

Data Access Advisory Group

Minutes of meeting held 27 February 2014

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

In attendance: Nicola Mallender-Ward, Diane Pryce, Frances Hancox (Secretariat)

Apologies: Sean Kirwan, Richard Wild

270214-a	<p>Welcome</p> <p>Alan Hassey welcomed the attendees and it was noted that since Mark Davies had stepped down due to a conflict of interest, Alan would be acting as chair of DAAG. It was also noted that Dawn Foster was attending the meeting as a nominated reserve for Richard Wild, who had sent his apologies.</p> <p>It was noted that the DAAG Terms of Reference had been updated to list Alan Hassey and Richard Wild as members, and this change had been signed off by Mark Davies as DAAG Chair prior to the meeting.</p> <p>The Group were informed that work was taking place to review HSCIC advisory bodies and how these should function in future. It was anticipated that no further DAAG meetings would be scheduled until this work had been completed and any changes to the Group's structure and remit had been formalised in the Terms of Reference. In light of this it had been agreed that for the current meeting DAAG would not approve any applications, but would instead make recommendations to the HSCIC regarding whether applications should be approved.</p>
270214-b	<p>Minutes of the Previous Meeting</p> <p>The minutes of the 30 January 2014 meeting were agreed as an accurate record. However, it was agreed that Mark Davies should be asked to review the section regarding out of committee decisions in particular, as the DAAG members present were not aware of the details of the application discussed.</p>
270214-c	<p>Matters Arising</p> <p>(a) Overview of Outstanding Actions</p> <ul style="list-style-type: none">• <i>240413-c1: Diane Pryce and Clare Sanderson to discuss differences between the application process in Scotland and England, and consider meeting with NHS Scotland.</i> A query was raised regarding how to proceed with this action, and it was agreed that Alan Hassey and Diane Pryce would discuss this outside the meeting.• <i>310713-c1: Clare Sanderson to schedule a workshop to review the data sharing contract and invite other DAAG members to participate.</i> It was agreed that the updated data sharing contract would be shared with DAAG members via email.• <i>300114-c1: Mark Davies to ensure Alan Perkins and Kingsley Manning are aware of the CQC application (270613-d)</i> Mark Davies had provided an update regarding this by email, and it was noted that this action had been completed.

- *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.*

Due to a key member of staff being on sick leave, it was unclear whether this letter had been sent. It was agreed that this would be determined outside the meeting.

In addition, a response from the applicant had been received to the letter sent in December 2013 stating that they would update their consent materials based on DAAG feedback. However the applicant did not intend to include a reference to 'other central UK NHS bodies', but the Group noted that this wording was intended to cover any future changes to healthcare organisations to ensure that the consent materials would still be valid. The applicant had also not used the recommended wording regarding future contact with participants, as they stated that participants had already provided their contact details, but the Group noted that the recommended wording was intended to cover instances where the applicant might want to use the central register in future to obtain updated contact details for any participants who had moved. It was agreed that the Acting DAAG Chair would contact the applicant regarding these points.

- *300114-g2: Frances Hancox to draft an update for the DAAG Terms of Reference.*

The DAAG Terms of Reference had been updated to reflect the new DAAG membership, and this change had been approved by Mark Davies out of committee. It was agreed that the Terms of Reference would require further updates, and it was suggested that amending the Group membership to include lay members would be beneficial, but no further changes would be made until further clarity was available regarding the future of DAAG.

- *300114-g3: Dawn Foster to contact the ICO regarding consent obtained from individuals who subsequently lost mental capacity.*

This action had been completed but a response had not yet been received from the ICO.

(b) Overview of Outstanding Applications

MR1337: Mortality outcome in the London COPD cohort

This application had been discussed at the 30 January 2014 DAAG meeting and a query had been raised regarding the fact that the Section 251 approval for the application only covered individuals who were deceased. It was confirmed that the applicant had only requested data for individuals who were known to be deceased, and no data about living individuals would be shared. It was also noted that the application was on hold pending an organisational move and subsequent requirement for an updated Information Governance Toolkit.

