Data Access Advisory Group

Minutes of meeting held 24 April 2012

Members: Clare Sanderson, Patrick Coyle, Sean Kirwan

In attendance: Dawn Foster, Susan Milner, Diane Pryce, Chris Quinn, Frances Hancox (Secretariat)

Apologies: Mark Davies, Tom Latham

240412-a	**Welcome** Clare Sanderson welcomed everyone and chaired the meeting in the absence of Mark Davies.
240412-b	**Minutes of the Previous Meeting** The minutes of the previous meeting, 28 February 2012, were ratified. An update was given on the application MR1276, a pilot study of twins. The applicant had withdrawn this application as list cleaning by MRIS was no longer required.
240412-c	**Matters Arising** **a) Overview of Outstanding Applications** <u>310112-a- BUPA Health Dialog (BHD)</u> This application had been approved at the previous meeting subject to satisfactory review of the applicant's SLSP. This has now been completed and the application is closed. **(b) Decisions Out of Committee** <u>MR737 - ESRC Millennium Cohort Study (MCS)</u> This application was for an extension to the current approvals for the above study; it had been reviewed by Clare Sanderson with comments from Patrick Coyle, and the application was approved. **(c) Other** <u>Web based consent</u> A request for advice had been received regarding plans for study participants to complete an online consent form rather than using paper consent forms. Participants would be invited to access the survey website and directed to a page where they would be asked to read the patient information sheet and give their consent. Participants would not be able to continue on to the survey page unless they had opened the patient information sheet and given consent, and no information would be collected from those who did not give consent. The Group agreed that more technical information would be needed regarding security, and that this should be reviewed as part of a security assessment. There were also some concerns as to how an individual's identity would be confirmed when completing the form

	online. **Action:** Diane Pryce to inform the customer that a technical assessment is required and share the Group's query about confirming identity. **(d) Outstanding Actions:** <u>Application security assessments and IG Toolkit</u> The outcome letter had been drafted but was waiting for approval from Mark Davies. **Action:** Dawn Foster to resend the letter to Clare Sanderson, who will discuss with Mark Davies. <u>Terms of Reference</u> Updated Terms of Reference had been circulated to the Group. Dawn Foster noted that she had not yet received confirmation from Clare Sanderson as to whether the Terms of Reference need EDG sign off. **Action:** Clare Sanderson to confirm if EDG approval is required, and Dawn Foster to circulate final approved ToR to ECC for information. <u>Nomination from ECC for member to participate in DAAG</u> Clare Sanderson had discussed this with Alan Doyle. It was noted that Patrick Coyle had now been invited to participate again in ECC, and that he could provide ECC representation for the purposes of DAAG. <u>Glossary of terms for MHMDS applications</u> A glossary of terms for sensitive data items had been produced and circulated to the Group for review, but there had been very few comments. All were content with the glossary and agreed to raise specific queries should they arise. <u>Future Forum - Consent</u> As discussed at previous meetings, Dame Fiona Caldicott has been asked to carry out a review of consent and it was suggested that DAAG put together some points to submit to the Future Forum. Clare Sanderson confirmed that no further details were available at present, but that this item should continue to be held as an open action as the initial stages of this work will take some time.
240412-d	**HES Applications** <u>240412-a – University Hospitals Birmingham</u> This request was an update to a previous request for sensitive data, which had been approved by DAAG on 19 April 2011. Access was requested to Local Patient Identifier, Consultant code, the code of patient's registered or referring GP and the referrer. The purpose of the request was to enable monitoring and drive improvement in the clinical quality of care via a Root Cause Analysis.

