

Data Access Advisory Group (DAAG)

Minutes of meeting held 12 May 2015

Members: Alan Hassey, Eve Sariyannidou, Dawn Foster, John Craven, Sean Kirwan

In attendance: Frances Hancox, Victoria Williams, Dickie Langley, Garry Coleman, Diane Pryce, Stuart Richardson, Paula Moss, Neil McCrerrick, Jennifer Donald, Susan Mayne

Apologies: Patrick Coyle

1	<p>Review of previous minutes and actions</p> <p>The minutes of the 5 May 2015 meeting were reviewed and agreed as an accurate record.</p> <p>It was noted that a query had been raised at the 5 May meeting about whether sampling techniques could be an alternative to applicants requesting complete national data, and it was agreed that it would be helpful if this could be discussed in more detail at a future training session.</p> <p>Action: DAAG Secretariat to invite the HSCIC Statistics Head of Profession to attend a future DAAG training session regarding sampling techniques.</p> <p>Action updates were provided (see table on page 7).</p> <p>Out of committee recommendations</p> <p>The following application had previously been recommended for approval subject to caveats, and it had been confirmed out of committee that the caveats had now been fulfilled:</p> <ul style="list-style-type: none">• HSCIC Clinical Audit Support Unit (CASU) – Oesophago-Gastric Cancer Audit NIC-303776-B2X1W• HSCIC CASU – Bowel Cancer Audit NIC-298631-R9Y3L• Clinical Commissioning Group (CCG) Group application 2 (NHS West Suffolk CCG NIC-301873-Y8P9M, NHS Ipswich and East Suffolk CCG NIC-301841-M9K4K)
2	<p>Data applications</p> <p>2.1 <u>NHS Brent CCG (Presenter: Stuart Richardson) NIC-341637-R6P4X</u></p> <p>Application: This application was to renew the flow of non-sensitive Secondary Uses Service (SUS) data that was identifiable at the level of NHS number (weakly pseudonymised) under the section 251 support for stage 1 accredited safe havens (ASH). An application for this flow of data had previously been considered and recommended for approval by DAAG on 9 October 2014, and renewal was now sought. It was noted that the applicant had a satisfactory Information Governance (IG) Toolkit score and held an appropriate registration under the Data Protection Act 1998 (DPA).</p> <p>Discussion: It was confirmed that no significant changes had been made since the previous approval for this flow of data, and no concerns were raised.</p> <p>Outcome: Recommendation to approve.</p>

<p>2.2</p>	<p><u>Yorkshire and Humber Commissioning Support Unit (CSU) (Presenter: Stuart Richardson) NIC-301908-K6H2W</u></p> <p>Application: This application was to amend the flow of non-sensitive SUS data identifiable at the level of NHS number (weakly pseudonymised) under the section 251 support for stage 1 in order to include an additional flow of data through the North of England Data Services for Commissioners Regional Office (DSCRO) and onward to a number of additional CCGs. It was noted that the CSU would act as data processor for CCGs with a legitimate relationship with the CSU, as authorised by NHS England, and each CCG would be data controller for their own data. Each CCG would only receive data if a signed contract was in place between them and the HSCIC. The CSU had achieved a satisfactory IG Toolkit score and held an appropriate DPA registration.</p> <p>Discussion: DAAG queried whether the processing activities referred to in the application summary were carried out by the CSU or by CCGs, and it was agreed that the application would be updated to clarify that outputs would be produced by the CSU.</p> <p>A query was raised about whether amending an existing data flow to include new CCGs would always require an application to be brought to DAAG. It was clarified that amendments to which CCGs would receive data through a particular CSU would not usually require an updated application, as this was managed through the legitimate relationships process, but in this instance a new application had been required due to the addition of a data flow through a different DSCRO.</p> <p>The DPA registration details provided were discussed, and DAAG asked for this to be updated to include the DPA registration wording for CCGs that were a stage 1 ASH.</p> <p>Outcome: Recommendation to approve. Application form to be updated in line with DAAG comments.</p>
<p>2.3</p>	<p><u>University of Nottingham (Presenter: Dickie Langley) NIC-342891-K7W5K</u></p> <p>Application: This was an application for pseudonymised, non-sensitive, filtered Hospital Episode Statistics (HES) data as well as Office for National Statistics (ONS) mortality data, in order to support research into the use of surgical lung biopsy for diagnosing interstitial lung disease. The application had previously been considered by DAAG on 31 March 2015, when DAAG had been unable to recommend approval. Further information had been requested on proportionality, how outputs would be disseminated and what individuals were involved in the PhD work described.</p> <p>Discussion: DAAG discussed the additional information that had been provided regarding dissemination, and while this was welcomed there remained some concerns that this appeared to be focused on academia. Members agreed that the outputs of this work were likely to be of interest to the general public and to national bodies such as NICE, and it was agreed that the applicant should be encouraged to ensure outputs would be publicised appropriately.</p> <p>There was a discussion of the individuals involved in the PhD work, as there was some uncertainty regarding a reference to the PhD supervision team and whether those individuals listed would also have access to data, but it was confirmed that only the two ONS users listed would be able to access ONS data.</p> <p>DAAG discussed the need for proportionality and the data minimisation efforts that had been made, as it was noted that while the HES data requested was highly filtered this would still cover a large number of data years. The application had been updated to state that this number of data years would be required to ensure sufficient data was available about a relatively rare condition.</p> <p>Outcome: Recommendation to approve subject to further clarification of how the outputs from this</p>

