

Data Access Advisory Group (DAAG)

Minutes of meeting held 13 April 2015

Members: Alan Hassey, Eve Sariyannidou, John Craven, Dawn Foster

In attendance: Frances Hancox, Alex Bell, Nicola Mallender-Ward, Victoria May, Paul Arrowsmith, Garry Coleman, Stuart Richardson, Paula Moss, Dave Cronin

Apologies: Sean Kirwan, Patrick Coyle

1	<p>Review of previous minutes and actions</p> <p>The minutes of the 7 April 2015 meeting were reviewed and agreed as an accurate record. Action updates were provided (see table on page 6).</p> <p>Out of committee recommendations</p> <p>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 fulfilled:</p> <ul style="list-style-type: none">• University of Manchester (NIC-252254-F6T9V)• CPRD (NIC-326073-Z0M3Q)
2	<p>Data applications</p> <p>2.1 <u>Public Health England - Cancer Registry (Presenter: Garry Coleman) NIC-332566-K2H4G</u></p> <p>Application summary: This application was to extend and renew an existing agreement for the applicant to receive identifiable, sensitive Diagnostic Imaging Dataset (DID) data. An earlier application for this data had been considered by DAAG on 22 October 2014 (application reference NIC-297344-D6J1W), then subsequently recommended for approval out of committee and reported in the 23 December 2014 DAAG minutes. The data would be used to support cancer registration and to support investigations into the use of GP direct access and the diagnosis, care and treatment of patients.</p> <p>DAAG were informed that discussions were underway between the HSCIC and Public Health England regarding a draft Memorandum of Understanding (MoU) that would enable the flow of data to Public Health England without the need for separate data sharing agreements. However as the MoU had not yet been signed, the data requested in this application was currently planned to flow under the existing agreement.</p> <p>Discussion: DAAG queried how this application had changed since it was previously considered, as when the application had been considered on 22 October 2014 DAAG had been unable to recommend approval. It was clarified that following that meeting, additional information had been provided and the application had subsequently been recommended for approval out of committee, and that the current application had not changed significantly from that version of the previous application. The legal basis for the requested flow of data was queried, and it was confirmed that the legal basis was Regulation 2 of the Health Service (Control of Patient Information) Regulations 2002.</p> <p>Concerns were raised regarding the applicant's version 12 Information Governance (IG) Toolkit score, as this had been self-assessed as not satisfactory. It was agreed that confirmation would be</p>

sought from the HSCIC External IG Delivery team of whether this had been reviewed and whether an agreed improvement plan was in place.

A query was raised regarding the statement that the applicant would not have one specific processing address for the data received. It was explained that the data would be processed at multiple Public Health England offices, but would only be accessible through a secure N3 connection. It was noted that this application included the requirement for the applicant to continue to hold previously received DID data, from 2012 onwards, and DAAG noted the need to ensure that historic data would be appropriately disposed of once this ceased to be required.

Outcome: Recommendation to approve subject to confirmation from the External IG Delivery team that an agreed plan is in place for remediation of the applicant's IG Toolkit score.

Note: This confirmation was provided prior to the end of this meeting, and the application was therefore recommended for approval.

DAAG requested sight of the draft MoU as well as clarification of their role, if any, in such data releases.

Action: Garry to raise with the DARS team that DAAG have requested sight of the draft MOU between the HSCIC and Public Health England.

2.2 Public Health England - Centre for Infectious Disease Control and Surveillance (Presenter: Garry Coleman) NIC-290817-T6R4D

Application summary: This was a new application for identifiable, sensitive Hospital Episode Statistics (HES) data in order to support the applicant's functions relating to the surveillance, control and prevention of respiratory diseases. It was noted that in future the requested flow of data would also be expected to fall under the MoU referred to above.

Discussion: A query was raised regarding the data requested, as the application summary stated that this include pseudonymised, non-sensitive data as well as identifiable data. It was clarified that some elements of the HES data requested were pseudonymised, but that these would be linked to identifiable sensitive data and the dataset as a whole was therefore considered to be identifiable.

