Data Access Advisory Group (DAAG)

Minutes of meeting held 22 December 2015

Members: John Craven, Alan Hassey (Acting Chair), Eve Sariyiannidou

In attendance: Garry Coleman, Dave Cronin, Gaynor Dalton, Frances Hancox, Steve Hudson, Julia King, Dickie Langley, Stuart Richardson, Vicki Williams

Apologies: Joanne Bailey, Dawn Foster, James Wilson

1	Declaration of interests				
	No conflicts of interest relevant to this meeting were declared.				
	Review of previous minutes and actions				
	The minutes of the 15 December 2015 meeting were reviewed and agreed as an accurate record. DAAG noted that for application 2.7 (University College London, NIC-353402-X1B2T) it had been agreed that written evidence of ONS approval would be provided, and it was agreed that this would be sent to the Acting Chair out of committee for confirmation.				
	Action updates were provided (see table on page 10).				
	Out of committee recommendations				
	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:				
	 NIC-02077-R7M9C Imperial College London NIC-371031-B8K6D University of York NIC-379725-X1R1X Imperial College London NIC-389320-R4M6Z University of Nottingham NIC-353402-X1B2T University College London 				
2	Data applications				
2.1	Herts Valleys CCG Risk Stratification (Presenter: Stuart Richardson) NIC-352540-P3F9F				
	Application: This was a renewal application for Secondary Uses Service (SUS) data identifiable at the level of NHS number for use in risk stratification. Data would flow via North East London CSU as a landing point only, then to MedeAnalytics who would act as data processor on behalf of the CCG and provide a risk stratification tool. GPs would then be able to securely log into the risk stratification tool to access data relating to patients registered at their own practice only, and the CCG itself would only be able to access anonymised data.				
	It was noted that the applicant organisation had recently updated their fair processing notice following feedback from DAAG, and all organisations involved had achieved satisfactory Information Governance (IG) Toolkit scores. DAAG were informed that the HSCIC had advised MedeAnalytics to update their Data Protection Act (DPA) registration to include processing health data about patients or healthcare users.				
	Discussion: DAAG noted that MedeAnalytics would act as data processor for this applicant, and requested confirmation that the data storage location listed in the application summary was				

	accurate.					
	 Outcome: Recommendation to approve, subject to: Confirmation from MedeAnalytics that the data storage location provided is accurate. 					
2.2	2 Group CCG Application ¹ for pseudonymised data (Presenter: Stuart Richardson)					
Application: This was a group application to renew the flow of pseudonymised SUS da CCGs for commissioning purposes. Kent & Medway Health Informatics Service would a processor for each of the three CCGs, then provide the processed pseudonymised data each CCG. All organisations had achieved satisfactory IG Toolkit scores and held approDPA registrations.						
	Discussion: DAAG noted that this was a renewal application, and encouraged the Data Services for Commissioners team to ensure that future renewal applications contained more information about the benefits that had been achieved over the previous year with the data that the applicant had already received. DAAG acknowledged that it would not be practical to provide a detailed update for each individual applicant, but asked for future applications to include an indication of benefits achieved overall. It was agreed that this would be discussed with the team. In addition, DAAG noted that any changes in the planned data retention period should be justified as part of renewal applications in future.					
	Outcome: Recommendation to approve. DAAG recommended that renewal applications from the Data Services for Commissioners team should provide details of the benefits achieved with data already provided in the last year, and should include clarification of changes in the planned data retention period.					
2.3	Thurrock Council (Presenter: Gaynor Dalton) NIC-391309-T4N4V					
	Application: This application was to receive the standard pseudonymised Hospital Episode Statistics (HES) dataset for Local Authorities with public health functions. DAAG were informed that the applicant had achieved a satisfactory IG Toolkit score and held an appropriate DPA registration, but the applicant had not published an appropriate privacy notice. The applicant had committed to publish this within eight weeks.					
	Discussion: No concerns were raised regarding this application. DAAG reiterated their previous comments that Local Authorities should ensure that their privacy notices are accessible and easy to locate on their website.					
	Outcome: Recommendation to approve. DAAG drew attention to the fact that the applicant should consider updating their DPA registration entry to refer to processing data for public health purposes about patients or healthcare users. DAAG also drew the applicant's attention to the ICO privacy notices code of practice and commented that the applicant would need to publish a notice in line with this within eight weeks, including an explanation of the type of data processed and for what purposes, how individuals can opt out, and should ensure that the notice would be easy to find on their website.					
2.4	London Borough of Hackney (Presenter: Gaynor Dalton) NIC-387526-Y0J4L					
	Application: This application was to receive the standard pseudonymised Hospital Episode Statistics (HES) dataset for Local Authorities with public health functions. It was noted that the					

