

Independent Group Advising on the Release of Data (IGARD)

Minutes of meeting held 19 April 2018

Members: Joanne Bailey (by telephone), Chris Carrigan (Chair), Kirsty Irvine, Eve Sariyiannidou.

In attendance: Jane Cleave, Dickie Langley, Stuart Richardson, Aaron White, Vicki Williams.

Apologies: Sarah Baalham, Anomika Bedi, Nicola Fear, Jon Fistein,

1	<p>Declaration of interests</p> <p>There were no declarations of interest.</p> <p>Review of previous minutes and actions</p> <p>The minutes of the 12 April 2018 IGARD meeting were reviewed 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>University of Birmingham: supporting health services research activity in the School of Health & Population Sciences (Presenter: Dickie Langley) NIC-02544-M7M7G</u></p> <p>Application: This was an amendment application to request additional pseudonymised Hospital Episodes Statistics (HES) data to allow the two projects to complete by 2019. In addition, the HES Admitted Patient Care (APC) data is to be re-supplied along with a flag indicating whether a patient died within 30 days of the episode. Project 1 is to deliver a programme of applied health services research under the Collaboration for Leadership in Applied Health Research Care Programme (CLAHRC). Project 2 will evaluate the roll of the Government's seven-day service initiative.</p> <p>NHS Digital noted this was a NIHR funded application.</p> <p>Discussion: IGARD noted this was a NIHR funded application and noted the clarity contained in the benefits section, albeit lengthy.</p> <p>IGARD queried if the British Heart Foundation should be considered as a Data Controller and noted that the contract provided between the University of Birmingham and British Heart Foundation contained a number of clauses including the British Heart Foundation having involvement in the research and having involvement in assessing the processing of data which indicated the British Heart Foundation may be considered as a Data Controller. It was noted that it was not clear what the British Heart Foundation's role or relationship was with the applicant and that this should be clearly described within section 5a along with its contractual ability to be involved in the performance of research and influence research outputs. IGARD also asked that it be explicitly stated that the British Heart Foundation would not have access to data supplied by NHS Digital. IGARD also noted that the contract between the applicant and the British Heart Foundation appeared to still be in force since the funding was still in place and through to 2019.</p> <p>IGARD queried if data would be linked to any other data and that it be explicit stated within section 5b of the application that the applicant will not link data in this application except those permitted under this application / agreement. IGARD also queried the re-supply of HES APC data and mortality flagging. NHS Digital noted the applicant did not have an indication of the</p>

<p>data mortality flag on historically held HES data previously supplied and IGARD suggested that a clearer explanation be given within section 5 that the data mortality flag was a recent inclusion within the HES dataset with a clear explanation stating why the whole HES data set was being re-supplied, along with confirmation if a certification of data destruction was required for previously held data.</p> <p>IGARD noted that the abstract gave a general description of project 1, however it was suggested that this be updated to clearly reflect that project 1 was specifically about maternity and child health. It was also noted that a clearer justification for the number of years requested for project 1 be provided, noting that a clear justification had been given for the number of years requested for project 2.</p> <p>IGARD also suggested that University of Birmingham update their DPA registration to clearly state that data is processed about patients or health care users and as previously advised and noted that the DPA registration expiry date should be updated as it appeared that the Data Controller DPA had expired however the Data Processor DPA for the same organisation was current.</p> <p>It was noted that historic phrasing was being used in section 4, Fair Processing and may be out of date by the time the applicant's sign their contract / DSA with NHS Digital. It was suggested that new standard wording for use with pseudonymised data be used: "All data required by the Data Controller under this application is pseudonymised and therefore is considered as personal data under the General Data Protection Regulation (GDPR). All Data Controllers are expected to provide a privacy notice that is compliant with the GDPR notice requirements." IGARD also suggested that the ICO web link in section 4 be deleted and the special condition referencing fair processing notices be removed, since it was not relevant to this application.</p> <p>IGARD noted that language throughout section 5 of the application should be consistent to note that the project started in 2014 rather than was due to start in 2014.</p> <p>Outcome: recommendation deferred pending:</p> <ul style="list-style-type: none"> • The involvement of the British Heart Foundation (BHF) to clearly describe in section 5a including its role and relationship with the applicant, its access to the data supplied by NHS Digital, its involvement in the performance of the research and its influence on the research outputs. • Update the wording in section 5 to reflect that the project started in 2014 rather than was due to start in 2014. • Confirmation within section 5b of the application that the applicant will not link the data further and the only data linkages are those permitted under this application / Data Sharing Agreement. • Providing a clear justification for the number of years of data requested for project 1 (as has been done for project 2). • To update the abstract and section 5a to clearly state why the whole data set is being re-supplied and confirm if a Certificate of Data Destruction is required for previously held data. • To update section 5 to explain the data mortality flag. • To update the abstract to clearly state that project 1 is specifically about maternity and child health. • The Fair Processing section to be amended to include the new standard wording: "All data required by the Data Controller under this application is pseudonymised and