DAAG noted that the legal basis for this flow of data would be Regulation 3 of the Health Service (Control of Patient Information) Regulations 2002¹, and suggested that given the extensive amount of data requested the application should have more clearly explained that data was required as part of the organisation's statutory functions. It was agreed that the application summary would be updated to clarify that the data requested would be used to support Public Health England's statutory functions.

As with the previous application there were some concerns regarding the applicant's IG Toolkit score, and it was agreed that further information would be requested.

Outcome: Recommendation to approve subject to confirmation from the External IG Delivery team that an agreed plan is in place for remediation of the applicant's IG Toolkit score.

Note: This clarification was provided prior to the end of this meeting, and the application was therefore recommended for approval.

¹ **Update 30/04/15:** These minutes previously erroneously referred to Regulation 2. This has now been corrected to state that the legal basis for this flow of data (NIC-290817-T6R4D) is Regulation 3 of the Health Service (Control of Patient Information) Regulations 2002.

2.3	<p><u>University College London - Mortality outcome in the London COPD cohort (Presenter: Garry Coleman) NIC-321523-F3W6D</u></p> <p>Application summary: This application had previously been considered at the 17 March 2015 meeting, when DAAG had been unable to recommend approval. Further information had been requested regarding the renewal of support under section 251 of the NHS Act 2006 and regarding fair processing activities, and this additional information had now been provided.</p> <p>Discussion: DAAG noted that the applicant's section 251 support had now been renewed, although it was noted that the application summary incorrectly referred to the date of the final approval letter. It was agreed that most concerns previously raised regarding this application had now been addressed, but it had previously been recommended that this application should be reviewed internally by the HSCIC Data Access and Information Sharing (DAIS) team and this had not yet taken place. In addition, it was noted that while the applications version 11 IG Toolkit score was satisfactory, an updated version 12 score had not been provided.</p> <p>Outcome: Recommendation to approve subject to confirmation from the DAIS team that there are no additional concerns regarding this application, and subject to the confirmation of a satisfactory version 12 IG Toolkit score.</p>
2.4	<p><u>University of Birmingham - Cohort study of mortality and cancer incidence in UK oil refinery and petroleum distribution workers (Presenter: Garry Coleman) NIC-324388-L6C2Q</u></p> <p>Application summary: This application was to renew an existing agreement for the applicant to receive Personal Demographics Service (PDS), ONS mortality and cancer registration data for a specific cohort. The data would be used as part of research into whether occupational exposures in the industry had any deleterious effects on serious medical conditions. The applicant had previously received identifiable data supported by section 251, but this identifiable data had now been deleted by the applicant and pseudonymised data would be provided instead. DAAG were informed that the applicant had made a request to the Information Commissioner's Office (ICO) to update their Data Protection Act (DPA) registration wording, but that this had not yet been completed.</p> <p>Discussion: DAAG queried what Office for National Statistics (ONS) mortality data the applicant would receive, and whether this was appropriately covered by the applicant's Approved Researcher status. It was agreed that the DAIS team would confirm whether there were any outstanding concerns regarding the approval for the applicant to receive ONS data.</p> <p>The pseudonymisation process was queried, and it was confirmed that the HSCIC would hold the key for the pseudonymised identifiers and the applicant would not be able to identify individuals from the data provided. It was noted that members of the study cohort were flagged on PDS.</p> <p>A query was raised regarding the expected benefits of this research. It was noted that this was a long term study that had commenced some decades previously and a number of publications about the study so far had already appeared in medical journals, on topics such as evidence of an occupational cancer hazard for mesothelioma in oil refinery workers. The applicant intended to make further publications including in an open-access medical journal that could be viewed online.</p> <p>Outcome: Recommendation to approve subject to confirmation from the DAIS team that there are no outstanding concerns relating to the ONS approval.</p> <p>Action: Garry Coleman and Dawn Foster to discuss the process for applications requesting access to ONS data.</p> <p>A query was raised regarding how the renewal of stage 1 accredited safe haven (ASH)</p>

