Independent Group Advising on the Release of Data (IGARD) Minutes of meeting held 28 February 2019

Members: Sarah Baalham, Joanne Bailey, Nicola Fear, Kirsty Irvine (Chair).

In attendance: Stuart Blake, Louise Dunn, Rachel Farrand, Karen Myers, Vicki Williams.

Apologies: Anomika Bedi, Maria Clark, Priscilla Maguire, Eve Sariyiannidou.

Observers: Geoffrey Schrecker.

1 Declaration of interests:

Nicola Fear noted a personal link to University College London (UCL) [NIC-137864-T1P9B] but noted no specific connection with the application or staff involved and it was agreed this was not a conflict of interest.

Joanne Bailey noted professional links to the University of Cambridge [NIC-199682-T1L7Z] but noted no specific connection with the application or staff involved and it was agreed this was not a conflict of interest.

Review of previous minutes and actions:

The minutes of the 21st February 2019 IGARD meeting were reviewed and agreed as an accurate record of the meeting.

Out of committee recommendations

An out of committee report was received (see Appendix B).

2 Data applications

2.1 <u>University College London (UCL): MR1450 - National Child Development Study (NCDS)</u> (Presenter: Stuart Blake) NIC-137864-T1P9B

Application: This was a renewal application for identifiable Medical Research Information Service (MRIS) data to receive two further List Clean Reports and to amend the previous agreement to include three additional Data Processors, for a study following all those born in one week in 1958 through the course of their lives, charting the effects of experiences in early life on outcomes and achievements later on. The study was originally designed to examine the social and obstetric factors associated with stillbirth and death in early infancy among children born in that one week.

NHS Digital advised IGARD that the Health Research Authority Confidentiality Advisory Group (HRA CAG) register had not been updated, however the applicant had advised NHS Digital that the annual review had been submitted.

Discussion: IGARD welcomed the application and noted the importance of this long-running study. IGARD also noted that whilst the HRA CAG register had not been updated, they were satisfied that the annual review had been submitted.

IGARD queried whether the applicant had informed HRA CAG of the change in respect of the changes to the data processors outlined within the application. IGARD asked that the applicant provide evidence that an amendment application had been submitted to HRA CAG detailing this change; or to provide a satisfactory explanation to NHS Digital outlining why an amendment application is not required. The query arose because a similar application from the same Data Controller had notified CAG of such a change.

IGARD queried the statement in section 5(b) (Processing Activities) that "all personal information will be destroyed by ...Kantar Public on completion of their contract" and asked for further clarification as to what "personal information" was held by Kantar Public.

IGARD queried the statement in section 5(b) "It is this final scenario that defines both NatCen and Kantar Public as Data Processors" and asked that this be amended to provide clarity as to what was meant by 'final scenario'.

IGARD queried if NHS Digital had been provided with evidence of funding and asked that section 7 (Approval Considerations) be updated to include any evidence of funding and to update NHS Digital's Customer Relationship Management System (CRM) with the appropriate evidence of funding documentation.

IGARD noted that whilst some information had been provided in section 5(c) (Specific Outputs Expected) outlining some of the outputs, this should be updated to include a brief summary of further outputs.

IGARD noted that section 5(a) (Objective for Processing) should be updated to include clearer examples for processing and how the applicant has been using the data. IGARD also suggested that the applicant provide further details of pathways for disseminating the outputs and benefits of the study be provided and to consider how the various benefits could be summarised in a language suitable for a lay reader, perhaps utilising materials already in use.

Outcome: recommendation to approve subject to the following condition:

 The applicant should investigate whether it is necessary to update HRA CAG on the change in data processor and provide either (a) evidence that they have submitted an amendment application to HRA CAG detailing the change of the data processor, or (b) a satisfactory explanation to NHS Digital as to why an amendment application to HRA CAG is not required.

The following amendments were requested:

- 1. To provide clarification in section 5(b) what "personal information" is held by Kantar Public.
- 2. To amend section 5(b) to clarify what is meant by 'final scenario'.
- 3. To include a brief summary of the further outputs within section 5(c).
- To amend section 7 approval considerations to include reference to the evidence of funding and to also update the CRM holder with the appropriate evidence of funding documentation.

The following advice was given:

 IGARD suggested that on renewal that further details of pathways of dissemination of the outputs and benefits be provided and to consider how the various benefits could be summarised in a language suitable for a lay reader, perhaps utilising materials already in use.

