

## Independent Group Advising on the Release of Data (IGARD)

### Minutes of meeting held 12 July 2018

**Members:** Joanne Bailey, Anomika Bedi, Chris Carrigan (Chair), Jon Fistein, Eve Sariyiannidou.

**In attendance:** Duncan Easton, Frances Hancox (Observer), James Humphries-Hart, Karen Myers, Kimberley Watson, Vicki Williams.

**Apologies:** Sarah Baalham, Nicola Fear, Kirsty Irvine

1	<p><b>Declaration of interests</b></p> <p>Jon Fistein and Chris Carrigan noted professional links to the University of Leeds (NIC-120105-F0K2L University of Leicester) but noted no specific connection with the applicant of staff involved, and it was agreed this was not a conflict of interest.</p> <p><b>Review of previous minutes and actions</b></p> <p>The outcomes of the 5 July 2018 IGARD meeting were reviewed and were agreed as an accurate record of that aspect of the meeting.</p> <p>The minutes of the 5 July 2018 IGARD meeting were reviewed out of committee by IGARD following conclusion of the meeting, and subject to a number of minor changes were agreed as an accurate record of the meetings.</p> <p><b>Out of committee recommendations</b></p> <p>An out of committee report was received (see Appendix B).</p>
2	<p><b>Data applications</b></p>
2.1	<p><u>NHS Gloucestershire CCG: DSfC - An amendment for Gloucestershire CCG to receive data for: commissioning, risk stratification and invoice validation. (Presenter: James Humphries-Hart) NIC-182332-B2F4M</u></p> <p><b>Application:</b> This was an amendment application to receive Secondary Uses 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) and Diagnostic Imaging Data Set (DIDS) for the purpose of commissioning, risk stratification and invoice validation.</p> <p>NHS Digital noted that the application had been previously considered on the 21 June 2018 when IGARD had recommended for approval. Following that meeting, it has been confirmed that Sollis Partnership were working as a Data Processor on behalf of the CCG and would therefore have access to identifiable data, and that this information was not part of the original application.</p> <p><b>Discussion:</b> 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 and as per recent discussions between NHS Digital and IGARD, including the processing being undertaken.</p> <p>IGARD noted that the abstract should make specific reference to Article 9(3) GDPR and Section 11(1) of the Data Protection Act (DPA) 2018 and clearly describe how the schedule conditions are met in order to meet the legal basis for dissemination.</p>

	<p>IGARD noted that the applicant had provided fair processing materials but that it contained misleading information and that the privacy notice be updated to be compliant with GDPR privacy notice requirements, and suggested that the first paragraph within section 4 starting “the privacy notice does meet the criteria met...” be removed since it was not relevant to this application. It was suggested that within one month of dissemination of the data, NHS Digital should check whether the applicant had published a privacy notice that is compliant with the GDPR notice requirements and additionally, suggested that NHS Digital provide an update to IGARD as to whether the applicant had published a GDPR-compliant privacy notice and within 6 weeks after dissemination of the data.</p> <p>IGARD noted that the applicant was listed in section 1 of the application as a Data Controller and Data Processor but that this be updated to clearly state that the applicant was a Data Controller who also processed data.</p> <p>IGARD suggested that 5a be updated from ““Risk Stratification provides a forecast of future demand by identifying high risk patients” to “Risk Stratification provides a focus for future demands by enabling commissioners to prepare plans for patients” for transparency for and for a lay audience.</p> <p><b>Outcome:</b> recommendation to approve</p> <p>The following amendments were requested:</p> <ol style="list-style-type: none"> <li>1. To update the abstract section on Article 9 to expressly refer to Article 9(3) GDPR and section 11(1) DPA 2018, to the conditions found therein and how these are met.</li> <li>2. The application should be updated to clarify that NHS Gloucestershire CCG is a Data Controller who also processes data.</li> <li>3. To remove from section 4 the paragraph starting “the privacy notice does meet the criteria met...” since it is not relevant to this application.</li> <li>4. To amend the sentence within section 5a “Risk Stratification provides a forecast of future demand by identifying high risk patients” to “Risk Stratification provides focus for future demands by enabling commissioners to prepare plans for patients” and for a lay audience.</li> </ol> <p>The following advice was given:</p> <ol style="list-style-type: none"> <li>1. Within one month after the dissemination of the data, NHS Digital should check whether the applicant has published a privacy notice that is compliant with the GDPR notice requirements. Additionally, NHS Digital is requested to provide an update to IGARD as to whether the applicant has published a GDPR-compliant privacy notice. This update to IGARD should be provided within 6 weeks after dissemination of the data.</li> </ol>
2.2	<p><u>NHS Airedale, Wharfedale and Craven CCG: DSFC – NHS Airedale, Wharfedale and Craven CCG - Comm. (Presenter: James Humphries-Hart) NIC-143777-Q0Q1S</u></p> <p><b>Application:</b> This was a new application for a number of pseudonymised datasets 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 CCG area.</p> <p><b>Discussion:</b> 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</p>

