

Data Access Advisory Group (DAAG)

Minutes of meeting held 17 February 2015

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

In attendance: Alex Bell, Frances Hancox, Susan Milner, Garry Coleman, Dickie Langley, Paula Moss, Jo Simpson

Apologies: Patrick Coyle, Sean Kirwan

1	<p>Review of previous minutes and actions</p> <p>The minutes of the 10 February 2015 meeting were reviewed and agreed as an accurate record.</p> <p>Action updates were provided (see table on page 6).</p> <p>The Group received a short update on the number of applications awaiting review and it was noted that the applications 'backlog' that had accumulated prior to August 2014 had now been cleared. The process by which applications were added to the DAAG agenda was briefly discussed, and the Group asked if it could be specified which applications had gone through the pre-DAAG review process and which had not. It was suggested that the overall applications process could be discussed at a future DAAG training session. In addition it was agreed that representatives from the Health Research Authority Confidentiality Advisory Group (HRA CAG) should be invited to a future DAAG training session.</p> <p>Action: Alex Bell to schedule a discussion of the applications process for a future DAAG training session, and specify on meeting agendas which applications have gone through the pre-DAAG review process.</p> <p>Action: Alex Bell to invite HRA CAG representatives to attend a future DAAG training session.</p> <p>Out of committee recommendations</p> <p>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:</p> <ul style="list-style-type: none">• City University London, NIC-273840-N0N0N• Imperial College London, NIC- 287804-H1T1R• Doncaster CCG, NIC-309763-P0N1M• University of Bristol, NIC-281848-W3T5B
2 2.1	<p>Data applications</p> <p><u>NHS Coastal West Sussex Clinical Commissioning Group (CCG) – Stage 1 Accredited Safe Haven (Presenter: Garry Coleman) NIC-291185-S3Q1H</u></p> <p>Application summary: This application was from a stage 1 accredited safe haven CCG requesting Secondary Uses Services (SUS) data identifiable at NHS number level (weakly pseudonymised) for commissioning purposes. A monthly data flow was requested, but it was stated that this could become a daily data flow within the specified period depending on the applicant's requirements. This use of data was covered by the overarching section 251 approval given by HRA CAG for the provision of data to stage 1 accredited safe havens for commissioning</p>

purposes. It was noted that NHS South Commissioning Support Unit (CSU) would act as data processor for the applicant, and both organisations had achieved satisfactory Information Governance (IG) Toolkit scores.

Discussion: It was noted that the application form referred to sharing outputs with potential partners, and it was clarified that this was limited to NHS provider organisations that had a legitimate relationship with the CCG. Each NHS provider would only be able to access to data related to their particular organisation, and it was agreed that the application form would be amended to clarify this. There was a query whether this could include any private organisations, and it was confirmed that private organisations providing NHS services would also be included in the definition of NHS providers.

The Group noted that the IG Toolkit details for NHS South CSU had not been listed on the application form provided, and it was agreed that this would be corrected. The Data Protection Act (DPA) registration wording was discussed, and the Group requested confirmation that the applicant would not also use the data requested for the other uses listed within this wording. It was suggested that only the relevant sections of the DPA registration wording should be listed on application forms.

A reference to contributing to reports was queried, and it was clarified that this referred to reports produced by the CCG which would include aggregated data or graphs produced from the data provided. Some minor concerns were raised regarding the language used in the application form, and the Group encouraged the use of plain English where possible.

Outcome: Recommended for approval subject to updating the application form to list the CSU's IG Toolkit score and to clarify the applicant's DPA registration wording, and also clarifying that providers will only be able to access relating to their own organisation.

NHS Doncaster CCG – Risk Stratification (Presenter: Garry Coleman) NIC-314376-C4D3X

2.2

Application summary: This application from a stage 1 accredited safe haven was for SUS data identifiable at the level of NHS number (weakly pseudonymised) for risk stratification. The applicant had previously been granted approval to receive this data, and it was clarified that the current application to DAAG was to use the data received for an additional purpose by sharing the data with the Data Services for Commissioners Regional Office (DSCRO) South London. The DSCRO would analyse this data using risk stratification tools and provide anonymised data back to the CCG, and in addition would allow general practices within the CCG to identify patients within their practice who would be most likely to benefit from early intervention. It was noted that the CCG would not have access to this identifiable data, and general practices would only have access to data about patients within their own practice.

Discussion: Queries were raised regarding the two separate flows of data, as it was not thought to be explained clearly within the application form that following risk stratification data would be made available to general practices as well as anonymised data being made available to the CCG. It was also not clear which organisation would be the data controller and data processor for each flow of data, and the specific outputs and measurable benefits listed did not appear to specify what benefits would arise from providing data to general practices. The Group also queried the section 251 approval details listed, as it was thought that the dates listed were incorrect.

