

# Data Access Advisory Group (DAAG)

## Minutes of meeting held 15 December 2015

**Members:** John Craven, Dawn Foster, Alan Hassey (Acting Chair), Eve Sariyiannidou, James Wilson

**In attendance:** Noela Almeida, Garry Coleman, Dave Cronin, Gaynor Dalton, Jennifer Donald, Frances Hancox, Vicki Williams

**Apologies:** Joanne Bailey

1	<p><b>Declaration of interests</b></p> <p>DAAG noted that James Wilson was employed by University College London, but that he did not have any involvement with the application scheduled for discussion (NIC-353402-X1B2T) or with the applicants.</p> <p><b>Review of previous minutes and actions</b></p> <p>The minutes of the 8 December 2015 meeting were reviewed and agreed as an accurate record. It was confirmed that the draft minutes of the 1 December 2015 meeting had been updated and agreed out of committee.</p> <p>Action updates were provided (see table on page 8).</p> <p><b>Out of committee recommendations</b></p> <p>The following applications had previously been recommended for approval subject to caveats, and it had been confirmed out of committee that the caveats had now been met:</p> <ul style="list-style-type: none"><li>• NIC-388376-R4T5R Halton Borough Council</li><li>• NIC-390662-Q9Q1N Kent County Council</li><li>• NIC-389715-Y4S3N North Lincolnshire Council</li><li>• NIC-363645-R5W0Z Camden CCG</li><li>• NIC-364160-R1T5K Camden CCG</li><li>• NIC-387994-T3R5C Oldham Metropolitan Borough Council</li><li>• NIC-387811-M7J2B Gloucestershire County Council</li><li>• NIC-364047-D2S6C Knowsley CCG</li><li>• NIC- 384137-V8F6H University College London</li></ul>
2	<p><b>Data applications</b></p> <p><b>2.1</b> <u>Wirral Borough Council (Presenter: Gaynor Dalton) NIC-03429-L9Y1D</u></p> <p><b>Application:</b> This application was to receive the standard pseudonymised Hospital Episode Statistics (HES) dataset for Local Authorities with Public Health functions. DAAG were informed that the applicant did not yet have an adequate privacy notice that covered data processing for public health purposes, but that the applicant had committed to update their notice within eight weeks. The applicant's DPA registration entry did not refer to processing data about patients or healthcare users, and it was confirmed that the applicant would be advised to amend this.</p> <p><b>Discussion:</b> DAAG discussed the applicant's DPA registration wording, and noted that although this did refer to processing data for 'carrying out health and public awareness campaigns' it did not</p>

include processing personal data about patients or healthcare users, and did not include any more specific wording relating to public health.

**Outcome:** Recommendation to approve.

DAAG drew attention to the fact that the applicant should consider updating their DPA registration entry to refer to processing data for public health purposes about patients or healthcare users. DAAG also drew the applicant's attention to the ICO privacy notices code of practice and commented that the applicant would need to update their notice in line with this within eight weeks, including an explanation of the type of data processed and for what purposes, how individuals can opt out, and should ensure that the notice would be easy to find on their website.

## 2.2 London Borough of Merton (Presenter: Gaynor Dalton) NIC-388466-F2Z7Q

**Application:** This application was also to receive the standard pseudonymised Hospital Episode Statistics (HES) dataset for Local Authorities with Public Health functions. DAAG were informed that the applicant did not yet have an adequate privacy notice that covered data processing for public health purposes, but that the applicant had committed to update their notice within eight weeks. The applicant's DPA registration entry did not refer to processing data about patients or healthcare users, and it was confirmed that the applicant would be advised to amend this.

**Discussion:** No concerns were raised regarding this application.

DAAG discussed the possibility of considering similar Local Authority public health applications as a class of applications, meaning that similar applications could be grouped together into a single application summary with a table listing the differences for each applicant organisation. It was suggested that any applications that were substantively different from the generic template application, for example if the applicant had achieved a lower than usual Information Governance (IG) Toolkit score, then those applications should be considered separately.

