

# Data Access Advisory Group (DAAG)

## Minutes of meeting held 27 October 2015

**Members:** John Craven, Dawn Foster, Alan Hassey (Interim Chair), Eve Sariyannidou

**In attendance:** Dave Cronin, Gaynor Dalton, Frances Hancox, Dickie Langley, Paula Moss, Stuart Richardson, Vicki Williams

**Apologies:** Joanne Bailey, Sean Kirwan, James Wilson

1	<p><b>Declaration of interests</b></p> <p>No conflicts of interests relevant to this meeting were declared.</p> <p><b>Review of previous minutes and actions</b></p> <p>The minutes of the 20 October 2015 meeting were reviewed and subject to a minor change they were agreed as an accurate record.</p> <p>Action updates were provided (see table on page 8).</p> <p><b>Out of committee recommendations</b></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 met:</p> <ul style="list-style-type: none"><li>• NIC-364047-D2S6C Knowsley CCG</li><li>• NIC-344511-H6N5B British Society of Gastroenterology (IBD Registry)</li><li>• NIC-365623-T3W4S University of Manchester</li><li>• NIC-345760-Q0M2Z University of Manchester</li></ul>
2  2.1	<p><b>Data applications</b></p> <p><u>Southend CCG – Risk stratification (Presenter: Stuart Richardson) NIC-381643-Q6Q2Z</u></p> <p><b>Application:</b> This was a renewal application for Secondary Uses Service (SUS) data identifiable at the level of NHS number (weakly pseudonymised) under the overarching section 251 support for risk stratification. Data would flow via North East London Commissioning Support Unit (CSU) as a landing point only, then onto PI Benchmark who would act as data processor for the CCG. The data would be used in a risk stratification tool which GPs within the CCG could log into to access risk stratification data about patients registered to their own practice only, while the CCG could only access aggregated data. DAAG were informed that the CCG and its data processors had achieved satisfactory IG Toolkit scores and held current registrations under the Data Protection Act 1998 (DPA). It was noted that the applicant had previously used MedeAnalytics as a data processor, before moving to use PI Benchmark.</p> <p><b>Discussion:</b> DAAG discussed the applicant's fair processing notice, and agreed that this should be updated in line with the advice that DAAG had previously provided to the applicant in order to ensure that the legal basis for data processing was not impacted by any incorrect or misleading statements. In addition, DAAG noted an error on the fair processing notice in a reference to the applicant's DPA registration number, and suggested that this should be corrected.</p> <p>DAAG noted that the DPA registration for PI Benchmark did not refer to healthcare or to</p>

	<p>processing data about patients, and suggested that PI Benchmark should be advised to update this wording.</p> <p>A query was raised regarding the process for renewal applications where a CCG changed data processors, and it was noted that as this could potentially happen multiple times in a year this could result in a significant number of applications being submitted to DAAG in future. The possibility of considering these changes through a fast track process was suggested.</p> <p>The change in data processors from MedeAnalytics to PI Benchmark was discussed, and DAAG noted that it was unclear whether MedeAnalytics had now destroyed the data they had previously held or whether this data had been securely transferred to PI Benchmark. It was agreed that the application should be withdrawn until this could be clarified.</p> <p><b>Outcome:</b> Application withdrawn.</p> <ul style="list-style-type: none"> <li>• Clarification is required of the transfer of data following the change of data processors, and in particular whether data has already been transferred or if the previous data processor has provided a data destruction certificate.</li> <li>• The CCG's fair processing notice should be updated in line with the comments previously provided by DAAG, and to provide the correct reference number for the CCG's DPA registration.</li> </ul> <p>DAAG advised that PI Benchmark should consider updating their DPA registration wording to specifically refer to healthcare.</p>
2.2	<p><u>Mid Essex CCG – Risk stratification (Presenter: Stuart Richardson) NIC-381572-Z7ROV</u></p> <p><b>Application:</b> This was a new application for SUS data identifiable at the level of NHS number (weakly pseudonymised) for the purpose of risk stratification. Data would flow via North East London CSU as a landing point only, then to the data processor United Healthcare UK (Optum) who would provide a risk stratification tools for GPs to log into and access data about their own patients only. DAAG were informed that the application summary referred to the data processor under the name 'Optum Health Solutions' in some places due to a recent name change, and that both names referred to the same organisation. The CCG and data processors had achieved satisfactory IG Toolkit scores and held appropriate DPA registrations.</p> <p><b>Discussion:</b> DAAG noted that as with the previous application from Southend CCG, this applicant's fair processing notice needed to be updated in line with the comments previously provided by DAAG.</p> <p>DAAG discussed the DPA registration wording for United Healthcare UK (Optum) and noted that while this referred to health research it did not specifically state that the organisation processed healthcare data or data about patients. It was suggested that the organisation should consider updating this wording.</p> <p><b>Outcome:</b> Recommendation to approve subject to:</p> <ul style="list-style-type: none"> <li>• The CCG's fair processing notice should be updated in line with the comments previously provided by DAAG, and to provide the correct reference number for the CCG's DPA registration.</li> </ul> <p>DAAG advised that United Healthcare UK (Optum) should update their DPA registration wording to more directly refer to healthcare and that they process data about patients.</p>
2.3	<p><u>North East Essex CCG – Risk stratification (Presenter: Stuart Richardson) NIC-381638-T2R0V</u></p> <p><b>Application:</b> This application was for SUS data identifiable at the level of NHS number (weakly</p>