	<p>applications would be managed, and it was agreed that this would be raised internally.</p>
2.5	<p><u>North East London commissioning support unit (CSU) invoice validation (Presenter: Stuart Richardson) NIC- 301858-Z4C7Z</u></p> <p>Application summary: This was a new application for the flow of non-sensitive Secondary Uses Service (SUS) data identifiable at the level of NHS number (weakly pseudonymised) into the applicant's Controlled Environment for Finance for the purpose of invoice validation, supported by section 251. It was noted that the applicant had achieved a satisfactory version 11 IG Toolkit score and held an appropriate DPA registration.</p> <p>Discussion: DAAG noted that version 12 IG Toolkit scores had not been provided, and asked for this to be updated on the application summary.</p> <p>It was noted that the data controllers for the data provided would be the clinical commissioning groups (CCGs) with a legitimate relationship with the CSU, as managed by NHS England. References in the application summary to the stage 1 ASH status of the CCGs were queried, and it was noted that the status of the CCGs was not relevant for this application as the data provided would only be processed within the CSU Controlled Environment for Finance. It was agreed that the application would be updated to remove references to the stage 1 ASH status of CCGs. However it was also noted that a number of the CCGs listed did not currently appear to have a data sharing framework contract in place with the HSCIC, and data would not be released until this was in place.</p> <p>Outcome: Recommendation to approve subject to the confirmation of a satisfactory version 12 IG Toolkit score and subject to minor corrections to the application summary.</p>
2.6	<p><u>Northern, Eastern and Western Devon CCG risk stratification (Presenter: Stuart Richardson) NIC-276358-G5Q2Y</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) for use in risk stratification, covered by the section 251 support for the disclosure of commissioning datasets for risk stratification. The applicant had achieved a satisfactory IG Toolkit score under version 11 and held an appropriate DPA registration, although it was noted that a version 12 IG Toolkit score had not been provided.</p> <p>Discussion: DAAG queried how GPs would access data for the patients registered to their practice, and it was confirmed that this would be managed via smartcards.</p> <p>Outcome: Recommendation to approve subject to the confirmation of a satisfactory version 12 IG Toolkit score.</p>
2.7	<p><u>North East London CSU risk stratification (Presenter: Stuart Richardson) NIC-320932-F6C3S</u></p> <p>Application summary: This application was also to renew the flow of non-sensitive SUS data identifiable at the level of NHS number (weakly pseudonymised) for use in risk stratification, covered by the section 251 support for the disclosure of commissioning datasets for risk stratification. It was noted that the CCGs with a legitimate relationship with the CSU, as managed by NHS England, would act as data controllers for their own data. DAAG were informed that due to an error the application form was missing the statement that it would be ensured that the IG toolkit score and DPA registration of all organisations were valid prior to data being disclosed, and the application would be amended to include that statement.</p>

	<p>Discussion: It was confirmed that GP access to data for the patients registered to their practice would be managed via smartcards, and it was suggested that it would be helpful if this could be specified on applications in future. A reference to the stage 1 ASH status of the CCGs was queried, and it was confirmed that this was not relevant to this application as the CCGs would not receive any identifiable data.</p> <p>Outcome: Recommendation to approve subject to the confirmation of a satisfactory version 12 IG Toolkit score.</p> <p>2.8 <u>South East CSU stage 1 ASH (Presenter: Stuart Richardson) NIC-291393-B5R8B</u></p> <p>Application summary: This application was to renew to renew the flow of non-sensitive SUS data identifiable at the level of NHS number (weakly pseudonymised) to a CSU under the section 251 support for stage 1 ASH. CCGs with a legitimate relationship with the CSU, as managed by NHS England, would act as data controllers and it was noted that those CCGs that were a stage 1 ASH would receive a copy of the identifiable data, whereas those CCGs that were not a stage 1 ASH would only receive aggregated outputs.</p> <p>It was noted that version 12 IG Toolkit scores had not been provided. The CSU held an appropriate DPA registration, but it was noted that for a number of the CCGs with a legitimate relationship with the CSU their DPA registration had not been confirmed and this would need to be clarified prior to data disclosure.</p> <p>Discussion: There were concerns that a number of the CCGs listed had not achieved a satisfactory version 11 IG Toolkit score, and it was noted that the application summary would be updated to include version 12 IG Toolkit scores. Updated DPA registration details would also be provided, and it was agreed that it would need to be confirmed that these were valid before any data could be disclosed.</p> <p>Outcome: Recommendation to approve subject to updating the application summary table of CCG details to ensure all DPA registrations are up to date and version 12 IG Toolkit scores are reflected.</p> <p>Action: DAAG Secretariat to notify DARS team that all applications should now include version 12 IG Toolkit scores rather than version 11.</p>
<p>3</p>	<p>Any other business</p> <p>DAAG had been asked to discuss the consent materials for the SCOT Trial (NIC-323893-J8B4H), but it was noted that the correct version of the consent materials had not been provided and the discussion was therefore postponed.</p> <p>There was a discussion about data access requests from the SIGGAR/SOCCER studies at Imperial College London. DAAG members felt that any application from Imperial College relating to SOCCER and SIGGAR was extremely unlikely to be recommended for approval through DAAG at the current time. DAAG expressed concerns around the lack of fair processing information, the fact that the applicant did not have an IG Toolkit score, and that their Section 251 cover for SIGGAR had lapsed. DAAG also wished to express concerns that there may not be an adequate legal basis for the applicant to continue to hold data for these studies and will write to the SIRO to ask if he would wish to consider issuing a data destruction notice for these studies.</p> <p>Action: Acting DAAG Chair to write to HSCIC SIRO regarding SIGGAR/SOCCER studies at Imperial College London.</p>

