

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

## Minutes of meeting held 30 March 2017

**Members:** Joanne Bailey, Chris Carrigan (Chair), Nicola Fear, Kirsty Irvine, James Wilson

**In attendance:** Noela Almeida, Garry Coleman, Gaynor Dalton, Louise Dunn, Frances Hancox, Louise Hill, Stuart Richardson, Robyn Wilson

**Apologies:** Sarah Baalham, Anomika Bedi, Jon Fistein, Debby Lennard, Eve Sariyiannidou

<p>1</p>	<p><b>Declaration of interests</b></p> <p>James Wilson declared a potential conflict of interests in NIC-06527-J1Q6T University College London due to both his employment by that organisation and his working relationship with the applicants. Nicola Fear also declared a potential interest in that application due to working relationships with the applicants but it was not considered that this should prevent her from commenting on the application.</p> <p><b>Review of previous minutes and actions</b></p> <p>The minutes of the 23 March IGARD meeting were reviewed and agreed as an accurate record of the meeting.</p> <p>Action updates were provided (see Appendix A).</p> <p><b>Out of committee recommendations</b></p> <p>An out of committee report was received (see Appendix B).</p>
<p>2</p>	<p><b>PCMD update – Local Authority privacy notices</b></p> <p>IGARD received a verbal update on progress against the requirement for Local Authorities receiving Primary Care Mortality Database (PCMD) access to appropriately update their privacy notice within twelve weeks of data sharing agreement (DSA) signature. It was noted that 25 organisations had so far updated their privacy notice and passed review, with a number of others currently in progress, and that none had so far exceeded the agreed twelve week deadline.</p>
<p>3</p> <p>3.1</p>	<p><b>Data applications</b></p> <p><u>Group application for three Local Authorities<sup>1</sup> (Presenter: Robyn Wilson)</u></p> <p><b>Application:</b> This was an application for access to Office for National Statistics (ONS) births and deaths data via PCMD. The application was based on a previously agreed template, which had most recently been considered at the 23 March 2017 IGARD meeting as part of a group application for five Local Authorities. IGARD were alerted that the version 13 IG Toolkit score for Peterborough Council had been reviewed as satisfactory with an improvement plan, and additional supporting documents had been provided regarding this.</p>

<sup>1</sup> NIC-37047-V8V0H Peterborough City Council; NIC-39315-W4J4J North Lincolnshire Council; NIC-45168-S6S7W Royal Borough of Greenwich

**Discussion:** IGARD discussed the IG Toolkit review process and noted that under current processes, NHS Digital would not usually undertake an additional review to confirm whether an organisation's improvement plan had been met and it was therefore not usually possible to confirm whether an organisation's score could now be considered satisfactory until the next year's IG Toolkit was reviewed. It was agreed that the IGARD Chair would contact the NHS Digital Caldicott Guardian to discuss the processes around this, and how appropriate assurances could be sought for organisations whose IG Toolkit submission had been reviewed as satisfactory with an improvement plan. In addition it was agreed that for this application and for similar applications over the coming months, a special condition should be included to state that the DSA is contingent on the applicant organisation's version 14 IG Toolkit score being reviewed as satisfactory.

There was a discussion about the controls in place around the use of ONS data and it was confirmed that only named individuals would have access to the data. IGARD suggested that statements in the application that 'only the named applicants' could access data should be amended to be clear that this referred to specific Local Authority employees, in line with commitments elsewhere in the application. IGARD queried a statement in the template wording that the mortality data would be used to analyse incidence of disease, and it was suggested this wording should be clarified. In addition there was a discussion about the ways in which data could be linked.

It was suggested the table of difference headings should be updated to remove a reference to 'approval by DAAG'. In addition it was noted that the table of differences would be updated to include the satisfactory reviewed IG Toolkit details for Cambridgeshire County Council.

**Outcome:** Recommendation to approve

It was agreed the application would be amended to confirm that a special condition will be included in the DSA for Peterborough Council that data access is dependent on the organisation achieving a satisfactory reviewed version 14 IG Toolkit score.

The application should be amended to correct the wording in the summary section regarding named ONS users being listed in section 8, and to clarify in section 5 that only the aforementioned named employees will have access to record level data. It was noted the table of differences would be updated to list the IG Toolkit score for Cambridgeshire County Council.

**Action:** IGARD Chair to contact the NHS Digital Caldicott Guardian regarding how NHS Digital handles applications from organisations whose IG Toolkit has been reviewed as satisfactory with an improvement plan.

3.2

Hambleton, Richmondshire and Whitby CCG (Presenter: Stuart Richardson) NIC-90670-W8H6P

**Application:** This application was to consolidate and renew the applicant's existing data sharing agreements to use pseudonymised Secondary Uses Service (SUS) data, local provider flows, mental health (MHMDS, MHLDDS, MHSDS), Maternity Services Dataset (MSDS), Improving Access to Psychological Therapies (IAPT), Children and Young People's Health Dataset (CYPHs), and Diagnostic Imaging Dataset (DIDs) data for commissioning purposes as well as using SUS data identifiable at the level of NHS number for risk stratification and invoice validation. No changes were proposed to the data flows previously agreed under the existing data sharing agreements. North of England CSU, eMBED Health Consortium (Kier Business Services Limited and Dr Foster Limited) and the Partnership Commissioning Unit (PCU) hosted by Scarborough and Ryedale CCG would act as data processors.

