

Independent Group Advising on the Release of Data (IGARD)

Minutes of meeting held 7 November 2019

In attendance (IGARD Members): Kirsty Irvine (Chair), Eve Sariyannidou, Geoffrey Schrecker, Maurice Smith.

In attendance (NHS Digital): Nicola Bootland, Stuart Blake, Garry Coleman, Louise Dunn, Dickie Langley, Karen Myers, Kimberley Watson, Alyson Whitmarsh, Vicki Williams.

Not in attendance (IGARD Members): Sarah Baalham, Anomika Bedi, Maria Clark, Nicola Fear.

Observers: Mujiba Ejaz, Michael Tsangari

1	<p>Declaration of interests:</p> <p>Maurice Smith and Geoffrey Schrecker highlighted their roles as active / retired GP's in relation to the NHS GP Workforce Statistics Briefing Paper (item 2.2). This was not considered a conflict of interest and both members remained in the room for the discussion.</p> <p>Review of previous minutes and actions:</p> <p>The minutes of the 31st October 2019 IGARD meeting were reviewed and subject to a number of minor amendments 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	Data applications
2.1	<p><u>Clinical Registries, Databases and Audits – Briefing Paper (Presenter: Dickie Langley)</u></p> <p>The briefing paper was to inform IGARD about the new Clinical Registries, Databases and Audits product. In line with the Data Services for Commissioners Directions, NHS England requires defined clinical data extracts from specified Clinical Databases, Registries and Audits to be able to fulfil their statutory functions as a commissioner of NHS Services, as determined by the Health and Social Care Act 2012.</p> <p>The briefing was an 'overarching briefing' which intends to cover all relevant information to the inclusion of any clinical database or audit in the NHS England and NHS Digital Data Sharing Agreement (DSA) as all the material details in terms of legal basis for the purposes for and processing of the data flows is the same for all Clinical Database, Registry and Audit extracts.</p> <p>This briefing paper was previously presented to IGARD on the 17th October 2019, where IGARD made a number of comments and suggested amendments.</p> <p>IGARD welcomed the updated draft briefing paper and made the following additional comments, and looked forward to receiving the further updated briefing paper before the 12th December 2019 meeting:</p> <ol style="list-style-type: none">1. To clearly outline within the briefing paper and relevant appendices who the Data Controller(s) and Data Processor(s) are and why.2. To be explicit within section 3 if there is scope for anyone else to be considered as a joint Data Controller for Clinical Registries.3. To provide a clear explanation in section 3 why NHS Digital is regarded as a joint Data Controller since it acts under the direct instruction and mandatory request of NHS England which is the Data Controller.

	<ol style="list-style-type: none"> 4. To explain in section 1.7 why it is NHS England that would carry out validation of the legal basis for each registry, audit and database and provide assurances and not the corresponding Data Controllers and why NHS Digital is not part of this process especially as it is described in the briefing paper as a joint Data Controller. 5. To make it clear in the executive summary that the briefing paper relates to a product currently containing just four data sets. 6. To clarify how the issue of data minimisation will be addressed by the applicant(s) within application(s). 7. To check that the privacy notices for the Clinical Registries includes information on how the data will be used and reflects that the data will be used for commissioning. 8. To expand point 2.5 within the paper to include further details on the scope and to specifically state that currently the registry data cannot be used for research. 9. To update point 7.5 within the paper to confirm that any data linkage will be detailed within the application(s). 10. To make it clear within the paper that NHS Digital are putting together a dataset for the commission of services that future commissioners may want to access. 11. To make it clear within the executive summary that this briefing paper is designed for commissioning and to outline what it does not cover in particular, the paper may wish to focus on the generic commissioning by NHS England for specialised services rather than specifying CCGs 12. To update the briefing paper to include the minutes from the 17th October 2019 IGARD meeting (and the minutes from the 7th November 2019 once ratified).
<p>2.2</p>	<p><u>NHS GP Workforce Statistics – Briefing Paper (Presenter: Alyson Whitmarsh / Nicola Bootland)</u></p> <p>The briefing paper was to inform IGARD about the General Practice (GP) Workforce data set, which contains data on individual staff members providing services at a General Practice in England. The Department for Health and Social Care (DHSC) and other Arms-Length Bodies (ALBs) use the data for policy formulation and workforce planning.</p> <p>The General Practice (GP) workforce data set is currently being onboarded into NHS Digital's Data Access Request Service (DARS) at the request of stakeholders. This data has been collected by NHS Digital via the National Workforce Reporting System (NWRS), formally known as the Primary Care Web Tool, since Sept 2015. Prior to that, an annual GP workforce census used information provided by National Health Applications and Infrastructure Services (NHAIS).</p> <p>Noting that this briefing was still a “work-in-progress”, IGARD welcomed the draft briefing paper and offered additional support out of committee from a GP specialist member and looked forward to receiving the updated briefing note at a future meeting.</p> <p>IGARD provided the following comments:</p> <ol style="list-style-type: none"> 1. To include two additional sections to the briefing paper: <ol style="list-style-type: none"> a. the purpose for processing including the type of data for each purpose; and b. the type of processing activities undertaken and why (which will link to the legal basis). 2. To include a section detailing who the Data Controllers are for each processing activity, once they have been clearly defined in point 1. 3. To create a separate section for “<i>Transparency</i>” in order to clearly outline the fair processing undertaken. 4. To clearly describe the actors involved, where the data is coming from and what organisations may have interest in the dataset either now or in the future.

