# Independent Group Advising on the Release of Data (IGARD) Minutes of meeting held via videoconference 26<sup>th</sup> March 2020

In attendance (IGARD Members): Anomika Bedi, Maria Clark, Kirsty Irvine (Chair), Geoffrey Schrecker, Maurice Smith.

**In attendance (NHS Digital):** Nicola Bootland, Dave Cronin, Louise Dunn, Karen Myers, Tracy Taylor.

In attendance (Office for National Statistics): Jim Newman, Jo Pickering (item 2).

Not in attendance (IGARD Members): Nicola Fear, Imran Khan.

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1	Declaration of interests:						
	There were no declarations of interest.						
	Review of previous minutes and actions:						
	The minutes and outcomes of the 19 <sup>th</sup> March 2020 IGARD meeting were reviewed out of committee by IGARD following conclusion of the meeting, and subject to a number of change were agreed as an accurate record of the meetings.						
	Out of committee recommendations:						
	An out of committee report was received (see Appendix B).						
2	Office for National Statistics (ONS) update on Longitudinal Study and Census (Presenters; Jim Newman / Jo Pickering)						
	Jim Newman and Jo Pickering from ONS attended IGARD to provide an overview of the ONS Longitudinal Study.						
	The study contains linked census and life event data on a one per cent sample of the population of England and Wales. It contains records on over 500,000 people at each point in time and it is largely representative of the whole population. The study is the largest longitudinal data resource in England and Wales.						
	The study has linked records at each census since the 1971 Census, for people born on one of four selected dates in a calendar year. These four dates were used to update the sample at the 1981, 1991, 2001 and 2011 Censuses. Life events data are also linked for study members, including births to sample mothers, deaths and cancer registrations. New members enter the study through birth and immigration (if they are born on one of the four selected birth dates).						
	IGARD welcomed the overview and thanked Jim and Jo for attending the meeting to provide the overview of the study and looked forward to welcoming the ONS application(s) in due course via Data Access Request Service (DARS).						
3	Data Applications						
3.1	NHS Gloucestershire CCG: DSfC - NHS Gloucestershire CCG / Gloucestershire County Council - Population Health (Presenter: Louise Dunn) NIC-343158-Z2L4D						
	<b>Application:</b> This was a new application for pseudonymised Secondary Uses Service (SUS+), 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), Civil Registries Data (CRD), National Cancer Waiting Times Monitoring Data Set (CWT), National Diabetes Audit (NDA), Patient Reported Outcome						

Measures (PROMs), Mental Health Minimum Data Set (MHMDS), Mental Health Learning Disability Data Set (MHLDDS), Diagnostic Imaging Data Set (DIDS).

The purpose of the application is to provide intelligence to support the commissioning of health services.

**Discussion:** IGARD noted the references within the application to other live Data Sharing Agreements (DSA) (NIC-342229-X7K0T and NIC-343158-Z2L4D) linked to the CCG and asked that a further detailed description was included within section 1 (Abstract) detailing how they link together and that assurance was provided confirming that there would be no duplicate flow of data.

In addition, IGARD suggested that as part of the review of this application, that the other DSA's referred to were also reviewed and amended as appropriate, to address any data linkage that would be taking place.

IGARD noted that NIC-182332 would be "shut-down" and replaced with this DSA in order to facilitate a joint DSA with the local authority; and asked that section 1 was updated with confirmation of what would happen to the data currently held under NIC-182332.

IGARD noted and endorsed NHS Digital's review that the applicant did **not** meet NHS Digital's Standard for privacy notices and that the applicant should work with NHS Digital on a Privacy Notice that was compliant with the General Data Protection Regulation (GDPR).

IGARD queried the reference within the application to data linkage and noted the information provided in the data flow diagram appeared to confirm that all the data was being linked and that all Data Controllers and Data Processors would have access to this. IGARD asked that section 1 and section 5 (Purpose / Methods / Outputs) were updated with confirmation of who would be received the linked data and that further clarification was provided of what data was being linked.

