

Data Access Advisory Group (DAAG)

Minutes of meeting held 1 December 2015

Members: Joanne Bailey, John Craven, Eve Sariyannidou, James Wilson, Dawn Foster

In attendance: Vicki Williams, Dave Cronin (part), Gaynor Dalton (part), Steve Hudson, Dickie Langley, Paula Moss (part), Stuart Richardson (part), Terry Hill (part)

Apologies: Alan Hassey (Acting Chair), Sean Kirwan

1 It was agreed that Joanne Bailey would chair the meeting in the absence of the Acting Chair.

Declaration of interests

James Wilson declared a conflict of interest for application 2.6 University College London and it was noted that he would take part in discussions, as required, but would not vote.

Review of previous minutes and actions

The minutes of the 24 November 2015 meeting were reviewed and agreed as an accurate record subject to minor amendments to the attendees and additional caveat added to NIC-365714 NHS England Temporary National Repository (see matters arising below).

Action updates were provided (see table on page 9):

Terry Hill to provide a written report on the SIGGAR/SOCCER application (NIC 291981) application. This application was considered by DAAG on the 10 November 2015 and was not recommended for approval as DAAG did not see a legal basis to support the flow of data. After conclusion of the DAAG meeting the Information Governance Team sought additional information to establish the legal basis including that relating to ONS. DAAG noted that a written note had been received from Terry Hill and a SIRO letter had been issued to the applicant without further consideration by DAAG and the data flowed to the applicant.

ACTION: DAAG members asked Alan Hassey to seek clarification from HSCIC with regard to their policy and processes where they either don't seek DAAG advice or take action contrary to DAAG's advice with regard to the release of data.

DAAG Members noted that the Data Dissemination Framework was currently in draft and to ensure transparency, would like to contribute to this document.

Terry Hill to provide a written report on the Imperial College London (SAHSU NIC 204903) application. This application had been considered by DAAG on the 10 November and recommended for approval subject to two caveats. Terry Hill provided a written note stating that the HSCIC would ensure the caveats had been addressed and the applicant had been issued with a data sharing agreement with a stated condition that data could be released until the HSCIC had decided that the caveats were closed.

Matters Arising

DAAG noted that further information with regard to application NIC 365714 NHS England Temporary National Repository which was considered at the 24 November meeting had been made available at today's meeting by HSCIC, and subsequently a further caveat would be added to the minutes:

- *Assurances were sought that the data is pseudonymised and that the two sets of data (pseudonymised and identifiable) are kept separate, that there is no access to the key and*

	<p><i>that appropriate security policies were in place.</i></p> <p>Out of committee recommendations</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"> • NIC-393388 Northumberland, Tyne & Wear NHS Foundation Trust • NIC-355868 Ramsay Health Care • NIC-374630 University Hospital of Leicester NHS Trust
2	<p>Data Applications</p>
2.1	<p><u>Southend CCG Risk Stratification (Presenter: Stuart Richardson) NIC-381643-Q6Q2Z</u></p> <p>Application: This application is to use Secondary Use Service (SUS) data, identifiable at the level of NHS number by Southend CCG for use in risk stratification. Risk stratification provides a forecast of future demand by identifying high risk patients which enables commissioners to initiate proactive management plans for patients that are potentially high service users. The original risk stratification application (NIC-301903-D9C4N) was approved by DAAG on 12 November 2014. The application was presented to DAAG on the 27 October but withdrawn.</p> <p>Discussion: DAAG queried why their previous question around the data destruction or transfer of data from MedeAnalytics to PI Benchmark had not been answered and asked for clarification as to whether MedeAnalytics had destroyed the data or transferred it to PI Benchmark.</p> <p>DAAG noted that the Data Processor was set to change again in the future and asked that information with regard to data deletion or transfer of data be included in any future applications and that this was automatically included within the HSCIC processes.</p> <p>DAAG noted that Fair Processing could be re-written in Plain English as the current fair processing notice contained a lot of jargon. DAAG briefly discussed the Data Protection Act (DPA) registration wording and DAAG suggested that the applicant should consider updating this to include reference to General Practitioners.</p> <p>Outcome: Recommendation to approve subject to the following caveat:</p> <ul style="list-style-type: none"> • Clarification sought as to whether the data was destroyed by MedeAnalytics or transferred to the new Data Processor, PI Benchmark. <p>In addition, DAAG advised that in places the Fair Processing Notice be re-drafted in Plain English. DAAG advised that DPA registration wording be updated to include reference to sharing with General Practitioners.</p>
2.2	<p><u>Group application – Risk Stratification (Doncaster CCG, NIC-390126-V0L6H Surrey Downs CCG, NIC-390111-Q6Q9D Wandsworth CCG) (Presenter: Stuart Richardson) NIC-390205-R2J2J</u></p> <p>Application: This is a group renewal application for Doncaster Clinical Commissioning Group (CCG), Surrey Downs CCG and Wandsworth CCG to use Secondary Uses Service (SUS) data identifiable at the level of NHS number for use in risk stratification. Risk stratification provides a forecast of future demand by identifying high risk patients which enables commissioners to initiate proactive management plans for patients that are potentially high service users.</p> <p>Discussion: Stuart Richardson noted that the IG Toolkit score for the Commissioning Support Unit (CSU) was not included in the application and that it was 100%.</p>