	<ol style="list-style-type: none"> 5. To make it clear why the national insurance number is being requested, and that it will not be disseminated to customers nor used for processing. 6. To update the paragraph on page 5 <i>“Where the applicant does not have a lawful basis to request identifiable data...”</i> to make clear that the applicant must be clear what the legal basis is. 7. To provide further clarity on the right to opt-out for the data subjects involved. 8. To remove section 7 since it is no longer relevant. 9. To update the data flow diagram to correctly reference pseudonymised, identifying and aggregated data. 10. To clarify what data won't be permitted to be published, as outlined in the technical specification (not included within the supporting documentation provided). 11. To ensure that when this briefing paper returns to IGARD, that the DPIA, technical specification and any papers submitted to EMT (and any related minutes, note of approval etc) should also be included in the pack. 12. To update the briefing note to include the IGARD minutes from the meeting of the 7th November, once ratified.
2.3	<p><u>Dr Foster Limited: Summary Hospital-level Mortality Indicator (SHMI) data (Presenter: Stuart Blake) NIC-368020-R5L2K</u></p> <p>Application: This was an amendment application to include pseudonymised summary Hospital-level mortality Indicator, an additional analytical service for NHS customers. The primary objective of processing is to produce and analyse statistics so that NHS organisations can use to improve their understanding of mortality. Dr Foster provides their NHS customers with a dashboard that allows them to analyse and benchmark their performance in terms of the Summary Hospital Mortality Indicator (SHMI) measure of mortality as compared to the Hospital Standardised Mortality Ratio (HSMR) produced by Dr Foster. In addition to this free of charge dashboard, Dr Foster wish to provide a value-added service which will be chargeable.</p> <p>Discussion: NHS Digital advised IGARD that an audit was undertaken on Dr Foster Limited at the end of October 2019, however the audit report findings were currently not published. IGARD noted that since they had not been made aware of the audit report findings asked that NHS Digital provide written confirmation that there was no major non-conformity(ies) raised during the recent audit.</p> <p>IGARD queried if the reports and outputs that Dr Foster Limited were producing for customers would not include pseudonymised record level data and asked that this was clarified in section 5(a) (Objective for Processing); and that this was also included as a special condition in section 6 (Special Conditions).</p> <p>IGARD noted that when this application was previously reviewed on the 15th November 2018, IGARD had advised that on renewal the applicant should provide further details of the benefits, which could include a representative case study from a user of the tool. IGARD reiterated this point and asked that specific analyses were provided of how the yielded benefits had benefitted and made a difference to the health and social care system.</p> <p>IGARD queried how the new products outlined in the application would result in outputs that benefitted patients and asked that this was clearly articulated in section 5(d) (Benefits).</p> <p>Outcome Summary: recommendation to approve subject to the following conditions:</p> <ol style="list-style-type: none"> 1. To provide written confirmation that there were no major non-conformity(ies) raised in the recent (October 2019) audit.