IGARD were informed of an error within the application, as a reference to pseudonymised non-sensitive data should instead refer to sensitive data.

**Discussion:** IGARD noted that points previously raised about Dr Foster and Kier’s respective DPA registration wording continued to apply, and that the standard CCG privacy notice special condition wording should apply to these applications. It was noted that the errors in data flow diagrams raised at the previous IGARD meeting had already been addressed for these applications, and that wording about only substantive employees accessing data had been incorporated into the applications.

A query was raised about what data the applicant already held, what data had been previously approved or recommended for approval but was not yet held, and what data was requested as part of the current application. IGARD noted that due to the consolidation of a number of different data sharing agreements, this application appeared to indicate that some of the data requested, including historical extracts, was a new request whereas in fact this data had previously been approved and in some cases was already held by the applicant. IGARD suggested that the tables of data already held and data requested should be updated to more clearly demonstrate which data had previously been recommended for approval, to be clearer that any data already supplied to the applicant would not be re-issued.

IGARD queried the section 251 support review date, as this was imminent. It was confirmed that NHS Digital had not yet received formal confirmation of renewal, but that it was thought the support had been extended.

It was noted that the privacy notices for the CCG applications at this meeting had all been reviewed against the agreed nine point criteria. IGARD requested assurance that these checks continued to be carried out by staff with appropriate training and experience in the area.

**Outcome:** Recommendation to approve

The application should be amended to correct a reference to pseudonymised non-sensitive data, and to amend the table of data already held to be clearer what data has previously been recommended for approval by DAAG or IGARD.

IGARD advised that Dr Foster and Kier should review their DPA registrations to ensure they reflect the use of data for this purpose and for these data subjects in order to comply with the Data Protection Act 1998.

IGARD advised that a special condition should be included within the DSA to state that: “As a result of your application IGARD would like to draw your attention to the importance of the accessibility and clarity of your Privacy Notice. In the interests of transparency, you are advised to regularly review your notice against the ICO’s Privacy Notices Code of Practice to ensure it reflects best practice. You will be expected to demonstrate progress against this recommendation in any audit undertaken and for any renewal or new application for data.”

3.3

Hull CCG (Presenter: Stuart Richardson) NIC-90668-X5R4Y

**Application:** This application was to consolidate and renew the applicant’s existing data sharing agreements to use pseudonymised SUS data, local provider flows, mental health (MHMDS, MHLDDS, MHSDS), MSDS, IAPT, CYPHs and DIDs data for commissioning purposes as well as using SUS data identifiable at the level of NHS number for risk stratification and invoice validation. No changes were proposed to the data flows previously agreed under the existing data sharing agreements. North of England CSU as well as eMBED Health Consortium (Kier Business Services Limited and Dr Foster Limited) would act as data processors.

IGARD were informed of an error within the application, as a reference to pseudonymised non-sensitive data should instead refer to sensitive data.

**Discussion:** IGARD noted the similarities with NIC-90670-W8H6P Hambleton, Richmondshire and Whitby CCG and reiterated the points raised in relation to that application.

This application included a change of data processors for risk stratification, with eMBED taking over from North of England CSU to provide this service. IGARD queried the data destruction process for this situation and it was agreed that NHS Digital should be asked to provide information about the business as usual data destruction process for changing data processors, such as whether data destruction certificates were required as standard.

**Outcome:** Recommendation to approve

The application should be amended to correct a reference to pseudonymised non-sensitive data, and to amend the table of data already held to be clearer what data has previously been recommended for approval by DAAG or IGARD.

IGARD advised that Dr Foster and Kier should review their DPA registrations to ensure they reflect the use of data for this purpose and for these data subjects in order to comply with the Data Protection Act 1998.

IGARD advised that a special condition should be included within the DSA to state that: "As a result of your application IGARD would like to draw your attention to the importance of the accessibility and clarity of your Privacy Notice. In the interests of transparency, you are advised to regularly review your notice against the ICO's Privacy Notices Code of Practice to ensure it reflects best practice. You will be expected to demonstrate progress against this recommendation in any audit undertaken and for any renewal or new application for data."

**Action:** To provide assurances for IGARD about how data destruction is managed under BAU processes when data processors change

### 3.4

#### Leeds North CCG (Presenter: Stuart Richardson) NIC-90673-L0Q4M

**Application:** This application was to consolidate and renew the applicant's existing data sharing agreements to use pseudonymised SUS data, local provider flows, mental health (MHMDS, MHLDDS, MHSDS), MSDS, IAPT, CYPHs and DIDs data for commissioning purposes as well as using SUS data identifiable at the level of NHS number for risk stratification and invoice validation. No changes were proposed to the data flows previously agreed under the existing data sharing agreements. North of England CSU as well as eMBED Health Consortium (Kier Business Services Limited and Dr Foster Limited) would act as data processors.

