

Data Access Advisory Group

Minutes of meeting held 30 January 2014

Members: Mark Davies (Chair), Patrick Coyle, Sean Kirwan

In attendance: David Cronin, Dawn Foster, Alan Hassey, Susan Milner, Frances Hancox (Secretariat)

Apologies: Richard Wild, Diane Pryce

300114-a	<p>Welcome</p> <p>Mark Davies welcomed the attendees and chaired the meeting. It was noted that Alan Hassey was attending the meeting as an observer, and would be joining DAAG as a member for future meetings.</p>
300114-b	<p>Minutes of the Previous Meeting</p> <p>The minutes of the 17 December 2013 meeting were agreed as an accurate record.</p>
300114-c	<p>Matters Arising</p> <p>(a) Overview of Outstanding Actions</p> <ul style="list-style-type: none">240413-c1: Diane Pryce and Clare Sanderson to discuss differences between the application process in Scotland and England, and consider meeting with NHS Scotland. <p>Two possible meeting dates had been proposed, and it was agreed that these dates would be shared with Mark Davies and Rich Wild.</p> <ul style="list-style-type: none">310713-c1: Clare Sanderson to schedule a workshop to review the data sharing contract and invite other DAAG members to participate. <p>A workshop for Information Asset Owners had been scheduled, and Dawn Foster agreed to provide a further update at the 27 February 2014 DAAG meeting.</p> <p>(b) Overview of Outstanding Applications</p> <p>An application from CQC for a MHMDS-HES bridging file (270613-d) had initially been discussed at the 27 June 2013 DAAG meeting, where it was approved subject to assurances from CQC that appropriate access controls will be in place. CQC had provided a privacy impact assessment as requested, and this had been reviewed by staff within the HSCIC. It was noted that the privacy impact assessment was not in the standard format that had been expected, but no concerns were raised regarding the content of the document.</p> <p>Dave Cronin stepped out of the meeting at this stage.</p> <p>It was noted that CQC's most recent information governance toolkit score was unsatisfactory, and this raised some concerns. The Group agreed that CQC should be asked to provide additional assurances that appropriate arrangements would be in place to securely handle confidential data.</p> <p>Action: Mark Davies to ensure Alan Perkins and Kingsley Manning are aware of the CQC application (270613-d)</p>

	<p>(c) Decisions Out of Committee</p> <p><u>OC/HES/030: Cabinet Office (Project: National Citizen Service (NCS) Data Linkage Project)</u></p> <p>This request was considered and approved by DAAG members out of committee, but had not been recorded in the relevant minutes. The members agreed that this should be included in the January minutes to ensure that it was on record.</p> <p>This was a request to check that consent in place on the website was appropriate for possible linkage of the NCS evaluation data to HES and/or MHMDS data. No data was requested.</p> <p>The project submitted a proposed consent question to include in the NCS evaluation baseline survey to allow the matching of participant data to government data sets. The intention was to be able to link to HES/MHMDS data in the future.</p> <p>NCS works to develop more cohesive, engaged and responsible young people between the ages of 16 and 17, through a programme of personal development and a social action project tailored to the young person's community</p> <p>The project wanted to enhance the evaluation of NCS by capturing more tangible outcomes for NCS participants and stated that 'One way we would like to do this is by linking evaluation data to data held on young people's health behaviours and engagement with the NHS. With the programme growing at a rapid rate (providing spaces for 50,000 young people this year), this is a great opportunity to better understand the immediate and on-going impact of NCS in this area. We would like to do this by linking to Hospital Episode Statistics and the linked Mental Health Minimum Data Set (MHMDS).'</p> <p>This was approved out of committee.</p>
<p>300114-d</p>	<p>HES Applications</p> <p><u>300114-a: HES - Northgate Information Solutions</u></p> <p>It was noted that the circulation of papers for this application had been delayed, and the application would be discussed at the 27 February 2014 meeting.</p> <p><u>300114-b: Learning Disabilities Census data - Public Health England</u></p> <p>The applicant had requested learning disabilities census data, which included sensitive fields relating to legal status and source of referral. This data would be used to inform a final report for the Winterbourne View Joint Improvement Programme. In addition to considering the request for data, DAAG were also asked to confirm that they would be happy to consider other requested for learning disabilities census data.</p> <p>Dave Cronin re-joined the meeting at this stage.</p> <p>The Group queried whether the applicant intended to link the sensitive fields with any other data, and it was agreed that the applicant should be asked to confirm that they did not intend to do so.</p> <p>Outcome: Approved subject to assurances that the applicant will not link sensitive fields with any other data</p>

