

# Data Access Advisory Group

## Minutes of meeting held 23 December 2014

**Members:** Alan Hassey (Acting Chair), Eve Sariyiannidou, John Craven, Patrick Coyle, Dawn Foster

**In attendance:** Alex Bell, David Evans, Garry Coleman, Karen Myers

**Apologies:** Diane Pryce, Frances Hancox, Sean Kirwan

1	<p><b>Review of previous minutes and actions</b></p> <p>The minutes of the 16 December 2014 meeting were reviewed and agreed as an accurate record of the meeting.</p> <p>Action updates were provided (see table on page 5).</p> <p><b>Out of committee recommendations</b></p> <p><u>Public Health England - NIC-297344-D6J1W</u></p> <p>This was an application for Cancer Registry to access DID's data. This was previous discussed at the 26/06/2014 DAAG Meeting and was recommended for approval with caveats around Section 2.5.1 and fair processing. This was reviewed OOC and was recommended for approval.</p>
2	<p><b>Data applications</b></p> <p>2.1 <u>Central North and South Manchester NIC-310337-N3Z8X Presented by Garry Coleman</u></p> <p>This application had been considered at 16/12/2014 DAAG, where DAAG members had asked for further information around why the customer needed local patient ID. An update was provided by the IAO that the customer now did not need local patient ID so it has been removed from the application. DAAG members also raised a query around the applicant's security details and why an SLSP was sent through rather than an IG toolkit score. It was felt that as this is an NHS body, an IG Toolkit score should be provided.</p> <p>It was agreed that the IG Toolkit score would be checked and sent round to members. As a general rule, DAAG members asked that NHS applications submit their IG toolkit score.</p> <p><b>Outcome:</b> Recommended for approval subject to clarification that the IG toolkit score is satisfactory. If the toolkit score is not satisfactory then DAAG would want to see an action plan in place. DF will confirm the toolkit score to DAAG members.</p> <p>Action: DAAG Secretariat to inform the DARS team that applications from NHS Organisations should have an IG Toolkit score, whether it is satisfactory or not. If an applicant is unable to provide an IG Toolkit score then an explanation should be provided.</p> <p>2.2 <u>Kings College London NIC-236594-T3Q6W Presented by Garry Coleman</u></p> <p>This application was discussed at the 18/11/2014 DAAG Meeting where a number of items were raised. JC declared a conflict of interest in this application so did not participate in the discussion. The applicant confirmed that they are only looking for data in specific areas of England (where there are main airports) and that linkage will not be done at record level. The</p>

	<p>applicant has also added the benefits of this work to the application. DAAG members asked for clarification on which airports the study will cover, the application shows the initial focus to be Heathrow, although data will be needed to draw comparisons with other airports. There was concern that the applicant would receive more data than they initially need. It was felt that the Processing activities section was not clear what the specific outputs are, further details of this was requested. Clarification was also required on the processing section.</p> <p><b>Outcome:</b> Recommended for approval with the caveat that the amount of data is proportionate to the airports being studied and that more information is provided around processing activities. GC to confirm and ES and DF can consider this application OOC.</p>
2.3	<p><u>RES consortium NIC-280016-T1G4D Presented by Garry Coleman</u></p> <p>This application was discussed at the 9/12/2014 DAAG meeting where further information for the specific objectives of data processing, and clarification of the involvement of the pharmaceutical company was requested. Justification was requested for why national data is required rather than a sample of the population. The application was also to be updated to include a clear statement that the data requested can only be used for the purposes listed, and no additional purposes. It was felt the issues discussed around the statistical validity of the analysis had not been resolved. It was felt that RES consortium didn't have specific methodologies in mind for the data for the data. There was confusion around the relationships and roles for the application and it was not clear how the relationships fit together. It was not clear who was the data processor. It was also noted that there was also no reflection of RES being a commercial body in the application form.</p> <p><b>Outcome:</b> Unable to recommend for approval. DAAG members felt there were still significant areas of concern. Further information was requested on the specific methodology and process description, further clarification around the three individuals involved in this application form, confirmation who is the data processor, why the pharma company are funding, does the study need ethics approval, could the HRA Toolkit score be provided in the application form and could they provide a sample of the data needed (eg is all the data required)</p>
2.4	<p><u>Lightfoot Solutions NIC-292299</u></p> <p>This is a new application for pseudo, non - sensitive data. Lightfoot would like to be a standard extract customer, which means they will have a monthly drop of data. DAAG members asked which public sector bodies would have access to the solution, which is referred to in the application. The IAO confirmed that this is National NHS bodies and health related public sector organisations. There was a question raised for what the statistical process control view is. The IAO confirmed that it is the way the tool operates and the statistical analysis that they apply. The IAO also confirmed that organisations using the tool can view outputs on the screen but can't get the record level data. It was felt the processing activities section wasn't clear, it should show what the organisation is doing with the data, not where it will be held. DAAG members would like to identify the major organisations that are referred to in the application.</p> <p><b>Outcome:</b> Recommended for approval with the caveat that clarification is provided around who the major customers are. DAAG members gave general feedback around the correct content being in the right boxes on the application form, although this was not a caveat. Members felt that clarification on who customers are would be useful for all commercial organisations. This does not need to come back to a further DAAG, but the interim chair would like to see the updated application. This is something to be added for general discussions between HSCIC and CAG.</p>
2.5	<p><u>University College London NIC-307654-L9T2Q</u></p>

