

Data Access Advisory Group (DAAG)

Minutes of meeting held 17 November 2015

Members: Joanne Bailey, John Craven, Eve Sariyannidou, James Wilson

In attendance: Dave Cronin, Gaynor Dalton, Frances Hancox, Terry Hill, Steve Hudson, Dickie Langley, Peter Thomson, Vicki Williams

Apologies: Dawn Foster, Alan Hassey (Interim Chair), Sean Kirwan

1	<p>Matters arising</p> <p>DAAG received an oral update on the application they had discussed at the 10 November 2015 meeting from the Imperial College London's Small Area Health Statistics Unit (SAHSU) NIC-204903-P1J7Q. This application had been recommended for approval subject to caveats, one caveat being for the applicant to provide information about planned website updates within four weeks. DAAG were informed that the HSCIC had been in contact with the applicant and it was anticipated that the applicant would provide information on these updates as soon as possible so that data could then be shared.</p> <p>DAAG also received an oral update on the SIGGAR/SOCCER application (Imperial College London NIC-291981-Y7J2F) which DAAG had discussed at the 10 November 2015 meeting and been unable to recommend for approval. HSCIC had reviewed the information available to them, and given the time pressures involved the HSCIC intended to approve the application. It was agreed that a written report would be provided to the 24 November 2015 DAAG meeting to provide the context and justification for this decision.</p> <p>Action: Terry Hill to provide a written report on the SIGGAR/SOCCER application (NIC-291981-Y7J2F Imperial College London)</p> <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 10 November 2015 meeting were reviewed and agreed as an accurate record, subject to two minor changes.</p> <p>Action updates were provided (see table on page 7).</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-361343-G9Z4S Genomics England
2	<p>Data applications</p> <p>2.1 <u>University of Sheffield - Impact of closing Emergency Departments in England (Presenter: Dave Cronin) NIC-392342</u></p>

	<p>Application: This application for pseudonymised Hospital Episode Statistics (HES) data had previously been considered at the 27 October 2015 meeting, when DAAG had been unable to recommend approval and had requested additional information regarding what efforts could be made to minimise the amount of data disseminated. An updated application was now presented, whereby the applicant had requested HES data for 61 former Primary Care Trust (PCT) areas out of a possible 152 PCTs, and this smaller subset of data would be used to select the control group for the study.</p> <p>DAAG were informed that one section of the application summary still stated that national HES data was required, which was no longer accurate, and this section would therefore be updated.</p> <p>Discussion: DAAG acknowledged the work that had taken place to minimise the amount of data that would be required, and were content with the proposed approach. DAAG encouraged the HSCIC to discuss data minimisation with applicants in detail before bringing applications to DAAG, wherever possible.</p> <p>It was noted that a six month Data Sharing Agreement would be issued, and that by the end of this period the applicant would delete data for all but the ten Emergency Department sites selected.</p> <p>Outcome: Recommendation to approve. DAAG noted that the application summary would be updated to remove a reference to receiving national HES data.</p>
2.2	<p><u>University of Oxford - The Arthroplasty Candidacy Help Engine (ACHE) tool (Presenter: Dave Cronin) NIC-392690-F7H2Q</u></p> <p>Application: This application for pseudonymised HES and Patient Reported Outcome Measures (PROMs) data had been considered previously at the 8 September 2015 meeting. DAAG had requested evidence of a favourable ethics review, and noted that the application summary should reflect the final study protocol. The protocol had now been updated and a copy of this was provided, and the applicant had provided evidence that ethics approval was not required at this stage although it was acknowledged that ethics approval would be sought for a later stage of the process that would make use of identifiable data. DAAG were informed that the study protocol referred to linking data to National Joint Registry data, but that the methodology for this had not yet been confirmed and this linkage could only take place subject to further approvals as it was not part of the current application.</p> <p>Discussion: The planned data retention period was queried, as this had been changed from 2020 to 2023. It was explained that the applicant had stated they would need to retain data for five years post publication, and that publication was expected to take place in 2018. DAAG noted that a number of academic applicants had previously indicated that data should be retained for differing periods of time following publication, and there was a suggestion that advice should be sought from the academic community on appropriate data retention periods. It was agreed that this should be discussed at a future DAAG training session.</p> <p>DAAG queried the HSCIC framework contract expiry date for the applicant, and it was confirmed that the Big Health Data Group within the University of Oxford were covered by the overarching framework contract for the university.</p> <p>Outcome: Recommendation to approve.</p>
2.3	<p><u>University of Aberdeen - A pragmatic multicentre randomised controlled trial comparing stapled haemorrhoidopexy to conventional excisional surgery for haemorrhoidal disease (Presenter: Dave Cronin) NIC-394629-C5Z4P</u></p>

