

# Data Access Advisory Group (DAAG)

## Minutes of meeting held 18 August 2015

**Members:** Eve Sariyannidou (Chair), John Craven, Patrick Coyle, Dawn Foster

**In attendance:** Frances Hancox, Victoria Williams, Stuart Richardson, Steve Hudson, Dave Cronin, Diane Pryce, Paula Moss, Julia King, Joanne Treddenick

**Apologies:** Alan Hassey, Sean Kirwan, Joanne Bailey

1	<p><b>Review of previous minutes and actions</b></p> <p>The minutes of the 13 August 2015 meeting were reviewed and agreed as an accurate record.</p> <p>Action updates were provided (see table on page 6).</p> <p><b>Out of committee recommendations</b></p> <ul style="list-style-type: none"><li>• None</li></ul>
2	<p><b>Data Applications</b></p>
2.1	<p><b>North East Lincolnshire CCG Stage One ASH (Presenter: Stuart Richardson) NIC-367272-S3F7W</b></p> <p><b>Application:</b> this application was a new agreement for the flow of Secondary Uses Service (SUS) data identifiable at the level of NHS Number to provide intelligence to support commissioning of health services. It was confirmed that the applicant held a satisfactory IG Toolkit score and DPA registration.</p> <p><b>Discussion:</b> DAAG queried the data flow between the CCG and GPs in relation to the diagram submitted in the summary section of the application and noted that the two way flow between the CCG and GPs was not explained, in particular around the role of the GPs, what data is being provided to the GP and why it is being provided to the GP. DAAG also asked for clarity as to what data flowed back from the GP to the CCG.</p> <p>DAAG queried the lengthy and overly complicated fair processing notice on the CCG's website but noted that it was fairly accurate.</p> <p>DAAG suggested that CCGs may wish to work with their patient focus groups to look at their fair processing notices to ensure they are easily accessible and written using plain English so that all patients could easily understand the content. DAAG noted the progress made but noted that CCG's need to continue to update their fair processing notices using guidance provided by the Information Commissioners Office (ICO).</p> <p><b>Outcome:</b> Recommendation to approve subject to the application summary and diagram being amended to clarify the data flow between the CCG and GPs. DAAG noted that the fair processing notice should be in line with the ICO guidance.</p>
2.2	<p><b>NHS Redbridge CCG (Presenter: Stuart Richardson) NIC-362881-H4V3C</b></p> <p><b>Application:</b> this application was a new agreement for the flow of Secondary Uses Service (SUS) data identifiable at the level of NHS Number as a Stage 1 Accredited Safe Haven (ASH). In order to support commissioning of patient care by validating non-contracted activity in the CCG, the data</p>

will also be used for the purpose of invoice validation. It was confirmed that the applicant held a satisfactory IG Toolkit score and DPA registration

**Discussion:** DAAG were confused by the diagram within the application and stated that local flows to the DSCRO in the diagram should either be explained within the application or removed. DAAG also asked how the local data flows related to invoice validation and the type of data required. DAAG noted that the fair processing notice on the applicants website relating to personal information from SUS was dated November 2014, the date is incorrect. The fair processing notice had no reference to the use of identifiable data for risk stratification and DAAG advised that the notice needed to be updated in line with guidance on the Information Commissioner's Office (ICO) website and comments made on the previous application (2.1) above.

**Outcome:** Unable to recommend for approval. Confirmation was required around the local data flow to the DSCRO relating to invoice validation and the application summary and diagram to be updated to include the type of data required. The fair processing notice on the CCG website to be updated with regard the 2014 typo error, no reference to the use of identifiable data for risk stratification and the fair processing notice to be updated in line with guidance on the ICO website.

### 2.3 **Liverpool CCG (Presenter: Stuart Richardson) NIC-361654-X9Y6P**

**Application:** this application was a renewal for the flow of Secondary Uses Service (SUS) data identifiable at the level of NHS Number to provide intelligence to support the commissioning of health services. It was noted that the previous Accredited Safe Haven (ASH) application for the applicant (NIC-292083-R2Y3M) was approved by DAAG on the 4 November 2014 with no caveats. DAAG were informed that the fair processing section of the application incorrectly referenced commercial organisations, which were not relevant to this renewal application and would be corrected. It was also noted that the applicant's name was not included in the IG toolkit section of the application form and this would be corrected.

**Discussion:** DAAG asked that the errors within the fair processing and IG toolkit sections of the application be amended. DAAG noted that the DPA registration was due to expire on the 20 August 2015 and asked that this be reviewed and updated. DAAG advised that the fair processing notice needed to be updated in line with guidance on the Information Commissioner's Office (ICO) website and comments made on the previous application (2.1) above.

