

Independent Group Advising on the Release of Data (IGARD)

Minutes of meeting held 27th February 2020

In attendance (IGARD Members): Sarah Baalham, Maria Clark, Nicola Fear, Kirsty Irvine (Chair), Maurice Smith.

In attendance (NHS Digital): Nicola Catto (Item 2), Rich Cole (Item 2), Dave Cronin, Arjun Dhillon (Item 5), Louise Dunn, Karen Myers, Peter Short (Item 5), Vicki Williams.

Not in attendance (IGARD Members): Anomika Bedi, Geoffrey Schrecker.

Observers: Noor Altuf (Item 2), Frances Hancox (Items 3.4, 3.5, 4, 6.1), Jonathan Trepczyk (Item 2)

1	<p>Declaration of interests:</p> <p>There were no declarations of interest.</p> <p>Review of previous minutes and actions:</p> <p>The minutes of the 6th February 2020 IGARD meeting were reviewed and subject to a number of amendments were agreed as an accurate record of the meeting.</p> <p>The minutes of the 13th February 2020 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	<p><u>NHS e-Referral (e-RS) dataset – Briefing Paper (Presenters: Rich Cole / Nicola Catto)</u></p> <p>The briefing paper was to inform IGARD about the NHS e-Referral Service (e-RS) dataset, which NHS Digital have been directed to establish and operate by the Secretary of State for Health and Social Care.</p> <p>The NHS e-RS went live in June 2015 and is a national IT system that enables patient referrals, primarily from GPs to first hospital or clinic appointments, to be booked into health care services at a location, date and time to suit the patient. GPs and hospitals are obliged, via their respective contracts, to ensure that all GP to consultant referrals are made via e-RS.</p> <p>The primary purpose of processing e-RS data is to enable the correct operation of the e-RS system, subsequent processing transforms the data into appropriate extracts for recipients.</p> <p>IGARD welcomed the draft briefing paper and looked forward to receiving an updated briefing paper in due course. IGARD made the following additional comments:</p> <ol style="list-style-type: none">1. To provide a copy of the Data Protection Impact Assessment (DPIA) (along with the updated briefing paper).2. To provide further background as to why the Direction for NHS Digital was established, in particular to provide clarity as why the potential recipients of this data were so wide-ranging.3. To amend the reference in point 4.4 from “<i>inappropriate referrals</i>” to “<i>unwarranted clinical variation</i>”.4. To amend point 4.4 to expand further to clarify who will undertake the analysis.5. To make clear in section 1 who the Data Controllers and Data Processors are.

	<p>6. To update point 6.2 to replace the reference to “<i>Clear disseminations</i>” with “<i>identifiable</i>”.</p> <p>7. To update section 9 of the briefing paper to include the General Data Protection Regulation (GDPR) Article 9 legal basis.</p> <p>8. To revise the statement in section 12 in relation to retaining the data.</p>
3	Data Applications
3.1	<p><u>Carnall Farrar: Application for Carnall Farrar to access NHS Digital data, to permit more detailed insights into the needs of the population and the challenges facing the system when shaping clinically and financially sustainable health and social care services across England. (Presenter: Dave Cronin) NIC-243790-Y8K8C</u></p> <p>Application: This was a new application for pseudonymised Hospital Episode Statistics (HES), Secondary Uses Service (SUS+), Emergency Care Data Set (ECDS), Mental Health Services Data Set (MHSDS) and Mental Health Minimum Data Set (MHMDS). The purpose is to control the conditions of data aggregation, perform bench-marking analysis as well as specific demands of the NHS stakeholders, to allow them to make effective decisions based on the most up-to-date information.</p> <p>NHS Digital advised IGARD that following the meeting on the 26th September 2019 where IGARD had recommended the application for approval, further significant updates had been made to section 5(a) (Objective for Processing) at the request of NHS Digital’s Associate Director, Data Access.</p> <p>Discussion: IGARD noted the update provided by NHS Digital in relation to the significant updates that had been made to the application following the last review by IGARD on the 26th September 2019. IGARD queried if any data had been disseminated to the applicant since the last review and were advised by NHS Digital that no data had flowed.</p> <p>IGARD noted the effort that had been made to update section 5(a) (Objective for Processing) to ensure this was in-line with NHS Digital’s current Commercial Purpose Standard 5(e); however asked that section 5(e) of the application (Is the Purpose of this application in anyway commercial) was revised further to reflect the Standard such as the point where money is paid for a service, noting that the Standard was currently in the process of being reviewed; and that this was the consistent approach taken by IGARD with other recent commercial applications submitted to IGARD.</p> <p>IGARD queried the figures quoted in section 5(d) (Benefits) and asked that the applicant ensured that these figures were both realistic and achievable with the data being requested; that this section was updated as far as possible, noting that some of the dates referenced had now lapsed (for example the reference to expected savings of £490m over a four-year period).</p> <p>IGARD noted that section 5(a) referenced “<i>7 NHS organisations</i>” under the ‘Current users’ heading, however only 6 NHS organisations had been listed; and asked that this was updated to list all of the relevant NHS organisations.</p> <p>IGARD noted the reference to Carnall Farrar’s internal Data Security Committee in section 5(b) (Processing Activities) and suggested that they may wish to consider independent public/patient involvement as part of this Committee (as previously advised on the 26th September 2019).</p> <p>Outcome Summary: recommendation to approve</p> <p>The following amendments were requested:</p>