satisfy the relevant tests associated with the legal basis suggested and as per recent discussions between NHS Digital and IGARD, including the processing being undertaken.

IGARD noted that the abstract should make specific reference to Article 9(3) GDPR and Section 11(1) of the Data Protection Act (DPA) 2018 and clearly describe how the schedule conditions are met in order to meet the legal basis for dissemination.

IGARD noted that the applicant had provided fair processing materials and that the privacy notice be updated to be compliant with GDPR privacy notice requirements, and suggested that the first paragraph within section 4 starting “the privacy notice does meet the criteria met...” be removed since it was not relevant to this application. It was suggested that within one month of dissemination of the data, NHS Digital should check whether the applicant had published a privacy notice that is compliant with the GDPR notice requirements and additionally, suggested that NHS Digital provide an update to IGARD as to whether the applicant had published a GDPR-compliant privacy notice and within 6 weeks after dissemination of the data.

IGARD noted that explanation of the black box process and suggested that a clearer explanation of the black box arrangements in place and how it met the common law duty of confidentiality be included within section 5 of the application.

**Action:** the Caldicott Guardian to give consideration of the black box arrangements undertaken by organisations and if further action or justification was required, or if further information should be included within applications.

IGARD suggested that 5a be updated from “Risk Stratification provides a forecast of future demand by identifying high risk patients” to “Risk Stratification provides focus for future demands by enabling commissioners to prepare plans for patients” for transparency for and for a lay audience.

IGARD noted a typo within the abstract referring to ‘Article 9’.

**Outcome:** recommendation to approve

The following amendments were requested:

1. To update the abstract section on Article 9 to expressly refer to Article 9(3) GDPR and section 11(1) DPA 2018, to the conditions found therein and how these are met.
2. To remove from section 4 the paragraph starting “the privacy notice does meet the criteria met...” since it is not relevant to this application.
3. To clarify why duplicate data is to be flowed to the CSU and no data destruction notice will be issued for the previously held data under a separate agreement.
4. To amend the sentence within section 5a “Risk Stratification provides a forecast of future demand by identifying high risk patients” to “Risk Stratification provides focus for future demands by enabling commissioners to prepare plans for patients” and for a lay audience.

The following advice was given:

1. Within one month after the dissemination of the data, NHS Digital should check whether the applicant has published a privacy notice that is compliant with the GDPR notice requirements. Additionally, NHS Digital is requested to provide an update to IGARD as to whether the applicant has published a GDPR-compliant privacy notice. This update to IGARD should be provided within 6 weeks after dissemination of the data.

University of Leicester: Critically ill children and young people: do national Differences in access to Emergency Paediatric Intensive Care and care during Transport affect clinical outcomes and patient experience The DEPICT study (Presenter: Kimberley Watson) NIC-120105-F0K2L

**Application:** This was a new application for pseudonymised Hospital Episode Statistics (HES) data and Office for National Statistics (ONS) mortality data. Critically ill children who are admitted to district general hospitals can require specialist transport to a paediatric intensive care unit (PICU). There is considerable variation in the care provided prior to admission to paediatric intensive care. The objective of the DEPICT study is to study the association between timelines of access to paediatric intensive care and 30-day mortality.

**Discussion:** IGARD welcomed the application and noted the importance and value of the work being undertaken by using data to improve care.

