Data Access Advisory Group (DAAG)

Minutes of meeting held 3 March 2015

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

In attendance: Alex Bell, Karen Myers, Frances Hancox, Susan Milner, Dickie Langley, Jen Donald, Garry Coleman, Dave Roberts, Stuart Richardson, Paula Moss

Apologies: Dawn Foster, Sean Kirwan

1	**Review of previous minutes and actions** The minutes of the 24 February 2015 meeting were reviewed and agreed as an accurate record. Action updates were provided (see table on page 7). **Out of committee recommendations** The following applications had previously been considered by DAAG and recommended for approval subject to caveats, and it had been confirmed out of committee that the caveats had now been completed: • University Hospitals Birmingham, NIC-325819-D6V9H • University of Sheffield, NIC-315175-P8X6Z • RAND Europe, NIC-323322-M3H0S • NHS Doncaster Clinical Commissioning Group (CCG), NIC-314376-C4D3X
2	**Data applications**
2.1	University College London - Mortality outcome in the London COPD cohort (Presenter: Jen Donald) NIC-321523-F3W6D **Application summary:** This was a new application for date and cause of death Office for National Statistics (ONS) data for a cohort of individuals with chronic obstructive pulmonary disease (COPD). The cohort members had consented to participate in the study, but as that consent had not included the linkage of mortality data section 251 support had been obtained from the Health Research Authority Confidentiality Advisory Group (HRA CAG) to cover this in addition to Approved Researcher accreditation. The data requested would be used to examine mortality rates within the cohort, with the intention that results would be published and discussed with key groups such as the British Thoracic Society. It was confirmed that data would not be provided for any individuals who had withdrawn their consent. **Discussion:** The Group were generally supportive of the application, but it was noted that the section 251 renewal date stated on the application form was incorrect. It was not clear if renewal had already been sought; it was agreed that this would need to be confirmed, and a copy of the most recent approval letter provided. **Outcome:** Application withdrawn. Updated application to be considered at a future meeting.
2.2	Imperial College London – Nottingham Study of Neurotic Disorder (Presenter: Jen Donald) NIC-311095-K1Q0B **Application summary:** This application was for latest address and cause of death ONS data for a consented cohort. The applicant would use this data to contact cohort members and ask them to

	consent to take part in an interview, with the mortality data being requested to reduce the risk of causing distress to relatives by attempting to contact deceased individuals. Cause of death data would also be analysed for signs of premature mortality. It was noted that anonymised, aggregated data would be made available to researchers in the National Institute for Health Research. **Discussion:** The legal basis for receiving ONS data was queried, as it was noted that while the consent forms referred to using data from 'other central UK NHS bodies' it was not thought that this could be considered to include ONS, and therefore patient consent would not be a valid legal basis for the data requested. It was agreed that this would need to be clarified, and the Group suggested that the applicant should seek section 251 support to receive the ONS data requested. The consent materials were discussed and it was suggested that the consent form should be updated to align more closely with the participant information sheet, for example by including the statement that choosing not to take part would not affect future care. It was also agreed that additional details of the complaints procedure should be provided. A query was raised regarding a reference in the consent form to 'other central UK NHS bodies' and whether this wording was considered to be appropriate. It was noted that this wording had previously been recommended by the HSCIC, but the Group were concerned that this wording could be considered too vague although it was noted that being overly specific could also cause difficulties in future when NHS bodies were reorganised. It was agreed that the current recommended wording should be circulated to the Group by email for discussion, with the possibility that this would need to be updated in future. **Outcome:** Unable to recommend for approval due to lack of a legal basis for the release of ONS data. DAAG also suggested that the consent form should be updated to more closely reflect the participant information materials, and further details added to these materials regarding the complaints procedure. **Action:** DAIS team to circulate the current recommended consent wording to DAAG members. **Action:** DAAG members to discuss the current recommended consent wording.
2.3	Imperial College London - Airwave Health Monitoring Study (Presenter: Dickie Langley) NIC-319622-D1J4Y **Application summary:** This application requested ONS data and list cleaning in addition to pseudonymised, non-sensitive Hospital Episode Statistics (HES) data using participant consent as the legal basis. The data would be used to analyse health outcomes such as coronary heart disease, irritable bowel syndrome and cancer. **Discussion:** Concerns were raised about the participant consent forms that had been provided. In particular it was suggested that the consent forms should clearly state that choosing not to participate would have no negative consequences for the individual, and in general the consent form should be updated to reflect the guidance that had previously been produced by DAAG members. It was noted that while the participant consent forms had been provided, the accompanying participant information leaflets had not been included with the application. The possibility of the applicant seeking updated consent from all study participants was raised, but it was agreed that it would be more appropriate for existing participants to be sent the updated information materials and be given the option to withdraw their consent if they wished to do so. It was agreed that due to the concerns about the consent forms, the current data flow should be put on hold. **Outcome:** Unable to recommend for approval. The consent form should be updated in line with