**Action:** Garry Coleman to work with IG ISA team regarding processing Local Authority public health applications as a class.

**Outcome:** Recommendation to approve.

DAAG drew attention to the fact that the applicant should consider updating their DPA registration entry to refer to processing data for public health purposes about patients or healthcare users. DAAG also drew the applicant's attention to the ICO privacy notices code of practice and commented that the applicant would need to update their notice in line with this within eight weeks, including an explanation of the types of data processed and for what purposes, how individuals can opt out, and should ensure that the notice would be easy to find on their website.

## 2.3 Sefton Council (Presenter: Gaynor Dalton) NIC-394183-K3Q7F

**Application:** This application was to receive the standard pseudonymised Hospital Episode Statistics (HES) dataset for Local Authorities with Public Health functions. It was noted that there was not yet a signed data sharing framework contract in place for this applicant, meaning that data would not flow until this was in place. DAAG were informed that the applicant did not yet have an adequate privacy notice that covered data processing for public health purposes, but that the applicant had committed to update their notice within eight weeks. In addition the applicant's DPA registration entry did not refer to processing data about patients or healthcare users, and it was confirmed that the applicant would be advised to amend this.

**Discussion:** No concerns were raised regarding this application.

**Outcome:** Recommendation to approve.

DAAG drew attention to the fact that the applicant should consider updating their DPA registration entry to refer to processing data for public health purposes about patients or healthcare users. DAAG also drew the applicant's attention to the ICO privacy notices code of practice and commented that the applicant would need to update their notice in line with this within eight weeks, including an explanation of the types of data processed and for what purposes, how individuals can opt out, and should ensure that the notice would be easy to find on their website.

**2.4** Redcar and Cleveland Council (Presenter: Gaynor Dalton) NIC-387559-Y5P4P

**Application:** This application was to receive the standard pseudonymised Hospital Episode Statistics (HES) dataset for Local Authorities with Public Health functions. It was noted that Tees Valley Shared Services would act as a data processor for the applicant, as part of the public health functions they carried out on behalf of Darlington Local Authority, Hartlepool Local Authority, Middlesbrough Local Authority, Redcar & Cleveland Local Authority, and Stockton-On-Tees Local Authority.

DAAG were informed that the applicant did not yet have an adequate privacy notice that covered data processing for public health purposes, but that the applicant had committed to update their notice within eight weeks. However it was noted that the DPA registration for both the applicant and their data processor Tees Valley Shared Service did include appropriate references to public health services and processing data about patients. DAAG were also informed that there was not yet a signed data sharing framework contract in place for the applicant organisation and data would not flow until this was in place.

**Discussion:** DAAG queried a sentence in the application summary that referred to 'Tees Valley Public Health Shared Services' as the applicant; it was confirmed that this was an administrative error and the applicant was in fact Redcar and Cleveland Council. The Tees Valley shared service IG Toolkit score was discussed, as DAAG noted that the application stated this had been reviewed in 2014.

The nature of the public health shared service was discussed, and it was confirmed that the Tees Valley shared service carried out public health functions on behalf of the Local Authorities listed but that data would not be shared with any other third parties. DAAG suggested that the Local Authorities making use of this shared service should clearly inform the public of this through their privacy notices.

**Outcome:** Recommendation to approve.

DAAG drew the applicant's attention to the ICO privacy notices code of practice and commented that the applicant would need to update their notice in line with this within eight weeks, including an explanation of the types of data processed and for what purposes, how individuals can opt out, and should ensure that the notice would be easy to find on their website. In particular all Local Authorities who are party to the Tees Valley shared service should ensure that their privacy notices are accessible and reflect the use of this shared service.