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 the statement: "data flows posing an additional risk to individual's health data", in the abstract under the necessity test, be updated to state "data processing which would be more intrusive to the data subjects." IGARD suggested the typo referring to 'section 6' within the abstract be updated to read 'Article 6'.

IGARD queried the framework of the workstreams and the interaction between the University of Leicester with Great Ormond Street Hospital (GOSH) in terms of how and what role GOSH played in the workstream outlined, and suggested that section 5 clearly describe the role, design and responsibility of GOSH including any access to the data. It was also suggested that a special condition be included in section 6 that data will only be held by and processed by the University of Leicester, noting that it was outlined in section 5.

IGARD also noted the role of HQIP and their usual role in leading processes and queried how they were involved including their role in the design and performance of the project, their overall role and responsibilities and if they had any access to data.

It was noted that the applicant was leading the workstreams, however noted that both the University of Leeds and ICNARC flowed data into NHS Digital, and wanted further clarification as to the legal basis for NHS Digital to receive data from both the University of Leeds and ICNARC under GDPR. IGARD also queried the University of Leeds role in the design and performance of the project, their overall role and responsibilities and if they had any access to data and asked that it be provided in section 5.

The outputs and level of data disseminated by the applicant to GOSH, University of Leeds and ICNARC was queried with regard to the role of the wider study and it was suggested that the sentence in section 5a: "University of Leicester will not release any record level data to third party organisations" be updated to reflect that record level data will be disseminated to University of Leeds, ICNARC and GOSH and that these were not '3<sup>rd</sup> party' organisations. It was also suggested that reference to 'returned data' be clarified within section 5b for transparency and the lay reader.

IGARD noted the applicant should provide a fair processing notice that it is compliant with the notice requirements under the GDPR and suggested that they work with NHS Digital to amend their current privacy notice including removing reference to anonymised data, noting that the University will not get identifiable data, reference that data will not identify individuals, correct that the workstream don't have access to the data and to include further information with regard the role of GOSH and the DPO contact details.

