

Independent Group Advising on the Release of Data (IGARD)

Minutes of meeting held 11 May 2017

Members: Joanne Bailey, Chris Carrigan, Nicola Fear, Kirsty Irvine, Debby Lennard, Eve Sariyiannidou, James Wilson (agenda items 1 – 2.8)

In attendance: Garry Coleman, Gaynor Dalton, Frances Hancox, Louise Hill, James Humphries-Hart, Dickie Langley, Paul Niblett, Stuart Richardson, Kimberley Watson, Vicki Williams, Robyn Wilson

Apologies: Sarah Baalham, Anomika Bedi, Jon Fistein

1	<p>Declaration of interests</p> <p>Nicola Fear noted a minor connection with the Institute of Occupational Medicine application (NIC-149506-6C4GX) due to previous work on projects linked with the applicants, but no current involvement. Kirsty Irvine declared a potential interest in the Royal College of Obstetricians and Gynaecologists application (NIC-44356-Y8N6R) due to paid examiner work for that organisation as well as involvement in women's networks. Chris Carrigan declared a potential interest in the NHS Digital – National Bowel Cancer Audit application (NIC-376603-K2J9R) due to his employment by the University of Leeds with links to that audit.</p> <p>Review of previous minutes and actions</p> <p>The minutes of the 4 May 2017 IGARD meeting were reviewed and a minor change was agreed to the recommendation wording for one application. In addition some minor changes had been suggested to the Chair before the meeting by email. Subject to these changes the minutes were agreed as an accurate record of the meeting.</p> <p>Action updates were provided (see Appendix A).</p> <p>Out of committee recommendations</p> <p>An out of committee report was received (see Appendix B).</p>
2 2.1	<p>Data applications</p> <p><u>NCMP letter – for advice (Presenter: Paul Niblett)</u></p> <p>Application: IGARD were asked to provide advice on a draft updated letter to parents for the National Child Measurement Programme (NCMP). This updated draft included more information about the processing of data for secondary purposes and provided website links for any parents wishing to find out more information.</p> <p>Discussion: IGARD noted that at present it did not seem possible for parents to only opt out of data sharing for secondary purposes, without also opting out of their child being measured entirely and thereby losing the benefits of local uses of this data. It was suggested that Public Health England should further consider de-coupling the opt out processes for these two uses of data. There was a suggestion that some parents might be put off by the requirement for secondary data sharing and therefore be more likely to choose to opt their child out entirely, although it was acknowledged that at present NCMP participation rates were high.</p> <p>IGARD raised concerns about the way data sharing with NHS Digital and Public Health England was described in the updated letter, as this appeared to say that only anonymised</p>

data would be shared whereas NHS Digital received identifiable data. IGARD suggested that the letter wording should instead only state that data would not be published in a way that could lead to individual children being identified, and to more clearly state which organisations would have access to identifiable data or to data that could potentially identify a child. It was suggested that Public Health England might wish to work with parent groups to review the language used to describe identifiable, potentially identifying or anonymised data.

In addition IGARD advised that the letter should more clearly describe the potential for data to be linked with other datasets, including providing examples such as linkage with dental health survey data before going on to explain in a second sentence what types of organisation this linked data could be shared with. There was a suggestion that the NHS Choices webpage linked to in the letter could be updated to provide more information about planned data linkages as these arose. IGARD suggested that parents might find it reassuring if this section of the letter included a statement that this type of data sharing would always be subject to relevant approvals.

Outcome: IGARD advised that the new wording within the letter should be updated to correct some factual errors around which organisations would have access to identifiers or to data that could not directly identify children, including updating potentially misleading references to anonymised data. References to linkage to other data should also be further explained, possibly with reassurances that linkage and further data sharing would be subject to relevant approvals. A statement that NCMP data would not be shared in a way that could identify children should also be amended.

IGARD suggested that NHS Digital or PHE should consider working with parent groups to specifically test the terminology describing of the level of data.

In addition IGARD advised that PHE should consider the best practice approach of separating opting out from measurement and feedback to parents from opting out of national data sharing.

2.2

Sheffield CCG (Presenter: James Humphries-Hart) NIC-89613-L9D8C

Application: This application was to amend an existing data sharing agreement to add the use of Secondary Uses Service (SUS) data identifiable at the level of NHS number for the purpose of invoice validation, and to add a number of data processors. North of England CSU, MedeAnalytics International Ltd, Sheffield Hallam University, the University of Sheffield, Attain Health Management Services Ltd, Sheffield City Council, Rotherham CCG and Sheffield CCG would now all act as data processors on behalf of Sheffield CCG.

