

Data Access Advisory Group

Minutes of meeting held 26 February 2013

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

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

Apologies: None

260213-a	<p>Welcome</p> <p>Mark Davies welcomed everyone to the meeting.</p>
260213-b	<p>Minutes of the Previous Meeting</p> <p>The minutes of the previous meeting, 31 January 2013, were ratified.</p>
260213-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 the updated data sharing agreement was awaiting legal feedback.• 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. This meeting had not yet been scheduled, due to the planned handover of responsibilities from ECC to the HRA Confidentiality Advisory Group (CAG). It was agreed that it would still be beneficial for DAAG to agree a way forward with the CAG.• 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 agreed that an update on this would be given at the following meeting. <p>(b) Overview of Outstanding Applications</p> <p><u>031012a: University Hospitals Birmingham</u></p> <p>An outcome letter had been sent to the applicant, and this application was now closed.</p> <p><u>OC/HES/025: Million Women Study (University of Oxford)</u></p> <p>An outcome letter had been sent to the applicant, and this application was now closed.</p>

	<p><u>310113-a, b and c: Clatterbridge Cancer Centre NHSFT</u></p> <p>Final letters to this applicant had been drafted, and would be sent to the DAAG Chair to review prior to being sent out to the applicant.</p> <p><u>310113-f1: National Diabetes in Pregnancy Audit</u></p> <p>This application had been approved subject to the circulation of some additional information. It was noted that this was ongoing, and that additional information should be circulated shortly.</p> <p>(c) Decisions Out of Committee</p> <p>None.</p>
260213-d	<p>Hospital Episode Statistics (HES) Applications</p> <p><u>260213-a: Department of Health HES Business Objects application for sensitive data items</u></p> <p>This request for access to sensitive data items through HES Business Objects was from an individual at the Centre for Health Service Economics and Organisation, based at Nuffield College in the University of Oxford and funded by the Department of Health. It was noted that the applicant had requested access until the end of 2014, but HES Business Objects would cease operating at the end of 2013.</p> <p>There were some concerns about the intention to link HES Business Objects data with local GP data from the General Medical Council (GMC), as this type of linkage was not the intended use of HES Business Objects. It was also unclear what could be learned by linking this data, as the data produced would be mainly focused on GP referral patterns and it was thought that a variety of research on this had already taken place. There was also a query around whether the type of research suggested in the application could be carried out without first gaining REC approval.</p> <p>It was agreed that this request was inconsistent with the intended uses of HES Business Objects, and that sufficient justification had not been provided for the use of the requested data. It was suggested that the HSCIC should work with the applicant to more clearly define what the intended outcomes of this work would be.</p> <p>Sean Kirwan noted a conflict of interest with this application, due to his role with the Department of Health.</p> <p>Outcome: Not approved</p>
260213-e	<p>NHS Central Register – MRIS Applications</p> <p><u>MR1257: CREST (The role of endoluminal stenting in the acute management of obstructing colorectal cancer)</u></p> <p>This application was for flagging to receive data on deaths, including cause, and cancer data. It was noted that the original consent materials had been out of date but had referenced the NHS, and the updated consent materials now included the recommended wording.</p> <p>Outcome: Approved</p>

	<p><u>MR1311: Childhood Arthritis Prospective Study (CAPS)</u></p> <p>This application requested flagging for deaths, including cause, and cancer data. Recruitment had commenced in 2003 and was ongoing. It was noted that the consent materials had been updated to include the recommended wording, and that the applicant would ensure the up to date consent materials would be used for all new participants recruited.</p> <p>Outcome: Approved</p> <p><u>MR1314: FRAGMATIC - A Randomised phase III clinical trial investigating the effect FRAGMin® Added to standard Therapy In patients with lung cancer</u></p> <p>The applicant had requested flagging and status checking for cause of death. It was noted that the consent form had contained an older version of the recommended wording, but as recruitment had now closed it was agreed that approval could be given. The applicant would be asked to update the consent form and patient information leaflet if planning any future projects.</p> <p>Outcome: Approved</p> <p><u>MR1316: HCV Research UK - Host and viral factors associated with outcomes of infection with hepatitis C virus</u></p> <p>HCV Research UK requested flagging for deaths, cancer data and exits and re-entries. The Group were informed that the applicant also intended to submit an application for HES data at a later date.</p> <p>It was noted that some data would be transferred outside of the UK, and that this was included in the consent materials provided to adult participants and to parents asked to consent on behalf of their child. A query was raised regarding how the data transferred to other organisations would be anonymised, as this had not been specified, and it was noted that if the data transferred were considered identifiable then Section 251 approval would be required.</p> <p>An additional query was raised regarding parents being asked to consent for their child, since the data would be retained for several years and the children participating in the study would gain capacity over time. It was unclear whether participants who were recruited as children would be asked to re-consent once they were older.</p> <p>It was agreed that these queries should be passed on to the applicant for clarification.</p> <p>Outcome: Not approved</p>
260213-f	<p>Consent Forms</p> <p><u>National Wisdom Tooth Treatment Audit</u></p> <p>It was noted that these consent forms had previously been circulated by email for DAAG members to review, but that it had been agreed that this should be discussed in full at a DAAG meeting.</p> <p>There were some concerns about a reference in the consent forms to linking information held on existing databases, as it was not specified what databases this would include. On balance it was agreed that this was acceptable, due to the potential for changes to what databases were held where. It was noted that it would be the responsibility of the HSCIC to provide adequate information to the public on its databases.</p>

	<p><u>University of Kent - Personal Social Services Research Unit (PSSRU)</u></p> <p>Copies of a consent form for the linkage of HES data and adult social care survey responses had been circulated for comment. As the recruitment cohort would include individuals with learning difficulties the research unit had attempted to simplify the recommended consent wording into a format that would be easier to read and understand, and feedback was requested on whether the simplified wording adequately described the planned use of data.</p> <p>Overall it was agreed that the simplified consent materials were of a high standard, but it was felt that describing access to data on national databases as asking to 'check your information on the computer' was not an adequate description and seemed oversimplified.</p> <p>In addition the Group queried whether there had been any patient involvement in the production and review of the consent materials, as it was suggested that it would be helpful to have feedback from people with learning disabilities.</p> <p>It was agreed that these comments should be passed on to the research unit, and the Group asked whether the final version of the simplified consent materials could be brought back to a later DAAG meeting; it was thought that this could be helpful in providing advice to organisations taking a similar approach to consent materials in future.</p>
260213-g	<p>Any Other Business:</p> <p>It was noted that a query regarding consent forms for a Born in Bradford study had been received, and that this would be brought to the next DAAG meeting for consideration. There were some concerns regarding references within the consent materials to data being shared with individuals working on other ethically approved studies within Europe, as it was not made clear whether this would include any identifiable data. In addition there were concerns about the intention to use data for unspecified future projects, and it was suggested that a more appropriate consent model for this might be to ask study participants to consent to being contacted in future to give their consent to additional studies taking place at that point.</p>
260213-h	<p>Date of Next Meeting: Tuesday 26 March 14:00 – 15:00</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
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