applicant did not yet have a signed Data Sharing Framework Contract in place and data would not flow until this had been completed. In addition to processing data for their own public health functions, the applicant would also process data for public health functions on behalf of the City of London.

DAAG were informed that the applicant had achieved a satisfactory IG Toolkit score and held an appropriate DPA registration, but the applicant's privacy notice did not appropriately reflect their public health functions. The applicant had committed to publish an amended privacy notice to include this within eight weeks. In addition, the HSCIC had advised the applicant that the City of London website should include a link to the London Borough of Hackney privacy notice given that they would process data on behalf of the City of London.

Discussion: No concerns were raised regarding this application. DAAG reiterated their previous comments that Local Authorities should ensure that their privacy notices are accessible and easy to locate on their website.

Outcome: Recommendation to approve.

DAAG drew attention to the fact that the applicant should consider updating their DPA registration entry to refer to processing data for public health purposes about patients or healthcare users. DAAG also drew the applicant's attention to the ICO privacy notices code of practice and commented that the applicant would need to update their notice in line with this within eight weeks, including an explanation of the type of data processed and for what purposes, how individuals can opt out, and should ensure that the notice would be easy to find on their website.

2.5 Royal Society for the Prevention of Accidents (Presenter: Gaynor Dalton) NIC-311183-X5Q2F

Application: This application was to renew an existing agreement for the applicant to receive a tabulation of aggregated HES data, with small numbers not suppressed. The data would be used to develop and deliver targeted accident prevention programmes, and understand trends in hospital admissions for accidents and injury. The applicant had provided a brief summary of how this data had been used previously, such as demonstrating the effectiveness of the Safe At Home National Home Safety Equipment Scheme. DAAG were informed that the HSCIC had advised the applicant to update their DPA registration to include the promotion of health and processing data about patients or healthcare users, and the applicant had confirmed that this would be done when their registration was renewed.

Discussion: It was confirmed that although the applicant had requested data with small numbers unsuppressed, any published outputs would suppress small numbers. DAAG noted that the applicant's Data Sharing Framework Contract was shortly due to expire, and that data would not flow if this was not renewed. In addition it was confirmed that if the contract lapsed, the applicant would be required to destroy the data that they had previously received from the HSCIC.

DAAG queried the amount of data requested, and whether the tabulation included the entirety of HES for the data years requested. It was clarified that the data would be filtered by specific ICD-10 codes relating to injuries and external cause of morbidity, and DAAG asked for the application summary to be amended to clarify the reference to ICD-10 codes and what these related to.

A query was raised regarding how the applicant demonstrated public benefit from this use of data, and whether for example this would be reflected in the organisation's registration on the Charity Commission website or if the organisation published details of the work on their own website for the general public. It was agreed that in future any renewal applications should provide additional information about how public benefits were demonstrated.

Outcome: Recommendation to approve.

