Data Access Advisory Group

Minutes of meeting held 3 October 2012

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

In attendance: Tom Latham, Chris Quinn, Diane Pryce, Frances Hancox (Secretariat)

Apologies: None

031012-a	**Welcome** Mark Davies welcomed everyone to the meeting.
031012-b	**Minutes of the Previous Meeting** The minutes of the previous meeting, 30 August 2012, were ratified.
031012-c	**Matters Arising** **(a) Overview of Outstanding Actions** *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.* It was noted that this action continued to be ongoing, with an intended deadline of the end of November. *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, but an update was given on ongoing work around the process for customers who did not complete the IG Toolkit. The draft security assurance document had been shared with Phil Walker (Department of Health), who was satisfied with the proposed approach of requiring applicants without an IG Toolkit score to complete this document. It was noted that this might change in the future, as more applicants might be required to complete the IG Toolkit.; it was also noted that some applicants such as universities could potentially complete a 'hosted services' view that would only include the area accessing the sensitive data, which could reduce the burden of completing the IG Toolkit. The Group agreed that a meeting with ECC to discuss this issue should still be scheduled. *260712-f1: Diane Pryce and Louise Dunn to look into finding a technical solution for sharing DAAG documents.* This action was agreed to be ongoing. *300812-c1: Dawn Foster to circulate the draft assurance form to DAAG members.* It was noted that this document had been shared with some members, and would be

	circulated more widely following this meeting. *300812-d1: Tom Latham to circulate an explanation of the referrer code.* This action had been completed, and members were satisfied with the explanation provided. *300812-f1: Diane Pryce to circulate further details of the study taking place outside the UK.* Details of this application (ref: MR1304) had been circulated to DAAG members. It was noted that ONS had raised some queries with the applicant around data flow and what data would be shared outside the UK. One DAAG member had provided comments, and it was agreed that these would be passed on to the applicant. **(b) Overview of Outstanding Applications** 300812-a Institute for Fiscal Studies This application had been approved at the previous DAAG meeting (30 August 2012) subject to clarification around usage of GP age and GP gender. The customer had confirmed that they would consult their colleagues regarding this before providing a response and returning the security assurance form. 300812-b Department of Health This application had been approved subject to clarification of the referrer field code. An explanation of this field had been shared with DAAG members outside the meeting, and as this was satisfactory the application had been approved. OC/HES/022 University of York It was noted that the customer had posted the completed security assurance form, but that this had not yet been received. **(c) Decisions Out of Committee** OC/HES/024 Department of Health Sciences, University of York This application requested Census Output Area, Consultant Code, Person Referring Patient and the identifiable data item NHS Number for use in a study investigating haematological malignancies. The application was originally approved by DAAG in June 2011 and the applicant had now requested an additional data year (2010/11) from HES. It was noted that the applicant had received partial ECC approval for these fields, and as the consent statement had not changed since the previous DAAG approval the Chair approved this application out of committee. A security assurance form had been sent to the applicant for completion. 031012-a University Hospitals Birmingham The Group noted that this application had originally been considered out of committee, but that the decision had been made to bring the application to a full DAAG meeting.
031012-d	**HES and MHMDS Applications** 031012-a University Hospitals Birmingham The applicant had requested HES data for a research project aimed at measuring differences in outcomes for patients with bladder cancer who undergo surgery and radiotherapy. The

	cohort of patients had participated in a trial and signed a patient consent form. It was noted that this applicant's post was funded by the HSCIC as part of a collaboration between University Hospitals Birmingham and the HSCIC. Some concerns were raised regarding the consent documents as these did not mention the HSCIC or state that HES data would be used. This had previously been discussed with the applicant, who had given the opinion that HES data should be considered part of the patient's medical notes, and that patients had consented for their medical records to be used. The Group were not in agreement with this view; it was noted that HES data was based on medical records but held in a different location in a different form, and for a different purpose that was not related to direct patient care, and so should not be considered part of the medical record itself. It was also noted that it would not be clear to patients that their identifiable data would be linked to HES data as part of this study. The Group noted that recruitment for this research project had now closed, and so agreed that it would not be necessary for the applicant to alter the consent materials. However it was agreed that, as the applicant was in regular contact with the patient cohort, information regarding the use of HES data and the involvement of the Health and Social Care Information Centre should be provided to patients so that they would be given the opportunity to opt out if they wished to. It was further agreed that the applicant should include this information in the consent materials for any future studies. **Outcome:** Approved subject to applicant informing patients of the use of HES data and the involvement of the HSCIC in this study
031012-e	**NHS Central Register – MRIS Applications** <u>MR710: International Breast Cancer Intervention Screening (IBIS)</u> This application requested an extension to current approvals for a study to evaluate the impact of tamoxifen on the incidence of and mortality from breast cancer. The current process of the study was to follow up individuals' medical records by contacting general practices directly, but there had been difficulties maintaining up to date information on which practices patients were registered with. The applicant had requested the GP practice code to facilitate this follow-up process. DAAG members agreed that this was in line with the study methods and objectives already approved. **Outcome:** Approved <u>MR1300: A pilot study towards 'SABRE 3G - Southall And Brent REvisited'</u> This applicant had requested birth weight data as part of a feasibility study, but it was noted that there would be practical difficulties providing this data from before 1979. Consent would be sought from participants, and it was noted that ONS had approved the release of available data to MRIS. **Outcome:** Approved <u>MR1301: Prospective Study in the Lung Endpoints (PROFILE)</u> For this study, idiopathic pulmonary fibrosis patients who had given their consent to participate would be flagged for deaths and cancer information. There were some concerns regarding the consent materials provided, as these were contradictory; the patient information leaflet explained that data held by the NHS Information Centre would be used to monitor

	ongoing health, and that participants would be 'tagged' at the Central Register, but elsewhere stated that no identifying information would leave the hospital. Members were content that the consent material did broadly reflect what would happen to participants' data, but it was agreed that the consent material should be updated to remove this contradiction for any future participants. **Outcome:** Approved subject to customer amending consent documentation for future participants <u>MR1302: Outcomes of patients undergoing cardiothoracic surgery with very poor left ventricular function with ejection fraction less than 20%</u> The applicant had requested cause of death data. It was noted that the study was described as 'research/service evaluation' rather than pure research, and would be carried out by members of the care team, meaning that explicit patient consent would not be sought. There was a brief discussion of this, as although the data at a local level would only be handled by the care team, identifiers would be sent to MRIS in order to obtain cause of death data. The Group noted that there was an ECC precedent for this. **Outcome:** Approved <u>MR1303: The Clopidogrel vs Aspirin in Chronic Heart Failure (CACHE) Trial</u> Some concerns were raised regarding this application as the consent material was slightly out of date. It was agreed that the application would be approved, but that the outcome letter sent to the applicant should include the concerns raised by DAAG regarding the consent material, so that the same issue would be less likely to be raised in any future applications. **Outcome:** Approved
031012-f	**Any Other Business:** It was noted that work on the draft Code of Practice was ongoing, and that the draft would be shared with ECC at the next meeting. **Action:** Clare to circulate the draft Code of Practice to DAAG members for feedback.
031012-g	**Date of Next Meeting:** Tuesday 30 October 2:00 – 3:00

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.	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
260712-f1 (ongoing)	Diane Pryce and Louise Dunn to look into finding a technical solution for sharing DAAG documents.	Diane Pryce and Louise Dunn
031012-f1	Clare to circulate the draft Code of Practice to DAAG members for feedback.	Clare Sanderson