**2.5** Royal National Orthopaedic Hospital NHS Trust - Getting It Right First Time (GIRFT) and Department of Health, Clinically-led quality and efficiency programmes surgical performance dashboard (Presenter: Gaynor Dalton) NIC-393384-L9Z2J

**Application:** This application for pseudonymised HES data had previously been discussed at the 13 October 2015 meeting when DAAG had been unable to recommend approval, in part because DAAG felt that given the significant expansion of purpose this should have been presented as a new application rather than using tracked changes against the previous application. An updated

application now provided additional detail about the expanded purpose and the expected benefits, with an explanation of the role of University College London as data processor and evidence that the expanded dashboard had been commissioned by the Department of Health. The updated application also included a statement that data would not be used for sales or marketing purposes. DAAG were informed that one of the data processors for this application, NA Wilson, had contacted the ICO to request an update to their DPA registration wording but that this change was not yet live on the ICO's online DPA register.

**Discussion:** The number of surgical specialties included was queried, as DAAG noted that this was inconsistently referred to in the application summary as either ten or eleven. It was confirmed that this should be eleven.

DAAG agreed that the majority of queries previously raised had been addressed, but felt that further clarity was still required regarding the role of University College London as a data processor. The application summary stated that University College London would evaluate the success of the dashboard, but it was unclear why patient level data was required for this evaluation and why aggregated data could not be used instead. In addition DAAG queried the relationship with the Collaborations for Leadership in Applied Health Research and Care (CLAHRC) as this was not clearly explained.

**Outcome:** Recommendation to approve, subject to caveats:

- Additional clarification of the role of University College London as data processors and the relationship with the CLAHRC programme.
- Provision of a justification for why University College London require access to patient level data, rather than being able to use aggregated data.

**2.6** Royal College of Anaesthetists - National Emergency Laparotomy Audit (NELA) (Presenter: Gaynor Dalton) NIC-355855-R4G6G

**Application:** This application, which was to link HES admitted patient care and Office for National Statistics (ONS) mortality data with the applicant's anonymised version of the National Emergency Laparotomy Audit (NELA) data, had previously been considered at the 1 December 2015 meeting. The application had been deferred pending clarification regarding the applicant's section 251 support, the data flow diagram provided to HRA CAG, the role of the two data processors, and clarification of the data flow; an updated application was now provided that addressed the points. Wording had been added to the application summary to clarify that all individuals accessing the data would be employees of either the Royal College of Anaesthetists or the Royal College of Surgeons, and to state that HQIP as data controllers had committed that all their data processors carrying out audits would provide appropriate security assurances.

**Discussion:** DAAG noted that the applicant's section 251 letter at one point referred to the Royal College of Anaesthetists as data controller. It was clarified that this was an error in the letter and in fact HQIP as the audit commissioner would act as data controller, although it was noted that HQIP would not have access to the data. It was noted that a number of items listed on the data flow diagram were marked as 'to be confirmed', but DAAG were informed that these did not relate to the current application. DAAG noted that the applicant had submitted their section 251 renewal for consideration by HRA CAG and it was confirmed that if this resulted in any relevant changes or the suspension of the section 251 support then the HSCIC would be informed.

A reference to the NELA data as anonymised was queried, and it was agreed the application summary would be updated to correct this. In addition it was agreed that references to pseudonymised or identifiable data should be clarified in order to be consistent with the data flow diagram provided.

DAAG discussed the list of identifiers that would be provided, and noted that this list still included address which was not covered by the applicant's section 251 support. It was agreed that the list

of identifiers would be added to the 'Data requested' table within the application, and that address would be removed from the list as this would not be provided.

DAAG suggested that it might be helpful for future applications to include a table to list the identifiable data that would be provided to the HSCIC for the purpose of linkage, rather than solely listing the data that would be provided from the HSCIC to the applicant. In addition DAAG suggested that the identifiers that would be provided to the HSCIC should be discussed at an early stage of the application process, to ensure any queries regarding consent or legal basis for this could be addressed before the application reached DAAG.