Application summary to be updated to clarify what the ICD-10 codes listed relate to. DAAG advised that additional information about the public benefits provided by the applicant organisation

 should be included in applications in future. DAAG noted that the applicant's Data Sh Framework Contract was shortly due to expire, and that if this was not renewed then not be able to flow and that the data already held would need to be destroyed. DAAG that the applicant intended to update their DPA registration to include processing dat patients or healthcare users for purposes relating to health. 2.6 <u>NHS England - Reconciliation of 2015 Learning Disabilities (LD) Census and Assuring Transformation data (Presenter: Netta Hollings) NIC-385750-C7W4H</u> Application: This was a new application for bespoke extracts of Learning Disability of Assuring Transformation data. NHS England would use this data to identify any under the statement of the					
	the Assuring Transformation data and hold commissioners to account for the completeness of their data. Discussion: DAAG noted that the outputs section of the application referred to a target date of December 2015, and that this would no longer be feasible. It was confirmed that the applicant was aware data would likely not be provided before the end of December 2015.				
	The applicant's section 251 support was discussed, and DAAG noted that the section 251 letter indicated that this support would end in March 2016. It was confirmed that work was underway to renew this support, but that if the section 251 support ended then the HSCIC would cease to provide data to the applicant.				
	DAAG discussed the legal basis for this data flow, and queried whether the section 251 support or the Directions for Assuring Transformation provided the appropriate legal basis. It was suggested that support was probably provided by section 251 rather than by the Directions, but it was agreed that confirmation would be sought.				
	 Outcome: Recommendation to approve, subject to: Clarification of the legal basis for data flows described in this application. DAAG noted that the applicant's Section 251 support was due to end in March 2016, and that an application to renew this was underway. 				
2.7	Janssen Healthcare Innovation (Presenter: Dickie Langley) NIC-375954 – X4W9H				
	Application: This was an extension and renewal application for the receipt of HES and Mental Health and Learning Disabilities Dataset (MHLDDS) data. Data would be used to support the consultancy work of Janssen Healthcare Innovation, which was a subsidiary of the Johnson & Johnson group, and to provide consultancy services to the Oxford Academic Health Science Network. DAAG were informed that the application should have also listed Janssen Healthcare Innovation as data processor, and that the HSCIC would seek confirmation of storage addresses.				
	Discussion: DAAG felt that the first purpose described in the application summary, which related to using data internally within the applicant organisation to support consulting work, appeared to be wholly commercial. DAAG therefore agreed that it given the restrictions placed on the HSCIC by the Care Act 2014, it would not be appropriate to provide data for this purpose. In addition, it was felt to be unclear whether the second purpose described was also solely commercial and additional assurance would need to be provided regarding this. It was agreed that more information would be required about the work of the Oxford Academic Health Science Network and how the data requested would be used to benefit health and social care. Given the need to ensure benefits to health and social care, DAAG requested confirmation that outputs would be either made publicly available or shared appropriately for the improvement of health services.				
	DAAG noted that Janssen Healthcare Innovation was a team within Janssen-Cilag. Given that this was a subsidiary of Johnson & Johnson, DAAG noted that although security assurance had been				

provided for Johnson & Johnson it was not specified whether these security policies also applied to Janssen-Cilag or if Janssen-Cilag should have provided separate security assurance.

In relation to the second purpose, DAAG agreed that sufficient justification had not been provided for why national data was required to support work for the Oxford Academic Health Science Network rather than minimising the amount of data required, for example by providing data for the Oxford area along with a sample of national data.

DAAG also queried the data controller for the work described, and whether this was in fact Janssen-Cilag as stated or if the organisations who had commissioned work should instead be considered data controllers. DAAG noted that the applicant was already in receipt of HSCIC data, and requested confirmation that this was not being used for product development, sales and marketing purposes. Given the international nature of Johnson & Johnson it was agreed that confirmation would be required that data would not be used overseas. DAAG noted that the application included a statement that data would not be shared 'with any other part of the Johnson & Johnson Group' but that elsewhere the application referred to 'internal use' within Johnson & Johnson. In addition, DAAG queried whether the data would be linked with any other data held by the organisation.

The role of data processors Skyscape Cloud Services and Ark Data Centres Limited were queried as it was unclear what processing these organisations would carry out, and DAAG requested clarification of data storage arrangements. It was noted that the applicant's DPA registration was shortly due to expire, and that data could not be shared if this was not renewed.

Outcome: Unable to recommend for approval.

