

Data Access Advisory Group (DAAG)

Minutes of meeting held 21 July 2015

Members: Alan Hassey (Acting Chair), Eve Sariyannidou, Joanne Bailey, Patrick Coyle, Sean Kirwan, Dawn Foster

In attendance: Frances Hancox, Stuart Richardson, Paula Moss, Sophie Fletcher, Gaynor Dalton, Dave Cronin, Garry Coleman, Julia King, Steve Hudson

Apologies: John Craven

1	<p>Review of previous minutes and actions</p> <p>The minutes of the 14 July 2015 meeting were reviewed and a minor change was suggested. The minutes were agreed as an accurate record.</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:</p> <ul style="list-style-type: none">• NIC-349413-F1J1N University College London (Centre for Longitudinal Studies) <p>It had been confirmed out of committee that the caveat had been met, and the request to add NatCen as data processor was recommended for approval. It was noted that the application was for tracing purposes and a request for access to NHS number was not approved as there was not a legal basis to provide this. It was noted that NHS number had previously been provided and a review was taking place to understand the basis for this dissemination.</p> <p>It was noted that HSCIC Executive Director changes had been raised under Any Other Business at the previous meeting, and DAAG agreed that Rob Shaw should be invited to attend a future meeting to discuss this.</p> <p>Action: DAAG Secretariat to invite Rob Shaw to attend a future DAAG meeting to discuss HSCIC Executive Director changes.</p>
2	<p>Data applications</p> <p>2.1 <u>Essex Clinical Commissioning Groups (CCGs) group application¹ - Stage One Accredited Safe Haven (ASH) Renewal (Presenter: Stuart Richardson)</u></p> <p>Application: This was a group application to renew or amend the flow of non-sensitive Secondary Uses Service (SUS) data identifiable at the level of NHS number (weakly pseudonymised) under the section 251 support for stage one ASHs to a number of CCGs in Essex. DAAG were provided with a copy of the collaboration agreement between these CCGs, and were informed that the CCGs shared the identifiable data between themselves on the basis of this agreement.</p> <p>Discussion: DAAG requested additional details about the data shared between CCGs and what</p>

¹ NIC-347011-K2C7K Basildon & Brentwood CCG, NIC-347039-J1Y3R West Essex CCG, NIC-364551-S0N0K Southend CCG, NIC-364749-N2L6J Mid Essex CCG, NIC-364570-H3C7X North East Essex CCG, NIC-347024-V8H6H Castle Point & Rochford CCG, NIC-364370-D6Z4P Thurrock CCG

the legal basis was for this, as it was not thought that enough information had been provided about that aspect. In particular, a reference to sharing data with a Local Authority was queried. It was agreed that the Health Research Authority Confidentiality Advisory Group (HRA CAG) would be contacted to seek confirmation of whether the section 251 support covered data sharing between CCGs.

It was suggested that an application for the renewal of existing data flows to the CCGs should be brought to DAAG, with a separate application then brought to DAAG regarding the collaboration agreement and the sharing arrangements between CCGs. DAAG noted that the CCGs' fair processing responsibilities should include making information available to patients about this data sharing and also noted that there would need to be a clear justification for why data should be shared between CCGs, which could potentially include the need for certain CCGs to act as lead CCG to commission local services or the movement of patients between CCGs. DAAG noted that the fair processing notices for some CCGs were difficult to find on the CCG website, some used terms such as 'non-direct care' that could be considered confusing, and there was an incorrect statement that explicit consent was required to share identifiable data for purposes other than direct care.

The possibility of halting current data flows was raised; it was agreed that data could continue to flow to the CCGs for a period of four weeks to allow time for a renewal application to be brought to DAAG, but DAAG advised that data sharing between the CCGs should halt with immediate effect.

Outcome: Unable to recommend for approval. Clarification was required of what data the applicants intended to share between CCGs and on what legal basis. DAAG suggested that HRA CAG should be asked to confirm whether the section 251 support in place is adequate for the purposes stated, and applicants would need to confirm how their fair processing responsibilities will be addressed. A clear justification was required for the requested data sharing between CCGs, which might include demonstrating the flow of patients between CCG areas. DAAG agreed that current data flows could continue for a period of four weeks while an updated application was prepared, but agreed that no other data sharing between CCGs should occur with immediate effect.

