

Data Access Advisory Group

Minutes of meeting held 26 March 2013

Members: Mark Davies (Chair; item 260313-c onwards), Clare Sanderson, Patrick Coyle, Sean Kirwan

In attendance: Susan Milner, Mansoor Sahibzada, Nicola Mallender-Ward, Diane Pryce, Charlotte Skinner, Frances Hancox (Secretariat)

Apologies: None

260313-a	<p>Welcome</p> <p>Clare Sanderson welcomed everyone and chaired the meeting until Mark Davies arrived during agenda item 260313-c.</p>
260313-b	<p>Minutes of the Previous Meeting</p> <p>The minutes of the previous meeting, 23 February 2013, were ratified.</p>
260313-c	<p>Matters Arising</p> <p>(a) Overview of Outstanding Actions</p> <ul style="list-style-type: none">260712-c1: Diane Pryce and Louise Dunn to review the existing data sharing agreement and suggest how this could be updated to form a two-stage process. (Update: Louise Dunn to provide an update on ongoing work at February 2013 meeting.) It was noted that legal feedback on the updated data sharing agreement had now been received and would be reviewed internally.260712-c2: Clare Sanderson and Louise Dunn or Diane Pryce to meet with ECC and HRA representatives to discuss the use of IG Toolkits and the process for customers who do not complete the IG Toolkit; Patrick Coyle and Sean Kirwan to be invited once a meeting date is set. It had been suggested that this discussion should take place at the first HRA Confidentiality Advisory Group meeting, and it was agreed that this action would remain open. <p>At this point Mark Davies joined the meeting.</p> <ul style="list-style-type: none">260712-f1: Diane Pryce and Louise Dunn to look into finding a technical solution for sharing DAAG documents. (Update: Dave Cronin to provide an update at the February 2013 meeting.) It was thought that the upgraded Customer Relationship Management (CRM) software would provide this functionality. Diane Pryce agreed to provide a further update when this was available to use. <p>(b) Overview of Outstanding Applications</p> <p><u>MR578</u></p> <p>This was an update of an application that had been discussed by the Group at the 19 December 2012 meeting under Any Other Business; the update requested an extension in order to use the data obtained for a new study. It was noted that this application was currently on hold due to awaiting a response from the applicant.</p>

	<p><u>260213-f (b): University of Kent</u></p> <p>This applicant's consent form for individuals with learning disabilities had been discussed at the 26 February 2012 DAAG meeting, and the Group's feedback had been passed on to the applicant. A response had been received to confirm that the consent form's reference to looking at information on a computer had now been updated, and it was noted that the applicant had now received approval from a Social Care Research Committee.</p> <p>(c) Decisions Out of Committee</p> <p><u>MR1315: Development of a clinical decision rule for referral of patients presenting to primary care with chest pain: a feasibility study</u></p> <p>This applicant had previously received approval for HES data, and had additionally requested mortality data in order to develop a clinical decision rule for individuals presenting with chest pains. It was noted that the consent materials had included the suggested wording verbatim, and the application had been approved out of committee.</p>
260313-d	<p>NHS Central Register – MRIS Applications</p> <p><u>SR197: Lifelong health and wellbeing of the 'Scotland in Miniature' cohort</u></p> <p>This application requested current status, flagging and list-cleaning for death, cancer, exits and re-entries; the majority of the cohort were resident in Scotland, and the applicant intended to write to individuals within a sub-cohort. It was noted that similar recent projects that had involved sending a mail-out in this way had required Section 251 approval, but that in this instance NIGB ECC Secretariat had stated that it was thought this decision would fall within the HSCIC's new organisational powers from 1 April 2013 onwards.</p> <p>There was some uncertainty regarding what had been meant by this statement, as it was unclear which of the HSCIC's new powers would apply to this situation. It was suggested that this should be discussed with the HRA Confidentiality Advisory Group after 1 April 2013 to seek further clarity.</p> <p>Action: Mark Davies to write to HRA Confidentiality Advisory Group regarding the SR197 and seek clarity regarding how the HSCIC's new powers would apply to this situation.</p> <p>Some concerns were also raised regarding the consent form for this application, as the current recommended wording had not been included, and it was suggested that the consent form should be updated for use in this study. It was agreed that the applicant should be advised to use the recommended consent wording, and advised that a further update would be provided following discussion with the HRA Confidentiality Advisory Group.</p> <p>Some additional concerns were raised regarding the length of time taken to process applications, and it was suggested that this should be reviewed following 1 April 2013.</p> <p>Outcome: Approved subject to outcome of discussions with HRA Confidentiality Advisory Group, and subject to consent forms being updated</p>
260313-e	<p>Contact Database</p> <p>At this point Mark Davies resumed the chair of the meeting.</p> <p>An enquiry had been received regarding plans to create a contact database, for which individuals would be asked to give their consent to be contacted and asked to participate in</p>

	<p>future studies. It was noted that this would in some ways be similar to the work carried out by UK Biobank, and there were some concerns about UK Biobank being seen as a precedent to create additional databases of this kind. It was suggested that the customer should be advised to contact NIGB ECC to discuss this further.</p>
260313-f	<p>Any Other Business:</p> <p>A request had been received from University Hospitals Birmingham (UHB) relating to a project they were working on with Bosch Healthcare to evaluate the impact of a telemonitoring system called 'Bosch Health Buddies' on the outcomes for patients with long term conditions. The project would involve UHB accessing data provided on the cohort participating in the telemonitoring system under consent. UHB had requested advice on whether they could access the data provided under the consent and link to HES data held by UHB.</p> <p>The Group noted that the consent form was specifically related to taking part in the 'Bosch Health Buddies' telemonitoring system and there was no mention of UHB accessing the data and using the information for linkage with HES data.</p> <p>Outcome: Members advised that if UHB wished to access the data obtained under the 'Bosch Health Buddies' telemonitoring system it would be necessary for them to obtain specific consent from the cohort for this purpose.</p>
260313-g	<p>Date of Next Meeting: Wednesday 24 April 9:30 – 10:30</p>

Summary of Actions

Reference	Action	Owner
260712-c1 (ongoing)	Diane Pryce and Louise Dunn to review the existing data sharing agreement and suggest how this could be updated to form a two-stage process. (Update: Louise Dunn to provide an update on ongoing work at February 2013 meeting.)	Diane Pryce and Louise Dunn
260712-c2 (ongoing)	Clare Sanderson and Louise Dunn or Diane Pryce to meet with ECC and HRA representatives to discuss the use of IG Toolkits and the process for customers who do not complete the IG Toolkit; Patrick Coyle and Sean Kirwan to be invited once a meeting date is set.	Clare Sanderson
260712-f1 (ongoing)	Diane Pryce and Louise Dunn to look into finding a technical solution for sharing DAAG documents. (Update: Dave Cronin to provide an update at the March 2013 meeting.)	Diane Pryce and Louise Dunn
260313-d1	Mark Davies to write to HRA Confidentiality Advisory Group regarding the SR197 and seek clarity regarding how the HSCIC's new powers would apply to this situation.	Mark Davies