Application: This application for identifiable HES data had previously been discussed at the 10 November 2015 DAAG meeting. DAAG had recommended that list cleaning should be undertaken to ensure up to date addresses were used to contact participants, and that an updated newsletter should be sent to participants to clarify the role of the HSCIC in sharing identifiable data. An updated newsletter had now been provided, and in addition the applicant had agreed to review their organisation's DPA registration based on DAAG's feedback.

Discussion: A query was raised regarding the involvement of an individual employed by NHS Highlands & Islands, and it was clarified that this individual had been involved in establishing the study but would not have access to the data provided. DAAG asked for a statement to be added to the application summary to clarify this, by stating that only individuals employed by the University of Aberdeen would have access to the data.

DAAG queried a reference within the revised newsletter to the applicant providing name and date of birth and address to the HSCIC, as it was unclear whether NHS number would also be used. It was agreed that the applicant would be asked to confirm that the newsletter accurately reflected the identifiable data items that would be provided.

The applicant's Data Protection Act (DPA) registration wording was discussed, and DAAG suggested that the applicant should consider updating this to refer to processing data about the subjects of research.

DAAG also discussed the wording used in the updated newsletter, and suggested that participants might potentially find the phrase 'if you no longer wish for your data to be used' easier to understand rather than referring to opting out.

Outcome: Recommendation to approve, subject to:

- Updating the application summary to state that all individuals with access to data are employed by the University of Aberdeen.
- Confirmation that the level of data referred to in the newsletter accurately reflects the level of data items provided by the applicant to the HSCIC.

DAAG suggested that the newsletter could more clearly refer to participants who 'no longer wish for their data to be used' rather than referring to this as opting out. In addition, DAAG suggested that the applicant's DPA registration wording should refer to processing data about the subjects of research.

Local Authority Public Health Applications

At the 13 August 2015 meeting, DAAG had reviewed a template for Local Authority applications to receive pseudonymised HES data for use in their statutory public health functions. The template had been recommended for approval with some agreed changes, including adding a statement that data would not be shared with any third parties and clarifying the employment arrangements of the Director of Public Health. These changes had been made, and DAAG were now asked to consider a number of applications from Local Authorities using that template. It was noted that some applicants did not yet have a signed HSCIC framework contract in place, but that no data would flow to the applicant until this had been completed. DAAG were informed that the applicant Local Authorities had been advised to update their DPA registration entries to include processing data about healthcare users and to refer to the provision of health services.

Fair processing was briefly discussed, and it had previously been agreed that any Local Authority who had not published a privacy notice or whose privacy notice was not of the appropriate standard would be given a period of eight weeks from the signature of the Data Sharing Agreement to address this. If the privacy notice had not been updated within eight weeks, a data destruction notice would be issued immediately. DAAG expressed their expectation that as time went on they would hope that more Local Authorities would have addressed the need for an

appropriate privacy notice before their application reached DAAG rather than continuing to rely on the agreed eight week period to address issues.