2.2 Nuffield Trust (Presenter: Dave Cronin) NIC-342809-H1V7F

Application: An application for this applicant to hold pseudonymised Hospital Episode Statistics (HES) data for use in six different projects had previously been recommended for approval by DAAG on 3 March 2015, and a subsequent application to use that data for a seventh project had been recommended for approval on 7 July 2015. This application was now to use the same pseudonymised HES dataset for an eighth project which related to surveillance of patterns in hospital admission and costs at area level in England, aimed at identifying areas where innovation in service delivery was taking place.

Discussion: DAAG noted that the application summary incorrectly stated that two additional projects would be added, rather than one, and it was agreed that this would be corrected.

The potential impact of the eighth project was discussed, and while it was noted that the work would feed into a Nuffield Trust report DAAG asked for the application summary to be amended to describe the anticipated benefits more clearly.

Outcome: Recommendation to approve. It was agreed that the application summary would be updated to clarify the expected benefits and to state that only one project will be added.

2.3 University of Oxford - Introducing Standardized and Evidence Based Thresholds for Hip and Knee Replacement Surgery (Presenter: Dave Cronin) NIC-275706-T4D6W

Application: This application was to extend and amend an existing agreement, so that the applicant could continue to retain pseudonymised HES and Patient Reported Outcome Measures (PROMs) data as well as using this data for an additional purpose, to support the 'Introducing Standardized and Evidence Based Thresholds for Hip and Knee Replacement Surgery - The Arthroplasty Candidacy Help Engine (ACHE) tool' project.

Discussion: It was noted that the University of Oxford had not yet signed a Data Sharing Framework Contract with the HSCIC, and therefore applicants could not receive any data until this had been completed even if applications were recommended for approval. The practicalities of DAAG continuing to consider applications at this stage were discussed.

The use of acronyms in the application summary was noted, and DAAG reiterated that acronyms should be spelled out in full the first time they were used in documents. A reference to HES data being filtered 'as above' was queried, and it was confirmed that the same filter applied to the PROMs data would be used. A letter confirming NIHR funding had been provided, but DAAG noted that this was not the most recent letter.

DAAG noted that the application summary stated that the tool produced would not be a product to be marketed and sold, but there was some uncertainty regarding the statement that license holders of instruments included in the tool may impose a charge. It was agreed that the application summary should be updated to state that no other third party or intellectual property included in the tool would result in this being used for sales and marketing purposes.

Outcome: Recommendation to approve subject to provision of the most recent NIHR funding letter, and subject to including a sentence in the application summary that no other third party or intellectual property included in the product will result in this data being used for sales or marketing purposes.

2.4 Imperial College London – Airwave Health Monitoring Study (Presenter: Gaynor Dalton) NIC-341335-G3S3B

Application: This application for Office for National Statistics (ONS) data and list cleaning in addition to pseudonymised, non-sensitive HES data had previously been considered at the 3 March 2015 meeting, when DAAG had been unable to recommend approval and had advised that consent forms should be updated and participants should be contacted with updated materials. An updated application had now been provided which limited the scope of the work to specific health impacts only. While it was noted that recruitment had completed and the consent form had therefore not been updated, draft wording had been provided for a newsletter update and a withdrawal form that would be sent to all participants.

Discussion: DAAG acknowledged the work that had been done to address concerns previously raised. However some concerns were raised about a statement within the participant information leaflet that 'You will never be personally identified to any researcher outside the Airwave Health Monitoring Study team' and that there were 'no circumstances, short of a court order, where we will discuss any of the information we hold about you with any third party' as it was felt that this could lead participants to believe that their identifiable data would not be shared with any other organisation such as the HSCIC. DAAG considered this to contradict statements elsewhere in the consent materials that data held by the HSCIC would be used to follow participants' health status and to keep in touch with participants, given that individuals would need to be identified to the HSCIC for this to take place.

Given this contradiction, DAAG agreed that the most appropriate way forward would be to carry out listing cleaning to ensure participants who had died would not be contacted, and then for the applicant to send out an updated withdrawal form and information for participants about the role of the HSCIC prior to any further data being provided. It was noted that the updated materials should explain the role of the HSCIC in contacting participants and that participant identifiers would be

shared with the HSCIC to enable this.

