

Independent Group Advising on the Release of Data (IGARD)

Minutes of meeting held 5 October 2017

Members: Joanne Bailey, Chris Carrigan (Chair), Kirsty Irvine, Nicola Fear

In attendance: Jen Donald, Louise Dunn, Dickie Langley, Kimberley Watson, Vicki Williams

Apologies: Sarah Baalham, Anomika Bedi, Jon Fistein, Eve Sariyiannidou

1	<p>Declaration of interests</p> <p>No relevant interests were declared</p> <p>Review of previous minutes and actions</p> <p>The minutes of the 28 September 2017 IGARD meeting were reviewed and agreed as an accurate record of the meeting.</p> <p>Action updates were provided (see Appendix A).</p> <p>Out of committee recommendations</p> <p>An out of committee report was provided (see Appendix B).</p>
2.1	<p>Data Applications</p> <p>University of Oxford – a study of cardiovascular events in diabetes (Presenter: Jen Donald) NIC-302994-C2Q2Y</p> <p>Application: This amendment and renewal application for a cohort who had participated in a clinical trial had been previously considered by DAAG on 27 September 2016 and is to continue to receive and process HES data, receive ONS / cancer data previously supplied under NIC-148435-2T54S, to receive HES data before the start of the ASCEND trial and to receive GP practice code data.</p> <p>Discussion: IGARD acknowledged the significance of the long standing trial and the important benefits that could arise from the use of data. IGARD noted that as previously requested by DAAG a clearer justification for the requested data retention period to indicate why this period was required and how this complied with the appropriate legislation should be included in this application and any future applications. IGARD suggested the applicant should commit to contact those with whom they have lost touch, via the GP Practice in order that they receive a copy of the most up to date fair processing notice and current newsletter.</p> <p>There was a discussion on the references to EU Directives 2005/28/EC and 2003/63/EC included in section 8 of the application and that further information should be provided via a copy of the full protocol. A reference in the processing activities should be updated to clarify the use of the term 'source of event'.</p> <p>OUTCOME: Recommendation to approve subject to the following conditions:</p> <ul style="list-style-type: none">• Providing a copy of the full protocol as referenced in the application summary• The applicant commits to an undertaking to make reasonable endeavours to contact members of the cohort with whom they have lost touch with via the GP Practice in order that the cohort members receive a copy of the up to date fair processing notice and current newsletter, including information about how their addresses were obtained

	<p>and how to opt out.</p> <p>The following amendments were requested:</p> <ul style="list-style-type: none"> • IGARD requested that the justification for the requested 15 year data retention period be made clear (as requested by DAAG on the 26 September 2016) with updated reference to the relevant EU guidelines • Section 5 of the processing activities should be updated to clarify the use of source of event <p>It was agreed the above condition would be reviewed out of committee by a quorum of IGARD members.</p>
2.2	<p>Northgate Public Services (UK) Limited – National Joint Registry Annual Extract 2016 (Presenter Louise Dunn) NIC-07289-G8J6C</p> <p>Application: This renewal application is for HES, ONS and PROMS linked data in order to support the work of the National Joint Registry. It was explained that HQIP would act as the data controller for this work but would not themselves receive any data, Northgate Public Services and University Bristol would be data processors, destroying data already held before receiving a refresh of data under this renewal.</p> <p>Discussion: IGARD acknowledged the significance of this work and the benefits and outputs achieved and noted in section 5 of the application summary.</p> <p>IGARD queried the references with regard to data flow from the Isle of Man and Northern Ireland and asked for clarification. IGARD queried the legal basis for the different cohorts included within the application, including those not on the register, and it was suggested that the data flow diagram be updated to clearly identify the data flows in line with section 5.</p> <p>IGARD noted that the data flow diagram and section 5 of the application referred to sub-licencing and asked for clarification that no other storage locations or data processors, other than those referenced in the application, could access the data. Data minimisation was discussed and IGARD asked that the data minimisation table in section 3 be updated to clearly reflect the data flows in section 5 of the application. A query was raised with regard to data destruction and IGARD were informed that a data destruction certificate would be issued for the relevant data, and that no refresh of data or new data would be disseminated under this application until historical data had been destroyed by the applicant.</p> <p>IGARD suggested that Northgate Public Services (UK) Limited update their DPA registration to remove reference to processing data on our patients.</p> <p>Outcome: Recommendation deferred pending:</p> <ul style="list-style-type: none"> • Clarification of references to data flow from the Isle of Man and Northern Ireland • Clarification of the legal basis for data flow for the different cohorts, including those not on the register, and to update the data flow diagram to clearly identify the data flows in line with section 5 of the processing activities • Clearer statement within Section 5 that no other data processor or storage locations can access or share the data, including sub-licencing other than those already noted within the application summary • The data minimisation table at section 3b to be updated to accurately reflect the data flows contained within section 5 of the application summary • The applicant commits to data destruction before any new data can flow • IGARD advised that Northgate Public Services (UK) Limited should update their DPA registration to remove reference to processing data about our patients <p>IGARD advised that the application should return to IGARD within four weeks.</p>