IGARD noted the data minimisation criteria outlined in section 5(b) (Processing Activities) in relation to the data sets listed within the application and asked that this was expanded further to include additional context to the data minimisation criteria outlined.

IGARD queried the role of Optum Health Solutions UK Limited, noting they were referenced throughout the application; and asked that section 1 and section 5(a) (Objective for Processing) were updated with a further detailed description including confirmation of the activities they carry out.

IGARD noted that there were references within the application to "Risk Stratification" and, noting this application was for the purpose of Commissioning, asked that the application was revised throughout to ensure that any references to risk stratification were clearing identified as being for the purpose of Commissioning. In addition, IGARD also queried, why for example there was reference to "identification of specific patients" and asked that if this was not relevant to the purpose of commissioning that such references were removed.

IGARD queried the reference in section 5(b) to a "specific named individual" and asked that this was revised and that consideration was given to replacing this with "specific named role"; and that clarification was provided that this role would be separate from any other roles that may lead to a conflict.

Outcome Summary: Recommendation to defer, pending:

- 1. To update section 1 and section 5(a) with a further detailed description of Optum Health Solutions UK Limited and the activities they carry out.
- 2. To revise the application throughout to ensure that any references to "Risk Stratification" activities are for the purpose of commissioning; and to explain why, for

- example, there is reference to "identification of specific patients", or remove such references if they are not relevant to the purpose of commissioning.
- 3. To update section 1 and section 5 with confirmation of who will be receiving the linked data and clarification of what data is being linked.
- 4. To revise the references in section 5(b) to a "specific named individual" and consider replacing this with "specific named role"; and to clarify that this role will be separate from any other roles that may lead to a conflict.
- 5. The applicant should work with NHS Digital on a Privacy Notice that is GDPR compliant.
- 6. To update section 5(b) to further expand on the data minimisation criteria outlined.
- 7. To update section 1 with a more detailed description of how the other Data Sharing Agreements referenced link together and assurance that there is no duplicate flow of data.
- To provide further confirmation in section 1 of what is happening to the data under NIC-182332.

#### The following advice was given:

 IGARD suggested that as part of the review of this application, that the other Data Sharing Agreement's referred to were also reviewed and amended as appropriate to address any data linkage that will be taking place.

# 3.2 Monitor: IGARD DSA extension April 2020 to June 2020 (3 months) (Presenter: Louise Dunn) NIC-15814-C6W9R

Application: This was a short-term 3 month renewal application for pseudonymised Hospital Episode Statistics (HES), Mental Health Minimum Data Set (MHMDS), Mental Health Learning Disability Data Set (MHLDDS), Mental Health Services Data Set (MHSDS), Improving Access to Psychological Therapy (IAPT), Secondary Uses Service (SUS) Payment By Results (PbR), Patient Reported Outcome Measures (PROMS), Diagnostic Imaging Data Set (DiDs), Civil Registration Data, Patient Level Information Costings Systems (PLICS), National Cancer Waiting Times Monitoring Data Set (CWT), Emergency Care Data Set (ECDS) and Community Services Dataset (CSDS).

The data will be used to support the delivery of the applicant's statutory function and support direct improvement and / or oversight of Trusts.

The application was previously considered on the 28<sup>th</sup> November 2019 when IGARD had been unable to make a recommendation pending: to produce the appropriate official document(s) that expressly sets out the mandatory request(s) for all the requested datasets that would flow to NHS England in order for NHS England to perform its statutory functions; to clarify the legal basis for NHS Digital to disseminate each of the datasets requested under the mandatory request(s); to consider the reference to the private organisation "Circle" within the application and check it is still necessary and accurate.

NHS Digital advised that following IGARD's review of this application on the 28<sup>th</sup> November 2019, NHS Digital were satisfied that the issues raised by IGARD posed no increased risk and the data had therefore been disseminated.