	<ol style="list-style-type: none"> 1. To revise section 5(e) to reflect NHS Digital's Commercial Purpose Standard 5(e) (currently in the process of being updated). 2. To ensure that that the figures quoted in section 5(d) are both realistic and achievable with the data being used; and that this section is as up to date as possible noting some of the dates have lapsed, for example the £490m of savings referenced. 3. To update the list of "<i>current users</i>" in section 5(a) to ensure all the relevant NHS organisations are listed. <p>The following advice was given:</p> <ol style="list-style-type: none"> 1. IGARD suggested that Carnall Farrar's internal Data Security Committee may wish to consider independent public and patient involvement.
<p>3.2</p>	<p><u>British Thoracic Society: BTS National Adult Community Acquired Pneumonia Audit 2018-19 (Presenter: Dave Cronin) NIC-219944-G9X4V</u></p> <p>Application: This was a new application for pseudonymised Civil Registrations and Hospital Episode Statistics (HES) data for the purpose of linkage with data collected by the British Thoracic Society (BTS) Adult Community Acquired Pneumonia (CAP) Audit 2018/19, to enable a more accurate analysis of a wider range of important outcome measures including mortality after discharge and readmission rates. The additional data will also allow further review on the presence of one or more additional conditions, whilst considering their current social class and living conditions, as these are known factors in increased risk of developing CAP.</p> <p>NHS Digital advised IGARD, that following submission of the application for their review, the applicant had also confirmed that in addition to the data requested within the application, they also required an additional month's worth of data for April 2019 and that this amendment was not outlined in the application IGARD had reviewed.</p> <p>Discussion: IGARD noted the update from NHS Digital in relation to the additional data requested by the applicant for April 2019; and that this was in addition to the request outlined in the application they had reviewed. NHS Digital noted that the application had been subsequently updated to reflect the addition of this data and that the purpose of the application remained unchanged.</p> <p>IGARD commended the effort that had gone into the application, specifically in relation to minimising the data requested and section 5(d) (Benefits).</p> <p>IGARD noted and endorsed NHS Digital's review that the applicant did not meet NHS Digital's Standard for privacy notices.</p> <p>IGARD queried if the applicant's NHS Health Research Authority Confidentiality Advisory Group (HRA CAG) Annual Review had been submitted, and were advised by NHS Digital that this had been completed; IGARD asked that for audit purposes that this was added to NHS Digital's Customer Relationship Management (CRM) system.</p> <p>IGARD noted the information provided in section 5(a) in relation to the patient group that had been consulted as part of the proposed audit; and asked that this was further updated to include details of the range of continued patient involvement, in-line with the condition which was part of the ongoing support by HRA CAG.</p> <p>IGARD noted the reference to "<i>Westcliff</i>" within section 5(a) (Objective for Processing); and asked that this was amended to ensure the full reference of "<i>Westcliff Solutions Limited</i>" was referenced upon first use.</p> <p>IGARD queried the reference in section 5(c) (Specific Outputs Expected) to "<i>pseudo anonymised</i>" and asked that this was updated to correctly state "<i>pseudonymised</i>".</p>

