data flow diagram clarifying the flows to and from NHS Digital including legal basis and to clearly identify the full history of the flows, where appropriate <p>It was agreed that the conditions be approved OOC by the IGARD Chair</p>
<p>2.4</p>	<p><u>Institute of Cancer Research: MR465 - National Cohort study of mortality and cancer incidence in patients with cytogenetic and paediatric endocrine disorders (Presenter: Dave Cronin) NIC-147749-3SSRF</u></p> <p>Application: This was a renewal and extension application to permit the retention, reuse and receipt of further Personal Demographics data, Cancer Registration data and Office for National Statistics (ONS) data. For over 20 years the Institute has been conducting a national cohort study in Britain of cancer and cause specific mortality risks in long follow up of patients with cytogenetic disorders and paediatric endocrine disorders.</p> <p>IGARD were informed that the applicant had been working with NHS Digital about their fair processing notice but that it had not yet been published because the applicant was awaiting feedback from IGARD.</p> <p>Discussion: IGARD welcomed the study and noted the importance of the research.</p> <p>IGARD noted that they had tried to access the applicant's fair processing notice on their website but were unable and suggested that the applicant review their fair processing against the ICO's Privacy Notice Code of Practice to ensure it meets best practice standards and publish their privacy notice as soon as possible. IGARD also noted 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) and suggested the fair processing information be published before data can flow, the data controller should be clearly identified within the privacy notice, the level and type of data be specific, the purpose of processing be clearly</p>

	<p>explained, be clear who they are sharing data with for each study with a general overarching data sharing statement and the privacy notice be written in plain English</p> <p>IGARD noted that it was not clear within the application which original studies, projects and cohorts were being referred to within the application and that because this was a longitudinal study it was imperative to ensure the history and evidence were clear. NHS Digital noted that previously the applicant had been advised to merge the 4 original studies outlined into one application, however IGARD noted that section five did not adequately describe this, and suggested that the applicant endeavour to provide a clear history of the study from its inception to the present day, a clearer description of the original cohort including cohort numbers, and how the original and subsequent s251 support relate to the application, using clearer language that could be understood by the general public when published as part of the data release register.</p> <p>IGARD noted that Research Ethics Committee (REC) would be reviewed annually and a query was raised with regard REC approval for this study and that the documentation provided had expired in 2017 and that a copy of the most recent REC approval should be provided with a clear explanation of who is accessing the data.</p> <p>IGARD noted that the applicant's DSA with NHS Digital had expired and that NHS Digital should progress as per due process.</p> <p>Outcome: Not recommended for approval.</p> <ul style="list-style-type: none"> • Section 5b of the application should be updated to be explicit about who is accessing data and that these be clearly listed under Approved Researcher. • Confirmation that Ethics approval was still valid and to provide a copy of the most recent REC letter. • A clearer explanation of the history of the study from its inception to present day, including a clear description of how the original cohort and approvals relate to this application. • A clear statement should be included in the application summary that NHS Digital have checked the privacy notice against NHS Digital's nine minimum criteria (to be known as NHS Digital's fair processing criteria) and have assured themselves that it meets current fair processing criteria. <p>The following advice was given:</p> <ul style="list-style-type: none"> • IGARD advised the applicant should review their fair processing against the ICO's Privacy Notices Code of Practice to ensure it reflects best practice standards, and in the interests of transparency, update their privacy notice as soon as possible. <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>
2.5	<p><u>University of Oxford: MR1447 - Long-term follow-up of Asymptomatic Carotid Surgery Trial (ACST-1) (Presenter: Jen Donald) NIC-78397-Z1F1Q</u></p> <p>Application: This was an application requesting Office for National Statistics (ONS) and National Dementia and Antipsychotic Prescribing (DAP) data for a cohort study, and to continue to retain and process Hospital Episode Statistics (HES), Mental Health and Demographics (date of death) data. The ACST-1 Trial was a randomised trial which recruited</p>

