

Data Access Advisory Group (DAAG)

Minutes of meeting held 3 November 2015

Members: Joanne Bailey, John Craven, Dawn Foster, Alan Hassey (Interim Chair), Eve Sariyannidou, James Wilson

In attendance: Dave Cronin, Gaynor Dalton, Jennifer Donald, Frances Hancox, Julia King, Dickie Langley, Stuart Richardson, Vicki Williams

Apologies: Sean Kirwan

1	<p>Declaration of interests</p> <p>No conflicts of interests relevant to this meeting were declared.</p> <p>Review of previous minutes and actions</p> <p>The minutes of the 27 October 2015 meeting were reviewed and agreed as an accurate record.</p> <p>Action updates were provided (see table on page 7).</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-371011-F4X5F NHS England• NIC-347470-X0W7J University of Leeds• NIC-371018-K1P2X East & North Hertfordshire Clinical Commissioning Group (CCG)• NIC-368543-C3J4B CHKS Ltd• NIC-368020-R5L2K Dr Foster Ltd
2 2.1	<p>Data applications</p> <p><u>Camden CCG - Stage One Accredited Safe Haven (ASH) (Presenter: Stuart Richardson) NIC-363645-R5W0Z</u></p> <p>Application: This was an application for the receipt of Secondary Uses Service (SUS) data identifiable at the level of NHS number (weakly pseudonymised) under the section 251 support for stage one ASH. DAAG had previously considered this application at the 4 August 2015 meeting and had been unable to recommend approval due to the need for confirmation that both the CCG and its data processor had deleted the previously held data that was identifiable at the level of postcode. Confirmation of this had now been received, and in addition the applicant had updated their fair processing notice based on DAAG's comments.</p> <p>Discussion: DAAG discussed the applicant's updated fair processing notice, and while it was agreed that this was much improved there remained some concerns. In particular DAAG noted that the notice incorrectly stated that health information would not be shared without explicit patient consent, and suggested that this should be corrected. In addition it was agreed that the description of the patient opt out process should not refer to 'withdrawing consent' as this term was not applicable and could be misleading.</p> <p>A query was raised regarding a reference in the application summary to linking data across</p>

	<p>providers, but it was confirmed that this was carried out using the SUS data requested and no additional data was linked.</p> <p>Outcome: Recommendation to approve, subject to:</p> <ul style="list-style-type: none"> The applicant updating their fair processing notice to remove the incorrect references to explicit patient consent, including revising the description of opting out to remove reference to withdrawing consent.
2.2	<p><u>Camden CCG - Risk Stratification (Presenter: Stuart Richardson) NIC-364160-R1T5K</u></p> <p>Application: This renewal application was for the use of SUS data identifiable at the level of NHS number for the purpose of risk stratification. Data would flow via North East London Commissioning Support Unit (CSU) as a landing point only, then on to MedeAnalytics who would act as data processor on behalf of Camden CCG. GPs within the CCG would be able to securely log into the risk stratification tool provided by MedeAnalytics to access data about patients registered to their practice only, while the CCG would only be able to access anonymised data.</p> <p>Discussion: It was noted that as discussed for the previous application (NIC-363645-R5W0Z), the fair processing notice for Camden CCG required updating. DAAG also agreed that this fair processing notice should include a statement that MedeAnalytics would act as a data processor for the CCG.</p> <p>The Data Protection Act 1998 (DPA) registration entry for MedeAnalytics was discussed, and DAAG noted that the updated entry referred to processing de-identified patient information whereas for the purpose of this application they would in fact process patient data that was identifiable at the level of NHS number. It was agreed that appropriate staff within the HSCIC Information Governance team would liaise with MedeAnalytics regarding this.</p> <p>Outcome: Recommendation to approve, subject to:</p> <ul style="list-style-type: none"> The applicant updating their fair processing notice in line with previous DAAG comments, and to state that MedeAnalytics are used as a data processor. <p>DAAG advised that MedeAnalytics should consider updating their DPA registration to refer to processing identifiable patient data.</p> <p>Action: Information Governance team to liaise with MedeAnalytics regarding their DPA registration to ensure that it reflects recent applications.</p>
2.3	<p><u>Camden CCG - Invoice Validation (Presenter: Stuart Richardson) NIC-364161-B0R1L</u></p> <p>Application: This application was for the use of SUS data identifiable at the level of NHS number for the purpose of invoice validation. Data would flow to the Controlled Environment for Finance within North East London CSU, with Camden CCG only receiving aggregate reports.</p> <p>Discussion: No concerns or queries were raised regarding this application.</p> <p>Outcome: Recommendation to approve.</p>
2.4	<p><u>Newcastle University - Survivors and predictors of survival in children born with congenital heart conditions; BINOCAR (Presenter: Jen Donald) NIC-389825-C0D9C</u></p> <p>Application: This application for a one-off linkage of Office for National Statistics (ONS) mortality data and Index of Multiple Deprivation (IMD) score for a particular cohort had previously been discussed at the 13 October 2015 meeting, when DAAG had been unable to recommend approval.</p>

