

Data Access Advisory Group (DAAG)

Minutes of meeting held 24 January 2017

Members: Chris Carrigan (Chair), John Craven, Dawn Foster, Eve Sariyannidou

In attendance: Anomika Bedi (observer), Garry Coleman, Jen Donald, Louise Dunn, Nicola Fear (observer), Jon Fistein (observer), Frances Hancox, Terry Hill (observer), Dickie Langley, Vicki Williams

Apologies: Joanne Bailey, James Wilson

1	<p>Declaration of interests</p> <p>No interests were declared.</p> <p>Review of previous minutes and actions</p> <p>The minutes of the 17 January 2017 meeting were reviewed and agreed as an accurate record.</p> <p>Action updates were provided (see Appendix A).</p> <p>Out of committee recommendations</p> <p>An out of committee report was received (see Appendix B).</p>
2	<p>Data applications</p>
2.1	<p><u>Department for Transport (Presenter: Jen Donald) NIC-381383-Z9F2P</u></p> <p>Application: This renewal application requested pseudonymised non-sensitive Hospital Episode Statistics (HES) data linked to specific road accident diagnosis codes and to a cohort supplied by the Department of Transport of reported road accidents from 2011 to 2016, in addition to the retention of data already held for 1999-2011. The application had previously been considered at the 8 November 2016 meeting when DAAG had deferred making a recommendation. The application had now been updated to clarify that only statistical data would be shared with the European Commission and to provide more information about benefits. The applicant had also provided the proposed update to their website fair processing information and confirmed that they had requested a change to their DPA registration wording.</p> <p>Discussion: DAAG noted an error in section 5E of the application and it was agreed this would be corrected.</p> <p>A query was raised about the statement within the application that 'Researchers from recognised research institutes can apply for access to the sensitive variables' and it was agreed that this statement should be further explained.</p> <p>DAAG queried the description of linking to other data and the statement that these data items 'are not identifiable and could not be used to re-identify an individual'. It was clarified that this was intended to refer to data such as road conditions or speed limits, and DAAG asked for the wording to be amended to state this more clearly. It was agreed a special condition would be added that the applicant would not make any attempt to re-identify the data.</p> <p>DAAG queried the purpose for the applicant to retain data from 1999 to 2011, and it was</p>

confirmed that this was required to carry out the work described. DAAG asked for the application wording to be updated to more clearly state the reason to retain this data, and to include a special condition that once the particular work requiring this data was completed then the historic data would be securely destroyed. In addition it was agreed a special condition should be added that the applicant would not share record level data with any third parties or EU funded projects.

There was a discussion of the proposed updates to the applicant's fair processing information, and DAAG noted that this did not yet seem to be available on the Department for Transport website. Some concerns were raised about the clarity of the proposed wording and whether this would be considered sufficiently transparent and understandable by members of the general public. In particular DAAG noted that some of the wording appeared potentially contradictory.

Outcome: Recommendation to approve, subject to:

- Removing a word from section 5E
- Providing further information about a statement that "Researchers from recognised research institutes can apply for access to the sensitive variables".
- Providing a clearer explanation about the specific work for which the historic data will be used, and including a special condition that once this work is completed the pre-2011 data will be securely destroyed.
- Further explaining a statement that "These data items are not identifiable and could not be used to re-identify an individual" and include a special condition that the applicant must not attempt to re-identify the data.
- Including a special condition that the applicant will not provide record level data to any third parties or EU funded projects.
- Providing evidence that the fair processing information within this application is now readily available on the Department for Transport website.
- A commitment from the applicant to update the fair processing information on their website within six weeks to be clearer and more accessible.

It was agreed these caveats would be reviewed out of committee by the Director for Data Dissemination.

2.2

KPMG - National Cancer Vanguard baseline and contract modelling project (Presenter: Dickie Langley) NIC-69707-G0Q7Z

Application: This application was for access to pseudonymised HES data via the HES Data Interrogation Service (HDIS), in addition to an extract of pseudonymised Secondary Uses Service (SUS) data. The Christie NHS Foundation Trust and Royal Marsden Hospital NHS Foundation Trust would act as data controllers and processors. The application had been discussed at the 17 January 2017 meeting, when DAAG had been unable to recommend approval. The application had been updated to list the two Trusts as data controllers in common and attempted to address the points previously raised by DAAG, including offering an explanation of why KPMG had been listed as a data processor rather than also being a data controller.