study can be made available to the general public and to other relevant bodies.

2.5 Institute for Fiscal Studies (Presenter: Garry Coleman) NIC-310364-Z4K2F

Application: This was a new application for pseudonymised HES and Patient Reported Outcome Measures (PROMs) data in order to support six projects focusing on patient choice and the impact of demographic changes on the NHS. It was noted that the applicant had previously received HES data under a separate agreement, and a number of the data years previously received would be deleted as these were no longer required. Justifications had been provided for why each project required the data requested, as well as what the anticipated benefits and outputs would be, and examples had also been provided of the benefits derived from the HES data previously provided.

Discussion: It was noted that the applicant's DPA registration wording did not currently appear to cover the work described, but that the applicant had contacted the Information Commissioner's Office (ICO) to request an amendment to this. The applicant's security assurance was queried, and DAAG were informed that this had been reviewed and approved by the relevant HSCIC team. A reference to linking with aggregated data was also queried, and it was confirmed that this would be geographical data and should not significantly increase the risk of individuals being re-identified.

A point of accuracy was raised about a reference in the application summary to data deletion; it was confirmed that the applicant would delete the HES data years they already held that were no longer required, and the application summary would be amended to state this more clearly.

DAAG discussed the fact that the work and outputs described focused on healthcare economics, and whether this met the requirements of the Care Act 2014. It was acknowledged that the work described were expected to be of significant interest to bodies such as the Department of Health, NHS England and Monitor and could impact on healthcare policy, and DAAG agreed that this seemed to be appropriate within the requirements of the Care Act 2014.

There was a discussion around the questions that these projects intended to address and it was felt that for the first project in particular, which focused on patient choice in maternity care, it was not clear how the HES data requested would support the level of detail required to examine patient choice.

Outcome: Recommendation to approve. The discussion was noted around whether the HES data requested would actually support the level of detail outlined in relation to project 1.

2.4 University of Birmingham - Birmingham Atrial Fibrillation Treatment of the Aged Follow-up Study (Presenter: Jen Donald) NIC-309500-F4X1B

Application: This was a new application for ONS mortality data in order to follow up a specific cohort who had been recruited to the study approximately 10 years previously. This data would be used to investigate the long term effects of anticoagulants. It was noted that the applicant had applied to the Health Research Authority Confidentiality Advisory Group (CAG) to apply for support under section 251 of the NHS Act 2006, but that CAG had advised that the consent previously obtained from the participants appeared to be sufficient to allow access to the requested data without requiring section 251 support. The applicant's DPA registration wording did not currently seem to cover the work described, but it was noted that this was in the process of being updated.