DAAG raised concerns that the template application summary may not provide sufficient information about the particular arrangements within each applicant Local Authority. It was highlighted that the template included the statement that 'data will only be processed by Local Authority employees in fulfilment of their public health function' and DAAG were informed that in any instances where a Local Authority's requirements differed substantively from the template, that applicant would need to submit a bespoke application rather than using the standard template. While this was acknowledged, DAAG requested a data flow diagram with each application in order to clarify how data would flow and any instances where a Local Authority may wish to share data with third parties, for example where statutory public health functions were carried out by Health and Wellbeing Boards or local CCGs. DAAG noted that one applicant organisation's fair processing notice stated that data would not be shared with third parties 'other than those who process information on our behalf' and it was agreed that assurance would be needed that applicants were aware data could not be shared with third parties under any circumstances unless this had been specifically included as part of their application.

The need to ensure a standard and fair approach for all similar applicants was noted, but it was agreed that the first few applications of this type should be considered 'pathfinders' while processes were refined.

A reference in the template to Public Health England funding was queried, and it was agreed that this would be removed. DAAG suggested that once data had been provided, it might be appropriate for the HSCIC to consider auditing a random selection of Local Authorities to review their use of data for public health purposes.

2.4 Gloucestershire County Council (Presenter: Gaynor Dalton) NIC-387811-M7J2B

Application: This application was for pseudonymised HES data, using the agreed template for Local Authority Public Health applications.

Discussion: As discussed above, it was agreed that a data flow diagram would be provided to clarify arrangements for this particular applicant.

DAAG discussed the applicant's fair processing efforts, and it was agreed that their privacy notice should be updated to be in line with the ICO privacy notices code of practice. In particular it was noted that the current privacy notice did not explain that data would be used for public health purposes.

Outcome: Recommendation to approve, subject to:

- Providing a data flow diagram.

DAAG noted that the applicant would need to update their privacy notice in line with the ICO privacy notices code of practice, within eight weeks.

Action: Gaynor Dalton to update DAAG on Local Authority progress regarding privacy notices.

2.5 Oldham Metropolitan Borough Council (Presenter: Gaynor Dalton) NIC-387994-T3R5C

Application: This application was for pseudonymised HES data, using the agreed template for Local Authority Public Health applications.

Discussion: As discussed above, it was agreed that a data flow diagram would be provided to clarify arrangements for this particular applicant. DAAG noted that this applicant had not yet published a privacy notice.

As with the other Local Authority applications for public health purposes, DAAG noted that the applicant would need to update their DPA registration entry to more clearly reflect the use of data about health service users.

Outcome: Recommendation to approve, subject to:

- Providing a data flow diagram.

DAAG noted that the applicant would need to publish a privacy notice in line with the ICO privacy notices code of practice, within eight weeks.

2.6 Halton Borough Council (Presenter: Gaynor Dalton) NIC-388376-R4T5R

Application: This application was for pseudonymised HES data, using the agreed template for Local Authority Public Health applications.

Discussion: As discussed above, it was agreed that a data flow diagram would be provided to clarify arrangements for this particular applicant.

DAAG noted that this applicant's fair processing notice stated that they would not share personal data with third parties 'other than those who either process information on our behalf, or in connection with a legal function' and there were concerns that the applicant might therefore assume that the pseudonymised HES data requested could be shared with these exceptions. It was agreed that this would be clarified.

Outcome: Recommendation to approve, subject to:

- Providing a data flow diagram.
- Confirmation from the applicant that the restriction not to disseminate data to third parties includes organisations processing data on their behalf, or in connection with legal functions.

DAAG noted that the applicant would need to update their privacy notice in line with the ICO privacy notices code of practice, within eight weeks.

2.7 North Lincolnshire Council (Presenter: Gaynor Dalton) NIC-389715-Y4S3N

Application: This application was for pseudonymised HES data, using the agreed template for Local Authority Public Health applications.

Discussion: As discussed above, it was agreed that a data flow diagram would be provided to clarify arrangements for this particular applicant. DAAG noted that it was difficult to find information about public health functions on the Council website, and advised that the applicant would need to make their privacy notice easily accessible to the public.