	<p>IGARD noted and supported the statement in section 7 (Ethics Approval) that ethics approval was not required due to the data being used for purposes defined as audit; and asked that in addition, confirmation was also provided in section 1 (Abstract) that any local ethical or governance approvals for clinical audit had been considered and were not required.</p> <p>Outcome Summary: recommendation to approve</p> <p>The following amendments were requested:</p> <ol style="list-style-type: none"> 1. To amend section 5(a) to ensure the reference to “<i>Westcliff Solutions Limited</i>” is referenced in full upon first use. 2. To provide further detail in section 5(a) of the range of continued patient involvement. 3. To update section 5(c) to replace the reference to “<i>pseudo anonymised</i>” with “<i>pseudonymised</i>”. 4. To confirm in section 1 that any local ethical or governance approvals for clinical audit have been considered and are not required.
<p>3.3</p>	<p><u>University of Cambridge: Pregnancy Outcome Prediction Study: transgenerational and adults review (POPStar) (MR1489) (Presenter: Louise Dunn) NIC-261326-F9S5D</u></p> <p>Application: This was a new application for identifiable Medical Research Information Service (MRIS) and pseudonymised Hospital Episode Statistics (HES) data. The purpose of the study is to look at pairs of mothers and children with whom very detailed information was collected in a separate study (Pregnancy Outcome Prediction Study (POPS)), to link detailed pregnancy data of participants to their later-life health and educational outcomes. The over-arching aim of this application is to explore new ways of interpreting pregnancy data to find out how this relates to long-term health outcomes in women and their children.</p> <p>NHS Digital advised IGARD that although there was reference to MRIS List Cleaning Report in section 5 (Purpose / Methods / Outputs) of the application, this had not been referred to in section 1 (Abstract) and that this would be updated accordingly.</p> <p>Discussion: IGARD noted the additional amendment outlined by NHS Digital, to update section 1 to reference the MRIS List Cleaning Report as outlined in section 5 of the application.</p> <p>IGARD noted and endorsed NHS Digital’s review that the applicant did not meet NHS Digital’s Standard for privacy notices as confirmed in section 1; and asked that section 4 was updated to correctly state that the applicant’s privacy notice ‘does not’ meet the NHS Digital’s Standard for privacy notices.</p> <p>IGARD noted that even though the applicant was relying on section 251 support as the legal basis, consent forms were usually provided as supporting documents, to ensure that the processing was not in contrary to any express statement or undertaking in the consent materials. Accordingly, IGARD requested to see a copy of the latest consent materials and Patient Information Sheet, to ensure that these were consistent with the proposed processing outlined.</p> <p>IGARD noted the high standard of materials for participants and the consultation with youth groups, but suggested that if any of the transparency materials were revised, the applicant may wish to consider making these more visual for the 8-10-year olds involved in the study, rather than it being predominately text.</p> <p>IGARD queried the reference in section 1(c) (Data Processor(s)) to Virgin Care Ltd acting as a Data Processor; and noting that there was no reference elsewhere within the application to this organisation, asked that a description was provided of their role as a Data Processor within section 5 (Purpose / Methods / Outputs) or they be removed as a Data Processor.</p>