It was agreed the condition be approved OOC by the IGARD Chair

2.2 University College London (UCL): 1970 British Cohort Study - MR21 (Presenter: Stuart Blake) NIC-17218-B0W9X

Application: This was a renewal application for identifiable Medical Research Information Service (MRIS) data to receive two further List Clean Reports and to amend the previous agreement to include three additional Data Processors, for a study following a large sample of individuals born in one week in 1970 through the course of their lives, charting the effects of events and circumstances in early life on outcomes and achievements later on. They show

how histories of health, wealth, education, family and employment are interwoven for individuals and vary between them.

Discussion: Again IGARD commented on the importance and significance of these long-running cohort studies and welcomed the application. IGARD noted that section 3(a) (Data Access Already Given) included details of intended data minimisation and should be amended to reflect the data minimisation that had taken place for the data that was already held. IGARD also noted that section 5(a) (Objective for Processing) referred to "untraced study members" and asked that this information be included in section 3(b) (Additional Data Access Requested) to provide a more accurate description of the data minimisation efforts which would be undertaken.

IGARD noted the reference to "subcontractor organisations" in section 5(b) (Processing Activities) and suggested that confirmation be sought that the individuals accessing the data were substantive employees of University College London and that standard wording be included within section 5 with regard to access controls and that only members of the University College London would access the data.

IGARD queried if NHS Digital had been provided with evidence of funding and asked that section 7 (Approval Considerations) is updated to include any evidence of funding and to update NHS Digital's Customer Relationship Management System (CRM) with the appropriate evidence of funding documentation.

Outcome: recommendation to approve

The following amendments were requested:

- 1. To update the data minimisation column in section 3(a) to reflect the data actually held.
- 2. To update section 3(b) to reflect the wording in section 5(a) for a more accurate description of the data minimisation which would be undertaken.
- 3. To amend section 5(b) to reflect the standard wording on substantive employees accessing data supplied by NHS Digital.
- 4. To amend section 7 approval considerations to include reference to the evidence of funding and to also update the CRM holder with the appropriate evidence of funding documentation.

2.3 Newcastle University: Examining inequalities in the provision of elective surgical and diagnostic procedures (Presenter: Rachel Farrand) NIC-167794-K1P8H

Application: This was a new application for pseudonymised Hospital Episode Statistics (HES) data to examine the impact of patient choice in the NHS in both secondary care as choice of provider and in primary care as choice of GP. Following the NHS Plan in 2000, providers of health care services have expanded rapidly through the commercial contracting of NHS services.

Discussion: IGARD queried if GP Practice codes were included as part of the specification and asked for clarification of this, as well as further justification of why they were included and what consideration had been given to measures taken to determine if GP Practice codes were necessary. IGARD asked that section 5(a) (Objective for Processing) was updated with this information, including a further description of the data minimisation efforts undertaken.

IGARD noted that there was a reference in section 5(a) to a specific GP Practice and asked that this be removed.

IGARD noted that section 5(a) should be updated to include clearer examples for processing and how the applicant has been using the data. IGARD also suggested that the applicant provide

further details of pathways for disseminating the outputs and benefits of the study be provided including examples of how the findings will be disseminated to the public.

Outcome: recommendation to approve subject to the following condition:

1. To clarify within section 5(a) that the GP Practice codes are part of the specification and provide justification of why they are included, including the consideration of the measures taken to determine that the GP Practice codes are in fact necessary; and a description of any data minimisation efforts undertaken.

The following amendments were requested:

1. To remove reference to a specific GP Practice from section 5(a).

The following advice was given:

 IGARD suggested that on renewal further details of pathways of dissemination of the outputs and benefits be provided including examples of how the findings will be disseminated to the public.

It was agreed the condition be approved OOC by IGARD Members.

2.4 Cambridge University: MR1475: WRAP-Up: 5 and 10 year follow up of the WRAP trial – access to HES data (Presenter: Stuart Blake) NIC-199682-T1L7Z

Application: This was a new application for identifiable Hospital Episode Statistics (HES) data and Medical Research Information Service (MRIS) data for a trial assessing the effect of referral to a community based open-group programme versus standard care, on weight and glycaemia at 12 and 24 months. The 5-year follow-up of the trial participants is to provide the NHS with vital evidence about the long-term impact of commonly commissioned weight management services on health and health resource use. It will be used to inform policy makers about which weight management services offer best value for money and will support commissioning.

Discussion: IGARD and NHS Digital agreed that only the MRIS List Clean part of the application would be reviewed as there was no clear legal basis in law for the HES data requested to be disseminated by NHS Digital.

IGARD noted that under the Common Law Duty of Confidentiality legal basis within section 1 (Abstract) there is reference to "in this case NHS Digital" and asked that this be removed.