Discussion: DAAG noted the verbal update regarding KPMG's security assurances and asked for the application to be updated to reflect this. There was a discussion around whether any further information was required on the access controls in place, and it was confirmed that access controls were considered as a standard part of the security assurance process. Given a previous query raised about staff access to other data, DAAG were assured that the application included a commitment that the SUS and HES data could not be linked to any other datasets. DAAG suggested that this wording should be updated to further clarify that the SUS data and HES data could not be linked with each other.

DAAG reiterated their previous query regarding whether KPMG should also be listed as a data

controller, as it was felt that this point had not been adequately addressed. Based on the application provided, it appeared as though KPMG were undertaking responsibilities for how data would be processed and for what purpose in a way that would suggest they were acting as a data controller; however, DAAG were verbally assured that while KPMG were acting as applicant on behalf of the two Trusts, they would only act as a data processor as per their contract with the two Trusts. DAAG noted these verbal assurances but drew attention to the fact that the application did not accurately reflect these assurances. DAAG were informed that section five of the application had been developed with input from the Trusts and therefore reflected the data controllers' view of the purpose, processing, outputs and benefits rather than these relating solely to KPMG. It was agreed that section five of the application would be amended to accurately reflect KPMG's data processor role, and ensure that this did not describe them undertaking any responsibilities that could imply data controllership. There was a suggestion that a special condition should be added to the application to restrict KPMG from using the outputs of this work for any other commercial purposes.

DAAG also repeated their previous query regarding the indicative data retention period, and it was agreed that a clearer justification was needed for why data should be retained for this long a period. DAAG noted that the justification should more clearly link to the expected outputs of the work. In addition DAAG asked for the application wording to be updated to show that the data retention period related to the retention by the two Trusts, rather than by KPMG as data processor.

A query was raised about the possibility for staff working outside the UK to access data, but it was confirmed that the data sharing agreement would stipulate that data must only be processed and stored at the specific England locations listed in the application. There was a further discussion around the controls in place for staff accessing the data, to ensure that only those with a legitimate need to access the data would do so; it was confirmed that the data sharing agreement would restrict data use to only the specific purposes outlined in the application.

Outcome: Recommendation deferred, pending:

- Updating the application to show that the security assurance for KPMG has been accepted by NHS Digital.
- Clearly stating within the application that in addition to not linking with any other datasets, the SUS and HES data must not be linked with each other.
- Rewording section five of the application to be clearer that KPMG will be acting as data processor on behalf of the two Trusts, rather than taking responsibilities that could be considered to imply data controllership.
- Adding a special condition that the outputs of this work cannot be used by KPMG to support any other commercial work.
- Clarifying that the indicative data retention period relates to the two Trusts, rather than data being retained by KPMG for this period.
- Providing a clearer justification for the indicative data retention period in relation to the planned outputs.

2.3

Queen Mary University of London – IBIS II (Presenter: Louise Dunn) NIC-324220-P6W9Y

Application: This application was to renew and amend an existing agreement, which had been previously considered at the 1 March 2016 DAAG meeting. The applicant wished to continue to hold and receive cause of death and cohort event data, and had now also requested Diagnostic Imaging Dataset (DIDs) data. It was noted that the applicant had wished to receive DIDs data at the time of the previous application, and that their section 251 support had not covered it at that point in time but that this had now been amended.

DAAG were informed that an incorrect IRAS form had been provided as a supporting document, and that the correct form would be supplied.

Discussion: DAAG noted that in some places the application referred to Queen Mary University of London providing data to NHS Digital, while in a different section it was stated that the Barts Centre for Cancer Prevention would provide this data. It was clarified that the Barts Centre was part of Queen Mary University of London rather than being a separate legal entity, and DAAG asked for the application wording to be amended to refer to the organisation consistently. In addition it was noted that the list of data provided to NHS Digital appeared to differ slightly and this would need to be made consistent.

A query was raised about the supporting document SD11, in which a Chief Investigator from the University of Manchester indicated that Queen Mary University of London would act as data controller. DAAG requested more information about this letter, with confirmation that only Queen Mary University of London would have access to the data disseminated.

The potential benefits of this work were acknowledged. DAAG noted the time lapse between the applicant's initial request for DIDs data, and this updated application for the receipt of DIDs data; there was a suggestion that NHS Digital might wish to consider any lessons learned from the cause of this delay.

