

Data Access Advisory Group (DAAG)

Minutes of meeting held 17 March 2015

Members: Alan Hassey, Sean Kirwan, Eve Sariyannidou, John Craven, Patrick Coyle, Dawn Foster

In attendance: Alex Bell, Karen Myers, Frances Hancox, Susan Milner, Dickie Langley, Jennifer Donald, Stuart Richardson, Jonathan Jackson, Sophie Fletcher

Apologies: None

1	<p>Review of previous minutes and actions</p> <p>The minutes of the 10 March 2015 meeting were reviewed and agreed as an accurate record. Action updates were provided (see table on page 10).</p> <p>Out of committee recommendations</p> <p>No recommendations had been made out of committee.</p>
2	<p>Data applications</p> <p>2.1 <u>University College London - Mortality outcome in the London COPD cohort (Presenter: Jennifer Donald) NIC-321523-F3W6D</u></p> <p>Application summary: This application, which had previously been discussed by DAAG at the 3 March 2015 meeting, was for date and cause of death Office for National Statistics (ONS) data for a cohort of individuals with chronic obstructive pulmonary disease (COPD). Section 251 support and ONS Approved Researcher status were in place. 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. The application had been withdrawn from the 3 March 2015 meeting as the renewal date for section 251 support had passed and no information about renewal was available, but confirmation had now been received from the Health Research Authority Confidentiality Advisory Group (CAG) that support would continue to be in place while the review process was underway.</p> <p>Discussion: Some concerns were raised regarding the fact that the section 251 renewal process was not yet complete, and it was suggested that it would be best if DAAG could review the application after that process had completed when the outcome letter from CAG could be provided. The section 251 expiry date was queried, and it was noted that this was incorrectly stated in the application form and would need to be updated.</p> <p>Further information was requested about fair processing activities, or if appropriate a clear justification for why this was not required.</p> <p>Outcome: Unable to recommend for approval, as the application did not provide the key information required for DAAG to reach a recommendation. Evidence required that the section 251 renewal process has been completed, and that there are no outstanding concerns from CAG. Application to undergo internal information governance checks prior to re-submission. Further information requested about fair processing activities, with confirmation that either this has been addressed or that it is not relevant for this application. Section 251 expiry date to be corrected in application form.</p>

It was agreed that for all future applications where the section 251 renewal process was underway, it would be best if applications could be brought to DAAG once that process was complete and not sooner. DAAG secretariat to inform key internal stakeholders about this decision

2.2 University of Oxford - Heart Protection Study (Presenter: Jennifer Donald) NIC-301690-P3L4M

Application summary: This application was to renew an existing data sharing agreement and for the applicant to retain data they already held, which included demographic details to follow up the study cohort and ONS cancer and mortality data. The application was covered by Class Action, and had submitted an application to CAG for future section 251 support. Approved Researcher accreditation was in place to access ONS data. The data was used to assess the long-term safety of statins and antioxidant vitamins.

Discussion: The Group queried the legal basis for this application, and it was explained that a number of studies had been included in the Class Action work to provide an interim legal basis to allow time for them to move towards making individual applications for section 251 support. This applicant had applied for section 251 support ahead of the deadline set, but the application had not yet been reviewed by CAG. It was agreed that due to this, the Group would recommend approval for a short period of time only with the expectation that an updated application would be submitted once section 251 support had been secured. It was suggested that it would have been helpful if details of the Class Action could have been provided along with the application papers, including the relevant letter from CAG.

The Group expressed their support for this work, and it was hoped that the applicant would ensure the findings of the study would be made available to care professionals and to the general public. However, the difficulty of feeding study findings directly back to the NHS was raised and it was agreed that this should be discussed at a future DAAG training day. The importance of fair processing was discussed and it was agreed that when a renewal application was submitted this should include copies of fair processing materials.

Outcome: Recommendation to approve until 30 June 2015 subject to the applicant signing a data sharing contract, with fair processing materials and evidence of direct section 251 support to be provided when a renewal application is made. Applicant to be encouraged to consider how the potential results of the study could be more widely disseminated to care professionals and the public.

