

Data Access Advisory Group (DAAG)

Minutes of meeting held 14 July 2015

Members: Alan Hassey (Acting Chair), Eve Sariyannidou, Joanne Bailey, Patrick Coyle, Sean Kirwan

In attendance: Frances Hancox, Stuart Richardson, Paula Moss, Julia King, Diane Pryce, Steve Hudson, Gaynor Dalton, Dickie Langley, Dave Cronin, Garry Coleman

Apologies: John Craven, Dawn Foster

1	<p>Review of previous minutes and actions</p> <p>The minutes of the 7 July 2015 meeting were reviewed and a minor correction was raised. Subject to this amendment the minutes were agreed as an accurate record.</p> <p>Action updates were provided (see table on page 8).</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">• NIC-351522-Y6W3L Health and Safety Laboratory• NIC-341598-H3G7P University of Cambridge• NIC-356143-V5D7L UK Biobank• NIC-363128-Z8X5U ICON Health Economic
2 2.1 and 2.2	<p>Data applications</p> <p><u>Luton Clinical Commissioning Group (CCG) - Invoice Validation (Presenter: Stuart Richardson)</u> <u>NIC-356458-R7D6T</u> and <u>Bedfordshire CCG - Invoice Validation NIC-349029-L0M9Y</u></p> <p>Application: These two applications were for the flow of non-sensitive Secondary Uses Service (SUS) data identifiable at the level of NHS number (weakly pseudonymised) into the applicants' Controlled Environment for Finance for the purpose of invoice validation, supported by section 251. It was noted that North East London Commissioning Support Unit (CSU) would act as a landing point for the data for both CCGs. The organisations involved had achieved satisfactory Information Governance (IG) Toolkit scores and held appropriate registrations under the Data Protection Act 1998 (DPA). DAAG were informed that the Bedfordshire CCG application incorrectly referred to requesting sensitive data, and in fact only non-sensitive data was requested.</p> <p>Discussion: DAAG noted that work was underway to update the applicants' fair processing materials in line with the Information Commissioner's Office (ICO) Privacy Notices Code of Practice and advice from the HSCIC, and queried how soon this work would be complete. It was agreed that an update would be provided to DAAG within two months. The website structures used when publishing privacy notices was discussed, and DAAG noted the importance of ensuring that fair processing information was accessible to the general public and easy to find on CCG websites.</p> <p>A reference to 'meeting commissioning objectives without compromising patient confidentiality' was queried, and it was suggested that it would be more accurate to instead refer to reducing the risk to patient confidentiality. A query was raised regarding the section 251 support letters from the Health Research Authority Confidentiality Advisory Group (HRA CAG) relating to these</p>

	<p>applications, and it was noted that these were available to members on the DAAG SharePoint site.</p> <p>Outcome: Recommendation to approve. Stuart Richardson to provide evidence within two months of work in progress for the CCGs to meet their fair processing obligations to make information accessible, in line with the ICO's Privacy Notices Code of Practice and with advice from the HSCIC.</p>
2.3	<p><u>Bedfordshire CCG - Risk Stratification (Presenter: Stuart Richardson) NIC-348707-N0X2Z</u></p> <p>Application: This application was to renew the flow of non-sensitive SUS data identifiable at the level of NHS number (weakly pseudonymised) covered by the section 251 support for the disclosure of commissioning datasets for risk stratification. Data would flow via the North East London CSU as a landing point, and it was noted that MedeAnalytics would then act as a data processor to facilitate risk stratification. All organisations involved held appropriate DPA registrations and satisfactory IG Toolkit scores.</p> <p>Discussion: As with the previous application from this CCG it was noted that work was underway to update the applicant's fair processing notice, and DAAG requested an update on this within two months.</p> <p>The wording of the specific outputs section of the application summary was queried, as it was suggested that stating that the output from the risk stratification tool was limited to aggregate reporting could be misleading. DAAG suggested that this wording should be amended to clarify that aggregate reporting would be provided to the CCG, while GPs would be able to access identifiers for patients registered to their practice.</p> <p>DAAG discussed the expected benefits described, and suggested that for future renewal applications information should be provided about the benefits that had already been achieved through the use of data previously provided.</p> <p>A query was raised regarding the caveats to DAAG's recommendation from when this application was previously considered in November 2014, and it was confirmed that both caveats had been met.</p> <p>Outcome: Recommendation to approve. In future DAAG would like to see evidence of benefits and impact achieved to date, rather than aspirational statements of future benefits. Stuart Richardson to provide evidence within two months of work in progress for the CCG to meet their fair processing obligations to make information accessible, in line with the ICO's Privacy Notices Code of Practice and with advice from the HSCIC.</p>
2.4	<p><u>NHS Herts Valleys CCG - Stage One ASH (Presenter: Stuart Richardson) NIC-350318-T4Z0H</u></p> <p>Application: This application was to renew the flow of non-sensitive SUS data identifiable at the level of NHS number (weakly pseudonymised), covered by the section 251 support for stage one accredited safe havens (ASH) to support the commissioning of health services. Data would flow via the North East London CSU as a landing point, and through the data processor MedeAnalytics. The organisations held appropriate DPA registrations and satisfactory IG Toolkit scores. It was noted that since the application summary had been issued to DAAG, the applicant had provided an updated draft fair processing notice that included reference to data linkage.</p> <p>Discussion: DAAG discussed the applicant's fair processing information, and suggested that it would be helpful if the language used could be reviewed to ensure that it could be understood by the general public. It was agreed that the structure of this notice appeared more straightforward and easy to follow than some other fair processing notices had been. However, there were concerns regarding the statements made about sharing data with non-NHS organisations, as in</p>