2.3	<p>Wilmington Healthcare (Presenter: Kimberley Watson) NIC-16016-Y9H1D</p> <p>Application: This renewal and extension application is to address the fact that Binley's, NHiS and Wellards have now come together under the one name of Wilmington Healthcare and that Wilmington Healthcare are to become the sole Data Controller and Data Processor for the agreement. IGARD were informed that a data destruction notice had been issued for data held before 2006/07.</p> <p>Discussion: IGARD queried Wilmington Healthcare's customer base and were informed that 23% of their customer base were in the health and social care sector, however IGARD asked for further clarity on their customers to better understand the applicant's purpose and access to data already held and how it benefits health and social care. IGARD noted that the data flow diagram should be updated to accurately reflect the processing activities of section 5 and that a clearer justification, with examples, be given as to why Wilmington Healthcare require 10 years of data.</p> <p>IGARD queried references within the application to Rackspace Data Centre and asked if they should be considered as a data processor. IGARD noted Wilmington Healthcare's advisory board and asked for further clarification, including Terms of Reference for the group if available, as to how the advisory board ensures the benefits and outputs meet the statutory requirements of the Health and Social Care Act 2012</p> <p>IGARD suggested that Wilmington Healthcare update their DPA registration to include reference to patients and healthcare users and remove reference to NHiS Limited. Wilmington Healthcare's website should be updated to reflect the receipt of data from NHS Digital and how they use the data, for transparency purposes.</p> <p>Outcome: Recommendation deferred pending:</p> <ul style="list-style-type: none"> • Further detail with regard to Wilmington Healthcare's customer base to better understand the purpose of and access to data currently held and the benefits to healthcare • Clarification of references to the use of Rackspace Data Centre and whether they should be considered as a data processor • The data flow diagram should be updated to reflect the processing activities of section 5 • Clearer justification as to why Wilmington Healthcare require 10 years of data for certain purposes outlined in section 5 and to clarify in section 5 that they are only processing 5 years of data for the other purposes outlined. • Further clarity around the benefits to health and social care achieved and how the Advisory Board ensure benefits and outputs meet the statutory requirements of the Health and Social Care Act 2012 <p>The following advice was given:</p> <ul style="list-style-type: none"> • IGARD advised that Wilmington Healthcare should update their DPA registration to include patients and healthcare users and remove reference to NHiS Limited • IGARD advised that Wilmington Healthcare should update their website for transparency purposes to reflect the receipt of data from NHS Digital and how they use the data
2.4	<p>Public Health England (PHE) – estimating Hepatitis B (HBV) prevalence in pregnant women (Presenter: Louise Dunn) NIC-111903-G9D0R</p> <p>Application: This was a new application requesting country of birth for a cohort of patients who were tested for Hepatitis B (HBV) during antenatal appointments. IGARD were informed that there was an outstanding query with regard the legal basis.</p>