**Outcome:** Recommendation to approve.

Application summary to be updated to be consistent with the data flow diagram provided, to correct references to anonymised data that should refer to pseudonymised data, and to clarify that the NELA data used is pseudonymised. 'Data requested' table to be updated to include the list of identifiers, with reference to receiving address data to be removed.

2.7

University College London - Policy Research Unit for Children, Young People and Families  
(Presenter: Dave Cronin) NIC-353402-X1B2T

**Application:** This application was to extend and amend an existing data sharing agreement for the use of pseudonymised HES and linked ONS mortality data. The applicant had received this data in 2012 for two separate projects and had requested to continue using the data for one of these projects only, which related to child maltreatment and had been commissioned by the Department of Health. The data sharing agreement would be updated to remove the second project, which no longer required data, to amend the list of ONS data users, and to update the data storage and processing address to the applicant's new safe haven.

Queries had been raised within the HSCIC regarding the security assurance for a Guildford Road address where the applicant intended to access the data by logging into the safe haven secure server, as it was noted that the applicant's ISO 27001 certification did not include this address. DAAG were informed that the applicant were in the process of completing version 13 of the IG Toolkit to cover that address, but this had not yet been completed and reviewed.

**Discussion:** DAAG noted that the application summary stated that IG ISA had confirmed that ONS were content for the applicant to retain ONS mortality data. DAAG requested sight of the relevant email or other evidence of this. It was noted that this application was both to extend and amend the existing data sharing agreement, whereas at some points the application summary referred to it only as an amendment; it was agreed this would be clarified.

The transfer of data to the applicant's safe haven was noted. DAAG discussed the applicant's intention to access the data via the Guildford Road address, and agreed that this was not appropriate at this time as there was no security assurance available for that address. It was agreed that the application summary would be updated to confirm that data would not be accessed at that address until adequate security assurance had been provided.

**Outcome:** Recommendation to approve, subject to caveats:

- Updating the application summary to confirm that data will not be accessed at the Guildford Road location until adequate security assurance has been provided for that location.

Additional detail to be provided regarding the ONS approval for the applicant to continue to retain mortality data. Application summary to be updated to clarify references to an amendment or extension.

2.8

Hull and East Yorkshire NHS Trust (Presenter: Dave Cronin) NIC-392244-H3M3G

**Application:** This application was for identifiable Personal Demographic Service (PDS) and ONS mortality data about a cohort of patients who had attended a diabetes clinic in Hull and East Yorkshire, with section 251 support providing the legal basis for this use of data. The study intended to assess the relationship between obesity, cardiovascular disease and mortality in diabetes mellitus, and it was noted that earlier findings had indicated a potential 'obesity paradox' where overweight individuals with this condition may survive longer than average weight counterparts. DAAG were informed that the study was funded through the Weill Cornell Medical College in Qatar, as the Chief Investigator had relocated to there from the University of Hull, but it was confirmed that Weill Cornell would not have access to the data.

**Discussion:** DAAG discussed the information poster that the applicant had produced, and while the improvements suggested by the HSCIC were noted it was suggested that the poster should more clearly explain the use of data to the general public. For instance, it was felt that only referring to anonymised data in the 'What about my consent?' section could be considered misleading, and similarly the statement that identifiable data would be destroyed by the HSCIC once the research had terminated could be misrepresentative as in fact the HSCIC would only hold identifiers for as long as was required to carry out the data linkage. DAAG agreed that the poster should be clear about the type of data that will be used, where this data will be obtained from, what purposes the data will be used for, how data will be stored, whether any identifiable data would be shared with third parties, and how individuals could opt out.

DAAG considered the applicant's expected outcomes and benefits, and suggested that it might be helpful to also share any findings with relevant organisations such as Diabetes UK. The reference to influencing policy was discussed, and it was felt that while this was an important piece of research it was unlikely that policy would be influenced until further work had been carried out. DAAG noted that only one individual was listed as an ONS data user, and suggested that given the nature of the findings to date the applicant might wish to consider greater involvement from a statistician.