	<p>particular it was felt that a statement that health information would not be disclosed without explicit consent was incorrect and misleading. It was suggested that it would be helpful for the fair processing notice to distinguish between data shared for the purpose of direct patient care and data shared for secondary purposes.</p> <p>Outcome: Recommendation to approve subject to fair processing materials being updated to remove misleading references to not sharing data without explicit consent, and to clearly state that a commercial organisation will act as data processor. Fair processing materials should be updated in line with the ICO's Privacy Notices Code of Practice and with HSCIC advice.</p>
2.5	<p><u>Prescribing Services Ltd (Presenter: Dave Cronin) NIC-313914-X6B9F</u></p> <p>Application: This application was to extend and renew an existing agreement for the applicant to receive monthly extracts of pseudonymised, non-sensitive SUS PbR data, and it was noted that although this was a renewal the application had not previously been considered by DAAG.</p> <p>Discussion: DAAG expressed surprise at the suggestion that this application might not have been brought to DAAG, particularly given the commercial aspects of the work described and the need to ensure that this was compatible with the requirements of the Care Act 2014. It was agreed that more information was required about the commercial aspects of the application.</p> <p>Queries were raised regarding the organisations listed as 'partners' on the applicant's website, including GP system suppliers such as EMIS and TPP, and what level of cooperation there was with these organisations – for example, whether any general practice prescribing data was supplied that would be linked with the SUS data provided by the HSCIC and whether this could lead to the pseudonymised SUS data being re-identified. It was agreed that more evidence was required of how data had previously been used with these partner organisations and what benefits to healthcare had been derived. Significant concerns were raised that the application summary did not appear to accurately describe any data already held by the applicant that would be used in conjunction with the SUS data requested.</p> <p>The request for the full SUS dataset was queried, as justification had not been provided for why data for the whole country was required. In addition, DAAG queried the lack of a fair processing notice on the applicant's website and suggested that this might be required if the applicant were using identifiable data from other sources.</p> <p>DAAG agreed that given the concerns raised, an update on this application should be provided within four weeks and the HSCIC SIRO would be contacted to suggest that he consider halting any further flow of data.</p> <p>Outcome: Unable to recommend for approval. Further information was required about the data the applicant already held from other sources and any planned linkage, any partner organisations and their involvement, and the commercial aspects of this application as well as a clear justification for why data for the whole of England is required. DAAG members expressed considerable concerns regarding this application, and in view of those concerns recommended that the HSCIC SIRO should consider halting any further data flow under this agreement with immediate effect.</p>
2.6	<p><u>University Hospitals Bristol NHS Foundation Trust (Presenter: Dave Cronin) NIC-319738-F3W3L</u></p> <p>Application: This application had previously been considered by DAAG a number of times, most recently on 30 June 2015 when a recommendation had been deferred due to requesting additional information on honorary contract arrangements, fair processing, and approvals for the use of Office for National Statistics (ONS) mortality data.</p>

Discussion: Additional information on honorary contract arrangements had been provided out of committee, and it was agreed that this point had now been addressed.