Outcome: Recommendation to approve for the purposes of list cleaning only, subject to agreement that an updated withdrawal form will be sent out to participants accompanied by updated information that makes clear the role of the HSCIC.

2.5 Ernst and Young LLP (Presenter: Garry Coleman) NIC-328264-N2K2J

Application: This application was to amend an existing agreement for the receipt of pseudonymised, non-sensitive HES data but it was noted that the previous application had not been considered by DAAG. The requested amendment was to extend the territory of use to allow benchmarking data to be shared with a public sector client in Jersey. It was noted that the channel islands were not part of the EEA, but that the ICO's published guidance included Jersey on a list of countries outside the EEA with adequate data protection. DAAG were informed that the applicant already held HES data under the existing agreement and no additional data would be released to them as a result of this application.

Discussion: DAAG discussed the application's stated purpose and whether this could be considered compliant with the requirements of the Care Act 2014, and there was some discomfort regarding the fact that the previous application had not been considered by DAAG. It was noted that a renewal application should be brought to DAAG in approximately November 2015 and DAAG agreed that this should be considered at that point.

The role of the private sector within healthcare in Jersey was noted; it was suggested that more information should be given about the applicant's public sector client and whether this was specifically a health organisation.

DAAG noted that the application stated that all outputs shared would be aggregated with small numbers suppressed. A query was raised regarding the applicant's existing agreement and whether this would in fact allow anonymised, aggregated data to be shared outside the UK. The application was withdrawn until this could be confirmed.

Outcome: Application withdrawn, pending review of the original data sharing agreement.

2.6 University of Oxford – Missing data in PROMs (Presenter: Gaynor Dalton) NIC-358191-T5P4G

Application: This application for pseudonymised HES and PROMs data had previously been considered at the 28 April and 27 May 2015 DAAG meetings. DAAG had previously been unable to recommend approval and had requested clarification of how the results of this work would be used to benefit healthcare, as per the requirements of the Care Act 2014. An updated application summary with additional information regarding outputs and expected benefits had now been provided.

Discussion: DAAG agreed that the questions previously raised regarding this application had now been addressed, and no further concerns were raised.

Outcome: Recommendation to approve.

2.7 Imperial College London (Presenter: Garry Coleman) NIC-366210-V2H5M

Application: This application to amend an existing data sharing agreement for pseudonymised, non-sensitive HES data had previously been discussed at the 5 May 2015 DAAG meeting. DAAG had requested a clear justification for the amount of data requested as well as evidence of benefits achieved from the data already received. An updated application summary had now been

	<p>provided, which provided examples of the impact made by research to date. This included an explanation that the applicant wished to retain the data years already held to examine the effects of policy changes over time, with examples given of specific policies and the applicable dates.</p> <p>Discussion: DAAG discussed the outputs and expected benefits described, and it was agreed that given the importance of providing evidence to support healthcare policy decision making this use of data was considered to be compatible with the requirements of the Care Act 2014.</p> <p>DAAG noted that a number of routes were described to share research outputs with those developing policy, but suggested that the applicant should also consider how outputs could be made available to and drawn to the attention of the general public.</p> <p>Outcome: Recommendation to approve. DAAG suggested that the applicant should consider whether more could be done to highlight outputs to the general public.</p> <p>2.8 <u>Midlands and Lancashire CSU (Presenter: Steve Hudson) NIC-363897-P5D9L</u></p> <p>Application: This application was to amend a previous application (NIC-316784-W1H2D) that had been considered by DAAG on 3 March 2015 and recommended for approval for a period of six months. The requested amendment was to include ONS mortality data, as the legal basis for the CSU to receive this under Section 42(4) of the Statistics and Registration Service Act 2007 had now been confirmed.</p> <p>Discussion: DAAG requested evidence of the applicant's legal basis to hold ONS data in order to ensure this was in line with current guidance from ONS.</p> <p>A query was raised regarding what organisation would act as data controller for the proposed use of ONS data, as it was unclear whether this should be NHS England or whether a customer organisation instructing the CSU might be considered the data controller. In addition, information was requested about the CSU's customers and their geographical bases for the additional Project D that had been added to the updated application. DAAG also requested further information about any commercial aspects of Project D.</p> <p>DAAG noted that a number of questions had been raised regarding the previous application when this was discussed in March 2015, particularly regarding commercial aspects and proportionality, and it was confirmed that these points would need to be addressed when a renewal application was provided in October 2015.</p> <p>Outcome: Unable to recommend for approval. In relation to Project D DAAG requested evidence of the legal basis for ONS data, confirmation of what organisation is acting as data controller, further details of the applicant's customer organisations and their geographical base, and clarification of commercial aspects.</p>
<p>3</p>	<p>Any other business</p> <p><u>Imperial College London - COSMOS (Presenter: Garry Coleman) NIC-345889-J5J0V</u></p> <p>Application: This application was brought to DAAG for advice on consent materials only, particularly in relation to the applicant's intention to share data outside the UK and outside the EEA.</p>

