

Data Access Advisory Group (DAAG)

Minutes of meeting held 13 October 2015

Members: Joanne Bailey, Patrick Coyle, John Craven, Dawn Foster, Eve Sariyannidou

In attendance: Frances Hancox, Vicki Williams, Steve Hudson, Jen Donald, Gaynor Dalton, Dickie Langley, Dave Cronin, Stuart Richardson, Julia King, Netta Hollings, Emma Lawler

Apologies: Alan Hassey, James Wilson, Sean Kirwan

1	<p>In the absence of the Interim DAAG Chair it was agreed that Joanne Bailey would chair the meeting.</p> <p>Declaration of interests</p> <p>John Craven declared a potential conflict of interest with the Kings College London application scheduled for discussion, and agreed not to participate in the discussion of that item. Eve Sariyannidou declared that she had been a student at the University of Bristol some years previously but it was agreed that this did not present a conflict of interest that would prevent her from participating in the discussion.</p> <p>Review of previous minutes and actions</p> <p>The minutes of the 6 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 9).</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- 371050-X4H9L East and North Hertfordshire CCG Stage One Accredited Safe Haven• NIC-376184-B2F2K University of York
2 2.2	<p>Data applications</p> <p><u>Group Invoice Validation Application for 4 CCGs¹ (Presenter: Stuart Richardson)</u></p> <p>Application: This was a group application for each clinical commissioning group (CCG) to receive Secondary Uses Service (SUS) data for their CCG that was identifiable at the level of NHS number. This data would be transferred via North East London Commissioning Support Unit (CSU) as a landing point, then stored in each CCG's Controlled Environment for Finance and used for the purpose of invoice validation. This was covered by an overarching section 251 support for invoice validation, and it was noted that all organisations held appropriate DPA registrations and had achieved satisfactory IG Toolkit scores.</p>

¹ Mid Essex CCG NIC-381543-V2J4W, North East Essex CCG NIC-381544-K1V8Q, Southend CCG NIC-381547-V1J5Z, Thurrock CCG NIC-381537-H4V4M

Discussion: A query was raised regarding how applicants who had not previously received SUS data for the purpose of invoice validation had carried out the validation process to date. It was agreed that further information about this would be requested.

Concerns were raised regarding the CCGs' fair processing notices, as it was felt that these contained some misleading statements that could potentially impact the legal basis for using data for purposes such as risk stratification. However it was agreed that these did not impact the use of data for invoice validation. DAAG noted that one CCG also had an outdated notice still available on their website and suggested that this should be removed to avoid confusion.

Outcome: Recommendation to approve.

- DAAG advised that the applicants should update their fair processing notices in line with the ICO Privacy Notices Code of Practice, particularly in terms of accessibility and readability, and amend some statements that could affect the legal basis for other purposes such as risk stratification. This would be expected to have been completed prior to making a renewal application.

Action: Stuart Richardson to provide an update on how CCGs have validated invoices up to this point.

2.3

Newcastle University - Survivors and predictors of survival in children born with congenital heart conditions; BINOCAR (Presenter: Jen Donald) NIC-325182-Q4K2S

Application: This application was for a one-off linkage of ONS mortality data and Index of Multiple Deprivation (IMD) score for a cohort of children born with congenital heart disease; it was noted that the applicant had obtained Approved Researcher accreditation from ONS. The HSCIC would receive identifiers for this cohort and carry out linkage, before sending pseudonymised linked data to the Public Health England (PHE) Regional Maternity Survey Office.

Discussion: DAAG noted that PHE would receive data, and queried why Newcastle University were listed as the applicant as they would not process any data. It was explained that Newcastle University were the sponsor for this work and that they had previously intended to take part in the data processing, but that it had been agreed data would be sent directly to PHE for practical reasons. DAAG discussed this at some length, and it was agreed that as Newcastle University now did not have a role in data processing then PHE should have been listed as the applicant organisation. It was noted that the study protocol provided referred to data being transferred to Newcastle University and DAAG requested clarification of this.

The section 251 support for this study was discussed, and it was noted that the letter from the Health Research Authority Confidentiality Advisory Group (HRA CAG) referred to sending anonymised data to PHE whereas the application summary provided to DAAG stated that pseudonymised data would be shared. This discrepancy was queried, and while it was suggested that this could be due to differences in how data was described by different bodies it was agreed that a copy of the original section 251 application would need to be requested in order to confirm whether or not the section 251 support covered sharing pseudonymised data.

