

Data Access Advisory Group (DAAG)

Minutes of meeting held 22 September 2015

Members: Alan Hassey, James Wilson, Joanne Bailey, Eve Sariyiannidou

In attendance: Vicki Williams, Frances Hancox, Stuart Richardson, Sophie Fletcher, Garry Coleman, Kemi Adenubi, Steve Hudson, Dave Cronin, Gaynor Dalton, Dickie Langley

Apologies: Sean Kirwan, Patrick Coyle, John Craven, Dawn Foster

1	<p>Declaration of interests</p> <p>Joanne Bailey declared a conflict of interest regarding the applications for East and North Hertfordshire CCG and Herts Valley CCG, and did not participate in these discussions.</p> <p>Review of previous minutes and actions</p> <p>The minutes of the 15 September 2015 meeting were reviewed and agreed as an accurate record, subject to a minor amendment to the outcome wording for application 2.2 (NIC-365623-T3W4S University of Manchester).</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 371831 Leeds City Council• NIC 371832 Lincolnshire County Council• NIC 371828 Norfolk County Council• NIC 351722 CRAB C-CI• NIC 352300 University of Birmingham• NIC 356458 Luton Invoice Validation• NIC 361611 Luton Risk Stratification• NIC 349029 Bedfordshire Invoice Validation• NIC 347795 Basildon & Brentwood Risk Stratification• NIC 347865 Castle Point & Rochford Risk Stratification• NIC 348118 West Essex Risk Stratification
2 2.1	<p>Data applications</p> <p><u>East and North Hertfordshire Clinical Commissioning Group (CCG) – Stage One Accredited Safe Haven (Presenter: Stuart Richardson) NIC-371050</u></p> <p>Application: This application was to renew the flow of non-sensitive Secondary Uses Service (SUS) data identifiable at the level of NHS number (weakly pseudonymised) to a stage 1 accredited safe haven (ASH), using support under section 251 of the NHS Act 2006 as the legal basis. The application had previously been considered at the 25 August 2015 DAAG meeting, when DAAG had been unable to recommend approval and requested clarification of local data flows and the data flow diagram, as well as noting that the applicant's fair processing notice should</p>

be updated. The application summary had now been updated to provide clarification, and DAAG were informed that the applicant's fair processing notice had been updated.

Discussion: The intended local data flows were noted for information, and DAAG noted that local data flows would be discussed in more detail under agenda item 2.3.

There remained concerns regarding the applicant's fair processing notice, as in particular statements that patients' explicit consent was required to share personal data were factually incorrect given the flow of data under section 251. It was considered that these statements could lead members of the public to believe that no personal data would be shared unless they provided their explicit consent, and DAAG agreed that this could affect the legal basis for data to flow.

Outcome: Recommendation to approve, subject to an undertaking within two weeks from the applicant that they will rectify the factually incorrect statements within their fair processing notice that are essential to providing a legal basis, and will do so within a further six weeks.

2.2 East Riding CCG - Risk Stratification (Presenter: Stuart Richardson) NIC-344973-C1R6J

Application: This application to renew the flow of identifiable non-sensitive SUS data, covered by the section 251 support for the disclosure of commissioning datasets for risk stratification, had previously been considered at the 9 June 2015 DAAG meeting and recommended for approval subject to a caveat regarding fair processing. Data had not yet been provided to the applicant; the applicant's application had now been amended and fair processing materials had been updated.

Discussion: A reference was queried to risk stratification tool outputs being used to support multi-disciplinary team (MDT) discussions, and it was confirmed that MDT staff would not have access to the data. DAAG discussed the CCG's registration under the Data Protection Act 1998 (DPA), and asked for more detail regarding the registration wording to be included in applications in future.

The applicant's fair processing notice was discussed, and DAAG commented that a statement that data used for risk stratification 'cannot be tracked back to individuals' could be considered misleading. A reference to a 'section 251 exemption' was noted, and DAAG suggested this should more accurately refer to section 251 support. It was agreed that these comments should be fed back to the applicant, but on balance this was not considered to impact the legal basis for the applicant to receive data.

Outcome: Recommendation to approve.

2.3 Template for CCG S1 ASH group applications (Presenter: Kemi Adenubi)

DAAG were provided with an example template for a group CCG application, where applicants using the same data processor had been grouped together. This approach would allow a single application summary to be presented to DAAG to cover a larger number of applicants, with a table of differences provided to outline any differences between the applicant organisations. It was noted that an individual Data Sharing Agreement (DSA) would still be required for each applicant. DAAG emphasised that the differences between applicants would need to be clearly stated, and noted that any significant differences in data flows might mean that an applicant should not be included in the group application. This approach to group applications was agreed in principle.