Discussion: DAAG noted that the online consent forms used from 2010 onwards did not appear to refer to sharing data with third parties unless participants clicked a link for more information, and there were concerns that a significant number of participants would not have clicked this link and therefore could not be considered to have given informed consent to their data being shared.

The use of the term 'anonymised' to refer to record level pseudonymised data was queried, and DAAG noted that data should only be considered anonymised if it met the standard of the ICO anonymisation code of practice.

Overall it was felt that the consent materials did not provide sufficient information about the collection and use of health data, and did not specifically state that record level data would be shared outside the UK.

Outcome: DAAG advised that there were concerns regarding the consent form and patient information leaflet, as these did not explicitly state that record level data would be shared overseas. There were in addition concerns that not enough information had been provided about how health data would be collected and used, who those would be shared with, and to what use it might be put. This advice was given without prejudice to the consideration of future applications.

DAAG were informed that work was underway within the HSCIC to develop guidance for applicants, and DAAG members agreed to review and comment on appropriate areas.

Summary of Open Actions

Date raised	Action	Owner	Updates	Status
24/02/15	Dawn Foster 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	<p>03/03/15: Discussions were taking place with HRA CAG, and the response would be fed back to a future DAAG meeting.</p> <p>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.</p> <p>17/03/15: Ongoing.</p> <p>25/03/15: Ongoing.</p> <p>31/03/15: Ongoing.</p> <p>07/04/15: Ongoing.</p> <p>13/04/15: Ongoing.</p> <p>21/04/15: Ongoing.</p> <p>28/04/15: Ongoing.</p> <p>05/05/15: It was agreed that Dawn Foster would raise this separately with CAG.</p> <p>12/05/15: Clarification had been requested from NHS England regarding a particular request for both identifiers.</p> <p>19/05/15: Ongoing.</p> <p>27/05/15: Ongoing.</p> <p>02/06/15: Ongoing.</p> <p>09/06/15: Ongoing.</p> <p>30/06/15: No response had yet been received from NHS England, and a further reminder would be sent.</p> <p>07/07/15: It was agreed that if no response was received within a week then this application should be closed.</p> <p>14/07/15: Ongoing.</p> <p>21/07/15: A response from NHS England had been received, and this would be discussed with the HRA CAG Secretariat.</p>	Open
16/06/15	Garry Coleman to speak to Chris Roebuck	Garry	30/06/15: No update available.	Open

	regarding Public Health England's approach to fair processing.	Coleman	07/07/15: Ongoing. It was agreed that Steve Hudson would provide an update at the following meeting. 14/07/15: Ongoing. 21/07/15: Ongoing.	
07/07/15	Steve Hudson to provide DAAG Secretariat with contact details for the Disclosure Control Panel, and DAAG Secretariat to schedule discussion of the Disclosure Control Panel process for a future DAAG training session.	Steve Hudson	14/07/15: Ongoing. 21/07/15: An update had been provided to the DAAG Chair by email, and Steve Hudson would be invited to discuss this at the August training session.	Closed
21/07/15	DAAG Secretariat to invite Rob Shaw to attend a future DAAG meeting to discuss HSCIC Executive Director changes.	DAAG Secretariat		Open