**Discussion:** IGARD noted the update from NHS Digital in relation to the data being disseminated following IGARD's review on the 28<sup>th</sup> November 2019. IGARD noted that the application had been updated to reflect most of the comments previously made.

IGARD noted that NHS England had been added to the Data Sharing Agreement (DSA) for the purposes of the PLICS data sharing and that this was expressly permitted in terms of the mandatory request ("...such persons as may be agreed..."). IGARD asked that evidence was

provided of an e-mail exchange (or similar) between NHS Improvement and NHS Digital confirming the agreement to disseminate the data to NHS England, as permitted by the mandatory request.

In addition, IGARD also asked that section 1 (Abstract) was updated with confirmation that NHS Improvement and NHS Digital have expressly agreed to disseminate the data to NHS England in line with the discretion granted to them in the mandatory request.

IGARD noted that they had previously queried the role of the private organisation 'Circle' within this application and advised that they were still unclear on this, and asked that further clarity of this was provided including a further explanation if there was anything unique about Circle's involvement / role; and if not then consideration should be given to removing references to Circle from this application.

IGARD queried the benefits and outputs outlined in section 5 (Purpose / Methods / Outputs), specifically the language when describing these, for example the reference to saving the NHS [£]5bn by 2020; and asked that this was revised to ensure the benefits and outputs were both realistic and achievable.

IGARD noted the reference in section 5(b) (Processing Activities) to General Medical Council (GMC) numbers being used for the 'Getting It Right First Time Programme' (GIRFT) and asked that further justification was provided confirming the reason for this.

IGARD queried the statement in section 5(b) "Monitor would like to share the its analysis with the CMA Mergers Team only." and asked that further clarification was provided of what analyses would be provided to the CMA Mergers Team.

IGARD noted the sentence in section 5(a) (Objective for Processing) that stated "NHS Improvement (NHSI) was launched on 1 April 2016 and is the operational name for the organisation that brings together Monitor and the NHS Trust Development Authority ("TDA" plus **a number of other teams**)." and queried who the other teams referenced were; and if there were no other teams, then this reference should be removed.

IGARD noted that an Article 9 legal basis had been provided, but queried if the Article 9 of the General Data Protection Regulation (GDPR) legal basis referenced within the application was the most appropriate and suggested that the applicant may wish to consider if an alternative Article 9 legal basis would be more appropriate for the activities outlined.

IGARD suggested that in-light of the current pressures on the health and social care system in relation to Covid-19, that NHS Digital may wish to consider a renewal of 6-months as opposed to the initial 3-months outlined.

IGARD advised that they would wish to review this application again when it comes up for renewal.

Outcome Summary: recommendation to approve subject to the following condition:

1. To provide evidence of an e-mail exchange (or similar) between NHS Improvement and NHS Digital confirming the agreement to disseminate data to NHS England as expressly permitted in terms of the mandatory request ("...such persons as may be agreed...").

The following amendments were requested:

1. To provide further clarity of the role of the 'Circle' and to provide a further explanation if there is anything unique about their involvement / role, and if not then to consider removing any reference to 'Circle' from the application.

- 2. To revise the language in section 5 when describing the potential benefits and outputs and to ensure that these are realistic and achievable, for example the reference to saving the NHS [£]5bn by 2020.
- 3. To update section 5(b) with further justification of why GMC numbers will be used for the GIRFT programme.
- 4. To provide further clarification in section 5(b) of what analysis will be provided to the CMA Mergers Team.
- 5. To amend section 5(a) to remove the reference to "plus a number of other teams".
- 6. To consider if an alternative Article 9 legal basis would be more appropriate for the activities outlined.
- 7. To update section 1 with confirmation that NHS Improvement and NHS Digital have expressly agreed to disseminate the data to NHS England in line with the discretion granted to them in the mandatory request.

The following advice was given:

- 1. IGARD suggested that NHS Digital may wish to consider a renewal of 6-months as opposed to the initial 3-months outlined.
- 2. IGARD advised that they would wish to review this application again when it comes up for renewal.