- Purpose one was felt to be a solely commercial purpose, and assurance would be required that purpose two was not also solely commercial. As defined by the Care Act 2014, data should be made available for a wide range of health related purposes including commissioning of services and epidemiological research needed at early stages of developing new treatments, but not for solely commercial purposes. (*Ref: Notes on section 122 Care Act 2014, The Health and Social Care Information Centre: Restrictions on Dissemination of Information*)
- In addition, purpose two would require evidence of data minimisation efforts, such as providing data for the Oxford area only along with a sample of national data.
- Confirmation would be required that outputs will be made publicly available or generally available to improve healthcare services.
- Clarification was needed of whether Janssen-Cilag and Janssen Health Innovation were covered by the security assurance provided for Johnson & Johnson
- Clarification of whether data would be linked with any other data held.
- Clarity would be required about who the data controller for this work is.
- Confirmation that data already held by the applicant organisation is not being used for product development, marketing and sales.
- Clarification of arrangements for data storage, and confirmation that data will be retained wholly within the UK with appropriate security assurance.

2.8 Private Healthcare Information Network (PHIN) (Presenter: Dave Cronin) NIC-391557-K2H0W

Application: This application was for pseudonymised, linked HES and Patient Reported Outcome Measures (PROMs) data with no filters applied. The data would be used to provide services to the public including statistical information on private healthcare providers in comparison with NHS healthcare providers and on consultants operating across NHS and private healthcare provision, as the applicant had been mandated by the Competition and Markets Authority (CMA) to make this information available.

It was noted that the applicant had indicated that the purpose of this work was not in any way commercial, although it related to private healthcare. DAAG were informed that a reference in the

application summary to staff accessing data remotely 'via a dedicated internet connection' would be removed, and replaced with a statement that data would only be processed at the two storage addresses listed. **Discussion:** DAAG questioned how closely the described purpose aligned with the applicant's CMA mandate, as it was thought that this mandate related to making information available to the general public whereas the application also referred to providing pseudonymised data to private hospitals and private patient units. Concerns were raised that this could result in data being used for sales or marketing purposes by the PHIN member organisations. Furthermore it was not felt to be clear whether some of the work described could be carried out using data already in the public domain about consultant performance, and whether some of the data requested might not therefore be required. A query was raised regarding the legal status of PHIN, as it was unclear whether this was a legal entity in its own right or if this was a network hosted by another organisation. DAAG also gueried the planned data retention period as this was stated to be 'ongoing', and members suggested that this should relate to the purpose for which data would be used. Confirmation was requested that data would not be linked to any other data held by the applicant. The references in the application summary to the applicant being 'legally obliged' to carry out this work were challenged, and it was agreed that this would be replaced with the word 'mandated'. In addition DAAG requested a justification for the requested frequency of data extracts. **Outcome:** Unable to recommend for approval. Confirmation was required that data will only be used as part of the applicant's CMA mandate to provide information for the general public, and not to provide information to private healthcare providers that could then be used for sales or marketing purposes. Confirmation that parts of the described purpose could not be covered using data on consultant performance that is already publicly available. The legal status of PHIN should be clarified. Confirmation was required of an appropriate data retention period in line with the purpose. Confirmation was needed that data will not be linked to any other data held by the applicant. The application summary should be updated to replace 'legally obliged' with 'mandated'. A justification was requested for the proposed frequency of data extracts. 2.9 CHKS Ltd (Presenter: Dave Cronin) NIC-387691-G9T8K **Application:** This application was to extend, renew and amend an existing data sharing agreement, which DAAG had considered and recommended for approval on 25 August 2015 (NIC-352414-W9M3F). The updated application now requested to retain data for longer than the six month retention period previously approved, and to receive the sensitive HES field of consultant code. DAAG were notified that two separate data storage providers had been listed in the application summary as the applicant was in the process of transferring between these two providers. It was confirmed that the two organisations only provided a storage location and did not have access to the encrypted data stored there by the applicant organisation. Discussion: DAAG queried how the data previously provided to the applicant had been used, in order to ensure that appropriate benefits to health and social care had been realised. It was confirmed that the application summary did include examples of how data had been used for NHS organisations with links to relevant case studies. The transition between data storage providers was discussed, and DAAG requested confirmation of when this transfer was expected to be completed. The HSCIC could then request confirmation

