

Data Access Advisory Group (DAAG)

Minutes of meeting held 28 July 2015

Members: Alan Hassey (Acting Chair), Eve Sariyannidou, Sean Kirwan, Dawn Foster, John Craven

In attendance: Frances Hancox, Victoria Williams, Diane Pryce, Sophie Fletcher, James Salt, Dickie Langley, Steve Hudson, Garry Coleman

Apologies: Joanne Bailey, Patrick Coyle

1	<p>Review of previous minutes and actions</p> <p>The minutes of the 21 July 2015 meeting were reviewed and agreed as an accurate record.</p> <p>Action updates were provided (see table on page 7).</p> <p>DAAG requested an update on the process to update the application summary template, in line with an action raised earlier in the year.</p> <p>Action: Garry Coleman to provide an update on the process to update the application summary template.</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>Luton Clinical Commissioning Group (CCG) – Risk Stratification (Presenter: Sophie Fletcher) NIC-361611-Y4W8X</u></p> <p>Application: This application was to renew the flow of non-sensitive Secondary Uses Service (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. It was noted that DAAG had considered an application for this CCG to receive data identifiable by NHS number as a stage one accredited safe haven (ASH) at the 16 June 2015 meeting and had recommended that application for approval. North East London Commissioning Support Unit (CSU) would act as a landing stage to receive the data and then transfer it on to the CCG, but it was confirmed that the CSU would otherwise not process the data. MedeAnalytics would also act as data processor. All organisations held satisfactory Information Governance (IG) Toolkit scores and appropriate registrations under the Data Protection Act 1998 (DPA).</p> <p>Discussion: A link to the relevant section 251 letter was queried, and it was agreed that the link text should be updated to clarify that this was a link to a document stored on the DAAG SharePoint site. DAAG noted the expected future benefits, and expressed the hope that future renewal applications would be able to provide evidence of the benefits that had been delivered.</p> <p>A reference in the processing activities section of the application summary to the CCG receiving aggregated data from MedeAnalytics was queried, and it was agreed that this would be clarified.</p> <p>DAAG queried the wording for MedeAnalytics' DPA registration wording, as the section copied was not consistent with the wording provided for similar applications and it was felt that this did not</p>

	<p>appropriately cover the work described. It was agreed that this would be raised with MedeAnalytics to suggest that they should ask the Information Commissioner's Office (ICO) to update their registration wording.</p> <p>Outcome: Recommendation to approve. The application summary should be amended to clarify data flows, and MedeAnalytics should be contacted about the need to update their DPA registration wording.</p>
2.2	<p><u>Essex CCGs group application¹ - Stage one ASH renewal (Presenter: Sophie Fletcher)</u></p> <p>Application: This was a group application to renew the flow of non-sensitive SUS data identifiable at the level of NHS number (weakly pseudonymised) to five CCG stage one accredited safe havens. An application from these CCGs had previously been considered at the 21 July 2015 DAAG meeting but concerns had been raised due to the inclusion of a collaboration agreement to share data between the applicant CCGs, and therefore no data sharing between CCGs was included as part of the current application.</p> <p>It was noted that MedeAnalytics would act as a data processor for Basildon and Brentwood CCG and West Essex CCG, but not for the other CCGs included in this group application, while Castlepoint and Rochford CCG and Thurrock CCG would use North East London CSU as a landing point for the data and Southend CCG would use North East London CSU as a data processor. DAAG were informed that all organisations involved had achieved satisfactory IG Toolkit scores and held current DPA registrations.</p> <p>Discussion: The data flow diagram provided for Basildon and Brentwood CCG in particular was discussed, and while the diagram showed data identifiable at the level of NHS number flowing from MedeAnalytics back to the CCG the processing activities section of the application summary instead stated that data would instead be accessed on the MedeAnalytics system via NHS Smartcards. DAAG asked for the diagram to be amended to clarify this data flow.</p> <p>DAAG noted that the five applicant CCGs all had the same individual listed as the named contact. It was confirmed that this individual worked on behalf of all five CCGs, and it was agreed this should be made clearer in the application summaries.</p> <p>The planned data retention period wording was queried, as this differed from the wording used in similar applications; it was agreed this would be amended to be consistent with other applications.</p> <p>Outcome: Recommendation to approve. MedeAnalytics should be contacted about the need to update their DPA registration wording, the application summary should be amended to clarify data flows, the planned data retention period wording should be updated in line with DAAG's previous recommendations, and the applicant details should be amended to confirm that the named contact works on behalf of all the applicant CCGs.</p>
2.3	<p><u>University of Cambridge - European Prospective Investigation into Cancer (Presenter: Steve Hudson) NIC-321968-S4Q6L</u></p> <p>Application: At the 7 April 2015 meeting DAAG had considered an application for this applicant to receive identifiable Patient Demographic Service data, Office for National Statistics (ONS) mortality data and ONS cancer registration data for a long-term study cohort. That application had been recommended for approval subject to caveats, which had subsequently been met. The applicant had now requested Hospital Episode Statistics (HES) data in addition to the data already</p>