<p>IGARD also queried the reference within section 1(c) to the Healthcare Quality Improvement Partnership (HQIP) as Virgin Care Ltd's 'DPA Organisation Name' and asked that further clarity of this was provided or the correct information be included within the application.</p> <p>IGARD noted the incorrect references throughout the application to the "<i>Office <u>of</u> National Statistics</i>" and asked that these were updated to correctly state the "<i>Office <u>for</u> National Statistics</i>".</p> <p>IGARD noted the references within section 1 and section 5(a) (Objective for Processing) to "<i>pregnancy until delivery</i>" and suggested that the word "<i>delivery</i>" was replaced with the term "<i>birth</i>".</p> <p>IGARD queried the statement in section 5(c) (Specific Outputs Expected) "<i>The University of Cambridge will also engage in public engagement activities...</i>" and asked that this was updated with further information of the type of public engagement activities being undertaken.</p> <p>IGARD queried the 'amendment' that was referenced in supporting document 1.2, the NHS Health Research Authority – East of England – Cambridge Central Research Ethics Committee letter; and asked that a further explanation was provided of the amendment; or that the supporting document was removed if this was deemed not relevant.</p> <p>IGARD noted the medical benefits of the study outlined in the application; and asked for a more detailed explanation of the specific benefits to the children involved. In addition, a further outline of the benefits of linking the Health and Social Care data to the Department for Education data and that further details were provided of how this would flow.</p> <p>IGARD queried text within section 1 in relation to "ONS SRS" and were advised by NHS Digital that this had been added in agreement with NHS Digital's Security Advisor. IGARD noted the inclusion and asked that for ease of reference this was made clear within section 1 by adding "<i>assured by the NHS Digital security advisor...</i>" or such like.</p> <p>Outcome Summary: recommendation to approve subject to the following conditions:</p> <ol style="list-style-type: none"> 1. To provide IGARD with a copy of the latest consent materials and the Patient Information Sheet; and to ensure these are consistent with the proposed processing outlined. 2. To provide a description of Virgin Care Ltd's role as a Data Processor within Section 5; and to clarify the reference to HQIP as Virgin Care Ltd's 'DPA Organisation Name' within the application. <p>The following amendments were requested:</p> <ol style="list-style-type: none"> 1. To ensure all references to the 'Office <u>for</u> National Statistics' are correctly referenced throughout the application. 2. To update section 4 to correctly state that the applicant's privacy notice 'does not' meet the NHS Digital's Standard for privacy notices. 3. To replace the reference to "<i>delivery</i>" in section 1 and section 5(a) with "<i>birth</i>". 4. To update section 5(c) to provide further information on the public engagement activities referenced. 5. To provide a further explanation to the 'amendment' referred to in SD1.2; or to remove the supporting document if this is deemed not relevant. 6. To provide a more detailed explanation of the benefits to the children involved in the study; and an outline of the benefits of linking the Health and Social Care data to DfE data and further details of how this will flow. 7. To update section 1 to clearly reference the text that has been agreed with NHS Digital's Security Advisor. 8. To update section 1 to specify that this application is also for a list clean.
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	<p>The following advice was given:</p> <ol style="list-style-type: none"> 1. IGARD suggested that if any of the transparency materials were revised, the applicant may wish to consider making these more visual for the 8-10-year olds involved in the study. <p>It was agreed the condition would be approved Out of Committee (OOC) by IGARD members.</p>
3.4	<p><u>Medicines and Healthcare Products Regulatory Agency (MHRA): Clinical Practice Research Datalink (CPRD) Routine Linkages Application (Presenter: Louise Dunn) NIC-15625-T8K6L</u></p> <p>The application was withdrawn by the presenter at the request of IGARD due to the minutes of the 6th February 2020, where this application was last discussed, not being published.</p>
3.5	<p><u>London Ambulance Service NHS Trust: MPDS Maternity Study (Presenter: Louise Dunn) NIC-320147-M9K6K</u></p> <p>Application: This was a new application for pseudonymised Hospital Episode Statistics (HES) and Emergency Care Data Set (ECDS), for the purpose of a study looking at a number of queries in relation to the Advanced Medical Priority Dispatch System (MPDS) Protocol 24, which is used to triage 999 callers with pregnancy, childbirth and miscarriage related issues.</p> <p>The study aims to 1) determine the accuracy of MPDS Protocol 24 in identifying maternity emergencies; 2) to identify predictors of maternity emergencies at the time of 999 call that can alert emergency medical dispatchers (EMDs) to potentially life threatening conditions developing; 3) to identify which of the current key questions on MPDS predict maternity emergencies; 4) to understand the experiences of Emergency Medical Dispatchers in using Protocol 24 that would not be gained from analysing clinical data; and 5) To explore if MPDS Protocol 24 triage has any impact on how ambulance clinicians manage patients.</p> <p>Discussion: IGARD noted and endorsed NHS Digital's review that the applicant did not meet NHS Digital's Standard for privacy notices.</p> <p>IGARD queried if the applicant's NHS Health Research Authority Confidentiality Advisory Group (HRA CAG) Annual Review had been submitted, noting that this was due at the end of January 2020; and asked that section 1 was updated with confirmation of if it had been submitted and the date.</p> <p>IGARD queried the data minimisation efforts that had been considered for this study since the breadth of data requested did not all relate to a maternal emergency (Date Items Requested – supporting document 11) and the HRA CAG application (supporting document 12) stated that the applicant would not be including pregnant women under 16 years old, prisoners or patients who had previously indicated they did not wish to be involved in the research. IGARD suggested that section 3(b) (Additional Data Access Requested) be updated with further information to reflect the breadth of the data requested, such as the number of fields and if they are specific to maternal care. In addition, since the HRA CAG application stated that the lower age limit of the mother would be 16 years of age, that this be clearly specified in section 3(b) to be in line with the CAG support.</p> <p>IGARD queried the accuracy of the statistics provided in sections 5(a) (Objective for Processing) and section 5(d) (Benefits), for example “...<i>women from black and ethnic minority groups are four times more likely to die in childbirth...</i>”; and asked that these were revised to ensure they were accurate. In addition, IGARD suggested that references within the application to “<i>patients</i>” could be updated throughout to replace these references with “<i>women</i>”.</p>