	<p>therefore is considered as personal data under the General Data Protection Regulation (GDPR). All Data Controllers are expected to provide a privacy notice that is compliant with the GDPR notice requirements.”</p> <ul style="list-style-type: none"> • To remove the special condition about Fair Processing, since this has been superseded by updated wording in the Fair Processing section. • To remove the ICO web link in the Fair Processing section. • The applicant should update their DPA registration to more clearly state that data is processed about patients or healthcare users and ensure the DPA expiry date is up to date.
2.2	<p><u>Group of 8 CCG's¹: to receive Secondary Use Service (SUS) and Local Provider Flows for the purpose of commissioning to support the Sustainable Transformation Footprint (STP) (Presenter: Stuart Richardson) GA04-AMD-SC</u></p> <p>Application: This was an application to receive pseudonymised sensitive SUS and Local Provider Flows data to provide intelligence to support commissioning of health services. The application had previously been presented to IGARD on the 3 August 2017 and IGARD had recommended for approval subject to the following conditions: further information about NHS Digital's review of Carnall Farrar's security arrangements with clarification why NHS Digital is content for data to flow prior to the Penetration Test taking place; and the CCGs should update their privacy notices in line with NHS Digital's nine criteria.</p> <p>NHS Digital noted that the table of difference provided should be updated to correct the CCG's DPA registration expiry dates.</p> <p>NHS Digital also noted that a Data Sharing Framework Contract expiry date had not been updated for NHS Coastal West Sussex CCG.</p> <p>Discussion: IGARD noted that the DPA registration expiry dates for all CCG's listed in the table of difference should be revisited to ensure that all dates listed were updated. It was also noted that the Data Sharing Framework Contract expiry date for NHS Coastal West Sussex CCG had expired and should be updated to reflect the correct expiry date.</p> <p>IGARD also suggested that Carnall Farrar Limited update their DPA registration to clearly state that data is processed about patients or health care users and as previously advised.</p> <p>IGARD noted that the ISO 27001 certification V1.2 start date for Carnall Farrar Limited was dated January 2016 and queried if the certification expired and suggested that clarification be sought as to whether it was still current.</p> <p>IGARD noted that the abstract wording with regard to fair processing was incorrect and should be updated to reflect current standard wording about privacy notices.</p> <p>IGARD noted that previously they had requested further information about NHS Digital's review of Carnall Farrar's security arrangements and clarification that NHS Digital were content for data to flow prior to the penetration testing taking place. IGARD noted a special</p>

¹ NIC-91808-P5Z1F; NIC-91799-G0T9X; NIC-91865-Y2L1H; NIC-91866-V4R5J; NIC-91825-W4M1H; NIC-91827-P6J6X; NIC-91866-V4R5J; NIC-91825-W4M1H; NHS Brighton & Hove CCG; NHS Coastal West Sussex CCG; NHS Crawley CCG; NHS East Surrey CCG; NHS Eastbourne, Hailsham and Seaford CCG; NHS Hastings & Rother CCG; NHS High Weald Lewes Havens CCG; NHS Horsham & Mid-Essex CCG