	<p>Discussion: IGARD noted this was an important study. IGARD requested a briefing paper to provide more information and clearly explain the legal basis for this flow of data from PHE, including any supporting response from PHE's Caldicott Guardian. IGARD discussed the purpose and use of the data and agreed that the application should more clearly explain this, with the explanation detailing how the data requested within this application contributes to and meets the objectives and aims of the programme of work. IGARD noted that screening for Hepatitis B is routinely offered antenatally. IGARD queried reference to the objective of this work being similar to work being undertaken around Hepatitis C and HIV and requested clearer detail in section 5 of the application.</p> <p>IGARD noted that there were a number of duplicate paragraphs within section 5 of the application which should be removed and asked that acronyms be clearly explained.</p> <p>Outcome: Not recommended for approval</p> <ul style="list-style-type: none"> • Providing a briefing paper including relevant supporting documents to clearly explain the legal basis for receipt of the data from PHE, including a response from the PHE Caldicott Guardian • Clearer explanation of how the data requested contributes to the aims and objectives of the programme of work and particularly how the data requested will meet those aims, noting that screening for Hepatitis B is routinely offered antenatally. • Clearer explanation of the work being undertaken around Hepatitis C and HIV outlined in section 5 • Section 5 should be amended to ensure acronyms are clearly explained and to remove duplicate paragraphs
2.5	<p>University College London – Acute day units as crisis alternatives to residential care (Presenter: Kimberley Watson) NIC-93084-W4B4L</p> <p>Application: This was a new application for pseudonymised HES Admitted Patient Care, Accident and Emergency and Mental Health minimum dataset. IGARD were advised that NHS Digital advised the applicant to remove the opt out wording currently on their website.</p> <p>Discussion: IGARD noted that discussions had taken place between NHS Digital and the applicant with regard to the work undertaken to explore technical solutions to minimise the flow of data from NHS Digital to the application and the then subsequent deletion of data records by the applicant, however this should be clearly reflected in the data flow diagram provided and with a clearer explanation in section 5 processing activities. IGARD noted that any acronyms in section 5 of the application be clarified, including NHIR and that a clarification be given of the term social variables.</p> <p>IGARD suggested that University College London update their DPA registration to include reference to patients and healthcare users. IGARD noted that opt out wording on their website be removed as advised by NHS Digital and it was agreed that the applicant should be advised to review and make appropriate fair processing information available through this website.</p> <p>IGARD queried the special conditions within section 6 of the application and queried the contradictions within the bulleted points and asked the presenter to clarify the standard wording.</p> <p>Outcome: Recommendation to approve The following amendments were requested:</p> <ul style="list-style-type: none"> • The data flow diagram should be updated to reflect the processing activities of section 5 with a clearer explanation in section 5 that NHS Digital have undertaken work to explore the technical solutions to minimise the flow data to University College London and subsequent deletion of data records • Clarification in section 5 of the term 'social variables'

	<ul style="list-style-type: none"> The special conditions to be clarified with regard to the suppression of data due to a contradiction within the bulleted points. <p>The following advice was given:</p> <ul style="list-style-type: none"> IGARD advised that University College London should update their DPA registration to include patients and healthcare users IGARD advised that reference to the acronym 'NHIR' in Section should be spelled out in full. IGARD advised that opt out wording on their website should be removed as advised by the presenter. IGARD advised the applicant should review their website against the ICO's Privacy Notices Code of Practice to ensure they reflect best practice standards. The EU General Data Protection Regulation recognises that pseudonymised data should be considered as information on an identifiable natural person and also places a greater focus on the need to demonstrate transparency of data processing in the information provided to data subjects.
3	AOB
3.1	Group of 3 CCGs (GA03b-AMD-GEM) NIC-47167-H3M4V NHS South Warwickshire CCG; NIC-82378-M2B6C NHS Coventry and Rugby CCG; and NIC-82394-W7G7J NHS Warwickshire North CCG presented to IGARD on the 29 June had used incorrect reference numbers, so this application should be been referred to as: NIC-120037-G1Z7C NHS Coventry and Rugby CCG; NIC-120057-H3L3B NHS South Warwickshire CCG; and NIC-120064-Z5S8S NHS Warwickshire North CCG
3.2	Sean Walsh, Director of Operations and Assurance Services and Senior Information Risk Owner, attended IGARD to discuss NHS Digital's risk based approach paper. It was agreed that the finalised paper be disseminated to IGARD for comment.