IGARD were informed of an error within the application, as a reference to pseudonymised non-sensitive data should instead refer to sensitive data.

**Discussion:** IGARD noted the similarities with NIC-90670-W8H6P Hambleton, Richmondshire and Whitby CCG and reiterated the points raised in relation to that application. This application included a change of data processors for risk stratification, with eMBED taking over from North of England CSU to provide this service.

**Outcome:** Recommendation to approve

The application should be amended to correct a reference to pseudonymised non-sensitive data, and to amend the table of data already held to be clearer what data has previously been recommended for approval by DAAG or IGARD.

IGARD advised that Dr Foster and Kier should review their DPA registrations to ensure they reflect the use of data for this purpose and for these data subjects in order to comply with the Data Protection Act 1998.

IGARD advised that a special condition should be included within the DSA to state that: "As a result of your application IGARD would like to draw your attention to the importance of the accessibility and clarity of your Privacy Notice. In the interests of transparency, you are advised to regularly review your notice against the ICO's Privacy Notices Code of Practice to ensure it reflects best practice. You will be expected to demonstrate progress against this recommendation in any audit undertaken and for any renewal or new application for data."

3.5

Leeds South and East CCG (Presenter: Stuart Richardson) NIC-90659-F0S2P

**Application:** This application was to consolidate and renew the applicant's existing data sharing agreements to use pseudonymised SUS data, local provider flows, mental health (MHMDS, MHLDDS, MHSDS), MSDS, IAPT, CYPHs and DIDs data for commissioning purposes as well as using SUS data identifiable at the level of NHS number for risk stratification and invoice validation. No changes were proposed to the data flows previously agreed under the existing data sharing agreements. North of England CSU as well as eMBED Health Consortium (Kier Business Services Limited and Dr Foster Limited) would act as data processors.

IGARD were informed of an error within the application, as a reference to pseudonymised non-sensitive data should instead refer to sensitive data.

**Discussion:** IGARD noted the similarities with NIC-90670-W8H6P Hambleton, Richmondshire and Whitby CCG and reiterated the points raised in relation to that application. This application included a change of data processors for risk stratification, with eMBED taking over from North of England CSU to provide this service.

**Outcome:** Recommendation to approve

The application should be amended to correct a reference to pseudonymised non-sensitive data, and to amend the table of data already held to be clearer what data has previously been recommended for approval by DAAG or IGARD.

IGARD advised that Dr Foster and Kier should review their DPA registrations to ensure they reflect the use of data for this purpose and for these data subjects in order to comply with the Data Protection Act 1998.

IGARD advised that a special condition should be included within the DSA to state that: "As a result of your application IGARD would like to draw your attention to the importance of the accessibility and clarity of your Privacy Notice. In the interests of transparency, you are advised to regularly review your notice against the ICO's Privacy Notices Code of Practice to ensure it reflects best practice. You will be expected to demonstrate progress against this recommendation in any audit undertaken and for any renewal or new application for data."

3.6

Leeds West CCG (Presenter: Stuart Richardson) NIC-90684-T3G4X

**Application:** This application was to consolidate and renew the applicant's existing data sharing agreements to use pseudonymised SUS data, local provider flows, mental health (MHMDS, MHLDDS, MHSDS), MSDS, IAPT, CYPHs and DIDs data for commissioning purposes as well as using SUS data identifiable at the level of NHS number for risk stratification and invoice validation. No changes were proposed to the data flows previously agreed under the existing data sharing agreements. North of England CSU as well as eMBED Health Consortium (Kier Business Services Limited and Dr Foster Limited) would act as data processors.

IGARD were informed of an error within the application, as a reference to pseudonymised non-sensitive data should instead refer to sensitive data.

**Discussion:** IGARD noted the similarities with NIC-90670-W8H6P Hambleton, Richmondshire and Whitby CCG and reiterated the points raised in relation to that application. This application did not include a change of risk stratification data processors.

IGARD noted that the request title incorrectly referred to Leeds South and East CCG and suggested that this should be amended.

**Outcome:** Recommendation to approve

The application should be amended to remove a reference to Leeds South and East CCG, to correct a reference to pseudonymised non-sensitive data, and to amend the table of data already held to be clearer what data has previously been recommended for approval by DAAG or IGARD.

IGARD advised that Dr Foster and Kier should review their DPA registrations to ensure they reflect the use of data for this purpose and for these data subjects in order to comply with the Data Protection Act 1998.

IGARD advised that a special condition should be included within the DSA to state that: "As a result of your application IGARD would like to draw your attention to the importance of the accessibility and clarity of your Privacy Notice. In the interests of transparency, you are advised to regularly review your notice against the ICO's Privacy Notices Code of Practice to ensure it reflects best practice. You will be expected to demonstrate progress against this recommendation in any audit undertaken and for any renewal or new application for data."