pseudonymised) for the purpose of risk stratification. Data would flow via North East London CSU as a landing point only, then to the data processor South East CSU to provide a risk stratification tools for GPs to log into and access data about their own patients only. The CCG itself would only have access to anonymised data. The CCG and CSUs had achieved satisfactory IG Toolkit scores and held appropriate DPA registrations.

**Discussion:** DAAG noted that they had previously provided advice on the CCG's fair processing notice, and had highlighted a particular section that was factually incorrect and should be removed. This change had not yet been made, and it was agreed that this should be raised with the applicant.

**Outcome:** Recommendation to approve subject to:

- The CCG's fair processing notice being updated to remove an incorrect section, as per the previous undertaking from the applicant, and to provide the correct reference number for the CCG's DPA registration.

**2.5** PricewaterhouseCoopers – Transition of services on behalf of Monitor (Presenter: Dickie Langley) NIC-380902-S7H1C

**Application:** This application was for aggregated SUS data with small numbers unsuppressed. This data had previously been provided to CHKS, who had previously acted as data processor on behalf of the data controller Monitor, and following a contract tender process PricewaterhouseCoopers would now be acting as data processor for Monitor instead. The data would be used to deliver a Payment by Results (PbR) Data Assurance Framework for Monitor in 2015/16.

**Discussion:** Concerns were raised about the lack of a storage address for the data requested, as it was noted that without this it was not possible to determine whether the applicant's ISO 27001 certification covered this location and therefore no security assurance could be given.

A reference to returning a hard drive once data had been cleansed from it was queried, but it was confirmed that data could be securely destroyed without requiring the physical disk to be destroyed. DAAG noted the size of the PricewaterhouseCoopers organisation, and requested assurance that data would not be shared internally with other parts of the company for any reason. In addition, it was noted that the applicant's DPA registration was shortly due to expire and that this would need to be renewed.

DAAG queried the data transfer process following the change of data processors, and it was confirmed that data would be transferred from CHKS, via Monitor onwards to PricewaterhouseCoopers. DAAG noted that Monitor's data processor for this work could continue to change in future as the contract was renewed, and requested assurance from Monitor of how the change in data processor was securely managed.

**Outcome:** Unable to recommend for approval:

- A storage address was required for where data will be processed, in order to provide assurance that the applicant's ISO 27001 certification covers this location.
- Assurance was requested that data will not be shared with other parts of the PricewaterhouseCoopers company.
- An explanation was required from Monitor of how the change of data processors will be managed securely when contracts are renewed.