Discussion: IGARD queried the large number of data processors set out in this application. It appeared from the information provided that some of these organisations would be carrying out the same processing activities to produce the same outputs and benefits, and IGARD felt that this could represent excessive processing. It was agreed that in particular more information was needed about how the outputs and benefits provided by Sheffield Hallam and the University of Sheffield would differ from each other and from those provided by the other six data processors, as this was unclear from the generic wording provided. IGARD highlighted this as a potential limitation of the generic template wording approach typically taken with these applications, and emphasised that when different processing activities were being carried out for different purposes than the expected generic setup then this should be made clear. The role of Yorkshire & Humberside Collaboration for Leadership in Applied Health Research and Care (CLAHRC) in the University of Sheffield's processing activities was queried. IGARD welcomed the information that had been provided in the summary section about the roles of the different data processors but asked for this to be reflected along with additional details in section five of the application.

IGARD also queried the role of Sheffield City Council in this application and requested a clearer explanation of the reason that this organisation would act as a data processor on

behalf of the CCG rather than requesting data separately in their own right for joint commissioning purposes. Confirmation was requested of whether this Local Authority held similar data for a related purpose, such as whether they were in receipt of Hospital Episode Statistics (HES) data or had access to the HES Data Interrogation Service (HDIS).

A further query was raised about the use of 'group one' data as shown on the data flow diagram, as this did not appear to be reflected within the application. It was confirmed that the application was missing the standard text describing how this data would be used for commissioning purposes and IGARD asked for the application to be updated to include this.

IGARD queried a reference in the application to the CSU receiving 'the following identifiable GP data from GP Practices' as there was no following list of data. A query was raised about the DSCRO pseudonymisation process and it was agreed this should be further explained within section five of the application.

IGARD noted that the DPA registration for MedeAnalytics referred to processing data about patients on behalf of public sector clients, and suggested that the other data processors should review their registration wording to ensure these appropriately covered this use of data.

IGARD noted that the privacy notice for Sheffield CCG included a section about data processors, but were concerned that the majority of data processing organisations listed within this application were not mentioned as this could cause the information within the privacy notice to be potentially misleading. Confirmation was requested that the privacy notice was still considered to meet the necessary nine point criteria given this potentially misleading section.

Outcome: Recommendation deferred:

- Providing a clearer explanation of how the processing carried out by the various data processors will vary, and in particular how the outputs and benefits for Sheffield Hallam and the University of Sheffield will differ from each other and the other data processors. The role of the CLARHC collaboration in this application should also be more clearly explained.
- Providing a clearer explanation of the role of the Local Authority, with clarification of whether this organisation already holds similar data for this purpose, and the reason for this organisation to act as data processor on behalf of the CCG rather than directly apply for data for their joint commissioning purposes.
- Confirmation that Sheffield CCG's privacy notice meets the nine point criteria, as it did not appear to list the various different data processors.

The processing activities section of the application should be amended to include the relevant text for commissioning using group one data as shown on the data flow diagram, to remove or clarify a reference to 'the following identifiable GP data', and to more clearly explain the DSCRO pseudonymisation process.

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 suggested that the data processors should review their DPA registration wording to ensure it includes processing data about patients or healthcare users.

2.3

Brent CCG (Presenter: Stuart Richardson) NIC-86054-Q4Y8W

Application: This application requested an amendment to an existing agreement, to add the use of SUS data identifiable at the level of NHS number for invoice validation, to change the level of data used for commissioning purposes from identifiable to pseudonymised, and to amend the flow of risk stratification data to remove the involvement of the CSU in this flow.

IGARD were informed of an error on the data flow diagram where this referred to South East CSU, as following a merger this data processing would now be carried out by North East London CSU. In addition IGARD were informed that data destruction had already been carried out for any data identifiable at the level of NHS number that would now be replaced by pseudonymised data under this agreement.

Discussion: IGARD queried whether data destruction had been confirmed for all previous data flows for commissioning purposes, including mental health data, or whether this had only been confirmed for SUS data. It was agreed a reference in the application to the 'deletion' of data should be amended to instead refer to data destruction.

A further query was raised for the timeline for data destruction, and what data the CCG had been using for commissioning purposes given that the data identifiable at the level of NHS number had already been destroyed. IGARD asked for the application to be amended to state more clearly that the NHS Digital had already provided pseudonymised data for this purpose. In addition it was agreed the application should be updated to confirm that the identifiable data for commissioning purposes listed within the application as 'approved but not yet held' would no longer be disseminated.