The planned data retention period of 10 years was discussed, and a clearer justification for this period was requested. It was noted that the fair processing materials for the study were in the process of being updated and DAAG requested sight of the updated materials. A reference in the application summary to address data was queried, as it was not thought that this would be covered by the section 251 support. DAAG were informed that address data would not be used, and the application would be updated to correct this. There was a discussion of the employment status of the two individuals named in the application, one of whom was jointly employed by Newcastle University and PHE and the other of whom was a PhD student working under an honorary contract. DAAG requested clarification of whether this study was part of a PhD project.

Outcome: Unable to recommend for approval

- The application should be resubmitted with PHE as the applicant organisation.
- The data flow diagram should be updated to remove references to addresses.
- Clarification is required of the PhD student's status and whether they are also employed by PHE, and whether this study is part of a PhD project.
- Updated fair processing materials should be provided.
- The study protocol still refers to transferring pseudo-anonymised data to Newcastle University, and this should be clarified.
- A copy of the section 251 application submitted to HRA CAG should be provided.
- A clearer justification is needed for the planned data retention period.
- The applicant should be advised to ensure that outputs are disseminated to appropriate professional bodies.

2.4

King's College London - The Developmental consequences of very-preterm birth (Presenter: Jen Donald) NIC- 370701-M8F1H

Application: This was a new application for list cleaning services, in order for the applicant to receive latest address and GP registration details for a cohort of infants whose parents had provided consent to participate in a study. As the original consent had not been deemed appropriate for the data processing requested, the applicant had obtained section 251 support to provide a legal basis. It was acknowledged that the application summary referred to using next of kin data, but a query regarding this had been raised prior to the DAAG meeting and it had now been confirmed that this was not covered by the applicant's section 251 support. Next of kin data would therefore not now be used.

Discussion: DAAG were generally content to recommend this application for approval. However a query was raised regarding the applicant's DPA registration wording, as the full text had not been provided and it was not clear from the excerpt included whether the wording was clear that the organisation processed health data from individuals other than those connected to the College. It was agreed that the full wording would be circulated.

Outcome: Recommendation to approve, subject to providing the applicant's full DPA registration wording to DAAG members.

2.5

University of Bristol - Cluster randomised trial of testing for Prostate cancer (Presenter: Dave Cronin) NIC-319171-G7H8K

Application: This was an application to receive pseudonymised Hospital Episode Statistics (HES) and Diagnostic Imaging Dataset (DIDs) data for a specific cohort, in addition to the ONS mortality and cancer registration data already received for this study under separate data sharing agreements. Data would be transferred to the Secure Anonymised Information Linkage (SAIL) databank at the University of Swansea, who would link the data together with other pseudonymised data and provide the linked pseudonymised data back to the University of Bristol. DAAG were informed that the use of SAIL in order to link data had not been included in the applicant's previous application to ONS, and the applicant had therefore applied to ONS for an amendment.

Discussion: DAAG noted that although the applicant had made an amendment application to ONS, confirmation had not been received of whether or not this had been approved. The most recent documentation for the applicant's section 251 support had not been provided, and DAAG requested sight of this. DAAG also noted that the applicant had already received data for this purpose under a separate data sharing agreement, and asked for this to be listed in the application summary in order to provide context for the current request. The planned data retention period was queried, and a clearer justification for this period was requested.

The need to ensure appropriate dissemination of outputs was discussed, in order to ensure that benefits to health and social care would be realised. DAAG discussed the possibility of making a Plain English report of the trial results available to the public, but on balance felt that it would be more appropriate for the applicant to share outputs with appropriate bodies such as NICE or the Cochrane Centre.

It was noted that the application summary referred to the applicant updating posters and fair processing materials, and DAAG requested sight of these updated materials. In addition it was noted that the application summary stated that the applicant had applied for a major amendment to the study's ethical approval, and DAAG requested confirmation that this had been approved. A reference to data being transferred to 'the University' was queried, and it was agreed this would be amended to clarify that this referred to the University of Bristol.

Outcome: Unable to recommend for approval.

- Confirmation is required from ONS that the requested amendment has been approved.
- A clearer justification is needed for the planned data retention period.
- A copy of the updated fair processing materials should be provided.
- Confirmation is required of ethical approval for the major amendment referred to.
- Copies of the applicant's section 251 documentation were requested.
- The applicant should be advised to ensure outputs are shared with appropriate bodies such as NICE or the Cochrane Centre.
- The application form should be updated to list the data already held by the applicant for this purpose, and to clarify a reference to 'the University'.