300114-e	<p>Data Linkage and Extract Service (MRIS) Applications</p> <p><u>MR1347: Venous thromboembolism among care home residents (VTEC)</u></p> <p>This application was for patient flagging for date and cause of death in order to study venous thromboembolism (VTE) related deaths among care home residents. It was noted that the consent materials used the recommended wording, and the application was approved.</p> <p>Outcome: Approved</p> <p><u>MR1337: Mortality outcome in the London COPD cohort (for notification)</u></p> <p>This application was received for notification, as it had received Section 251 approval. However, it was noted that the Section 251 approval obtained only applied to individuals who were now deceased or who had been lost to follow-up, and that it was expected the applicant would seek consent from any individuals who were still available for follow-up. It was agreed that the consent materials would be circulated for consideration out of committee.</p>
300114-f	<p>DAAG Register of Approved Applications</p> <p>It was noted that a number of enquiries had been received regarding previous DAAG approvals, and due to the need for transparency the importance of keeping the Register of Approved Applications up to date was emphasised. It was agreed that the practicalities around updating the Register should be discussed in more detail at the following meeting.</p>
300114-g	<p>Any Other Business:</p> <p>An application from the University of Cardiff was discussed. This application had originally been discussed by DAAG at the 23 August 2011 meeting (170511-a) and the applicant had now requested an update of data, including the data previously requested as well as 2011-12 data. The applicant had confirmed that they would delete the data previously received so that they would not hold any duplicate data. It was also confirmed that no additional data items had been requested, and the Group approved the requested update.</p> <p>Outcome: Approved</p> <p>An application from the University of Sheffield was also discussed. This application (191113-d1) had been discussed at the 19 November 2013 DAAG meeting and had not been approved, as the Group did not feel that the consent materials used were acceptable. The applicant had now updated the consent materials to use the standard wording recommended by DAAG, and it was agreed that the updated consent materials would be circulated for consideration out of committee. It was noted that a large number of participants had already been recruited using the old consent form, and the applicant had stated that they would be re-contacting these individuals to update their consent. There was a discussion regarding the difficulties of re-contacting such a large number of participants, and the need to consider what approach should be taken for individuals who did not respond to the planned mail-out.</p> <p>Action: 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.</p> <p>A query was raised regarding the DAAG Terms of Reference, as it was noted that these required updating. It was agreed that the Secretariat would draft an update for the following meeting.</p>

	<p>Action: Frances Hancox to draft an update for the DAAG Terms of Reference.</p> <p>A query had been received regarding the recruitment of new DAAG members to replace those who were leaving. It was noted that no recruitment process was currently in place, as a review of advisory group functions was ongoing.</p> <p>A further query had been received from a customer regarding obtaining consent from individuals at the beginning of study, and whether this consent would be considered to still apply if the individual lost mental capacity during the course of the study. It was agreed that the HSCIC would contact the Information Commissioner's Office to seek advice on this.</p> <p>Action: Dawn Foster to contact the ICO regarding consent obtained from individuals who subsequently lost mental capacity.</p>
300114-h	<p>Date of Next Meeting: Thursday 27 February 14:00 – 15:00</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-c1	Mark Davies to ensure Alan Perkins and Kingsley Manning are aware of the CQC application (270613-d)	Mark Davies
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.	Mark Davies
300114-g2	Frances Hancox to draft an update for the DAAG Terms of Reference.	Frances Hancox
300114-g3	Dawn Foster to contact the ICO regarding consent obtained from individuals who subsequently lost mental capacity.	Dawn Foster