DAAG were informed that as it had been determined that data processors could not enter into a DSA with the HSCIC, Commissioning Support Units (CSUs) were currently unable to fulfil the necessary to become a stage one ASH. Work was underway to address this, but DAAG were made aware that it was not expected that any CSU stage one ASH applications would be brought to DAAG for review until this had been resolved.

There was then a discussion of local data flows through Data Services for Commissioners

Regional Offices (DSCROs), as it had been proposed that the HSCIC acted as data controller for these flows. It was noted that these flows would need to be reflected on the HSCIC data release register. DAAG were asked to consider what level of oversight for these flows might be appropriate, given the large number of different flows and the significant number of changes that occurred each month. DAAG were in principle supportive of taking a pragmatic approach to managing these changes, but requested additional information. In addition it was agreed that Garry Coleman and Kemi Adenubi should discuss the likely impact for the DARS process.

Action: 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.

Finally, DAAG were asked to consider the possibility of considering large group applications for national datasets from CCGs who had already been approved to receive a different dataset for the same purpose. It was agreed that a pragmatic approach would need to be taken to process the anticipated large number of applications, and DAAG emphasised the importance of ensuring that this group application approach could only be taken when an existing DSA was in place and had not lapsed. It was suggested that Kemi Adenubi should discuss the approach to these applications with the HSCIC Caldicott Guardian. In addition, DAAG requested information about applications where the DSA had lapsed and what the reasons for this had been.

2.4 Herts Valley CCG - Invoice Validation (Presenter: Stuart Richardson) NIC-353328-K0L2W

Application: This was a new application for non-sensitive SUS data identifiable at the level of NHS number, for use in invoice validation. Data would flow via the North East London CSU as a landing point, then into the Controlled Environment for Finance at the CCG. DAAG were informed that each organisation had achieved a satisfactory IG Toolkit score, and held an appropriate DPA registration.

Discussion: DAAG discussed the applicant's fair processing notice, and a suggestion was made that some of the terminology used could be more clearly explained using Plain English. In addition it was suggested that some of the statements made in the notice, such as that 'Only members of staff directly involved in reviewing your care' could view data, could be considered misleading. It was agreed that additional feedback on these points would be provided outside the meeting by email, in order for this to be shared with the applicant.

Outcome: Recommendation to approve.

2.5 Redbridge CCG - Invoice Validation (Presenter: Stuart Richardson) NIC-362881-H4V3C

Application: This application for SUS data identifiable at the level of NHS number had previously been considered at the 18 August 2015 DAAG meeting, when DAAG had been unable to recommend approval due to a query regarding local data flows and concerns regarding the applicant's fair processing notice. The application summary had been updated to remove local data flows as the CCG had confirmed these were not required, and the fair processing notice had been updated.

Discussion: DAAG noted that the applicant's fair processing notice was difficult to locate on their website, and suggested that the applicant should consider making this more easily accessible.

Outcome: Recommendation to approve.

2.6 Group application - Norfolk CCGs¹

Application: This was a new group application from two CCGs requesting pseudonymised SUS

¹ NIC-373396-M9R2G North Norfolk CCG, and NIC-365617-Z0G0Z South Norfolk CCG

data linked to local data. Data would flow via North East London CSU as a data processor, where the SUS data and local data would be linked, and pseudonymised linked data would then be provided to each CCG. It was confirmed that the organisations involved had achieved satisfactory IG Toolkit scores, and held appropriate DPA registrations.

Discussion: DAAG discussed the process for updates to local data flows, and it was agreed that the application summary would be amended to state that this process had not yet been agreed but that the process agreed between DAAG and the relevant Director would be followed.

Outcome: Recommendation to approve. Application summary to be updated to amend the described process for local data flows.

2.7 UK Biobank (Presenter: Garry Coleman) NIC-371826-W9C3Z

Application: This application, which requested an amendment to the territory of usage so that data could be shared worldwide, had been considered at the 18 August 2015 DAAG meeting when DAAG had deferred making a recommendation. Queries had been raised regarding how previous caveats had been met, the potential for commercial uses of data, clarification of sharing pseudonymised or anonymised data, and clarification regarding worldwide data sharing.