3.7

East Riding of Yorkshire CCG (Presenter: Stuart Richardson) NIC-90658-F0W4R

**Application:** This application was to consolidate and renew the applicant's existing data sharing agreements to use pseudonymised SUS data, local provider flows, mental health (MHMDS, MHLDDS, MHSDS), MSDS, IAPT, CYPHs and DIDs data for commissioning purposes as well as using SUS data identifiable at the level of NHS number for risk stratification and invoice validation. No changes were proposed to the data flows previously agreed under the existing data sharing agreements. North of England CSU as well as eMBED Health Consortium (Kier Business Services Limited and Dr Foster Limited) would act as data processors.

IGARD were informed of an error within the application, as a reference to pseudonymised non-sensitive data should instead refer to sensitive data. In addition it was noted the application erroneously stated the applicant had five previous data sharing agreements, when this should state four.

**Discussion:** IGARD noted the similarities with NIC-90670-W8H6P Hambleton, Richmondshire and Whitby CCG and reiterated the points raised in relation to that application. This application did not include a change of risk stratification data processors.

IGARD also noted that the privacy notice link provided in this application did not currently seem to work, although the privacy notice was accessible on the CCG website.

**Outcome:** Recommendation to approve

The application should be amended to correct a reference to five previous DSAs in the summary section, to provide the correct privacy notice link, to correct a reference to pseudonymised non-sensitive data, and to amend the table of data already held to be clearer what data has previously been recommended for approval by DAAG or IGARD.

IGARD advised that Dr Foster and Kier should review their DPA registrations to ensure they reflect the use of data for this purpose and for these data subjects in order to comply with the Data Protection Act 1998.

IGARD advised that a special condition should be included within the DSA to state that: "As a result of your application IGARD would like to draw your attention to the importance of the accessibility and clarity of your Privacy Notice. In the interests of transparency, you are advised to regularly review your notice against the ICO's Privacy Notices Code of Practice to ensure it reflects best practice. You will be expected to demonstrate progress against this recommendation in any audit undertaken and for any renewal or new application for data."

3.8

North Lincolnshire CCG (Presenter: Stuart Richardson) NIC-90680-M5B5W

**Application:** This application was to consolidate and renew the applicant's existing data sharing agreements to use pseudonymised SUS data, local provider flows, mental health (MHMDS, MHLDDS, MHSDS), MSDS, IAPT, CYPHs and DIDs data for commissioning purposes as well as using SUS data identifiable at the level of NHS number for risk stratification and invoice validation. No changes were proposed to the data flows previously agreed under the existing data sharing agreements. North of England CSU as well as eMBED Health Consortium (Kier Business Services Limited and Dr Foster Limited) would act as data processors.

IGARD were informed of an error within the application, as a reference to pseudonymised non-sensitive data should instead refer to sensitive data. In addition it was noted the application erroneously stated the applicant had five previous data sharing agreements, when this should state two.

**Discussion:** IGARD noted the similarities with NIC-90670-W8H6P Hambleton, Richmondshire and Whitby CCG and reiterated the points raised in relation to that application. This application did not include a change of risk stratification data processors.

**Outcome:** Recommendation to approve

The application should be amended to correct a reference to five previous DSAs in the summary section, to correct a reference to pseudonymised non-sensitive data, and to amend the table of data already held to be clearer what data has previously been recommended for approval by DAAG or IGARD.

IGARD advised that Dr Foster and Kier should review their DPA registrations to ensure they reflect the use of data for this purpose and for these data subjects in order to comply with the Data Protection Act 1998.

IGARD advised that a special condition should be included within the DSA to state that: "As a result of your application IGARD would like to draw your attention to the importance of the accessibility and clarity of your Privacy Notice. In the interests of transparency, you are advised to regularly review your notice against the ICO's Privacy Notices Code of Practice to ensure it reflects best practice. You will be expected to demonstrate progress against this recommendation in any audit undertaken and for any renewal or new application for data."

### 3.9

Wakefield CCG (Presenter: Stuart Richardson) NIC-90713-T3K1V

**Application:** This application was to consolidate and renew the applicant's existing data sharing agreements to use pseudonymised SUS data, local provider flows, mental health (MHMDS, MHLDDS, MHSDS), MSDS, IAPT, CYPHs and DIDs data for commissioning purposes as well as using SUS data identifiable at the level of NHS number for risk stratification and invoice validation. No changes were proposed to the data flows previously agreed under the existing data sharing agreements. North of England CSU as well as eMBED Health Consortium (Kier Business Services Limited and Dr Foster Limited) would act as data processors.

IGARD were informed of an error within the application, as a reference to pseudonymised non-sensitive data should instead refer to sensitive data. In addition it was noted the application erroneously stated the applicant had five previous data sharing agreements, when this should state three.

**Discussion:** IGARD noted the similarities with NIC-90670-W8H6P Hambleton, Richmondshire and Whitby CCG and reiterated the points raised in relation to that application. This application did not include a change of risk stratification data processors.

It was noted that the DPA registration for Wakefield CCG was shortly due to expire and that this would need to be renewed.

**Outcome:** Recommendation to approve

The application should be amended to correct a reference to five previous DSAs in the summary section, to correct a reference to pseudonymised non-sensitive data, and to amend the table of data already held to be clearer what data has previously been recommended for approval by DAAG or IGARD.