¹ Basildon and Brentwood CCG NIC-347011-K2C7K, West Essex CCG NIC-347039-J1Y3R, Castle Point and Rochford CCG NIC-347024-V8H6H, Thurrock CCG NIC-364370-D6Z4P, Southend CCG NIC-364551-S0N0K

received. DAAG were informed that the applicant's section 251 support had been amended to cover the use of HES data, and ONS had provided approval for the ONS data to be linked with HES data.

Discussion: DAAG discussed the additional data requested and agreed that this appeared to be justified. However it was unclear why HES data had not been included as part of the application for data in April, and clarification on this point was requested. The applicant's plans to disseminate outputs of this work were discussed, and additional evidence of dissemination was requested.

The applicant's DPA registration wording was discussed, and it was suggested that it might be appropriate for organisations using healthcare data to ensure that this was clearly reflected in their registration rather than just referring to undertaking research relating to health, as health research might not necessarily be considered to include the use of healthcare data such as HES. DAAG agreed that it would be helpful to discuss DPA registration wording at a future training session.

A query was raised regarding whether recruitment to the study cohort was ongoing, but this was not thought to be the case. DAAG queried a statement in the applicant's section 251 renewal letter that no changes had been made to the project, and it was agreed that the applicant should be asked to confirm that the revised application and their amended section 251 support were compatible. In addition, it was agreed that the application summary wording would be amended to clarify that ONS had given approval for ONS data to be linked with HES, but that the legal basis for HES data to be provided was under the applicant's section 251 support.

Outcome: Recommendation to approve subject to confirmation from the applicant that their section 251 support is consistent with the revised application. DAAG also requested better evidence of dissemination, clarification of why HES data had not been included as part of the previous application, and asked for the application summary wording to be amended to clarify that ONS approval had been given for the ONS data to be linked with HES.

2.4 Imperial College London - Practice level associations with joint replacement rates (Presenter: Dickie Langley) NIC-349023-R3Z1V

Application: This application was to receive pseudonymised, sensitive Patient Reported Outcome Measures (PROMs) data in order to investigate the associations between general practice level hip and knee joint replacement operation rates and a number of healthcare and population predictors. DAAG were informed that Clinical Practice Research Datalink (CPRD) general practice data would be used in combination with the data provided.

Discussion: DAAG queried how practice level analysis would be carried out and whether this could result in data being reidentified. It was felt to be unclear how data from other sources would be 'combined' with the PROMs data, as this was not clearly described in the application summary. DAAG asked for this to be clarified, and in particular queried what practice level data would be used and how PROMs data could be analysed at practice level.

A query was raised regarding whether joint replacement operations were also carried out in the private sector and if so whether this would be taken into account in the analysis.

The intention to retained data for only six months was queried, as DAAG noted that the applicant aimed to publish outputs in peer-reviewed journals and suggested that it might become necessary to retain data for longer in case of peer challenge. It was agreed that the applicant would be asked to confirm whether the stated data retention period was realistic.

Outcome: Unable to recommend for approval. Clarification was required of how the requested data would be used in combination with other data sources and whether this would increase the risk of reidentification, and in particular whether this involves the use of practice level data. In addition DAAG queried the intended six month data retention period and whether this was realistic.

