

Data Access Advisory Group (DAAG)

Minutes of meeting held 10 January 2017

Members: Joanne Bailey, Chris Carrigan (Chair), John Craven, Dawn Foster, Eve Sariyannidou, James Wilson

In attendance: Anomika Bedi (observer), Pam Cairns (observer), Dave Cronin, Jen Donald, Louise Dunn, Jon Fistein (observer), Frances Hancox, Alan Hassey (observer), Kirsty Irvine (observer), Vicki Williams

Apologies: None

1	<p>Declaration of interests</p> <p>Chris Carrigan noted a potential conflict of interest with the University of Leeds application (NIC-17649-G0X4B) due to his employment by that organisation, but noted no particular involvement with the study or the individual applicants.</p> <p>Review of previous minutes and actions</p> <p>The minutes of the 20 December 2016 meeting were reviewed and agreed as an accurate record.</p> <p>Action updates were provided (see Appendix A).</p> <p>DAAG discussed the points that had been raised at the previous meeting regarding security assurance for HQIP and suggested that this should be raised more formally within NHS Digital to determine the appropriate way forward.</p> <p>Action: To speak to NHS Digital colleagues regarding security assurance for HQIP.</p> <p>Out of committee recommendations</p> <p>An out of committee report was received (see Appendix B) and DAAG asked for this to be included within the published meeting minutes.</p> <p>DAAG were notified that a further application (NIC-32833 Competition & Markets Authority) had previously been signed off by the Director for Data Dissemination outside of the usual out of committee process and DAAG requested further information about this for the next meeting.</p>
2 2.1	<p>Data applications</p> <p><u>London Borough of Redbridge Council – Local Authority Public Health / HDIS (Presenter: Louise Dunn) NIC-73678-Y1T0Y</u></p> <p>Application: This was a new application for access to the Hospital Episode Statistics (HES) Data Interrogation Service (HDIS) for public health purposes. DAAG were informed that while similar Local Authorities had requested an extract of HES data for this purpose, this applicant had requested HDIS access due to data storage limitations.</p> <p>Discussion: DAAG noted the commitment within the application that record level data would not be processed outside the analysis team, and asked for this wording to be updated to more clearly state that only the Local Authority's HDIS users would have access to the downloaded record level data. In addition a query was raised about the requirement to download record</p>

level data, as it was noted that the majority of HDIS applications had only included the ability to download aggregated data including small numbers. Confirmation was requested of whether any other Local Authorities were currently able to download record level data from HDIS for public health purposes, as this has been a previous restriction, and if not a clearer justification was requested for why this was required.

DAAG noted that this application included the standard special condition wording about the need for the applicant to update their privacy notice; however it was suggested that this wording was not entirely appropriate in this instance, as the applicant's privacy notice did explain the use of data for public health purposes. In addition DAAG queried the suggested privacy notice wording referred to in the application as it was felt that referring to NHS Digital by name would be more appropriate than only referring to data from 'a range of sources including hospitals'.

A query was raised about a reference within the application to the Licensing Act 2003, as it was unclear how this was relevant to the application. DAAG noted that this was part of the standard template wording for Local Authority public health applications, but suggested that the template wording should be updated for clarity.

DAAG noted that at some points the application referred to both HDIS2 and HDIS and queried whether there was a difference between how the two terms had been used. It was agreed the application would be updated to use consistent terminology.

Outcome: Recommendation to approve, subject to:

- Updating the wording in section five to be clear that only the Local Authority's HDIS users will have access to the downloaded record level data.
- Confirmation of whether any other Local Authorities are currently able to download record level data from HDIS, and if not then providing a clearer justification for why it is required for this application.
- Amending the special condition wording about the applicant's privacy notice, including changing the advice wording to take out the statement that public health functions are not referred to.
- Clarifying a reference to the applicant requiring data under the Licensing Act.
- Updating the application wording to be clear that access will be to HDIS II rather than HDIS I.

DAAG noted that the applicant's DPA registration wording should be updated to refer to processing data about patients or health service users for public health purposes. It was agreed these caveats would be reviewed out of committee by DAAG.

2.2

NHS Digital (CARMS) - National COPD Audit (Presenter: Louise Dunn) NIC-25780-T1F4G

Application: This application was submitted by the NHS Digital Clinical Audit Registries Management Service (CARMS), with CARMS and the Royal College of Physicians both acting as data processors on behalf of HQIP. Pseudonymised HES data linked to Office for National Statistics (ONS) mortality data was requested for a specific cohort, with participant consent and Section 42(4) of the Statistics and Registration Services Act 2007 providing a legal basis.