IGARD noted that the applicant's fair processing notice did not meet NHS Digital's fair processing criteria for privacy notices and suggested that section 4 be updated to clearly state that the application privacy notice 'does not' meet the criteria.

IGARD noted that point 4 in the Privacy Notice Review checklist within section 1 which refers to the purposes of the processing ought to be updated to ensure the purposes outlined in the privacy notice reflect those outlined in the protocol. IGARD also noted that point 8 of the checklist which refers to the recipients or categories of recipients of the personal data, ought to made clear that identifiers are being sent to NHS Digital.

With respect to the HES data requested within the application IGARD noted there was no clear basis in law for the HES data requested to be disseminated to NHS Digital and suggested that with regard to the HES data requested, the applicant works closely with NHS Digital to revise their consent materials.

IGARD noted the type of conditions listed in the patient information sheet and queried if the data minimisation applied was in-line with the opt-out protocol and suggested that applicant

and NHS Digital consider further, including adding more detail about the conditions being looked into.

IGARD suggested that further clarification is provided in section 5(b) (Processing Activities) to outline what will happen with the HES data which also includes explicit details of the processing and linkage.

IGARD suggested that upon return, NHS Digital ensure the relevant approvals for the proposed processing are in place.

Outcome: IGARD recommended to approve in respect of the MRIS List Clean only. IGARD was unable to make a recommendation in respect of the HES data requested as there was no clear legal basis for the HES data requested to be disseminated by NHS Digital.

The following amendments were requested with regard to the MRIS list clean only:

- 1. To amend the Common Law Duty of Confidentiality legal basis within the abstract (section 1) to remove reference to 'in this case NHS Digital'.
- 2. To amend section 4 to state that the Privacy Notice does not meet NHS Digital's fair processing notice criteria for privacy notices

The following advice was given in respect of the MRIS List Clean only:

 IGARD advised NHS Digital that point 4 in the Privacy Notice Review checklist within section 1 (abstract) be updated to ensure the purposes outlined in the privacy notice reflect those outlined in the protocol; and point 8 to make clear that identifiers are being sent to NHS Digital.

The following comments were made in respect of the HES data part of the application:

- 1. IGARD noted that there was no clear basis in law for the HES data requested to be disseminated by NHS Digital.
- 2. IGARD suggested that NHS Digital work closely with the applicant to revise their consent materials.
- 3. IGARD suggested that the applicant and NHS Digital consider if the data minimisation is in line with the opt-out protocol.
- 4. IGARD suggested that clarification be provided in section 5(b) outlining what will happen with the HES data including explicit details about the processing and linkage.
- 5. IGARD suggested that upon return, NHS Digital ensure the relevant approvals for the proposed processing are in place.

2.5 NHS England (Quarry House): National Cancer Waiting Times Monitoring Data Set (NCWTMDS) with derivation of deprivation age and gender (Presenter: Louise Dunn) NIC266008-T3S9D

Application: This was a new application for pseudonymised National Cancer Waiting Times Monitoring Dataset (CWT) with four additional data fields for monitoring times. This application is for a one-off extract of the data that will be used specifically for a piece of work that focuses on how age, gender and deprivation affect cancer outcomes and waiting times.

Discussion: IGARD queried what the fourth additional data field was as referenced within the application and were advised by NHS Digital that this was the Lower Super Output Area (LSOA), IGARD asked that the application was updated to clearly reflect this throughout.

Outcome: recommendation to approve

The following amendment was requested:

1. To amend the application to reflect throughout that the Lower Super Output Area (LSOA) is the fourth additional data field.

2.6 Imperial College London: SCAMP: Study of Cognition, Adolescents, and Mobile Phones MR1439 (Presenter: Louise Dunn) NIC-27085-C5L5G

Application: This was a renewal application for identifiable Hospital Episode Statistics (HES) data, Medical Research Information Service (MRIS) data and Diagnostic Imaging Dataset (DIDs) for a study which aims to address current scientific uncertainties by investigating whether the use of mobile phones and / or other technologies that use radio waves may affect adolescents cognitive or behavioural development, as well as exploring wider health outcomes. Although this was described as a renewal application, for technical reasons no data had been previously disseminated under the earlier version.

Discussion: IGARD noted that supporting document 4b (Information Booklet for Parents) appeared to be in draft format as it still had drafting notes and queries and asked that the final version sent to participants was shared with IGARD. IGARD also queried which version of the consent form was used for participants and was advised by NHS Digital that it was version 6, IGARD asked for sight of the patient information sheet that accompanied this consent form, and that such documents should clearly describe NHS Digital or its predecessor's involvement.

IGARD noted that the common law duty of confidentiality within section 1 (Abstract) was incomplete and asked that this be updated with the current standard wording.