2.6

University College London - Mixed methods analysis of the London Hyperacute Stroke System: identifying lessons on 24/7 working (Presenter: Dickie Langley) NIC-370861-N5H8G

Application: This was an application for identifiable, linked HES and ONS mortality data. The application had previously been considered at the 7 April 2015 DAAG meeting (NIC-310876-D4S7B) when DAAG had been unable to recommend approval. Evidence had been requested of the legal basis for release of data, which had now been provided with confirmation from ONS that Section 42(4) of the Statistics and Registration Services Act 2007 applied. As requested additional information had been supplied about how data would be filtered to focus on ischaemic heart diseases, and about how outputs would be disseminated to maximise benefit to the health and care system. In addition following DAAG's previous comments on the applicant's fair processing materials, updated draft website text had now been provided which referred to the HSCIC and indicated that individuals should contact the HSCIC if they wished to opt out.

Discussion: DAAG agreed that the majority of the concerns previously raised had now been addressed. However there remained some concerns regarding the draft website text, as it was felt that this should be written more clearly using Plain English that members of the public could more easily understand. In addition DAAG suggested that the HSCIC should work with the applicant to update this wording to provide a clearer explanation of the role of the HSCIC and how individuals could object.

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

- 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.

2.7

Specialist Orthopaedic Alliance – Surgical performance dashboard (Presenter: Gaynor Dalton) NIC-369580-J4P0N

Application: This application was to amend and extend an existing agreement, which had previously been considered and recommended for approval by DAAG at the 27 January 2015 meeting (NIC-275445-L6X9T). The previous application had been for pseudonymised HES data for use in an orthopaedic and spinal performance dashboard; no additional data was requested, but the applicant now wished to retain that HES data for a further twelve months and use it for an expanded surgical performance dashboard. In addition a third data processor (University College London) had been added to the application.

Discussion: DAAG discussed the change in purpose from an orthopaedic and spinal performance dashboard to an overall surgical performance dashboard. It was agreed that this was a significant expansion of the original purpose, and this should have been submitted as a new application rather than an amendment to the existing application. More information was required about the expected benefits of this expanded dashboard, as the benefits currently cited were mostly focused on orthopaedics rather than the expanded surgical remit, and DAAG noted the importance of ensuring that outputs were disseminated appropriately in light of the new expanded purpose. It was noted that the application summary stated that the expanded dashboard had been commissioned by the Department of Health, and DAAG requested sight of the evidence for this in support of the application.

The role of the additional data processor was queried, as it was unclear what work they would undertake and whether this would affect the flow of data to the other organisations involved. DAAG suggested that a data flow diagram would help to clarify this.

DAAG noted that during the previous discussion of the application on 27 January 2015, a query had been raised regarding whether data would be used for any commercial purposes. While it was acknowledged that this concern had been addressed at the time, it was suggested that the application summary should be updated to include a statement that data would not be used for marketing or sales purposes. In addition, a reference in the application summary to 'partners' was queried and it was agreed that this would be clarified.

Outcome: Unable to recommend for approval.

- The application should be resubmitted as a new application, with evidence that the Department of Health have commissioned the expanded dashboard.
- Additional information should be provided about the expected benefits of the expanded dashboard, with details of how outputs will be appropriately disseminated.
- Clarification is needed of the role of the additional data processor, potentially with the use of a data flow diagram.
- The application summary should be updated to include a statement that data will not be used for sales or marketing purposes, and to amend a reference to 'partners' to refer to the specific data processors.

2.8 McKinsey and Co (Presenter: Gaynor Dalton) NIC-368233-L2N0W

Application: This application was to renew an existing agreement for the applicant to receive pseudonymised, non-sensitive HES and SUS data for use in benchmarking and analysis services for NHS organisations. The applicant had confirmed that any data more than three years old would be deleted, so that at any time they would only retain the most recent three years of data.

Discussion: The amount of data requested by the applicant was discussed, and while only a relatively small number of projects making use of this data were described it was noted that these were only examples of the work undertaken. A suggestion was made that the applicant should in future consider whether any further efforts could be made to minimise the amount of data required, such as by making use of sampling techniques, but it was acknowledged that the provision of national data for these purposes was at present consistent with the approach taken with other similar applications.