<p>IGARD queried why two study protocols were provided as supporting documents and suggested that an explanation be given in section 8 of the application</p> <p>IGARD noted that the applicant was listed in section 1 of the application as a Data Controller and Data Processor but that this be updated to clearly state that the applicant was a Data Controller who also processed data.</p> <p>IGARD noted that reference to S42(4) of the Statistics and Registration Service Act 2007 for the receipt of ONS data within sections 3b and 5a should also include the subsection being relied upon for transparency.</p> <p>IGARD noted a discrepancy in the number of data years requested between sections 3b (2012/13 to 2018) and 5a (2014 to 2017) and suggested that the section(s) be updated with the corrected period of years.</p> <p>It was also suggested that reference to 'the agreement' be updated to clearly reference 'this agreement' for transparency.</p> <p><b>Outcome:</b> recommendation deferred pending,</p> <ol style="list-style-type: none"> <li>1. To amend the statement 'data flows posing an additional risk to individual's health data', in the abstract under the necessity test, to state 'data processing which would be more intrusive to the data subjects.'</li> <li>2. Giving a clear explanation within section 5 of the application the roles and responsibilities of Great Ormond Street Hospital outlined within the application, including any access to data.</li> <li>3. Giving a clear explanation within section 5 of the application the roles and responsibilities of HQIP and the University of Leeds outlined within the application, including their role in the design and performance of the project and any data they may have access to.</li> <li>4. To clarify the legal basis for NHS Digital to receive data from University of Leeds and ICNARC under GDPR.</li> <li>5. To amend the sentence in 5a "University of Leicester will not release any record level data to third party organisations" to reflect that record level data will be disseminated to University of Leeds, ICNARC and Great Ormond Street Hospital</li> <li>6. The applicant should work with NHS Digital on a fair processing notice that does not contain misleading statements and is GDPR compliant.</li> <li>7. To clarify reference to 'returned' data to the University of Leicester within section 5b</li> <li>8. To clarify the subsection within s.42(4) for the receipt of ONS data within section 3b and 5a of the application.</li> <li>9. To include a special condition in section 6 that only the University of Leicester can hold and process the data.</li> <li>10. To explain within section 8 why two study protocols were provided with the application</li> <li>11. To clarify the number of data years requested and update the correct periods within section 3b and 5b.</li> <li>12. Any reference to 'the agreement' within section 5 must be updated to refer to 'this agreement'.</li> <li>13. To amend references within the application from 'section 6' to state 'Article 6'.</li> </ol>
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<p><b>2.4</b></p>	<p><u>Health Navigator Limited: To assess whether a new tele-coaching model, Proactive Health Coaching (PHC), can reduce non-elective admission activity and cost within the NHS. (Presenter: Kimberley Watson) NIC-171305-K9S1Q (for advice)</u></p> <p><b>Application:</b> This is a new application for pseudonymised Secondary Uses Service (SUS) Payment by Results (PBR) data. The purpose is to evaluate its health coaching programme in the framework of the research study “Implementation of a Telephone-Based Case Management Intervention Study in the English NHS”.</p> <p>NHS Digital asked IGARD if the consent met the common law duty of confidentiality and if IGARD would review the application for advice on consent.</p> <p><b>Discussion:</b> IGARD noted that the application had come for advice on consent and if it met the common law duty of confidentiality. IGARD noted the cohort were vulnerable service users.</p> <p>IGARD noted a number of queries relating to the application presented and did not think that the applicant was the appropriate organisation to have the overall responsibility of the project or undertake the reconsenting, since they may have an interest in the results and were funded based on results and that there may be a conflict of interest.</p> <p>It was noted that a clearer justification was required as to why Health Navigator was listed as the Data Controller and not as the Data Processor and that a clearer justification why the other organisations involved in the study, including the principal investigator, were not listed as Data Controllers.</p> <p>IGARD noted that the protocol provided did not appear to reflect the application presented and that they needed to have a clearer understanding of the research study including the processes involved, how it was in the public interest and noted that the roles of the organisations involved in the design and performance of the project should be clearly described.</p> <p>IGARD also requested further detail about the intervention group and control group and how they would be reconsented. It was noted that s.251 support was not the appropriate route and that both cohorts would need to be reconsented.</p> <p>IGARD suggested that the applicant work with NHS Digital on a fair processing notice that was GDPR compliant.</p> <p><b>Outcome:</b> IGARD were unable to give advice on consent due to a number of issues raised</p>
<p><b>2.5</b></p>	<p><u>Health Data Interrogation System (HDIS) Briefing Note (Presenter: Duncan Easton)</u></p> <p>The briefing note was to inform IGARD that HDIS is being superseded by a new system called the Data Access Environment (DAE). Customers who have agreements allowing them to use HDIS to access Hospital Episode Statistics (HES) data, will still have the same level of access and therefore it is necessary to amend the Data Service Agreements to remove HDIS references and replace with updated wording.</p> <p>IGARD noted the contents of the briefing note and suggested that DARS update it when the system goes live later in 2018 and bring back to a future meeting.</p>
<p><b>3</b> <b>3.1</b></p>	<p><b>AOB</b></p> <p><b>NIC 177068 Office For National Statistics</b></p> <p>IGARD noted that following the 7<sup>th</sup> June 2018 when IGARD had recommended for approval subject to a condition:</p>



### Independent Group Advising on Releases of Data (IGARD): Out of committee report 06/07/18

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-192305-X3T0Y	NHS England	07/06/2018	<ol style="list-style-type: none"> <li>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.</li> <li>2. To provide confirmation that the Direction has been formally approved.</li> </ol>	IGARD Members	Quorum of IGARD Members	N/A
NIC-147749-3SSRF	Institute of Cancer Research	24/05/2018	<ol style="list-style-type: none"> <li>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.</li> <li>2. To clearly describe the data held and data requested within section 3 of the application.</li> <li>3. Section 3 should clearly identify the original cohorts whose data is requested and within section 5 clearly describe how the four original cohorts relate to the purpose and the</li> </ol>	IGARD Members	Quorum of IGARD Members	<ul style="list-style-type: none"> <li>• Amendment: the reference to DPA 18 Schedule 1 Part 1 (4) also needs to expressly state that the processing is <b>in the public interest</b> , and a brief assessment of how that is met.</li> <li>• Amendment: abstract be amended to read "...regarding the section 251 support for the two cohorts as described in this application"</li> </ul>