	<p>IGARD queried the role of the funder; and were advised by NHS Digital that this had been discussed with the applicant who had confirmed that there was no commercial interest in this study: IGARD noted the update and asked that section 5 (Purpose / Methods / Outputs) was updated to state that the funder would not have any influence on the outcomes nor suppress any of the findings of the study.</p> <p>IGARD suggested that the applicant may wish to give further consideration to the dissemination of the outputs (as outlined in section 5(c)) to relevant cohort audiences, to make it more inclusive to those using the service.</p> <p>Outcome Summary: recommendation to approve</p> <p>The following amendments were requested:</p> <ol style="list-style-type: none"> 1. To update section 1 with confirmation that the HRA CAG Annual Review has been submitted. 2. To update section 3(b) with further information on the breadth of the data requested. 3. To specify in section 3(b) that the lower age limit of the Mother is 16 years, in line with HRA CAG support. 4. To revise the statistics quoted in section 5(a) and section 5(d) to ensure that they are accurate, for example in relation to <i>“...women from black and ethnic minority groups are four times more likely to die in childbirth...”</i>. 5. To confirm within section 5 that the funder will not have influence on the outcomes nor suppress any of the findings of the research. 6. To update the application throughout to replace the reference to <i>“patients”</i> with <i>“women”</i>. <p>The following advice was given:</p> <ol style="list-style-type: none"> 1. IGARD suggested that the applicant may wish to give further consideration to the dissemination of the outputs (as outlined in section 5(c)) to relevant cohort audiences.
4	<p><u>Returning Applications</u></p> <p>IGARD noted that they do not scrutinise every application for data, however they are charged with providing oversight and assurance of certain data releases which have been reviewed and approved solely by NHS Digital.</p> <ul style="list-style-type: none"> • NIC-363464-J4F8N The King’s Fund • NIC-351722-W7D4N CRAB Clinical Informatics • NIC-272668-H4M3S Wolfson Institute of Preventive Medicine • NIC-148468-KFJZ5 Ministry of Defence <p>IGARD welcomed the four applications as part of their oversight and assurance role and noted a number of comments to NHS Digital and suggested that further information and comments be provided in an IGARD Oversight and Assurance Report which would be published separately to the minutes of the meetings, for transparency of process, and on a quarterly basis.</p>
5	<p><u>GP Data for Planning and Research (Presenter: Dr Peter Short)</u></p> <p>NHS Digital’s Clinical Lead for GP Data for Planning and Research, Dr Peter Short attended IGARD to provide background and context in relation to the GP Data for Planning and Research Project that will be delivered by NHS Digital.</p> <p>IGARD welcomed the update and thanked Dr Peter Short for attending and looked forward to receiving further information in due course.</p>

6	<p><u>AOB:</u></p>
6.1	<p><u>Adult Social Care Surveys – Briefing Paper</u></p> <p>The briefing paper was previously discussed at IGARD on the 19th December 2019 and this updated version was provided to reflect comments provided at this meeting.</p> <p>The purpose of the briefing paper was to inform IGARD of two data sets that are due to be made available through the Data Access Request Service (DARS), the Adult Social Care Survey (ASCS) and the Survey of Adult Carers in England (SACE).</p> <p>Both of the surveys had previously been available to external customers, however this was outside of DARS processes. Historically, Adult Social Care Surveys have been managed and disseminated by NHS Digital’s Adult Social Care Statistics Team.</p> <p>Access to the Adult Social Care survey data is required for all Councils with Adult Social Services Responsibilities (CASSRs), for the purpose of: answering Freedom of Information (FOI) requests; benchmarking against other Councils; measuring / monitoring local performance; service development; planning and improvement; and management information, local reporting, accountability.</p> <p>IGARD welcomed the updated briefing paper and confirmed they had no further comments to make.</p>
6.2	<p>There was no further business raised, the IGARD Chair thanked members and NHS Digital colleagues for their time and closed the application section of the meeting.</p>

Independent Group Advising on Releases of Data (IGARD): Out of committee report 21/02/20

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-338789-M0T3Q	Group application for 3 CCG's The CCG's were: NHS Bedfordshire CCG; NHS Luton CCG; NHS Milton Keynes CCG	13/02/20	1. To remove the references to " <i>social care data</i> " from the application.	IGARD Chair	IGARD Chair	N/A
NIC-148331-5F2FS	St George's, University of London	13/02/20	1. To clearly state within the application that the retired Principal Investigatory Professor will not have any access to the data at SGUL.	IGARD Chair	IGARD Chair	N/A

In addition, a number of applications were processed by NHS Digital following the Precedents approval route. IGARD carries out oversight of such approvals and further details of this process can be found in the Oversight and Assurance Report.

In addition, a number of applications were approved under class action (addition of Liaison Financial Service and Cloud storage):

- None notified to IGARD