	<p>condition had been included with regard to penetration testing however noted lack of clarity if the penetration testing had been undertaken by the applicant.</p> <p>Outcome: recommendation to approve</p> <p>The following amendments were requested:</p> <ul style="list-style-type: none"> • The application to be updated to ensure all DPA expiry dates for all CCG's are up to date. • The Data Sharing Framework Contract expiry date for NHS Coastal West Sussex CCG should be updated to reflect the correct expiry date. • To clarify that the ISO 27001 certificate for Carnall Farrar Ltd is still current. • The condition response in the summary to be amended to reflect the updated wording about Fair Processing. <p>The following advice was given:</p> <ul style="list-style-type: none"> • Carnall Farrar Ltd should update their DPA registration to clearly state that data is processed about patients or healthcare users.
2.3	<p><u>NHS Great Yarmouth and Waveney CCG: An amendment for the CCG to move Data Processor from North of England Commissioning Support Unit to Arden and Greater East Midlands Commissioning Support Unit for the purposes of Risk Stratification (Presenter: Stuart Richardson) NIC-185897-R6T5S</u></p> <p>The application was withdrawn by the presenter.</p>
2.4	<p><u>Group of 4 CCG's²: An amendment for 4 CCGs to move Data Processor from North East London Commissioning Support Unit (CSU) to Arden and Greater East Midlands CSU for the purposes of Commissioning (Presenter: Stuart Richardson) GA09a-GEM-AMD</u></p> <p>Application: This was an amendment application for 4 CCG's to move Data Processor from North East London CSU to Arden and Greater East Midlands CSU for the purpose of commissioning and receive pseudonymised Secondary Use Service+ (SUS+) data, Local Provider Flows data, Mental Health Minimum data set, Mental Health Learning Disability data set, Mental Health Services data set, Improving Access to Psychological Therapies, Maternity Services data set, Children & Young People's Health, Community Services data set and Diagnostic Imaging data set.</p> <p>NHS Digital noted that the application was for the purpose of commissioning and there would be a period of 20 days dual running of both Data Processors before the data was destroyed by North East London CSU.</p> <p>Discussion: It was noted that historic phrasing was being used in section 4, Fair Processing and may be out of date by the time the applicant's sign their contract / DSA with NHS Digital. It was suggested that new standard wording for use with pseudonymised data be used: "All data required by the Data Controller under this application is pseudonymised and therefore is considered as personal data under the General Data Protection Regulation (GDPR). All Data Controllers are expected to provide a privacy notice that is compliant with the GDPR notice requirements." IGARD also suggested that the ICO web link in section 4 be deleted and the special condition referencing fair processing notices be removed, since it had been superseded by updated wording in the Fair Processing section.</p>

² NHS North Norfolk CCG - NIC-173542-R1B5F; NHS Norwich CCG - NIC-173530-W8D5F; NHS South Norfolk CCG - NIC-173549-H8J3R; NHS West Norfolk CCG - NIC-173518-N4P7Y

