

Independent Group Advising on the Release of Data (IGARD)

Minutes of meeting held 17 May 2018

Members: Sarah Baalham, Joanne Bailey Kirsty Irvine (Chair), Eve Sariyiannidou

In attendance: Dave Cronin, Arjun Dhillon, Louise Dunn, James Humphries-Hart, Dickie Langley, James Smith (Observer) Aaron White, Vicki Williams.

Apologies: Anomika Bedi, Chris Carrigan, 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 outcomes of the 10 May 2018 IGARD meeting were reviewed and were agreed as an accurate record of that aspect 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>Salford Royal NHS Foundation Trust: Programmes of analysis and service improvement AQuA (Presenter: Dave Cronin) NIC-07141-L2S0B</u></p> <p>Application: This was an application for the Advancing Quality Alliance (AQuA) (hosted by the Trust) to destroy Hospital Episode Statistics (HES) Accident & Emergency (A&E) and HES Outpatient datasets supplied under previous data sharing agreements (DSA) and to extend retention of HES Admitted Patient Care (APC). AQuA supports long term quality improvement programmes across the North West of England to provide longitudinal analysis to identify trends and year on year comparison.</p> <p>NHS Digital noted that the fair processing notice (FPN) section would be updated to include the new FPN wording.</p> <p>Discussion: IGARD noted that historic phrasing was being used in section 4, Fair Processing and may be out of date by the time the applicant's sign their contract / DSA with NHS Digital.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 within a reasonable period after obtaining the personal data, but at the latest within one month."</p> <p>IGARD noted that NHS Digital had included within the abstract the applicant's legal basis under the General Data Protection Regulation (GDPR) Article 6 and 9, however IGARD suggested that a clear justification for each choice indicated should be given in terms of how the specific criteria and additional requirements would be met since the applicant would need to satisfy the relevant tests associated with the legal basis suggested.</p> <p>IGARD noted that the sources of funding in section 8b should be updated to confirm that any funders would not place any restrictions or limitation on the dissemination of outputs from the study.</p> <p>IGARD suggested that confirmation be sought that the individuals accessing the data were substantive employees of the Salford Royal NHS Foundation Trust and that standard wording</p>

	<p>be included in section 5 with regard to access controls to access the data and that only members of the AQUA team would access the data.</p> <p>IGARD noted that a duplicate special condition was included in section 5b and suggested that the special condition in section 6: “All organisations party to this agreement must comply with the Data Sharing Framework Contract requirements, including those regarding the use (and purposes of that use) by “Personnel” (as defined within the Data Sharing Framework Contract i.e. employees, agents and contractors of the Data Recipient who may have access to that data)” be removed.</p> <p>IGARD queried the lack of outputs, a defined process within section 5 along with yielded benefits with examples of patient and public engagement in order to be transparent for the general public when this was published within NHS Digital’s data release register and suggested on renewal further information would be expected to be provided.</p> <p>Outcome: recommendation to approve subject to the following condition:</p> <ul style="list-style-type: none"> • To provide the relevant sections under Article 6 and 9 of GDPR and a clear justification for the choice of each section in terms of how the specific criteria and additional requirements are met. <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 within a reasonable period after obtaining the personal data, but at the latest within one month.” • Confirmation within section 5 of the application that the individuals accessing the data are substantive employees of Salford Royal NHS FT and that only members of the AQUA team will access the data. • To update the source(s) of funding in section 8b and clarify that any funders will place no restrictions or limitations on the dissemination of outputs. • To remove from Section 6 the special condition ““All organisations party to this agreement must comply with the Data Sharing Framework Contract requirements, including those regarding the use (and purposes of that use) by “Personnel” (as defined within the Data Sharing Framework Contract i.e. employees, agents and contractors of the Data Recipient who may have access to that data)” as this is a duplication referenced in 5b. <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 yielded benefits, outputs and a more robustly defined purpose. <p>It was the view of IGARD that this application would not be appropriate for renewal by IAO and Director delegated authority.</p> <p>It was agreed the condition would approved OOC by IGARD Members</p>
2.2	<p><u>St George’s University of London: sudden cardiac death and the Early Repolarisation ECG Pattern in young adults (Presenter: Louise Dunn) NIC-45477-B9W1L</u></p>

Application: this was a new application for identifiable Medical Research Information Service (MRIS) flagging current status report and MRIS cause of death report. The study aims to identify individuals who have died and the causes of death from a database of approximately 4,600 individuals who underwent voluntary cardiac screening with a medical questionnaire and ECG through a programme organised by the Cardiac Risk in the Young (CRY) Charity.

NHS Digital noted that the General Data Protection Regulation (GDPR) legal basis should be included in the abstract.

Discussion: IGARD welcomed the application and noted the valuable work being undertaken.

IGARD noted that NHS Digital should include within the abstract the applicant's legal basis under the General Data Protection Regulation (GDPR) Article 6 and 9 and suggested that a clear justification for each choice be given in terms of how the specific criteria and additional requirements would be met, since the applicant would need to satisfy the relevant tests associated with the legal basis suggested.

