

Data Access Advisory Group

Minutes of meeting held 19 November 2013

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

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

Apologies: None

191113-a	<p>Welcome</p> <p>Mark Davies welcomed the attendees to the meeting.</p>
191113-b	<p>Minutes of the Previous Meeting</p> <p>The minutes of the 25 September 2013 meeting were agreed as an accurate record.</p>
191113-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> A meeting had not yet been scheduled due to diary conflicts, although it was noted that the option of arranging a teleconference instead of a face to face meeting had been offered. It was agreed that Diane Pryce would raise this with NHS Scotland ahead of the upcoming quarterly meeting, and that if a meeting date could not be found by the following DAAG meeting then the action should be closed.• <i>270613-f1: Clare Sanderson to discuss UK Biobank application (MR1109) with the HRA Confidentiality Advisory Group.</i> This action had been completed, and a letter to UK Biobank had been drafted.• <i>310713-c1: Clare Sanderson to schedule a workshop to review the data sharing contract and invite other DAAG members to participate.</i> A workshop had not yet been scheduled as the revised data sharing contract was still being piloted.• <i>310713-f1: Mark Davies to write to Martin Liddament regarding updates to the DAAG webpages.</i> Discussions about the DAAG webpages had taken place, and it was agreed that this action should be closed. It was suggested that Martin Liddament should be invited to attend a DAAG meeting in the new year.• <i>250913-f1: Diane Pryce to re-circulate ADL Smartcare papers for consideration out of committee.</i> This had been re-circulated but no comments had been received. The application was re-circulated again electronically. <p>(b) Overview of Outstanding Applications</p> <p><u>270613-b: CHKS</u></p> <p>This application had been considered by DAAG at the 27 June 2013 meeting and was not approved as an access control protocol had not been provided. An outcome letter had been</p>

	<p>sent to the applicant and the applicant's response, which described how data access would be controlled, had been circulated to DAAG members. The applicant intended that reports would be made available to the named consultant in each trust or the appraisal manager where the consultant's main contract was held. It was noted that consultants who worked across more than one trust would only be able to see aggregated data if both trusts were clients of CHKS, and it was noted that data would not be linked for trusts that were not clients of CHKS. The Group noted that data would not be made available to the public, and that the data requested could be beneficial for consultants using it in their own appraisals as well as employers reviewing performance.</p> <p>A query was raised around consultants that only worked at one trust, and it was noted that only consultants who worked across more than one trust would need to be identified.</p> <p>Based on the assurances given around access controls, the Group agreed that the application should proceed.</p> <p>Outcome: Approved</p> <p><u>310713-a: HES Sensitive Data Application Form (Nicodemo)</u></p> <p>This application had been discussed at the 25 September 2013 DAAG meeting and not approved. The applicant had been asked to seek Research Ethics Committee approval, but had responded asking to discuss this with someone. It was agreed that Mark Davies would write to the applicant.</p> <p>Action: Mark Davies to contact Catia Nicodemo regarding her application for sensitive data items through HES Business Objects.</p> <p><u>OC/HES/027: University of Oxford</u></p> <p>This application had been approved out of committee subject to the applicant's security arrangements being deemed satisfactory. The applicant had responded that their department was in the process of completing the NHS Information Governance Toolkit, and asked that their application be kept open until this had been completed.</p> <p>(c) Decisions Out of Committee</p> <p>An application for a monthly extract of CAMHS data for commissioners (241013-a) had been considered by DAAG via email, and subsequently approved by Chair's Action</p>
<p>191113-d</p>	<p>HES Applications</p> <p><u>191113-d1: University of Sheffield - The South Yorkshire Cohort Project</u></p> <p>The applicant had requested linked HES and ONS data, as well as flagging for future mortality on ONS. The application had previously been discussed informally with one DAAG member and concerns had been raised that the consent obtained did not appear sufficient for the data requested.</p> <p>The consent wording reference to 'medical records and GP records' was queried, as this was not considered to make it clear to participants that their data would be processed and linked with other healthcare data. In addition there were concerns around a statement that data would not be shared outside the study team, which was thought to be misleading.</p> <p>It was noted that a large number of participants had already been recruited, but that recruitment was ongoing. The Group agreed that for ongoing recruitment the consent form</p>