Appendix A: Summary of Open Actions

Date raised	Action	Owner	Updates	Status
20/04/17	IGARD Chair to contact key stakeholder organisations regarding the benefits of uses of data to feed into the IGARD annual report.	IGARD Chair	14/09/17: Ongoing. It was agreed this would be discussed during the educational session. 05/10/17: It was agreed that the first draft would be discussed at December's education session.	Open
27/04/17	IGARD Chair to contact the NHS Digital Caldicott Guardian regarding GPs' data controller responsibilities for fair processing around risk stratification.	Arjun Dhillon	18/05/17: Ongoing. It was agreed this would be discussed with the Deputy Caldicott Guardian. 22/06/17: Ongoing; it was suggested the Deputy Caldicott Guardian should discuss this in more detail with Joanne Bailey. 29/06/17: It was noted this action would be taken forward by the Deputy Caldicott Guardian, and the action owner was updated. 20/07/17: It was agreed the Deputy Caldicott Guardian would provide an update on the current status of this. 10/08/17: An update from NHS England had been requested. 05/10/17: Ongoing.	Open
18/05/17	Garry Coleman to provide information about different arrangements for data storage and backup locations, for consideration of whether the organisations involved would be considered to be processing data.	Garry Coleman	15/06/17: IGARD had been advised by email that a paper about this would be submitted to an upcoming IGARD meeting. 22/06/17: It was anticipated that this would be discussed at the 6 July 2017 IGARD meeting. IGARD asked for some information to be circulated by email prior to the meeting in order to inform members who would not be present at that particular meeting. 27/07/17: An email had been circulated requesting further information from IGARD members. 03/08/17: Two IGARD members had responded by email and the action remained ongoing. 10/08/17: It was anticipated that a paper on this would be brought to IGARD within the following two weeks. 24/08/17: The paper was in the process of being updated based on recently published ICO guidance.	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>05/10/17: ongoing</p>	
15/06/17	Data Services for Commissioners to work with NHS Digital IG staff to check the privacy notices for these 4 CCGs (South Kent Coast CCG; Ashford CCG; Thanet CCG; Canterbury & Coastal CCG) as part of the ongoing training, and provide a copy of the outcome of this check to IGARD for information.	Stuart Richardson	<p>29/06/17: Ongoing. It was suggested it would be helpful to discuss this at an upcoming educational session.</p> <p>05/10/17: It was confirmed this would be discussed at the October education session</p>	Open
06/07/17	Stuart Richardson to ensure that privacy notice checklists are provided for all DSfC applications for a trial period of three months from 13 July IGARD meeting.	Stuart Richardson	05/10/17: It was confirmed this would be discussed at the October education session	Open
20/07/17	Garry Coleman to provide an update within two weeks on how NHS Digital manage the risk involved in CCGs using South Central and West CSU as a data processor in light of data sharing breaches and recent audits.	Garry Coleman	<p>10/08/17: It was anticipated that a paper on this would be brought to IGARD within the following two weeks.</p> <p>24/08/17: IGARD received a verbal update on the work that had taken place following both audits and verbal assurances that NHS Digital were content with the level of risk involved in this organisation continuing to act as a data processor. IGARD welcomed this update and requested written confirmation.</p> <p>31/08/17: IGARD were notified that the requested written confirmation should be provided within one day.</p> <p>14/09/17: An email response had been circulated on 31 August, and IGARD noted that they were awaiting receipt of the post-audit report.</p> <p>05/10/17: ongoing</p>	Open
20/07/17	Garry Coleman to categorise different standard lengths of indicative data retention periods for general research and clinical trials, with appropriate	Garry Coleman	05/10/17: ongoing	Open

	justification.			
27/07/17	Arjun Dhillon to provide information for IGARD about the robustness of different funding processes and how this might affect the level of scrutiny applied to or information included in applications provided to IGARD.	Arjun Dhillon	10/08/17: Ongoing. It was thought that this action might be addressed within the context of a forthcoming paper on a risk-based approach to application, which it was anticipated would be brought to IGARD for discussion soon. 24/08/17: Ongoing, pending wider work on a risk-based approach. 05/10/17: Ongoing	Open
31/08/17	Garry Coleman to report back on how cancer registration data was previously described as pseudonymised PDS data within older versions of applications, and present to a future education session on changes to how MRIS reports are now shown within applications.	Garry Coleman	05/10/17: Ongoing	Open
14/09/17	Stuart Richardson to provide IGARD with a copy of the Directions relating to the Emergency Care Data Set (ECDS) with confirmation of the date this was approved by the NHS Digital Board.	Stuart Richardson	21/09/17: The Directions had been provided by email. IGARD members were asked to provide any comments by email, ahead of potentially closing the action at the next meeting. It was noted that confirmation would still be required of NHS Digital Board approval. 05/10/17: Ongoing	Open
14/09/17	Stuart Richardson to provide IGARD with a copy of the Directions relating to Social Care Data with confirmation of the date this was approved by the NHS Digital Board.	Stuart Richardson	21/09/17: The Directions had been provided by email. IGARD members were asked to provide any comments by email, ahead of potentially closing the action at the next meeting. It was noted that confirmation would still be required of NHS Digital Board approval. 05/10/17: Ongoing	Open
21/09/17	Dickie Langley to provide a briefing paper (with relevant supporting documents) regarding the legal basis for receipt of data from Department for Education, and for this to be reviewed by the IG Advisor prior to circulation to IGARD.	Dickie Langley	05/10/17: Ongoing	Open
21/09/17	Dickie Langley to provide IGARD with a copy of the new standard DSA terms and conditions.	Dickie Langley	05/10/17: Ongoing	Open

Appendix B: Out of committee report (as of 29/09/17)

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

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-389320	University of Nottingham	14/09/17	<ul style="list-style-type: none">Confirmation of whether the applicant will be undertaking list cleaning to ensure they have up to date address details for all participants being sent a newsletter, or what other steps have been taken to ensure address details are up to date. If list cleaning has not been undertaken then the applicant should commit to carry this out within three months. If list cleaning is undertaken, information about this should be included in the upcoming newsletter and on a study website	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