DAAG noted that the fair processing notices had misleading and missing information which may affect the legal basis and asked for an undertaking within two weeks that the notice would be updated within a further six weeks in line with DAAG advice.

DAAG also queried why they had not had sight of NHS England's privacy notice and asked that the website link be provided for review, noting that NHS England are processing the data.

DAAG queried whether the CCG's would have sight of or access to the other CCG's data and asked for clarification that each CCG would only have access to their own patient data for the purpose of risk stratification.

Outcome: The group applications were approved subject to the following caveats:

- Undertaking within two weeks that the applicant will update their fair processing notices within a further six weeks in line with DAAG advice, with DAAG to be notified once the changes have been made.
- Section 7 of the application to be updated to include the correct IG Toolkit score for the CSU.
- The application be updated to include the privacy notice website link for NHS England.
- Clarification was sought that each CCG will only have access to their own patient data and updated in the application.

2.3 Clinical Practice Research Datalink (CPRD) – clinical practice data (Presenter: Dickie Langley) NIC-366782-V7J8C

Application: This application is a request to add Mental Health Minimum Data Sets (MHMDS) and Patient Reported Outcome Measures (PROMs) data to CPRD's agreement as well as to receive an additional year of Hospital Episodes Statistics (HES) data. Previous agreement NIC-326073 gained DAAG approval in March 2015 this was for the addition of Diagnostic Imaging Dataset (DIDs) data. An extra year of HES data was applied for under NIC-368694-D8G4M. Dickie Langley noted that he had not clarified whether the Mental Health Data was sensitive or non-sensitive.

Discussion: DAAG noted that posters and leaflets would be available at the surgeries but noted their unhappiness with regard to the limited information given to patients around the opportunity to opt out and would like to see the CPRD address this issue. DAAG advised that the CPRD should consider supporting the General Practitioner (GP) Practices fulfil their commitments as Data Controller to ensure that patients, where possible, have full sight of all posters and leaflets.

DAAG noted that the patient information leaflet should be updated to include clearer information with regard to opting out and also note within the leaflet that opting out would not affect the care that they receive.

DAAG asked that the future tense wording within the application be addressed along with the removal of the named data system. DAAG also queried the use of Mental Health data acronyms and it was noted that this was due to the change in what the data set contained. DAAG asked for clarification and a full explanation.

DAAG queried the legal basis for Office for National Statistics (ONS) data and S251 support including the lack of a list of approved researchers. It was noted that ONS did not see this is disclosive and had not asked for a list of names, however DAAG queried this and it was agreed that ONS be asked as why a list of names was not required. DAAG also queried the data dissemination route and asked for clarification with regard to the impact including a link to the website.

Outcome: Recommendation to approve, subject to the following caveats:

- Application to be updated to amend future tense wording and removal of the named

system.

- Application to be updated to include further information around data dissemination route and the impact.
- Application to be updated with regard to the mental health data being sensitive or non-sensitive.
- Mental health data sets to be explained in full and the application form updated.
- Clarification of legal basis for ONS data.
- Clarification of whether DAAG should be provided with a list of researchers.

In addition, DAAG advised CPRD to consider supporting GPs fulfil their data controller obligations. DAAG advised that the patient leaflet be updated to give patients 'how to opt out' information and to include wording that opting out won't affect the care they receive.

2.4 Imperial College London – Diversity in Ethnicity, Lung function and Birth weight in Young Adults (DELBYA) study (Presenter: Dave Cronin) NIC-01189-Y2V3W

Application: This application is a request from the National Heart and Lung Institute at Imperial College London for the HSCIC to provide the birth weight of 112 consented participants of the DELBYA study. Recruitment is complete and the PIS and consent form are no longer in active use.