**Outcome:** Recommendation to approve, subject to caveats:

- Confirmation from the applicant that they will update their fair processing poster in line with the advice given by DAAG.

DAAG suggested that it might be helpful for findings to be disseminated to relevant national organisations such as Diabetes UK, and suggested that the application summary should be updated to remove references to influencing policy as this was felt to be unlikely at this stage. DAAG members commented that given the potentially paradoxical nature of the findings, the applicant might wish to give further thought to whether the department statistician should have greater involvement in the study design and techniques used.

## 2.9 Imperial College London - Diversity in Ethnicity, Lung function and Birth weight in Young Adults (DELBYA) study (Presenter: Dave Cronin) NIC-01189-Y2V3W

**Application:** This application for birth weight data for a small consented cohort had previously been discussed at the 1 December 2015 DAAG meeting, when the application had been withdrawn pending clarification of the source of the data and the appropriate legal basis. Clarification had now been provided that both civil registration data and ONS data would be used, depending on the data year in question, and ONS had confirmed that they were content for the HSCIC to access this data and share it with the applicant. DAAG were informed that the birth weight data would be used as part of a pilot study and that the applicant would assess the feasibility of potential future work. The HSCIC had previously given feedback on the applicant's consent materials, as it was felt that these could have more clearly described the involvement of the HSCIC in the study, and as the consent materials were no longer in use the applicant had agreed to update participants regarding this through a newsletter.

**Discussion:** DAAG were content that the queries previously raised had now been addressed.

	<p>DAAG questioned whether the applicant would use the data provided for any other future studies in addition to the pilot work described. It was confirmed that if the applicant wished to use the data for an extended study in future then this would need to be subject to a further application.</p> <p>DAAG noted the statement in the application summary that a 'more detailed report will be produced' was potentially misleading, and it was agreed that this sentence would be amended.</p> <p><b>Outcome:</b> Recommendation to approve. Application summary to be updated to remove a reference to providing a report from IG ISA.</p> <p><b>2.10</b> <u>Health and Safety Executive - Patient status for The Prospective Investigation of Pesticide Applicators' Health Study (PIPAH) study members (Presenter: Jen Donald) NIC-385032-K3N9S</u></p> <p><b>Application:</b> This application was for patient status (dead/alive) for a cohort of individuals who had given informed consent for their data to participate in the study. The applicant intended to send a survey to participants, and wished to carry out this list cleaning first to remove any individuals who were now deceased to avoid causing distress. The participant consent materials were provided, and in addition it was noted that the applicant would provide additional information about the role of the HSCIC in a future newsletter to participants.</p> <p><b>Discussion:</b> DAAG agreed that the consent materials provided seemed to provide appropriate cover for the list cleaning activities described. A reference to sharing address data was briefly discussed; DAAG were informed that the HSCIC would only provide dead/alive status for participants and that any other data used by the applicant had been collected separately.</p> <p>A query was raised regarding the study base referred to in the application, which was stated to be under development. DAAG noted that for future applications, IGARD would likely be interested in the status and structure of the study database.</p> <p>A further query was raised regarding a reference to follow-up of participant health status, and it was confirmed that this was not part of the current application but would be subject to a further application in future.</p> <p><b>Outcome:</b> Recommendation to approve.</p>
<p><b>3</b></p>	<p><b>Any other business</b></p> <p><u>NIC-392342-C3Y7R - University of Sheffield</u></p> <p>Garry Coleman gave a verbal update on this application, which DAAG had considered at the 17 November 2015 meeting and recommended for approval. The application reviewed by DAAG had been for HES data filtered by CCGs, but following approval it had been determined that providing data filtered by Lower Layer Super Output Area (LSOA) instead of CCG would be more appropriate for the applicant. DAAG were informed that the geographical areas involved were very similar, and it was not anticipated that filtering data by LSOA instead of CCG would create any additional risk of patient data being reidentified. DAAG noted this update.</p> <p>DAAG discussed the process for agreeing minor changes to applications following approval, and agreed with the principle that changes resulting in an applicant receiving less data than originally requested or receiving less identifiable data should not require a further DAAG review. However it was agreed that DAAG should be informed of these changes, and that these should be recorded in the meeting minutes to ensure transparency. It was suggested that this should be reflected in the IGARD Standard Operating Procedures in future.</p>