	<p>and patient information leaflet should be updated to reflect the recommended wording, and that where possible participants who had already consented should be contacted in order to notify them that their data would be shared and linked, and to give them the opportunity to dissent. It was noted that the consent form had asked participants whether the project could contact them again, and that the applicant would need to consider how to alert individuals who had opted out of further contact. It was suggested that this could include website updates and the use of publicity, and it was also suggested that the applicant should be asked what percentage of participants had opted out of further contact.</p> <p>Outcome: Not approved</p> <p><u>OCHES032: The Million Women Study</u></p> <p>This application had previously been reviewed by the Database Monitoring Subgroup (DMsG), the predecessor of DAAG, and had been given approval to receive data for three years. This period was now coming to an end, and DAAG confirmed that the approval should be extended.</p> <p>Outcome: Approved</p>
191113-e	<p>Data Linkage and Extract Service (MRIS) Applications</p> <p><u>MR1328: The Birmingham Lung Improvement Studies (BLISS)</u></p> <p>This application requested bespoke linked HES and ONS mortality data in order to complete two sub-studies on chronic obstructive pulmonary disease (COPD). Written patient consent had been obtained to share data with NHS bodies and ‘regulatory authorities’ but concerns were raised that it was not clear from the consent materials that this would include the HSCIC, which was not considered to be a regulatory authority.</p> <p>It had been suggested to the customer that they should use the recommended consent wording provided on the DAAG webpages for ongoing recruitment, but the customer had declined to do this. DAAG members asked whether changing the consent wording would mean that the customer would need their application to be reviewed again by a Research Ethics Committee (REC); it was thought that they would be required to notify their REC, and potentially re-submit the application depending on advice from the REC.</p> <p>Some concerns were also raised around a statement in the patient information leaflet that ‘No one outside the study team can access your personal information’ as this appeared to contradict the consent form wording that data would be shared with NHS bodies.</p> <p>The Group suggested that for ongoing recruitment the applicant should amend the consent wording to align with the recommended wording. For patients already recruited using the existing consent form and patient information leaflet, it was suggested that the applicant should be asked to consider how they intended to comply with the Data Protection Act (1998) requirement of fair processing</p> <p>Outcome: Not approved</p> <p><u>MR1331: PAINTED study (PAndemic INfluenza Triage in Emergency Departments)</u></p> <p>DAAG were notified that this application had received provisional section 251 support for if a pandemic should occur. DAAG members agreed that this approach seemed appropriate, given the nature of pandemics where there would be significant time pressures involved.</p>

	<p><u>TMC Pharma Services</u></p> <p>This study requested flagging for a small cohort of patients with Stargardt's Macular Dystrophy. It was noted that the draft consent materials contained the current recommended consent wording, and that as this study was not expected to commence recruitment until 2017 the applicant would be notified of any changes to the recommended wording that took place in this time. No concerns were raised.</p> <p>Outcome: Approved</p>
191113-f	<p>Web based consent</p> <p><u>191113-f1: National Third Molar Audit</u></p> <p>Consent materials for the National Wisdom Tooth Treatment Audit had previously been discussed at DAAG meetings on 31 January 2013 and 26 February 2013, and feedback had been given to the audit lead. An updated version of the consent materials had now been submitted for review. DAAG noted that the updating wording now included a reference to linking to other data such as those about hospital visits or data held by ONS, and DAAG approved of the changes that had been made.</p> <p>Outcome: Approved</p>
191113-g	<p>Any Other Business:</p> <p>Application 221112-a from Imperial College London had previously been approved by DAAG at the 22 November 2012 meeting, and the applicant had requested that this approval be renewed for a further year. It was agreed that for renewal applications where no changes to the purpose or data requested had been made, applications should be considered by Chair's action and then notification given at DAAG meetings.</p> <p>UK Biobank had requested data from a number of different areas; it was agreed that these requests should be brought to DAAG for consideration as one application.</p> <p>A joint HES-MIDAS application (MR1313) had also been received from UK ITP and had been reviewed by one DAAG member in addition to the DAAG Chair. The HRA Confidentiality Advisory Group (CAG) had granted Section 251 approval for one section of this work, but the applicant had also requested a pseudonymised HES extract of all instances of idiopathic thrombocytopenic purpura (ITP). The HRA CAG Secretariat had advised that this would not require Section 251 support as the data would be pseudonymised by the HSCIC before it was provided to the applicant. DAAG agreed that they were content for the application to proceed.</p> <p>DAAG were informed that work was ongoing to manage the relationship between the HSCIC and the research community, and that this would include activity such as a full day discussion forum with representatives from the research community.</p> <p>DAAG were also notified of work taking place within the HSCIC to review internal advisory groups, and it was noted that it would be important for this work to align with separate work led by Sir Nick Partridge to review the role of external advisory groups such as the HRA Confidentiality Advisory Group.</p>
191113-h	<p>Date of Next Meeting: Tuesday 19 December 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</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
191113-c1	Mark Davies to contact Catia Nicodemo regarding her application for sensitive data items through HES Business Objects.	Mark Davies