	that the former storage provider had appropriately destroyed all data.			
	Outcome: Recommendation to approve. Applicant to provide an expected completion date for the transfer of storage providers, and agree to notify the HSCIC once the transfer is complete so they can confirm destruction of data by the former storage provider.			
2.10	North Bristol NHS Trust - Is pleural infection associated with longer survival in people with mesothelioma? (Presenter: Dave Cronin) NIC- 381891-X5K3X			
	Application: This was a new application for pseudonymised HES data filtered to episodes relating to mesothelioma or pleural infection, linked to Office for National Statistics (ONS) data including the identifier date of death. Data would be used to examine a possible link between pleural infection and longer survival rates in people with mesothelioma, with the intention that if a positive correlation was shown then this might lead to a clinical trial and the development of new treatment options for mesothelioma. It was noted that one of the two individuals who would have access to the data was employed on an honorary contract.			
	Discussion: DAAG noted the potential importance of this work and expressed their support. It was agreed that any concerns regarding the use of honorary contracts for this organisation had previously been addressed in relation to other applications. The data requested was discussed, and it was confirmed that the only identifier to be provided was the date of death included in the ONS mortality data.			
	DAAG noted the intention to carry out a clinical trial in future. It was agreed that the application summary would be updated to include a statement that data could only be retained and used for the specified purpose, and that any other use of data in future would need to be subject to a further application.			
	Outcome: Recommendation to approve. Application summary to be updated to state that data can only be retained for the specified purpose, and that any change in purpose or request to use data for a future clinical trial would be subject to a further application.			
2.11	Frontier Economics Ltd (Presenter: Dave Cronin) NIC-377469-D2R0D			
	Application: This was a new application for a tabulation of aggregated HES data with small numbers not suppressed. The data would be used by the applicant for work funded by the Health Foundation to examine whether GPs who are involved in training, commissioning and other initiatives achieve better outcomes for patients. A reference in the application to 'LSOA of patients' was clarified as referring to the average LSOA of patients within each general practice, rather than the specific LSOA of each individual patient.			
	Discussion: DAAG discussed the purpose of this application, and agreed that it was unclear what hypothesis would be tested using the data requested as well as why the particular data requested was needed for this purpose. Given this there was uncertainty as to how benefits to health and care could be realised through the work described.			
	In addition DAAG were unclear whether the work described could instead be carried out using data already in the public domain, or using aggregated data with appropriate small number suppression applied. In addition, DAAG queried whether tabulated data for the whole country would be required or whether a sample of tabulated data would suffice. A reference in the application summary to requesting data for 'four conditions' was queried, as a number of different conditions appeared to be listed under the different sets of HES data requested.			

	 DAAG queried the duration of the funding agreement between the applicant organisation and the Health Foundation, in order to confirm that this was not a shorter period than the planned data retention period. It was agreed that this would be clarified. In addition DAAG queried whether the Health Foundation should be considered data controller, as they had funded the work, but it was clarified that the work had been funded via an open call and the Health Foundation had therefore not directly commissioned the work. DAAG noted that the application referred to carry out primary research via surveys, and queried whether the applicant had sought ethical review. Outcome: Unable to recommend for approval. The hypothesis to be tested was unclear, as was the link between the hypothesis and the data requested. It was therefore not clear how the statistical analysis described could lead to any benefits to health and social care. DAAG queried whether the wider work described, such as surveying GPs, could be considered research and whether the applicant should therefore complete the HRA tool to determine whether ethical review is required. Applicant to confirm the duration of Health Foundation funding.
2.12	Nuffield Trust - The care of frail older people, and the role of the Comprehensive Geriatric Assessment (Presenter: Steve Hudson) NIC-383324-D6B8TApplication: This application was to amend an application DAAG had considered and recommended for approval on 22 September 2015 (Nuffield Trust, NIC-316705-C9F9J). The amendment was to receive the HES-IDs for the project cohort in order to link the pseudonymised data already held for this cohort. It was explained that patient identifiers for the study cohort would be provided to the HSCIC by three universities, for which section 251 support was in place, but that no identifiable data would be provided to the Nuffield Trust.
	A query had been raised prior to the meeting about the patient information leaflet for Newcastle University referred to in the section 251 support letter from HRA CAG, and whether DAAG could have sight of this leaflet. This was not yet available to members, but it was agreed that this would be circulated to DAAG following the meeting.
	Discussion: DAAG agreed that the patient information leaflet should be reviewed out of committee.
	It was noted that DAAG had previously advised this applicant to update their DPA registration, and that this had not yet been completed. DAAG were informed that the applicant had committed to update this registration, although the changes had not yet been made. DAAG proposed that these changes should be done within a reasonable timescale, such as by the applicant's DPA registration renewal date.
	 Outcome: Recommendation to approve, subject to: DAAG having sight of and being content with the patient information leaflet from Newcastle University. DAAG noted that they had previously advised that the applicant's DPA registration should be updated; this had not yet been completed and should be done by an appropriate date, such as their DPA registration renewal date.
3	Any other business <u>NIC-288323-C6W6M University of Oxford</u>