Discussion: There was a lack of clarity about which consent material version had been used to initially obtain participant consent and it was agreed the application should be updated to state this more clearly. In addition DAAG noted that some of the consent material or fair processing links within the application appeared to be incorrect and DAAG asked for the application to be updated with the correct links for the 2015 cohort, rather than more recent cohorts.

DAAG noted the use of the acronym PR within the application to mean pulmonary rehabilitation, and encouraged applicants to ensure all acronyms are explained the first time

2.3	<p>they are used within documents.</p> <p>A query was raised about a statement within the application that ‘further identifiers may be provided’ to NHS Digital, as it was noted that all identifiers covered by the applicant’s section 251 support already appeared to be included within the application. It was agreed that this statement should be removed from the application.</p> <p>The role of HQIP as data controller was noted and DAAG reiterated their previously raised concerns that appropriate security assurances had not been provided for this organisation. It was agreed that the statement about HQIP providing security assurances for their data processors should be removed from the application. In addition there was a discussion about the DPA registration wording for HQIP and DAAG noted that either this should be updated to include clinical audit, or the existing wording about research should be amended to remove a statement that research data is about survey respondents. In addition a query was raised about the NHS Digital DPA registration wording but it was confirmed that the application did not include the current registration wording and would need to be updated.</p> <p>A typographical error in the application was noted and it was agreed this would be corrected.</p> <p>There was a discussion about the planned outputs and expected benefits. While DAAG acknowledged that this work could potentially realise significant benefits, it was considered that these were not clearly described within the application itself and DAAG suggested that more information could have been provided about how outputs would be disseminated in a way that would help achieve healthcare benefits. It was agreed that the applicant should provide more detail about this in any future applications.</p> <p>Outcome: Recommendation to approve, subject to:</p> <ul style="list-style-type: none"> • Confirmation of which consent form version was used to obtain participant consent. • Removing a statement that further identifiers may be provided. • Correcting the fair processing links provided in the application to include the correct link for the 2015 audit cohort. • Removing a statement about HQIP providing security assurances for data processors. • Correcting a typographical error where the word ‘follow’ is used instead of ‘flow’. • Updating the DPA registration wording provided in the application for NHS Digital. <p>DAAG noted that for future applications where HQIP acts as data controller, an update would be expected regarding security assurances for HQIP.</p> <p>DAAG suggested that HQIP’s DPA registration should be updated to either describe the use of data for clinical audit, or remove the statement that research is carried out only on data about survey respondents, and the wording should also be updated to reflect the processing of personal data described in this application.</p> <p>DAAG advised that in future the applicant would be expected to more clearly explain the anticipated outputs and how these would result in healthcare benefits.</p> <p>It was agreed these caveats would be reviewed out of committee by the DAAG Chair.</p> <p><u>University of Leeds - Hospitalisation and Mortality after Acute Myocardial Infarction (Presenter: Dave Cronin) NIC-17649-G0X4B</u></p> <p>Application: This was a new application for pseudonymised HES data linked to a number of fields derived from ONS mortality data. DAAG were given a verbal overview of the applicant’s data minimisation efforts, which included filtering to a cohort of patients with acute myocardial infarction in certain years and excluding patients within a previous acute myocardial infarction diagnosis.</p> <p>Discussion: There was a discussion of the potential clinical impact of this study and DAAG noted the possible benefits of this work. It was felt that the application itself could have made a clearer case for the expected benefits and DAAG suggested that for any future applications</p>
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	<p>the applicant should more clearly describe how outputs would be disseminated in order to help achieve healthcare benefits. DAAG considered that the data minimisation efforts taken were appropriate.</p> <p>DAAG queried a statement within the application about NHS Digital staff providing assurances regarding the mortality data. It was clarified that IG staff had provided assurances that the mortality data derived from ONS data was not identifiable and could be disseminated under the Health and Social Care Act 2012; DAAG asked for the application wording to be updated to state this more clearly.</p> <p>A query was raised about the funding provided from the British Heart Foundation and DAAG requested confirmation that this funding did not include any requirements that would influence the results of this study or how the results would be disseminated.</p> <p>Outcome: Recommendation to approve, subject to:</p> <ul style="list-style-type: none"> • Providing a clearer explanation within the application that the mortality data is not considered identifiable and therefore can be disseminated under the Health and Social Care Act 2012. • Confirmation that the applicant's funding from the British Heart Foundation does not include any requirements that may influence the results or their dissemination. <p>DAAG suggested that for further applications the applicant should more clearly describe how outputs will be disseminated to help achieve the expected benefits. It was agreed these caveats would be reviewed out of committee by the DAAG Chair.</p>
2.4	<p><u>IMS Health Ltd - Using Patient Data in Amyloidosis to Understand Complex Diagnosis Pathways and Treatment Patterns (Presenter: Dave Cronin) NIC-60624-B1R2Q</u></p> <p>Application: This was a new application for pseudonymised HES data for a specific cohort, with identifiers being provided to NHS Digital under section 251 support to allow linkage for the study cohort. The proposed data flow was described and DAAG were informed that this processing had been designed to reduce the risk of any organisation re-identifying the linked pseudonymised data.</p> <p>DAAG were asked to disregard two sentences within the application, including a statement that GlaxoSmithKline cannot control outputs in any way, as the presenter was uncertain if the applicant had confirmed their accuracy and a further grammatical error.</p> <p>Discussion: There was a discussion about the possible flow of NHS numbers for individuals who had withdrawn consent, in order that data about these individuals' hospital episodes could be removed from the dataset and not onwardly shared. DAAG initially noted that this seemed contrary to individuals' wishes as the NHS number would be shared without their consent. However overall it was agreed that this was the most appropriate way forwards, as it would be unsatisfactory to share the dataset containing data about hospital episodes of individuals who had withdrawn their consent and the only way to achieve this opt out appeared to be for NHS number to flow. This was considered to be in line with the approach taken by NHS Digital to implement Type 2 objections.</p> <p>A query was raised about re-identification and DAAG asked for the application to be updated to be clear that IMS Health Ltd would not be able to re-identify the data provided to them.</p> <p>DAAG queried the contractual arrangements between Royal Free London NHS Foundation Trust and IMS Health Ltd for this work, as it was noted that the application referred to a data re-use agreement between the two organisations but that this had not been provided. A query was raised regarding the National Amyloidosis Centre (NAC) and its legal status, and it was confirmed that the NAC was part of Royal Free London NHS Foundation Trust.</p>

