

# Data Access Advisory Group (DAAG)

## Minutes of meeting held 20 October 2015

**Members:** Joanne Bailey, John Craven (agenda items 1 - 2 only), Dawn Foster, Alan Hassey (Interim Chair), Eve Sariyannidou, James Wilson

**In attendance:** Dave Cronin, Gaynor Dalton, Chris Dew, Frances Hancox, Steve Hudson, Julia King, Dickie Langley, Paula Moss, Stuart Richardson, Tracy Taylor

**Apologies:** Sean Kirwan

1	<p><b>Declaration of interests</b></p> <p>Joanne Bailey declared a conflict of interest for East and North Hertfordshire CCG and did not participate in the discussion of those two applications.</p> <p><b>Review of previous minutes and actions</b></p> <p>The minutes of the 13 October 2015 meeting were reviewed and subject to minor changes 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- 345760-Q0M2Z University of Manchester</li><li>• NIC- 337151-T252K University of Leeds</li><li>• NIC- 328464-Y5Y8F University of Kent</li><li>• NIC- 335133-K2Y2S Institute of Occupational Medicine</li><li>• NIC- 370701-M8F1H King's College London</li></ul>
2	<p><b>Data Services for Commissioners local data flows</b></p> <p>Following the discussion of local data flows at the 22 September 2015 meeting, DAAG were provided with a paper outlining the proposed approach to these flows along with several example applications.</p> <p>The definition of 'local data flow' was discussed, and it was noted that this was defined in the published DSCRO directions as data relating to the provision of health services pursuant to a particular commissioning contract. It was agreed that the paper provided should be updated to include this clearer definition, to ensure clarity about which data flows were included. In addition, it was suggested the paper should include definitions of terms such as 'clear data' and a glossary may be helpful. In addition it was agreed that the published directions would be made available to DAAG members for information.</p> <p>DAAG queried whether DSCRO local data flows had been reviewed by the Standardisation Committee for Care Information (SCCI); it was confirmed that these flows had not yet been taken through the SCCI process but that it was anticipated this would happen in future once work was underway to reduce the number of local data flows.</p>

	<p>There was a suggestion that it would be helpful if DAAG could have sight of a 'master list' of all the different types of data flows that were included, although it was acknowledged that due to the high number of different flows it would not be practical to list every single one individually. However, it was agreed that more detail about the types of data flow included would help provide context for DAAG's review of future applications. In addition, further information was requested about the process for determining whether or not new data flows fit into one of the existing categories of data, as it was highlighted that this would need to be a transparent and robust process.</p> <p>DAAG suggested that the example applications should more closely reflect the paper provided by specifying which categories of local data were applied for.</p> <p>DAAG queried the purpose of the five categories of data, as it was understood that most applications might include data from each of the five categories. It was agreed that further work was required to clarify the purpose of categorisation and to ensure that the correct categories had been selected, rather than for example splitting data out into the different purposes for which it would be used, such as invoice validation or risk stratification.</p> <p>It was agreed that an updated paper would initially be shared with Dawn Foster and Alan Hassey, and subsequently brought to a future DAAG meeting for further discussion.</p> <p><b>Action:</b> Paula Moss to provide an updated paper on DSCRO local data flows.</p> <p><b>Action:</b> DAAG Secretariat to make the published DSCRO directions available to DAAG members via SharePoint.</p>
<p><b>3</b></p> <p><b>3.1</b></p>	<p><b>Data applications</b></p> <p><u>East and North Hertfordshire CCG - Risk Stratification (Presenter: Stuart Richardson) NIC-371018-K1P2X</u></p> <p><b>Application:</b> This was a renewal application for receipt of Secondary Uses Service (SUS) data identifiable at the level of NHS number (weakly pseudonymised), for the purpose of risk stratification with the legal basis being section 251 support. Data would flow from the relevant DSCRO via North East London CSU as a landing point, then to MedeAnalytics who would act as data processor and provide a risk stratification tool. GPs would be able to access data for their own patients only by logging into the risk stratification tool. DAAG were informed that all organisations involved had achieved satisfactory Information Governance (IG) Toolkit scores and held appropriate registrations under the Data Protection Act 1998 (DPA).</p> <p><b>Discussion:</b> DAAG discussed the fair processing notice for the CCG, and it was noted that for a previous application considered at the 29 September meeting (NIC-371050-X4H9L) DAAG had asked the applicant to update this notice as there were concerns that some of the statements included were misleading and could potentially affect the legal basis to disseminate data. It was acknowledged that some changes to this notice had been made in response to DAAG feedback, but there remained some concerns. It was agreed that the applicant should be reminded of the need to update this process in a timely fashion, and DAAG would be informed once changes had been made.</p> <p>A typographical error in section 5 of the application summary was noted, and it was agreed that this would be corrected.</p> <p>DAAG discussed the DPA registration details for MedeAnalytics, and expressed concerns that this only referred to processing data about individuals such as customers, staff and business contacts rather than specifically referring to data about patients. It was agreed that they should be advised</p>