Discussion: DAAG agreed that the point made at the 18 August 2015 meeting about reflecting the caveats previously made had now been addressed, although it was noted that some relevant sentences within the application summary had been deleted in error and these would be reinserted.

DAAG discussed the second point previously made, regarding clarification around sharing anonymised or pseudonymised data. It was noted that the data would be treated as pseudonymised, although reasonable steps had been taken to de-identify the data and it could potentially be considered anonymised in context. The Material Transfer Agreement used by UK Biobank for worldwide data sharing included a strict prohibition on attempting to reidentify individuals within the data received. DAAG discussed the use of the Material Transfer Agreement, which stated that the agreement was governed by and in accordance with English law, and discussed the sanctions that could apply if an organisation breached its agreement with UK Biobank. DAAG agreed that this second point had also been addressed.

The potential for data to be shared with commercial organisations was noted, but DAAG acknowledged UK Biobank's governance arrangements and noted that UK Biobank only accepted applications for data where the researcher would carry out health-related research that was in the public interest. It was agreed that the point DAAG had previously raised regarding potential commercial uses of data had therefore also been addressed.

DAAG emphasised the importance of ensuring fair processing by making information about worldwide data sharing available to participants, and recommended that UK Biobank should publish some additional details about worldwide data sharing on the study website as soon as was reasonably possible. Given the potentially substantial benefits that could be achieved by sharing data worldwide, it was suggested that the HSCIC could work with UK Biobank over the coming months to produce a case study on the benefits of international data use.

Outcome: Recommendation to approve.

DAAG recommended the application for approval, noting the significant benefits being obtained from the work of UK Biobank, and DAAG welcomed the approach of Biobank to transparency including making all scientific papers available on their website. DAAG felt that this approach could be built on further, and would invite the HSCIC and UK Biobank by time of reapplication to develop a case study of benefits of international use of the data which could be made available on the HSCIC / UK Biobank websites as appropriate. This would help participants within UK Biobank appreciate further the international use of data. DAAG also recommended more immediately that strengthening the understanding around worldwide use of data (perhaps via a separate paragraph on the website detailing what data is being used where) would assist with Fair Processing. Finally

DAAG asked that a specific sentence is included in the outputs section of the application summary such that international use is made explicit. Whilst these are not formal caveats to the approval, DAAG would expect that all have been addressed in a timely manner before a renewal application is considered.

2.8 Nuffield Trust - The care of frail older people and the role of the Comprehensive Geriatric Assessment (Presenter: Garry Coleman) NIC-316705-C9F9J

Application: This application was for the receipt of Patient Reported Outcome Measures (PROMs) and Office for National Statistics (ONS) mortality data, in addition to using the Hospital Episode Statistics (HES) dataset already held by the applicant for a different project, for use in a study into the care of older people. It was noted that the applicant held Approved Researcher accreditation for the receipt of identifiable ONS data.

Discussion: DAAG queried the different cohort age ranges listed under data minimisation efforts, and it was clarified that this was due to the different data years available as all individuals in the age ranges listed would now be over 65. The involvement of other organisations in this project was queried, but it was confirmed that no other organisations would receive access to record level data.

DAAG discussed the applicant's DPA registration wording, and noted that the reference to survey respondents in the section about using data for research could be misconstrued. In addition it was suggested that the use of NHS data could be more clearly explained.

Outcome: Recommendation to approve. DAAG commented that the applicant's DPA registration wording could be more clearly written, and that the applicant should consider amending this ahead of making an annual renewal application for the receipt of HES data.

2.9 London School of Economics (Presenter: Dave Cronin) NIC -354497-V2J9P

Application: This application was to combine and renew two existing agreements for the receipt of pseudonymised HES and PROMs data. This data would be used to support research into evaluating the impact of policy reforms on patient outcomes, comparing healthcare system performances to identify best practice, and developing indicators of healthcare quality and outcomes. Outputs would be presented to health and social care policymakers and to clinicians, to ensure the findings could be used for the benefit of health and social care.

Discussion: A question was raised regarding the statement that the server on which data would be stored within LSE would only be accessed by authorised researchers. It was agreed that the wording of this statement would be clarified.

DAAG asked what the justification was for requesting this amount of data, and it was stated that the applicant had requested this in order to examine national trends. It was suggested that the applicant might in future be able to request a smaller dataset if sampling techniques were used.