2.3 Newcastle upon Tyne Hospitals NHS Foundation Trust - ALTER-10 study (Presenter: Jennifer Donald) NIC-292948-H6S2Q

Application summary: This application was for ONS mortality data as well as GP practice code for a cohort of patients who had previously undergone a particular blood test. The application had previously been considered by DAAG on 17 February 2015 when they had been unable to recommend approval. Further information had now been provided on fair processing activities and the applicant's dissemination plan.

Discussion: The Group discussed the expected outputs of the work, and it was noted that the applicant intended to share results widely and publish in relevant journals with the intention that this would inform the development of regional guidelines.

The fair processing materials were discussed, and it was suggested that the poster might not be easily understood by members of the public and did not explain what information would be used by the study. It was agreed that the poster should be updated, and it was suggested that it would be helpful if posters could also be made available to general practices where patients within the cohort had been identified as registered at those practices.

	<p>Outcome: Recommendation to approve subject to fair processing materials being updated to provide additional information about the study, in language appropriate for the audience. It was suggested that posters should also be made available to general practices where patients within the cohort have been identified as registered at those practices.</p>
2.4	<p><u>University of Sheffield – The Design, Development, Commissioning and Evaluation of Patient Focused Vascular Services (Presenter: Dickie Langley) NIC-310132-K3Z8B</u></p> <p>Application summary: This application had previously been considered at the 17 July 2014 DAAG meeting (application reference 170714-e2). The applicant had requested Hospital Episode Statistics (HES) and ONS data in order to help reconfigure NHS vascular services in England. This work was funded by the National Institute for Health Research (NIHR), and it was noted that NIHR would receive project reports and the findings of the work would be shared at conferences and published within peer reviewed journals.</p> <p>The Group were informed of an incorrect date on the application form, which would be corrected. It was noted that the applicant's Data Protection Act (DPA) registration wording did not currently reflect the work described and work was underway to update the registration details.</p> <p>Discussion: The Group noted that the applicant intended to update their DPA registration wording, and requested sight of the updated wording to ensure that this would make it clear that data would be processed from individuals with no connection to the university.</p> <p>Some minor points of accuracy were raised: one individual who would access the data had been listed without a job title, and it was suggested that this should be added; and at one point the application form stated that the programme grant would feed into reconfiguration, when it was thought this meant the work funded by the programme grant. In addition, it was suggested that more information could have been provided about the other three workstreams referred to in the application form.</p> <p>The Group discussed the size of the dataset requested, and while it was agreed that this was considered to be proportionate to the purpose for which the data would be used it was also agreed that it would have been helpful if a clear statement on proportionality could have been included with the application papers.</p> <p>Outcome: Recommendation to approve subject to clarification regarding the applicant's DPA registration wording.</p>
2.5	<p><u>HSCIC Clinical Audit Support Unit – COPD Audit (Presenter: Dickie Langley) NIC-310862-Q1W5Y</u></p> <p>Application summary: This application was for the HSCIC clinical audit support unit to receive and process identifiable HES and HES-ONS mortality data on behalf of the Health Quality Improvement Partnership (HQIP) as part of the national COPD audit. Linked, pseudonymised data would be shared with the Royal College of Physicians for analysis. Section 251 support was in place, and the legal basis for access to ONS data was stated to be section 42(4) of the Statistics and Registration Act 2007. The audit aimed to improve the quality of services for people with COPD, measuring and reporting the delivery of care as defined by guidance standards and the aggregated analysis produced would be fed back to healthcare professionals.</p> <p>Discussion: The Group queried references in the application form to both pseudonymised and identifiable data. It was clarified that identifiable data was requested by the clinical audit support unit, but that this would be pseudonymised before being passed on to the Royal College of Physicians.</p> <p>The patient information leaflet was discussed, and it was noted that this did not specifically refer to</p>