2.6	<p>This is an application for aggregate data with small number unsuppressed to be released to NICOR for the purpose to compare the audit they currently carry out. Small number unsuppressed will be provided to NICOR, NICOR would publish with small numbers suppressed. It was noted that the DPA registration expires soon and would need to be updated.</p> <p><b>Outcome:</b> Recommended for approval with no caveats</p> <p>Action – DAAG Secretariat to include details of original meeting and agenda item number for returning applications.</p> <p><u>Experian NIC-291975-X2R1W Presented by Garry Coleman</u></p> <p>This is a new application to DAAG, but is not a new application to the HSCIC. The IAO specifically noted that this is not linked to the credit referencing part of the company. DAAG members raised concerns about some information in the specific outputs section of the application form, where it states ‘sold to commercial organisations’ Members asked what form is it being sold in and what controls are in place? It was noted that any information that is shared by Experian should be under a sub licence to restrict further onward distribution..</p> <p>DAAG members were content that the application form stated that the data will be destroyed, but wanted to be clear that there is no risk of re- identification to users.</p> <p>DAAG members recommended that the HSCIC gain some assurance that the rich health data it shares with Experian (and other commercial organisations) in a pseudonymised form is protected by the organisation and HSCIC can be assured that it is not used for other purposes.</p> <p><b>Outcome:</b> Unable to recommend for approval. A revised application was invited, which limited the purposes to health and social care and excluded commercial purposes.</p> <p>Action – members recommend that Experian are added to the list of organisations to be audited, irrespective of the outcome of this application.</p>
2.7	<p><u>BMJ Publishing Group Ltd - NIC-292310-D7B7R Presented by Garry Coleman</u></p> <p>This application was considered at the 28/10/2014 DAAG meeting where the following comments were raised ‘Further information requested regarding BMJ IG Toolkit score. Clarification to be sought regarding what efforts have been made to inform the general public of this use of data.’ It was felt that the points previously identified had not been addressed.</p> <p>It was noted that the applicant’s Data Protection Registration is for the publishing side of the business and not the healthcare side.</p> <p>DAAG members asked for clarification on which sensitive fields are actually being requested and asked who their customers are and do they have any customers signed up? It was queried who were the “normal” clinical staff that are mentioned at the bottom of purpose and aims section of the application form. It was also noted that the data retention period was not updated.</p> <p><b>Outcome:</b> Unable to recommend for approval. The points raised from 28/10/2014 DAAG need addressing, further information was requested about the DPA registration as the one stated is for the publishing side of the business and not the Healthcare side. Clarification is needed on which sensitive fields are being requested. Further information on who the customers are (if any). Information requested on who ‘normal clinical staff’ are. Data retention period needs updating. The IAO to check that the framework agreement is consistent with our</p>

	<p>obligations under the Health and Social Care Act section 2.6.1, 1a and as modified by the Care Act 2014.</p> <p>Action - GC obtain further information on framework agreement for the customer and DF to research to understand the criteria for applicants for framework agreement and see what implications are for them accessing the data.</p>
<b>3</b>	<p><b>Any other business</b></p> <p>The chair thanked DAAG members for their support in 2014 and wished everyone a Happy Christmas.</p>

## Summary of Open Actions

Date raised	Action	Owner	Updates	Status
16/12/2014	Alan Hassey to write to the HSCIC Caldicott Guardian and Senior Information Risk Owner on behalf of DAAG regarding the use of identifiable rather than pseudonymised data by CQC and the need to ensure that this is appropriately justified.	Alan Hassey	23/12/2014: This is now complete.	Closed
16/12/2014	Diane Pryce to provide a briefing paper on home nations cross-border relationships and known issues.	Diane Pryce	23/12/2014: Diane did not attend the meeting. Ongoing.	Open
16/12/2014	Diane Pryce and Alex Bell to discuss self-assessed IG Toolkit scores with Marie Greenfield.	Diane Pryce	23/12/2014: Ongoing	Open
16/12/2014	Marie Greenfield to be invited to the next DAAG training day to discuss IG Toolkit.	Alex Bell	23/12/2014: This will be added to the agenda.	Closed
16/12/2014	Alan Hassey to respond to letters received from HSCIC Caldicott Guardian.	Alan Hassey	23/12/2014: This is now complete	Closed
09/12/2014	Eve Sariyannidou and David Evans to provide bullet points on consent materials to assist discussions at DAAG training day.	David Evans	16/12/14: This action was ongoing. 23/12/2014: Ongoing	Open
09/12/2014	David Evans to consider the fair processing aspects of the University of Surrey application (NIC-203503-X7K8K) and share comments by email.	David Evans	16/12/14: There had been a discussion regarding this application via email, and it was agreed that Garry Coleman would share further details regarding the intended data flow with David Evans. 23/12/2014: This is now complete	Closed
09/12/2014	DAAG members to agree updated wording for University of Sheffield application discussion in the 2 December 2014	Sean Kirwan	16/12/14: Garry Coleman and Eve Sariyannidou to agree revised wording. 23/12/2014: This is now complete.	Closed

	meeting minutes.			
23/12/2014	DAAG Secretariat to inform the DARS team that applications from NHS Organisations should have an IG Toolkit score, whether it is satisfactory or not. If an applicant is unable to provide an IG Toolkit score then an explanation should be provided.	Alex Bell		
23/12/2014	DAAG Secretariat to include details of original meeting and agenda item number for returning applications.	Alex Bell		
23/12/2014	DF to ensure that Experian are added to the list of organisations to be audited, regardless of the decision of the outcome of this application.	Dawn Foster		
23/12/2014	GC obtain some information on framework agreement for BMJ (NIC-292310-D7B7R) and DF to research to understand the criteria for applicants for framework agreement and see what implications are for them accessing the data.	Garry Coleman		