IGARD queried the relationship between CRY and St George's University of London and NHS Digital confirmed that CRY had funded the project but were not accessing the data, however IGARD suggested that the role of the CRY team be outlined in section 5 and it be confirmed if the CRY team had access to the data. IGARD noted that the lead researcher's email address was Papworth Hospital and suggested that clarification be sought that he was a substantive employee of St George's University of London, along with clarifying if he will access the data with the appropriate restrictions in place. IGARD also queried if Greg Mellor had an ONS approved researcher status and sought evidence of that.

IGARD noted that the applicant's fair processing did not meet NHS Digital's nine minimum criteria for privacy notices including visibility and accessibility on the Data Controller's website plus the involvement of St George's University of London. 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) and before data can flow.

IGARD noted that a duplicate special condition was included in section 5b and suggested that the special condition in section 6: "All organisations party to this agreement must comply with the Data Sharing Framework Contract requirements, including those regarding the use (and purposes of that use) by "Personnel" (as defined within the Data Sharing Framework Contract i.e. employees, agents and contractors of the Data Recipient who may have access to that data)" be removed.

It was noted that a general description was included in section 5 of the larger research project being undertaken by the clinical researchers at St George's Hospital Medical School Research Department and IGARD suggested a clear description be included how this larger project interacts with the project outlined within this application.

IGARD noted that the Microdata Release Panel (MRP) documentation had been provided however the approved researcher status information was not included for consideration by IGARD and asked for documentary evidence that the researcher who was accessing the data had APR researcher status.

IGARD 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

	<p>requirements within a reasonable period after obtaining the personal data, but at the latest within one month.”</p> <p>IGARD suggested that supporting document 12, the data flow diagram, be updated to correct a factually incorrect statement.</p> <p>IGARD also suggested that the applicant update their DPA registration to clearly state that data is processed about patients or health care users</p> <p>Outcome: recommendation to approve subject to the following condition:</p> <ol style="list-style-type: none"> 1. To provide the relevant sections under Article 6 and 9 of GDPR and a clear justification for the choice of each section in terms of how the specific criteria and additional requirements are met. 2. Providing documentary evidence that the researcher with access to the data has an APR researcher status. 3. The Fair Processing Notice be amended to meet the NHS Digital nine minimum criteria (to be known as NHS Digital's fair processing criteria) for privacy notices and it is also published on the data controller's website. 4. To clearly describe within section 5 the purpose of the larger research project undertaken by clinical researchers at St. George's Hospital Medical School Research Department and how it relates to the project in this application. <p>The following amendments were requested:</p> <ol style="list-style-type: none"> 1. 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 within a reasonable period after obtaining the personal data, but at the latest within one month.” 2. To correct factually incorrect information within the data flow diagram. 3. To remove from Section 6 the special condition ““All organisations party to this agreement must comply with the Data Sharing Framework Contract requirements, including those regarding the use (and purposes of that use) by “Personnel” (as defined within the Data Sharing Framework Contract i.e. employees, agents and contractors of the Data Recipient who may have access to that data)” as this is a duplication referenced in 5b. 4. To clarify that the lead researcher is a substantive employee of St George's, where he will access the data and ensure the appropriate restrictions are in place plus confirming he is also the ONS researcher. 5. Clarifying within section 5 the role of the CRY team and if they have access to data. <p>The following advice was given:</p> <ol style="list-style-type: none"> 1. The applicant should update their DPA registration to more clearly state that data is processed about patients or healthcare users. <p>It was agreed the condition would approved OOC by IGARD Members</p>
2.3	<p><u>University of Essex: the residential mobility of Mental Health Service Users (MHSUs)</u> (Presenter: Louise Dunn) NIC-58974-T3M1M</p>

Application: This was a new application for pseudonymised Mental Health Minimum dataset to support the Administrative Data Research Network (ADRN) project to investigate different type of mental health service usage and provision. The mental health data will be supplied by the Office for National Statistics (ONS) who will link to via the Lower Super Outputs Area (LSOA) to their statistical data, with data hosted in ONS's secure environment where it would be securely accessed by University of Southampton researchers. The application was previously considered by DAAG in 24 May 2016 when it had not been recommended for approval.

NHS Digital noted that the ADRN are the applicants and for clarification ADRN staff at the University of Essex handle the applications function and no University of Essex staff would have access to any data provided by NHS Digital under this application.

Discussion: IGARD noted that NHS Digital should include within the abstract the applicant's legal basis under the General Data Protection Regulation (GDPR) Article 6 and 9 and suggested that a clear justification for each choice be in given in terms of how the specific criteria and additional requirements would be met, since the applicant would need to satisfy the relevant tests associated with the legal basis suggested.

IGARD noted that a duplicate special condition was included in section 5b and suggested that the special condition in section 6: "All organisations party to this agreement must comply with the Data Sharing Framework Contract requirements, including those regarding the use (and purposes of that use) by "Personnel" (as defined within the Data Sharing Framework Contract i.e. employees, agents and contractors of the Data Recipient who may have access to that data)" be removed.

