

Data Access Advisory Group (DAAG)

Minutes of meeting held 7 July 2015

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

In attendance: Frances Hancox, Victoria Williams, Diane Pryce, Steve Hudson, Louise Dunn, Dickie Langley, Dave Cronin, Jennifer Donald

Apologies: Sean Kirwan

1	<p>Review of previous minutes and actions</p> <p>The minutes of the 30 June 2015 meeting were reviewed and minor corrections were raised. Subject to these amendments, the minutes were agreed as an accurate record.</p> <p>Action updates were provided (see table on page 9).</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">NIC-339273-J7S5V University of York
2	<p>Data applications</p>
2.1	<p><u>The Nuffield Trust (Presenter: Dave Cronin) NIC-342809-H1V7F</u></p> <p>Application: This was an amendment to the Nuffield Trust application (NIC-326736-Q0F3G) that DAAG had considered and recommended for approval on 3 March 2015. Approval had been given for the Nuffield Trust to receive pseudonymised, non-sensitive Hospital Episode Statistics (HES) data and use this for six different projects, and this amendment was for the addition of a seventh project to make use of the same data. DAAG were informed that an eighth project, which had previously been included in this amendment application, had now been withdrawn and the application was therefore for the addition of a seventh project only.</p> <p>Discussion: No concerns were raised regarding the addition of the seventh project, although some concerns were noted regarding the eighth project that had now been withdrawn.</p> <p>DAAG discussed the applicant's plans to disseminate outputs and it was noted that the seventh project would feed into a Nuffield Trust report, which would presumably be made available online. Members supported attempts to focus dissemination of the outputs to relevant target audiences to ensure benefits could be realised.</p> <p>Outcome: Recommendation to approve. DAAG would encourage and support attempts at focused dissemination of outputs to relevant target audiences.</p>
2.2	<p><u>Royal College of Surgeons – National Vascular Registry (Presenter: Dickie Langley) NIC-358185-N3R6Q</u></p> <p>Application: This application had previously been considered on 27 May 2015 (NIC-337091-P9S7M) when DAAG had been unable to recommend approval due to the need for further</p>

	<p>information about outputs and anticipated benefits, as well as the need for a clear explanation of why small numbers were required not to be suppressed. Additional details had now been provided, including a clearer explanation of the tabulated data requested.</p> <p>Discussion: DAAG expressed their support for the work of the National Vascular Registry, and noted that this request would enable discrepancies between the registry data and HES data to be checked. The explanation that small numbers were required in order to accurately identify discrepancies was noted, and although a query was raised regarding the discrepancies that could be caused by individuals who had not consented to be included in the registry it was suggested that the applicant would undertake further work to determine the cause of discrepancies.</p> <p>A query was raised regarding the role of the HSCIC Disclosure Control Panel and whether they should be asked to consider this request, but on balance this was not felt to be necessary. DAAG requested further information about the Disclosure Control Panel and its processes.</p> <p>Outcome: Recommendation to approve.</p> <p>Action: 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.</p>
2.3	<p><u>University of Cambridge – Cardiovascular Epidemiology Unit (Presenter: Dave Cronin) NIC-341598-H3G7P</u></p> <p>Application: This application had previously been considered at the 31 March 2015 DAAG meeting (NIC-321397-T0Q1R) when DAAG had requested further details of a reference to EU funding, as well as a clearer justification for the number of data years requested and clarification of the applicant's dissemination plan for outputs. The number of data years requested had now been reduced from 25 to 14, with filters applied to limit the dataset only to episodes relevant to the study, and clarifications had been provided as requested. DAAG were informed that a reference to EU funding had been in error, as the only project funding was from the British Heart Foundation.</p> <p>Discussion: There was a discussion of the number of data years requested, and DAAG queried why specifically 14 years had now been requested; it was explained that this was due to the need to balance requesting the minimum amount of data necessary with the need to examine outcomes over a long period of time. It was also noted that using data from the past 14 years would potentially mean that data would be of higher quality, and be more relevant to current clinical practice than using older data.</p> <p>DAAG queried references in the application summary to a future planned project; it was confirmed that this potential future project was not part of the current application, and it was agreed that these references should be removed.</p> <p>It was felt that more specific details could have been provided regarding outputs and expected benefits, but on balance it was agreed that the details provided seemed appropriate.</p> <p>Outcome: Recommendation to approve subject to removing references to a potential future project from the application summary.</p>
2.4	<p><u>Institute of Occupational Medicine - Hard Metal Manufacturing (Presenter: Jennifer Donald) NIC-335133-K2Y2S</u></p> <p>Application: This application for identifiable, sensitive demographic data and Office for National Statistics (ONS) mortality data was presented to DAAG for advice only. DAAG's views were sought on whether the expected benefits described would be considered to be in line with the</p>