**2.4** Methods Analytics (Presenter: Dickie Langley) NIC-380295-L7C8M

**Application:** This application was to renew and amend an application that had previously been considered and recommended for approval at the 1 September 2015 DAAG meeting (NIC-363259-

M1X8F). The applicant had now requested additional Office for National Statistics (ONS) data in order to fulfil the original purpose of the application, and the application had also been updated to extend the proposed agreement end date and to list an additional user for the ONS data.

**Discussion:** A query was raised regarding the process for adding new ONS data users to an existing data sharing agreement. It was confirmed that a process was in place for these changes that would not usually require DAAG to review an updated application.

There was a further query raised about why the applicant now required additional data if the purpose of the application had not changed since they previously applied. It was clarified that the applicant had initially intended to apply for the historical ONS data, but that this had not been included on the previous application pending clarification from ONS. DAAG were informed that the required ONS approvals were now in place.

**Outcome:** Recommendation to approve.

## 2.10 University Hospitals Birmingham - SHMI (Presenter: Dickie Langley) NIC- 381984-B7X3S

DAAG members discussed the fact that this application had been a late submission, and emphasised the importance of ensuring that late submissions or withdrawals were only made in very exceptional circumstances as this impacted their ability to prepare for meetings. The particular circumstances for this late submission were explained. It was agreed that Dickie Langley would review whether there were any upcoming application deadlines that would be likely to impact on DAAG business processes.

**Application:** This application was to receive identifiable Summarised Hospital-level Mortality Indicator (SHMI) data, including the identifiable field Date of Death derived from ONS mortality data. The applicant would make record level data (with the Date of Death field removed) available to hospital trusts via an online tool, or provide reports containing aggregated data with small numbers suppressed.

**Discussion:** A query was raised regarding whether the applicant would use sub-licenses for organisations accessing data through their tool, and it was agreed that this would need to be clarified.

DAAG discussed the statement that this application was not commercial, as it was noted that the applicant intended to recover costs from customers. It was acknowledged that as part of the criteria set by ONS for use of this data, the applicant could only use data for health and social care purposes and not for any additional commercial purposes.

DAAG noted that the commissioning letter that had been provided as evidence for the receipt of ONS data was not on letter-headed notepaper, and requested an amended letter to ensure that this would meet the requirements set by ONS. It was also noted that this letter only referred to the release of data, and not to the retention of data already held by the applicant. In addition, the list of customer organisations provided appeared to include some organisations that were not bodies listed in Section 42(4) of the Statistics and Registration Service Act 2007.

**Outcome:** Recommendation to approve subject to:

- Provision of a letter on appropriately headed notepaper.
- Confirmation that only bodies covered under Section 42(4) of the Statistics and Registration Service Act 2007 that are customers of the applicant will receive data from the applicant.
- Clarification of whether sub-licenses are used, and if so what terms and conditions are included.

**Action:** Dickie Langley to review any upcoming application deadlines that could be likely to affect

DAAG business processes.

**2.6** University of Sheffield - Impact of closing Emergency Departments in England (Presenter: Dave Cronin) NIC-340495-Q7R8B

**Application:** This application for pseudonymised Hospital Episode Statistics (HES) data had previously been considered at the 13 October 2015 meeting, when DAAG had deferred making a recommendation pending discussions between the HSCIC and the applicant about whether any further data minimisation efforts could be made to reduce the need to disseminate national data to the applicant solely for the selection of a control cohort of five Emergency Departments. DAAG were informed that further discussions had taken place, and no options for data minimisation had been identified that would be appropriate.

**Discussion:** The importance of data minimisation was discussed, and DAAG felt that it still had not been clearly explained why the HSCIC could not select the cohort of five Emergency Departments for the applicant rather than sending the applicant national data for them to select the cohort. DAAG requested further information about why this was not a practical option, as well as about whether or not the Secure Data Facility would provide an alternative solution when this became available. In addition, DAAG queried whether the applicant could attend the HSCIC to select the cohort before data was released.

DAAG noted that it was still unclear how much additional data was requested, as the total number of Emergency Departments in England had not been provided and it was therefore unclear what proportion the cohort of five Emergency Departments would be of this total.