Outcome: Recommendation to approve, subject to caveats:

- Providing a copy of the IRAS form for IBIS II rather than IBIS I, and reflecting this accurately within the application.
- Ensuring the application consistently refers to either Barts Centre for Cancer Prevention or Queen Mary University of London as a single entity, and consistently listing the same data that will be provided to NHS Digital.
- Providing further information about the letter provided as SD11, with confirmation that only Queen Mary University of London will have access to the data.

It was agreed these caveats would be reviewed out of committee by the Director for Data Dissemination.

2.4

Clinical Practice Research Datalink (CPRD) (Presenter: Louise Dunn) NIC-15625-T8K6L

Application: This application requested a renewal, amendment and extension to an agreement following the previous application (NIC-366782-V7J8C, considered at the 1 December 2015 DAAG meeting). The application covered the release of HES, mental health data (MHMDs, MHLDDs), Patient Reported Outcome Measures (PROMs), DIDs, and Office for National Statistics (ONS) mortality data linked to the CPRD cohort. CPRD would then process the data and release this under sub-license to third party organisations for agreed purposes only (following review by the Independent Scientific Advisory Committee), and DAAG were informed that CPRD had received legal advice that the data they released was considered anonymised due to the multiple pseudonym layers applied prior to release. In addition DAAG were informed that CPRD had committed that NHS Digital could directly undertake audits of the third parties who received data via sub-license.

NHS Digital highlighted the potential similarities between this application and the IMS application that was shortly due for discussion (NIC-24629-X6B6N).

Discussion: DAAG noted that the commissioning letter provided was an unsigned copy, and requested sight of the final signed version. DAAG asked for section three of the application to be updated to correctly list the identifiability of the data, as due to an error this was not currently displayed correctly.

DAAG queried the information provided about outputs and benefits, as it was unclear what efforts CPRD made to confirm that the outputs produced from using this data would be disseminated in a way that would enable health or social care benefits to be achieved.

	<p>DAAG noted that they had previously advised that CPRD should support GPs to fulfil their data controllership responsibilities regarding fair processing, and some disappointment was expressed that it did not appear from the application that any steps had been taken regarding this. The importance of openness and transparency about data processing was emphasised; DAAG welcomed the applicant's intention to publish more information about the third parties to whom data was disseminated under sub-license, and encouraged CPRD to consider making more comprehensive information about this available to the general public as soon as possible. Some concerns were raised about the existing CPRD fair processing materials and DAAG agreed that these ought to be more accessible to the general public and clearly describe what data CPRD collect and onwardly disseminate. DAAG queried what steps CPRD had taken to meet the HRA CAG requirement from 2012 regarding patient notification.</p> <p>DAAG were asked to consider the assurances provided regarding sharing data worldwide, the governance of releasing data under sub-license via the Independent Scientific Advisory Committee, and the sub-licensing arrangements themselves. There was some discussion but DAAG noted that if the data released under sub-license was anonymous then these assurances were less relevant than if pseudonymised data were to be released. It was noted that it would still be important to ensure that data would be used for appropriate purposes in line with the requirements of the Care Act 2014, and DAAG noted that the sub-license arrangements included restrictions such as that third parties must not attempt to re-identify the data or link with other data. Some queries were raised about the assurance that any data released was anonymous, and it was agreed the application should be updated to clearly state that only anonymous data would be released to third parties. In addition DAAG asked for the application to provide further information about the controls in place and the steps taken to ensure that the data could be considered anonymous.</p> <p>Outcome: Recommendation deferred, pending:</p> <ul style="list-style-type: none"> • Providing a clearer explanation of how CPRD ensure that outputs are disseminated in a way that will enable healthcare benefits can be achieved. • A commitment from the applicant to update their fair processing materials to clearly state what data CPRD collect and onwardly disseminate, with evidence that they have met the HRA CAG requirement from 2012 regarding patient notification. • Providing a signed copy of the commissioning letter. • Updating the table of data requested to correct the identifiability listed. • Clearly stating within section five of the application that only anonymous data will be onwardly shared by CPRD, and documenting the controls or measures undertaken that ensure that this is the case in section 5B. <p>DAAG welcomed the applicant's intention to publish more information in future about the organisations to which data is disseminated, and advised that this should be made available as soon as possible in the interests of openness and transparency.</p>
3	<p>NIC-24629-X6B6N IMS Health Information Solutions Medical Research Ltd – proposed sub-licensing arrangements (for discussion)</p> <p>DAAG received an update on the proposed sub-licensing arrangements for IMS Health ISMR following the discussions of application NIC-24629-X6B6N at DAAG, most recently at the 13 December 2016 meeting.</p> <p>DAAG broadly welcomed the proposed changes as an improvement to the existing sub-licensing arrangements, but suggested a number of points that NHS Digital might wish to raise with IMS Health ISMR. These included the use of Quintiles IMS letterhead, despite the fact that this appeared to be a separate legal entity to IMS Health ISMR that would not be party to the agreement, and the importance of being clear in all documentation that NHS Digital's role would related to all linked HES-THIN data as well as any HES data alone. An incorrect reference to NHS Digital as a 'trading name' was noted. DAAG noted the important role that the Independent Scientific Ethics and Advisory Group (ISEAC) would be expected to have in</p>