IGARD advised that Dr Foster and Kier should review their DPA registrations to ensure they reflect the use of data for this purpose and for these data subjects in order to comply with the Data Protection Act 1998.

IGARD advised that a special condition should be included within the DSA to state that: "As a result of your application IGARD would like to draw your attention to the importance of the accessibility and clarity of your Privacy Notice. In the interests of transparency, you are advised to regularly review your notice against the ICO's Privacy Notices Code of Practice to ensure it reflects best practice. You will be expected to demonstrate progress against this recommendation in any audit undertaken and for any renewal or new application for data."

IGARD noted that the DPA registration for Wakefield CCG was shortly due to expire and would need to be renewed in order for data to continue to flow.

3.10

Bassetlaw CCG (Presenter: Stuart Richardson) NIC-90700

**Application:** This application was to consolidate and renew the applicant's existing data sharing agreements to use pseudonymised SUS data, local provider flows, mental health (MHMDS, MHLDDS, MHSDS), MSDS, IAPT, CYPHs and DIDs data for commissioning purposes as well as using SUS data identifiable at the level of NHS number for risk stratification and invoice validation. North of England CSU, eMBED Health Consortium (Kier Business Services Limited and Dr Foster Limited), Attain Health Management Services Ltd and Rotherham CCG would act as data processors, and it was noted that Attain and Rotherham CCG were additional data processors added since the previous applications had been considered.

IGARD were informed of an error within the application, as a reference to pseudonymised non-sensitive data should instead refer to sensitive data, and in addition a reference to identifiable social care data would need to be removed from the application as this had been included in error. IGARD were also informed that the DPA registration for Rotherham CCG appeared to have passed its expiry date and confirmation would be required that this had been renewed before data could be shared.

**Discussion:** IGARD reiterated the previously raised points regarding privacy notice special conditions, Dr Foster and Kier DPA registration wording, and clarifying in the data held and data requested tables what data had previously been recommended for approval. In addition IGARD suggested that Attain should also review their DPA registration wording to ensure it reflects data processing for this purpose and about these data subjects.

It was noted that the table of data already held for this application indicated that SUS data was currently held for invoice validation, whereas the summary section appeared to contradict this by stating that invoice validation is currently carried out without using SUS data. IGARD asked for this apparent contradiction to be clarified.

IGARD suggested that the CCG might wish to consider updating their privacy notice to note the additional data processing carried out by the two new data processors. IGARD queried a reference to eMBED as data processor three; it was confirmed that eMBED should be consistently referred to as data processor two, with data processor three being Attain and that the application should be amended to correct this.

There was a discussion about the outputs and benefits sections, as no additional information seemed to have been added for the work carried out by the two additional data processors.



IGARD were informed that the two data processors would carry out the same type of work already described previously for the other data processors, and it was suggested that in general it would be helpful for IGARD to have more information about the considerations for a CCG when commissioning data processing work from a new data processor. It was agreed this should be discussed at a future educational session. More specifically it was agreed that this application should be updated to provide a clearer statement about what anticipated outputs and benefits would arise from the work carried out by the two additional data processors.

**Outcome:** Recommendation to approve

The application should be amended to clarify whether or not SUS data has previously flowed for this data applicant for the purpose of invoice validation.

The application should be amended to remove a reference to identifiable social care data, to list the data processor numbers consistently, to provide a clearer explanation in the summary section of what the additional outputs or benefits will be from the additional data processor, to correct a reference to pseudonymised non-sensitive data, and to amend the table of data already held to be clearer what data has previously been recommended for approval by DAAG or IGARD.

IGARD advised that Dr Foster, Kier and Attain should review their DPA registrations to ensure they reflect the use of data for this purpose and for these data subjects in order to comply with the Data Protection Act 1998.

IGARD advised that a special condition should be included within the DSA to state that: "As a result of your application IGARD would like to draw your attention to the importance of the accessibility and clarity of your Privacy Notice. In the interests of transparency, you are advised to regularly review your notice against the ICO's Privacy Notices Code of Practice to ensure it reflects best practice. You will be expected to demonstrate progress against this recommendation in any audit undertaken and for any renewal or new application for data." In addition IGARD advised the applicant should consider updating their privacy notice in particular to note the additional processing of identifiable data by new data processors. IGARD noted that the DPA registration for Rotherham CCG appeared to have expired and would need to be renewed in order for data to continue to flow.

It was agreed an updated copy of this application would be shared with IGARD out of committee for information.

3.11

Lancashire Care NHS Foundation Trust – The Innovation Agency (Presenter: Stuart Richardson) NIC-79728-X2C2X

**Application:** This application was for pseudonymised SUS and local provider data for residents registered within CCGs in the North West Coast area, to support the work of the North West Coast Connected Health Cities programme. IGARD had previously considered an application for this purpose at the 2 March 2017 meeting and recommended approval; it was noted that the previous application had requested data for only the Liverpool CCG area, but that prior to data being shared the applicant had notified NHS Digital that they would require data for this larger area to meet the stated purpose of their work. In addition the application had been amended to include Arden and GEM CSU as an additional data processor, to carry out necessary data quality checks and derivation of fields necessary to the purpose.

