

Data Access Advisory Group

Minutes of meeting held 31 July 2013

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

In attendance: Susan Milner, Nicola Mallender-Ward, Frances Hancox (Secretariat)

Apologies: Diane Pryce, Charlotte Skinner

310713-a	<p>Welcome</p> <p>Mark Davies welcomed the attendees to the meeting.</p>
310713-b	<p>Minutes of the Previous Meeting</p> <p>The minutes of the 27 June 2013 meeting were agreed as an accurate record.</p>
310713-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. The updated data sharing contract was now in use for data services commissioning. However it was suggested that a workshop should be scheduled to review the data sharing contract and consider whether it would still be appropriate to have one data sharing contract for all business requirements. It was agreed that this action should be closed. <p>Action: Clare Sanderson to schedule a workshop to review the data sharing contract and invite other DAAG members to participate.</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. A potential date for a meeting in Scotland had been found, but it was thought that this date would no longer be possible for some attendees. It was suggested that the meeting could be scheduled to coincide with another meeting that NHS Scotland representatives would be attending in Southport.270613-d1: Mark Davies to write to HRA Confidentiality Advisory Group regarding the provision of a HES and MHMDS bridging file to CQC. This action was ongoing.270613-f1: Clare Sanderson to discuss UK Biobank application (MR1109) with the HRA Confidentiality Advisory Group. This action was ongoing. It was noted that Clare intended to raise this with the Confidentiality Advisory Group by email initially to determine whether a more formal discussion would be required, and Susan Milner was asked to provide copies of the relevant paperwork by email. <p>(b) Overview of Outstanding Applications</p> <p><u>260313-f: UHB/Bosch Health Buddies</u> and <u>310113-g - Born in Bradford Study</u></p> <p>Letters had been sent to these two applicants, but no response had been received. There</p>

	<p>was a brief discussion regarding how to proceed with applications when no response was received within a set time period, and it was agreed that the applicants should be contacted again. It was suggested that the Group's Terms of Reference should be updated to include a three month timeframe for applicants to respond following receipt of an outcome letter, and that applicants should be informed that if no response was received within this time then their application would be closed.</p> <p>(c) Decisions Out of Committee</p> <p><u>OC/HES/027: University of Oxford</u></p> <p>This application had been considered by the Group out of committee and approved.</p>
<p>310713-d</p>	<p>HES and MHMDS Applications</p> <p><u>310713-b: HSpot Ltd FindMeHealth</u></p> <p>The applicant had requested HES data including consultant codes, with the intention of publishing this data online to enable patients to compare procedures by hospital and clinician. Consent to publish the data would be sought from consultants using an online consultant registration page.</p> <p>The Group confirmed that the consent wording provided was appropriate, but it was emphasised that it would be important for the registration page to present the consent wording and tick box clearly and prominently. It was also suggested that the customer could consider sending a confirmation email to consultants who gave their consent through the webpage. In addition, the Group noted that if the applicant later wished to use the data provided through HES for any other purposes then this would need to be considered again by DAAG, and additional consent sought from consultants if appropriate.</p> <p>It was noted that the DAAG Chair had been contacted by the applicant, and that the applicant had been informed it would not be appropriate to discuss the application prior to the meeting.</p> <p>Outcome: Approved subject to the applicant ensuring that the online consent wording and tick box are displayed clearly and prominently.</p> <p><u>310713-c: University of Oxford - Unit of Healthcare Epidemiology</u></p> <p>It was noted that the applicant held HES data as well as ONS mortality spanning from 1999 to 2011, which included partial identifiers used for linkage, in addition to the Oxford Record Linkage Study (ORLS) dataset, which covered the former Oxford NHS Region spanning 1963 to 1998. The applicant had requested that the HSCIC encrypt the ORLS dataset using encrypted identifiers, which would allow the data to be linked with the HES and ONS data they also held. It was noted that the applicant would also need to gain ONS approval for this.</p> <p>The Group were in support of the proposed purpose of this application, which was to use the linked dataset to create a capability for studies of perinatal factors and disease in mothers and their offspring. A query was raised regarding whether the applicant would decrypt the data they held before it was passed on to the HSCIC to re-encrypt, as at that stage the identifiers would be visible, and it was suggested that the HSCIC should carry out the necessary decryption as well as the re-encryption to ensure the data linkage could be carried out securely.</p> <p>It was agreed that the HSCIC should confirm with the customer that the HSCIC would carry out the required decryption in order to link and then re-encrypt the data without the customer</p>