	<p>the role of the HSCIC in the audit. It was also felt that some patients might not potentially understand the term COPD and so might not be aware of whether they would be included in the audit.</p> <p>The legal basis for the provision of ONS data was queried. It was noted that a commissioning letter from HQIP had been provided, but it was suggested that HQIP were not one of the organisations empowered by the Statistics and Registration Act 2007 to access ONS data. It was agreed that the legal basis for providing ONS data would need to be queried further, and that the application would need to undergo internal information governance checks to clarify this point. There were some concerns that this check had not already taken place, and it was agreed that this would be raised internally.</p> <p>Outcome: Unable to recommend for approval, as the application did not provide the key information required for DAAG to reach a recommendation. Copy of commissioning letter from an appropriate body required in order to provide a legal basis for the provision of ONS data. Application to undergo internal information governance checks prior to re-submission</p>
2.6	<p><u>Department of Health – research study into variation in the intensity of care delivered to chronically ill patients in the last two years of life (Presenter: Dickie Langley) NIC-314521-S8M1Q</u></p> <p>Sean Kirwan declared a conflict of interests for this application and did not participate in the discussion.</p> <p>Application summary: This application was for pseudonymised, non-sensitive HES and sensitive, identifiable linked HES-ONS mortality data in order to support research into end of life care. The outcomes of the work would be used to provide advice to the Secretary of State for Health and inform wider departmental work on healthcare activity.</p> <p>Discussion: The applicant's security assurance was queried, and it was explained that the Department of Health did not completed the Information Governance (IG) Toolkit but that their system level security policy had been signed off by the relevant HSCIC team.</p> <p>The expected benefits of this work were discussed, and the Group queried whether the amount of data requested would be considered proportionate to the work described and the potential benefits. The Department of Health's statutory role was acknowledged and the Group recognised that the expected benefits of this use of data would be demonstrated through the Department's health policy role. It was stated that due to the unique nature of the Department of Health, this should not be considered a precedent for other organisations to make similar applications.</p> <p>The Group discussed how data would be accessed once it was held by the Department of Health, and it was noted that only one ONS data user was listed. It was suggested that the data sharing agreement should make it clear that the data could only be used for the purpose outlined in this application, and not for any additional purposes.</p> <p>It was noted that a signed commissioning letter was required from the Department of Health in order to provide a legal basis for access to ONS data, and the letter provided as part of the application form had not been signed. There were significant concerns about the provision of an unsigned letter as part of the application papers, and it was agreed that this would be fed back to the Department of Health.</p> <p>Outcome: Recommendation deferred pending sight of a signed authorisation letter from the Department of Health.</p>
2.7	<p><u>Competition and Markets Authority (Presenter: Dickie Langley) NIC-330916</u></p>

Application summary: This application was for HES data in order to analyse mergers or potential mergers of NHS trusts. It was noted that the applicant had previously had approval to receive this data, but the data had not been received before the data sharing agreement expired.

Discussion: Concerns were raised about the amount of data that had been requested in order to assess any number of possible future mergers as this was not felt to be proportionate, and it was suggested that it would be more appropriate if a more specific geographic dataset was requested for each potential merger when the Competition and Markets Authority was asked to assess them. There were also concerns that the purpose as currently outlined might not be considered to be consistent with the requirements of the Care Act 2014. The Group agreed that they would welcome back an application for a more limited dataset proportionate to the specific potential merger or mergers that would be assessed.

It was noted that the applicant's security assurance had not yet been reviewed by the relevant HSCIC team, and it was also noted that a query had been raised with the Data Access and Information Sharing team regarding the legal basis under the Health and Social Care Act 2012 but that this query had not yet been resolved. The members were concerned that this application had been brought to DAAG before these checks had been completed.

The applicant's DPA registration wording was discussed, and it was felt that this did not reflect the purposes for which data would be used.

Outcome: Unable to recommend for approval, as the application did not provide the key information required for DAAG to reach a recommendation. DAAG would welcome back an application relating to specific mergers requesting data proportionate to those proposed mergers, and would strongly recommend that the applicant's DPA registration wording should reflect the purposes for which data will be used.