**Outcome:** Recommendation for approval subject to the application being updated in line with DAAG discussions: removal of points a and f in the fair processing section; the DPA renewal date to be updated to 2016; the IG Toolkit section be updated to include Liverpool CCG organisation details. DAAG noted that the fair processing notice should be in line with guidance on the ICO website.

### 2.5 **University of Nottingham (Presenter: Dave Cronin) NIC-363953-T0K2D**

**Application:** this application is for an extension and renewal of the existing data sharing agreement in order to authorise the ongoing retention and reuse of data linkage of Admitted Patient Care, Critical Care, Accident and Emergency and Outpatient data supplied for academic purposes under the existing agreement. The application is also to renew an existing data sharing agreement relating to data linkage of Hospital Episode Statistics (HES) Admitted Patient Care, Critical Care, Accident and Emergency, and Outpatient data supplied for academic research in order to receive additional data for the same purpose described within the original agreement. DAAG were informed that QResearch is a not for profit collaboration between the University of Nottingham and Egton Medical Information Systems (EMIS) and that QResearch are not a separate legal entity, but a division of the University of Nottingham. It was also noted that although any academic could apply to use the data, only University of Nottingham staff would have access to the HES data

**Discussion:** DAAG questioned the indirect benefits and noted that the case study did not show specific benefits and that more examples were required. DAAG also noted the reference to ClinRisk within the case study and asked how they are involved, what their role was in this particular study and what they were using data for. DAAG noted that this was a particularly interesting database which used a new algorithm (QRisk) and that it seemed to be more efficient tool encrypting data at both ends of the process so that identifiers are never exchanged.

DAAG asked if sub-licencing arrangements were in place to ensure compliance with Care Act 2014. DAAG queried the link between QResearch and the University of Nottingham and asked for clarity around the legal status and asked if sat just within the University. DAAG also asked for clarification around EMIS involvement. The data controller listed in the application was also noted as incorrect.

DAAG noted inconsistencies within the application with regard to the researchers' access to data noting the application stated "researchers are charged for access to the data". DAAG asked for clarity as to whether the researchers would have access to the data or just the outputs. Clarification was also sought around the HES data and if it would become identifiable if linked to the data QResearch were receiving around ONS and cancer from other sources. DAAG questioned the legal basis for the receiving of the data.

DAAG suggested the inclusion of questions with regard to how the use of data would benefit health and social care, other than through publication in peer journals. DAAG suggested that they may wish to monitor these benefits and bring back further case studies to ensure that the data is benefitting health and social care.

It was noted that the applicant currently holds data, however DAAG asked that an updated application addressing issues raised come back for consideration before the end of September 2015, otherwise DAAG would recommend to HSCIC that the flow of data be stopped.

**Outcome:** Unable to recommend for approval. Clarification was sought with regard to EMIS involvement; the data controller section of the application to be updated to clearly state it is the University of Nottingham; the application to clearly state that only University of Nottingham staff will have access to data and that outside researchers will only have access to the outputs; clarification that HES data will not become identifiable if linked to the ONS / Cancer data from other sources; clarification of the legal status of Q-Research; and sub-licence arrangements should be used to ensure uses of data by researchers are compliant with the Care Act 2014. DAAG asked that an updated application be resubmitted to DAAG by the end of September otherwise the flow of data would be stopped.

## **2.6 University of Oxford (Presenter: Dave Cronin) NIC-359084-W8G8T**

**Application:** it was noted that the application included in the agenda pack was the incorrect version and a paper copy was supplied for the meeting. DAAG noted that they had not had time to read the printed application.

DAAG approved on the 21 July 2015 a University of Oxford application (NIC-275706-T4D6W) with caveats seeking approval to retain and continue to reuse Hospital Episodes Statistics (HES) and Patient Reported Outcome Measures (PROMS) data previously supplied to the Nuffield Department of Population of Health at the University. It was noted that the caveats were met on the 31 July and a SIRO letter issued.

This application for a renewal of data and to amend the approval given on the 31 July to enable provision of additional HES and PROMS data and permit the sharing of data with the Big Health Data Group, Nuffield Department of Orthopaedic, Rheumatology and Musculoskeletal Science at the University. It was noted that the two departments were collaborating on the same project and working towards the same outputs as previously approved, including the project aims. DAAG were informed that the processing and outputs section of the application had been extensively reworded

and that two applications for the same project from different parts of the organisation had been submitted and that they had been merged into the one application for consideration.