Discussion: DAAG sought written assurance from the IG ISA and DAT teams as to the source of the data and whether the appropriate route was used as a legal basis. DAAG suggested a data flow diagram might be helpful.

DAAG queried how the cohort was being kept informed as students are a highly mobile population. DAAG also asked for any information with regard to a link between the pilot study and larger study.

Outcome: The application was withdrawn.

2.5 Imperial College London – practice level associations with joint replacement rates (Presenter: Dave Cronin) NIC-379725-X1R1X

Application: This is an application from Imperial College London for Patient Reported Outcome Measures (PROMs) data including two linked Hospital Episodes Statistics (HES) fields for use in a research study. This application was previously considered by DAAG on 28th July 2015 under reference NIC-349023-R3Z1V and was not recommended for approval.

Discussion: DAAG noted the previous concerns raised on the 28 July had been addressed.

DAAG noted that this was a programme of work rather than a project and sought clarification that the data would not be used in conjunction with any other data received and that the application be updated. DAAG also queried reference to a report being published and it was noted that the terminology should be updated to 'output'.

DAAG queried linkage and level of data required and it was noted that the applicant was only interested in the practice level data to compare against national thresholds and social deprivation.

Outcome: Recommendation to approve subject to the following caveats:

- Clarification sought with regard to data requested.

Application to be updated to state 'dissemination of the outputs' and remove reference to the dissemination of the data.

2.6

University College London Hospitals (UCLH) NHS Foundation Trust – Brightlight (Presenter: Gaynor Dalton) NIC-384137-V8F6H

Application: The applicant is seeking a tailored data linkage and HES extract of individual episodes including in patient (admitted patient care), outpatient, and Accident & Emergency (A&E) data. UCLH requires Hospital Episodes Statistics (HES) data in order to derive a measure of specialist care for the BRIGHTLIGHT teenage and young adult (TYA) cancer cohort study, specifically the proportion of overall hospital care taking place in dedicated teenage cancer centres or specialist cancer centres within the first six months of diagnosis. This information will then be used to evaluate the added benefit to patients of being treated at a specialist unit in relation to their general health and wellbeing, and the cost-effectiveness of specialist care in comparison to other types of cancer care. UCLH will provide the HSCIC with study ID, NHS number and date of birth for linkage to HES. The HSCIC will provide the linkage to HES Admitted Patient Care (APC), outpatients and A&E.

Discussion: DAAG queried whether the NHS Trust and University were both Data Processors and sought clarity. In relation to this query, DAAG then asked if the individuals accessing the data were employed by either of the Data Processors and asked that a statement be added to the application to clarify this, stating that only individual employed by the Data Processors would have access to the data.

DAAG queried the protocol with regard to partners and asked that the application be updated to clarify that project partners will not have access to data.

DAAG briefly discussed the Data Protection Act (DPA) registration wording and DAAG suggested that the applicant should consider updating this to refer to processing data about healthcare users or patients.

Outcome: Recommendation to approve, subject to the following caveats:

- Clarification sought with regard to who is the Data Processor.
- Updating the application summary to state that all individuals with access to data are employed by one of the Data Processors.
- Application to be updated to add in a sentence clarifying that partners will not have access to data.

DAAG advised that the applicant should consider updating their DPA registration entry to refer to processing data about patients or healthcare users.

2.7

Public Health Dorset – Pseudonymised HES Extract Service (Dorset County Council, Bournemouth Unitary Authority, Poole Unitary Authority) (Presenter: Gaynor Dalton) NIC-387891-W3F3B

Application: This application is a request for Dorset County Council to access the standard set of pseudonymised HES data for all upper tier Local Authorities (with a Public Health function) in England. Public Health Dorset, hosted by Dorset County Council for the purposes of information governance controls, finance, HR etc., has the responsibility for the public health, and public health intelligence, of three authorities - Dorset County Council, Bournemouth Unitary Authority and Poole Unitary Authority, commonly referred to as the Pan-Dorset area.

Discussion: DAAG noted that data was only being processed by the public health team at Public Health Dorset and noted that the summary information was helpful in explaining the Pan-Dorset area set up, however DAAG asked that future applications using the template ensure that paragraph two of the summary be struck through if not appropriate to the application, including this application.