**Outcome:** Unable to recommend for approval.

- Confirmation was required of how much additional data was requested, based on the number of Emergency Departments in England.
- Further details were requested about why the HSCIC was unable to create the cohort for the applicant.
- Confirmation was requested of when the Secure Data Facility would be available, and whether or not the Secure Data Facility would provide a solution for this application rather than providing national data to the applicant.
- In the absence of the Secure Data Facility, confirmation was requested of whether the applicant could attend the HSCIC in person to produce the cohort.

**Action:** Interim DAAG Chair to contact the Statistics Head of Profession to request advice on data minimisation and how the DPA requirements can be met to ensure that disseminated data is not excessive, particularly in relation to the University of Sheffield application NIC-340495-Q7R8B.

**2.7** Northumberland Tyne & Wear NHS Foundation Trust - Use of Mental Health currency data to predict prognosis (Presenter: Netta Hollings) NIC-385906-V4T9P

**Application:** This application for pseudonymised Mental Health & Learning Disabilities Data Set (MHLDDS) data had previously been considered at the 29 September 2015 meeting, when DAAG had been unable to recommend approval. Additional details had now been provided about outputs, fair processing and the data minimisation efforts that had been considered.

**Discussion:** The updated application summary clarified that Sheffield University would not have access to the data requested, but there remained some uncertainty regarding the Care Pathways and Packages Consortium and the fact that the individual listed as applicant was employed by both organisations. DAAG suggested that both the Care Pathways and Packages Consortium and Northumberland, Tyne & Wear NHS Foundation Trust should be considered joint data controllers, and that the application should be resubmitted with both these organisations as co-applicants.

DAAG discussed data minimisation, and while it was acknowledged that the applicant had considered a number of ways to limit the amount of data requested and had not found these to be appropriate, it was still felt to be unclear whether the applicant could use a statistical sample of data. DAAG also discussed the expected benefits, and whether these could be considered to meet the requirement under the Care Act for the HSCIC to only disseminate data for healthcare purposes or the promotion of health. Additional details were requested about Output Two that had been listed in the application in order to clarify what impact this was expected to have.

**Outcome:** Unable to recommend for approval.

- The application should be re-submitted with both organisations as co-applicants and joint data controllers.
- A clearer justification is required of why a statistical sample could not be used instead of requiring the larger dataset.
- Further information is required about Output Two and how this will have an impact.

## 2.8 Central Manchester University Hospitals NHS Foundation Trust – CMFT Business Analytics (Presenter: Gaynor Dalton) NIC-376374-F8D0M

**Application:** This application was for pseudonymised, sensitive HES data in order to carry out benchmarking within the applicant organisation. The applicant had indicated that the full HES dataset was required to allow for analysis across the UK, given the Trust's role as a national tertiary centre.

**Discussion:** DAAG noted that the applicant intended to produce reports that would only be made available to staff within the Foundation Trust. Given that these reports would only contain aggregated data with small numbers suppressed, and given the use of national data, DAAG suggested that the applicant could consider making reports more widely available to see if the outputs could be beneficial for other similar NHS organisations.

DAAG asked whether the data requested by the applicant could be filtered according to the specialities provided by this Trust, in order to minimise the amount of data provided. It was suggested that the full dataset might be required if the Trust provided a full range of healthcare services, and DAAG agreed that this should be clarified along with confirming that it would not be appropriate to make any other data minimisation efforts.

A reference in the application to an analyst team was queried, and DAAG requested confirmation that this referred to employees of the Trust and not to any outsourced functions.

**Outcome:** Recommendation to approve subject to:

- Confirmation that the trust provides a full range of services and therefore requires the full HES dataset requested, and that other data minimisation efforts are not appropriate.
- Confirmation that the teams referred to in the application are employees of the Trust.

DAAG advised that given the use of national data, it would be beneficial if the outputs could be made more widely available to ensure wider benefits to the health and social care system.