**Discussion:** DAAG noted that they could only discuss the application which was submitted as part of the agenda pack and could not review the new application submitted. DAAG also noted that the application submitted did not address if previous caveats had been met. DAAG asked that the correct version of applications be submitted to DAAG.

DAAG noted that the University had not signed a Data Sharing Framework Contract with the HSCIC.

DAAG asked for clarity around the involvement of the Big Health Data Group and what data they would have access to, in addition to the work Health Economics Research Centre (HERC) are already doing as per the previous application submitted on the 21 July.

DAAG noted that additional data years and additional data fields had been requested but within the same classification of data already requested. It was noted that the applicant had received provisional data for 2010/11 previously and now wanted final data.

**Action:** DAAG asked that all applications coming to DAAG need to clearly identify, if applicable, how caveats had been met and clearly identifiable to members.

**Outcome:** The application was deferred due to an incorrect application being provided to members. DAAG asked that the application come back to a future DAAG providing clarity around previous caveats; Big Health Data Group data access and involvement; and clarity around the data controller.

## 2.7 UK Biobank (Presenter: Steve Hudson) NIC-371826-W9C3Z

**Application:** this application was considered by DAAG on the 9 June and recommended for approval with caveats. It was noted that the caveats had been addressed on the 13 July and a SIRO letter issued. The application is an amendment to a clerical error in the previous application which stated the 'UK' as the territory of use when it should have stated 'worldwide'. It was noted that this was the only amendment to the application. It was also noted that the IAO had concerns with regard to the patient safety leaflet and consent.

**Discussion:** DAAG noted that the application submitted did not address if previous caveats had been met. DAAG asked that the correct version of applications be submitted to DAAG.

DAAG noted that apart from the mention of 'worldwide' in the territory section of the application there was no additional information as to how the data would be shared worldwide, for what purpose it would be used, how long it would be held for, specific examples and data sharing security issues specific to individual countries, therefore DAAG could not adequately address the territory change or make an informed recommendation. DAAG asked for clarity around confusing terminology regarding anonymised and pseudonymised and that it could potentially be disclosive if shared worldwide.

DAAG noted that the consent materials did not adequately address if patients had been informed that their data would be shared outside of the UK and that the applicants' website needed to be updated accordingly. DAAG also noted that the application was not explicit in excluding the use of data for commercial purposes and as per DAAG's previous caveat.

**Outcome:** The application was deferred. The application submitted did not reflect if the previous caveats raised by DAAG had been met. Clarification was also required around pseudonymised and anonymised data and that it could potentially be disclosive if data was shared worldwide, DAAG asked for clarity around how worldwide data sharing will work with specific examples and data sharing issues specific to certain countries. DAAG also noted the need to be explicit in

	excluding the use of data for commercial purposes.
<b>3</b>	<p><b>Any other business</b></p> <p>A draft proposal with regard to a proposed DAAG / IGARD appeals process to be circulated to members with an item added to the next training day agenda.</p> <p>It was agreed that due to the potential tube strike in London next Tuesday, 25 August, the start time of DAAG would be pushed back to 10.30am</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> <p>04/08/15: This action was ongoing pending feedback from HRA CAG.</p> <p>13/08/15: HRA CAG had confirmed that the section 251 support did not include the use of more than one identifier and it was their expectation that if more than one identifier is required, a further application would be made to them; they had not received any such application.</p>	Closed
04/08/15	DAAG Secretariat to send DAAG members a copy of the HSCIC Board minutes that covered the discussion of changes to HSCIC Executive Director team and Caldicott Guardian arrangements.	DAAG Secretariat	<p>13/08/15: The relevant Board minutes had not yet been published.</p> <p>18/08/15: The next meeting of the Board is on the 23 September after which the draft minutes will be agreed. DAAG secretariat to circulate following publication</p>	Open

04/08/15	Steve Hudson to provide a diagram of current DARS team setup.	Steve Hudson	13/08/15: It was agreed that Terry Hill would pick up this action. 18/08/15: The action has been chased with Terry Hill via the Secretariat	Open
04/08/15	Dawn Foster and Steve Hudson to discuss data disseminations process.	Dawn Foster	13/08/15: Ongoing. 18/08/15: Meeting took place on the 13 August 2015.	Closed
13/08/15	Garry Coleman to confirm within eight weeks whether the privacy notices for Leeds City Council, Lincolnshire County Council and Norfolk County Council have been appropriately updated.	Garry Coleman	18/08/15: Garry Coleman to update DAAG at the next board meeting	Open
13/08/15	Stuart Richardson to ensure that the privacy notice for Castle Point and Rochford CCG is appropriately updated.		18/08/15: Stuart Richardson to continue to work with applicants and feedback update at future DAAG.	Open