	<p>having access to identifiers, and subject to this the Group approved the application.</p> <p>Outcome: Approved subject to HSCIC carrying out the required decryption</p> <p><u>310713-d: University of York - Centre for Health Economics</u></p> <p>This application requested sensitive MHMDS and sensitive HES psychiatric fields, in addition to a bridging file to link the two datasets. The applicant intended to use this data to carry out research into economic matters relating to mental health and mental health care provision, and it was stated that using both HES and MHMDS data would allow the applicant to study the full patient pathway.</p> <p>There was a discussion regarding whether linking the HES and MHMDS with a bridging file would make the data more identifiable; it was noted that this would not make the data patient identifiable. The sensitivity of mental health data was also discussed, as it was noted that some individuals might not consider data about their mental health to be particularly sensitive while others might.</p> <p>Outcome: Approved</p> <p><u>310713-e: University Hospitals Birmingham</u></p> <p>This application requested approval to link HES data held by the applicant with UK Transplant data, using NHS number. This would be for use in a study to evaluate whether kidney donation was linked to an increased risk of admission to hospital and mortality.</p> <p>Patients had been asked to consent to their data being stored on the UK Transplant Registry, and 'shared when necessary'. The Group raised concerns that the consent form used did not explain how data could be used, and that patients could assume data would only be shared for direct healthcare purposes. It was also not felt that the consent form adequately covered the linkage of this data with HES data.</p> <p>It was noted that some similar issues had been raised when discussing other applications from University Hospitals Birmingham, and it was suggested that a meeting with University Hospitals Birmingham representatives should be scheduled in order to discuss themes that it would be helpful to consider for any future applications.</p> <p>Action: Mark Davies to write to Daniel Ray and offer a meeting to discuss future University Hospitals Birmingham applications</p> <p>The Group strongly supported the strategic intent of this application, but there were significant concerns regarding the ambiguity of wording in the patient information leaflet. It was suggested that the applicant should consider writing to the patients in the cohort to seek further consent for this study, and that if this were not practical the applicant could potentially seek Section 251 approval. It was also noted that the application did not include any reference to REC approval, and the applicant should be asked whether this had been sought.</p> <p>Outcome: Not approved</p>
310713-e	<p>Data Linkage Service (MRIS) Applications</p> <p><u>MR1325: Control Sample – University of York (E Kane)</u></p> <p>The Group were notified that this application had received Section 251 approval. No concerns were raised.</p>

310713-f	<p>Any Other Business:</p> <p>The DAAG webpages were briefly discussed, and it was agreed that the webpages required updating. It was suggested that this should also include examining reference to DAAG elsewhere on the HSCIC website, and updating these where appropriate.</p> <p>Action: Mark Davies to write to Martin Liddament regarding updates to the DAAG webpages</p>
310713-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 31/07/13</i> : It was suggested that the meeting could be scheduled to coincide with another meeting that NHS Scotland representatives would be attending in Southport.	Clare Sanderson
270613-d1 (ongoing)	Mark Davies to write to HRA Confidentiality Advisory Group regarding the provision of a HES and MHMDS bridging file to CQC	Mark Davies
270613-f1 (ongoing)	Clare Sanderson to discuss UK Biobank application (MR1109) with the HRA Confidentiality Advisory Group. (<i>Update 31/07/13</i> : It was noted that Clare intended to raise this with the Confidentiality Advisory Group by email initially to determine whether a more formal discussion would be required, and Susan Milner was asked to provide copies of the relevant paperwork by email.)	Clare Sanderson
310713-c1	Clare Sanderson to schedule a workshop to review the data sharing contract and invite other DAAG members to participate.	Clare Sanderson
310713-f1	Mark Davies to write to Martin Liddament regarding updates to the DAAG webpages.	Mark Davies