	<p>DAAG discussed the applicant's DPA registration wording, and noted that due to the way this had been phrased it could be interpreted that the applicant only processed health data relating to survey respondents. It was agreed that the applicant should be advised to update this to avoid confusion. In addition DAAG noted that the applicant's DPA registration was shortly due to expire, and requested confirmation once this had been renewed.</p> <p>Outcome: Recommendation to approve.</p> <ul style="list-style-type: none"> • DAAG will be provided with confirmation once the applicant's DPA registration had been renewed. • The applicant should be advised to update their DPA registration wording to avoid the implication that the health data processed only relates to survey respondents.
2.10	<p><u>Care Quality Commission – KP90 data (Presenter: Netta Hollings) NIC-380095-G0Q4C</u></p> <p>Application: This was an application to receive a bespoke extract of data on admissions, changes in status and detentions under the Mental Health Act 2007 (KP90 data). This would be used to inform the production of the applicant's annual report on uses of the Mental Health Act, as part of CQC's statutory function to monitor the use of this Act.</p> <p>Discussion: DAAG queried whether the Mental Health and Learning Disabilities Dataset (MHLDDS) data held by the applicant should have been listed on the application form; it was confirmed that while MHLDDS data did include some information about uses of the Mental Health Act, the applicant did not currently use that data for this purpose.</p> <p>A query was raised regarding whether KP90 data included any identifiers, and it was confirmed that the data requested was aggregated data with small numbers unsuppressed but with no identifiers. A reference to needing pre-release approval from the Statistical Governance team was also queried, but it was confirmed that this was an internal HSCIC process and was not expected to impact the release of data. Some references to pseudonymised data and small number suppression in the application form were queried, and it was agreed that this should be updated to clarify that the data requested was aggregate with no small number suppression.</p> <p>Outcome: Recommendation to approve</p> <ul style="list-style-type: none"> • The application summary would be updated to correct references to pseudonymised data and small numbers.
2.11	<p><u>University of Sheffield - Impact of closing Emergency Departments in England (Presenter: Dave Cronin) NIC-340495-Q7R8B</u></p> <p>Application: This was a new application for pseudonymised HES data to support a study into the impact of closing Emergency Departments, funded by the National Institute for Health Research (NIHR). The study would focus on five Emergency Departments that had been closed, and the applicant intended to use national HES data to select five other Emergency Departments as a control group. Data was requested for a period of six months only, and it was anticipated that at the end of this period the applicant would be able to confirm that they had deleted any national data not relevant to the control group they had selected. The applicant intended to apply for ONS mortality data at a later date, pending clarification of the legal basis for this.</p> <p>Discussion: DAAG noted that the funding letter provided stated that 'this award is not secure until the work has been contracted' and requested clarification. DAAG were informed that the letter had an incorrect date, and that a more recent funding letter was available that confirmed the applicant's funding; DAAG requested sight of this more recent letter.</p> <p>It was noted that the study would require ONS mortality data to complete some of its deliverables, but that data had not yet been applied for pending discussions around the legal basis for the use</p>

of mortality data. DAAG discussed whether the applicant would still be able to make use of the HES data requested if the ONS mortality data was not available, and on balance it was recognised that the applicant should be able to achieve healthcare benefits using only the HES data requested.

There was a discussion of data minimisation efforts; it was acknowledged that the HSCIC had discussed data minimisation with the applicant and that the applicant had agreed that once the five Emergency Departments had been selected as controls then the remaining national data not pertaining to those departments would be deleted. However, DAAG remained uncertain about the provision of this amount of national data solely to select a cohort of five Emergency Departments. DAAG queried whether other options had been considered, such as whether the applicant could use the HSCIC Secure Data Facility to select their control group or whether the HSCIC could use the applicant's eligibility criteria to select five Emergency Departments and only send the data for those five departments to the applicant. DAAG agreed to defer making a recommendation until it could be clarified whether these options had been explored and if any would be feasible alternatives to releasing national data to the applicant.

DAAG noted the potential political sensitivities regarding the closure of Emergency Departments; it was hoped that the applicant would be aware of this and that any published outputs would be handled sensitively.

Outcome: Recommendation deferred, pending discussions between the applicant and the HSCIC about whether any further data minimisation efforts could be made, in particular by making use of the Secure Data Facility.