IGARD 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 within a reasonable period after obtaining the personal data, but at the latest within one month."

IGARD also suggested University of Essex update their DPA registration to clearly state that data is processed about patients or health care users

IGARD noted updated wording within the abstract with regard to common law duty of confidentiality and suggested that the wording be updated to be clear that there is no requirement to meet the common law duty of confidentiality as the processing involved pseudonymised data only.

IGARD noted that the University of Southampton had been listed within section 2b of the application and suggested that they be removed from the data processor section.

Outcome: recommendation to approve subject to the following condition:

1. To provide the relevant sections under Article 6 and 9 of GDPR and a clear justification for the choice of each section in terms of how the specific criteria and additional requirements are met.

The following amendments were requested:

2. To remove from Section 6 the special condition ""All organisations party to this agreement must comply with the Data Sharing Framework Contract requirements, including those regarding the use (and purposes of that use) by "Personnel" (as defined within the Data Sharing Framework Contract i.e. employees, agents and contractors of

	<p>the Data Recipient who may have access to that data)” as this is a duplication referenced in 5b.</p> <ol style="list-style-type: none"> 3. To remove University of Southampton from the Data Processor section of the application. 4. To amend the summary/abstract of the application to clarify the statement that there is no requirement to meet the common law duty of confidentiality as the processing involves pseudonymised data only. 5. 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 within a reasonable period after obtaining the personal data, but at the latest within one month.” <p>The following advice was given:</p> <ol style="list-style-type: none"> 6. The applicant should update their DPA registration to more clearly state that data is processed about patients or healthcare users. <p>It was agreed the condition would approved OOC by IGARD Members</p>
2.4	<p><u>The Newcastle Upon Tyne Hospitals NHS Foundation Trust (NUTH): quarterly Hospital Episodes Statistics (HES) and Office for National Statistics (ONS) extracts (Presenter: Rachel Farrand) NIC-170211-Z1B4</u></p> <p>Application: This was a new application for pseudonymised Hospital Episode Statistics (HES) data linked to Office for National Statistics (ONS) mortality data (including month and year of death). The Northern Medical Physics & Clinical Engineering (NMPCE), a clinical directorate within NUTH, carries out a programme of research into novel medical technologies and interventional procedure. The ONS data will be used for NICE external assessment centre work and the HES data will be used across the programme of research to assess peri-procedural, short term and long-term safety and efficacy.</p> <p>Discussion: IGARD welcomed this application and noted that ONS data was in the process of moving to NHS Digital controllership and that the application was clearly stating the current and future legal basis for the dissemination of data.</p> <p>IGARD noted that NHS Digital should include within the abstract the applicant’s legal basis under the General Data Protection Regulation (GDPR) Article 6 and 9 and suggested that a clear justification for each choice be in given in terms of how the specific criteria and additional requirements would be met, since the applicant would need to satisfy the relevant tests associated with the legal basis suggested.</p> <p>IGARD queried the data linkage and that it be explicit within section 5b of the application that the applicant will not link data in this application except those permitted under this application / data sharing agreement.</p> <p>IGARD queried the data retention date of 2043 and suggested that the applicant provide a clear justification for the number of years requested and the data retention date.</p> <p>IGARD 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</p>

	<p>requirements within a reasonable period after obtaining the personal data, but at the latest within one month.”</p> <p>IGARD noted that section 5a should be updated to include clearer examples for processing and how the applicant has been using the data, using examples from supporting documentation provided with the application. IGARD also suggested that the applicant provide further details of pathways for disseminating the outputs of the study to patients and the public including specific examples of public / patient engagement.</p> <p>Outcome: recommendation to approve under the current legal basis and until such time as the ONS data has moved to NHS Digital controllership and subject to the following conditions:</p> <ol style="list-style-type: none"> 1. To provide the relevant sections under Article 6 and 9 of GDPR and a clear justification for the choice of each section in terms of how the specific criteria and additional requirements are met. 2. 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. 3. To provide clear justification for the retention period of 2043. <p>The following amendments were requested:</p> <ol style="list-style-type: none"> 1. To provide clearer examples in section 5a of the objectives for processing and how and what the applicant is using data for 2. To provide further details of pathways of dissemination of the outputs including any specific examples of public / patient engagement. 3. 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 within a reasonable period after obtaining the personal data, but at the latest within one month.” <p>It was agreed the condition would approved OOC by IGARD Members</p>
2.5	<p><u>Imperial College London: effectiveness and value for money of prescribed specialised services (PSS) commissioning for quality and innovation (CQUIN) (Presenter: Louise Dunn) NIC-172334-W0G2L</u></p> <p>Application: this was a new application for pseudonymised Hospital Episodes Statistics (HES) and Mortality Flags for the PSS CQUIN research project. The PSS CQUIN schemes were introduced by NHS England in 2016 with the primary aim of the incentive programme to improve the healthcare quality of specialised services (rare and complex conditions) in NHS Hospitals.</p> <p>NHS Digital noted this was a NIHR funded application however section 5 was not a direct copy of the NIHR application section.</p> <p>Discussion: IGARD noted that NHS Digital should include within the abstract the applicant’s legal basis under the General Data Protection Regulation (GDPR) Article 6 and 9 and suggested that a clear justification for each choice be in given in terms of how the specific criteria and additional requirements would be met, since the applicant would need to satisfy the relevant tests associated with the legal basis suggested.</p> <p>IGARD noted that NHS Digital had provided the NIHR application however it was not clear from the documentation provided whether the project was still live and suggested that</p>

application be updated to indicate that funding was still in place and provide relevant evidence such as a funding letter.