IGARD welcomed the move from sharing identifiable data to instead using pseudonymised data for the purpose of commissioning.

The CCG's privacy notice was briefly discussed and IGARD noted that this still referred to the previous CSU rather than North East London CSU who were now acting as a data processor on their behalf. IGARD suggested that this should be updated, and asked for the application to be updated to note which team within NHS Digital had reviewed the organisation's privacy notice. In addition it was noted that the address details listed within the application for the CSU were not up to date.

A reference to risk stratification data being 'pseudonymised aggregate' was queried and IGARD asked for this to be corrected. It was agreed the table of data requested would be updated to clarify which data had previously been provided and would continue to be retained. In addition IGARD noted that the data flow diagram omitted the flow of an aggregate report to the CCG as described within the application.

Outcome: Recommendation to approve

The application should be updated to confirm that any identifiable data previously received from NHS Digital for the purpose of commissioning has been destroyed, not just SUS data, and to confirm that the identifiable data listed as 'approved but not yet held' will no longer be released.

A reference to data deletion should be amended to instead state data destruction. The application should also be amended to be clear which team carried out the privacy notice check, and to correct the address details provided for the CSU. The application should also be updated to be clear that the applicant organisation already hold pseudonymised data for these purposes. A reference to pseudonymised/aggregated data should be corrected to state this is pseudonymised data. The data flow diagram should be updated to add the flow of an aggregated report. The table of data requested should be updated to include which data will continue to be retained.

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." It was suggested that Brent CCG should in particular update their privacy notice to refer to North East London CSU as a data processor.

<p>2.4</p>	<p><u>University of Dundee - Data linkage request for 'Allopurinol and cardiovascular outcomes in patients with ischaemic heart disease ALL-HEART' study (Presenter: Dickie Langley) NIC-369348-H6H8B</u></p> <p>Application: This application for identifiable HES, cancer registration and cause of death data for a consented study cohort had previously been considered at the 4 May 2017 meeting when IGARD had deferred making a recommendation. The application had now been updated in response to the points raised at that meeting.</p> <p>Discussion: IGARD discussed the responses provided and agreed that in most cases the previously raised issues had now been adequately addressed. There remained an outstanding query regarding the involvement and influence of the funding organisation, as it had not been confirmed whether the Department of Health were content with restriction set out. Given that the application indicated that the majority of outputs would not be due for publication until after a further annual renewal would be due, IGARD asked for a special condition to be added to the application to require appropriate evidence regarding these contractual arrangements when an annual renewal application was submitted.</p> <p>IGARD queried whether the applicant had updated their fair processing information and it was confirmed that a time-limited special condition had been included in the application to require this to be completed by the end of July.</p> <p>It was noted that the legal basis for Office for National Statistics (ONS) mortality data listed within the application did not seem to refer to the correct section of the relevant Act, and IGARD asked for this to be amended.</p> <p>IGARD noted that some references within the application to 'the research team' remained unclear. IGARD therefore asked for the application to be amended to more clearly state that while only substantive University of Glasgow employees would have access to and process the data provided under this agreement, the wider research team would include staff from different organisations.</p> <p>Outcome: Recommendation to approve.</p> <p>A special condition should be added to state that when a renewal application is submitted, the applicant must provide evidence of appropriate contractual arrangements with the Department of Health, including that this organisation cannot suppress the dissemination of outputs. References to 'the research team' should be amended to be clearer that while only University of Glasgow staff will have access to and process data, the wider research team will involve employees from different organisations and the application should specify which organisations this includes. The reference to the legal basis under the Statistics and Registration Service Act 2007 should be updated to refer to 39(4)(h).</p> <p>It was the view of IGARD that this application would not be suitable for renewal via the delegated authority process.</p>
<p>2.5</p>	<p><u>Westminster City Council PCMD (Presenter: Robyn Wilson) NIC-75133</u></p> <p>Application: This was an application for access to ONS births and deaths data via the Primary Care Mortality Database (PCMD) based on a previously agreed template application. It was noted that for this application, Westminster City Council requested data for their own Council but also for London Borough of Hammersmith & Fulham Council and the Royal Borough of Kensington & Chelsea Council and that they would process data from these organisations on behalf of each of the three Councils as part of a Tri-Borough Service. It was confirmed that data would only be processed and stored at Westminster City Council premises, with no record level data being shared beyond the specific named individuals. A</p>