	<p>to update this.</p> <p><b>Outcome:</b> Recommendation to approve subject to an undertaking within two weeks that the applicant will update their fair processing notice, with DAAG to be notified once the changes have been made.</p> <p>DAAG expressed concerns that the DPA registration wording for MedeAnalytics did not specify that they processed data about patients, and DAAG would expect this to be addressed before any future applications were made.</p>
3.2	<p><u>East and North Hertfordshire CCG - Invoice Validation (Presenter: Stuart Richardson) NIC-371093-L8G2C</u></p> <p><b>Application:</b> This was a new application for SUS data identifiable at the level of NHS number (weakly pseudonymised) to be received into the CCG's Controlled Environment for Finance, for the purpose of invoice validation. Data would flow via North East London CSU as a landing point only, and DAAG were informed that both organisations help appropriate DPA registrations and satisfactory IG Toolkit scores.</p> <p><b>Discussion:</b> DAAG noted that the application summary listed data that the applicant had previously received for this purpose, as the applicant had not previously made an application for risk stratification. It was explained that this referred to data received for a different purpose, and it was suggested a separate table should be used in future to clarify this.</p> <p><b>Outcome:</b> Recommendation to approve.</p>
3.3	<p><u>NHS England - Reconciliation of HES and Assuring Transformation Data (Presenter: Gaynor Dalton) NIC-371011-F4X5F</u></p> <p><b>Application:</b> This was a new application for linkage of Hospital Episode Statistics (HES) and Assuring Transformation data, for the purpose of comparative analysis to support the Transforming Care programme and understand any underreporting of hospital admissions of people with learning disabilities. The data provided would be pseudonymised, with the Health and Social Care Act 2012 providing a legal basis for the dissemination.</p> <p><b>Discussion:</b> DAAG recognised the importance of this work, given the context of the Transforming Care programme's work. A suggestion was made that the applicant could consider using a sample rather than receiving national data, but DAAG were informed that as the applicant intended to use the national data to work with commissioners to improve Assuring Transformation reporting then using a sample would not be practical.</p> <p>Queries were raised about whether it would be possible for this pseudonymised dataset to be linked to the identifiable Assuring Transformations data already held by NHS England. It was noted that the applicant had committed that this data would be stored separately and that no attempt would be made to link the two; DAAG requested additional information about what controls were in place to prevent linkage. DAAG noted the number of different datasets that NHS England received for a range of purposes, and queried whether the HSCIC might wish to carry out an audit of NHS England at some point to review how these different datasets were stored separately.</p> <p><b>Outcome:</b> Recommendation to approve subject to the customer providing more detailed information on the measures in place to stop the pseudonymised data provided for this application being linked with the identifiable data already held.</p>
3.4	<p><u>University of Leeds - The Paediatric Intensive Care Audit Network (Presenter: Gaynor Dalton) NIC-376211-Y8B6R</u></p>

**Application:** This application was for HES data for a specific cohort to be linked with records maintained by the Paediatric Intensive Care Audit Network (PICANet), in order to help audit the care of children in intensive care units. The applicant had been granted section 251 support for the use of this data; the support had included a condition to update patient information materials to inform individuals of how to opt out, and this update had been made.