IGARD noted that a duplicate special condition was included in section 5b and suggested that the special condition in section 6: "All organisations party to this agreement must comply with the Data Sharing Framework Contract requirements, including those regarding the use (and purposes of that use) by "Personnel" (as defined within the Data Sharing Framework Contract i.e. employees, agents and contractors of the Data Recipient who may have access to that data)" be removed.

IGARD noted updated wording within the abstract with regard to common law duty of confidentiality and suggested that the wording be updated to be clear that there is no requirement to meet the common law duty of confidentiality as the processing involved pseudonymised data only

IGARD noted that section 5a should be updated to include clearer examples for processing and how the applicant has been using the data on rare and complex conditions, using examples from supporting documentation provided with the application. IGARD noted the applicant had suggested disseminating outputs via social media, however it suggested that the applicant provide further details of pathways for disseminating the outputs of the study to patients and the public including specific examples of public / patient engagement via for example patient or voluntary groups, and within section 5 of the application. IGARD noted that section 3b of the application be updated to clearly describe the data minimisation effort based on rare and complex conditions.

IGARD 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 within a reasonable period after obtaining the personal data, but at the latest within one month."

IGARD suggested that the typo 'collage' within section 5b be updated to correctly reference 'college'.

IGARD queried the special condition referenced in section 6: the use of any cloud-based solution for data storage is not permitted under this agreement. Any changes must be reflected through an amendment and subsequent approval of the agreement. NHS Digital confirmed this was not a standard special condition but noted that the applicant was looking at cloud-based storage for the future. IGARD suggested for transparency that the special condition wording be included in section 5.

Outcome: recommendation to approve subject to the following conditions:

1. To provide the relevant sections under Article 6 and 9 of GDPR and a clear justification for the choice of each section in terms of how the specific criteria and additional requirements are met.
2. The application should be amended to confirm that funding is in place and provide relevant evidence.

The following amendments were requested:

1. To provide clearer examples in section 5 of how and what the applicant is using data for

	<ol style="list-style-type: none"> 2. To provide details of pathways of dissemination of the outputs including examples of public / patient engagement. 3. To remove from Section 6 the special condition ““All organisations party to this agreement must comply with the Data Sharing Framework Contract requirements, including those regarding the use (and purposes of that use) by “Personnel” (as defined within the Data Sharing Framework Contract i.e. employees, agents and contractors of the Data Recipient who may have access to that data)” as this is a duplication referenced in 5b. 4. A typo within section 5b referring to ‘collage’ be updated to correctly reference ‘college’. 5. To update section 3b to clearly describe a rare or complex condition 6. The special condition “the use of any cloud-based solution for data storage is not permitted under this agreement. Any changes must be reflected through an amendment and subsequent approval of the agreement” must be reflected in section 5 of the application, for transparency. 7. To amend the summary/abstract of the application to clarify the statement that there is no requirement to meet the common law duty of confidentiality as the processing involves pseudonymised data only. 8. 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 within a reasonable period after obtaining the personal data, but at the latest within one month.” <p>It was agreed the condition would be approved OOC by IGARD members.</p>
2.6	<p><u>Group of 31 CCGs¹: to receive SUS+ and Local Provider Flows to support commissioning (Presenter: James Humphries Hart) GA09-NW-AMD</u></p> <p>Application: This was a new application for Salford Royal NHS Foundation Trust to receive pseudonymised Secondary User Service (SUS+) and Local Provider Flows (Acute). The pseudonymised data will provide intelligence to support the commissioning of health services. The data (containing both clinical and financial information) is analysed so that health care provision can be planned to support the needs of the population within the North West region, detailed within the data minimisation. Salford Royal host the Advancing Quality Alliance (AQuA) and the North West Utilisation Management (UM) Team with both team made up of employees of Salford Royal. The team work across the region of 31 CCG’s providing support for a range of quality improvement programmes, undertaking analysis and producing aggregated reports of outputs and findings.</p> <p>Discussion: IGARD advised that NHS England should continue to work with CCG’s to support their transition to General Data Protection Regulations (GDPR) and noted that due to the public</p>