relevant requirements of the Care Act 2014.

Discussion: DAAG discussed the expected benefits, and it was agreed that while there was the potential for benefits to health and social care these would need to be described explicitly within the application summary rather than being implied.

DAAG queried the second phase described in the application summary, which would request for pseudonymised data to be shared with the University of Pittsburgh, as it was not clear whether any benefits could be attained from the first phase alone if an application for the second phase was not successful. It was agreed that more information was required about the interdependence of these two phases, and that it might be more appropriate to submit a single application to cover both phases.

Clarification was requested about what demographic data was requested, and a copy of the Health Research Authority Confidentiality Advisory Group (HRA CAG) section 251 support letter dated February 2013 was requested as it was noted that the other HRA CAG letters provided stated that they should be read in conjunction with this. DAAG noted that the final support letter stated that data should be de-identified prior to transfer to the University of Pittsburgh. In addition to these points, concerns were raised regarding the leaflet provided to workers and whether this provided sufficient information about what data would be used and how it would be processed. The importance of ensuring outputs would be disseminated in an appropriately transparent way was noted.

Outcome: DAAG advised that clarification was required about the interdependency of the second phase described, and the application form should be in line with the content of the section 251 support letter which stated that data will be fully deidentified prior to disclosure to the University of Pittsburgh. Health benefits should be made explicit within the application summary rather than implicit. Clarification was required about what demographic data was requested, the section 251 letter from February 2013 should be provided, and dissemination of outputs should be appropriately transparent. DAAG raised concerns about the fair processing materials provided as it was felt that these did not provide sufficient information.

This advice was given without prejudice to the consideration of future applications.

2.5 Institute of Occupational Medicine - Rubber and Cable Manufacturing (Presenter: Jennifer Donald)
NIC-323309-L2G9T

Application: This application was for ONS mortality and Personal Demographics Service (PDS) demographic data for a cohort of individuals who had worked in the rubber and cable manufacturing industries. DAAG were informed that workers had been contacted with information about this study via trade unions, and it was noted that section 251 support was in place.

Discussion: There were concerns regarding whether the benefits as currently described could be considered compatible with the requirements of the Care Act 2014, and it was agreed that the anticipated benefits to health and care needed to be described more clearly and explicitly rather than being implicit. In addition to this, concerns were raised regarding the need to ensure fair processing as it was felt that more information should have been made available to participants.

A query was raised regarding the data requested, as the application summary referred to participant addresses but this was not referred to in the section 251 support letter provided. Confirmation was requested that the data requested was consistent with the applicant's section 251 support.

DAAG queried the interdependency of this phase of the project with the second phase, whereby the applicant wished to share data with Bristol University and the International Agency for Research in Cancer subject to a subsequent application being approved. It was agreed that if the

two phases were interdependent, and benefits could not be realised from the first phase alone, then it would be more appropriate to consider the two phases as a single application.

