Data Access Advisory Group

Minutes of meeting held 13 May 2014

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

In attendance: Susan Milner, Diane Pryce, Garry Coleman (Item 130514-d1) Louise Dunn (Item: 130514-e1), Richard Langley

Apologies: Frances Hancox (Secretariat)

130514-a	**Welcome** The Acting Chair welcomed all to the meeting.
130514-b	**Minutes of the previous meeting** The minutes of the 7th May meeting were agreed as an accurate record with a slight amendment to the required action where further action was required by applicants and had not therefore been approved.
130514-c	**Matters Arising** The Acting Chair advised that there may potentially be a large number of applications which would need to be considered by DAAG. There were also potentially 30 consent requests at present. He asked members to consider how DAAG might be able to deal with an increased workload. One potential way forward would be for a longer meeting, perhaps all day, if the amount of business required this. AH asked for a meeting to be arranged to discuss how the potential workload for DAAG could be managed. RL was asked to raise this with Simon Gray. Members were advised that a large number of potential applications may depend on the role CAG will be expected to take in the future. This would be dependent on the outcome of the Care Bill which is currently passing through Parliament. It was hoped that details on this would be available shortly. The tracker listing potential applications for submission to DAAG and their status was discussed and this will be provided with the papers for future meetings. DAAG were advised that the HSCIC DAIS team were able to pick up additional requests requiring IG expertise in order to take the current backlog forward. **Action:** Members to provide feedback on how more applications might be managed. **Action:** 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. **(a) Overview of outstanding actions** • ***300114-g1****: Mark Davies to write to University of Sheffield (application 191113-d1) regarding re-contacting participants who had consented to participate in the study using*

the old consent form.

A letter had been sent to the applicant seeking further information.

Update 13.5.14: DAAG were advised that no response had been received from the applicant.

- ***070514-d1****: Sean Kirwan* to suggest updated DAAG Terms of Reference wording to replace current reference to NIGB.

  Update 13.5.14: The proposed amendments to the DAAG Terms of Reference were discussed and agreed by the members.

- ***070514-d2****: Amendments to be made to the Terms of Reference and published. Copy of the amended TOR to be provided to Rob Shaw.*

(b) Overview of outstanding applications

MR1337: Mortality outcome in the London COPD cohort

This application remained on hold due to organisational changes within the applicant organisation.

MR1328: The Birmingham Lung Improvement Studies BLISS

This application had been recommended for approval at the 27 February 2014 DAAG meeting, but as this was an application for new data it was suggested that it would be appropriate to discuss it with the relevant Information Asset Owner (IAO) and bring back through the updated DAAG process as soon as possible.

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

This application had also been recommended for approval at the 27 February 2014 DAAG meeting, but it was thought to be on hold due to uncertainties around the current process in place. It was agreed that this would be discussed outside the meeting.
Update 13.5.14: The letter had been prepared, however it had not yet been approved for signature.

270214-b: The MIDSHIPS Trial

This application had been recommended for approval, and an outcome letter from Rob Shaw would be going out to the applicant.

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

The Group had discussed this application at the 27 February 2014 meeting and suggested that the applicant should go back to the HRA Confidentiality Advisory Group (CAG) as the requested data appeared to be identifiable. It was confirmed that the data requested would be encrypted with one-way encryption, and that CAG had been content that it would not require Section 251 support. It was agreed that the draft outcome letter would be sent to the Acting Chair for review.
13.5.14: There was no update on this application.

171213-d1: UK Biobank

This applicant had previously applied to DAAG for additional data; this was discussed at the 17 December 2013 DAAG meeting and the Group had written to the applicant to emphasise the importance of ensuring fair processing of data under the Data Protection Act, particularly by making information available to participants about how their data would be used. In addition the Group had requested sight of the information materials that would be sent to participants. The applicant had subsequently responded and their response was circulated

around the Group. However it was noted that due to the updated DAAG process, this application might need to be brought back to the Group once it had been discussed with the relevant IAO.

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

For this application, the applicant would provide NHS numbers, dates of birth, postcode and patient initials in order for the HSCIC to create a linked HES extract. Some concerns had been raised with the applicant that the consent materials used did not adequately described the intended data sharing and processing, and as recruitment would continue for a number of years it had been suggested that the consent materials should be updated for all future recruitment. The applicant had provided a response, which was included with the application papers provided.

The Group agreed that the applicant's consent materials should be amended to include the recommended wording about data sharing and processing, and that the updated consent materials should be used for all future recruitment. A query was raised regarding whether this would mean the applicant would need to go back to their Research Ethics Committee (REC) to gain approval again, and it was stated that this would depend on the individual REC.

It was also noted that as the application was for a worldwide study, there would be the potential for data to be shared outside the UK although the applicant had confirmed that this would not include personal identifiable data. The Group were informed that the applicant would need to seek further approvals to share data outside the UK.

Outcome: The Group were unable to recommend for approval. Further information requested from applicant.