	<p>Outcome: recommendation to approve</p> <p>The following amendments were requested.</p> <ul style="list-style-type: none"> • The Fair Processing section to be amended to include the new standard wording: “All data required by the Data Controller under this application is pseudonymised and therefore is considered as personal data under the General Data Protection Regulation (GDPR). All Data Controllers are expected to provide a privacy notice that is compliant with the GDPR notice requirements.” • To remove the special condition about Fair Processing, since this has been superseded by updated wording in the Fair Processing section. • To remove the ICO web link in the Fair Processing section.
2.5	<p><u>Group of 4 CCG's³: An amendment for 4 CCGs to move Data Processor from North East London Commissioning Support Unit to Arden and Greater East Midlands Commissioning Support Unit for the purposes of Invoice Validation (Presenter: Stuart Richardson) GA09b-GEM-AMD</u></p> <p>Application: This was an amendment application for 4 CCG's to move Data Processor from North East London CSU to Arden and Greater East Midlands CSU for the purpose of invoice validation and receive pseudonymised Secondary Use Service+ (SUS+) data. Invoices are submitted to the CCG so they are able to ensure that the activity claimed for each patient is their responsibility which is done by processing and analysing SUS+ data, which is received into a secure Controlled Environment for Finance (CEfF). The SUS+ data is identifiable at the level of NHS number and the NHS number is only used to confirm the accuracy of backing-data sets and will not be used further.</p> <p>NHS Digital noted that fair processing had not been assessed against NHS Digital's nine minimum criteria for privacy notices.</p> <p>Discussion: IGARD noted that the 4 CCG's fair processing had not been assessed against NHS Digital's nine minimum criteria for privacy notices and therefore did not meet the criteria. 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 the application referenced pseudonymised data and the application should be updated to clearly reflect that this was in fact an application for identifiable data for the purpose of invoice validation and that the applicant is expected to provide a fair processing notice that meets NHS Digital's fair processing criteria. IGARD also suggested that the ICO web link within section 4 be removed since the link was no longer relevant.</p> <p>IGARD offered support in reviewing the draft privacy notices before publication.</p> <p>IGARD suggested that on renewal further measurable benefits in a language that was suitable for a lay reader be provided by the applicants.</p> <p>IGARD noted that Interxion UK was listed as a storage location and stated their view that it would be more appropriate to also list this organisation as an additional data processor. It was acknowledged that there was currently an open action with NHS Digital regarding storage locations and how to reflect their role as data processors.</p>

³ NHS North Norfolk CCG - NIC-173542-R1B5F; NHS Norwich CCG - NIC-173530-W8D5F; NHS South Norfolk CCG - NIC-173549-H8J3R; NHS West Norfolk CCG - NIC-173518-N4P7Y

	<p>Outcome: recommendation to approve subject to the following condition:</p> <ul style="list-style-type: none"> The fair processing notices for the 4 CCG's be reviewed against NHS Digital's nine minimum criteria (to be known as NHS Digital's fair processing criteria) for privacy notices and before data can flow. <p>The following amendments were requested:</p> <ul style="list-style-type: none"> This application request is for personal data and the applicant is expected to provide a fair processing notice that meets NHS Digital's fair processing criteria. Remove the ICO web link in the Fair Processing section. <p>The following advice was given:</p> <ul style="list-style-type: none"> IGARD suggested that on renewal the applicant would be expected to provide further measurable benefits that would be in language suitable for a lay reader. <p>It was agreed the condition would be approved OOC by the IGARD Members</p>
3	<p>Group of 11 CCG's⁴ (Presenter: Stuart Richardson) GA01-NW-STP</p>
3.1	<p>Application: The group application was recommended for approval with one member dissenting on the 15 March 2018 and was a new application to receive pseudonymised data to provide intelligence to support the commissioning of health services. After presentation to IGARD it was noted that NIC-140056-C7W9S NHS Wirral CCG was missing from the application presented to IGARD and should have been a group of 12 CCG's. NHS Digital confirmed that NHS Wirral would be included in the Data Sharing Agreement and data minimisation with no changes to the data periods, datasets or Data Processors.</p> <p>Outcome: IGARD noted the inclusion of NHS Wirral CCG into the group application but noted that NHS Warrington CCG's DPA had expired and the application should be updated.</p>
3.2	<p>National Centre for Social Research – Adult Psychiatric Morbidity Survey (APMS)</p> <p>Garry Coleman, Director Data Dissemination, noted that NIC-159399-K2M6H had been considered by IGARD on the 18th January 2018 when IGARD had been unable to make a recommendation but believed there was an authority to collect the data outlined within the application, but that evidence of the legal basis was not available for IGARD to consider. The Director Data Dissemination noted that IGARD had recognised the importance of the work involved and that NHS Digital may choose to continue to flow the data.</p> <p>The Direction Data Dissemination noted that NHS Digital had now reviewed all documentation available and that they were content that there was a legal basis for the collection of data and on that basis APMS data would continue to flow.</p> <p>IGARD noted that NHS Digital would continue to flow APMS data and were supportive of the work undertaken by NHS Digital and pragmatic approach taken.</p> <p>Action: The Director of Data Dissemination agreed to forward IGARD the documentation relied on by NHS Digital to reach this conclusion.</p>