Summary of Open Actions

Date raised	Action	Owner	Updates	Status
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.	Garry Coleman	<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> <p>25/03/15: Ongoing.</p> <p>31/03/15: Ongoing.</p> <p>07/04/15: Ongoing.</p> <p>13/04/15: DAAG requested an update on when the application form was next scheduled to be updated, and Garry Coleman agreed to seek clarification on this point.</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 DAAG members for information.</p> <p>17/03/15: Ongoing.</p> <p>25/03/15: Ongoing.</p> <p>31/03/15: Ongoing.</p> <p>07/04/15: Ongoing.</p> <p>13/04/15: Ongoing.</p>	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 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. 25/03/15: Ongoing. 31/03/15: Ongoing. 07/04/15: Ongoing. 13/04/15: Ongoing.	Open
25/03/15	Dawn Foster and Eve Sariyannidou to update the recommended consent wording following discussions at 25 March training day.	Dawn Foster	31/03/15: Ongoing. 07/04/15: Ongoing. 13/04/15: Email discussion was underway regarding the draft wording. It was suggested that it would not be possible to specify one recommended phrase that could be used for all studies, but that advice could be given on the type of wording that would best fit a range of different scenarios. It was also suggested that the guidance on consent should be dated and version controlled, to ensure that if advice changed in future then it would be possible to determine whether applicants had followed the appropriate advice at the time when they had sought consent.	Open
25/03/15	DAAG dashboard to be updated to include recommendation themes, the number of times applications are considered by DAAG and a breakdown of recommendations by applicant type (academic, NHS trust, commissioning organisation, commercial organisation).	Alex Bell	31/03/15: Ongoing. 07/04/15: Ongoing. 13/04/15: It was agreed that an updated dashboard would be provided for the next training session, and DAAG asked for a copy to be circulated prior to the meeting.	Open
07/04/15	DAAG Secretariat to include discussion of ONS approval process on a future DAAG training day agenda.	DAAG Secretariat	13/04/15: It was agreed that an update would be provided at the 5 May training session.	Closed
07/04/15	DAAG members to provide feedback on National OG Cancer Audit application (NIC-303776) by email.	Acting DAAG Chair	13/04/15: DAAG members were reminded to provide feedback on this application, although it was noted that one set of comments had been emailed directly to the application presenter.	Open

13/04/15	Garry to raise with the DARS team that DAAG have requested sight of the draft MOU between the HSCIC and Public Health England.	Garry Coleman		Open
13/04/15	Garry Coleman and Dawn Foster to discuss the process for applications requesting access to ONS data.	Dawn Foster		Open
13/04/15	DAAG Secretariat to notify DARS team that all applications should now include version 12 IG Toolkit scores rather than version 11.	DAAG Secretariat		Open
13/04/15	Acting DAAG Chair to write to HSCIC SIRO regarding SIGGAR/SOCCER studies at Imperial College London.	Acting DAAG Chair		Open