

Data Access Advisory Group (DAAG)

Minutes of meeting held 8 December 2015

Members: Joanne Bailey, John Craven, Dawn Foster, Alan Hassey (Acting Chair), Eve Sariyannidou, James Wilson

In attendance: Noela Almeida, Garry Coleman, Gaynor Dalton, Jennifer Donald, Frances Hancox

Apologies: None

1	<p>Declaration of interests</p> <p>No conflicts of interests relevant to this meeting were declared.</p> <p>Review of previous minutes and actions</p> <p>The minutes of the 1 December 2015 meeting were reviewed, and a number of changes were agreed. It was agreed that the revised draft minutes would be circulated and finalised by the DAAG members out of committee.</p> <p>Action updates were provided (see table on page 6).</p> <p>Out of committee recommendations</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">• NIC-376211-Y8B6R University of Leeds• NIC-394629-C5Z4P University of Aberdeen• NIC-392358-J2H2D Imperial College London• NIC-381643-Q6Q2Z Southend CCG• NIC-370861-N5H8G University College London <p>DAAG dashboard</p> <p>The DAAG Secretariat provided an updated copy of the DAAG dashboard, and members provided feedback on this. It was agreed the dashboard would be updated to include the number of applications withdrawn, and that the Secretariat would review the 'reasons DAAG are unable to recommend approval' chart to determine if the 'Other' column could be split out any further. DAAG noted that the largest proportion of applications considered had been from academic organisations, and noted the work underway to improve HSCIC working relationships with academia.</p> <p>Action: DAAG Secretariat to provide a copy of the DAAG dashboard to the HSCIC SIRO and Caldicott Guardian.</p> <p>Action: IG ISA Manager to provide an update at a future DAAG meeting about the merger between IG ISA and the DAAG Secretariat.</p>
2	<p>Data applications</p> <p>2.1 <u>West Sussex County Council (Presenter: Gaynor Dalton) NIC-393518-S1R6D</u></p>

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 this application used the template application for Local Authorities requesting this data, and that this template had been updated following recent DAAG feedback.

DAAG were informed that the Data Protection Act (DPA) registration details listed in the application summary were incorrect, and the application would be updated to correct this.

Discussion: The applicant's fair processing notice was discussed, and it was agreed that this should be updated in line with the ICO privacy notices code of practice. In particular DAAG emphasised that the privacy notice should refer to processing health data for the purpose of public health and explain how individuals can opt out. DAAG members added that privacy notices should be made easy to find on each Local Authority's website. In addition DAAG noted that the applicant's DPA registration entry should be updated to refer to public health.

Some concerns were raised regarding the number of Local Authority privacy notices and DPA registration details that did not seem to appropriately reflect their public health functions. It was agreed that this should be raised with PHE and with the ICO so that they could advise Local Authorities on this point.

Outcome: Recommendation to approve. Application to be updated to provide the correct DPA registration details.

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. 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.

Action: 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.

2.2 Southampton City Council (Presenter: Gaynor Dalton) NIC-00574-V2H1F

Application: This application was to receive the standard pseudonymised HES dataset for Local Authorities with Public Health functions. Confirmation had been given that data would only be processed by employees of the Local Authority and no data would be shared with third parties.

Discussion: Some concerns were raised regarding the applicant's privacy notice, as this did not appear to refer explicitly to health data and included statements that were inaccurate and misleading if they were applied to health data, such as stating that individuals could only object to their data being processed if they could demonstrate undue distress. It was agreed that the applicant should consider the relevant ICO guidance and update this privacy notice to appropriately describe the use of health data.

DAAG noted that the applicant's DPA registration wording referred to carrying out health and public awareness campaigns, but that it did not specifically refer to using data about patients or healthcare users.

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. 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

	<p>notice would be easy to find on their website. DAAG also commented that the current privacy notice included language that could be regarded as inaccurate or coercive regarding objections in relation to health data.</p>
2.3	<p>Brighton and Hove City Council (Presenter: Gaynor Dalton) NIC-390531-R7S3D</p> <p>Application: This application was to receive the standard pseudonymised HES dataset for Local Authorities with Public Health functions. DAAG were informed that this applicant had not yet published a privacy notice and that the applicant had committed to publish an appropriate notice within eight weeks.</p> <p>Discussion: DAAG noted that the applicant's DPA registration should be updated to include processing data for public health purposes, and this feedback had already been passed on to the applicant.</p> <p>DAAG discussed the need for the applicant to publish an appropriate privacy notice and it was confirmed that if this was not completed within eight weeks, the HSCIC would issue a data destruction notice.</p> <p>Outcome: Recommendation to approve.</p> <p>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. DAAG also drew the applicant's attention to the ICO privacy notices code of practice and commented that the applicant would need to publish a privacy 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.</p>
2.4	<p>Public Health - Swindon Borough Council (Presenter: Gaynor Dalton) NIC-394179-J5W3F</p> <p>Application: This application was to receive the standard pseudonymised HES dataset for Local Authorities with Public Health functions. DAAG were informed that the applicant had achieved an IG Toolkit score of 40%, which had been reviewed as satisfactory with an improvement plan in place.</p> <p>Discussion: DAAG discussed the applicant's low IG Toolkit score, and there were some concerns that this affected key areas relating to the receipt of HSCIC data such as providing IG training for staff and including appropriate clauses in staff contracts. It was noted that an improvement plan was in place, and that the score had been deemed satisfactory with this improvement plan, but it was not known whether this improvement plan would address the areas particularly relevant to receiving data. It was agreed that the IG ISA team should work with the External IG Delivery team to provide assurance on this point.</p> <p>The applicant's privacy notice was discussed, and it was agreed that this needed to be updated in line with the ICO privacy notices code of practice.</p> <p>Outcome: Unable to recommend for approval.</p> <ul style="list-style-type: none"> DAAG members expressed concerns regarding the applicant's IG Toolkit score. The IG ISA team should work with the External IG Delivery team to provide assurance that the applicant's IG Toolkit improvement plan included timely improvements to the relevant key areas in relation to receiving data. <p>DAAG drew attention to the fact that the applicant should consider updating their DPA registration entry to refer to processing data 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</p>