**Discussion:** A query was raised regarding the request for ordinance survey (OS) grid reference, as this was not clearly referred to in the applicant's section 251 support letters. It was noted that the section 251 support covered the use of postcode, so as OS grid references covered a larger area than postcodes then these would also be expected to be covered; confirmation of this was requested.

DAAG discussed the amount of data requested, and why data going back to 1997 was required. There was a suggestion that 20 years of data might be required in order to monitor outcomes over an appropriately long period of time, but it was agreed that this should be more clearly justified in the application summary. In addition, DAAG requested a clearer explanation of why identifiable data was required rather than using pseudonymised data.

It was noted that the information leaflet for parents referred to a number of funding organisations, including one international organisation. DAAG asked for clarification of any international funding, and any implications that this may have for data flows. The process for individuals to opt out was queried, as DAAG noted that the information leaflets for parents simply stated that parents should 'tell the nurse or doctor caring for your child' if they wished to opt out.

A query was raised regarding whether the applicant's section 251 support covered receipt of 'legal status' data and it was felt to be unclear why this data was required. In addition DAAG noted that the applicant's section 251 annual review date appeared to have passed, and no information was available about if an annual review application had been made or if this was in progress. It was agreed that this should have been confirmed prior to the application being brought to DAAG, and the application was therefore withdrawn.

**Outcome:** Application withdrawn, pending clarification of section 251 status and confirmation that the section 251 covers all data items requested such as legal status and patient identifiers including OS grid reference.

- A clearer justification was required of why identifiable data is required rather than pseudonymised, why 20 years of data are required and why data going back to 1997 is required.
- Clarification was requested of international funding, and any implications for data flows.
- Clarification was also requested of the process for opting out.

### 3.5 University Hospitals Coventry and Warwickshire NHS Trust (Presenter: Gaynor Dalton) NIC-368976-Z9X8S

**Application:** This was an application for pseudonymised HES data for use in comparative analysis and clinical benchmarking of the applicant organisation.

**Discussion:** DAAG queried references in the application to a commercial analytics team, and agreed that the application summary should be updated to include a clearer statement that the applicant would not seek to use the data requested to develop any commercial offerings.

Some concerns were raised regarding the amount of data requested, as DAAG were unsure whether providing the full dataset of national data solely to benchmark a single organisation could be considered proportionate. It was suggested that the applicant should clarify what specialities their organisation provided, as this might help to narrow down the number of data fields required if they did not need data on certain specialities. Another suggestion was that the applicant could identify a specific number of peer organisations to benchmark against, rather than comparing to

the entire country. In addition, confirmation was requested of why a monthly data feed was required rather than using a one-off data extract.

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

- The applicant should further consider what data minimisation efforts could be made and provide clarification about who are their peer organisations, what specialities do they provide, and why is a monthly feed required for benchmarking.

**3.6** University of Manchester - Trauma Audit and Research Network (TARN) (Presenter: Dave Cronin) NIC-326033-G1P7Q

**Application:** This application requested identifiable HES data, filtered to specific diagnoses relating to traumatic injury. This data would be used by TARN to measure completeness of data submissions to the TARN database for each hospital or trust, and to support service improvement by providing analytical feedback to trusts. DAAG were informed that the applicant had obtained section 251 support for the receipt of this data. Data was requested on a rolling basis with each year's data being destroyed once analysis was complete, and not retained for longer than a maximum of five years.

**Discussion:** The number of trusts participating in TARN was queried, as DAAG noted that membership of the network required the payment of a fee and it was suggested that if a significant proportion of trusts were not members then it might be disproportionate to provide data for the whole country. It was confirmed that membership was mandatory for all major trauma centres in the country.