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

This applicant had approached the HSCIC for HES data for a small number of the participants in their study, as the data previously obtained from their general practice records had been incomplete. The participants had previously been contacted by their GP to ask them to consent to participate in the study, and there were some concerns raised around using this consent as the basis for the proposed data sharing as the GP letter had indicated that the study would be completed in 2011, and gave no indication that HES data would be used.

It was noted that the number of participants for whom data had been requested was relatively small, and the Group agreed that if the applicant were still in contact then it would be practical for the applicant to inform each applicable participant about the proposed data extraction and ask them for their consent to this. The Group agreed that the applicant should ask the relevant participants to re-consent to the proposed use of their data.
Outcome: The Group were unable to recommend for approval. Further information requested from applicant.

Update 13.5.14: Letter had been prepared for signature and the Acting Chair confirmed this could be sent to the applicant.

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

It was explained that the HSCIC had an existing agreement in place with the applicant to allow them to access HES data, and that the applicant had S251 support for this. The applicant had now been asked by the Department of Health to carry out an investigation into a series of death of mothers and newborn babies with Morecambe Bay NHS Foundation Trust, and this would require an amendment to the existing agreement. It was noted that the Section 251 approval from HRA CAG was now out of date and that CAG were looking at extending this to cover the requested work.

	The Group agreed that this was an important piece of work, and there were no concerns around the application. It was agreed that the application should be recommended for approval, once the CAG application to extend the Section 251 approval had been completed. **Outcome:** Recommendation to approve. **Update 13.5.14:** Members were advised that CAG are currently considering this request in order to provide an extension to the current Section 251 approval. This should be provided shortly. The DAIS team are in direct contact with the customer in order to take this forward once CAG confirm their decision. **070514-f MR1332: The Cleft Collective Cohort Studies** The applicant had requested biannual reports of patient identifiable data from MIDAS for the participants who had consented to take part in the study. This data would be used to study the impact of being born with a cleft palate. The Group agreed that they were content with the consent materials provided, and that the proposed study seemed like an appropriate use of data. **Outcome:** Recommendation to approve. **(c) Decisions out of committee** No out of committee decisions had been made since the previous DAAG meeting.
130514-d **130514-d1**	Garry Coleman joined the meeting for this application. **University Hospitals Birmingham (UHB) – HES/Stampede Linkage** This request was submitted for consideration of consent wording for linkage of data from the STAMPEDE Trial and HES data. This would allow the team to determine whether their patients are admitted to any hospital with fractures, as skeletal weakness is a potential side effect of the treatment and patients may attend any hospital, rather than the hospital for which they are registered with for the purpose of the trial. The linkage will also provide further information on hospital procedures which are relevant to the trial, to determine quality of life of trial patients. Members discussed the consent wording and agreed that this was appropriate and met HSCIC requirements. Members queried whether all patients would be reconsented and this was felt to be the case. Members confirmed that they were content for the consent to be recommended for approval to the HSCIC SIRO. **Outcome:** Recommendation to approve.
130514-e **130514-e1**	**Request for consent form advice:** **National Diabetes Foot Care Audit** Louise Dunn, the IAA for the audit attended the meeting. This application was submitted to the meeting for advice on the proposed consent. Consent forms and patient information sheet had been provided to DAAG members for consideration. This is a project to check the care which is being provided to people with diabetes by foot care clinics in England and Wales. The members were advised that the wording on the consent had been drafted in conjunction with Diabetes UK and the steering group. The standard HSCIC wording had not been used in

	this case as the clinicians and Diabetes UK advised that the wording should be kept easy to understand as some patients had learning difficulties. The Clinical Audit team however wished to ensure that the consent wording was appropriate for future linkage to HES and MRIS data. Members agreed that the consent wording was fine, but felt that the 1st and 2nd bullets should be revisited to ensure that they were linked together. The Group advised that the patient information sheet could be more explicit with regard to the purpose of linkage with HSCIC data. It would be helpful to provide more information about why the data is being shared for this purpose. The IAA advised that the proposed launch of the audit was in July but testing would need to be undertaken first. Members agreed that the revised wording could be provided to the Acting Chair outside of the meeting, for circulation and feedback from members. **Action:** Louise Dunn to provide revised wording for the patient information sheet for review out of committee.
130514-f	**Any other business:** Future meetings were discussed and it was agreed that there should be a period of at least 2 weeks between meetings to allow sufficient time for applications to be prepared for submission to DAAG. It was agreed that the proposed meeting to be held on 9th June could be cancelled. **Action:** FH to cancel meeting on 9th June. DAAG members were advised that two further applications which are outstanding from previous DAAG meetings would be added to the DAAG Tracker.

Summary of Open Actions

Reference	Action	Owner
070514-d1	Sean Kirwan to suggest updated DAAG Terms of Reference wording to replace current reference to NIGB. Update: The proposed amendments were discussed at the meeting on 13th May and were approved by the members. The TOR to be published.	Sean Kirwan
070514-d2	Frances Hancox to publish updated DAAG Terms of Reference.	Frances Hancox
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
130514-e1	Louise Dunn to provide revised wording for the patient information sheet for review out of committee. (13-0514-e1)	Louise Dunn
130514-f1	FH to cancel meeting on 9th June.	Frances Hancox