that the notice would be easy to find on their website.

2.5

University Hospitals Coventry & Warwickshire NHS Trust - Setting efficiency and quality benchmarks to inform business planning (Presenter: Gaynor Dalton) NIC-388494-W3L6K

Application: This application for pseudonymised HES data had previously been considered by DAAG at the 20 November 2015 meeting (NIC-368976-Z9X8S), when DAAG had been unable to recommend approval due to concerns raised about the amount of data requested. The applicant had now discussed possible data minimisation efforts with the HSCIC, and the application had now been updated to request data for a specific geographic area only instead of national data and to request quarterly rather than monthly extracts. In addition references to the Commercial Analytics team had been clarified to confirm that data would not be used to develop any commercial offerings, and that all individuals processing data would be employees of the applicant organisation.

Discussion: DAAG expressed their support for this application and the efforts that had been taken to minimise the amount of data required. It was agreed that any concerns previously raised had been addressed.

The applicant's DPA registration was discussed, as it was noted that this was shortly due to expire. DAAG were informed that data would not flow if this registration was not renewed.

Outcome: Recommendation to approve.

DAAG noted that the applicant's DPA registration was shortly due to expire, and that data would not flow if this was not renewed.

2.6

University of York - Assessing the Trends in the Burden of Paediatric Neurology Diseases in England using Linked Administrative Data (Presenter: Gaynor Dalton) NIC-371031-B8K6D

Application: This was a new application for pseudonymised HES data for use in a project aiming to determine the numbers of children presenting to hospitals and A&E departments with neurological conditions. The HES data would be limited to children aged 0-19 at the time of treatment with specific ICD-10 codes relating to care by a paediatric neurology team. DAAG were informed that the study had been funded by the Leeds Children's Hospital Paediatric Neurology Research Fund, but that all analysis would be carried out by the University of York and the outputs made available following analysis would only contain aggregated data with small numbers suppressed. It had been confirmed that this study was not considered by the Health Research Authority (HRA) to be research and therefore ethical approval was not required.

Discussion: The amount of data requested was considered, and on balance DAAG felt that the number of data years requested was appropriate in order to follow-up and analyse trends over time. DAAG discussed the applicant's DPA registration, and while it was noted that this did not explicitly refer to processing data about patients or healthcare users it did include reference to processing data for the purpose of research relating to health.

DAAG noted that the application summary included a reference to 'whole-population, administrative medical/health data'. It was thought that this was intended to mean HES data, rather than referring to any other health data that would be linked to HES, but it was agreed that the paragraph would be amended to clarify this. In addition, DAAG noted that a consultant paediatric neurologist at Leeds Children's Hospital had provided clinical advice to the study but would not have access to any data; for clarity it was agreed that a statement would be added to the application that data would only be processed by employees of the University of York. There was a discussion of the applicant's plans to disseminate the study findings. DAAG requested additional clarity about this, in order to ensure that benefits to health and care could be realised.