There was a discussion of the applicant's fair processing efforts and DAAG noted that it was unclear whether any information materials had been made available to the general public yet. DAAG asked for further information about what efforts the applicant had made to notify patients ahead of data processing in line with the requirements of their section 251 support. Some concerns were raised that the fair processing information provided was not clearly written and contained language that could potentially confuse the general public. In addition DAAG suggested that fair processing information should be made available through additional routes, such as the NAC patient information website or other websites rather than relying solely on posters displayed in clinics and on the IMS website.

Concerns were raised regarding the role of GlaxoSmithKline, as it was noted that a supporting document indicated this organisation had a key role on the steering committee that would determine the dissemination of any potential outputs and there were concerns that this could potentially lead to the dissemination of some outputs being restricted for commercial reasons. In addition DAAG noted that the predictive algorithm that would be produced by this work appeared to be a purely commercial output and the application made no clear reference to this algorithm being made available for use in the public interest. Further information was requested about the planned outputs and anticipated healthcare benefits.

DAAG queried the terms used to describe the cohort subsets and asked for these to be used consistently throughout the document. Queries were raised about subset two in particular, as it appeared that the specialties outlined would include a very large number of patients without amyloidosis and it was unclear why this amount of data was required on these patients. DAAG noted that the study protocol appeared to refer to using a 10% random sample as a control group and it was queried whether a sample of these specialties would be more appropriate.

A query was raised about the different data controller responsibilities involved in this application, as it was suggested that from the activities described GlaxoSmithKline and Royal Free London NHS Foundation Trust might also be acting as data controllers.

Outcome: Unable to recommend for approval.

- Concerns were raised about the potential role of GSK to restrict the dissemination of outputs as per the role of the steering committee referred to in a supporting document.
- Concerns were raised that the resulting predictive algorithm appeared to be a purely commercial output rather than being more widely available in the public interest.
- Further information was required about the fair processing materials previously made available to patients to ensure that the Section 251 requirement for patient notification has been met.
- Clarification would be needed of the contractual arrangements between Royal Free and IMS, with provision of the data re-use agreement between IMS and the NAC.
- Confirmation was required that IMS would not be able to reidentify the HES data provided to them.
- Clarification was needed of data controller and processor responsibilities.
- Further clarification was required about the expected outputs and benefits.
- The application wording should be amended to refer to the cohort subsets consistently.
- Providing a clearer justification or further data minimisation efforts for data subset two as there currently appeared to be no clear justification to provide data about this range of specialties.

DAAG advised that the applicant should consider making fair processing information available through additional methods such as the NAC patient information site.