Outcome: Recommended for approval subject to clarification of the two data flows and who would act as data controller/processor for each flow; clarification of the relevant section 251 approval dates listed on the application form; and subject to amending the processing activities and specific outputs described in the application for to include the provision of data to GPs.

2.3

Newcastle upon Tyne NHS Foundation Trust – ALTER-10 Study (Presenter: Garry Coleman)
NIC-292948-H6S2Q

Application summary: This application was for Office of National Statistics (ONS) mortality data as well as GP practice code for a cohort of patients who had previously undergone a particular blood test, in order to study the long term implications and in particular the incidence of liver disease, cardiovascular disease and type 2 diabetes. The applicant intended to review general practice records for a subset of patients within the cohort. It was noted that section 251 approval was in place for the applicant to provide cohort identifiers to the HSCIC in order for these identifiers to be linked to ONS mortality data, and it was also noted that the applicant had achieved a satisfactory IG Toolkit score.

Discussion: The Group noted that the project had been funded by LIVErNORTH and the role of this organisation in the study was queried. It was clarified that LIVErNORTH had provided funding but that the organisation would not directly benefit from the outputs of the data provided, and it was agreed that this should be made clear in the application form.

Fair processing was discussed, and while the application form stated that patient information posters would be displayed 'on site' the Group felt that this was not by itself sufficient to meet the fair processing requirements of the Data Protection Act 1998. It was noted that the cohort was based on individuals who had undergone a particular blood test in 2003, and there were concerns that a significant number of individuals would be unlikely to see these posters or be aware of whether they would be included in the cohort. In particular it was not clear what sites were referred to and whether this would include general practices.

The Group queried whether the applicant's intention to review general practice records for a subset of the cohort had been included in the section 251 approval. It was confirmed that this was the case, and that general practices would be informed before this data was accessed.

The specific outputs and expected benefits to health and social care were discussed, and there were some concerns that the applicant had not provided sufficient evidence of any healthcare benefit in order to meet the requirements of the Care Act 2014. It was suggested that the applicant should be encouraged to consider how the outputs of the work could be shared more widely in order to ensure benefit to the healthcare system.

Outcome: Unable to recommend for approval. DAAG queried how the applicant would meet the fair processing requirements of the Data Protection Act 1998, and requested further evidence of how the outputs of the work could be disseminated more widely to promote benefits to the health and social care system.

2.4

University of Leeds - Clinical evaluation of magnetic resonance imaging in coronary heart disease (Presenter: Garry Coleman) NIC-294235-D5L0D

Application summary: This application was to renew an existing agreement between the HSCIC and the applicant. The applicant would provide identifiers for members of the study cohort, who had given their consent to participate, and the HSCIC would use this to provide the applicant with ONS data including International Classification of Disease (ICD) coding as well as fact, date and cause of death for the cohort. It was noted that the applicant had a satisfactory IG Toolkit score, but had not yet signed the HSCIC framework contract and no data would be provided until this had been completed.

Garry Coleman declared a minor interest relating to this application, as he held the role of honorary senior lecturer at the University of Leeds, but it was noted that this was not a paid role.

Discussion: There were some concerns regarding the appropriateness of the consent materials provided, and whether these still provided a sufficient legal basis for the dissemination of data. It