DAAG asked that the application, including the template for future applications, be updated to be clear that no data will be shared with any third party, this includes organisations processing data on behalf of the local authority or in connection with their legal function. DAAG also asked that the template and future applications be updated to move the paragraph starting “The Director of Public health...” to after sub-heading ‘Conditions of supply and controls on use of’ in order for the paragraph to flow better.

DAAG briefly discussed the Data Protection Act (DPA) registration wording and DAAG suggested that the applicant should consider updating this to refer to processing data about healthcare users or patients.

DAAG also noted that the applicant had made a considerable effort to update their privacy notice but asked that they update their notice in line with the ICO privacy notice code of practice, and within eight weeks.

DAAG noted that Public Health Dorset’s website was commendable and that the Public Health link be added to Bournemouth Unitary Authority and Poole Unitary Authority council websites.

Outcome: DAAG recommend for approval subject to the following caveats:

- The Public health website link for Public Health Dorset to be added to Bournemouth and Poole Council websites

It was agreed that the template application would be updated:

- To move the paragraph starting “The Director of Public health...” to after sub-heading ‘Conditions of supply and controls on use of’.
- To clarify no data will be shared with any 3rd party, this includes organisations processing data on behalf of the local authority or in connection with their legal function.
- To be updated to strike through in tracked changes paragraph 2, where applicable.

DAAG advised that the applicant should consider updating their DPA registration entry to refer to processing data about patients or healthcare users. DAAG also noted that the applicant would need to update their privacy notice in line with the ICO privacy notices code of practice and within eight weeks.

DAAG commended the Public Health Dorset website.

2.8 The Royal College of Anaesthetists – national emergency laparotomy audit (Presenter: Gaynor Dalton) NIC-355855-R4G6G

Application: This is a new application in order to link HES admitted patient care and ONS mortality data with the applicant’s anonymised version of the National Emergency Laparotomy Audit (NELA) data. The purpose of the audit is to improve treatment quality within hospitals, and research methods to monitor surgical outcomes. The NELA IT system that holds the identifiable database does not get updated with data from the HSCIC. The HSCIC data would only be linked to an extract of anonymised data from the NELA IT system, being linked with the system-generated NELA identifier and the Hospital Episodes Statistics Patient ID (HESID).

Discussion: DAAG noted that the HQIP security assurance wording was not included in the security section and the application be updated.

DAAG also queried why the S251 application was not included in the application pack along with the S251 letter from HRA CAG and asked that it be provided along with the data flow diagram, this was to assure DAAG that S251 support related to both Data Processors and the data flows.

DAAG queried the data being requested and asked that Section 3 of the application be updated to separate out the data flowing into the HSCIC and data flowing out and legal basis for both sets of

	<p>data flow. DAAG noted that S251 was due for renewal within the next two months and noted that they would expect to receive assurance from HSCIC's Information Governance ISA team who would liaise with HRA CAG.</p> <p>DAAG asked for clarification around who the Data Processor was and asked if the individuals accessing the data were employed by the Data Processor and asked that a statement be added to the application to clarify this, stating that only individual employed by the Data Processor would have access to the data.</p> <p>DAAG advised that the applicant should consider updating their Data Protection Act (DPA) registration entry to refer to processing data about patients or healthcare users and separate from entry relating to 'fundraising'.</p> <p>Outcome: The application was deferred to a future meeting of DAAG, with further information noted below:</p> <ul style="list-style-type: none"> • The S251 application to be provided to DAAG. • The data flow diagram provided to HRA CAG to be included with the application. • Clarification around the two Data Processors and who is doing what. • To update the application to clarify that all individuals with access to data are employed by one of the Data Processors. • To provide security assurance wording with regard to HQIP. • Clarification with regard to the data requested and separating the data flowing into the HSCIC and data flowing out. <p>DAAG advised that the applicant should consider updating their DPA registration entry to refer to processing data about patients or healthcare users and be separate from 'fundraising'.</p> <p>DAAG also noted that in future IG ISA (formally DAIS) be given sight, as per processes, of all applications where S251 renewal is within two months of the renewal date.</p>
<p>3</p> <p>a)</p> <p>b)</p>	<p>Any other business</p> <p>NIC-370861 University College London (Presenter: Dickie Langley) The application had been previously discussed at DAAG on the 13 October 2015 and had been recommended for approval with two caveats:</p> <ul style="list-style-type: none"> • The draft website wording should be redrafted to use Plain English. • The applicant should work with the HSCIC to update the draft wording in order to provide clearer information about the HSCIC, and about how individuals can object. <p>It was noted that DAAG were expecting that this Patient Objection Management System would be discussed in future and following review by Dame Fiona Caldicott.</p> <p>Outcome: DAAG members agreed that the second caveat be removed from the minutes without setting any future precedent and in anticipation of further guidance.</p> <p>NIC-382334 National Audit Office Terry Hill (TH) joined DAAG to update members on the National Audit Office (NAO) application (NIC-382334) and the release of data to the NAO which is Pseudo non-sensitive HES and SUS, and Pseudo sensitive Mental Health. TH noted that the release of data was requested under NAO statutory powers (The Audit Act 1983 (8)(1) and disseminated under the Health and Social Care Act S261(5d)). TH noted that he was not seeking approval for the application from DAAG and that the decision to disseminate data had been taken outside of the DAAG independent process.</p>