	<p>copy of the Information Sharing Protocol for the Tri-Borough Service had been provided.</p> <p>Discussion: IGARD queried the employment status of the individuals who would process identifiable data, as they were described within the application as 'employees of all three boroughs'. It was noted that the Tri-Borough team itself was not a separate legal entity. IGARD also queried whether the Director of Public Health as referred to in the standard application wording was an employee of Westminster City Council.</p> <p>A query was raised about the amount of data and whether at some stage organisations would destroy some of the older data held; IGARD were reminded that at present it was not possible to restrict PCMD access to only certain years of data. A reference within the application to sharing information 'both within the organisation and with its wider partners' was queried and IGARD agreed that the reference to wider partners should be removed.</p> <p>IGARD queried whether the Westminster City Council privacy notice had been reviewed against the nine point criteria and it was noted the application included a special condition that the privacy notice would need to be appropriately updated within the specified timescales. It was suggested that the other two Councils should update their privacy notices to specifically state that Westminster City Council would process identifiable data on their behalf.</p> <p>The application listed a DPA registration expiry date for one of the organisations that had now passed, and IGARD asked for the application to be updated to reflect that this had been renewed.</p> <p>IGARD noted that at the previous meeting they had queried the standard description of why type two objections were not applied to this flow of data, and that this point remained outstanding. It was confirmed that work was underway to address this action and a brief update was given. IGARD emphasised the importance of ensuring that this was addressed for any upcoming renewal applications, as well as ensuring that any published information on the NHS Digital website about exceptions to type two objections was not contradictory or misleading.</p> <p>Outcome: Recommendation to approve, subject to conditions:</p> <ul style="list-style-type: none"> • Clarifying the employment status of the Tri-Borough team and which organisation or organisations substantively employ these staff. • Confirmation of whether the Director of Public Health as referred to in the application template wording is a substantive employee of Westminster Council <p>The application should be amended to remove a reference to data sharing with wider partners. The DPA registration expiry date within the application for one Local Authority should be updated.</p> <p>IGARD advised that the privacy notices for London Borough of Hammersmith & Fulham Council and the Royal Borough of Kensington & Chelsea Council should be updated to reflect that Westminster Council processes data on their behalf.</p> <p>It was agreed these conditions would be reviewed out of committee by IGARD.</p> <p>2.6 <u>Institute of Occupational Medicine - Cohort mortality study of workers occupational exposed to lead in Great Britain (Presenter: Garry Coleman) NIC-149506-6C4GX</u></p> <p>Application: This application for demographic and cancer registration data for a linked cohort had previously been discussed at the 10 January 2017 DAAG meeting, when DAAG had deferred making a recommendation. A sub-license between the Institute of Occupational Medicine and the International Agency for Research on Cancer (IARC) had been drafted and included as a supporting document with the application, additional information about fair processing had been provided and it had been confirmed that although the applicant held previous ONS mortality data for this study, this had been provided directly by ONS rather than via NHS Digital. Additional wording had also been included in the application to emphasise the</p>
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<p>Institute of Occupational Medicine's responsibility for data processing carried out by IARC.</p> <p>Discussion: IGARD noted the potential benefits of this important work and expressed their support for the study. IGARD acknowledged the work that had been carried out and that progress had been made on a number of the issues previously raised by DAAG, but there remained a number of outstanding points.</p> <p>In particular, there remained some concerns about the sub-licensing arrangements as it was not clear whether the proposed terms had been drafted by the Institute of Occupational Medicine in isolation or whether IARC had already had sight of and agreed to this, as IGARD noted that no signed documents or evidence of IARC agreement had been provided. IGARD were informed that there could be difficulties in signing a finalised agreement before the NHS Digital data sharing agreement was in place, but IGARD advised that some form of written evidence was needed that IARC would agree to the terms set out around their use of this data. It was suggested that a signed copy of the contract would be the preferred form of evidence of this.</p> <p>IGARD noted a typo in the sub-license document as this referred to not allowing IARC to further de-identify the data, where this should instead have referred not being permitted to re-identify the data. It was agreed that this should be corrected.</p> <p>It was noted that the Approved Researcher accreditation for one individual appeared to have lapsed and IGARD requested evidence that this had in fact been renewed.</p> <p>There was a discussion of fair processing and IGARD suggested that this should be updated to include data sharing with an international organisation as well as the processing of cancer registration data. Concerns were raised that the version of the participant information leaflet already shared with trade unions had not contained this information, and in particular that the leaflet stated that participant details would not be shared with any third party 'except for the purposes of obtaining death details' which appeared to exclude sharing participant identifiers in order to receive cancer registration data. It was agreed that this contradictory statement would need to be corrected and that the updated leaflet should be re-issued to trade unions. It was also agreed that the application should include a special condition to publish the updated version of the leaflet online as it appeared that the study website currently featured an out of date leaflet. IGARD suggested that the applicant should also consider making outputs available to trade unions.</p> <p>It was suggested that section five of the application should be amended to include a statement that the standard ONS terms and conditions apply.</p> <p>Outcome: Recommendation deferred:</p> <ul style="list-style-type: none"> • An erroneous reference in the sub-licensing document to not allowing the organisation to further de-identify data should be correct to restrict the re-identification of data. • Confirmation via a signed contract that IARC have formally agreed to the terms and conditions set out within the sub-license document provided. • Confirmation that Approved Researcher accreditation has been renewed. • The patient information leaflet should be updated to correct a potentially contradictory statement about only sharing data to confirm death details, as well as to cover data sharing with an international organisation and processing of cancer registration data and this should be re-issued to the trade unions. • A special condition should be added to the application that the applicant's online fair processing information must be updated within six weeks to publish the new version of the updated patient information leaflet. • Section five of the application should be amended to include a statement that the standard ONS terms and conditions apply. <p>IGARD advised that outputs should be made available to Trade Unions.</p>
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Royal College of Obstetricians and Gynaecologists - National Maternity and Perinatal Audit (Presenter: Garry Coleman) NIC-44356-Y8N6R