	<p>was noted that the patient information leaflet was dated 2005, and the Group queried whether any more up to date materials were now in use. In particular it was suggested that the consent materials ought to clearly state the organisation that was responsible for the study and would hold the data, more clearly describe the complaints procedure, and more clearly explain the potential involvement of commercial companies as this was referred to on the consent form but not in the patient information leaflet. The Group noted that the applicant had achieved an IG Toolkit score of 95% and queried whether this was in line with the consent materials provided.</p> <p>It was agreed that the Group's advice on consent materials should be shared with the applicant, and a copy of the paper produced for a recent DAAG training session would be shared with the Information Asset Owner to facilitate discussions.</p> <p>Outcome: Unable to recommend for approval. There were concerns that the consent materials did not provide an adequate legal basis for the disclosure of data, and about the interaction between the consent materials and the applicant's IG Toolkit score. It was suggested that the consent materials should be updated in line with DAAG's recommendations on consent material, details of which would be provided by the Information Asset Owner.</p> <p>Action: Alex Bell to provide Garry Coleman with a copy of DAAG's advice on consent materials.</p>
2.5	<p><u>Public Health England – amalgamation of previous agreements (Presenter: Dickie Langley) NIC-323580-X3H8M</u></p> <p>Application summary: This was an application to merge existing data sharing agreements with this applicant into one agreement. Pseudonymised, non-sensitive Hospital Episode Statistics (HES) data with relevant filters applied was requested in order to monitor trends in the incidence of vaccine-preventable diseases, to monitor potential adverse effects of vaccines, and to estimate the burden of disease in order to inform economic analyses.</p> <p>Discussion: The Group discussed the IG Toolkit score for Public Health England (PHE), and it was noted that the HSCIC External IG Delivery team had provided assurance that an improvement plan was in place. The application form stated that no identifiable data would be shared with third parties, and this was queried as only pseudonymised data would be provided to the applicant; it was confirmed that this meant the pseudonymised data would not be shared, and this would be clarified in the application form.</p> <p>A query was raised regarding a statement in the application form that PHE were considered a legal entity and had signed the HSCIC framework contract, as it was thought that in fact the Department of Health should be considered the relevant legal entity.</p> <p>Outcome: Recommendation to approve subject to confirmation that a data sharing contract will be signed by the relevant legal entity, and amending a reference to identifiable data in the application form to clarify that this refers to pseudonymised data.</p>
2.6	<p><u>National Audit Office – Value For Money audit reports (Presenter: Dickie Langley) NIC-307558-L7P8M</u></p> <p>Application summary: This was brought to DAAG for advice on the applicant's request to continue receiving HES and SUS data, in addition to requesting Mental Health Minimum Dataset (MHMDS) data. Access to the HES Data Interrogation Service (HDIS) would also be requested. This data would be used to monitor spending by the Department of Health and to carry out value for money studies, with the intention of producing reports for parliament and the Health Select Committee as well as publishing reports online. It was noted that the applicant's DPA registration wording had been queried, and that discussions were underway regarding the legal basis for the provision of this data.</p>

	<p>Discussion: The Group noted that a large amount of data had been requested, and there were some concerns about whether this could be considered proportionate to the purposes described and whether this amount of data was justified by the legal basis for providing data.</p> <p>There was some uncertainty regarding why access to HDIS had been requested in addition to receiving HES extract data, as a clear justification for this had not been provided. It was noted that HDIS provided access to analytical tools that could be used to analyse the data, but it was agreed that this justification would need to be provided as part of the application form.</p> <p>While the Group noted the importance of the NAO's statutory function, there were some concerns that it had not been specified how the stated purpose aligned with the requirement under the Care Act 2014 for the HSCIC to only disseminate data for the purpose of the provision of health and social care or the promotion of health. It was agreed that this needed to be clarified, possibly with reference to the specific legislation underpinning the work of the NAO.</p> <p>The DPA registration wording was queried, as it was not felt that this reflected the use of healthcare data and the work described.</p> <p>The Group agreed that they would welcome receiving an updated application as soon as possible, subject to receiving the clarification they had requested.</p> <p>Outcome: DAAG sought further clarification regarding this application. The following areas were highlighted as needing clarification:</p> <ul style="list-style-type: none"> • The legal basis under which the applicant requested this amount of data in this form, with reference to the legislation applicable to the NAO. • Evidence of how the purpose of the application is compliant with the requirements of the Care Act 2014. • The DPA registration wording provided and how this reflects the work described. • A clearer justification for why HES extract data is required in addition to access to HDIS.
3	<p>Any other business</p> <p>Garry Coleman offered to share an update regarding the approach to applications for data for clinical audits, and stated that any feedback would be welcomed.</p> <p>There was a query about whether DAAG members would be willing to engage with an applicant whose application had previously been considered by DAAG, and it was suggested that it would be more appropriate for members to provide feedback via the Information Asset Owner rather than speaking to the applicant directly.</p> <p>Further email discussions had taken place with the Nuffield Trust following their request for advice on consent materials. The Group highlighted two key points that would need to be addressed in the draft consent materials, these being the option for individuals to withdraw their consent and the fact that data would not be shared with any external third parties. The Group agreed that if the consent materials were amended to incorporate those two points, they would be happy to consider an application for data based on those consent materials.</p>

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.	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.	Open
03/02/15	David Evans to raise the importance of fair processing in ongoing audits with HQIP.	David Evans	10/02/15: Ongoing. 17/02/15: Ongoing.	Open
03/02/15	Karen Myers to provide David Evans with a copy of the outcome letter for this application (University College London, NIC-291217-K6M8H) once sent.	Karen Myers	10/02/15: Ongoing. 17/02/15: This letter had not yet been sent to the applicant.	Open
17/02/15	Alex Bell to schedule a discussion of the applications process for a future DAAG training session, and specify on meeting agendas which applications have gone through the pre-DAAG review process.	Alex Bell		Open
17/02/15	Alex Bell to invite HRA CAG representatives	Alex Bell		Open

	to attend a future DAAG training session.			
17/02/15	Alex Bell to provide Garry Coleman with a copy of DAAG's advice on consent materials.	Alex Bell		Open