	<p>DAAG members sought assurances that processes would be put in place for any future disseminations of data to applicants that did not come to DAAG for consideration to ensure transparency and accountability. It was agreed that the DAAG Acting Chair would work with the HSCIC to inform process and ensure accountability and transparency for all releases of data.</p>
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	<p>DAAG members thanked TH for attending and providing a clear update on this application.</p>
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Summary of Open Actions

Date raised	Action	Owner	Updates	Status
20/10/15	Paula Moss to provide an updated paper on DSCRO local data flows.	Paula Moss	10/11/15: A draft paper had been provided to the DAAG Chair by email but had not yet been circulated to the group. 01/12/15: ongoing	Open
03/11/15	Information Governance team to liaise with MedeAnalytics regarding their DPA registration to ensure that it reflects recent applications.	Dawn Foster	01/12/15: Ongoing.	Open
10/11/15	Dawn Foster and Alan Hassey to contact NHS England Director for Data and Information Management Systems regarding the need for more formal evidence that NHS England support certain applications from CSUs, and invite her to attend a future DAAG training session.	Alan Hassey	01/12/15: Ongoing.	Open
10/11/15	Dawn Foster to contact HRA CAG regarding lack of clarity in section 251 support letters.	Dawn Foster	01/12/15: Dawn Foster & Alan Hassey meeting with HRA CAG on the 08/12/15	Open
10/11/15	Gaynor Dalton to inform DAAG once Imperial College London (SAHSU) have published information for patients and the public as per their implementation timeline.	Gaynor Dalton	01/12/15: Steve Hudson noted that the proposed website information had been received with a timeframe of publication of early next year. DAAG asked for an update at a future DAAG meeting	Open
17/11/15	Terry Hill to provide a written report on the SIGGAR/SOCCER application (NIC-291981-Y7J2F Imperial College London)	Terry Hill	01/12/15: This application was considered by DAAG on the 10 November 2015 and was not recommended for approval as DAAG did not see a legal basis to support the flow of data. After conclusion of the DAAG meeting the Information Governance Team sought additional information to establish the legal basis including that relating to ONS. DAAG noted that a written note had been received from Terry Hill and a SIRO letter had been issued to the applicant without further consideration by DAAG and the data flowed to the applicant.	Open
22/11/15	Terry Hill to provide a written report on the	Terry Hill	01/12/15: This application had been considered by DAAG on the 10	Open

	Imperial College London (SAHSU NIC-204903-P1J7Q) application.		November and recommended for approval subject to two caveats. Terry Hill provided a written note stating that the HSCIC would ensure the caveats had been addressed and the applicant had been issued with a data sharing agreement with a stated condition that data could be released until the HSCIC had decided that the caveats were closed.	
24/11/15	DAAG Secretariat to ask Dawn Foster to provide advice on the security aspects of encrypted data storage used solely for disaster recovery purposes, and the implications this has for DPA registration.	DAAG Secretariat	01/12/15: DAAG Secretariat to provide Dawn Foster with background information	Open
24/11/15	Alan Hassey to contact HRA CAG regarding the process for DAAG to consider applications when a section 251 annual review date is pending.	Alan Hassey	01/12/15: Dawn Foster & Alan Hassey meeting with HRA CAG on the 08/12/15	Open
01/12/15	DAAG members asked Alan Hassey to seek clarification from HSCIC with regard to their policy and processes where they either don't seek DAAG advice or take action contrary to DAAG's advice with regard to the release of data.	Alan Hassey		