- The most recent funding letter should be circulated.
- DAAG hoped that the applicant would be aware of the potential political sensitivities regarding the outcomes of this work.

2.12 University of Leicester - Mortality linkage for the Walking Away from Type 2 Diabetes trial (Presenter: Dave Cronin) NIC-347200-H9G0Q

Application: This application was for linkage of ONS mortality data and Personal Demographics Service data (fact of death) for a cohort that had been flagged as part of a completed consented study, 'Walking Away from Type 2 Diabetes'. DAAG were informed that a proportion of the participants in that study had consented to have their health status used for research purposes in future, and only the individuals who had specifically consented to that use of data would be included in this linkage. ONS had been asked to advise whether the consent materials were appropriate for the receipt of mortality data, and they had advised that they were content.

Discussion: A query had been raised prior to the meeting regarding the applicant's DPA registration wording, and whether this was appropriate for the uses of data described. DAAG noted that the DPA registration wording mentioned 'research relating to health' in the same sentence as 'services to our students and staff' and it was suggested that this could be interpreted to mean that the applicant organisation only processed health data about staff and students; there was a suggestion that the applicant should consider clarifying this wording to avoid confusion.

On the basis that ONS had advised the applicant's consent materials were appropriate, no other concerns were raised regarding this application.

Outcome: Recommendation to approve.

DAAG discussed the approach taken by ONS to patient consent, and there were some concerns that the advice given regarding different applications could in some cases be inconsistent. It was agreed that the Interim DAAG Chair would be asked to raise this with ONS.

<p>2.13</p>	<p>Action: Dawn Foster to speak to the Interim DAAG Chair regarding advice received from ONS on participant consent.</p> <p><u>Imperial College London - Mortality outcome in the London Chronic Obstructive Pulmonary Disease (COPD) cohort (Presenter: Jen Donald) NIC-340676-D5P9K</u></p> <p>Application: This was a request to amend an existing agreement, following the University College London application that DAAG had discussed and recommended for approval at the 13 April 2015 meeting (NIC 321523-F3W6D). This project had subsequently moved from University College London to Imperial College London; in addition the applicant had now obtained section 251 support and Approved Researcher accreditation from ONS to receive mortality data for the cohort members who had consented prior to May 2013, and ONS mortality data was therefore now requested.</p> <p>Discussion: DAAG noted that as a result of the project moving organisations, the data controller responsible for the data provided had now changed to Imperial College London. Further information was requested about the impact of this change, and in particular how and when data would be transferred from one organisation to the other or if this transfer had already taken place.</p> <p>It was noted that recruitment to the study was ongoing, and while the patient information leaflet referred to the involvement of Imperial College London and the consent form stated that samples would be used by third parties licensed by Imperial College London, the consent form did not refer to Imperial College London processing participants' data. Given the change in data controllers it was agreed that the consent form should be updated to clearly state that Imperial College London would be involved in data processing.</p> <p>Outcome: Unable to recommend for approval.</p> <ul style="list-style-type: none"> • Clarification is required of the change in data controller and the impact of this, such as whether data has already moved location and if so how this transfer has taken place. • The applicant's consent form should be updated, as this does not currently appear to give permission for Imperial College to process data.
<p>3</p>	<p>Any other business</p> <p>DAAG raised concerns regarding the withdrawal of applications prior to meetings, as this had begun to happen more frequently and DAAG members emphasised the negative impact this had on their ability to manage other commitments and prepare for meetings each week. HSCIC staff were reminded of the importance not submitting applications to DAAG for consideration before key points had been addressed.</p> <p>The possibility of moving meetings to another day of the week was raised, and it was agreed that this option should be discussed further with future IGARD members.</p> <p>The process for DAAG members to raise questions about applications prior to a meeting was discussed. It was agreed that members would submit questions to the DAAG mailbox, and that this process would be reviewed in one month.</p> <p>Patrick Coyle informed the group that due to the potential conflict of interest caused by his role with HRA CAG, he would step down from DAAG with immediate effect. DAAG formally thanked Patrick for his years of service, both as a DAAG member and with its predecessors.</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.	Open
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. 13/10/15: Ongoing.	Open
13/10/15	Stuart Richardson to provide an update on how CCGs have validated invoices up to this point.	Stuart Richardson		Open
13/10/15	Dawn Foster to speak to the Interim DAAG Chair regarding advice received from ONS on participant consent.	Dawn Foster		Open