Application: This application requested a cohort linkage and extract of HES data for the creation of the new National Maternity and Perinatal Audit (NMPA). Identifiable data for a particular audit cohort of mothers and babies was requested, and in addition pseudonymised data was requested for mothers and babies from 2000-01 onward including sensitive fields such as Census Output Area and Registered GP. It was noted that data would be physically stored at the RedCentric premises and that the Royal College of Obstetricians and Gynaecologists and the London School of Hygiene and Tropical Medicine would both remotely access the data held at that location. It was noted that NHS Digital would not disseminate mortality data as part of this application, and that references to mortality data within the application referred to Scottish mortality data only.

Discussion: IGARD noted the information provided about HQIP's DPA registration but suggested that the registration wording should also be updated to include that patient data is processed under their data controllership as part of the audits they commission.

References to 'the cohort' within the application were queried and IGARD asked for it to be made unambiguous whether the audit cohort or the wider HES cohort was referred to.

IGARD queried the dataset period as the applicant's section 251 support indicated data would be collected over a four year period from 2014, whereas the application referred to data from 2000 – 2011. It was clarified that this referred to pseudonymised data, and that no identifiable data for this period would be shared from NHS Digital. A further query was raised about why some HES data was only requested from 2007-8 onwards, and it was noted that this dataset had not been produced prior to that year. A reference in the application to 'all historical data' for the audit cohort was queried and IGARD asked for this wording to be clarified.

There was a discussion of the importance of fair processing, as well as the need for patient notification as per the applicant's section 251 support. It was suggested that fair processing information should include the planned data linkage and be more explicit about what data would be used. IGARD asked for a special condition to be added to the application that the applicant must update their website (as per the commitment within this application) within six weeks of signing the data sharing agreement. Some concerns were raised that mothers who had given birth some years previously would perhaps be unlikely to see the website now and so would be unaware of the data processing, but it was noted that this had been accepted as part of CAG's discussion of the applicant's section 251 support and it was considered that any further fair processing efforts would likely be disproportionate.

IGARD queried the statement within the application that 'data will be anonymised' through the use of a study ID, and requested either a further explanation of what steps would be taken to anonymise data or for this description to be changed to instead state that data would be pseudonymised.

There was a discussion of the role of the London School of Hygiene and Tropical Medicine as a data processor, and whether this organisation would have access to identifiable data. It was clarified that only two specific employees of the Royal College of Obstetricians and Gynaecologists would process identifiable data for the purpose of linkage. IGARD asked for the data flow diagram to be updated to reflect this.

IGARD noted that the applicant's fair processing information seemed to have been updated to remove references to mortality data, as this was no longer requested from NHS Digital, but it was also noted that the audit website referred to mortality data in other places. It was suggested that the applicant should consider whether their fair processing information ought to still contain some information about mortality data if this was being collected from other

sources.

Outcome: Recommendation to approve.