DAAG asked for the application summary to be updated to include a statement that record level data will not be shared with any third parties, and outputs will only contain aggregated data with small numbers suppressed. It was agreed that this statement would be added. A query was raised regarding the potential for small numbers, but it was noted that the applicant intended to assess national trends meaning that small numbers would be unlikely to arise.

Some concerns were raised about a statement in the application summary that including additional aggregated data 'cannot increase the risk of patient identification', as this was considered to be incorrect. It was agreed that this statement would be amended.

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

- Application summary to include a statement that record level data will not be shared with

	<p>any third parties, and outputs will only contain aggregated data with small numbers suppressed.</p> <ul style="list-style-type: none"> • Clarification was requested of a reference to the server on which data stored being accessible only to authorised researchers. • A factually incorrect statement that additional data 'cannot increase the risk of patient identification' should be removed from the application summary.
2.10	<p><u>University of Liverpool - Slipped Capital Femoral Epiphysis Surgery Study (Presenter: Dickie Langley) NIC-362142-K9C7P</u></p> <p>Application: This new application was for a single data year of HES data for a cohort who had a recorded diagnosis of slipped capital femoral epiphysis. The HES data would be used for the purpose of case ascertainment, with the applicant cross-checking data received from hospitals to determine accuracy.</p> <p>Discussion: DAAG queried the relationship between this study and the British Orthopaedic Surgery Surveillance (BOSS) study, and it was confirmed that this study was part of the wider BOSS study. It was agreed that this should have been explained more clearly in the application summary.</p> <p>DAAG noted that the study methodology involved working with a nominated representative at each hospital, and asked whether HES data was still required for any hospital that did not have a nominated representative. In addition, it was noted that in some instances the nominated representative might determine that individuals identified as part of the cohort might not have a diagnosis of slipped capital femoral epiphysis, and that data regarding these individuals would be requested; DAAG suggested that the ethical implications of providing data for individuals who did not have the diagnosis being studied ought to have been considered by a Research Ethics Committee.</p> <p>Concerns were expressed that the applicant had not yet obtained approval from a Research Ethics Committee, as although the application summary referred to a pending ethics application for the verification process this had not yet been completed. It was agreed that it would be more appropriate for DAAG to consider the application following ethical review.</p> <p>Outcome: Application withdrawn, pending clarification regarding the need for ethical approval.</p>
2.11	<p><u>Central and North West London NHS Foundation Trust - Research study into the effectiveness of music psychotherapy (Presenter: Gaynor Dalton) NIC-343357-K0Q1T</u></p> <p>Application: This was a new application for pseudonymised, non-sensitive HES data for use in a comparative analysis to evaluate the effectiveness of music psychotherapy to patients with particular mental health diagnoses.</p> <p>Discussion: DAAG discussed the amount of national data requested, and while some data minimisation efforts had been made by limiting this to patients with particular mental health diagnoses codes it was felt that the amount of data requested was not proportionate to the expected local benefits. It was suggested that the applicant could have provided details of how outputs would be disseminated to ensure wider benefit.</p> <p>It was proposed that the HSCIC should explore the possibility of providing the applicant with tabulated data in order to meet their key research requirements without requiring the disclosure of record level data.</p> <p>Outcome: Unable to recommend for approval. DAAG advised the applicant to explore with the HSCIC the possibility of obtaining a bespoke tabulation of data that would meet their key research questions without requiring the release of record level data.</p>