	<p>over 3000 patients between 1993 and 2003 with the aim to find out whether carotid surgery (endarterectomy) and best medical treatment prevented more strokes compared with the best medical treatment alone in patients with carotid stenosis. The follow up of the cohort involved in the original trial aims to assess the effect of carotid surgery on long term dementia risk and assess the long-term effect of carotid surgery on strokes.</p> <p>IGARD were informed that advice had been given to the applicant about their fair processing notice and adding mental health data sets and more information with regard to DAP.</p> <p>Discussion: IGARD suggested that the applicant's fair processing notice be updated to reference Mental Health datasets and DAP and that the privacy notice be easily accessible to the public. IGARD noted 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>IGARD noted the study protocol and collaboration notice and queried reference to the Swedish universities and suggested that an explicit statement be included in section 5 of the application that data will not be accessed or shared with University Uppsala, University Lund and NHS Scotland along with other 3rd parties.</p> <p>Outcomes: recommendation to approve.</p> <p>The following amendments were requested:</p> <ul style="list-style-type: none"> • Section 5 of the application be explicit that data will not be shared with NHS Scotland, University of Uppsala Sweden, University Lund Sweden along with other 3rd parties. • A clear statement should be included in the application summary that NHS Digital have checked the privacy notice against NHS Digital's nine minimum criteria (to be known as NHS Digital's fair processing criteria) and have assured themselves that it meets current fair processing criteria. <p>The following advice was given:</p> <ul style="list-style-type: none"> • IGARD advised that the applicant should review their website against the ICO's Privacy Notices Code of Practice to ensure it reflect best practice standard, and in the interests of transparency update their privacy notice as soon as possible to ensure that it referenced Mental Health data and Dementia & Antipsychotic Prescribing Audit (DAP) and ensure it was easily accessible to members of the public.
2.6	<p><u>University of Cambridge: Mortality data for OCCAMS cohort (REC10-H0305-1) (Presenter: Victoria May) NIC-38314-C3P0Z</u></p> <p>Application: This was an application for Office for National Statistics (ONS) mortality data for use in the Oesophageal Cancer Clinical and Molecular Stratification (OCCAMS) research study. This application was previously deferred by IGARD on the 21 December 2017 pending evidence on how the planned outputs would be disseminated in a way that would support health and social care benefits and section 5 of the application be explicit that this was a single research project detailing how the research related to other clinical trials in the same space.</p> <p>Discussion: IGARD noted the application had been mostly updated to reflect comments previously raised but noted an error within the 21 December 2017 minutes and it was noted that there was a typo within the 21 December 2017 minutes wording for NIC-38314 University of Cambridge and the paragraph should read:</p> <p><i>IGARD queried the role of Oxford University and it was explained that they were the original storage for the data and that the applicant used them for their study data,</i></p>

	<p><i>however it was confirmed that NHS Digital data would not be stored at Oxford University and associated with the application.</i></p> <p>IGARD noted that the applicant had given further information with regard to the relationship between the other clinical trials and the study, however it was still not clear, and that further information should be included within section 5b of the application to enable a lay reader to clearly understand the content as this text would feature on NHS Digital's data release register.</p> <p>It was noted that no yielded benefits had been included within section 5 of the application and IGARD noted that at renewal they would expect to see further information with regard to benefits and a clear description of yielded benefits.</p> <p>Outcome: recommendation to approve.</p> <p>The following amendments were requested:</p> <ul style="list-style-type: none"> • The relationship between the study and associated trials be clearly explained within section 5b of the application. <p>The following advice was given:</p> <ul style="list-style-type: none"> • IGARD advised when the application returns to IGARD for renewal, IGARD would expect to see further information with regard to benefits and a clearer description of the yielded benefits.
2.7	<p><u>University College London (UCL): MR1b - Health and Development Study - S251 Cohort members (Presenter: Kimberley Watson) NIC-86954-Y0R2N</u></p> <p>Application: This application was linked to application NIC-148100-6RFBK9, with this application being the portion of the cohort who were covered by section 251 support, whereas the other application covered the consented cohort. This application requested Medical Research Information Service (MRIS) data including Cohort Event Notification, Cause of Death report and Cancer Notifiables, and an MRIS List Cleaning Report. The application also requested Hospital Episode Statistics (HES) Admitted Patient Care, Accident & Emergency and Out Patient data.</p> <p>This application was previously deferred by IGARD on 3 August 2017 pending clarification that the applicant's section 251 support and how this was considered to cover the provision of address details; confirmation of the legal basis for the applicant to continue to hold Scottish Registration data; confirmation of whether the study privacy notice meets NHS Digital's nine minimum criteria (to be known as NHS Digital's fair processing criteria) and a number of amendments to the application summary.</p> <p>IGARD were informed that supporting document 17 should not have been provided with the application pack and that a copy of the Microdata Release Panel (MRP) approval been received by NHS Digital but had not been provided for consideration by IGARD.</p> <p>Discussion: IGARD noted the application had been updated to reflect comments previously raised however, IGARD queried if the applicant had a legal basis to hold Scottish data. NHS Digital confirmed that Scottish data and all reference to it had been removed from the application.</p> <p>IGARD requested sight of the MRP extension letter and noted that section 9 of the application be updated to clearly state that approval had been extended to 2022.</p>