2.8 Methods Insight Analytics (Presenter: Dickie Langley) NIC-330126-N1W7H

Application summary: This was a renewal application for the applicant to continue receiving monthly HES and Secondary Uses Service (SUS) data. This data would be used to support the organisation's work with NHS organisations by populating a quality variation tool and bespoke tools for individual NHS customers, as well as creating dashboards specifically for the Royal College of Surgeons and explorer tools that were publically available. A previous application for this data had been considered at the 18 November 2014 DAAG meeting, when it had been recommended for approval, and it was confirmed that no significant changes had been made to the application other than to amend the renewal dates.

Discussion: The applicant's DPA registration wording was discussed, as it was not thought that this made it clear that the applicant would handle health data for individuals with no connection to the organisation. In addition, a reference to a dashboard that was planned to go live in December 2014 was queried, as it was not clear whether this had yet gone live or not.

A query was raised about a reference in the application to funding for the PET application and further details about this were requested, as well as confirmation of whether there were any non-NHS customers for the work described. It was suggested that more information on the outputs and expected benefits should be provided for future applications.

Outcome: Recommendation to approve subject to clarification of funding arrangements for the PET application, confirmation of whether there will be any non-NHS customers for the data, and subject to DPA registration wording being updated to reflect the work described.

2.15	<p><u>Nottinghamshire group application¹ (Presenter: Stuart Richardson)</u></p> <p>Application summary: This was a group application to renew the flow of non-sensitive SUS data identifiable at the level of NHS number (weakly pseudonymised) to support the commissioning of health services. This was under the section 251 support for stage one accredited safe havens, and requested data to the end of April 2015 or in line with any extension of the section 251 support. Nottinghamshire Health Informatics Service (NHIS) would act as data processor for the five clinical commissioning groups (CCGs), while each CCG would be the data controller for its own data. All the organisations had achieved satisfactory IG Toolkit scores and had appropriate DPA registrations; it was noted that NHIS was hosted by Sherwood Forest Hospitals Foundation Trust and was covered by their DPA registration.</p> <p>Discussion: The Group queried a reference to data being ‘temporarily stored’ by NHIS, and it was explained that this was because NHIS would act as data processor before passing the relevant processed data on to each CCG. It was agreed that the application form would be updated to clarify this point.</p> <p>Outcome: Recommendation to approve. Application to be updated to clarify the term ‘temporarily stored’.</p>
2.10	<p><u>North West Commissioning Support Unit (CSU) (Presenter: Stuart Richardson) NIC-301934-W2M5X</u></p> <p>Application summary: This application was to renew the flow of non-sensitive SUS data identifiable at the level of NHS number (weakly pseudonymised) to support the commissioning of health services. This was under the section 251 support for stage one accredited safe havens, and requested data to the end of April 2015 or in line with any extension of the section 251 support. Data would be processed by North West CSU and then transferred on to the relevant CCGs who had a legitimate relationship with the CSU. The CSU had recently undergone a merger, and its two predecessor organisations had both previously achieved satisfactory IG Toolkit scores.</p> <p>An error in the application form was noted, and it was agreed that this would be corrected.</p> <p>Discussion: A query was raised regarding the legitimate relationship process between CCGs and CSU which was managed by NHS England, and whether the overarching contract for that meant that data sharing contracts between the CCGs and the HSCIC would not be needed for this work. The Group confirmed that all CCGs who would be data controllers for this data would need to have an appropriate framework contract in place with the HSCIC, as they would be the organisations responsible for any data breaches that might take place. It was noted that as legitimate relationships were liable to change under the process managed by NHS England, the data sharing framework contracts would also need to change and it would be helpful if these two processes could be linked.</p> <p>It was noted that IG Toolkit scores and DPA registration details had not been provided for each CCG, and these were requested. The two IG Toolkit scores for the CSU’s predecessor organisations were discussed; it was noted that work was now underway to complete version 12 of the IG Toolkit, and that if the merged organisation did not achieved a satisfactory score then the data sharing agreement would lapse.</p> <p>Outcome: Recommendation to approve for CCGs that have a data sharing contract with the HSCIC in place, provided that they have satisfactory IG Toolkit scores and appropriate DPA</p>

¹ Rushcliffe CCG NIC-319730, Newark and Sherwood CCG NIC-319703, Nottingham North and East CCG NIC-319713, Nottingham West CCG NIC-319725, Mansfield and Ashfield CCG NIC-319663.

registrations. Unable to recommend approval for the CCGs without a data sharing contract in place, until such a time as one is in place.