	guidance provided by DAAG, and in particular updated to specify that not participating in the study will have no negative consequences for individuals. The existing cohort should be re-contacted with the updated materials and given the opportunity with withdraw their consent.
2.6	Midlands and Lancashire Commissioning Support Unit (CSU) (Presenter: Garry Coleman) NIC-316784-W1H2D **Application summary:** This application was for pseudonymised, non-sensitive HES, Patient Reported Outcome Measures (PROMs), Secondary Uses Service (SUS), Mental Health Minimum Dataset (MHMDS) and Diagnostic Imaging Dataset (DID) data as well as the HES-MHMDS bridging file. The applicant was already in receipt of DID data, and the other datasets were requested in addition to this in order to support benchmarking and specifically to create QIPP opportunity packs for CCGs and trusts, to develop decision support tools, and to model expected mental health activity and capacity requirements within CCGs. It was noted that the CSU charged for these services, with work done at cost plus a margin set by NHS England. The applicant had achieved a satisfactory Information Governance (IG) Toolkit score. **Discussion:** The application stated that the applicant's customers for this work included Local Authorities for public health and social care purposes, and the Group queried whether any social care data would be linked with the data provided. It was confirmed that the data would not be linked at record level to any other datasets, but that publicly available organisation-level data such as Quality and Outcomes Framework (QOF) data could be linked. The Group queried the HES-MHMDS bridging file that had been requested, and it was clarified that this would enable the applicant to link the HES and MHMDS datasets together using pseudonyms without the need for any identifiable data to be provided. It was noted that the PROMs and MHMDS datasets were classed as sensitive, while the other data requested were non-sensitive. The Group acknowledged that work was ongoing within the HSCIC to consider the use of the term 'sensitive' and how this was defined. There was some uncertainty about the fact that national data had been requested, and whether this was proportional or whether it would be more appropriate to provide data only for the areas in which customer organisations of the CSU were located. The Group were informed that national data was required to provide benchmarking comparison against these customer organisations, and in addition the customer organisations were located in a wide range of areas across the country. However there remained some concerns, and it was agreed that the applicant should be asked to provide more details about these customer organisations and their geographic base in future. Concerns were raised regarding whether the fact that the CSU charged for their services and took part in tender processes meant that this should be considered commercial activity, although it was noted that the CSU did not make a profit. It was agreed that the HSCIC should consider what constitutes commercial activity in more detail. Given the concerns that had been raised about the definition of commercial activity and the need to ensure proportionality, it was proposed that the application could be granted approval for a period of six months only. It was suggested that the definition of what constitutes commercial activity could be discussed with HRA CAG at a later point. **Outcome:** Recommendation to approve for six months, subject to the applicant providing evidence about their customer base when a renewal application is submitted. DAAG raised concerns about the uncertainty surrounding what constitutes commercial activity, and additional concerns regarding the need to ensure that data releases are proportionate to the stated purpose.