Outcome: Recommendation to approve, subject to:

- Providing a data flow diagram.

DAAG noted that the applicant would need to publish a privacy notice in line with the ICO privacy notices code of practice, within eight weeks, and advised that this should be made easily accessible on their website.

2.8 Kent County Council (Presenter: Gaynor Dalton) NIC-390662-Q9Q1N

Application: This application was for pseudonymised HES data, using the agreed template for Local Authority Public Health applications.

Discussion: As discussed above, it was agreed that a data flow diagram would be provided to

	<p>clarify arrangements for this particular applicant.</p> <p>DAAG discussed the applicant's privacy notice, and there were some concerns regarding references to processing data 'using web services hosted outside the European Economic Area' (EEA). It was agreed that the applicant should confirm that the HES data requested would not be stored outside the EEA.</p> <p>Outcome: Recommendation to approve, subject to:</p> <ul style="list-style-type: none"> • Providing a data flow diagram. • Confirmation from the applicant that data will not be shared outside the EEA. <p>DAAG noted that the applicant would need to update their privacy notice in line with the ICO privacy notices code of practice, within eight weeks.</p>
2.9	<p><u>University of Sheffield - Investigation of the geographic and socioeconomic variation in alcohol and tobacco related hospital admissions to inform decision support models for policy in England (Presenter: Dickie Langley) NIC-366216-Z9H9Q</u></p> <p>Application: This was a new application for pseudonymised HES data in order to develop health-economics policy assessment models. DAAG were informed that the applicant would use a copy of the pseudonymised HES data already provided to the University of Sheffield for a separate application (NIC-306894-H7B0N, considered by DAAG on 13 January 2015) in addition to the data requested, so that the HSCIC would not have to provide a duplicate dataset to the applicant.</p> <p>Discussion: DAAG discussed the link between the previous application (NIC-306894-H7B0N) and the current application, as it was noted that both projects had related to alcohol. It was clarified that while both projects would make use of the same data, they were two separate projects with different members of staff involved in each project.</p> <p>DAAG noted that the project had been funded by both NIHR and the UK Centre for Tobacco and Alcohol Studies, but that neither organisation would have access to data. It was agreed that a sentence would be added to the application summary to state that only researchers employed by the University of Sheffield would have access to the data.</p> <p>The data controller for this work was queried, as it was noted that the applicant was listed as a particular school within the university. It was confirmed that the University of Sheffield would be the overall data controller.</p> <p>Outcome: Recommendation to approve, subject to:</p> <ul style="list-style-type: none"> • Adding a statement to the application summary that 'All researchers who will have access to the data are employed by the University of Sheffield'. • Updating the application summary to refer to the University of Sheffield as the overall data controller.
3	<p>Any other business</p> <p>DAAG discussed attendance for the 24 November 2015 meeting, and some concerns were raised regarding whether this meeting would be quorate.</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.	Paula Moss	10/11/15: A draft paper had been provided to the DAAG Chair by email but had not yet been circulated to the group. 17/11/15: Ongoing.	Open
03/11/15	Information Governance team to liaise with MedeAnalytics regarding their DPA registration to ensure that it reflects recent applications.	Dawn Foster	17/11/15: Ongoing.	Open
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	17/11/15: Ongoing.	Open
10/11/15	Dave Cronin to report back to DAAG by 5 January 2016 to confirm progress for NIC-389320-R4M6Z University of Nottingham.	Dave Cronin	17/11/15: Ongoing.	Open
10/11/15	Dawn Foster to contact HRA CAG regarding lack of clarity in section 251 support letters.	Dawn Foster	17/11/15: Ongoing.	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	17/11/15: Ongoing.	Open
17/10/15	Terry Hill to provide a written report on the SIGGAR/SOCCER application (NIC-291981-Y7J2F Imperial College London)	Terry Hill		Open
17/10/15	Gaynor Dalton to update DAAG on Local Authority progress regarding privacy notices.	Gaynor Dalton		Open