Discussion: DAAG expressed some uncertainty regarding the role of CAG in considering consent, and it was agreed that this would be raised with the CAG Secretariat. The consent materials provided were considered, and as these referred to flagging individuals on the NHS Central Register and to following up patient care it was agreed that the consent provided by participants could still be considered to apply.

The expected outputs and benefits were discussed, and while it was noted that publications in peer-reviewed journals were anticipated it was suggested that outputs would also be of particular interest to national bodies such as the Stroke Association or NICE. DAAG agreed that the applicant should be asked to provide further information about how outputs could be shared with these or other relevant bodies in order to maximise benefit.

Outcome: Recommendation to approve subject to further information being provided about how outputs will be disseminated to relevant public bodies, such as the Stroke Association and NICE.

Action: Dawn Foster to contact CAG Secretariat regarding their role in considering consent.

2.7 Imperial College London – Dr Foster Unit (Presenter: Garry Coleman) NIC-345991-H2F5N

Application: This application had previously been considered by DAAG on 28 April 2015, when DAAG had been unable to recommend approval. The application was for identifiable, sensitive HES data to flow to the Dr Foster Unit within Imperial College, with pseudonymised data then being shared with the commercial organisation Dr Foster Intelligence. It was noted that the identifiable data received by Imperial College would be used to provide a re-identification service to acute NHS trusts, but only for those trusts that were customers of Dr Foster Intelligence as providing this service to other trusts was not currently covered by the applicant's section 251 support.

DAAG had previously requested clarification on a number of points relating to this application. The additional CAG section 251 letters had been provided, and these referred to the sensitive fields requested as part of this application. Additional detail from the applicant's DPA registration had been provided. The application now included a statement that data would not be shared outside the European Economic Area, confirmed that the updated fair processing statement replaced the previous statement published online, and clarified references to Dr Foster Intelligence and Dr Foster Limited. The amount of data requested had been reduced: identifiable data was now only requested for Dr Foster Intelligence customers for the past three years, and previous identifiable data and sensitive fields prior to 2000 would be deleted.

Discussion: DAAG queried whether the data requested included date of death, and it was agreed that this would be clarified. The planned data retention period was also queried, as this was stated to be 'ongoing', and it was clarified that data would be destroyed after a maximum of three years on a rolling basis. A reference to rare diseases was queried, as it was not clear if this could increase the possibility of individuals being reidentified. It was agreed that the application should be updated to specify that small numbers would be suppressed within the pseudonymised data.

It was noted that the fair processing statement provided referred to the 'right to withdrawn consent', and it was suggested that the applicant should amend this wording as individuals had not provided explicit consent for this use of data. In addition, it was noted that this statement appeared to have been amended since the application was last considered by DAAG on 28 April 2015, and it was agreed that the application would be updated to confirm that the fair processing statement version referred to was the version currently published online.

A query was raised regarding the sensitive fields requested, and whether these were covered by the section 251 support. It was noted that these fields were referred to in the letter from CAG, but it was agreed that confirmation would be sought.

Outcome: Recommendation to approve subject to clarification of the data retention period and whether data of death is included in the application, as well as clarification of whether sensitive fields are covered by the section 251 support. Application to be updated to clarify that the fair processing materials referred to are the version currently available on the applicant's website, and to add a statement that small numbers will be suppressed in the pseudonymised data. DAAG advised that the fair processing materials should be updated to amend the phrase 'right to

withdraw consent’.

2.6 Primary Care Mortality Database (PCMD) access test case / Stockport Council PCMD
(Presenter: Susan Mayne) NIC-341398-T7R7M

Application: DAAG were asked to consider the process for applications from Local Authority public health teams to access the Primary Care Mortality Database (PCMD), which was maintained by the HSCIC under delegated authority from ONS. A test case was provided with a sample application from Stockport Council.

Discussion: DAAG noted that the test case application summary referred to birth data in addition to PCMD, and it was clarified that applicants could request access to mortality data, birth data or vital statistics reports, or a combination of all three. It was agreed that this would need to be clarified on application summaries as otherwise it could be assumed that only mortality data would be accessed through PCMD.

