

Data Access Advisory Group

Minutes of meeting held 25 September 2013

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

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

Apologies: None

250913-a	<p>Welcome</p> <p>Mark Davies welcomed the attendees to the meeting.</p>
250913-b	<p>Minutes of the Previous Meeting</p> <p>The minutes of the 31 July 2013 meeting were agreed as an accurate record.</p>
250913-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. There had been some difficulties in setting a date for this meeting, and 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.• 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 had been completed, and a reply had been received. It was agreed that the reply letter would be circulated to all DAAG members, and the action was closed.• 270613-f1: Clare Sanderson to discuss UK Biobank application (MR1109) with the HRA Confidentiality Advisory Group. This had been discussed with the Chair and Deputy Chair of the HRA CAG, who had queried whether the application had approval from a Research Ethics Committee (REC). It was noted that the customer believed this was covered by their original REC approval. The Group briefly discussed the Section 251 approval that had initially been used to contact possible participants for UK Biobank, but it was noted that the customer believed that the proposed additional contact with participants was included in the consent given by individuals to participate in UK Biobank. There was some discussion regarding whether the consent wording used had made that clear to participants, and it was thought to be unclear what scans participants would be asked to consent to. It was agreed that Mark Davies would contact UK Biobank to seek clarification around the points raised by DAAG.• 310713-c1: Clare Sanderson to schedule a workshop to review the data sharing contract and invite other DAAG members to participate. It was noted that there had been some initial difficulties with the use of the updated data sharing contract, and that due to this the scheduling of a workshop had been postponed. It was suggested that a workshop should be scheduled for mid-November.• 310713-f1: Mark Davies to write to Martin Liddament regarding updates to the DAAG webpages. An initial meeting had been held to discuss updating the DAAG webpages,

	<p>and the importance of considering how patients and potential customers would view the webpages was emphasised.</p> <p>(b) Overview of Outstanding Applications</p> <p><u>MR578: Recovery of immunity following lymphocyte depletion</u> This application had previously been approved by DAAG, but a query had recently been raised regarding whether the researcher should have had access to the data in question. Following discussion with the HRA Confidentiality Advisory Group it was concluded that it was appropriate for the researcher to have access to data.</p> <p><u>310713-e: University Hospitals Birmingham</u> Following a letter sent University Hospitals Birmingham on 15 August 2013, a response had been received agreeing to meet to discuss any concerns in more detail. There was a brief discussion regarding whether it would be beneficial for the customer to attend a DAAG meeting rather than scheduling a separate meeting with DAAG members, and it was agreed that both options should be suggested to the customer.</p> <p>(c) Decisions Out of Committee</p> <p>It was noted that CQC had replied to the letter regarding their application 270613-d for a HES-MHMDs bridging file, and had agreed to respond to the requested assurances, but no further details had yet been received. CQC had subsequently requested HES and MHMDs data for 2013/14 in addition to the 2012/13 data initially requested; the Group approved this additional data year.</p> <p><u>OC/DID/032:</u> This application for the HSCIC Diagnostic Imaging Dataset (DID) had been circulated by email and approved out of committee following comments from Clare Sanderson and Patrick Coyle.</p>
<p>250913-d</p>	<p>HES and MHMDs Applications</p> <p><u>310713-a: HES Sensitive Data Application Form (Nicodemo)</u></p> <p>This was an application from the Centre for Health Economics, part of the Department of Health. An application had initially been received and discussed by DAAG in February 2013 for access to sensitive fields through HES Business Objects. The Group had stated at the time that the purpose of this was unclear and queried whether ethical approval had been sought, and it was felt that the usage of HES Business Objects for data linkage would not be appropriate. The applicant had since sought advice from a Research Ethics Committee regarding ethical approvals, and it had now been confirmed that ethical approval would not be required on the condition that the HSCIC did not feel that it was necessary.</p> <p>There was some uncertainty regarding whether the data requested by the applicant would be appropriate for the stated purpose; it was noted that a large amount of work had already been carried out examining reasons for differences in referral rates, although it was felt that further work in this area could still prove beneficial.</p> <p>Sean Kirwan declared an interest in this application, as the customer was the Department of Health, and did not participate in the discussion.</p> <p>The Group agreed that the applicant should seek Research Ethics Committee approval.</p> <p>Outcome: Not approved</p>