MR1328: The Birmingham Lung Improvement Studies BLISS

This application had been discussed at the 19 November 2013 DAAG meeting and had not been approved due to concerns raised around the wording in the participant consent materials. The applicant had written to DAAG to respond to these concerns, and had agreed to update consent materials as well as writing to participants who had already been recruited to the study to inform them that their details would be shared with the HSCIC, giving individuals the opportunity to opt out of this. The Group agreed that they were content with the response provided.

Outcome: Recommendation to approve

	<p>(c) Decisions Out of Committee</p> <p>No out of committee decisions had been made since the previous DAAG meeting.</p>
270214-d	<p>HES Applications</p> <p><u>270214-a: The King's Fund (renewal)</u></p> <p>The applicant had applied for HES data in 2010 and this was discussed and approved at the 23 November 2010 meeting (231110-b). The applicant held pseudonymised HES data which contained the sensitive codes Consultant Code, Census Output Area 2001, Code of Patient's Registered or Referring Medical Practitioner and Person Referring Patient. Approval had been given for the applicant to hold this data for three years, and the applicant had now requested an extension so that they could continue to hold this data for a further 12 months.</p> <p>It was noted that no additional data had been requested, and the group recommended that this renewal request should approved.</p> <p>Outcome: Recommendation to approve</p> <p><u>270214-b: The MIDSHPIS Trial</u></p> <p>This application was for bespoke linkage of HES data for Accident and Emergency with Admitted Patient Care for 2013/14. The participants in the study had given their consent, and it was agreed that the consent materials used provided adequate information regarding the use of data. The applicant had stated that the data would be used for research into adults presenting at Accident and Emergency following self-harm, and it was thought that it would be in the public interest for this study to proceed.</p> <p>It was noted that the application was for a feasibility study only, and that if the applicant wished to obtain data for additional study participants then another application would need to be made.</p> <p>Outcome: Recommendation to approve</p> <p><u>270214-c: Unit of Health-Care Epidemiology, Oxford University</u></p> <p>The applicant had requested HES data, which would be used in a programme of research in addition to ONS mortality data. It was noted that the requested data included patient identifiers, and it was agreed that the applicant should apply to the Health Research Authority Confidentiality Advisory Group (HRA CAG) as DAAG was not empowered to approve access to identifiable data.</p> <p>Outcome: Recommendation to contact HRA CAG</p>
270214-e	<p>Data Sharing Contract</p> <p>This had been discussed under the overview of outstanding actions, and no further update was given.</p>
270214-f	<p>DAAG Terms of Reference</p> <p>This had been discussed under the overview of outstanding actions, and it was agreed that no further changes would be made until further details were available regarding the future of DAAG.</p>

270214-g	<p>DAAG Register of Approved Applications</p> <p>There was a discussion of the DAAG Register of Approved Applications, and the importance of agreeing responsibilities for updating this in future. It was agreed that a responsible owner should be determined, pending upcoming changes to DAAG, and in the interim the DAAG Secretariat would update the current Register.</p> <p>Action: Frances Hancox to update the DAAG Register of Approved Applications.</p>
270214-h	<p>Any Other Business:</p> <p>Alan Hassey formally thanked Mark Davies for his work chairing DAAG and the other members of the Group, pending any decision on its future.</p> <p>It was agreed that the March 2014 meeting would be cancelled.</p>

Summary of Open Actions

Reference	Action	Owner
240413-c1 (ongoing)	Diane Pryce and Clare Sanderson to discuss differences between the application process in Scotland and England, and consider meeting with NHS Scotland. (<i>Update 25/09/13: It was suggested that if a date could not be agreed for a face to face meeting then a videoconference or teleconference should be considered.</i>)	Diane Pryce
310713-c1 (ongoing)	Clare Sanderson to schedule a workshop to review the data sharing contract and invite other DAAG members to participate.	Dawn Foster
300114-g1 (ongoing)	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.	Mark Davies
270214-g	Frances Hancox to update the DAAG Register of Approved Applications.	Frances Hancox