DAAG had queried why Newcastle University were listed as the applicant rather than Public Health England, as Public Health England would act as both data processor and controller, and additional information had now been provided about the University's role as sponsor for the work. The original application for section 251 support had also been provided in order to address queries that had been raised regarding this. In addition, it had been confirmed that this work was not part of a PhD study and an updated protocol had been supplied.

Discussion: DAAG discussed the arrangements for staff working on an honorary contract between Public Health England and Newcastle University, and requested confirmation that if a confidentiality breach occurred then the member of staff responsible would be subject to appropriate disciplinary procedures by their substantive employer. In addition, given the involvement of Newcastle University in this application DAAG requested sight of the DPA registration details for that organisation. There remained some uncertainty regarding the role of Newcastle University, but on balance DAAG agreed that it was not inappropriate for Newcastle University to be listed as the applicant even though they would not be either a data processor or data controller for the data requested.

DAAG queried the legal basis for receipt of address data, as while this had been included in the original application for section 251 support this was not listed on the HRA CAG register. In addition, it was noted that the annual review date for the section 251 support was imminent and DAAG had not been informed whether this review was underway. It was agreed that the Information Governance team would help to clarify these points

DAAG also queried the planned data retention period of ten years. The applicant had stated that this was in case of any scrutiny following the publication of papers, but DAAG noted that Newcastle University intended to use anonymised data for the purpose of publications and it was therefore unclear why the pseudonymised data should be retained for this period of time. In addition DAAG pointed out that if the contract between Newcastle University and Public Health England came to an end sooner than this, then Newcastle University would have no route to access any data retained by Public Health England.

It was noted that the information leaflet provided did not clearly explain the role of the HSCIC in data processing and linkage, and DAAG suggested that the Information Governance team should review this and determine whether this would need to be addressed more clearly in fair processing materials. In addition, it was agreed that the application summary should be updated to clarify a reference to including date of delivery within deidentified data and DAAG requested clarification of references to either anonymised or pseudonymised data.

Outcome: Application withdrawn, pending the following:

- Confirmation that a confidentiality breach while working under an honorary contract would be subject to appropriate disciplinary actions by the substantive employer.
- Confirmation of whether address is covered by the applicant's section 251 support, as this is not listed on the HRA CAG register.
- Clarification of why pseudonymised data needs to be retained for ten years, when anonymised aggregated data will be used for the purpose of publication.
- Confirmation of whether annual review of the section 251 support is underway.
- Clarification of a reference to including date of delivery in deidentified data.
- Clarification of references to anonymised or pseudonymised data.
- The IG team will review whether fair processing materials need to clarify that identifiable data will be processed by the HSCIC in order to provide linkage.