2.4	NHS England - National Elective Revascularisation PROMS Pilot (Presenter: Dave Roberts) NIC-324251-J9T5N **Application summary:** This application had previously been considered at the 24 February 2015 DAAG meeting, when the Group had been unable to recommend approval. The application had been updated to clarify that as NHS England had commissioned this work, there was therefore a legal basis for the receipt of ONS data under section 42(4) of the Statistics and Registration Service Act 2007, as well as that this was part of a pilot study and consent materials would be updated for any future study to clearly state that ONS data would be used. The applicant had also indicated that subject to DAAG approval, the PROMs website would be updated to specify what data would be used for this project. Further information was also given about the consent process, and it was noted that approximately 6,000 people had given their consent to participate in the study and they had been talked through the consent materials by a member of staff. **Discussion:** While the Group acknowledged that the applicant intended to update the consent materials for any future studies and to publish information online, it was reiterated that the consent form provided did not state that ONS data would be used and this therefore could not be used as a legal basis for the linkage of ONS data. It was noted that recruitment for the pilot study had completed. The Group suggested that as the consent forms provided did not appear to provide an appropriate legal basis for the linkage of ONS data, the applicant should consider either obtaining section 251 support from HRA CAG or contacting the study cohort with updated participant information that specifically included the use of ONS data, and giving the cohort the opportunity to withdraw their consent. **Outcome:** Unable to recommend for approval due to the lack of a clear legal basis for the linkage of ONS data. DAAG advised that the applicant should either seek section 251 support, or write to the applicants informing them of the intended linkage and giving them the opportunity to opt out.
2.5	NHiS (Presenter: Dave Roberts) NIC-299649-J8G9Q **Application summary:** This application was to consolidate a number of existing agreements with the applicant into one, and for the applicant to continue to hold data for longer. The applicant requested pseudonymised, non-sensitive HES, MHMDS and DID data was well as the HES-MHMDS bridging file to enable linkage. It was noted that Binley's would provide IT support for data processing activities. The data provided would be used to create Disease Insight Reports and tabulations, and to populate the Q-PASS tool. **Discussion:** A reference within the application form to sub licensing was queried, and the Group were informed that this wording had been agreed by the HSCIC. It was noted that the applicant's Data Protection Act (DPA) registration details currently only referred to HES data rather than the other data they had requested, and the applicant had agreed to amend this. It was suggested that when applications listed benefits, these should include specific evidence to ensure that the benefits were credible. In particular it was noted that the applicant would not receive any data on compulsory detentions under the Mental Health Act, and the references to this work reducing bed days might not have taken these detentions into account; the applicant had been asked to include a statement regarding this in their outputs. The Group commented on the excellent quality of this application and commended the team that had prepared it. **Outcome:** Recommendation to approve subject to ensuring that the applicant's DPA registration details have been updated. DAAG noted the need to ensure that the benefits listed in applications are clearly evidenced and credible.

2.7	Midlands and Lancashire CSU – stage 1 accredited safe haven (Presenter: Stuart Richardson) NIC-304677-F7F6P **Application summary:** This application was for SUS data identifiable at the level of NHS number (weakly pseudonymised) under the section 251 support for stage 1 accredited safe havens. Data would flow from the North West Data Services for Commissioners Regional Offices (DSCRO) to the CSU, where it would be processed before being disclosed onwards in anonymised form only to CCGs with a legitimate relationship with the CSU. The data would then be used to support the commissioning of health services, and data was requested until either 30 April 2015 or in line with any extension of the relevant section 251 support. The application form stated that applicant had achieved a satisfactory IG Toolkit score, and that the applicant's DPA registration was in the process of being renewed. It was noted that the DPA registration had in fact already been renewed, and the application form would be updated to reflect this. Two minor errors on the form were noted, and these would be corrected. **Discussion:** The Group queried why the DSCRO had been listed as a data processor, and it was clarified that this was because the DSCRO would pre-process data before it was transferred to the CSU. It was noted that this had been queried at previous meetings, and the clarification would be discussed with DAAG members outside the meeting. There were some concerns regarding the statement that the data controllers for this work would be 'CCGs having a legitimate relationship with Midlands and Lancashire CSU', as it was felt that this was too vague. The Group were informed that a process was in place to track which CCGs had a legitimate relationship with which CSUs, as this was prone to change, and it was agreed that the application form would be updated to clarify this point. **Outcome:** Recommendation to approve subject to updating the DPA registration details listed on the application form, clarifying the statement that the data controllers will be CCGs with a legitimate relationship to the CSU, and clarifying the statement that the DSCRO will be a data processor to the satisfaction of DAAG members.
2.8	The Nuffield Trust (Presenter: Garry Coleman) NIC-326737-Q0F3G **Application summary:** This application was to retain pseudonymised HES data already held by the applicant, as well as to receive additional monthly HES extracts. The data would be used to support a number of projects that had been listed in the application form, including evaluating the impact of health and social care innovations on hospital utilisation and surveillance of hospital admission patterns. In addition it was intended that the data received would be used to link to additional data for future projects, but it was noted that DAAG were not asked to recommend approval of that linkage at this stage as separate applications would be brought for their consideration at a later date. **Discussion:** The Group queried a reference in the application form to 'additional projects' and it was explained that the data provided would not be used for linkage or for any additional projects unless approval was given for additional applications that would be made at a later date. It was suggested that it would be helpful if this could be clarified in the application form. The Group suggested that the applicant should consider how the findings of their work could be made available to the general public. In addition the Group noted that one of the stated purposes of the application was to inform public debate about hospital use, and emphasised that any data that was made available to the public would need to be aggregated with small numbers supressed. It was noted that the applicant's DPA registration wording did not currently cover using data for research explicitly, and the applicant was in the process of amending this wording to explicitly refer to research.

