

Data Access Advisory Group

Minutes of meeting held 4 June 2014

Members: Alan Hassey (Acting Chair), Patrick Coyle, Dawn Foster, Sean Kirwan

In attendance: Susan Milner, Garry Coleman (agenda items 040614-a to d), Dave Roberts, Jackie Gallagher, Steve Webster (agenda item 040614-e), Paul Eastwood (agenda item 040614-e)

Apologies: Diane Pryce

040614-a	<p>Welcome</p> <p>The Acting Chair welcomed all to the meeting.</p> <p>There was a discussion around the frequency of DAAG meetings, and the potential to meet more frequently in order to tackle the current backlog of applications awaiting review. The Group members were asked to consider this and provide feedback at the next meeting.</p> <p>There was also a discussion around the format of applications provided to DAAG members, and whether historical application documents could be stored in an archive that would be accessible to DAAG members rather than sending these out by email. It was agreed that this would be included as an agenda item for discussion at the 26 June 2014 DAAG meeting.</p>
040614-b	<p>Minutes of the previous meeting</p> <p>The minutes of the 13 May meeting were agreed as an accurate record.</p>
040614-c	<p>Matters Arising</p> <p>(a) Overview of outstanding actions</p> <ul style="list-style-type: none">• 070514-d1: Sean Kirwan to suggest updated DAAG Terms of Reference wording to replace current reference to NIGB. Update 13/05/14: The proposed amendments were discussed at the meeting on 13th May and were approved by the members. The TOR to be published.• 070514-d2: Amendments to be made to the Terms of Reference and published. Copy of the amended TOR to be provided to Rob Shaw. <p>It was confirmed that the updated Terms of Reference had been published on the DAAG webpage, and the two actions were closed.</p> <ul style="list-style-type: none">• 130514-c1: Members to provide feedback on how more applications might be managed. <p>It was agreed that the following DAAG meeting would include an agenda item for members to discuss the management of applications and provide feedback.</p> <ul style="list-style-type: none">• 130514-c2: RL to raise with Simon Gray the requirement to have another meeting/workshop to discuss how the DAAG workload could potentially be managed and invite key participants to attend. <p>No update was available, and it was agreed that this action would remain open.</p> <ul style="list-style-type: none">• 130514-e1: Louise Dunn to provide revised wording for the patient information sheet for review out of committee. (130514-e1)

The revised wording had been circulated by email and would be discussed under the overview of outstanding applications.

- **130514-f1:** *FH to cancel meeting on 9th June.*

This meeting had been cancelled, and the group were reminded that the meeting scheduled for 26 June had been amended to start 30 minutes earlier.

(b) Overview of outstanding applications

191113-d1: University of Sheffield

An outcome letter had been sent to the applicant regarding re-contacting participants, but no response had yet been received.

MR1337: Mortality outcome in the London COPD cohort

No update was available regarding this application.

MR1328: The Birmingham Lung Improvement Studies BLISS

An approval letter had been drafted and was awaiting approval.

270214-a: The King's Fund (renewal)

An approval letter had been drafted and passed on for issuing to the applicant.

270214-b: The MIDSHPIS Trial

An approval letter had been sent to the applicant.

270214-c: Unit of Health-Care Epidemiology, Oxford University

The applicant had been advised of DAAG's recommendation, and an outcome letter would be submitted for approval.

171213-d1: UK Biobank

This application had been resubmitted to DAAG and would be discussed under agenda item 040614-d.

070514-e1: The HALT-IT Trial, London School of Hygiene and Tropical Medicine

No update was available regarding this application.

070514-e2: Choosing Healthcare Options in Chronic Care Emergencies (CHOICE) quantitative study, Manchester Mental Health & Social Care Trust

Further information had been requested from the applicant, but a response had not yet been received.

070514-e3: Royal College of Surgeons (Morecambe Bay Investigation)

A letter had been received from the Health Research Authority Confidentiality Advisory Group (HRA CAG) confirming that S251 approval had been granted to cover the provision of data to the Royal College of Surgeons. A letter to the applicant had been drafted and would be shared with the Acting DAAG Chair for approval and onward circulation.