2.5 Imperial College London - Mortality outcome in the London COPD cohort (Presenter: Jen Donald)
NIC-389022-R6G62

Application: This application for ONS mortality data had previously been discussed at the 13 October 2015 meeting, when DAAG had been unable to recommend approval. DAAG had

requested further clarification regarding the change of data controller, and it had now been confirmed that data had already been transferred from University College London to Imperial College London. An updated consent form had also been provided following DAAG's previous comments.

Discussion: DAAG noted the updated consent form, and there were some concerns that members of the general public might not understand the terms 'data controller' and 'data processor'. It was suggested that the information leaflet should also be updated to clarify that the research team referred to was part of Imperial College London. DAAG noted that ONS had previously indicated some errors on the leaflet, and that these had not yet been amended, so it was suggested that the applicant could update the leaflet to make these changes at the same time.

The change in data controller from University College London to Imperial College London was discussed, and there was confusion regarding the timeline for this change and when the data had been transferred. It was felt that the updated application had not provided sufficient information regarding this to address the queries DAAG had previously raised, and DAAG suggested that the HSCIC Information Governance team should provide support to clarify this issue.

Outcome: Application withdrawn, pending the following:

- Clarification of roles, responsibilities and timelines in relation to this application.
- The patient information leaflet should clarify that the research team referred to is part of Imperial College London, as well as correcting the comments previously raised by ONS.

2.6 University of Oxford - MBRRACE-UK (Presenter: Dave Cronin) NIC-356346-P3W3S

Application: This application was for identifiable Hospital Episode Statistics (HES) data to support the work of the Maternal, Newborn and Infant Clinical Outcome Review Programme. HES data would be used to identify a national sample of eligible women meeting particular criteria, with the relevant hospitals then providing case notes for those individuals to the applicant. A query had been raised prior to the meeting regarding whether the applicant's section 251 support covered the provision of HES data, and confirmation was provided that this was covered.

Discussion: DAAG noted the potential importance of this work.

A query was raised regarding how the cohort of 32 individuals would be selected from the HES data. DAAG were informed that the HSCIC would apply the appropriate criteria to select this cohort and then transfer the HES data for those 32 cohort members only to the applicant, meaning that the amount of data disseminated had been minimised. It was confirmed that although the Healthcare Quality Improvement Partnership (HQIP) were data controller for this work, HQIP would not receive any personal data.

A further query was raised regarding the inclusion of local patient identifiers (LOPATID), as this had not been explicitly referred to in the section 251 support letters provided. It was clarified that this field was usually not considered identifiable, depending on context, and that in this instance as other identifiers (NHS number and date of birth) were provided under the section 251 support providing LOPATID was not considered to create any additional risk. A reference in the section 251 register entry to NN4B data was queried, and it was confirmed that although this may be relevant for future applications from this applicant it was not relevant to the current application.

DAAG discussed the DPA registration details for the University of Oxford, and although it was noted that this referred to 'research relating to health' the work described in this application was not strictly considered to be research. DAAG suggested that the applicant should consider updating this to also refer to using data for audit purposes and to refer to processing data about patients or healthcare users.