NHS Digital explained that they had reviewed the consent materials in detail and were of the view that while there was a discrepancy in the wording of the consent materials which sought to reassure the participant about who will "have access to and use the data", NHS Digital were of the view that the materials made very clear that data will be sought from NHS Digital and that in order to do so identifiable data will be shared with NHS Digital. Given the explicit statements in the consent materials NHS Digital view was that, it would be reasonable to expect that participants were aware of, and had consented to, the sharing of their data as set out in the application.

IGARD essentially agreed with NHS Digital's assessment, on balance, including because the overwhelming theme of all the consent materials was to set the scene for extensive data linkage, including educational achievement and mobile phone data. Taking these factors into account, on balance, IGARD's view was that participants would be unlikely to be surprised by sharing of information with NHS Digital for the purposes of the study.

IGARD queried if NHS Digital had been provided with evidence of continued funding and asked that section 7 (Approval Considerations) is updated to include a description and any evidence of funding and to update section 8 (Period and Funding) to reflect the current funding status.

IGARD noted the information outlining the data minimisation efforts undertaken for the HES data requested within supporting document 6 (Penetration Test and Vulnerability Assessment Report) and were advised by NHS Digital that a clear explanation should also be included within the application.

IGARD queried the information provided in supporting document 4b that states "Imperial College are collaborating with Birkbeck, University of London and the Swiss Tropical Public Health Institute" and asked that section 5(b) (Processing Activities) was updated to provide further clarity on the "collaborators"; to provide confirmation that they will not have access to record level data; and to describe the level of data they will have access to.

IGARD suggested that the applicant's Privacy Notice was updated to make an explicit statement on automated decision making.

Outcome: recommendation to approve subject to the following condition:

The provision of the final version of supporting document 4b which was sent out to
participants since the one provided appeared to be in draft and to provide a copy of the
patient information sheet that accompanied version 6 of the consent form, and that
such documents should clearly describe the involvement of NHS Digital or its
predecessor organisation.

The following amendments were requested:

- 1. To update section 7 with a description and evidence of continued funding and to update section 8 to reflect the current funding status.
- 2. To update the abstract to include the Duty of Confidentiality standard wording.
- 3. To update section 5(b) to clarify that the "collaborators" referred to within supporting document 4b will not have access to record level data and to describe the level of data they will have access to.
- 4. To provide a clear explanation of the data minimisation efforts undertaken for the HES data requested.

The following advice was given:

1. IGARD advised that the privacy notice be updated to make an explicit statement on automated decision making.

It was agreed the condition be approved OOC by IGARD Members.

2.7 NHS Kernow CCG: DSfC NHS Kernow CCG RS (Presenter: James Humphries-Hart) NIC-226613-D8S2N

Application: This was a new application for identifiable Secondary Use Service (SUS) for Commissioners data. The data required is for 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.

Discussion: IGARD queried information provided within section 1 (Abstract) on the privacy notice and were advised by NHS Digital that it did not pass NHS Digital's Fair Processing Notice checklist table, IGARD asked that the table be inserted into the section 1; or provide this information within a supporting document for transparency.

Outcome: recommendation to approve

The following amendment was requested:

1. To insert the NHS Digital Fair Processing Notice checklist table into the abstract or provide this information within a supporting document.

2.8 NHS Surrey Health CCG: DSfC - NHS Surrey Heath CCG; RS, IV & Comm (Presenter: James Humphries-Hart) NIC-43558-V8K7Z

Application: This was an amendment and renewal application for pseudonymised Secondary Use Service (SUS) for Commissioners data, Local Provider Flows, Mental Health Minimum Data Set (MHMDS), Mental Health Learning Disability Data Set (MHLDDS), Mental Health Services Data Set (MHSDS), Maternity Services Data Set (MSDS), Improving Access to Psychological Therapy (IAPT), Child and Young People Health Service (CYPHS), Community Services Data Set (CSDS), Diagnostic Imaging Data Set (DIDS), National Cancer Waiting Times Monitoring Data Set (CWT) and Civil Registries Data (CRD). The data required is for

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; Invoice Validation (IV) which is part of a process by which providers of care or services are paid for the work they do; and to provide intelligence to support the commissioning of health services.

Discussion: IGARD noted that point 16 of the Fair Processing Notice Checklist included within section 1 (Abstract) which asked about automated decision-making' had been answered with 'not applicable', IGARD suggested that this was updated with an explicit statement of whether or not there is automated decision making. IGARD also advised that the applicant's Privacy Notice is updated to make an explicit statement on automated decision making.