	<p>reviewing requests for data as well as sub-licensing arrangements, and it was suggested future applications should include an update on the progress made to establish this group.</p> <p>These comments were made without prejudice to the consideration of any future applications.</p>
4	<p>Any other business</p> <p>DAAG noted that this would be the final meeting for DAAG member John Craven, who would be stepping down at the end of the month. DAAG expressed their thanks to John for his work over the previous years and wished him well for the future.</p>

Appendix A: Summary of Open Actions

Date raised	Action	Owner	Updates	Status
15/11/16	To update DAAG on the feasibility of providing random samples of data to applicants, and to ask the Production Team to provide DAAG with further information about the options for data minimisation	Garry Coleman / Alan Hassey	<p>06/12/16: This action was ongoing and it was anticipated an update would be available in mid-January. There had also been a discussion during the training session about data minimisation, with a suggestion for Peter Short to contact the Production Team for further information, and it was agreed that would be incorporated into this action.</p> <p>20/12/16: It was anticipated an update would be available in mid-January.</p> <p>10/01/17: Ongoing. It was agreed that this action would be taken forward by Alan Hassey rather than Peter Short.</p> <p>17/01/17: A number of internal discussions had taken place and it was anticipated an update would be brought to DAAG within the next few weeks.</p> <p>24/01/17: Ongoing.</p>	Open
06/12/16	To provide feedback to the NHS Digital Caldicott Guardian on the minimum criteria for privacy notices and to suggest any necessary additional criteria.	DAAG Chair	<p>20/12/16: A draft document had been circulated amongst DAAG members for comments.</p> <p>10/01/17: A number of comments had been received and an updated draft would be urgently circulated.</p> <p>17/01/17: Further comments had been received on the updated draft; the agreed changes would be made and a final version circulated as soon as possible.</p> <p>24/01/17: The final version had now been provided to the Caldicott Guardian and the action was closed.</p>	Closed
06/12/16	To query the privacy notice review process within NHS Digital.	Dawn Foster	<p>13/12/16: This had been discussed with the Caldicott Guardian but further clarification was needed.</p> <p>20/12/16: This action was ongoing in light of developments in other areas, including the drafting of minimum criteria. It was agreed that the action would be taken forward by Dawn Foster and Noela</p>	Open

			Almeida. 10/01/17: Ongoing, pending updated criteria. 17/01/17: DAAG were given a brief verbal update on the work taking place. 24/01/17: Work was ongoing following receipt of the final DAAG comments on the minimum review criteria.	
10/01/17	To speak to NHS Digital colleagues regarding security assurance for HQIP.	Chris Carrigan	24/01/17: This had been raised with NHS Digital.	Open
17/01/17	To provide an update on the security assurances that NHS Digital would seek for applicants using contractors.	Garry Coleman	24/01/17: It was anticipated this update would be provided to a meeting within the next few weeks.	Open
24/01/17	To clarify the Local Authority Public Health application template wording regarding the Licensing Act.	Garry Coleman		Open

Appendix B: Out of committee report (as of 19/01/17)

These applications were previously recommended for approval with caveats by DAAG, and the caveats have subsequently been agreed as met out of committee.

The following application caveats have been signed off by DAAG:

- NIC-05934 Harvey Walsh (*considered at DAAG meeting 13/12/16*)

The following application caveats have been signed off by the DAAG Chair:

- NIC 17649 University of Leeds (*considered at DAAG meeting 10/01/17*)
- NIC-25780 National COPD Audit (*considered at DAAG meeting 10/01/17*)

IAO and Director approvals

The following applications were not considered by DAAG but have been progressed for IAO and Director extension/renewal only:

- NIC-15283 Nottinghamshire County Council
- NIC-376603 HSCIC