A query was raised regarding the legal basis for receipt of ONS data, as it was thought that the position on this might have changed since the application was previously considered, and it was agreed that confirmation of this would be sought from the Data Access and Information Sharing (DAIS) team within the HSCIC.

DAAG requested sight of the fair processing wording that the applicant intended to publish online, and it was agreed that this would be considered out of committee.

Outcome: Recommendation to approve subject to confirmation of the legal basis for receipt of ONS data, and subject to making fair processing information available to DAAG members for review out of committee.

2.7

Royal College of Physicians on behalf of HQIP- Sentinel Stroke National Audit Programme (Presenter: Gaynor Dalton) NIC-288067-G1D5K

Application: This application was to extend and renew an existing agreement for the applicant to receive identifiable HES and ONS mortality data for the Sentinel Stroke National Audit Programme cohort as well as other stroke patients. The Royal College of Physicians and Net Solving Ltd would both act as data processor on behalf of the data controller Healthcare Quality Improvement Partnership (HQIP), with Net Solving providing servers and software for the audit.

Discussion: DAAG expressed their support for this audit. However, questions were raised about the legal basis for the provision of HES data; section 251 support had been listed in the application summary, but it was noted that the section 251 support letter from HRA CAG referred to obtaining patient consent at a six month follow-up assessment. It was therefore unclear if the section 251 support covered all patients within the cohort, or only those who had not yet reached the six month follow-up assessment.

Some of the wording in the aphasia patient leaflet was queried, as it was felt that a reference to 'only selected people at each hospital' accessing data could be misleading as not all staff involved in the audit would be hospital-based. In addition, DAAG queried whether the updated patient information leaflet provided was now being used with patients or if not, when this would come into use. It was suggested that listing name, date of birth, postcode and NHS number under the heading 'What confidential information is collected' could be taken to mean that no other confidential data would be shared.

DAAG queried a statement in the application summary that HQIP had committed to provide IG Toolkit scores or equivalent 'on behalf of its data processors', and requested that this wording be clarified. Clarification was requested of a reference in the application summary to Public Health England linking data, as it was unclear whether Public Health England should therefore be listed as a data processors. In addition, DAAG suggested that the application summary should be amended to more clearly distinguish between patients within the audit cohort and other stroke patients.

Outcome: Unable to recommend for approval, as confirmation was required from the HRA CAG Secretariat of whether the applicant's section 251 support covers patients from six months post discharge onwards. The application summary should be updated to more clearly differentiate between the patients with an audit ID and other stroke patients, to clarify whether Public Health England act as data processors, and to clarify a reference to HQIP providing IG Toolkit scores on behalf of its data processors. A statement in one patient information leaflet that 'only selected people at each hospital' could access data should be clarified.