2.9 NHS Kernow CCG (Presenter: Stuart Richardson) NIC-285141-Q1Q9V

Application summary: This application was to renew the flow of non-sensitive SUS data identifiable at the level of NHS number (weakly pseudonymised) to support the commissioning of health services. This was under the section 251 support for stage one accredited safe havens, and requested data to the end of April 2015 or in line with any extension of the section 251 support. The applicant had achieved a satisfactory IG Toolkit score and had an appropriate DPA registration although renewal of this was underway. The applicant was in the process of being moved to the new format HSCIC framework contract, and it was noted that no data would be provided until this move had been finalised.

Discussion: No concerns were raised regarding this application.

Outcome: Recommendation to approve

2.11 NHS Kingston CCG (Presenter: Stuart Richardson) NIC-310879-V3Q8Y

Application summary: This was an application to renew the flow of non-sensitive SUS data identifiable at the level of NHS number (weakly pseudonymised) to support the commissioning of health services. This was under the section 251 support for stage one accredited safe havens, and requested data to the end of April 2015 or in line with any extension of the section 251 support. The applicant had a satisfactory IG Toolkit score and an appropriate DPA registration.

Discussion: No concerns were raised regarding this application.

Outcome: Recommendation to approve

2.12 NHS Greenwich CCG (Presenter: Stuart Richardson) NIC-318686-B3X4L

Application summary: This application was also to renew the flow of non-sensitive Secondary Uses Service (SUS) data identifiable at the level of NHS number (weakly pseudonymised) to support the commissioning of health services. This was under the section 251 support for stage one accredited safe havens, and requested data to the end of April 2015 or in line with any extension of the section 251 support. The applicant had achieved a satisfactory IG Toolkit score, and DPA registration was in the process of being renewed as this was due to expire in April.

Discussion: The Group noted that the applicant's DPA registration wording currently stated that they were a Primary Care Trust, and it was agreed that the applicant would be made aware of this. The review of IG Toolkit scores was discussed, and it was noted that work was currently underway to update the IG Toolkit process.

Outcome: Recommendation to approve. Applicant to be advised of an error in their DPA registration wording.

2.13 NHS North East Essex CCG (Presenter: Stuart Richardson) NIC-324680-P1Z1W

Application summary: This application had previously been considered at the 24 February 2015 DAAG meeting, when the Group had been unable to recommend approval and had requested clarification about data flows. The application was to renew the flow of non-sensitive Secondary Uses Service (SUS) data identifiable at the level of NHS number (weakly pseudonymised) to