	<p>2. To clarify in section 5(a) that the reports and outputs that Dr Foster Limited are producing for customers will not include pseudonymised record level data; and to include this text as a special condition in section 6.</p> <p>The following amendments were requested:</p> <ol style="list-style-type: none"> 1. Reiterating the request from the previous IGARD review on 15 November 2018, to provide specific analysis how the yielded benefits have benefitted and made a difference to the health and social care system (for example by way of a representative case study from a user of the tool). 2. To clearly articulate in section 5(d) how new product(s) will result in outputs that will benefit patients. <p>It was agreed the condition would be approved OOC by IGARD members.</p>
2.4	<p><u>NHS Health Scotland: Evaluating the impact of minimum unit pricing on alcohol attributable hospital admissions and deaths in Scotland (Presenter: Dave Cronin) NIC-250023-M6T9H</u></p> <p>Application: This was a new application for aggregated Hospital Episode Statistics (HES) Admitted Patient Care data. NHS Health Scotland has been commissioned by the Scottish Government to lead the evaluation of minimum unit pricing (MUP) for alcohol, which was implemented in Scotland on 1st May 2018. A portfolio of studies has been developed by NHS Health Scotland to evaluate MUP. The purpose of this study is to examine trends and patterns in alcohol-attributable hospital admissions in Scotland, making comparisons with England and two large, sub-national regions of England. The study will also use statistical techniques to assess the isolated impact of MUP on these trends.</p> <p>Discussion: IGARD welcomed the application and noted the importance of the study.</p> <p>IGARD noted the University of Glasgow was referenced as the Data Processor and asked that a written explanation was provided clarifying why the University of Glasgow was not considered a joint Data Controller, in light of the information provided.</p> <p>In addition, it was noted that there was a specific individual named within supporting document 2.0, the study protocol, and asked that the individuals employing organisation(s) was also noted; and that if necessary, they were also added as a joint Data Controller(s).</p> <p>IGARD queried the reference to the organisation “ATOS” within the application and if they were just providing the ‘building’, and asked that further clarity was provided on their role; and that if necessary that ATOS were also added as a Data Processor for the study.</p> <p>IGARD discussed the legal requirements for data minimisation and establishing the necessity for processing the data; and asked that further clarity was provided as to why ‘English’ data was necessary, for example to provide an explanation as to why the statistical data control of data from Scotland only was not sufficient to achieve the stated aims and outputs. IGARD also asked that if data from England was necessary that confirmation was provided as to why data was required for the whole of England and not just a smaller cross section of different socio-geographical areas in England.</p> <p>IGARD asked that once a case had been established for requiring England data, that a detailed explanation was provided outlining why the outputs of the research would be relevant to or would benefit England in order to influence policy.</p> <p>IGARD noted that the majority of the benefits outlined were specifically for Scotland, and queried the legal basis for NHS Digital to flow the data under the Health and Social Care Act 2012, specifically in terms of the benefit to health and social care in England and Wales and asked that this was clearly established.</p>