2.8	<p><u>Royal College of Physicians on behalf of HQIP – National Hip Fracture Database (Presenter: Gaynor Dalton) NIC-312474-H5Q0T</u></p> <p>Application: This was a new application for pseudonymised HES data, identifiable ONS mortality data and list cleaning. The Royal College of Physicians, Royal College of Surgeons Clinical Effectiveness Unit and Crown Informatics Ltd would act as data processors on behalf of HQIP in order to support this hip fracture audit.</p> <p>Discussion: It was noted that a commissioning letter from NHS England had been provided to confirm support for receipt of ONS mortality data under section 42(4) of the Statistics and Registration Act 2007, but that this letter was not on NHS England letter-headed paper.</p> <p>The proposed flow of data to Wales was queried, and it was confirmed that this was included in the applicant's amended section 251 support. A reference to 'PCT-run rehabilitation units' was queried, and it was suggested that this wording should be updated. There was a query regarding the flow of data from hospitals in Northern Ireland, but it was noted that this was not within DAAG's remit.</p> <p>The applicant's fair processing materials were discussed, and it was agreed that a statement in the application summary that the 'patient information leaflet does not mention the data processing activities by HSCIC' should be removed as this had now been addressed in the updated leaflet. DAAG queried the applicant's DPA registration wording, and confirmation was requested that this was appropriate and covered health research.</p> <p>The description of the HES data as pseudonymised was questioned, as the Royal College of Physicians would be able to re-identify cohort members within the data, and while it was confirmed that section 251 support was in place for the data flows described DAAG emphasised the importance of using terminology in a consistent way.</p> <p>Outcome: Recommendation to approve subject to confirmation that the applicant holds an appropriate DPA registration, and subject to the provision of a commissioning letter on letter-headed paper.</p>
2.10	<p><u>University College London - Centre for Longitudinal Studies (Presenter: Dickie Langley) NIC-349413-F1J1N</u></p> <p>Application: This application based on section 251 support had previously been raised under Any Other Business at the 7 July 2015 DAAG meeting, and had now been brought back for DAAG's consideration. DAAG were informed that the applicant had already been approved to receive identifiable, sensitive NHS registration data (recommended for approval by DAAG on 9 December 2014) and an amendment was now requested to reflect the fact that the organisation had merged with University College London, and to add the National Centre for Social Research (NatCen) as an additional data processor.</p> <p>A number of queries had been raised by a DAAG member in between meetings, and the applicant's responses were provided. The data retention period incorrectly referred to 2017, and this would be amended to early 2016. The data storage of addresses had been queried, and it was confirmed that NatCen as well as the Centre for Longitudinal Studies would hold participant addresses to facilitate contact. References to participant contact had been queried; it was clarified that the Centre for Longitudinal Studies had contacted participants to provide information about the survey launch but that NatCen would make contact to invite them to participate in the survey. A query had been raised about whether NHS numbers were included in the applicant's section 251 support. It was confirmed that updated Research Ethics Committee approval had been obtained, that no ONS data was requested, and that no further data flows from the HSCIC to the Centre for Longitudinal Studies were requested as the applicant already held this data.</p>

Discussion: A query was raised regarding the inclusion of fact of death data, and whether this required ONS approval. It was clarified that fact of death was provided as part of the NHS registration data, whereas other mortality data such as date or cause of death would have been provided from ONS mortality data and would therefore have required ONS approval. DAAG noted the need to provide fact of death data to reduce the likelihood of causing distress by contacting families of deceased individuals.

It was agreed that as the DAAG member who had raised questions by email was not present at this meeting, confirmation should be requested that the responses provided were satisfactory.

Outcome: Recommendation to approve, subject to confirmation from a DAAG member that the comments they raised out of committee have been addressed.

2.9 IMS Health Technology Services (Presenter: Steve Hudson) NIC-324360-T8R3T

Application: This application had been considered by DAAG on 30 June 2015, when DAAG had been unable to recommend approval due to a number of concerns, including whether the commercial purposes described could be considered compatible with the requirements of the Care Act 2014. Additional information had now been provided about the customers that the applicant worked with and about the expected benefits to the health and social care system. The applicant had stated that the ratio of pharmaceutical customers, provider customers and joint industry customers was 6:3:3, with one CCG, one NHS acute trust and one private provider listed as the provider customers.

Discussion: Concerns were raised about the small number of NHS customers for this work, and whether this meant that the benefit to the NHS was not proportionate to the amount of data requested and the commercial services described. It was also felt to be unclear if there was any overlap between the three categories of customers listed, and for example whether the same CCG might have been counted in the provider category as well as the joint category. In addition, it was not clear which of the 'offerings' described were currently live.

DAAG queried some of the language used in the application summary and asked for phrases such as 'key opinion leader' and technical terminology to be clarified. DAAG noted that the application summary listed an expired DPA registration for the applicant, but it was confirmed that this was an administrative error and the registration had in fact been renewed.

Clarification had previously been requested about the relationship between IMS Health Ltd and IMS Health Technology Services, as it was noted that despite being two separate legal entities employees from IMS Health Ltd would be involved in processing data, and it was felt that this point had not been sufficiently clarified. DAAG queried statements in the application summary that industry customers would not use data for marketing purposes, and requested that this be amended to specify sales purposes as well as marketing.

Overall, it was felt that the queries previously raised by DAAG had not been sufficiently addressed and there remained concerns regarding compatibility with the requirements of the Care Act 2014.

Outcome: Unable to recommend for approval. Clarification was required about the responses provided to queries previously raised by DAAG.