2.5

Institute of Occupational Medicine - Cohort mortality study of workers occupational exposed to lead in Great Britain (Presenter: Jen Donald) NIC-149506-6C4GX

Application: This application requested an amendment to an existing agreement. The

2.6	<p>applicant had previously received mortality data for a specific cohort; no additional mortality data was requested but the applicant had now requested demographic and cancer registration data for the linked cohort. The applicant held section 251 support to cover the flow of identifiable data, and it was noted that the applicant intended to share pseudonymised data with the International Agency for Research on Cancer (IARC). The presenter raised the similarities between this and a previous application DAAG had reviewed from the Institute of Occupational Medicine (NIC-323309, Rubber and Cable).</p> <p>Discussion: DAAG noted the potential benefits of this study and the rationale for requesting cancer registration data. It was confirmed that the release of demographic data would be a one-off release to address an issue caused by a corrupted dataset.</p> <p>There was a discussion about fair processing, as it was noted that the cohort had given their consent roughly 30 years previously and they therefore might be unlikely to remember to check the study website at this point in time. It was noted that the applicant had made efforts to maintain contact with the industry and unions, and it was unclear what other efforts could be made to inform participants at this stage. However DAAG noted that the fair processing materials provided with this application appeared to only refer to processing cancer data about individuals who were now deceased, whereas cancer data was requested for the entire cohort. Further information was requested about what other fair processing information had been made available, and whether this had clearly described that cancer data would be processed for the full cohort.</p> <p>Concerns were raised regarding the involvement of IARC, as it was unclear whether appropriate contractual arrangements were in place between the Institute of Occupational Medicine and IARC to cover the release of record level data. DAAG noted that these arrangements would need to mirror the terms and conditions set by the data sharing framework contract and the data sharing agreement between the Institute of Occupational Medicine and NHS Digital. Given these concerns DAAG also queried whether IARC currently held any data from the Institute of Occupational Medicine that had originated at NHS Digital. There was a suggestion that if appropriate contractual arrangements with IARC were not in place, the applicant might wish to instead consider only disseminating the aggregated outputs to IARC rather than requesting to share record level data.</p> <p>An error was noted within the application as this listed the DPA registration expiry date as 1990. The planned dissemination of outputs was discussed and DAAG suggested that the applicant should also consider providing these to industry and trade unions.</p> <p>Outcome: Recommendation deferred, pending:</p> <ul style="list-style-type: none"> • Confirmation of appropriate contractual arrangements covering the data sharing between the Institute of Occupational Medicine and IARC that reflect the terms and conditions of the NHS Digital DSA. • Further information about the fair processing information provided, with confirmation that this did not refer solely to cancer data about individuals who had died. • Clarification of whether IARC already hold any data provided from the Institute of Occupational Medicine originating from NHS Digital. • Correcting the DPA registration expiry date listed within the application. <p>DAAG advised that the applicant's DPA registration wording should be updated to correct references to 'our patients' and remove a statement that data used for research is about survey respondents.</p> <p>In addition DAAG advised that outputs should be provided to trade unions and industry.</p> <p><u>University of Bristol - The impact of geographic and socioeconomic variation on the incidence of hip fracture, and upon death and recovery after hip fracture (Presenter: Jen Donald) NIC-30645-Z2Z2K</u></p>
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	<p>Application: This was a new application requesting pseudonymised HES data and ONS mortality data for a cohort from the National Hip Fracture Database (NHFD) as well as patients not within that cohort who had hip fracture related codes within HES. DAAG were informed that two documents had been inadvertently removed from the application pack, which included confirmation from HRA CAG that the applicant's section 251 support was ongoing. The applicant held Microdata Release Panel approval and Approved Researcher accreditation for the processing of ONS mortality data.</p> <p>Discussion: Some queries were raised regarding the honorary contract information provided and whether this provided appropriate controls in the event of a data breach; however it was confirmed that the individual working on an honorary contract would not have any access to the data requested. It was agreed the application would therefore be updated to remove references to the honorary contract.</p> <p>The role of HQIP as data controller was noted and DAAG reiterated their previously raised concerns that appropriate security assurances had not been provided for this organisation. DAAG noted that section five of the application, which would be reproduced within the data sharing agreement and the data release register, did not specify what identifiers would be provided to NHS Digital and it was agreed this would be added to that section.</p> <p>The outputs and benefits sections were considered somewhat unclear, and in particular DAAG suggested that references to the involvement of particular individuals should be amended to give clearer information about how this would impact the dissemination of outputs and how the planned dissemination would result in the expected benefits.</p> <p>It was noted that the applicant's fair processing materials referred to the HSCIC rather than NHS Digital and DAAG suggested that the applicant should consider correcting this when it was practical to do so. There was a further suggestion that the general public might not understand the term 'list cleaning' and that this could be further explained within the fair processing information.</p> <p>Outcome: Recommendation to approve, subject to:</p> <ul style="list-style-type: none"> • Removal of references to an honorary contract. • Providing further clarification about the planned dissemination of outputs based on the involvement of the individuals referred to in section 5D, and how this will result in the expected benefits. • Updating section five to include the identifiers that will be received by NHS Digital. <p>DAAG suggested that the applicant's DPA registration should be updated to correct a reference to survey respondents.</p> <p>It was suggested that a reference to the HSCIC in the fair processing materials should in future be amended to refer to NHS Digital.</p> <p>DAAG noted that for future applications where HQIP acts as data controller, an update would be expected regarding security assurances for HQIP.</p> <p>It was agreed these caveats would be reviewed out of committee by the DAAG Chair.</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 / Alan Hassey	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. 20/12/16: It was anticipated an update would be available in mid-January. 10/01/17: Ongoing. It was agreed that this action would be taken forward by Alan Hassey rather than Peter Short.	Open
06/12/16	To provide feedback to the NHS Digital Caldicott Guardian on the minimum criteria for privacy notices and to suggest any necessary additional criteria.	DAAG Chair	20/12/16: A draft document had been circulated amongst DAAG members for comments. 10/01/17: A number of comments had been received and an updated draft would be urgently circulated.	Open
06/12/16	To query the privacy notice review process within NHS Digital.	Dawn Foster	13/12/16: This had been discussed with the Caldicott Guardian but further clarification was needed. 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. 10/01/17: Ongoing, pending updated criteria.	Open
20/12/16	Garry Coleman to provide an update on his previously closed action on Local Authorities and their requirement for national HES data.	Garry Coleman	10/01/17: Ongoing.	Open
10/01/17	To speak to NHS Digital colleagues regarding security assurance for HQIP.	Chris Carrigan		Open