¹ NHS Blackburn & Darwin CCG NIC-193413-S0G2G; NHS Blackpool CCG NIC-193426-C0J5H; NHS Bolton CCG NIC-193331-D5D0H; NHS Bury CCG NIC-193353-J4R3Q; NHS Chorley & South Ribble CCG NIC-193434-Z0K4C; NHS Cumbria CCG NIC-193466-V5Y6B; NHS Eastern Cheshire CCG NIC-193414-F0Q5M; NHS Fylde & Wyre CCG NIC-193448-F7L9Z; NHS Greater Preston CCG NIC-193456-W3M0H; NHS Halton CCG NIC-193420-F6W4M; NHS Heywood Middleton and Rochdale CCG NIC-193359-V6H2X; NHS Knowsley CCG NIC-193423-M4D6X; NHS Liverpool CCG NIC-193433-Y0J9D; NHS Manchester CCG NIC-193368-H5F0C; NHS Morecambe Bay CCG NIC-193461-Y9N0X; NHS Oldham CCG NIC-193375-V2Y3H; NHS Salford CCG NIC-193381-L9V3D; NHS South Cheshire CCG NIC-193444-W5L9D; NHS South Sefton CCG NIC-193451-T4M6J; NHS Southport & Formby CCG NIC-193334-V9K5N; NHS St Helens CCG NIC-193347-T3N2X; NHS Stockport CCG NIC-193389-L7L4M; NHS Tameside & Glossop CCG NIC-193396-Z2Q3C; NHS Trafford CCG NIC-193399-J0H9Q; NHS Vale Royal CCG NIC-193361-R1J0R; NHS Warrington CCG NIC-193369-B9F9X; NHS West Cheshire CCG NIC-193380-Z4Q1B; NHS West Lancashire CCG NIC-193464-P6W7Z; NHS Wigan CCG NIC-193408-G2H2W; NHS Wirral CCG NIC-193405-Y8K7F

	<p>interest and continued running of NHS services the data should continue to flow. IGARD suggested that a time limited special condition of 3 months be included in section 6. The applicant should clearly describe the relevant sections under Article 6 and 9 and GDPR and provide a clear justification for the choice of each section in terms of how the specific criteria and additional requirements are met</p> <p>IGARD suggested that the special condition wording within section 6 of the application be removed and suggested that new standard wording for use with pseudonymised data be used within the fair processing section: "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."</p> <p>IGARD noted that non-standard wording was still included in section "...specific locality of interest to the applicant..." and suggested that section 5 be updated to be clear that the CCG's require their own 'locality data'.</p> <p>IGARD queried if data would be linked to any other data held by the applicant and that it be explicit within section 5b of the application that the applicant will not link data in this application except those permitted under this application / data sharing agreement</p> <p>IGARD acknowledged an open action with NHS Digital with regard to contractual arrangements in place, the structure, enforcement strategy and how the agreements worked together so that the data disseminated by NHS Digital would be protected.</p> <p>Outcome: recommendation to approve</p> <p>The following amendments were requested:</p> <ol style="list-style-type: none"> 1. To add a special condition to section 6 that within 3 months the application clearly describes the relevant sections under Article 6 and 9 of GDPR and provides a clear justification for the choice of each section in terms of how the specific criteria and additional requirements are met. 2. 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 within a reasonable period after obtaining the personal data, but at the latest within one month." 3. 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 and that data will not be used for reidentification purposes. 4. To remove the special condition about Fair Processing, since this has been superseded by updated wording in the Fair Processing section. 5. To amend section 5 to be clear that the CCG's require 'locality data'.
2.7	<p><u>Group of 3 CCGs²: for commissioning Sustainable Transformation Partnership Footprint (Presenter: James Humphries Hart) GA11-CM-AMD</u></p> <p>Application: This was a new application for the three CCG's to act as Joint Data Controllers to receive pseudonymised data based on the Sustainable Transformation Partnership</p>

² NHS East Leicestershire and Rutland CCG NIC-102804-C2V0N; NHS Leicester City CCG NIC-102794-Q4D1M; NHS West Leicestershire CCG NIC-102825-Q3G3F

Footprint (STPF) to allow collaborative working. The pseudonymised datasets are required to provide intelligence to support commissioning of health services and include: Secondary User Service (SUS+); Local Provider Flows; Mental Health Minimum Data Set (MHMDS); Mental Health Learning Disability Data Set (MHLDDS); Mental Health Services Data Set (MHSDS); Maternity Services Data Set (MSDS); Improving Access to Psychological Therapy (IAPT); Child and Young People Health Service (CYPHS); Community Services Data Set (CSDS); Diagnostic Imaging Data Set (DIDS); National Cancer Waiting Times Monitoring Data Set (CWT)

Discussion: IGARD advised that NHS England should continue to work with CCG's to support their transition to General Data Protection Regulations (GDPR) and noted that due to the public interest and continued running of NHS services the data should continue to flow. IGARD suggested that a time limited special condition of 3 months be included in section 6. The applicant should clearly describe the relevant sections under Article 6 and 9 and GDPR and provide a clear justification for the choice of each section in terms of how the specific criteria and additional requirements are met.

IGARD suggested that new standard wording for use with pseudonymised data be used within the fair processing section: "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 NHS Midlands and Lancashire CSU update their DPA registration to clearly state that data is processed about patients or health care users

IGARD acknowledged an open action with NHS Digital with regard to contractual arrangements in place, the structure, enforcement strategy and how the agreements worked together so that the data disseminated by NHS Digital would be protected.