It was agreed the condition would be approved Out of Committee (OOC) by IGARD members.

3.3 National Institute for Cardiovascular Outcomes Research: National Audit for Percutaneous Coronary Interventions (Angioplasty) - HES Tabulation data (Presenter: Dave Cronin) NIC-318886-M1B9L

**Application:** This was a new application for aggregated Hospital Episodes Statistics (HES) data for the purpose of producing participation tables for audit purposes and to determine whether hospitals are fully participating in the audit.

The Healthcare Quality Improvement Partnership (HQIP) has commissioned, on behalf of NHS England as part of the National Clinical Audit and Patient Outcomes Programme (NACPOP), six national cardiovascular audits which are managed by the National Institute for Cardiovascular Outcomes Research (NICOR). The aim of these National Cardiac Audit Programme (NCAP) audits is to measure and report delivery of care against defined guidance standards and to enable the improvement of the quality of care and outcomes of patients with a range of cardiac conditions.

**Discussion:** IGARD noted the sentence in section 5(b) (Processing Activities) that stated "The data from NHS Digital will not be used for any other purpose other than that outlined in this agreement. It will also not be linked to any other datasets. There will be no attempt to reidentify the data." and asked that this was replicated in section 6 (Special Conditions) as a special condition.

IGARD queried the information within the data minimisation column in section 3(b) (Additional Data Access Requested) that stated "Please see Additional Production Details" and asked that this was updated to remove this reference and to replace with a brief lay summary of the data minimisation activities.

IGARD noted and endorsed NHS Digital's review that HQIP did **not** meet NHS Digital's Standard for privacy notices.

IGARD advised that they would wish to review this application again when it comes up for renewal.

IGARD suggested that this application would not be suitable for NHS Digital's Precedent route.

### Outcome Summary: recommendation to approve

- 1. To replicate the whole paragraph from section 5(b) that starts "The data from NHS Digital will not be used..." as a special condition in section 6.
- 2. To update the data minimisation column in section 3(b) to remove the reference to "additional production details" and replace with a brief lay summary.

The following advice was given:

- 1. IGARD advised that they would wish to review this application again when it comes up for renewal.
- 2. IGARD suggested that this application would not be suitable for NHS Digital's Precedent route.

# 3.4 <u>University of Bristol: MR159 - Speedwell Study - Longitudinal Study of Ischaemic Heart</u> <u>Disease (Presenter: Dave Cronin) NIC-147814-86GS4</u>

**Application:** This was an application to extend the existing Data Sharing Agreement (DSA) for identifiable Medical Research Information Service (MRIS) data; and an amendment to add an additional Data Controller The Speedwell study was set up by the University of Bristol as a prospective cohort study in the late 1970s to look at the determinants of cardiovascular disease, though over time other phenotypes of interest have been added.

The study was set up to examine risk factors for cardiovascular disease such as elevated cholesterol and obesity amongst around 2500 middle aged men living in Bristol. The data collected will enable the study to look at what risk or protective factors may be associated with a wide range of chronic diseases, such as heart disease, diabetes, stroke, dementia etc.

**Discussion:** IGARD noted the outputs and benefits outlined in section 5(c) (Specific Outputs Expected) and section 5(d) (Benefits), however queried how the outputs and benefits would be established to the Health and Social Care System in England and Wales, noting this was not clear, and asked that the application was updated to reflect this.

IGARD queried the information in section 1 (Abstract) in relation to the 'necessity' of the processing and asked that this was updated to accurately reflect that the University of Cambridge was a joint a Data Controller that already holds pseudonymised data.

IGARD noted and endorsed NHS Digital's review that the applicant did **not** meet NHS Digital's Standard for privacy notices and that the applicant should work with NHS Digital on a Privacy Notice that was compliant with the General Data Protection Regulation (GDPR).