2.5**Pathway Communications Ltd - Modelling patient pathways using Discrete Event Simulation (Presenter: Dickie Langley) NIC-310801-V3T5J**

Application: This was a new application for pseudonymised non-sensitive HES data for use in healthcare analytics, pathway simulation and hospital simulation. DAAG were informed that this work was funded by pharmaceutical companies, but that those companies had not imposed any conditions in relation to the outputs generated and that the beneficiaries of the work would be hospital trusts and CCGs. It was noted that the data storage address listed was owned by a different organisation, but that this organisation was not considered to be a data processor as the actual server within that building that would hold the data was owned and maintained by the applicant organisation.

Discussion: DAAG queried the role of the third party that was listed as a data storage address (UK Fast Campus). It was confirmed that although this organisation owned the building where data would be stored, they did not control the server on which data would be held and they would not act as a data processor. DAAG were informed that Pathway Communications staff would be able to access the data on that server from the processing address listed but that data would not be transferred and stored separately. The applicant's DPA registration wording was queried, as this stated that the applicant 'process personal information to enable us to provide health services to our patients' and it was suggested that this should be rephrased.

DAAG noted that the application summary did not clearly state whether or not this application was in any way commercial, and it was agreed that it should be considered commercial. Further explanation about the funding or sponsorship role of pharmaceutical companies was requested, as well as which companies specifically had provided funding for this work. The statement that pharmaceutical companies had funded this work but would not benefit from it was queried.

Concerns were raised regarding references on the applicant's website to the use of HES data, as it was felt that this implied the analysis could be used for sales and marketing purposes. In addition the small number of NHS customers listed was noted. The three different purposes listed in the application were discussed. DAAG noted that the first purpose, a healthcare analytics tool, did not yet have any NHS customers listed who intended to make use of this tool while another purpose, hospital simulation, did not provide a justification for why national data was required instead of using only local or regional data. Overall it was felt that the commercial aspects of the work described did not seem to be compatible with the requirements of the Care Act 2014.

Outcome: Unable to recommend for approval, on the basis that this application did not appear to be compatible with the requirements of the Care Act 2014 and was predominantly a commercial application. One purpose did not currently have any customers listed; one purpose was mostly funded by pharmaceutical companies who were not the apparent beneficiaries of the work, which appeared to contradict statements on the applicant's website; and for the third purpose it was unclear why national level data was required. A future application would need to provide clarification of where the applicant's data was stored and how it was accessed, with a list of any partner organisations and any health related data that they may hold, and how that data might be used or accessed by the applicant.

2.6**Local Authorities Public Health HES template (Presenter: Garry Coleman)**

Application: This updated template application was presented to DAAG for advice, following DAAG's consideration of a previous template at the 30 June 2015 meeting. It was intended that this template would be used for Local Authorities to apply for pseudonymised, non-sensitive HES data for use in fulfilling their public health responsibilities. The template had been amended based on DAAG's previous advice, but DAAG were informed that a number of Local Authorities no longer had a specific public health team as these functions were distributed throughout the organisation,

and this mean that the template could not state that data would only be used by public health teams.

Discussion: DAAG reiterated the need to ensure that the data provided could only be used to fulfil public health duties, and not to support Local Authorities' other statutory functions. It was agreed that while limiting use to public health teams might not be practical, application summaries and data sharing agreements should be worded to clearly state that data could only be used in fulfilment of a Local Authority's statutory public health duties. The possibility was raised that some public health functions might be carried out by other organisations, potentially including private companies, on behalf of Local Authorities and it was noted that data sharing agreements should restrict data from being shared outside the Local Authority itself.

An error in the template was noted, as the word 'not' had been omitted from a key sentence relating to sharing data with third parties.

DAAG discussed the approach to using a generic template for these Local Authority applications, and emphasised that there should be space on the template for specific local details to be included. Each Local Authority should provide information about the breadth of data requested and the justification for this based on the specific work that would be undertaken, and should also provide specific details of governance arrangements and how role based access controls would be implemented to ensure data could only be used in accordance with public health functions. It was suggested that due to the differences between Local Authorities it might be that some would not require national level data, and each Local Authority should provide an explanation for why national level data was required and how it would be used if they requested this.

It was suggested that confirmation should be sought of the minimum requirements for Local Authority public health functions, so that these minimum requirements could be reflected in the template application. Any additional requirements should be listed by each Local Authority with the justification for this, in order to ensure proportionality. The Acting DAAG Chair and the Head of IG agreed to meet with the Public Health England Data and Information Policy and Partnership Lead to discuss this.