**Discussion:** IGARD noted that the table of data requested listed the data 'SUS for commissioners' as being pseudonymised but also as containing NHS number and postcode. It was agreed this should be amended to clarify that the identifiers NHS number and postcode would not be provided in this data. There was a discussion about special conditions, and it was agreed that section five of the application should be amended to reflect some of the special conditions as appropriate.

IGARD suggested that the applicant organisation should consider whether their privacy notice

appropriately reflected the processing of data for Connected Health Cities. IGARD questioned why the DPA registration details for Arden and GEM CSU had not been included in the application; it was clarified that the details listed for NHS England would cover the CSU, and IGARD asked for the application to be amended to show this more clearly.

The application benefits were discussed and IGARD suggested that when a renewal application was next submitted, this should include details of what outputs had been produced and what benefits had been achieved through this use of data.

**Outcome:** Recommendation to approve

The application should be amended to correct a reference to pseudonymised data containing NHS number and postcode; section five of the application should be amended to reflect the special conditions as appropriate. The application wording regarding NHS England's DPA registration should be amended to be clear this covers Arden and GEM CSU.

IGARD advised that the applicant should consider updating their privacy notice in particular to reflect data processing for Connected Health Cities.

IGARD noted that when a renewal application was submitted, this would be expected to provide more information about the outputs produced and the benefits achieved through this use of data.

There was a discussion about an anticipated application for 209 CCGs to receive NHS 111 data and how this should be presented to IGARD. The suggestion made to IGARD was that rather than providing a table of differences listing the details for each of the 209 CCGs, instead IGARD would receive assurances that NHS Digital had undertaken appropriate checks to ensure that each of the CCGs met the necessary criteria such as having a satisfactory IG Toolkit score, a current and appropriate DPA registration, a current data sharing framework contract, and a privacy notice that met the agreed nine criteria. IGARD agreed that it would be appropriate for a suitably senior member of NHS Digital staff to take responsibility for assuring that these checks had been carried out prior to the application submission.

**3.12**

Leicestershire County Council - Local Authority Public Health SUS Extract Service (Presenter: Garry Coleman) NIC-93640-K3Z1Y

**Application:** This application was based on the template for Local Authority Public Health requests for SUS data, as discussed at the 16 February 2017 IGARD meeting as part of an application for a group of 10 Local Authorities. The application requested pseudonymised SUS data and IGARD were informed that the request was now for the Local Authority to use this for specific commissioning purposes in addition to public health purposes. It was noted that previous IGARD feedback on the template had been incorporated into this application, and that once changes had been agreed the wording regarding the Licensing Act would also be updated.

**Discussion:** IGARD discussed the updated application purpose and felt that it was not sufficiently clear what specific commissioning purposes data could be used for and what the outputs and benefits of this work would be. It was unclear whether some of the points described related to either Local Authority commissioning or to public health, and a specific query was raised about descriptions of using the data to analyse specific operative procedures and pathways or to monitor CCG outcome indicators as it was not thought that this was in line with the type of commissioning work typically undertaken by Local Authorities. IGARD suggested that the application should be updated so that when commissioning was referred to, it was clear in each instance whether this referred to public health commissioning, social care commissioning, joint commissioning with healthcare, or some other type of commissioning work.

IGARD noted that the updated application template still included references to processing data

for solely public health purposes and that these would need to be updated to reflect the additional commissioning purposes. It was also suggested that the request title should be amended as this currently only referred to public health.

IGARD acknowledged the particular circumstances of this application and the fact that this organisation already held SUS data without an appropriate data sharing agreement. Given the current position it was agreed that a data sharing agreement should be issued for a maximum of four weeks to cover the data already held, while work was undertaken to produce an updated application that could address the various points raised by IGARD. In addition it was noted that a number of other Local Authorities currently held this data without a data sharing agreement in place and IGARD acknowledged that NHS Digital might wish to take action under delegated authority to issue short term agreements while further work took place to prepare applications for submission to IGARD.

**Outcome:** Recommendation to approve for a period of four weeks only.

The proposed agreement end date should be limited to four weeks.

The application should be amended to reflect agreed changes to the standard wording around the Licensing Act, to correct references to using data for solely public health purposes, and to clarify references to the Local Authority using data about specific operative procedures and clinical pathways.

IGARD noted that when a renewal application was submitted within four weeks this would need to provide a clearer definition of the commissioning purposes for which the data will be used and the benefits of the use of this data for commissioning purposes.

3.13

University of Oxford - Knee Arthroscopy Rates of Surgery and Complications (Presenter: Louise Dunn) NIC-68703-R4Y6C

**Application:** This application for Hospital Episode Statistics (HES), Patient Reported Outcome Measures (PROMs) and ONS mortality data had previously been considered at the 16 March 2017 IGARD meeting and deferred. Further information had now been provided about the amount of data requested as well as evidence that Approved Researcher accreditation was in place for the use of ONS data. In addition IGARD were informed that the description of how patient objections would be applied had been updated to clarify that objections would be applied to HES and PROMs data, but not to ONS data.