Outcome: recommendation to approve.

The following amendments were requested:

1. To add a special condition to section 6 that within 3 months the application clearly describes the relevant sections under Article 6 and 9 of GDPR and provides a clear justification for the choice of each section in terms of how the specific criteria and additional requirements are met.
2. 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 within a reasonable period after obtaining the personal data, but at the latest within one month."

The following advice was given:

3. IGARD advised that the NHS Midlands and Lancashire Commissioning Support Unit (CSU) should update their DPA registration to refer to processing data about patients rather than 'our patients'.

2.8	<p><u>Group of 5 CCGs³: An amendment application for 5 CCGs to move data processors for the purpose of commissioning (Presenter: James Humphries Hart) GA13a-NW-AMD</u></p> <p>Application: This was an amendment application for the five CCG's to move data processors for the purpose of commissioning and to receive pseudonymised datasets to provide intelligence to support commissioning of health services: Secondary User Service (SUS+); Local Provider Flows; Mental Health Minimum Data Set (MHMDS); Mental Health Learning Disability Data Set (MHLDDS); Mental Health Services Data Set (MHSDS); Maternity Services Data Set (MSDS); Improving Access to Psychological Therapy (IAPT); Child and Young People Health Service (CYPHS); Community Services Data Set (CSDS); Diagnostic Imaging Data Set (DIDS); National Cancer Waiting Times Monitoring Data Set (CWT). The pseudonymised data will provide intelligence to support the commissioning of health services and the data (containing both clinical and financial information) is analysed so that health care provision can be planned to support the needs of the population within the CCG area.</p> <p>Discussion: IGARD advised that NHS England should continue to work with CCG's to support their transition to General Data Protection Regulations (GDPR) and noted that due to the public interest and continued running of NHS services the data should continue to flow. IGARD suggested that a time limited special condition of 3 months be included in section 6. The applicant should clearly describe the relevant sections under Article 6 and 9 and GDPR and provide a clear justification for the choice of each section in terms of how the specific criteria and additional requirements are met.</p> <p>IGARD suggested that new standard wording for use with pseudonymised data be used within the fair processing section: "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."</p> <p>IGARD noted that Interxion 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> <p>IGARD acknowledged an open action with NHS Digital with regard to contractual arrangements in place, the structure, enforcement strategy and how the agreements worked together so that the data disseminated by NHS Digital would be protected.</p> <p>Outcome: recommendation to approve.</p> <p>The following amendments were requested:</p> <ol style="list-style-type: none"> 1. To add a special condition to section 6 that within 3 months the application clearly describes the relevant sections under Article 6 and 9 of GDPR and provides a clear justification for the choice of each section in terms of how the specific criteria and additional requirements are met. 2. 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
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³ NHS Basildon and Brentwood CCG NIC-197669-K8J6D; NHS Castle Point and Rochford CCG NIC-197683-D6W9T; NHS Mid-Essex CCG NIC-197689-L5C7S; NHS Southend CCG NIC-197702-F2W7F; NHS Thurrock CCG NIC-197720-X1Z5B

	with the GDPR notice requirements within a reasonable period after obtaining the personal data, but at the latest within one month.”
2.9	<p><u>Group of 5 CCGs⁴: to move data processors for the purpose of Invoice Validation (Presenter: James Humphries Hart) GA13b-NW-AMD</u></p> <p>Application: This was an amendment application for five CCG’s to move data processor and receive identifiable Secondary User Service (SUS+) datasets for the purpose of invoice validation. Invoice validation is part of a process by which providers of care or services get paid for the work they do. Invoices are submitted to the CCG so they are able to ensure that the activity claimed for each patient is their responsibility and is done by processing and analysing SUS+ data, which is received into a secure Controlled Environment for Finance (CEfF).</p> <p>Discussion: IGARD advised that NHS England should continue to work with CCG’s to support their transition to General Data Protection Regulations (GDPR) and noted that due to the public interest and continued running of NHS services the data should continue to flow. IGARD suggested that a time limited special condition of 3 months be included in section 6. The applicant should clearly describe the relevant sections under Article 6 and 9 and GDPR and provide a clear justification for the choice of each section in terms of how the specific criteria and additional requirements are met.</p> <p>IGARD noted that the NHS Castlepoint and NHS Southend CCG’s fair processing did not meet NHS Digital’s nine minimum criteria for privacy notices, specifically the privacy notices were not being published or referencing current Data Processors. IGARD noted that a clear statement should then be added to the application summary that NHS Digital was satisfied that NHS Castlepoint and NHS Southend CCG’s fair processing meets the NHS Digital nine minimum criteria for privacy notices (to be known as NHS Digital’s fair processing criteria) and before data can flow.</p> <p>IGARD suggested that new standard wording for use with pseudonymised data be used within the fair processing section: “All data required by the Data Controller under this application is 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 within a reasonable period after obtaining the personal data, but at the latest within one month.” It was also suggested erroneous wording “Act 1998.” should be removed from the end of section 4 of the application.</p> <p>IGARD queried reference to NHS Ilkeston Community Hospital and it was confirmed by NHS Digital that they were not part of this application. IGARD suggested that any reference to the Community hospital be removed from the application.</p> <p>Outcome: recommendation to approve subject to the following condition:</p> <ol style="list-style-type: none"> 1. The Fair Processing Notice be amended to meet the NHS Digital nine minimum criteria (to be known as NHS Digital’s fair processing criteria) for privacy notices specifically published for NHS Castlepoint and NHS Southend CCG’s, and before data can flow. <p>The following amendments were requested:</p> <ol style="list-style-type: none"> 2. To add a special condition to section 6 that within 3 months the application clearly describes the relevant sections under Article 6 and 9 of GDPR and provides a clear