References to 'the cohort' within the application should be amended to be clear whether this refers to the study cohort or HES cohort. A special condition should be added that the applicant will update their website within six weeks.

The data flow diagram should be updated to be clear only the employees of RCOG will have access to identifiable data provided by this application.

A reference in section 5 to providing all historical data should be updated to include the applicable data minimisation efforts. References to data being anonymised through the use of an indirect identifier should be amended to instead refer to data being pseudonymised.

A statement that "The NMPA will collect the data of all women who give/gave birth in England between 1 April 2000 and 31 March 2018" should be clarified to be clear this refers to the collection of audit data and that no identifiable data from 2000 – 2011 will flow to NHS Digital.

IGARD advised that HQIP should update their DPA registration wording to include that personal confidential data is processed under their data controllership to support audits.

IGARD also advised that the applicant should consider whether fair processing information still needs to refer to mortality data collected from any different sources.

2.8

Royal College of Surgeons – National Prostate Cancer Audit (Presenter: Kimberley Watson)
NIC-96472-W0K5S

Application: This was a new application requesting list cleaning on a monthly basis, for mortality checks and address updates prior to sending out patient questionnaires as part of the National Prostate Cancer Audit. It was confirmed that HQIP commissioned the audit and would act as data controller for the purpose of this application, while the Royal College of Surgeons and Quality Health Ltd would act as data processors. IGARD were informed that prior to the implementation of type 2 objections, the Royal College of Surgeons had received data directly from the National Cancer Registration and Analysis Service (NCRAS) but that this flow had now halted.

IGARD were made aware of an error on the data flow diagram as this indicated that Quality Health would collate and analyse data, whereas in fact this organisation would only collate data. In addition it was noted that some security assurances remained outstanding and that the data sharing agreement would not be issued until these had been completed.

Discussion: IGARD noted that the DPA registration wording for HQIP referred to transferring data to territories around the world, and IGARD queried whether this was part of the current request. It was confirmed that this application restricted data use to within England and Wales only, and to only the listed data processing addresses.

It was agreed that section five of the application should be amended to more clearly describe NCRAS as part of Public Health England. There was a brief discussion about the reasons that previous data flows from NCRAS to the applicant had ceased and IGARD asked for this to be more clearly explained within the application.

IGARD queried a special condition that restricted Quality Health Research from accessing data. It was clarified that this was the parent organisation for Quality Health Ltd, and that for security reasons this special condition had been included to be clear that only Quality Health Ltd as its distinct legal entity would have access to data. IGARD requested confirmation of whether this was the full legal name for Quality Health Research, and asked for the application to be amended to consistently refer to Quality Health Ltd by its full name to be clear of the distinction between the two organisations.

It was noted that although the Royal College of Surgeons had been commissioned by HQIP to carry out this audit, the application also referred to collaboration with collaboration the British

Association of Urological Surgeons (BAUS) and the British Uro-Oncology group (BUG). It was confirmed that these organisations would not be permitted to process data, or to receive anything other than aggregated outputs with small numbers suppressed, under this data sharing agreement. IGARD requested a clearer explanation of their involvement in the audit, with an explanation of why these organisations should not be considered data controllers in the context of this application.

IGARD queried references in the application to data being 'anonymised' as it was unclear what steps were taken to anonymise data other than the use of an indirect identifier. It was agreed that the application should be updated to either further explain the anonymisation process or to instead refer to data being pseudonymised. IGARD also queried whether the applicant would request any data from NHS data as part of the audit following list cleaning, but it was confirmed this was not required for the current audit process.

Outcome: Recommendation to approve.

The application should be amended to include a clearer statement in section 5 that NCRAS is part of PHE. The description of why previous data flows ceased should be updated to be clear that this was to do with the requirement for list cleaning in addition to the application of type two objections.

Section five should be amended to clarify a reference to a collaboration with the British Association of Urological Surgeons (BAUS) and the British Uro-Oncology group (BUG) to explain their role within the audit with an explanation that these organisations should not be considered data controllers for the purpose of this application, and to be clear that these organisations will only have access to aggregated outputs with small numbers suppressed. The application should be amended to provide additional information about how data is anonymised beyond the use of an indirect identifier, or updating references to data anonymisation to instead refer to pseudonymisation. The application should also be amended to ensure the full legal name for Quality Health Research is given within the special conditions, and consistently using the full name for Quality Health Ltd. throughout the application. The data flow diagram should be updated to be clear that Quality Health Ltd only collate data rather than carrying out analysis.