**Discussion:** IGARD noted the explanation about the amount of data requested and agreed that the previous queries had now been addressed.

There was a discussion about patient objections and it was confirmed that these would be applied to the HES and PROMs data, but would not be applied to the mortality data as this was owned by ONS rather than NHS Digital. It was confirmed that the data would be linked but that this would only link to mortality data for patients who had not objected to the use of their data.

**Outcome:** Recommendation to approve

3.14

University College London - Farr Institute Variation in healthy life expectancy throughout childhood and adulthood in England (Presenter: Gaynor Dalton) NIC-06527-J1Q6T

**Application:** This application was presented to IGARD for advice only on the applicant's proposed model, where identifiable and sensitive HES and ONS mortality data would be disseminated to the applicant with no data minimisation applied. The data would then be used for research projects and to create outputs that would be shared with other researchers.

**Discussion:** There was a discussion of the two proposed purposes for which data would be

used. IGARD commented that these did not seem sufficiently specific and that compared to other applications, the purposes appeared to be quite vague. Some particular points of the application were considered unclear, such as how the data requested would be used to determine life expectancy and to realise the kind of benefits described. IGARD noted the importance of fairness and holding all applicants to the same standard in terms of consistent requirements to clearly describe the purposes for which data would be used, what processing activities would take place and what outputs and benefits were expected in a way that could justify the amount of data requested.

IGARD queried the legal status of the Farr Institute; it was thought that this was not a separate legal entity from University College London, but IGARD noted the existence of other Farr Institutes linked to different organisations and suggested that any future applications would need to be clear that the application only linked to the specific Farr Institute hosted by University College London. A further query was raised about a statement within the application that data would not be linked to 'external data', as it was unclear what data would be classed as external; IGARD noted that it was unclear how this aligned with a reference elsewhere to expertise in linking genomics data.

Overall it was considered to be unclear how the applicant would process data in a way that would add value and achieve healthcare benefits in a way above and beyond what could be achieved by third party researchers applying directly to NHS Digital for data. It was suggested that NHS Digital and similar organisations should further consider whether the type of service described would be of value to researchers, and if so what would be the most appropriate way to provide this. There was a further suggestion that it might be helpful for the Research Advisory Group to consider this.

IGARD noted the information provided about the applicant's intention to establish a Scientific Oversight Committee to review proposed projects that would make use of this data. It was agreed that any future application would be expected to provide more details about this group including its membership (in terms of roles rather than individuals), terms of reference, what governance procedures would be in place, and whether there would be Caldicott Guardian, information governance or ethical input into the committee and its review process. In addition it was agreed more details would be expected about the use of honorary contracts and whether this was in line with any relevant ONS controls on the use of mortality data.

IGARD noted that the applicant had not yet sought ethical review of this project. It was suggested that given the large volume of data requested and the fact that it would be linked to identifiable mortality data, the applicant should contact HRA with more information about the project and seek their advice on whether review by a Research Ethics Committee would be advisable.

**Outcome:** IGARD advised that the application did not seem to describe a sufficiently specific purpose for which data would be used in order for data to be disseminated, and how the described onward dissemination would add value in a way above the work normally carried out by NHS Digital.

There should be a clearer explanation of the legal status of the Farr Institute and confirmation that this only relates to the Farr Institute within UCL, rather than other partner organisations. More information was requested about the Scientific Oversight Committee, including the group's members, terms of reference, governance processes and whether the group has information governance or ethical input.

A statement that data would not be linked to 'external data' should be clarified, with an explanation of how this relates to a reference to expertise in linking genomics data.

IGARD advised the applicant should approach HRA with a clearer explanation of the use of identifiable mortality data for this purpose, for confirmation of whether this work requires ethical review.

This advice was given without prejudice to any future application.

**4**

**Any other business**

A brief verbal update was given on NHS Digital processes around the transition to version 14 IG Toolkit for applicants, and it was noted that applications should contain a special condition requiring satisfactory review of a version 14 IG Toolkit submission by the end of June.

There was a short discussion of HRA CAG processes and it was suggested that it would be helpful for a CAG representative to attend a future educational session.

IGARD were informed of a change to upcoming meeting paper deadlines due to the Easter holiday period.

## Appendix A: Summary of Open Actions

Date raised	Action	Owner	Updates	Status
15/11/16	To update DAAG on the feasibility of providing random samples of data to applicants, and to ask the Production Team to provide DAAG with further information about the options for data minimisation	Garry Coleman	<p>06/12/16: This action was ongoing and it was anticipated an update would be available in mid-January. There had also been a discussion during the training session about data minimisation, with a suggestion for Peter Short to contact the Production Team for further information, and it was agreed that would be incorporated into this action.</p> <p>20/12/16: It was anticipated an update would be available in mid-January.</p> <p>10/01/17: Ongoing. It was agreed that this action would be taken forward by Alan Hassey rather than Peter Short.</p> <p>17/01/17: A number of internal discussions had taken place and it was anticipated an update would be brought to DAAG within the next few weeks.</p> <p>31/01/17: Ongoing. It was agreed the IGARD Chair would request an update on progress of this action.</p> <p>09/03/17: Ongoing. A number of internal discussions continued to take place and it was agreed the action would be taken forward by Garry Colman.</p> <p>23/03/17: Ongoing. There was a suggestion it might be helpful to discuss the type of sampling used by the Department for Work and Pensions.</p> <p>30/03/17: Ongoing.</p>	Open
06/12/16	To query the privacy notice review process within NHS Digital.	Chris Carrigan	<p>13/12/16: This had been discussed with the Caldicott Guardian but further clarification was needed.</p> <p>20/12/16: This action was ongoing in light of developments in other areas, including the drafting of minimum criteria. It was agreed that the action would be taken forward by Dawn Foster and Noela Almeida.</p>	Open