	<p><u>130514-e1: National Diabetes Foot Care Audit</u></p> <p>The revised consent form and patient information leaflet had been circulated to DAAG members following their discussion of this application at the 13 May 2014 meeting. The Group confirmed that the consent materials were much improved, and confirmed that they were happy to recommend this for approval.</p> <p>Outcome: Recommendation to approve</p> <p>(c) Recommendations made out of committee</p> <p>No out of committee recommendations had been made since the previous DAAG meeting.</p>
<p>040614-e</p>	<p>Hospital Episode Statistics (HES) applications</p> <p><u>040614-e1: University Hospitals Birmingham</u></p> <p>This request was a request for a further six months of data, following the previous application for HES data (240412-a) which had been considered and approved by DAAG at the 24 April 2012 meeting. The data requested included the sensitive fields Consultant code, Local Patient Identifier, Code of Patient's Registered or Referring General Medical Practitioner, and Person Referring Patient, and this had been discussed at the 24 April 2012 meeting.</p> <p>The Group queried whether the request included any additional data items further to what had previously been approved, and it was confirmed that this would only be a 6 month extension of the same data as previously.</p> <p>A query was raised regarding a reference in the application summary to use data for 'initially west midlands trusts and then potentially wider' as it was felt that this was rather vague. It was clarified that this statement had been taken from the original data sharing agreement and that the data provided would be used for quality and benchmarking analysis nationally. A reference to sharing the data through analytical tools was also queried, and it was explained that the applicant would provide indicators to their analytics customers, rather than the raw data.</p> <p>Outcome: Recommendation to approve</p> <p>Steve Webster and Paul Eastwood joined the meeting at this point.</p> <p><u>040614-e2: UK Biobank</u></p> <p>This was an application to receive HES, Mental Health Minimum Dataset (MHMDS) and Diagnostic Imaging Dataset data in addition to a HES-MHMDS bridging file. The application had previously been considered at the 17 December 2013 DAAG meeting (application reference 171213-d1), and DAAG had subsequently written to the applicant to ask them to confirm that in future communications with participants they would clearly outline how Biobank will use participants' personal confidential data, and that they would engage with the HSCIC when planning these future materials. Due to changes in the DAAG application process, DAAG were asked to consider the applicant's response to confirm that they were content with this.</p> <p>The Group noted that they had previously discussed the UK Biobank consent model in detail, and agreed the importance of UK Biobank keeping participants informed about how their data would be used in order to ensure fair processing. The response provided by the applicant made reference to their annual newsletter, and the fact that they regularly updated their website regarding uses of data. The website also explained how participants could opt out if</p>

	<p>they wished to do so. It was agreed that the importance of keeping participants informed should again be emphasised in the final outcome letter to the applicant.</p> <p>It was noted that the applicant had offered to meet with DAAG to provide further information if this would be helpful, and it was agreed that this could be considered for any future applications from this applicant.</p> <p>It was noted that Diane Pryce, the case manager for this application, was not present at the meeting and it was agreed that she should be asked to confirm whether there were any additional outstanding queries regarding this application before sending a final outcome letter to the applicant.</p> <p>Action: Diane Pryce to confirm whether there were any additional outstanding queries regarding the UK Biobank application (040614-e).</p> <p>Outcome: Recommendation to approve</p> <p><u>040614-e3: CQC</u></p> <p>This was a request for a 6 month extension to the existing monthly contract between the HSCIC and CQC, under the same terms and conditions as previously. It was stated that CQC had statutory powers to hold the data requested due to their regulatory role. The Group noted that CQC's Information Governance Toolkit score had improved since the previous year, and commended them on this.</p> <p>Outcome: Recommendation to approve</p> <p>At this point Garry Coleman left the meeting.</p>
<p>040614-d</p>	<p>National Child Measurement Programme (NCMP) dataset application</p> <p><u>040614-d1: Public Health England</u></p> <p>It was explained that the NCMP dataset was collected by HSCIC as commissioned by Public Health England (PHE), and the Group were asked to consider the data sharing agreement for sharing this data with PHE to carry out secondary analysis and to disseminate the relevant data to each Local Authority. It was noted that this was governed by the NCMP regulations, and that some difficulties had been caused for PHE by delays in providing this data this year.</p> <p>A query was raised regarding whether the data would be provided to Local Authorities in identified or de-identified form, and it was stated that Local Authorities would receive data for their area in identified form but that if this were to be disclosed onwards to other organisations, it would first need to be anonymised.</p> <p>A further query was raised regarding the data sharing agreement between the HSCIC and PHE, and whether there would be one agreement to cover data sharing with all Local Authorities or a separate agreement for each Local Authority; it was confirmed that there would only be one data sharing agreement for this. The Group also queried whether the data sharing agreement would specifically forbid PHE to attempt to re-identify the data provided and it was noted that the new data sharing agreement, a draft of which was currently under review, would include this. It was agreed that given the potential sensitivities involved, the data sharing agreement used for this application should be amended to include the requirement not to attempt to re-identify the data.</p> <p>The Group noted that PHE had submitted an Information Governance Toolkit improvement plan for review by the HSCIC External IG Delivery team. It was suggested that the outcome letter to the applicant should include a statement that the HSCIC would look for improvement</p>