DAAG queried the legal status of TARN; it was confirmed that this was a network managed by the University of Manchester and that it was not a separate legal entity. It was noted that TARN had previously received HES data under two separate data sharing agreements, and the perceived duplication of data provided in the previous two data sharing agreements was queried; DAAG were informed that the first agreement had included the provisional 2012-13 data that was available at the time but that the second agreement had provided final 2012-13 data. DAAG briefly discussed the applicant's fair processing notice, and advised that the applicant should update this to more clearly explain the data processing activities that they undertook.

The planned data retention period of five years was queried, as DAAG noted that the applicant's section 251 support letter stated that NHS number should not be retained for longer than three years.

The provision of identifiable data to each trust was discussed. DAAG were informed that each trust would only receive the data that it had originally submitted via HES and TARN, meaning that no additional legal basis would be required for each organisation to receive its own data back. It was agreed that the application summary would be updated to clarify that identifiable data would not be made available to any organisation other than the originating organisation.

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

- Confirmation that the applicant do not hold NHS number for longer than three years, in accordance with the section 251 support.
- Application summary to be updated to clarify that identifiable data is made available only to the originating trust and not to any other organisation.

DAAG advised that the applicant should update their fair processing materials to include the processing activities undertaken.

**3.7** Dr Foster Ltd (Presenter: Dickie Langley) NIC- 368020-R5L2K

**Application:** This application was to receive pseudonymised Summarised Hospital-level Mortality

Indicator (SHMI) data. DAAG were informed that due to the recently issued Office for National Statistics (ONS) directions, information intermediaries such as this applicant were now able to receive mortality data if they met certain conditions set by ONS, including providing a commissioning letter from one of the bodies specified in Section 42(4) of the Statistics and Registration Service Act 2007. It was confirmed that the evidence provided by the applicant had met ONS's criteria. The applicant intended to use SHMI data for their dashboard tool in order to identify mortality trends and alert hospitals with higher than expected mortality levels.

**Discussion:** A reference to Imperial College London as a 'partner' of Dr Foster was queried. DAAG were informed that while Imperial College London did work with Dr Foster on other uses of data, for the purpose of this application and the SHMI data requested Imperial College London would have no involvement. DAAG also queried the HES-ONS bridging file referred to in the application. It was clarified that HES and ONS data were linked to produce SHMI data, and that the applicant would only receive the linked data rather than the bridging file itself. DAAG asked for this to be more clearly explained in future SHMI applications.

DAAG asked what benefits had previously been achieved by Dr Foster using SHMI data, and were informed that Dr Foster had contributed to the development of the SHMI methodology. It was suggested that this should have been explained more clearly as part of the application summary.

DAAG discussed the applicant's DPA registration wording, and noted that the section relating to health research included the statement 'This information is about survey respondents' which could be misleading. DAAG suggested that the applicant should update this wording to clarify that the organisation processed healthcare data about patients.

A question was raised regarding whether data could be used overseas, given the international nature of the applicant organisation. It was confirmed that England and Wales had been specified as the territory of use in the application, and that the data sharing agreement would restrict use to those two countries only.

DAAG queried the statement that there were no commercial aspects to this application; it was explained that while Dr Foster Ltd was a commercial organisation, the dashboard would be made available free of charge to NHS Trusts only and data would not be used for any other commercial purposes. It was agreed that when a renewal application was made in future, a clearer explanation would be needed of the benefits to health or social care that had been realised through the use of this tool along with a clearer statement that there continued to be no commercial aspects to the use of data.

**Outcome:** Recommendation to approve.

- DAAG invited the applicant to review their DPA registration wording, and consider updating this to specify that they processed data about patients.
- DAAG would in future expect a clearer explanation of whether there were any commercial aspects to this application along with evidence of the benefits to health and social care that had been achieved.

### **3.8** CHKS Ltd (Presenter: Dickie Langley) NIC-368543-C3J4B

**Application:** This was also an application for pseudonymised SHMI data. It was noted that the purpose of this application was partly commercial, as the applicant organisation would use the data to provide consultancy services to the NHS, but that data would not be used for any sales or marketing purpose and no third parties would be given access to the record level dataset.