Outcome: Unable to recommend for approval. DAAG raised concerns around demonstrating compliance with the requirements of the Care Act 2014, and the need to make health benefits explicit within the application summary rather than implicit. Concerns were also raised regarding fair processing, and clarity was required around the data requesting matching the applicant's section 251 support. In addition clarification was required about the interdependency of the second phase described, and any data leaving the UK should be fully anonymised.

2.6 University of Kent - Identifying the Impact of Adult Social Care Study and associated secondary analyses under the QORU programme (Presenter: Jennifer Donald) NIC-347033-P3Q2Q

Application: This application was for linkage of HES and Mental Health Minimum Dataset (MHMDS) data for a specific cohort, as well as list cleaning of the cohort for the purpose of improving the match rate with HES data. The cohort had previously provided their consent to participate in the study, and the consent materials had previously been reviewed by DAAG in February 2013, but some concerns had now been raised within the HSCIC as to whether the consent obtained covered this data processing. DAAG were informed that the applicant was not in direct contact with the cohort members.

Discussion: DAAG discussed the consent materials provided and it was agreed that these would not be considered appropriate by current standards as they did not clearly describe how data would be processed, and the explanation of health status was thought to be misleading in this context. There was therefore thought to be no apparent legal basis for the HSCIC to receive identifiers, link and disseminate data. The possibility was raised of the applicant seeking approval under Regulation 5 of the Health Service (Control of Patient Information) Regulations 2002, also known as section 251 support, and the need to demonstrate a medical purpose as defined by the NHS Act 2006 was noted.

The role of Accent, a social research field work provider, was discussed and it was noted that this organisation would provide identifiers for the purpose of linkage. DAAG noted that due to their use of identifiable data Accent should be considered a data processor, and requested relevant details such as the organisation's registration under the Data Protection Act 1998 (DPA).

DAAG discussed the specific outputs and anticipated benefits, and there were concerns that insufficient detail of benefits to health and care was provided in order to meet the requirements of the Care Act 2014.

Outcome: Unable to recommend for approval. DAAG felt that there was no legal basis under consent for the HSCIC to receive identifiers, link and disseminate data and suggested that the applicant should explore with HRA CAG the possibility of applying for Regulation 5 section 251 support, providing it meets the necessary criteria. An updated application with an appropriate legal basis would need to more clearly state the benefits to health and care as per the requirements of the Care Act 2014.

2.7 ICON Health Economic (Presenter: Dave Cronin) NIC-363128-Z8X5U

Application: This application for pseudonymised, non-sensitive HES data had been previously considered at the 2 June 2015 DAAG meeting. Additional information had now been provided in response to DAAG's queries. A reference to 'only the fields necessary' had been clarified, and references to a leading clinical expert had been amended to clearly state that this individual had provided advice only and would not be given access to the HES data.

Discussion: DAAG members expressed their support for this work. A query was raised regarding

data minimisation efforts, and it was confirmed that data filters would be applied so that only data relevant to status epilepticus, refractory status epilepticus and super refractory status epilepticus would be provided. DAAG noted that the contact name listed was for an individual based in the USA, and requested updated contact information for a named individual based in the UK in line with the data controller details provided.

The intended sharing of outputs with Sage Therapeutics was discussed, and it was agreed that the application should be amended to clearly state that this was for commercial purposes. It was noted that HES data would not be provided to Sage Therapeutics, and that the results of analysis would not be exclusive to Sage Therapeutics but would be made publicly available. DAAG asked for a statement to be added to the application summary that data would not be used for sales and marketing purposes.

DAAG queried references in the outputs and benefits sections of the application summary to a target completion date of 6 or 12 months, and asked for this to be clarified.

Outcome: Recommendation to approve subject to confirmation of a named UK contact with their address, which should be consistent with the data controller information provided. Also subject to adding a statement that the data will not be used for sales and marketing purposes, clarification of references to 6 and 12 months in the specific outputs and expected benefits sections of the application summary, and stating clearly that the application includes commercial purposes.