## Summary of Open Actions

Date raised	Action	Owner	Updates	Status
20/10/15	Paula Moss to provide an updated paper on DSCRO local data flows. (08/12/15: Dawn Foster to provide comments on the draft paper.)	Dawn Foster	10/11/15: A draft paper had been provided to the DAAG Chair by email but had not yet been circulated to the group. 24/11/15: Ongoing. 08/12/15: A draft paper was currently with Dawn Foster for review. 15/12/15: Dawn had reviewed the draft paper, and it was anticipated that the updated paper would be shared with other DAAG members in the near future.	Open
10/11/15	Gaynor Dalton to inform DAAG once Imperial College London (SAHSU) have published information for patients and the public as per their implementation timeline.	Gaynor Dalton	01/12/15: Steve Hudson noted that the proposed website information had been received with a timeframe of publication of early next year. DAAG asked for an update at a future DAAG meeting. 15/12/15: It was noted that the applicant had provided draft wording. Update to be provided in January 2016.	Open
24/11/15	DAAG Secretariat to ask Dawn Foster to provide advice on the security aspects of encrypted data storage used solely for disaster recovery purposes, and the implications this has for DPA registration. (Update 15/12/15: Audit team to confirm whether this is considered during audits.)	DAAG Secretariat	01/12/15: DAAG Secretariat to provide Dawn Foster with background information. 08/12/15: The Secretariat had provided details of the relevant application, and this had been raised with the DAO. 15/12/15: Dawn provided an update on this and noted that in the example application a University of York facility was used to host a University of Leeds server as a secure backup, but that York staff were unable to access the encrypted Leeds server and it was therefore suggested that the University of York should not be considered a data processor. A query was raised regarding whether the HSCIC audit team considered secure backup facilities while conducting external audits, and it was agreed that this would be raised with them.	Open
08/12/15	Alan Hassey and Dawn Foster to report back following their meeting with HRA CAG.	Alan Hassey and Dawn	15/12/15: Notes from the meeting had been circulated to DAAG members, and a verbal update was given. The confusion regarding	Closed



		Foster	some processes had been noted, particularly relating to annual reviews, and it had been agreed that these would be documented to ensure clarity. DAAG suggested that this might feed into the Data Dissemination Framework. CAG had accepted the feedback regarding the section 251 register, but had indicated that it would not be practical to update this immediately. It was agreed that DAAG member would be provided with a draft copy of the HSCIC processes relating to section 251 annual reviews once available.	
08/12/15	DAAG Secretariat to provide a copy of the DAAG dashboard to the HSCIC SIRO and Caldicott Guardian.	DAAG Secretariat	15/12/15: The dashboard had been provided and updated following comments.	Closed
08/12/15	IG ISA Manager to provide an update at a future DAAG meeting about the merger between IG ISA and the DAAG Secretariat.	Noela Almeida	15/12/15: Update to be scheduled for a future training session.	Closed
08/12/15	DARS team to contact PHE regarding Local Authority privacy notices not including public health. Dawn Foster to contact the ICO regarding including public health functions in Local Authority DPA registrations.	Garry Coleman, Dawn Foster	15/12/15: Dawn Foster had raised this with the ICO during a regular catch-up meeting. PHE had not yet been contacted regarding this.	Open
15/12/15	Garry Coleman to work with IG ISA team regarding processing Local Authority public health applications as a class.	Garry Coleman		Open
15/12/15	DAAG members to be provided with a draft copy of the HSCIC processes relating to section 251 annual reviews once available.	Dawn Foster		Open