Appendix B: Out of committee report

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

The following application caveats have been signed off by DAAG:

- Group application for 79 Local Authorities (PCMD) (*considered at DAAG 08/11/16*)
- NIC-14170 Clatterbridge Cancer NHS Foundation Trust (*considered at DAAG 22/11/16*)
- Amendment to GA03-CON-GEM Group application for 4 CCGs - NIC-47169-W2V9P NHS Lincolnshire West CCG only (*previously considered at DAAG 28/07/16*)
- Group of 4 CCGs (Airedale Vanguard) (*considered at DAAG 06/12/16*)
- NIC-13925 IMS Health Ltd (*considered at DAAG 20/12/16 – NB caveats agreed by two DAAG members and Director only*)

The following application caveats have been signed off by the DAAG Chair:

- NIC-43771-N0W3Q University of Cambridge (*considered at DAAG 13/12/16*)

The following application caveats have been signed off by the Director for Data Dissemination:

- NIC-24629 IMS Health ISMR (*considered at DAAG 13/12/16 – NB meeting minutes stated that caveats would be reviewed by DAAG*)
- Leeds City Council - Real-time matching of the NHS Number to Adult Social Care Clients (*considered at DAAG 29/11/16 – NB meeting minutes stated that caveats would be reviewed by DAAG*)
- Calderdale Council - Real-time matching of the NHS Number to Adult Social Care Clients (*considered at DAAG 29/11/16 – NB meeting minutes stated that caveats would be reviewed by DAAG*)
- NIC-01297 Compufile Systems Ltd UK (*considered at DAAG 20/12/16*)
- NIC-09122 Department of Health (HDIS) (*considered at DAAG 20/12/16*)
- NIC-203503 University of Surrey (LOLIPOP) (*considered at DAAG 13/12/16*)
- NIC-63736 Kirklees Council (LAPH) (*considered at DAAG 20/12/16*)

The following application's caveats have **not** been met and the application has been closed:

- NIC-45533 Royal Liverpool and Broadgreen (*considered at DAAG 13/12/16*)

In addition, the following applications have been progressed for IAO and Director extension/renewal only:

- NIC-368543 CHKS
- NIC-376374 Central Manchester University Hospitals NHS Foundation Trust
- NIC-07289 Northgate Public Services (UK) Limited
- NIC-06605 University Hospitals Birmingham NHS Foundation Trust
- NIC-325074 University of Leeds
- NIC-367152 University of Leeds
- NIC-373563 IMS Health Ltd