	<p>Outcome: Recommendation to approve.</p> <p>DAAG advised that the applicant should consider updating their DPA registration entry to refer to using data for the purpose of audit, and to refer to processing data about patients or healthcare users.</p> <p>2.7 <u>NHS England - National Cancer Waiting Times Monitoring Information System (Presenter: Gaynor Dalton) NIC-379704-S6H6R</u></p> <p>Application: This was a new application for Cancer Waiting Times data linked to Diagnostic Imaging Dataset (DIDs) data in order to investigate the waiting periods of cancer pathways. Pseudonymised data was requested for a cohort of patients on a cancer pathway, with the Health and Social Care Act 2012 providing a legal basis for this dissemination.</p> <p>Discussion: DAAG discussed the honorary contract arrangements between NHS England and Cancer Research UK, and it was not felt to be clear whether any confidentiality breaches would be subject to disciplinary procedure by the substantive employer or whether the only consequence could be the termination of the honorary contract. Clarification of this point was requested.</p> <p>DAAG noted that the application summary stated the data requested would be stored in the same database that held the Cancer Waiting Times data currently held by the applicant. Clarification was requested regarding this data already held and what the purpose would be of storing data in the same database.</p> <p>Outcome: Recommendation to approve, subject to:</p> <ul style="list-style-type: none"> • Confirmation that a confidentiality breach while working under an honorary contract would be subject to appropriate disciplinary actions by the substantive employer. • Clarification of the data already held by the applicant and what the purpose would be of holding the requested data in the same database. <p>2.8 <u>PricewaterhouseCoopers LLP (Presenter: Dickie Langley) NIC-380902-S7H1C</u></p> <p>Application: This application for aggregated SUS data with small numbers unsuppressed had previously been considered at the 27 October 2015 meeting, when DAAG had been unable to recommend approval. The applicant had now provided a storage address where the data would be held, confirmed that data would not be shared with any other part of the PricewaterhouseCoopers company, and confirmed that any future changes in data processors acting on behalf of Monitor would be subject to the standard HSCIC application process.</p> <p>Discussion: DAAG noted the storage address provided, and it was confirmed that this address was covered by the applicant's ISO 27001 certification. It was agreed that the application summary should be updated to more clearly state this. DAAG also noted that the previous data controller, CHKS, would need to destroy data once this had been transferred to PricewaterhouseCoopers and requested confirmation of this.</p> <p>The statement that no other part of the company would have access to data was welcomed, but DAAG asked for this statement to be clarified to more clearly state which team or department would be able to access data.</p> <p>Outcome: Recommendation to approve, subject to:</p> <ul style="list-style-type: none"> • Clarification of which team or department within PricewaterhouseCoopers will have access to this data. • Updating the application summary to include confirmation that the storage address is covered by the applicant's ISO 27001 certificate.
--	---

	Action: Dickie Langley to confirm that the previous data processor acting on behalf of Monitor (CHKS) will delete data following transfer to the new data processor (PricewaterhouseCoopers).
3	Any other business No other business was raised.

Summary of Open Actions

Date raised	Action	Owner	Updates	Status
29/09/15	University of York to be asked for clarification on their change of policy for providing access to data.	Steve Hudson	06/10/15: This had been raised with Garry Coleman, and formal contact would be made with the University of York to request clarification. 27/10/15: Ongoing. It was expected a response would be available for the 3 November DAAG meeting. 03/11/15: Ongoing.	Open
20/10/15	Paula Moss to provide an updated paper on DSCRO local data flows.	Paula Moss	27/10/15: Ongoing. 03/11/15: Ongoing.	Open
27/10/15	Dickie Langley to review any upcoming application deadlines that could be likely to affect DAAG business processes.	Dickie Langley	03/11/15: It was confirmed that there were currently no upcoming applications expected to run into this problem. DAAG emphasised the importance of having systems in place to manage this in future.	Closed
27/10/15	Interim DAAG Chair to contact the Statistics Head of Profession to request advice on data minimisation and how the DPA requirements can be met to ensure that disseminated data is not excessive (particularly in relation to the University of Sheffield application NIC-340495-Q7R8B.)	DAAG Chair	03/11/15: This action had been completed, and the response would be circulated to DAAG members.	Closed
27/10/15	Dawn Foster to ask Senior IG Adviser to draft a paper on list cleaning for discussion at the December DAAG training session.	Dawn Foster	03/11/15: Action completed	Closed
03/11/15	Information Governance team to liaise with MedeAnalytics regarding their DPA registration to ensure that it reflects recent applications.	Dawn Foster		Open
03/11/15	Dickie Langley to confirm that the previous data processor acting on behalf of Monitor (CHKS) will delete data following transfer to	Dickie Langley		Open

	the new data processor (PricewaterhouseCoopers).			
--	---	--	--	--