It was noted that some security assurances remained outstanding and that the DSA would not be finalised until these had been completed.

2.9

NHS Digital - National Bowel Cancer Audit (Presenter: Gaynor Dalton) NIC-376603-K2J9R

Application: This application requested an amendment to permit the linkage of HES and audit data to Intensive Care National Audit and Research Centre (ICNARC) data, and to permit the flow of identifiers to NHS Wales Informatics Service (NWIS) for the purpose of linking to Patient Episode Database for Wales (PEDW) data.

The application had been discussed at the 27 April 2017 meeting when IGARD had deferred making a recommendation, primarily due to the need for further evidence that the applicant's section 251 support covered the described Welsh data flows. The application had been updated to address a number of the points raised, including clarifying the legal basis for Patient Reported Outcome Measures (PROMs) data and adding a special condition around the publication of an updated patient information leaflet. Additional information had been provided about the chronology of the section 251 support, with verbal confirmation from one NHS Digital staff member that the application provided was the version that had been submitted in 2012, but it was confirmed that no further evidence was available as the section 251 application process at that time had not included listing application versions on the outcome letters.

Discussion: IGARD acknowledged the updates provided and the efforts that had been made to address the comments raised at previous meetings. However it was felt that without clearer evidence that the applicant's section 251 support did in fact cover the Welsh data flows

described within the application, and that there was therefore a legal basis for these flows, it would not be appropriate to recommend this application for approval. IGARD suggested that either NHS Digital or the applicant should contact HRA CAG for a written statement confirming that this was included within the applicant's section 251 support as it was unclear from the documents currently available. In particular IGARD noted that CAG should be made aware of the existence of two different section 251 application versions as part of this consideration, and that while one application version included Welsh data the other did not.

Outcome: Recommendation deferred:

- Written confirmation was requested from HRA CAG that the section 251 application version they considered was the version that included PEDW data flows.

2.10

Monitor - PLICS (Presenter: Dickie Langley) NIC-15814-C6W9R

Application: This application was an amendment and renewal to an application that had previously been considered at a number of DAAG meetings, most recently the 17 January 2017 meeting when DAAG had recommended approval. The requested amendment was to receive PLICS data from a wider range of Trusts due to the expansion of the PLICS pilot, and also to add the Royal National Orthopaedic Hospital NHS Trust as a data processor. IGARD were informed that the PLICS dataset was not explicitly listed in the table of data requested due to a technical limitation.

Discussion: There was a brief discussion about the controls in place for any individual sub-contractors employed by Monitor as compared to the security assurances required for organisations contracted by Monitor to act as data processors. IGARD noted that for the new data processor, the Royal National Orthopaedic Hospital NHS Trust, their version 13 IG Toolkit submission had been assessed as not satisfactory due to concerns around staff training and that their version 14 IG Toolkit score, although self-assessed as satisfactory, had not yet been reviewed. It was suggested that a special condition should be added to the application that until such a time as the version 14 IG Toolkit submission had been reviewed as satisfactory, only staff from that data processor who had completed the necessary IG training would be permitted to process data.

IGARD noted that in response to comments previously raised by DAAG, earlier versions of this application had included a special condition that '[a]ny future substantive application for PLICS data beyond the pilot scheme of seven Trusts should clarify the expected benefits of the PLICS pilot and how the PLICS pilot has influenced the design, collection, and use of the data.' This special condition was not included in the current application and was not referred to in the abstract; IGARD emphasised the importance of explicitly stating how applicable special conditions had been met for an application in the interests of transparency. Confirmation was requested of how the current application had addressed this previous special condition, and it was not considered appropriate to recommend the application for approval until this point had been clarified.

In addition it was noted that DAAG had previously queried the security arrangements for contractors, and had suggested that for future application it should be made clear 'whether this related to specific teams within those organisations or how else the data sharing would be managed'. Further information was requested about how this point had been addressed within the current application.