	For the original request for sensitive data, at the request of the Group, the applicant had produced a protocol document setting out how access to the sensitive data, and consultant data in particular, would be controlled. In addition, a form to be completed for approval by the Trust's Caldicott Guardian was also approved and in place. The applicant has confirmed that this protocol and Caldicott Guardian form will continue to be used. The Group discussed the request and confirmed approval for the sensitive data, subject to continued use of the Protocol for controlling access to sensitive data together with Caldicott Guardian sign off **Outcome:** Approved
240412-e	**NHS Central Register – MRIS Applications** <u>MR1278 - Looking Back at Becoming a Mother</u> This project was a long-term follow-up of participants from a study that took place in 1975-9. Participants had given verbal consent for the original study but this had not covered further follow-up. This application was for list cleaning (date of death) and for GP practice data to enable contact with participants via their GP. It was noted that the participant details collected for the original study had been retained for a very long time, which would not be expected if the study had been carried out more recently. However it was also noted that any participants contacted would be given the opportunity to opt out, and that if they chose to do so their personal details would be destroyed. The Group agreed to approve the application for GP practice code and for fact of death (not date of death). It was also suggested that the applicant's consent materials should be amended to refer to checking health status before any future contact was made. **Outcome:** Approved <u>MR1255 - Comparing Intracoronary Administration of Adenosine or Sodium Nitroprusside to Control for Attenuation of Microvascular Obstruction During Primary Percutaneous Coronary Intervention</u> The applicant requested flagging for date death only and HES linkage to receive serious adverse event data for the cohort. The Group agreed that the consent forms and patient information leaflets provided accurately covered both flagging for death and HES linkage. **Outcome:** Approved <u>MR1280 - MRC Cognitive Function and Ageing Study</u> This request was for flagging cause of death, exits and re-entries. The Group discussed the fact that the consent forms used had been out of date at the time of use, and whether it was still appropriate to accept this without attempting to re contact participants to confirm consent. It was noted that this could cause difficulties given the nature of the study if participants no longer had capacity to give consent, but had previously given consent when they had capacity. It was suggested that if consent sought in the past had been in keeping with best practice at the time, then this should be accepted. The Group agreed that this should be discussed with ONS. **Action:** To hold a discussion with ONS about whether accepting out of date consent is appropriate, with particular reference to this application. **Outcome:** Approved subject to discussion with ONS

	MR1283 - DARE - NE London Diabetes Research Network Locality The applicant originally requested list cleaning for dead or alive status, but following discussion with MRIS Applications Manager agreed that this would not meet their needs. The application sent to the Group therefore also included flagging for date and cause of death. It was noted that this was appropriately covered by the consent materials provided. **Outcome:** Approved MR1284 - Remote monitoring: an evaluation of implantable devices for management of heart failure patients REM-HF The aim of this study was to determine the clinical and cost-effectiveness of remote disease management devices for people living with heart failure, and the request was for current status and date of death for the study cohort. Prior to application submission the MRIS Applications Manager had suggested to the applicant that their patient information literature should be amended as it partly contradicted the consent form provided. This had now been amended. **Outcome:** Approved MR1287 - Contacting parents of twins on a large scale This request was part of a feasibility pilot study for a larger scale research project; the applicant requested NHS numbers, home addresses, and names and dates of birth for both the mothers and their twins for a randomly selected cohort. HSCIC would receive the data extract from ONS, carry out list cleaning to remove any deceased individuals and any adopted families, then send out letters inviting mothers to participate in the study. Individuals who consented to participate would have their details passed on to the applicant, and anyone who opted out would have their information removed from the extract. ONS had agreed to the release of data on a random sample of twins on a basis of the HSCIC carrying out list cleaning to mitigate the effect of contacting families who should not be contacted. It was noted that this would be the first time that MRIS had directly contacted potential participants, and that this could set a precedent for future studies. The Group were uncertain as to why this application had not gone to ECC for S251 approval. It was agreed that the application should be discussed with the ECC Secretariat for their decision on whether S251 approval was necessary. **Action:** Diane Pryce to discuss application with ECC Secretariat. **Notification to Committee:** MR1279 – National Diabetes Audit and MR1281 - National Oesophago-Gastric Cancer Audit The Group were notified that these two applications had received S251 approval.
240412-f	**Any Other Business:** None.

240412-g	**Date of Next Meeting:** 29 May 2012, 2-3pm

Summary of Actions

Reference	Action	Owner
240412-c	Diane Pryce to inform the customer that a technical assessment is required and share the Group's query about confirming identity.	Diane Pryce
240412-c	Dawn Foster to resend draft application security assessment letter to Clare Sanderson, who will discuss with Mark Davies.	Dawn Foster
240412-c	Clare Sanderson to confirm whether EDG approval of ToR required	Clare Sanderson
240412-c	Final approved copy of ToR to be sent to ECC for their information.	Dawn Foster
240412-e	To hold a discussion with ONS about whether accepting out of date consent is appropriate, with particular reference to this application.	Diane Pryce
240412-e	Diane Pryce to discuss MR1287 application with ECC Secretariat.	Diane Pryce