	<p>Outcome: Recommendation to approve, subject to:</p> <ul style="list-style-type: none"> • Further information being provided about the mechanism to disseminate the study findings. • Application to be updated to add a statement that data will only be processed by employees of the University of York, and to amend the paragraph referring to using whole-population health data. <p>2.7 <u>Imperial College London - Mortality outcome in the London Chronic Obstructive Pulmonary Disease (COPD) cohort (Presenter: Jennifer Donald) NIC-02077-R7M9C</u></p> <p>Application: This application for Office for National Statistics (ONS) mortality data had previously been considered by DAAG, most recently at the 3 November 2015 meeting (NIC-389022-R6G62) when the application had been withdrawn pending clarification. An updated application now provided clarification about the applicant moving organisations from University College London to Imperial College London with confirmation that no HSCIC data had been transferred as part of this move as the applicant had not yet received any HSCIC data. Updated consent materials were also provided following DAAG's previous feedback.</p> <p>Discussion: DAAG discussed the timescales for the applicant to begin using the updated consent materials, and noted that ethical approval was required for the updated materials. It was confirmed that the applicant had not yet received any HSCIC data for this project, and data would not flow until the updated consent materials had been approved and begun to be used. A query was raised regarding the comments ONS had previously provided on the consent materials and it was confirmed that these comments had been shared with the applicant.</p> <p>It was noted that the application summary listed a DPA registration expiry date that had now passed, but DAAG were informed that this registration had in fact been renewed. The upcoming section 251 support and ONS approvals renewal dates were also noted, and it was noted that these renewals would need to take place for data to continue to flow.</p> <p>DAAG noted the delays that this application had experienced, and suggested that it might be helpful for future applicants if the HSCIC could make guidance available for applicants moving organisations.</p> <p>Outcome: Recommendation to approve, subject to:</p> <ul style="list-style-type: none"> • The new consent materials being approved by Research Ethics Committee and used before data is shared, with confirmation that the old consent materials will no longer be used. <p>DAAG noted that the applicant had indicated DAAG had previously raised concerns that the application had been misrepresented; DAAG members wished it to be clear that they had not expressed any concerns of this nature. DAAG observed that it might be helpful for the HSCIC to consider publishing guidance for applicants who move organisations.</p>
<p>3</p>	<p>Any other business</p> <p>DAAG noted that the network and information security Directive recently adopted by the European Union could have an impact on their work in future, and agreed that it would be helpful to discuss this in more detail at a future date.</p> <p>The Acting Chair gave an update on the changes to the DAAG website and the transition to IGARD, in line with the recent decisions by the HSCIC Board.</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.	Open
03/11/15	Information Governance team to liaise with MedeAnalytics regarding their DPA registration to ensure that it reflects recent applications.	Dawn Foster	24/11/15: Ongoing. 08/12/15: The IG ISA team had contacted MedeAnalytics regarding this, and the action was closed.	Closed
10/11/15	Dawn Foster and Alan Hassey to contact NHS England Director for Data and Information Management Systems regarding the need for more formal evidence that NHS England support certain applications from CSUs, and invite her to attend a future DAAG training session.	Alan Hassey	24/11/15: Ongoing. 08/12/15: The DARS team were aware of the need for formal evidence of NHS England support, and it was thought that this would be addressed for any future application. The action was closed.	Closed
10/11/15	Dawn Foster to contact HRA CAG regarding lack of clarity in section 251 support letters.	Dawn Foster	01/12/15: Dawn Foster & Alan Hassey meeting with HRA CAG on the 08/12/15 08/12/15: A meeting had been scheduled to discuss this, and it was agreed that Dawn Foster and Alan Hassey would report back at the following DAAG meeting.	Closed
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. 08/12/15: Ongoing.	Open
17/11/15	Terry Hill to provide a written update on the SIGGAR/SOCCER application (NIC-291981-Y7J2F Imperial College London)	Terry Hill	01/12/15: This application was considered by DAAG on the 10 November 2015 and was not recommended for approval as DAAG did not see a legal basis to support the flow of data. After conclusion of the DAAG meeting the Information Governance Team sought additional information to establish the legal basis	Closed

			including that relating to ONS. DAAG noted that a written note had been received from Terry Hill and a SIRO letter had been issued to the applicant without further consideration by DAAG and the data flowed to the applicant. 08/12/15: A brief note had been provided, and the action was closed.	
22/11/15	Terry Hill to provide a written update on the Imperial College London (SAHSU NIC-204903-P1J7Q) application.	Terry Hill	01/12/15: This application had been considered by DAAG on the 10 November and recommended for approval subject to two caveats. Terry Hill provided a written note stating that the HSCIC would ensure the caveats had been addressed and the applicant had been issued with a data sharing agreement with a stated condition that data could be released until the HSCIC had decided that the caveats were closed. 08/12/15: A brief note had been provided, and the action was closed.	Closed
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.	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.	Open
24/11/15	Alan Hassey to contact HRA CAG regarding the process for DAAG to consider applications when a section 251 annual review date is pending.	Alan Hassey	01/12/15: Dawn Foster & Alan Hassey meeting with HRA CAG on the 08/12/15. 08/12/15: A meeting had been scheduled to discuss this, and it was agreed that Dawn Foster and Alan Hassey would report back at the following DAAG meeting.	Closed
01/12/15	DAAG members asked Alan Hassey to seek clarification from HSCIC with regard to their policy and processes where they either don't seek DAAG advice or take action contrary to DAAG's advice with regard to the release of data.	Alan Hassey	08/12/15: This will be covered in the Data Dissemination Framework and any such releases will be recorded in the Data Dissemination Register.	Closed
08/12/15	Alan Hassey and Dawn Foster to report back following their meeting with HRA CAG.	Alan Hassey and Dawn Foster		Open

08/12/15	DAAG Secretariat to provide a copy of the DAAG dashboard to the HSCIC SIRO and Caldicott Guardian.	DAAG Secretariat		Open
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		Open
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		Open