⁴ NHS Basildon and Brentwood CCG NIC-198066-F4H9X; NHS Castle Point and Rochford CCG NIC-198104-H9N9N; NHS Mid-Essex CCG NIC-198111-C2W4W; NHS Southend CCG NIC-198115-L1P3P; NHS Thurrock CCG NIC-198119-X9P3J

	<p>justification for the choice of each section in terms of how the specific criteria and additional requirements are met.</p> <ol style="list-style-type: none"> 3. To include a special condition for all 5 CCG's under the application that they must update the Fair Processing Notice in line with GDPR, and stating that "All data required by the Data Controller under this application is 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 within a reasonable period after obtaining the personal data, but at the latest within one month." 4. To remove Fair Processing wording referring to the DPA 1998 within that section since it is not relevant. 5. To remove reference to NHS Ilkeston Community Hospital since they were not part of this application. <p>It was agreed the condition would approved OOC by IGARD Members.</p>
2.10	<p><u>NHS Mid-Essex CCG: to remove NEL CSU as a data processor for the purpose of Risk Stratification following a period of dual running (Presenter: James Humphries Hart) NIC-197745-T1B4G (GA13c-NW-AMD)</u></p> <p>Application: This was an amendment application for the CCG to remove North East London CSU as a data processor and add Optum Health Solutions (UK) Limited for the purpose of risk stratification following a period of dual running and receive identifiable Secondary User Service (SUS) data. Risk stratification is a tool for identifying and predicting which patients are at high risk or are likely to be at high risk and prioritising the management of their care in order to prevent worse outcomes. Risk Stratification provides a forecast of future demand by identifying high risk patients. Commissioners can then prepare plans for patients who may require high levels of care. Risk Stratification also enables General Practitioners (GPs) to better target intervention in Primary Care.</p> <p>Discussion: IGARD advised that NHS England should continue to work with CCG's to support their transition to General Data Protection Regulations (GDPR) and noted that due to the public interest and continued running of NHS services the data should continue to flow. IGARD suggested that a time limited special condition of 3 months be included in section 6. The applicant should clearly describe the relevant sections under Article 6 and 9 and GDPR and provide a clear justification for the choice of each section in terms of how the specific criteria and additional requirements are met.</p> <p>IGARD suggested that new standard wording for use with pseudonymised data be used within the fair processing section: "All data required by the Data Controller under this application is 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 within a reasonable period after obtaining the personal data, but at the latest within one month." It was also suggested erroneous wording "Act 1998." should be removed from the end of section 4 of the application.</p> <p>IGARD noted that Interxion 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> <p>Outcome: recommendation to approve</p> <p>The following amendments were requested:</p>

	<ol style="list-style-type: none"> 1. To add a special condition to section 6 that within 3 months the application clearly describes the relevant sections under Article 6 and 9 of GDPR and provides a clear justification for the choice of each section in terms of how the specific criteria and additional requirements are met. 2. To include a special condition for all 5 CCG's under the application that they must update the Fair Processing Notice in line with GDPR, and stating that "All data required by the Data Controller under this application is 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 within a reasonable period after obtaining the personal data, but at the latest within one month." 3. To remove Fair Processing wording referring to the DPA 1998 within that section since it is not relevant.
2.11	<p><u>Group of 3 CCG's⁵: to receive data for commissioning purposes (Presenter: James Humphries Hart) GA06-NoE-STP</u></p> <p>Application: This was a new application for the three CCG's to act as Joint Data Controllers to receive pseudonymised data based on the Sustainable Transformation Partnership Footprint (STPF) to allow collaborative working. The CCGs will use pseudonymised data to provide intelligence to support the commissioning of health services. The data (containing both clinical and financial information) is analysed so that health care provision can be planned to support the needs of the population within the STP area. The CCGs commission services from a range of providers covering a wide array of services. Each of the data flow categories requested supports the commissioned activity of one or more providers. The datasets requested provide intelligence to support commissioning of health services: Secondary User Service (SUS+); Local Provider Flows; Mental Health Minimum Data Set (MHMDS); Mental Health Learning Disability Data Set (MHLDDS); Mental Health Services Data Set (MHSDDS); Maternity Services Data Set (MSDS); Improving Access to Psychological Therapy (IAPT); Child and Young People Health Service (CYPHS); Community Services Data Set (CSDS); Diagnostic Imaging Data Set (DIDS); National Cancer Waiting Times Monitoring Data Set (CWT)</p> <p>Discussion: IGARD advised that NHS England should continue to work with CCG's to support their transition to General Data Protection Regulations (GDPR) and noted that due to the public interest and continued running of NHS services the data should continue to flow. IGARD suggested that a time limited special condition of 3 months be included in section 6. The applicant should clearly describe the relevant sections under Article 6 and 9 and GDPR and provide a clear justification for the choice of each section in terms of how the specific criteria and additional requirements are met.</p> <p>IGARD suggested that the special condition wording within section 6 of the application be removed and suggested that new standard wording for use with pseudonymised data be used within the fair processing section: "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."</p> <p>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>