	<p>IGARD queried the reference in section 5(a) (Objective for Processing) to “<i>un-suppressed aggregated data</i>” and asked that clarification was provided as to why this was necessary.</p> <p>IGARD noted reference to a number of technical phrases and words within section 5 (Purpose / Methods / Outputs) and suggested that it be updated to ensure the use of technical jargon was used only where necessary and that it was written in a language suitable for a lay reader.</p> <p>IGARD queried the reference in section 5(c) (Specific Outputs Expected) that stated “<i>Small numbers will be suppressed in line with the HES Analysis Guide</i>” and asked that further clarity was provided.</p> <p>Outcome Summary: Recommendation to defer, pending:</p> <ol style="list-style-type: none"> 1. To provide a written explanation why the University of Glasgow are not considered a joint Data Controller. 2. To note the employing organisation(s) for the individuals referenced in the Protocol; and, if necessary, to be added as a joint Data Controller(s). 3. To provide further clarity on the role of ATOS; and if necessary to be added as a Data Processor. 4. In order to address the legal requirements for data minimisation and establishing the necessity for processing the data: <ol style="list-style-type: none"> a. to clarify why England data is necessary (e.g. explain why the statistical data control of Scotland data only is not sufficient to achieve the stated aims and outputs). b. if England data is necessary, to confirm why data is required for the whole of England and not just a smaller cross section of different socio-geographical areas in England. 5. To establish the legal basis for NHS Digital to flow the data under the Health and Social Care Act 2012 (in terms of it being for the benefit of health and social care in England and Wales (where the majority of the benefits of the study are expressed to be accruing to Scotland)). 6. To clarify in section 5(a) why unsuppressed aggregated data is necessary. 7. To provide detailed explanation as to why the outputs of the research would be relevant to or would benefit England so as to influence policy. 8. To update section 5 to ensure the use of technical jargon is used only where necessary; and where it is necessary, to be also written in language suitable for a lay reader. 9. To provide further clarity on the reference in section 5(c) to “<i>Small numbers will be suppressed in line with the HES Analysis Guide</i>”
2.5	<p><u>Monitor: IGARD amendments Sept 2019; include NHSE as a data controller, Plics timescales/sharing Plics data with NHSE, add PROCODE field in HESMMES, Theatres Data set Mandatory request and CSDS disclosure rules (Presenter: Louise Dunn) NIC-15814-C6W9R</u></p> <p>Application: This was an amendment application to 1) add NHS England as a joint Data Controller for all datasets disseminated to NHS Improvement under this Data Sharing Agreement (DSA); 2) include key updates for timescales relating to Patient Level Information Costings System (PLICs) data collections and a request to share this data with NHS England 3) request “PROCODE” field in the HESMMES dataset; and 4) add receipt of theatres data set discovery collection as per mandatory request and add disclosure control rules for Community</p>

	<p>Service Data Set (CSDS). The data will be used to support the delivery of their statutory function and support direct improvement and / or oversight of Trusts.</p> <p>Discussion: IGARD discussed the amendment request to add NHS England as a joint Data Controller and queried which datasets outlined in this Data Sharing Agreement (DSA) would flow to NHS England in order for them (NHS England) to perform their statutory functions; and asked that an official document was produced that expressly set out the mandatory request for the relevant datasets and uploaded to NHS Digital's Customer Relationship Management (CRM) system for future reference.</p> <p>IGARD queried the reference within section 5 (Purpose / Methods / Outputs) to the private organisation "<i>Circle</i>" and asked that further consideration was given to whether it was still necessary and accurate to refer to this organisation.</p> <p>IGARD noted that some of the acronyms within the application were not always defined upon first use and suggested the application be amended as necessary to make this clear.</p> <p>Outcome Summary: Recommendation to defer, pending:</p> <ol style="list-style-type: none"> 1. To produce the appropriate official document that expressly sets out the mandatory request for the datasets that would flow to NHS England in order for NHS England to perform its statutory functions. 2. To consider the reference to the private organisation "<i>Circle</i>" within the application and check it is still necessary and accurate. 3. IGARD suggested that all acronyms upon first use in the application be defined and further explained, as may be necessary for a lay reader.
2.6	<p><u>NHS Berkshire CCG: DSfC - NHS Berkshire West CCG - Comm, RS, IV (Presenter: James Humphries-Hart) NIC-186881-Z9P9B</u></p> <p>Application: This was an amendment application to add Graphnet Health Ltd and Microsoft UK as Data Processors; and a renewal application for pseudonymised 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 (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), Civil Registries Data (CRD) (Births), Civil Registries Data (CRD) (Deaths), National Diabetes Audit (NDA) and Patient Reported Outcome Measures (PROMs).</p> <p>The purpose is for Invoice Validation (IV) which is part of a process by which providers of care or services are paid for the work they do, Risk Stratification (RS) which is a tool for identifying and predicting which patients are at high risk or likely to be at high risk and prioritising the management of their care; and to provide intelligence to support the commissioning of health services.</p> <p>Discussion: IGARD noted that this application was similar to the application presented on the 17th October 2019 for NHS Buckinghamshire CCG (NIC-186888-X2K6T) and that there was an ongoing action for IGARD and NHS Digital to review the Risk Stratification Precedent. IGARD also confirmed that they would be speaking with the Caldicott Guardian regarding the difficulty of applying the national data opt-out, in-line with operational guidance, where the Data Processor is receiving identifiable data which is used for both direct care and purposes other than direct care.</p> <p>IGARD noted that the yielded benefits in section 5(d) (Benefits) (iii) (Yielded Benefits) had not been completed and asked that this was updated to reflect this information.</p>