2.11 University College London – Metal on metal hip prostheses (Presenter: Dickie Langley) NIC-344986

Application: This application had previously been considered by DAAG for advice on 30 June 2015. The application requested the creation of four datasets: National Joint Registry (NJR) data

	<p>linked with Clinical Practice Research Datalink data (CPRD), NJR linked with National Heart Failure Audit data, NJR linked with HES and NJR linked with ONS. DAAG had previously discussed the legal basis for this linkage and advised that consent would not be considered to provide an appropriate legal basis.</p> <p>Discussion: DAAG again reviewed the consent materials provided. A number of concerns were raised about potentially misleading statements in these materials such as the statement that participants would be asked for their approval before the registry shared any contact details, and that the majority of the research would use anonymised data ‘that means it is impossible to identify individuals’. Participant consent was therefore not considered to be an appropriate legal basis for the linkage requested.</p> <p>DAAG discussed the possibility that had previously been raised of whether a disclosure could be made on grounds of public interest and patient safety. The updated information provided was considered, and it was agreed that the applicant had not provided sufficient evidence to justify this. DAAG noted the importance of balancing the need to promote patient safety with the public interest in maintaining patient confidentiality and maintaining public confidence in the NHS and the HSCIC’s use of confidential data, particularly given that the study described included a comparator cohort of circa 400,000 patients who presumably would not directly benefit from the study.</p> <p>It was agreed that the applicant should be encouraged to seek section 251 support through the HRA CAG precedent set (fast track review) process, and given the importance of this work the Acting DAAG Chair agreed to support this as a matter of urgency.</p> <p>DAAG members were asked to provide any further comments on the application summary by email, so that key points could be addressed ahead of a potential future application following review by HRA CAG. DAAG requested justification for the size of the comparator cohort to ensure that this was not excessive, and clarification of references to individuals such as the President of the British Orthopaedic Association and whether these individuals would benefit from the study described.</p> <p>Outcome: DAAG recognised the importance of this piece of work, but were unable to recommend approval on the basis that the consent materials did not give an adequate legal basis for the HSCIC to provide the services requested. The applicant had failed to provide sufficient evidence to justify that the public interest to disclose data would outweigh the public interest to protect patient confidentiality and maintain public confidence in the NHS and the HSCIC to provide a confidential service. Therefore, DAAG strongly recommended that the applicant pursue the Precedent Set (fast track review) process for section 251 support through HRA CAG, and the Acting DAAG Chair would support this as a matter of urgency.</p>
<p>3</p>	<p>Any other business</p> <p>DAAG were informed that Andrew Maclaren, Director of Information and Analytics, had resigned from the HSCIC and Martin Severs, the HSCIC Caldicott Guardian, had been appointed as Acting Director of Information and Analytics.</p>

Summary of Open Actions

Date raised	Action	Owner	Updates	Status
24/02/15	Dawn Foster 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.	Dawn Foster	<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. A further query had been raised and discussions were ongoing.</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> <p>21/04/15: Ongoing.</p> <p>28/04/15: Ongoing.</p> <p>05/05/15: It was agreed that Dawn Foster would raise this separately with CAG.</p> <p>12/05/15: Clarification had been requested from NHS England regarding a particular request for both identifiers.</p> <p>19/05/15: Ongoing.</p> <p>27/05/15: Ongoing.</p> <p>02/06/15: Ongoing.</p> <p>09/06/15: Ongoing.</p> <p>30/06/15: No response had yet been received from NHS England, and a further reminder would be sent.</p> <p>07/07/15: It was agreed that if no response was received within a week then this application should be closed.</p> <p>14/07/15: Ongoing.</p>	Open
16/06/15	Garry Coleman to speak to Chris Roebuck regarding Public Health England's approach to fair processing.	Garry Coleman	<p>30/06/15: No update available.</p> <p>07/07/15: Ongoing. It was agreed that Steve Hudson would provide an update at the following meeting.</p>	Open

			14/07/15: Ongoing.	
30/06/15	DAAG Secretariat to notify HSCIC SIRO and Caldicott Guardian of DAAG's recommendation regarding this application (IMS Health Technology Services, NIC-324360-T8R3T).	DAAG Secretariat	07/07/15: Ongoing. 14/07/15: An updated application was scheduled for discussion at this meeting, and the action was closed.	Closed
07/07/15	Steve Hudson to provide DAAG Secretariat with contact details for the Disclosure Control Panel, and DAAG Secretariat to schedule discussion of the Disclosure Control Panel process for a future DAAG training session.	Steve Hudson	14/07/15: Ongoing.	Open