IGARD advised that upon renewal they would expect that the application was fully aligned with NHS Digital's published Standards and addressed the following (non-exhaustive) list of points: that the updated outputs and benefits were clearly outlined; the data held under the application to be pseudonymised with the identifiers destroyed and if this had not taken place, the application should have updated or refreshed permissions (for example s251 support, an updated protocol and ethics approval); an updated GDPR compliant Privacy Notice.

IGARD suggested that term of the Data Sharing Agreement was adjusted to 1 year from the signing of the agreement.

IGARD advised that they would wish to review this application again when it comes up for renewal.

IGARD suggested that this application would not be suitable for NHS Digital's Precedent route.

Outcome Summary: recommendation to approve

The following amendments were requested:

- 1. To update section 5(c) and section 5(d) to clarify how the outputs and benefits outlined to the Health and Social Care System in England and Wales will be established; and further details of the benefits flowing to patients.
- 2. The applicant should work with NHS Digital on a Privacy Notice that is GDPR compliant.
- 3. To update section 1 to revise the language in the 'necessity' paragraph to reflect that the University of Cambridge is a joint Data Controller that already holds pseudonymised data.

The following advice was given:

- 1. IGARD suggested that term of the Data Sharing Agreement was adjusted to 1 year from the signing of the agreement.
- 2. IGARD advised that they would wish to review this application again when it comes up for renewal.
- 3. IGARD suggested that this application would not be suitable for NHS Digital's Precedent route.
- 4. IGARD advised that upon renewal they would expect that the application was fully aligned with DARS Standards and addressed the following (non-exhaustive) list of points:
  - (a) Updated outputs and benefits clearly outlined.
  - (b) The data held under the application to be pseudonymised with the identifiers destroyed and if this has not taken place, the application should have updated or refreshed permissions (for example s251 support, an updated protocol and ethics approval).
  - (c) An updated GDPR compliant Privacy Notice.

### 4 NHS GP Workforce Statistics Briefing Paper (Presenters: Nicola Bootland)

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.

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).

This briefing paper was previously presented to IGARD on the 13<sup>th</sup> February 2020, where IGARD made a number of comments and suggested amendments.

IGARD welcomed the updated draft briefing paper and thanked NHS Digital for the effort in updating the paper and looked forward to receiving the (updated) briefing note as a supporting document with an application at a future meeting.

IGARD suggested further minor revisions be carried out to make explicitly clear that the paper addressed the fact that the General Data Protection Regulation (GDPR) rights to object to

processing would not be available to data subjects (as opposed to the national data opt out which was not relevant in this case). IGARD asked that it be made clear that data subjects include GP partners as well as employed GPs and other staff. IGARD also asked for an update on any steps that may have been taken with regard to liaising with the GP profession (as both employers and data subjects) and other affected employee groups working in GP practices.

# 5 Covid-19 Template Data Collection, Analysis and Dissemination Request Forms (Reviewed by IGARD Out of Committee (OOC)

**Background:** To support NHS Digital's ongoing work / response to Covid-19, IGARD were asked to review a number of templated Data Collection, Analysis and Dissemination request forms.

**Outcome:** IGARD provided initial comments on the templates in a short time frame and advised NHS Digital that this was an excellent comprehensive document and were cognisant of the vital work that this facilitates.

In addition, IGARD also confirmed that there would be time made available on the weekly IGARD meeting agendas to facilitate any Covid-19 related work / discussions and as to further support NHS Digital.

### 6 Returning Applications

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.

- NIC-204550-N7M4D NHS England
- NIC-95658-C4F7D Powys Teaching LHB

IGARD welcomed the two 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.

#### **7** AOB:

7.1

#### Anomika Bedi

Both IGARD and NHS Digital noted that this was Anomika Bedi's final meeting and wished to extend their sincere thanks for her significant contribution over the last three years during her tenure on IGARD.

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.

### Independent Group Advising on Releases of Data (IGARD): Out of committee report 20/03/20

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-261326- F9S5D	University of Cambridge	27/02/2020	<ol> <li>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.</li> <li>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.</li> </ol>	IGARD members	Quorum of IGARD members	None

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