	<p>support the commissioning of health services. This was under the section 251 support for stage one accredited safe havens, and requested data to the end of April 2015 or in line with any extension of the section 251 support.</p> <p>The applicant had achieved a 65% IG Toolkit score, but this had been deemed satisfactory with an improvement plan in place. North East London CSU, who would act as data processor, had a satisfactory IG Toolkit score and both organisations had appropriate DPA registrations.</p> <p>Discussion: A query was raised about why North East London CSU had not been listed as a data processor on the application form; it was confirmed that this organisation would hold data on behalf of the CCG and the application form would be updated to reflect this.</p> <p>It was noted that a sentence on page six of the application form appeared to have been included in error, and it was agreed that this sentence would be removed.</p> <p>The Group requested that when an application had previously been considered, the papers provided should include the date of the meeting when it had previously been discussed.</p> <p>Outcome: Recommendation to approve subject to updating the application form to clearly list North East London CSU as a data controller and to correct the name of the CCG, as well as to delete a sentence that had been copied into page 6 in error.</p> <p>2.14 <u>NHS Mid Essex CCG (Presenter: Stuart Richardson) NIC-324840-B2B2S</u></p> <p>Application summary: As for the previous application this had previously been considered at the 24 February 2015 DAAG meeting, when the Group had been unable to recommend approval and had requested clarification about data flows. This application was also to renew the flow of non-sensitive Secondary Uses Service (SUS) data identifiable at the level of NHS number (weakly pseudonymised) to support the commissioning of health services. This was under the section 251 support for stage one accredited safe havens, and requested data to the end of April 2015 or in line with any extension of the section 251 support.</p> <p>The applicant had achieved an IG Toolkit score of 65%, which had been deemed satisfactory with an improvement plan in place, and the data processor North East London CSU had achieved a satisfactory score. Both organisations held an appropriate DPA registration.</p> <p>Discussion: It was agreed that the same sentence referred to for the previous application (NHS North East Essex CCG) would be removed. It was also agreed that the application form would be updated to list North East London CSU as a data processor.</p> <p>Outcome: Recommendation to approve subject to updating the application form to clearly list North East London CSU as a data controller and to delete a sentence that had been copied into page 6 in error.</p>
<p>3</p>	<p>Any other business</p> <p>The Group discussed the increasing workload pressures due to the number of applications awaiting consideration. A number of suggestions to help address this were discussed, including increasing the number of DAAG members, potentially devolving some decision making in future once a consistent system of precedents had been established, ensuring appropriate guidance was given to applicants and internal staff to improve the quality of applications, and ensuring applications went through the appropriate internal checks prior to being submitted to DAAG. There were concerns around the possibility of devolving some decision making or considering more applications out of committee, and it was agreed that it might be more appropriate for this to be discussed again at a later date.</p>

	<p>Action: Acting DAAG Chair to request an update on how DAAG guidance materials can be shared with applicants and internal staff.</p>
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	<p>An applicant had requested clarification of DAAG's recommendation for their application, and it was agreed that the query would be circulated along with the relevant section of meeting minutes.</p>
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	<p>It was noted that Karen Myers would shortly leave the DAAG Secretariat team, and DAAG offered their thanks for her work to date.</p>
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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	<p>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.</p> <p>27/01/15: Ongoing.</p> <p>03/02/15: A briefing paper had been drafted and would be shared by email following clarification regarding HDIS extracts.</p> <p>10/02/15: Clarification had not yet been received.</p> <p>17/02/15: Ongoing.</p> <p>24/02/15: Ongoing.</p> <p>03/03/15: Ongoing.</p> <p>10/03/15: Ongoing. Alex Bell to request an updated from Garry.</p> <p>17/03/15: Ongoing.</p>	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	<p>27/01/15: This discussion had been scheduled, and details would be fed back to DAAG.</p> <p>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.</p> <p>10/02/15: Discussions had taken place about making changes to how information would be added to application forms.</p> <p>17/02/15: Ongoing.</p> <p>24/02/15: Ongoing.</p> <p>03/03/15: Ongoing.</p> <p>10/03/15: Ongoing.</p> <p>17/03/15: An update was requested on when the next planned update of the application form was scheduled to take place.</p>	Open
24/02/15	DAIS team to discuss the approach to local patient identifiers (LOPATID) with HRA CAG.	Diane Pryce	<p>03/03/15: Discussions were taking place with HRA CAG, and the response would be fed back to a future DAAG meeting.</p> <p>10/03/15: An initial response had been received and this would be shared with</p>	Open

			DAAG members for information. 17/03/15: Ongoing.	
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 NHS number and data that is identifiable by postcode.	Diane Pryce	03/03/15: Discussions were taking place with HRA CAG, and the response would be fed back to a future DAAG meeting. 10/03/15: An initial response had been received and this would be shared with DAAG members for information. A further query had been raised and discussions were ongoing. 17/03/15: Ongoing.	Open
03/03/15	DAAG members to discuss the current recommended consent wording.	Alan Hassey	10/03/15: Ongoing. 17/03/15: It was agreed that this would be discussed at the DAAG training day on 25 March 2015.	Open
17/03/15	Acting Chair to request an update on how DAAG guidance materials can be shared with applicants and internal staff.		17/03/15: Action completed prior to the end of the meeting.	Closed