**Discussion:** DAAG asked for clarification of what data the applicant would receive, as the 'data requested' table in the application summary listed identifiable ONS data including date of death. DAAG were informed that this was used to produce the SHMI data, but that the applicant would only receive the pseudonymised linked data and would not receive date of death.

3.9	<p>The expected benefits were discussed, and DAAG agreed that more detail on the benefits achieved would be expected in future renewal applications. DAAG advised that the applicant should review their DPA registration wording, as this included a statement about 'information about survey respondents' that could potentially be misleading.</p> <p><b>Outcome:</b> Recommendation to approve. The applicant would be advised to update their DPA registration wording.</p> <p><u>Request for advice: London School of Hygiene and Tropical Medicine (Presenter: Dave Cronin) NIC-384756-P9V0B</u></p> <p><b>Application:</b> DAAG were asked to provide advice on a request that had been received to list clean a cohort to remove individuals who had died, so that when the applicant wrote out to the cohort they would not cause distress to the relatives of deceased individuals. The cohort had consented to participate in a study, but the consent materials had not referred to providing identifiable information to the HSCIC for list cleaning and had in fact stated that participants' personal details would not be made available outside the research team. In addition, the study protocol that had undergone ethical review did not include the use of list cleaning.</p> <p><b>Discussion:</b> DAAG queried what internal HSCIC advice had been previously sought, and emphasised the need to discuss cases such as this with the Data Access and Information Sharing (DAIS) team before they were brought to DAAG for advice.</p> <p>DAAG agreed that while it might be considered best practice to carry out list cleaning before attempting to contact the cohort, this could not be carried out without a legal basis to do so. It was suggested that the applicant should consider applying for section 251 support.</p> <p><b>Outcome:</b> DAAG advised that the applicant should consider approaching HRA CAG to apply for section 251 support. In cases such as these the members advised that the DAIS team should be approached for IG advice before the application comes to DAAG.</p>
4	<p><b>Any other business</b></p> <p>DAAG briefly discussed a paper on data minimisation that two members had drafted. It was agreed that the DAAG Secretariat would circulate the paper, and that it would be discussed at a future training session.</p> <p><b>Action:</b> DAAG Secretariat to circulate data minimisation paper.</p> <p>The Independent Group Advising on the Release of Data (IGARD) transition was discussed, and members agreed to send comments on the updated draft Terms of Reference via the DAAG mailbox. There would be a private session for members to discuss the transition following the 4 November DAAG meeting, after which the IGARD Terms of Reference would be finalised.</p> <p>There was a brief discussion of the process for sending outcome letters for applications that DAAG had been unable to recommend for approval. It was agreed that the agreed outcomes could be used in these letters before the draft DAAG meeting minutes had been signed off, on the understanding that it would be made clear that this wording was provisional and could potentially be amended if any corrections or concerns were raised regarding the draft minutes.</p>

## Summary of Open Actions

Date raised	Action	Owner	Updates	Status
22/09/15	To provide DAAG with additional information regarding local data flows through DSCROs, and a proposal for what governance should be in place for changes to these flows.	Kemi Adenubi	06/10/15: Ongoing. 13/10/15: An update would be provided for the 20 October DAAG meeting. 20/10/15: This action had been completed and was closed.	Closed
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. 20/10/15: Ongoing.	Open
13/10/15	Stuart Richardson to provide an update on how CCGs have validated invoices up to this point.	Stuart Richardson	20/10/15: DAAG were informed that previously CCGs had used deidentified data to validate invoices, but that there had been some problems with this process that now meant a number of CCGs were instead applying to use SUS data for invoice validation.	Closed
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.	Open
20/10/15	Paula Moss to provide an updated paper on DSCRO local data flows.	Paula Moss		Open
20/10/15	DAAG Secretariat to make the published DSCRO directions available to DAAG members via SharePoint.	DAAG Secretariat		Open
20/10/15	DAAG Secretariat to circulate data minimisation paper.	DAAG Secretariat		Open