2.12	<p><u>University of Leeds – ‘Is quality of life a matter of distance?’ (Presenter: Gaynor Dalton) NIC-337151-T252K</u></p> <p>Application: This was a new application for identifiable, sensitive HES and PROMs data using section 251 support as the legal basis. This data would be used as part of a PhD study investigating the impact of the distance that patients travel for treatment.</p> <p>Discussion: The legal basis for the receipt of PROMs data was queried, and DAAG were informed that HRA CAG had confirmed that PROMs data was included in the applicant’s section 251 support.</p> <p>DAAG discussed the amount of data requested, and it was noted that this had been limited to patients within the local region who had certain diagnostic codes. A suggestion was made that it might be more appropriate in future if the HSCIC could run the required queries and provide tabulated data to the researcher, rather than needing to disclose record level data, but it was acknowledged that this was not currently feasible.</p> <p>The applicant’s fair processing materials were considered, and it was noted that the applicant had committed to update this information during the lifetime of the study. DAAG asked for details of what information was provided about how individuals could opt out of the study.</p> <p>Outcome: Recommendation to approve, subject to clarification of what information the applicant provides regarding how participants can opt out.</p>
2.13	<p><u>University of Leeds - Yorkshire Specialist Register of Cancer in Children and Young People NIC-347470-X0W7J</u></p> <p>Application: This application for identifiable, sensitive HES and Mental Health Learning Disability Dataset (MHLDDS) data had previously been considered at the 10 February 2015 meeting, when DAAG had been unable to recommend approval, and then presented to DAAG for advice on consent materials at the 21 April 2015 meeting. Consent materials had now been updated to attempt to address the concerns previously raised by DAAG, and HRA CAG had provided clarification regarding the applicant’s section 251 support.</p> <p>Discussion: DAAG had previously queried the legal basis for the data already held by the applicant, and it was agreed that the application summary would be updated to include confirmation that this was covered by the applicant’s section 251 support. In addition, it was noted that the applicant’s section 251 support had recently undergone annual review and DAAG requested sight of the most recent renewal letter from HRA CAG.</p> <p>The applicant’s updated consent materials were discussed, and DAAG noted that some improvements had been made but felt that it would be helpful if the applicant could also provide further information for participants about how and why data would be collected, as well as providing a clearer explanation of the benefits of maintaining a regional registry. A statement in the application summary that the consent materials now met ‘the standard set by DAAG’ was queried, and it was agreed that this wording would be clarified.</p> <p>Outcome: Recommendation to approve, subject to the following caveats:</p> <ul style="list-style-type: none"> • Provision of a copy of the most recent section 251 renewal letter. • Amending the application summary to confirm that the applicant’s section 251 support covers both the data requested and the data already held by the applicant. <p>DAAG advised the applicant that their consent and patient information materials could provide more details on what data is collected and why, and what the advantages are to maintaining a regional registry in addition to the national cancer registry.</p>

3

Any other business

University College London - Metal on metal hip prostheses NIC-344986

The Acting DAAG Chair provided an update on this study, which would return to DAAG once section 251 support had been obtained.

Summary of Open Actions

Date raised	Action	Owner	Updates	Status
04/08/15	DAAG Secretariat to send DAAG members a copy of the HSCIC Board minutes that covered the discussion of changes to HSCIC Executive Director team and Caldicott Guardian arrangements.	DAAG Secretariat	<p>13/08/15: The relevant Board minutes had not yet been published.</p> <p>18/08/15: The next meeting of the Board is on the 23 September after which the draft minutes will be agreed. DAAG secretariat to circulate following publication</p> <p>25/08/15: Ongoing – DAAG secretariat to circulate following ratification at the 23 September 2015 Board meeting.</p> <p>01/09/15: Ongoing, pending publication.</p> <p>22/09/15: The action has been completed and was closed.</p>	Closed
13/08/15	Stuart Richardson to ensure that the privacy notice for Castle Point and Rochford CCG is appropriately updated.	Stuart Richardson	<p>18/08/15: Stuart Richardson to continue to work with applicants and feedback update at future DAAG.</p> <p>25/8/15: Stuart Richardson to update members on the 8 September with regard to fair processing notices in general and progress to date – Secretariat to add to agenda as discussion item</p> <p>01/09/15: An update would be provided at the 8 September meeting.</p> <p>15/09/15: It was confirmed that Stuart Richardson would provide an update at the 22 September meeting.</p> <p>22/09/15: Stuart Richardson gave an update on this, and informed DAAG that some applicants had approached the ICO regarding fair processing. The ICO had advised that DAAG could provide guidance and recommend changes, but not require applicants to make changes to their fair processing notices. DAAG discussed this, and agreed that while applicants could not be required to make changes it remained appropriate to inform the SIRO of any instances where factually incorrect statements in an applicant's fair processing notice could mislead the general public and compromise the applicant's legal basis for receipt of data. It was therefore agreed that DAAG would continue to review fair processing materials and would raise concerns to the HSCIC SIRO if it was felt that these compromised the legal basis for data to flow. DAAG</p>	Closed

			would otherwise continue to offer advice and guidance on fair processing. It was also agreed that the Data Services for Commissioners team would work with DAAG members to provide examples of good practice for applicants.	
15/09/15	Eve Sariyiannidou to circulate paper on EU funded projects.	Eve Sariyiannidou	22/09/15: The action has been completed and was closed.	Closed
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		Open