	<p>in the applicant's Information Governance Toolkit score, although it was noted that this would depend on whether or not the applicant's improvement plan was accepted.</p> <p>Outcome: Recommendation to approve</p>
040614-f	<p>Data Linkage applications (MRIS)</p> <p><u>MR1317: Oxford University (Speed of Increasing Milk Feeds Trial)</u></p> <p>This application was for patient tracking of infants whose parents had consented for them to participate in a trial, in order to flag any participants who had left the health system. It was noted that the applicant had requested data for a retention period of 25 years, and that this had been queried, but that the applicant had provided a satisfactory explanation for this – specifically, that this was a standard policy for data retention in trials involving children.</p> <p>The Group noted that the consent materials had been revised to include the current recommended wording about the use of data by the HSCIC, and that the applicant had achieved a high Information Governance Toolkit score.</p> <p>Outcome: Recommendation to approve</p> <p><u>MR1356: Barts Health NHS Trust (Look back exercise to assess whether women who were inappropriately ceased from breast screening died with breast cancer)</u></p> <p>This application was for patient flagging in order to carry out a clinical audit of women who had inappropriately not been offered breast screening. The applicant had raised concerns with the HSCIC about the delay in receiving this data, as they felt that this was a clinical safety issue. However DAAG members queried the perceived urgency, as Barts Health NHS Trust should already be ensuring that women were receiving breast cancer screening appropriately.</p> <p>A query had been raised with the applicant about their intention to share pseudonymised data with a third party organisation (PHAST) and how this data would be pseudonymised, given that the HRA CAG had indicated that any information shared with third parties should be fully anonymised as otherwise Section 251 would be required. A response had been received from the applicant stating that they would remove patient identifiable fields such as name, but DAAG members felt that the full list of which identifiers would be removed should be supplied in order to determine whether this would be sufficient. It was agreed that the applicant's response would be circulated to the Group for consideration outside the meeting, in order to determine whether the applicant would need to be asked to provide any additional information, and members agreed to review this response and submit their comments within one working week.</p> <p>Outcome: The Group were unable to recommend for approval. Further information requested from applicant.</p>
040614-g	<p>Any other business:</p> <p>An application summary from Lincolnshire County Council had been circulated by email shortly prior to the meeting, and it was explained that this would be an application for a standard HES extraction using one Local Authority as a pilot, with the intention of extending this to all Local Authorities in future. It was noted that a large number of data fields had been requested, and that this included some additional fields over and above the standard fields. It was agreed that the application would be discussed in full at the following DAAG meeting.</p>

300114-b: Learning Disabilities Census data - Public Health England

The Group were informed that a response had been received from PHE regarding an application for Learning Disability Census data (300114-b) which had been considered by DAAG at the 30 January 2014 meeting. At the 30 January meeting the Group had approved the application subject to assurances that PHE would not link sensitive fields with any other data, and PHE had now confirmed this. The Group confirmed that on this basis they were happy to recommend that the application should be approved.

Outcome: Recommendation to approve

There was a brief discussion around the potential for DAAG to access advice from the Information Commissioner's Office, and whether a more formal route should be established to obtain this advice.

A query was raised regarding future meeting dates, as it was noted that August dates could be problematic due to lack of availability. It was suggested that the scheduled July meetings could be extended in order to consider additional applications if required.

Summary of Open Actions

Reference	Action	Owner
130514-c1	Members to provide feedback on how more applications might be managed.	DAAG members
130514-c2	RL to raise with Simon Gray the requirement to have another meeting/workshop to discuss how the DAAG workload could potentially be managed and invite key participants to attend.	Richard Langley
040614-d1	Diane Pryce to confirm whether there were any additional outstanding queries regarding the UK Biobank application (040614-e).	Diane Pryce