			<p>processing activities under this application.</p> <p>4. To produce a supporting document outlining HRA CAG s251 support for the two cohorts outlined in the application.</p>			
NIC-172334-W0G2L	Imperial College London	17/05/2018	<p>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.</p> <p>2. The application should be amended to confirm that funding is in place and provide relevant evidence.</p> <p>3.</p>	IGARD Members	Quorum of IGARD Members	<p>Add the new standard explanation that the University applicant is a Public Body with ref to DPA and FOIA</p> <p>2, insert the wording “(for data subjects)” after “less intrusive” in the Public Task section of the abstract</p> <p>3, insert “in the public interest” after “research purposes” in the Art 9(2)j section of the abstract</p>
NIC-183842-H8L1J	Health and Safety Executive	14/06/2018	<p>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.</p> <p>2. To provide clear justification for the retention period of 2034 that is consistent with the law.</p> <p>3. Confirmation within section 5b of the application that the applicant will not link the data further and the only data</p>	IGARD Members	Quorum of IGARD Members	<ul style="list-style-type: none"> <li>the reference to Schedule 1 Part 1 of DPA 2018 should also make an assessment that the research is <b>in the public interest</b>.</li> </ul>

			linkages are those permitted under this application			
NIC-15814-C6W9R	Monitor	24/05/2018	<ol style="list-style-type: none"> <li>1. To clarify the legal basis for the processing of Civil Registrations Data, and before data can flow.</li> <li>2. 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.</li> <li>3. To clarify who has access to and the level of data accessed for Cancer Waiting Times including the appropriate controls in place for those staff accessing the data and the agreements in place with NHS Digital.</li> <li>4. To clarify who has access to the flexible analytical tool iView Plus and clarification of the what data and the type of data held within the tool.</li> <li>5. To clearly describe why the process for the collection and analysis of PLICS data has not been used in the Cancer Waiting Time data.</li> <li>6. To clearly describe the type and level of data both the Data Controllers and Data Processors are accessing, including the Competition &amp; Markets Authority.</li> </ol>	IGARD Members	Quorum of IGARD Members	<ul style="list-style-type: none"> <li>• The following amendment is made to the abstract: the reference to Schedule 1 Part 1 of DPA 2018 should also make an assessment that the research is <b>in the public interest</b>.</li> </ul>

NIC-129819-V5P5Z	University of Sheffield	22/02/2018	<ol style="list-style-type: none"> <li>1. The fair processing notice for the applicant be updated to meet NHS Digital's nine minimum criteria (to be known as NHS Digital's fair processing criteria) for privacy notices, specifically providing additional contact details (email and/or postal address) for the cohort to opt out and expressly referring to the NHS Digital's involvement, and before data can flow.</li> <li>2. References to not accessing the data of non-respondents should be included within section 5b of the application in line with the HRA CAG final approval.</li> <li>3. Clarifying why the University of Leeds is not listed as a joint Data Controller, as both the University of Leeds and the University of Sheffield are running the study and the Chief Investigator is a substantive employee of Leeds University.</li> <li>4. To clarify within section 5 that this application does not include any dissemination of data for the longitudinal research cohort.</li> <li>5. To clarify in section 5 of the application that this application does not involve any dissemination of data for the longitudinal cohort.</li> </ol>	IGARD Members	Quorum of IGARD Members	<ul style="list-style-type: none"> <li>• The PN needs to be brought to <b>GDPR standard</b> within one month.</li> <li>• The application needs updating to include lawful basis under Art 6&amp;9 GDPR (see email to Dave Cronin 15.6.18) <ul style="list-style-type: none"> <li>- refer to supporting education legislation in support of university charter</li> <li>- refer to additional conditions in DPA 18 i.e. that the processing is in the public interest</li> </ul> </li> <li>• [IGARD] advise that references to consent in the cross-sectional study part of the PN are removed as they are potentially misleading.</li> </ul>
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NIC-177068-M1POL	Office for National Statistics	07/06/2018	2. 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.	IGARD Members	Service Director, Data Dissemination	N/A
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In addition, the following applications were not considered by IGARD but have been progressed for IAO and Director extension/renewal:

- None notified to IGARD