It was noted that the current application process for PCMD access involved internal checks taking place within the HSCIC of whether the applicant held an appropriate IG Toolkit score and DPA registration. DAAG emphasised the importance of transparency and ensuring appropriate independent scrutiny of applications.

DAAG were informed that current arrangements for PCMD access were due to be renewed at the end of the month, and concerns were expressed that this had not been raised earlier. A suggestion was made that DAAG could consider group applications for similar Local Authorities requesting access to PCMD, comparable to the process for the Data Services for Commissioners applications considered by DAAG, but there were significant concerns that it would be impractical to complete the review of PCMD applications prior to the end of May.

A number of practical aspects were discussed, including whether applications would be managed through the Data Access Request Service and whether data sharing contracts would be required between the HSCIC and Local Authorities in addition to the ONS Data Access Agreement. It was noted that in addition to ONS data, PCMD also provided access to NHS numbers that were provided by the HSCIC and this could impact the approach to whether contracts were required. A query was raised about whether CCGs could access PCMD, and it was confirmed that this was not the case.

A query was raised regarding whether the births data referred to could also be used by Local Authorities to assist with planning of children’s centres, but it was confirmed that the data accessed through PCMD could only be used by public health analysts for the stated purpose.

The potential impact of halting data access was noted. Given that existing arrangements for PCMD access were due for renewal at the end of May, and given the need for further work to develop appropriate processes for DAAG to provide scrutiny, DAAG suggested that the Local Authority teams currently accessing PCMD should be approved to continue to do so until the end of July 2015. This would allow time for processes to be established, but it was emphasised that this approval should not be considered to prejudice any future consideration of PCMD applications by DAAG.

Outcome: Recommendation to approve the continued use of data in its current form and for current purposes for a period of two months, in order to provide the opportunity to develop an appropriate scrutiny and assurance process within DAAG.

Any other business

University of Dundee – SCOT Trial (Presenter: Jennifer Donald) NIC-323893-J8B4H

At the 5 May 2015 meeting, DAAG had recommended approval of this application subject to an undertaking that fair processing work would commence before the database lock date, including writing to participants, writing to general practices and updating the information available online. The applicant had now provided draft copies of a letter to participants, a letter to general practices and a statement to be published online. The materials provided were discussed, and it was noted that the HSCIC was referred to as being part of the NHS which was incorrect. DAAG noted the efforts that the applicants had made, and would want to clarify that the HSCIC is not part of the NHS but acknowledged the rapid response of the applicant in terms of producing the materials requested.

It was noted that Alan Hassey, Acting Chair, would be unable to attend the following two meetings and Eve Sariyannidou agreed to act as Chair for those meetings.

DAAG members were reminded that the 23 June 2015 meeting had been cancelled, and it was suggested that the following meeting (30 June) should be made a full-day DAAG meeting rather than including a training session.

Summary of Open Actions

Date raised	Action	Owner	Updates	Status
24/02/15	DAIS team to raise with HRA CAG the possibility of stage 1 accredited safe havens receiving both data that is identifiable by NHS number and data that is identifiable by postcode.	Dawn Foster	03/03/15: Discussions were taking place with HRA CAG, and the response would be fed back to a future DAAG meeting. 10/03/15: An initial response had been received and this would be shared with DAAG members for information. A further query had been raised and discussions were ongoing. 17/03/15: Ongoing. 25/03/15: Ongoing. 31/03/15: Ongoing. 07/04/15: Ongoing. 13/04/15: Ongoing. 21/04/15: Ongoing. 28/04/15: Ongoing. 05/05/15: It was agreed that Dawn Foster would raise this separately with CAG. 12/05/15: Clarification had been requested from NHS England regarding a particular request for both identifiers.	Open
05/05/15	DAAG members to review the materials provided for advice on the DAAG webpages.	Acting Chair	12/05/15: Comments had been provided, and the updated materials would be published on the HSCIC website.	Closed
12/05/15	DAAG Secretariat to invite the HSCIC Statistics Head of Profession to attend a future DAAG training session regarding sampling techniques.	DAAG Secretariat		Open
12/05/15	Dawn Foster to contact CAG Secretariat regarding their role in considering consent.	Dawn Foster		Open