DAAG were informed of a change to an application that DAAG had considered in December 2014, with the change being an amendment to the storage address. It was confirmed that the amended address was covered by the University of Oxford Data Sharing Framework Contract.
The Acting Chair noted the recent improvement in the quality of applications presented to DAAG, and in the quality of the presentations. He expressed his thanks to the Data Access Request Service team.

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. (08/12/15: Dawn Foster to provide comments on the draft paper.)	Dawn Foster	 10/11/15: A draft paper had been provided to the DAAG Chair by email but had not yet been circulated to the group. 24/11/15: Ongoing. 08/12/15: A draft paper was currently with Dawn Foster for review. 15/12/15: Dawn had reviewed the draft paper, and it was anticipated that the updated paper would be shared with other DAAG members in the near future. 22/12/15: The updated paper had been circulated, and the action was closed. 	Closed
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	 01/12/15: Steve Hudson noted that the proposed website information had been received with a timeframe of publication of early next year. DAAG asked for an update at a future DAAG meeting. 15/12/15: It was noted that the applicant had provided draft wording. Update to be provided in January 2016. 22/12/15: Ongoing. 	Open
24/11/15	DAAG Secretariat to ask Dawn Foster to provide advice on the security aspects of encrypted data storage used solely for disaster recovery purposes, and the implications this has for DPA registration. (Update 15/12/15: Audit team to confirm whether this is considered during audits.)	DAAG Secretariat	 01/12/15: DAAG Secretariat to provide Dawn Foster with background information. 08/12/15: The Secretariat had provided details of the relevant application, and this had been raised with the DAO. 15/12/15: Dawn provided an update on this and noted that in the example application a University of York facility was used to host a University of Leeds server as a secure backup, but that York staff were unable to access the encrypted Leeds server and it was therefore suggested that the University of York should not be considered a data processor. A query was raised regarding whether the HSCIC audit team considered secure backup facilities while conducting external audits, and it was agreed that this would 	Closed

			be raised with them. 22/12/15: This had been raised with the audit team, and a response confirming that this was considered as part of audits had been circulated to DAAG.	
08/12/15	DARS team to contact PHE regarding Local Authority privacy notices not including public health. Dawn Foster to contact the ICO regarding including public health functions in Local Authority DPA registrations.	Garry Coleman, Dawn Foster	 15/12/15: Dawn Foster had raised this with the ICO during a regular catch-up meeting. PHE had not yet been contacted regarding this. 22/12/15: Ongoing. DAAG were informed that this would be raised at a regular meeting with PHE in early January. 	Open
15/12/15	Garry Coleman to work with IG ISA team regarding processing Local Authority public health applications as a class.	Garry Coleman	22/12/15: Ongoing.	Open
15/12/15	DAAG members to be provided with a draft copy of the HSCIC processes relating to section 251 annual reviews once available.	Dawn Foster	22/12/15: Ongoing.	Open