⁴ NIC-140059-P1J9L - NHS Eastern Cheshire CCG; NIC-140060-F9N0T - NHS Halton CCG; NIC-140062-H3Z0Z - NHS Knowsley CCG; NIC-140065-F8D0Z - NHS Liverpool CCG; NIC-140068-N0H9G - NHS South Cheshire CCG; NIC-140073-W4P9Y - NHS South Sefton CCG; NIC-140074-C5C2Y - NHS Southport & Formby CCG; NIC-140078-H0X3Z - NHS St Helens CCG; NIC-140081-T0L8R - NHS Vale Royal CCG; NIC-140083-S4L3M - NHS Warrington CCG; NIC-140086-B5J9R - NHS West Cheshire CCG

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>01/03/18: the March education session was cancelled, and it was agreed to take the draft annual report to the April education session.</p> <p>05/04/18: to seek clarification from the Chair if stakeholders have been approached and to bring back the draft to the May education session.</p> <p>12/04/18: The Chair noted he was yet to contact external to NHS Digital stakeholders.</p> <p>19/04/18:</p>	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>	Open

			<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>05/04/18: IGARD Secretariat had contacted Garry Colman and were awaiting a response.</p> <p>19/04/18: ongoing</p>	
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	<p>22/02/18: IGARD Secretariat to contact Garry Coleman to suggest presentation at the June education session.</p> <p>05/04/18/18: IGARD Secretariat were awaiting a response.</p> <p>19/04/18: ongoing</p>	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	<p>22/03/18: IGARD Secretariat noted had contacted Louise Dunn and were awaiting a response.</p> <p>05/04/18/18: IGARD Secretariat were awaiting a response.</p> <p>19/04/18: NHS Digital are working with the applicant on their applications currently in the system with regards to the language and terminology used in patient information materials. As with the implementation of GDPR the use of consent for the study will also be reviewed in line with the work being done with all applications in the system.</p> <p>It was agreed that the action can be closed and removed from the action plan</p>	CLOSE
15/03/18	Stuart Richardson to provide a briefing note clarifying the contractual arrangements in place, the structure, enforcement strategy and how the agreements worked together so that the data	Stuart Richardson	<p>05/04/18: A verbal update was provided that individual Data Sharing Framework Contracts (DSFC) were issued yet Data Sharing Agreements were joint Data Controllership and that DSFC's placed exactly the same terms and conditions upon organisations and NHS Digital believe the position to be acceptable. IGARD noted the</p>	Open

	disseminated by NHS Digital would be protected and provide a verbal update to IGARD on the progress of this note by 5 April 2018.		verbal update and asked that a briefing note be provided by NHS Digital confirming the arrangements in place by the end of April 2018. 19/04/18: ongoing	
05/04/18	IGARD to provide detailed feedback to NHS Digital with regard to application NIC-172240-R4R0L University of Oxford	IGARD	12/04/18: the detailed feedback had been circulated to members for final comment before dissemination by 16/04/18 to the DAO via the IGARD Secretariat 19/04/18: IGARD provided detailed feedback to the DAO. It was agreed that the action can be closed and removed from the action plan	CLOSE
12/04/18	IGARD Members to consider the HRA guidance on GDPR published on line IGARD Chair to provide feedback to the Caldicott Guardian	IGARD IGARD Chair	19/04/18: ongoing	Open
19/04/18	National Centre for Social Research – Adult Psychiatric Morbidity Survey (APMS): The Director Data Dissemination agreed to forward IGARD the documentation relied on by NHS Digital to reach this conclusion.	Garry Coleman		Open

Appendix B: Out of committee report

Independent Group Advising on Releases of Data (IGARD): Out of committee report 13/04/18

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-34548-M7R3H	Wilmington Healthcare	22/03/18	<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 published and accessible, and before data can flow.	IGARD Chair	IGARD Chair	N/A
NIC-152414-W3P6Q	University of Bristol	15/02/18	<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.	IGARD Members	Quorum of IGARD Members	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