			<p>10/01/17: Ongoing, pending updated criteria.</p> <p>17/01/17: DAAG were given a brief verbal update on the work taking place.</p> <p>24/01/17: Work was ongoing following receipt of the final DAAG comments on the minimum review criteria.</p> <p>31/01/17: A meeting was scheduled to discuss this later in the week.</p> <p>09/02/17: Ongoing. It was agreed this action would be taken forward by the IGARD Chair.</p> <p>16/02/17: It was noted that a meeting with the NHS Digital Caldicott Guardian was scheduled to discuss this.</p> <p>02/03/17: This had been discussed at the educational session and it was agreed the IGARD Chair would contact the Caldicott Guardian following that discussion.</p> <p>16/03/17: IGARD's comments had been shared with the Caldicott Guardian, particularly regarding an unclear table, and the IGARD Chair had requested sight of the updated paper.</p> <p>23/03/17: Ongoing, pending sight of the updated paper.</p> <p>30/03/17: Ongoing.</p>	
10/01/17	To speak to NHS Digital colleagues regarding security assurance for HQIP.	Garry Coleman	<p>24/01/17: This had been raised with NHS Digital.</p> <p>31/01/17: This had been raised with HQIP and it was thought that work was underway to provide assurances.</p> <p>16/02/17: Ongoing. It was suggested that Jon Fistein could support this work.</p> <p>02/03/17: It was agreed the action should be taken forward by Garry Coleman.</p> <p>09/03/17: Security assurance discussions with HQIP and NHS Digital had taken place and it was hoped to be resolved by the end of the month.</p> <p>16/03/17: NHS Digital had received a System Level Security Policy (SLSP) from HQIP and this was currently under review.</p> <p>30/03/17: Ongoing.</p>	Open
17/01/17	To provide an update on the security assurances	Garry	24/01/17: It was anticipated this update would be provided to a	Open

	that NHS Digital would seek for applicants using contractors.	Coleman	meeting within the next few weeks. 09/03/17: Ongoing. It was agreed that the IGARD chair would contact Garry Coleman. 16/03/17: An update had been provided by email; it was agreed this would be circulated to confirm whether this had addressed IGARD's query. 23/03/17: It was confirmed one query had been addressed by email; confirmation was requested if any queries remained outstanding. 30/03/17: Ongoing.	
09/03/17	NHS Digital to ensure that for all future DSfC applications, data flow diagrams should be provided and where appropriate the applications should be split in order to aid transparency of the process.	Stuart Richardson	30/03/17: Ongoing.	Open
23/03/17	To provide additional information about the application checks made by the Pre-IGARD process before applications are submitted to an IGARD meeting.	Gaynor Dalton	30/03/17: Ongoing.	Open
23/03/17	To provide a response to previously raised IGARD queries about indemnity.	IGARD Secretariat	30/03/17: Ongoing.	Open
30/03/17	To provide assurances for IGARD about how data destruction is managed under BAU processes when data processors change	Garry Coleman		Open
30/03/17	To contact the NHS Digital Caldicott Guardian regarding how NHS Digital handles applications from organisations whose IG Toolkit has been reviewed as satisfactory with an improvement plan.	Chris Carrigan		Open



## **Appendix B: Out of committee report (as of 10/03/17)**

These applications were previously recommended for approval with conditions by DAAG or IGARD, and the conditions have subsequently been agreed as met out of committee.

The following applications had the non-privacy notice caveats signed off by DAAG or IGARD, and then the privacy notice caveats signed off by the Director for Data Dissemination:

- NIC-55680 NHS Newham CCG
- NIC-47191 NHS Liverpool CCG
- NIC-36889 NHS South Tyneside CCG
- NIC-49736 NHS Chiltern CCG
- NIC-55694 NHS South Norfolk CCG
- NIC-55743-R8P3L NHS City and Hackney CCG
- NIC-49737-S2P1V NHS Gloucestershire CCG
- NIC-49725-M7Y0M NHS Swindon CCG
- NIC-49690-C6R1L NHS Aylesbury CCG
- NIC-49736-W5L3J NHS Chiltern CCG

### **IAO and Director approvals**

The following applications were not considered by DAAG or IGARD but have been progressed for IAO and Director extension/renewal only:

- NIC-371243 NHS North & East London CSU
- NIC-03581-H3Z4X Central and North West London NHS Foundation Trust
- NIC-368020-R5L2K Dr Foster Ltd