DAAG raised the need to ensure that each Local Authority met their fair processing responsibilities by making information available to the general public about this use of healthcare data, and suggested that applicants should ensure their approach was consistent with the ICO's privacy notices code of practice.

Outcome: DAAG advised that the template should be updated to provide space for locally tailored information, including clarification for the breadth of data requested with justification for each Local Authority based on the specific functions that they would undertake. Applications would need to include governance details and how role based access controls will be implemented. Applicants should ensure their fair processing responsibilities are met in a way consistent with the ICO's privacy notices code of practice, and DAAG encouraged applicants to adopt an appropriately layered approach to fair processing.

Action: Acting DAAG Chair and Head of Information Governance to meet with the Public Health England Data and Information Policy and Partnership Lead, along with a senior member of the DARS team, to discuss Local Authority public health requirements for data.

2.7

Local Authority Public Health – Lincolnshire County Council (Presenter: Garry Coleman)

Application: This was an application for pseudonymised, non-sensitive HES data using the template discussed above.

Discussion: Concerns were raised that the applicant's fair processing notice did not describe the use of healthcare data.

	<p>Outcome: Unable to recommend for approval due to the comments raised in relation to the template, and concerns about the applicant's fair processing notice.</p>
2.8	<p><u>Local Authority Public Health – Leeds City Council (Presenter: Garry Coleman)</u></p> <p>Application: This was an application for pseudonymised, non-sensitive HES data using the template discussed above.</p> <p>Discussion: As for the previous application, concerns were raised that the applicant's fair processing notice did not describe the use of healthcare data.</p> <p>Outcome: Unable to recommend for approval due to the comments raised in relation to the template, and concerns about the applicant's fair processing notice.</p>
2.9	<p><u>Local Authority Public Health – Norfolk County Council (Presenter: Garry Coleman)</u></p> <p>Application: This was an application for pseudonymised, non-sensitive HES data using the template discussed above.</p> <p>Discussion: DAAG noted that the applicant had provided a draft update to their fair processing notice that would include the use of healthcare data, but there remained concerns that insufficient information was provided about how this data would be used.</p> <p>Outcome: Unable to recommend for approval due to the comments raised in relation to the template and concerns about the applicant's fair processing notice, although DAAG recognised that efforts had been made to address the use of health data in the updated notice.</p>
3	<p>Any other business</p> <p>DAAG members were informed that funding for DAAG and the successor group IGARD had been secured to the end of the 2015-16 financial year. It was noted that a new independent member had been invited to join DAAG, and would begin observing meetings from approximately mid-August onwards.</p> <p>The DAAG Secretariat had received a request for a student intern working within the HSCIC to observe a future DAAG meeting, and DAAG were asked to consider whether this would be appropriate. No concerns were raised, although the potential need for a non-disclosure agreement was discussed. The possibility of academic staff involved in research applications also observing future DAAG meetings as a learning opportunity was also discussed, and DAAG agreed in principle that this could be beneficial but noted that this would need to be carefully managed.</p> <p>A brief update was given on the ONS directions which had now been approved at Minister level, and it was noted that work was underway to determine how current processes could be adapted to align with these directions.</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>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>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>21/07/15: A response from NHS England had been received, and this would be discussed with the HRA CAG Secretariat.</p> <p>28/07/15: Discussions with the HRA CAG Secretariat had taken place, and copies of the documents provided by NHS England had been shared with the Secretariat for their review.</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> <p>14/07/15: Ongoing.</p> <p>21/07/15: Ongoing.</p> <p>28/07/15: Garry Coleman agreed to raise this with Rob Scott.</p>	Open
21/07/15	DAAG Secretariat to invite Rob Shaw to attend a future DAAG meeting to discuss HSCIC Executive Director changes.	DAAG Secretariat	28/07/15: This action had been completed and was closed.	Closed
28/07/15	Garry Coleman to provide an update on the	Garry		Open

	process to update the application summary template.	Coleman		
28/07/15	Acting DAAG Chair and Head of Information Governance to meet with the Public Health England Data and Information Policy and Partnership Lead, along with a senior member of the DARS team, to discuss Local Authority public health requirements for data.	Acting DAAG Chair		Open