<p>250913-e</p>	<p>Data Linkage Service (MRIS) Applications</p> <p><u>MR740: Class Action Project (consent) – Ovarian Cancer Screening</u></p> <p>This study had previously received Class Action support to allow access to patient data, as it had previously been determined that the patient consent model used was not adequate for the use of data required. The Group confirmed that the consent materials used were out of date and not fit for purpose, and that the study would need to either seek Section 251 approval, update patient consent or use de-identified data.</p> <p>Outcome: Not approved</p> <p><u>MR1320: Is Survival of Patients with Chronic Total Coronary Occlusions Dependent upon Treatment Strategy? (Section 251 notification)</u></p> <p>It was noted that this application had received Section 251 approval.</p> <p><u>MR1318: General Health & Hospital Admissions in Children Born after ART: A Population Based Linkage Study (Section 251 notification)</u></p> <p>It was noted that this application had received Section 251 approval.</p>
<p>250913-f</p>	<p>Web based consent</p> <p><u>ADL Smartcare</u></p> <p>An enquiry had been received regarding the use of web based consent to contact individuals on a register. However, discussion of this application was delayed as it was noted that some members were unable to access one of the papers provided. It was agreed that the application papers would be re-circulated by email and considered out of committee.</p> <p>Action: Diane Pryce to re-circulate ADL Smartcare papers for consideration out of committee</p> <p><u>RAFT Dementia Research Register</u></p> <p>Feedback had been requested from DAAG on the consent materials provided, which asked patients to consider joining a dementia research register so that they could potentially be asked to participate in studies at a later date. It was noted that the form provided informed patients that consenting to join the register did not oblige them to participate in any studies, as patients were only asked to consent to being contacted in future.</p> <p>The Group discussed whether the materials provided would adequately cover all circumstances in which the customer might wish to contact participants, and this was compared to the lessons learned from the creation of registers such as UK Biobank. The use of online consent was discussed, and it was acknowledged that this could cause difficulties in securely confirming the identity of the person registering, but it was noted that additional consent for further participation would be sought on a study by study basis. The Group also noted that the materials provided did not include any reference to sharing participants' data with national databases, as might need to happen to keep the register up to date and remove the details of any individuals who had died.</p> <p>There was a brief discussion regarding guidance that could be given to any organisation seeking to use web based consent, and it was suggested that the updated DAAG webpages could include a list of resources for anyone designing a research study.</p>

250913-g	<p>Any Other Business:</p> <p>There was a brief discussion regarding the disclosure of identifiable data outside the European Union, and whether date of death was considered to be an identifier. It was noted that if date of death data had been obtained from ONS then it would be necessary to obtain ONS approval for the disclosure.</p>
250913-h	<p>Date of Next Meeting: Thursday 24 October 16:00 – 17:00</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>)	Clare Sanderson
270613-f1 (ongoing)	Clare Sanderson to discuss UK Biobank application (MR1109) with the HRA Confidentiality Advisory Group. (<i>Update 25/09/13: Mark Davies to write to UK Biobank.</i>)	Clare Sanderson and Mark Davies
310713-c1 (ongoing)	Clare Sanderson to schedule a workshop to review the data sharing contract and invite other DAAG members to participate.	Clare Sanderson
310713-f1 (ongoing)	Mark Davies to contact Martin Liddament regarding updates to the DAAG webpages.	Mark Davies
250913-f1	Diane Pryce to re-circulate ADL Smartcare papers for consideration out of committee	Diane Pryce