	<p>IGARD suggested that since this application was linked to NIC-148100 University College London that the data retention date for this application be updated to reflect that of the linked application.</p> <p>Outcome: recommendation to approve subject to the following condition:</p> <ul style="list-style-type: none"> Clarification that Microdata Release Panel (MRP) approval has been extended to 2022 and providing a copy of the extension MRP approval letter. <p>The following amendments were requested:</p> <ul style="list-style-type: none"> The MRP expiry date should be updated within section 9 of the application. IGARD suggested that the data retention period for the application be updated to correlate with NIC-148100 UCL application previously recommended for approval on 3 August 2017. <p>It was agreed that the condition be approved OOC by the IGARD Chair</p>
<p>2.8</p>	<p><u>The Royal College of Physicians (RCP): FLS-DB CCG linkage (Presenter: Kimberley Watson) NIC-128537-M2P7G</u></p> <p>Application: This was a new application requesting Medical Research Information Service (MRIS) List Cleaning for the purpose of the Fracture Liaison Service Database (FLS-DB), commissioned by the Health Quality Improvement Partnership (HQIP) and managed by RCP. The cohort will be submitted to NHS Digital for a list clean to obtain the GP practice code to enable patient data to be linked to Clinical Commissioning Group (CCG) level reports to enable the CCG to highlight gaps in resourcing for existing Fracture Liaison Services.</p> <p>IGARD were informed that organisations within the application summary had been incorrectly referenced as Data Controllers and confirmed that HQIP were the sole Data Controller for this application.</p> <p>IGARD were also informed that the funding date reference within the application was incorrect and would be updated to 2021.</p> <p>Discussion: IGARD noted that the use of terminology in section of the application was confusing and asked that it be updated to clearly state the relationship between the audits, programmes and database and that the terminology should be consistent throughout the application.</p> <p>IGARD also suggested that reference to 'combined' be replaced with 'linkage' within section 5 of the application and data flow diagram and that terminology be consistent. IGARD emphasised the importance of writing this section in a way that could be understood by the general public as this text would feature on NHS Digital's data release register.</p> <p>IGARD noted that HQIP be listed as the sole Data Controller within the application summary and that the funding date in section 8 should be corrected to 2021, noting that clear evidence should be provided for consideration. IGARD also suggested that a sentence within section 5b be clarified to state this is in reference to the 'CCG code' to enable a lay reader to clearly understand the content.</p> <p>IGARD noted 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>IGARD suggested that HQIP's security assurance information be removed from section 1b 'security assurances for the Data Controller' as it was not relevant to this application.</p>

	<p>Outcome: recommendation to approve subject to the following condition:</p> <ul style="list-style-type: none"> clarifying within section 5 the relationship between the audits, programmes and database and that terminology be consistent throughout the application. <p>The following amendments were requested:</p> <ul style="list-style-type: none"> Reference to 'combined' be replaced with 'linkage' within Section 5 of the application and data flow diagram and that terminology be consistent. An error within the abstract be corrected to clearly state that HQIP were the sole Data Controller. HQIP's security assurance information be removed from section 1b 'security assurances for the Data Controller'. The funding date within section 8 of the application be corrected to 2021. A sentence within section 5b be updated to clearly state this is in reference to the 'CCG code'. A clear statement should be included in the application summary that NHS Digital have checked the privacy notice against NHS Digital's nine minimum criteria (to be known as NHS Digital's fair processing criteria) and have assured themselves that it meets current fair processing criteria. <p>It was agreed the condition would be approved OOC by IGARD Members.</p>
3	<p>AOB – none</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>	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>08/02/18: 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> <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

			08/02/18: 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	08/02/18: 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	08/02/18: 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. 08/02/18: 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	08/02/18: 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	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	08/02/18: 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	08/02/18: 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'.	Open

Appendix B: Out of committee report

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

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-151212-B5Z3R	Barts Health NHS Trust	25/01/18	<ul style="list-style-type: none">In line with NHS Digital's nine minimum criteria, the fair processing information be published before data can flow.	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