	Outcome: Recommendation to approve. DAAG suggested that the applicant should consider how to inform the public at large about the findings of this work, for example by publishing reports online, and emphasised that any information shared in the public domain should only include aggregated data with small numbers supressed.
2.9	University College London – Institute of Child Health (Dave Roberts) NIC-307512-K9F3L **Application summary:** This application was for HES and HES-ONS data to support research into the healthcare of children and young people, which had been commissioned by the Department of Health. It was noted that the provision of ONS data was covered by section 42(4) of the Statistics and Registration Service Act 2007. The applicant intended to publish the findings in peer reviewed journals as well as presenting them to policy makers and service providers. **Discussion:** The Group expressed their support for this work. A query was raised regarding whether the applicant's DPA registration wording included the use of data for research, and it was confirmed that this was the case. **Outcome:** Recommendation to approve.
3	**Any other business** The agenda for the next DAAG training day was discussed, and it was noted that HRA CAG representatives would not be able to attend on that particular date. The Group were notified that the number of applications for their consideration was likely to increase, and full-day weekly meetings would be scheduled to ensure there would be sufficient time to consider the higher number of applications. Funding for the transition period before DDAG was established was briefly discussed. The Group were informed that the General Practice Extraction Service Independent Advisory Group (GPES IAG) had recently undertaken a lessons learned exercise, and a report based on that work had been published on the HSCIC website.

Summary of Open Actions

Date raised	Action	Owner	Updates	Status
13/01/15	Garry Coleman to provide DAAG with a briefing paper on HDIS.	Garry Coleman	20/01/15: It was agreed that a briefing paper would be circulated, but it was noted that no further HDIS applications would be brought to DAAG at this stage while internal discussions were ongoing. 27/01/15: Ongoing. 03/02/15: A briefing paper had been drafted and would be shared by email following clarification regarding HDIS extracts. 10/02/15: Clarification had not yet been received. 17/02/15: Ongoing. 24/02/15: Ongoing. 03/03/15: Ongoing.	Open
20/01/15	Alex Bell to discuss the application form template with DARS team and consider adding a section asking applicants to demonstrate how their intended use of data and dissemination of results would be compliant with the Care Act 2014.	Alex Bell	27/01/15: This discussion had been scheduled, and details would be fed back to DAAG. 03/02/15: It was agreed that this should be discussed with Garry Coleman in the context of the papers on data sharing drafted following the recent DAAG training day. 10/02/15: Discussions had taken place about making changes to how information would be added to application forms. 17/02/15: Ongoing. 24/02/15: Ongoing. 03/03/15: Ongoing.	Open
24/02/15	Acting DAAG Chair to write to HSCIC SIRO regarding NAO application.	Alan Hassey	03/03/15: This action had been completed and was closed.	Closed
24/02/15	DAIS team to discuss the approach to local patient identifiers (LOPATID) with HRA CAG.	Diane Pryce	03/03/15: Discussions were taking place with HRA CAG, and the response would be fed back to a future DAAG meeting.	Open
24/02/15	DAIS team to raise with HRA CAG the possibility of stage 1 accredited safe havens receiving both data that is identifiable by	Diane Pryce	03/03/15: Discussions were taking place with HRA CAG, and the response would be fed back to a future DAAG meeting.	Open

	NHS number and data that is identifiable by postcode.			
03/03/15	DAIS team to circulate the current recommended consent wording to DAAG members.	Susan Milner		Open
03/03/15	DAAG members to discuss the current recommended consent wording.	Alan Hassey		Open