## 2.9 Genomics England (Presenter: Gaynor Dalton) NIC-361343-G9Z4S

**Application:** This application was for identifiable and sensitive HES data as part of the 100,000 Genomes project. The applicant would provide the HSCIC with identifiers for participants who had consented to participate in the study, and the HSCIC would link HES data for the participants to a Study ID and return the linked data to the applicant. This data, which would contain the Study ID but no other identifiers such as name or NHS number, would be include in a research repository. Researchers or certain pharmaceutical companies (members of the GENE Consortium) could then apply to access the repository through a secure data centre, with requests being assessed to

	<p>ensure they meet the approved purposes set out in the Genomics England protocol.</p> <p><b>Discussion:</b> There was a discussion of the applicant's intention to link HES data to data from other sources in future, and it was noted that this would be subject to a further application to DAAG at a later date.</p> <p>DAAG queried how the data described as de-identified would be linked by Genomics England to the samples held. It was confirmed that Genomics England would use a Study ID code to link the pseudonymised data to the correct samples, and that identifiers such as name and date of birth would never be included in the repository that would be available to researchers.</p> <p>It was noted that an updated draft patient information sheet had been provided, following the advice on consent that DAAG had previously given. DAAG agreed that the applicant should implement these changes in a timely manner.</p> <p><b>Outcome:</b> Recommendation to approve subject to an undertaking that Genomics England will implement the changes seen in the draft patient information sheet in a timely fashion.</p>
3	<p><b>Any other business</b></p> <p>Following a discussion that had taken place between meetings regarding an application for list cleaning, it was agreed that a HSCIC Senior IG Adviser would be asked to draft a paper on list cleaning for discussion at the December DAAG training session. It was suggested that DAAG could also seek advice from HRA CAG on this topic in future.</p> <p><b>Action:</b> Dawn Foster to ask Senior IG Adviser to draft a paper on list cleaning for discussion at the December DAAG training session.</p> <p>DAAG briefly discussed the agenda for the upcoming training session, and noted that there would be a short session following the meeting for members to discuss the draft IGARD Terms of Reference. The Interim DAAG Chair agreed to share any feedback from the IGARD Steering Group.</p>

## Summary of Open Actions

Date raised	Action	Owner	Updates	Status
29/09/15	University of York to be asked for clarification on their change of policy for providing access to data.	Steve Hudson	06/10/15: This had been raised with Garry Coleman, and formal contact would be made with the University of York to request clarification. 27/10/15: Ongoing. It was expected a response would be available for the 3 November DAAG meeting.	Open
13/10/15	Dawn Foster to speak to the Interim DAAG Chair regarding advice received from ONS on participant consent. (20/10/15 UPDATE: Dawn Foster to discuss this with DAIS.)	Dawn Foster	20/10/15: DAAG discussed the concerns that had previously been raised regarding advice on ONS requirements for consent. It was agreed that rather than raising this directly with ONS, Dawn Foster would discuss this with the DAIS team in the first instance. 27/10/15: Work was underway to develop a clearer process for applications for ONS data, and it was agreed Dawn Foster would provide an update on this once a draft was available in a few weeks.	Closed
20/10/15	Paula Moss to provide an updated paper on DSCRO local data flows.	Paula Moss	27/10/15: Ongoing.	Open
20/10/15	DAAG Secretariat to make the published DSCRO directions available to DAAG members via SharePoint.	DAAG Secretariat	27/10/15: These directions had been made available on SharePoint, and the DAAG Secretariat would circulate a link to members.	Closed
20/10/15	DAAG Secretariat to circulate data minimisation paper.	DAAG Secretariat	27/10/15: The action had been completed and was closed.	Closed
27/10/15	Dickie Langley to review any upcoming application deadlines that could be likely to affect DAAG business processes.	Dickie Langley		Open
27/10/15	Interim DAAG Chair to contact the Statistics Head of Profession to request advice on data minimisation and how the DPA requirements can be met to ensure that disseminated data is not excessive (particularly in relation to the University of Sheffield application NIC-340495-Q7R8B.)	DAAG Chair		Open



27/10/15	Dawn Foster to ask Senior IG Adviser to draft a paper on list cleaning for discussion at the December DAAG training session.	Dawn Foster		Open