2.8 University College London – Catheter Infections in Children (Presenter: Dave Cronin) NIC-320023-X7F9B

Application: This application was to extend an existing agreement for two organisations, University College London and the Institute of Child Health at Royal Liverpool Children's Hospital, to continue to hold pseudonymised, non-sensitive HES data and sensitive HES-ONS linked mortality data that had previously been provided on the basis of consent. The data had been used as part of a project to determine the cost effectiveness of different types of central venous catheters; this project had now completed, and the applicant had requested to retain data in case a need arose to scrutinise the published findings. DAAG were informed that the University of Bangor had also previously received data for this project, but that the University of Bangor had confirmed data destruction.

Concerns had been raised within the HSCIC about the materials that had been used to obtain parental consent for the use of data, as it was not felt that these would be considered appropriate by current standards.

DAAG were informed that the DPA registration wording for the University of Liverpool, which hosted the Institute of Child Health at Royal Liverpool Children's Hospital, did not currently refer to the use of healthcare data and the applicant had contacted the Information Commissioner's Office to amend this.

Discussion: The consent materials provided were discussed, and DAAG agreed that these would not be considered appropriate by current standards. It was therefore not felt that the existing participant consent could provide a legal basis for continued data processing.

DAAG queried the intention for two different organisations to continue to hold this dataset, as a clear explanation for this apparent duplication was not provided. In addition, DAAG agreed that sufficient justification was not provided for holding the data for a period of 15 years rather than a shorter period. Moreover it was considered to be unclear whether the datasets held by each organisation would be pseudonymised or effectively anonymised, and whether other data held by the applicant could mean that data could be re-identified.

Outcome: Unable to recommend for approval on the basis that there was a lack of clarity

	<p>regarding whether the data held was pseudonymised or effectively anonymised, and whether individuals could be re-identified from the data held. If the data held was not effectively anonymised then a case had not been made for retention of dataset; the duration of retention did not seem in line with the DPA; there was no clear justification given for holding multiple copies of the dataset; and there was no apparent legal basis for further processing of this data, as by current standards the consent obtained would not be deemed adequate.</p>
3	<p>Any other business</p> <p><u>University College London – Centre for Longitudinal Studies NIC-349413-F1J1N</u></p> <p>This application was to amend an existing agreement (NIC-316681-W7P2R, recommended for approval by DAAG on 9 December 2014) for identifiable, sensitive NHS registration data as the previous applicant organisation, the Institute of Education, had now merged with University College London. The requested amendment was therefore to amend the data controller from the Institute of Education to University College London, and also to add the National Centre for Social Research as an additional data processor.</p> <p>There was some confusion regarding documentation, as two application summaries were provided and it was not clear what had been updated. It was noted that some confusion could have been caused due to the illness of a senior staff member involved in the application, and DAAG requested clarification. It was agreed that Dawn Foster and Alan Hassey would review the application and determine whether it would be appropriate for DAAG to consider it out of committee; if not, the updated application would be considered at the next DAAG meeting.</p>

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>	Open
16/06/15	Garry Coleman to speak to Chris Roebuck regarding Public Health England's approach to fair processing.	Garry Coleman	<p>30/06/15: No update available.</p> <p>07/07/15: Ongoing. It was agreed that Steve Hudson would provide an update at the following meeting.</p>	Open
30/06/15	DAIS team to inform the development of the	Diane Pryce	07/07/15: This would be included as part of the review process, and the	Closed

	next version of the HSCIC Data Sharing Framework Contract to ensure that it will cover the appropriate arrangements for students and those working under honorary contracts.		action was closed.	
30/06/15	DAAG Secretariat to notify HSCIC SIRO and Caldicott Guardian of DAAG's recommendation regarding this application (IMS Health Technology Services, NIC-324360-T8R3T).	DAAG Secretariat	07/07/15: Ongoing.	Open
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		Open