	<p>IGARD noted the reference in section 5(c) (Specific Outputs Expected) that Graphnet Healthcare Ltd would be working in partnership with the US organisation John Hopkins ACG, and asked that a special condition was added to section 6 (Special Conditions) confirming that no data would be shared with John Hopkins ACG.</p> <p>IGARD queried how the identifiable data would be flowed to the CCG's and asked that a special condition was added to section 6 stating that the identifiable data would not flow to the CCG's via Graphnet Healthcare Ltd.</p> <p>IGARD queried what pseudonymised and identifiable data flowed between the Data Processors, GP's and the CCG's as outlined in the application, and asked that further clarification was provided outlining this.</p> <p>IGARD noted the information provided in section 5(b) (Processing Activities) on "segregation" and asked that this was amended to clarify that the data would be segregated from that for the purpose of direct care.</p> <p>IGARD noted the statement provided in section 5(b) that stated <i>"Microsoft UK supply Cloud Services for Graphnet Healthcare Ltd and are therefore listed as a data processor. They supply support to the system, but do not access data. Therefore, any access to the data held under this agreement would be considered a breach of the agreement. This includes granting of access to the database[s] containing the data."</i> and asked that this was amended to make it explicitly clear that Microsoft UK would store but not otherwise process the data.</p> <p>Outcome Summary: recommendation to approve</p> <p>The following amendments were requested:</p> <ol style="list-style-type: none"> 1. To update the yielded benefits section of the application. 2. To update section 6 to include a special condition that no data will be shared with John Hopkins ACG. 3. To update section 6 to include a special condition that the identifiable data does not flow to the CCG's via Graphnet Healthcare Ltd. 4. To set out further clarification of the flows of pseudonymised and identifiable data between the Data Processors, GP's and CCG's. 5. To amend the "Segregation" section in 5(b) to clarify that the data will be segregated from that for the purpose of direct care. 6. To amend section 5(b) to make explicitly clear that Microsoft UK will store but not otherwise process the data.
3	<p><u>Oversight and Assurance: 5a Objective for Processing and 5e Commercial Purpose Standard and Commercial Applications</u></p> <p>The Associate Director Data Dissemination, Garry Coleman, attended IGARD to discuss with members the Objective for Processing (5a) and Commercial Standard (5e) and commercial applications in general.</p> <p>It was agreed that the Commercial Purpose Standard 5e would be updated to reflect discussions with NHS Digital and recirculated to both NHS Digital and IGARD for further comments and that the Objective for Processing Standards 5a be added to next week's meeting for further discussion.</p>
4	<p><u>AOB:</u></p>

	There was no further business raised, the IGARD Chair thanked members and NHS Digital colleagues for their time and closed the meeting.
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Independent Group Advising on Releases of Data (IGARD): Out of committee report 01/11/19

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-15625-T8K6L	Medicines and Healthcare Products Regulatory Agency (MHRA)	17/10/2019	1. To insert a new "Sub-licencing" section in the application to draw together all the statements (or to include additional information or refer to where supporting information can be found) to address all of the requirements of NHS Digital's Sub-licencing Standard.	Quorum of members	OOO by Quorum of members	N/A

In addition, the following applications were not considered by IGARD but have been progressed for IAO and Director extension/renewal:

- None