

Data Access Advisory Group

Minutes of meeting held 17 December 2013

Members: Mark Davies (Chair), Clare Sanderson, Patrick Coyle

In attendance: Susan Milner, Diane Pryce, Richard Wild, Frances Hancox (Secretariat)

Apologies: Sean Kirwan

171213-a	<p>Welcome</p> <p>The meeting attendees were welcomed, and it was agreed that Clare Sanderson would chair the meeting as Mark Davies would be participating by teleconference.</p> <p>The attendees were informed that Clare would be leaving the HSCIC at the end of the month, and that Mark would be leaving at the end of March 2014.</p> <p>Richard Wild was introduced, and it was anticipated that he would attend future DAAG meetings in place of Clare.</p>
171213-b	<p>Minutes of the Previous Meeting</p> <p>The minutes of the 19 November 2013 meeting were agreed as an accurate record.</p>
171213-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> <p>It was agreed that this should be added as an agenda item for the scheduled meeting with NHS Scotland in March 2014.</p> <ul style="list-style-type: none">• <i>310713-c1: Clare Sanderson to schedule a workshop to review the data sharing contract and invite other DAAG members to participate.</i> <p>A workshop for HSCIC business areas had been scheduled to take place in January 2014 led by Dawn Foster, and it was agreed that following this workshop Dawn should be invited to attend a DAAG meeting. It was also noted that a sign-off process would need to be agreed, and Mark Davies and Richard Wild intended to discuss this outside the meeting.</p> <ul style="list-style-type: none">• <i>191113-c1: Mark Davies to contact Catia Nicodemo regarding her application for sensitive data items through HES Business Objects.</i> <p>It was agreed that this would be discussed under the HES Applications agenda item (171213-d2), and the action was closed.</p> <p>(b) Overview of Outstanding Applications</p> <p><u>270613-d: CQC MHMDS/HES Bridging File</u></p> <p>This application had been discussed at the 27 June 2013 DAAG meeting, and had been approved subject to clarification from CQC about whether the code of practice on confidential</p>

	<p>personal information would continue to apply; it was also suggested that a privacy impact assessment should be completed. A response from CQC had been received, which had been circulated to DAAG members. CQC had confirmed that the code of practice would apply to the data requested, but noted that this code of practice was undergoing review and the HSCIC would be consulted on this. CQC had also provided a draft privacy impact assessment; it was suggested that this would be reviewed by appropriate HSCIC staff and Mark Davies would then share any comments with CQC. The Group noted that it was helpful that CQC had asked for feedback while these documents were still in draft form, and that this approach should be encouraged.</p> <p><u>MR1328: Birmingham Lung Improvement Studies (BLISS)</u></p> <p>This application had been discussed at the 19 November 2013 DAAG meeting and was not approved. The applicant had replied to the outcome letter stating that they would respond to the points raised by DAAG and would consider amending the consent materials used, but no further response had yet been received.</p> <p>(c) Decisions Out of Committee</p> <p>No decisions had been made out of committee.</p>
<p>171213-d</p>	<p>HES Applications</p> <p><u>171213-d1: UK Biobank (HES, MHMDS, MHMDS bridging file, DIDS)</u></p> <p>The applicant had requested HES, MHMDS and DIDs data in addition to a HES-MHMDS bridging file; this would be in addition to the HES Inpatient, Accident and Emergency, Critical Care and Outpatient data already held for UK Biobank participants.</p> <p>The Group discussed whether the consent obtained from UK Biobank participants appropriately covered this data, and it was noted that UK Biobank considered that the consent obtained was sufficient. It was noted that UK Biobank were in regular contact with the majority of participants, and provided newsletter updates; it was suggested that this could be used to make participants aware of the additional data that had now been requested.</p> <p>The Group emphasised the importance of keeping participants informed in order to ensure fair processing of data and it was agreed that this should be reiterated in the outcome letter to UK Biobank, particularly as the requested data included mental health data which some individuals could consider to be more sensitive than other data. The Group also suggested that they would welcome sight of the materials which UK Biobank sent out to participants.</p> <p>Outcome: Approved</p> <p><u>171213-d2: HES Sensitive Data Application Form (Nicodemo)</u></p> <p>This application was originally discussed at the 26 February 2013 DAAG meeting (Ref: 260213-a) and was not approved; it was resubmitted to the 25 September 2013 meeting and not approved, as the Group suggested that the applicant should seek Research Ethics Committee (REC) approval. The application was also discussed under the 'Outstanding Applications' agenda item at the 19 November 2013 meeting, as it was noted that a response had been received from the applicant seeking clarification.</p> <p>The applicant had now received a favourable REC opinion, subject to a number of conditions being met. On this basis DAAG approved the application.</p> <p>Outcome: Approved</p>

171213-e	<p>Data Linkage and Extract Service (MRIS) Applications</p> <p><u>MR1340: IBIS - I and IBIS - II (The International Breast Cancer Intervention Study)</u></p> <p>This study had requested linked HES data and patient tracking for cause of death; the application had received Section 251 support, but as the data requested included a sensitive item the Group were also asked to review the application.</p> <p>The Group supported the work being carried out by the study, and no concerns were raised regarding confidentiality of the data requested.</p> <p>Outcome: Approved</p> <p><u>MR1344: CoBaIT Study (Cognitive behavioural therapy for depression)</u></p> <p>This application had requested patient postcode and current registered GP details for approximately 100 study participants; the applicant intended to contact participants either through the GP or directly, in order to ask them to complete a questionnaire. It was noted that the participants' consent wording had included a statement about being contacted in the future, and it had also stated that if the participant moved house then their new address would be obtained through the NHS Central Register. The Group noted that the consent wording used was slightly out of date, but that it had been accurate at the time it was used.</p> <p>Outcome: Approved</p> <p><u>CRAB Systems</u></p> <p>This applicant had previously applied for data to support a mortality review across 14 hospitals led by Professor Sir Bruce Keogh, which DAAG had discussed and approved out of committee in April 2013. The applicant had now requested data to extend this system and make analysis available to other NHS Trusts.</p> <p>It was noted that the data requested included the consultant code, which was considered a sensitive field. The Group agreed that this was acceptable for the proposed use of the data.</p> <p>Outcome: Approved</p> <p><u>MR1346: National Hip Fracture Database (for notification)</u></p> <p>It was noted that this application had received Section 251 support.</p>
171213-f	<p>Any Other Business:</p> <p>A query was raised regarding dates for future meetings, given the upcoming changes to the Group's membership. It was agreed that meeting dates should be set for a full year, and that these could be rescheduled as required.</p>
171213-g	<p>Date of Next Meeting: TBC</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</i> : 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.)	Clare Sanderson
310713-c1 (ongoing)	Clare Sanderson to schedule a workshop to review the data sharing contract and invite other DAAG members to participate.	Clare Sanderson