A query was raised about the role of NHS England in this application, and it was agreed that the application should be amended to be clear that for the purposes of this application NHS England would only process data in its role as a data processor for Monitor. In addition it was noted that the application at one point stated that data processing would be restricted to Monitor, the NHS Trust Development Authority and NHS England and that this wording should be updated to include the Royal National Orthopaedic Hospital NHS Trust. IGARD queried a

	<p>reference to data held by Monitor ‘which will become available during the lifetime of the agreement’ and it was agreed this should be explained.</p> <p>Outcome: Recommendation deferred:</p> <ul style="list-style-type: none"> • IGARD noted that DAAG had previously raised a special condition that “Any future substantive application for PLICS data beyond the pilot scheme of seven Trusts should clarify the expected benefits of the PLICS pilot and how the PLICS pilot has influenced the design, collection, and use of the data.” Confirmation was required of how the special condition has been addressed. • Confirmation of how the application had addressed the point previously raised by DAAG regarding clarification of how data access is limited. • Clarification of the role of NHS England to be clear that for the purposes of this application they only handle data as a data processor on behalf of Monitor. <p>The application should be amended to add a special condition that employees of Royal National Orthopaedic Hospital NHS Trust who have not completed mandatory IG training cannot process data until the organisation’s version 14 IG Toolkit score has been reviewed as satisfactory.</p> <p>A reference to data access being limited to Monitor NHS TDA and NHS England should be amended to include Royal National Orthopaedic Hospital NHS Trust. A reference to data that ‘will become available during the lifetime of the agreement’ should be clarified.’</p>
3	<p>Any other business</p> <p>No other business was raised.</p>

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>11/05/17: This action was not discussed due to time restrictions.</p>	Open
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</p>	Open

			<p>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>20/04/17: It was confirmed that the HQIP SLSP had been reviewed and approved. IGARD requested sight of this for information.</p> <p>11/05/17: This action was not discussed due to time restrictions.</p>	
17/01/17	To provide an update on the security assurances that NHS Digital would seek for applicants using contractors.	Garry Coleman	<p>24/01/17: It was anticipated this update would be provided to a meeting within the next few weeks.</p> <p>09/03/17: Ongoing. It was agreed that the IGARD chair would contact Garry Coleman.</p> <p>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.</p> <p>23/03/17: It was confirmed one query had been addressed by email; confirmation was requested if any queries remained outstanding.</p> <p>11/05/17: This action was not discussed due to time restrictions.</p>	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	<p>06/04/17: Ongoing. It was anticipated a response would be provided at the following IGARD meeting.</p> <p>13/04/17: A verbal update was given on the Pre-IGARD process and it was agreed that it would be helpful on both sides to develop a Pre-IGARD checklist to define what checks would be carried out as standard for each application before reaching IGARD.</p> <p>27/04/17: Gaynor offered to provide a marked up application to demonstrate the types of comments raised at Pre-IGARD, but IGARD felt that this could be potentially prejudicial to the consideration of that application.</p> <p>04/05/17: Ongoing. This had been discussed as part of the morning educational session.</p> <p>11/05/17: Ongoing.</p>	Open

23/03/17	To provide a response to previously raised IGARD queries about indemnity.	IGARD Secretariat	06/04/17: An update had been provided and the action remained open. 13/04/17: This was ongoing within NHS Digital. 11/05/17: Ongoing.	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	06/04/17: This had been raised but a response had not yet been received. 11/05/17: Ongoing.	Open
20/04/17	IGARD Chair to contact key stakeholder organisations regarding the benefits of uses of data to feed into the IGARD annual report.	IGARD Chair	11/05/17: Ongoing.	Open
20/04/17	Louise Dunn to request an update from Garry Coleman about possible future improvements to the data release register, and whether this might include publishing data flow diagrams to add clarity.	Louise Dunn	11/05/17: Ongoing.	Open
27/04/17	IGARD Chair to contact the NHS Digital Caldicott Guardian regarding GPs' data controller responsibilities for fair processing around risk stratification.	Chris Carrigan	11/05/17: Ongoing.	Open
04/05/17	Robyn Wilson and Joanne Treddenick to agree updated wording for the PCMD application template on type two objections, ensuring that this is consistent with published NHS Digital information about exceptions to type two objections.	Robyn Wilson	11/05/17: The IG Advisor gave a verbal update with confirmation that in October 2016 NHS Digital had confirmed a decision that type two objections would not be considered to apply to this flow of data due to the specific legal gateways around ONS data sharing. Further work was planned to agree the specific application wording to describe this.	Open

Appendix B: Out of committee report (as of 05/05/17)

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

The following application conditions have been signed off by IGARD:

- NIC-58999 IMS Health Ltd (*Considered at 13th April 2017 IGARD meeting*)

The following application conditions have been signed off by the IGARD Chair:

- NIC-82493 University of Essex (*Considered at 27th April 2017 IGARD meeting*)
- Group application for 2 CCGs GA02-AMD-North England (*Considered at 20th April 2017 IGARD meeting*)