Outcome: recommendation to approve

The following amendment was requested:

1. IGARD suggested the narrative on point 16 of the Fair Processing Notice checklist be updated within the abstract to make an explicit statement whether or not there is automated decision making (rather than "not applicable").

The following advice was given:

1. IGARD advised that the privacy notice be updated to make an explicit statement on automated decision making.

2.9 NHS Lincolnshire CCG: DSfC - NHS North Lincolnshire CCG; RS, IV & Comm (Presenter: James Humphries-Hart) NIC-90680-M5B5W

Application: This was an amendment application for pseudonymised Secondary Use Service (SUS) for Commissioners data, Local Provider Flows, Mental Health Minimum Data Set (MHMDS), Mental Health Learning Disability Data Set (MHLDDS), Mental Health Services Data Set (MHSDS), Maternity Services Data Set (MSDS), Improving Access to Psychological Therapy (IAPT), Child and Young People Health Service (CYPHS), Community Services Data Set (CSDS), Diagnostic Imaging Data Set (DIDS), National Cancer Waiting Times Monitoring Data Set (CWT) and Civil Registration Births and Deaths Data (CRD). The data required is for 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; Invoice Validation (IV) which is part of a process by which providers of care or services are paid for the work they do; and to provide intelligence to support the commissioning of health services.

NHS Digital noted that NHS Hull CCG was incorrectly referenced within section 1 (Abstract) of the application and would need amending to correctly reference NHS North Lincolnshire CCG.

Discussion: IGARD noted that point 16 of the Fair Processing Notice checklist included within section 1 (Abstract) which asks about automated decision-making' had been answered with 'not applicable', IGARD suggested that this was updated with an explicit statement of whether or not there is automated decision making. IGARD also advised that the applicant's Privacy Notice is updated to make an explicit statement on automated decision making.

IGARD noted that reference to 'Dr Foster' was inconsistent within the application and asked the correct description of 'Dr Foster Limited' was correctly referenced throughout the application.

IGARD queried the ethics approval wording within section 7 (Approval Considerations) and were advised by NHS Digital that this was incorrect and would need updating with the standard wording suitable for this type of application.

Outcome: recommendation to approve

The following amendments were requested:

- 1. IGARD suggested the narrative on point 16 of the Fair Processing Notice checklist be updated within the abstract to make an explicit statement whether or not there is no automated decision making (rather than "not applicable").
- 2. To ensure the description of 'Dr Foster Limited' is correctly referred to throughout the application.
- 3. To update the ethics approval in section 7 with the standard wording suitable for this type of application.
- 4. To amend the abstract to remove reference to NHS Hull CCG and replace with NHS North Lincolnshire CCG.

The following advice was given:

1. IGARD advised that the privacy notice be updated to make an explicit statement on automated decision making.

2.10 NHS Hull CCG: DSfC - NHS Hull CCG - IV RS Comm (Presenter: James Humphries-Hart) NIC-90668-X5R4Y

Application: This was an amendment application for pseudonymised Secondary Use Service (SUS) for Commissioners data, Local Provider Flows, Mental Health Minimum Data Set (MHMDS), Mental Health Learning Disability Data Set (MHLDDS), Mental Health Services Data Set (MHSDS), Maternity Services Data Set (MSDS), Improving Access to Psychological Therapy (IAPT), Child and Young People Health Service (CYPHS), Community Services Data Set (CSDS), Diagnostic Imaging Data Set (DIDS), National Cancer Waiting Times Monitoring Data Set (CWT) and Civil Registration Births and Deaths Data (CRD). The data required is for 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; Invoice Validation (IV) which is part of a process by which providers of care or services are paid for the work they do; and to provide intelligence to support the commissioning of health services.

Discussion: IGARD noted that reference to 'Dr Foster' was inconsistent within the application and asked the correct description of 'Dr Foster Limited' was correctly referenced throughout the application.

IGARD queried the ethics approval wording within section 7 (Approval Considerations) and were advised by NHS Digital that this was incorrect and would need updating with the standard wording suitable for this type of application.

IGARD advised that the applicant's Privacy Notice is updated to make an explicit statement on automated decision making.

Outcome: recommendation to approve

The following amendments were requested:

- 1. To ensure the description of 'Dr Foster Limited' is correctly referred to throughout the application.
- 2. To update the ethics approval in section 7 with the standard wording suitable for this type of application.

The following advice was given:

1. IGARD advised that the privacy notice be updated to make an explicit statement on whether or not automated decision making takes place.

3 AOB None

Independent Group Advising on Releases of Data (IGARD): Out of committee report 22/02/19

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)
N/A						

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

None