⁵ NHS Ipswich & East Suffolk CCG; NHS North East Essex CCG; NHS West Suffolk CCG; NIC-192767-R0S9V; NIC-192781-Z0B0S; NIC-197501-G6P5D

<p>3.4</p>	<p>met. NHS Digital agreed with IGARD's recommendation however suggested that the DARS application should include "at least within one month" when referencing the privacy notice.</p> <p>NHS Digital suggested that a generic narrative be included within the abstract for applications submitted, however IGARD noted that the Article 6 or 9 narrative would be dependent on the purpose outlined in the application but that they would built into a catalogue of precedents for use by NHS Digital.</p> <p>NIC 148408 London North West Healthcare NHS Trust</p> <p>IGARD members worked with NHS Digital and agreed that the outcome for the application which was recommended for approval subject to conditions on the 22nd February 2018 would be amended from:</p> <ul style="list-style-type: none"> • To provide substantive details in the yielded benefits section 5d(iii), including examples of public / patient engagement. <p>To:</p> <ul style="list-style-type: none"> • Upon renewal or amendment there should be a fuller description of patient/public involvement in the running of the study and dissemination of the outputs <p>GA12-NW-VAN Group of 11 CCGs</p> <p>It was noted that GA12-NW-VAN group of 11 CCG's which was recommended for approval on the 26th April 2018 should have been listed under one NIC number since the 11 CCG's were acting as joint Data Controllers and as such would have single agreement. The NIC number for this application was confirmed as: NIC-191209-G3Z6Z</p>
<p>3.5</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>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: IGARD chair to update members at May's education session.</p> <p>03/05/18: The Chair of IGARD noted that he would be contacting key stakeholders over the coming weeks.</p> <p>17/05/18: ongoing</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</p>	Open

			<p>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>05/04/18: IGARD Secretariat had contacted Garry Colman and were awaiting a response.</p> <p>17/05/18: 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>17/05/18: ongoing</p>	Open
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 disseminated by NHS Digital would be protected and provide a verbal update to IGARD on the progress of this note by 5 April 2018.	Gaynor Dalton	<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 verbal update and asked that a briefing note be provided by NHS Digital confirming the arrangements in place by the end of April 2018.</p> <p>26/04/18: IGARD secretariat were awaiting a response following issue of a reminder</p>	Open

			<p>03/05/18: It was noted the issue was wider than DSfC applications and applies to all DARS applications, the action owner was amended to the Head of Data Access, Gaynor Dalton.</p> <p>10/05/18: The Director Data Dissemination noted that a briefing note would be provided to IGARD for the 24 May meeting.</p> <p>17/05/18: ongoing</p>	
12/04/18	<p>IGARD Members to consider the HRA guidance on GDPR published on line</p> <p>IGARD Chair to provide feedback to the Caldicott Guardian</p>	<p>IGARD</p> <p>IGARD Chair</p>	<p>19/04/18: IGARD members had considered the HRA guidance and asked the IGARD Chair to provide feedback to the Caldicott Guardian.</p> <p>26/04/18: IGARD Secretariat awaiting comment following issue of a reminder.</p> <p>03/05/18: the Chair of IGARD to provide a copy of the email sent to the Caldicott Guardian to the Secretariat team</p> <p>17/05/18: ongoing</p>	Open
26/04/18	<p>Stuart Richardson to complete, for transparency, on all future CCG applications the data already held information at section 3a, including such data as may be held under a different Data Sharing Agreement / NIC number.</p>	<p>Stuart Richardson</p>	<p>17/05/18: ongoing</p>	Open
26/04/18	<p>Stuart Richardson to provide for all future CCG applications a data flow diagram detailing all previously approved data flows alongside a new data flow diagram outlining the data flows for the presented application.</p>	<p>Stuart Richardson</p>	<p>17/05/18: ongoing</p>	Open

Appendix B: Out of committee report

Independent Group Advising on Releases of Data (IGARD): Out of committee report 11/0518

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-173508-F4X6P	Isle of Man Dept of Health & Social Care	03/05/18	<ul style="list-style-type: none">To provide evidence of the adequacy decision made by the European Commission with regard to the Isle of Man and provide a website link within the abstract and section 1 'territory of use' and a clear statement within section 5 explaining the effect of the adequacy decision	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