Data Access Advisory Group

Minutes of Meeting held 20th December 2011

Members: Clare Sanderson, Patrick Coyle, Vanessa Kaliapermall (deputising for Sean Kirwan)

In attendance: Susan Milner, Tom Latham, Dawn Foster, Diane Pryce, Jo Simpson (MHMDS items only), Olivia Podesta-Atkin (Secretariat)

Apologies: Sean Kirwin, Dr Mark Davies

201211-a	**Welcome** In the absence of the Chair, Clare Sanderson welcomed everyone to the meeting and chaired the meeting.
201211-b	**Minutes of the Previous Meeting** The minutes of the previous meeting were ratified. <u>i) Application security assessments and IG Toolkit</u> At the last meeting it was agreed that DF would draft a letter for review by CS and MD outlining the concerns of the members with regard to the move to using IGT scores rather than reviewing an SLSP. There was further discussion about the impact on some customers, for example those where staff had honorary contracts were also a concern as it would not be possible for the NHS to take disciplinary action should a breach of confidentiality occur. DF had circulated the draft letter to CS and MD; however, it had not been possible to obtain feedback in time for the meeting. **Action:** CS/MD to review the letter and provide feedback. Once agreed, the letter will be circulated to the group. <u>ii) Consent wording</u> The paper prepared by CS regarding consent wording was submitted to ECC and considered at the December meeting. No feedback has been received from ECC to-date. A discussion followed regarding the issues around consent for long term studies where the original consent wording does not fit the current 'DAAG ' agreed wording. In particular a request from CTSU which had been pending for some time was discussed. It was agreed that, in the absence of guidance from ECC, the Group was content for CS to confirm to the applicant that members had reconsidered the decision with regard to the consent wording and that, as the original consent was appropriate at the time of recruitment for the trial, then the consent wording for this long-term study would be accepted. <u>iii) De-identification standard</u> Work is continuing but nothing to report at this stage. CS advised the group that work on the standard is to be presented to the next NIGB / ECC meeting; CS will also provide an update for the next DAAG meeting. **Action:** CS to provide update for next meeting. <u>iv) Clarification on requests which have Section 251 in place</u> At the November meeting, CS raised the issue of the appropriateness of DAAG considering applications which have Section 251 support in place. It was agreed that CS would discuss the general issue of how such requests which subsequently require sensitive data fields should be dealt with. CS advised that, in view of the pending feedback from ECC on the consent issues, she had not yet raised this matter with ECC. **Action:** CS to discuss with ECC at an appropriate time.

201211-c	**Matters Arising** **a) Overview of outstanding applications** 221111- a – Clatterbridge Centre for Oncology NHS Foundation Trust 1) This application for an update of Admitted patient data for Cancer, Cardiac and North West Region was discussed at the November meeting. The request for an extract of updated data was approved. The applicant has now advised that they had omitted to request Outpatient data with the original request. As this additional request was for an update of data years for data previously received, the Group approved this application. **Action:** Applicant to be advised that the request for Outpatient data was approved. 2) Request for additional user to have access to restricted data fields through HES Business Objects The Group were advised that the customer had asked if the decision made at the November meeting rejecting the request to provide an additional user with access to restricted data through HES business objects at Clatterbridge could be re-considered. In support of the request, a letter had been received from Mike Richards, National Clinical Director for Cancer and End of Life Care. **Outcome:** The Group acknowledged the supporting letter from Mike Richards. The Group were however unable to revoke the original decision pending the result of the comprehensive review of access to Business Objects which is currently being carried out by the NHS. IC. **Action:** Applicant to be advised that the request for an additional user to access restricted data fields through HES Business Objects was not approved and the original decision stands. **(b) Decisions Out of Committee** MR1267 - Rapid Primary Care Initiation of Drug Treatment for TIA The pilot trial will recruit patients with symptoms suggestive of TIA or minor stroke in general practices from the catchment of three hospital TIA clinics (Birmingham, Cambridge and Oxford) and the emergency department of Addenbrookes Hospital, Cambridge. The patients will be randomised into two groups, Intervention plus usual care or usual care alone. Intervention patients will be treated with additional secondary prevention medications prior to referral to a specialist clinic. Treatment will comprise of dual antiplatelets, blood pressure lowering medication and simvastatin 40mg. The usual care alone group will be given 300mg aspirin and will be referred to a specialist clinic as per NICE guidelines. Patients will be followed up at 90 days in clinics held at the hospital. This will be supplemented by review of GP and hospital records. While the primary outcome measure will be all strokes within 90 days of randomisation, secondary outcomes include quality of life, adverse events, cost data, persistence with medications, all major bleeding events and other vascular events. The data required from MRIS will be Cause of Death with ICD coding for any individuals who die during the course of the study. They also require details of re-entries into the NHS in the event that a patient who is taking part in the study moves or leaves the area. They will use the data to ensure that they identify all deaths that occur in the study population, and the information on cause of death will help categorise the deaths. Where patients move over the course of the study, they will use the data to help trace these patients. **Outcome:** The application was approved by the Chair out-of-committee. Thames Cancer Registry (OC/HES/016) Sensitive HES data for 2010-11 was requested by Thames Cancer Registry. This is an update of data previously supplied; the Cancer Registries received out of committee approval for an update in July 2011 to include provisional 2010-11 data. The applicant now wishes to receive 2010-11 Annual Refresh data. The data will provide essential support to the analytical functions of the English cancer registries. The data is needed for linkage to cancer registration datasets covering up to diagnosis year 2010. The

	national cancer registration cycle has accelerated, placing stricter deadlines upon the English cancer registries to complete registration of a given diagnosis year. The Cancer Registries are permitted to receive patient identifiable data for those referred for the diagnosis or treatment of cancer without the need for informed consent under Regulation 2 of the Statutory Instrument on confidentiality. **Outcome:** The application was approved by the Chair out-of-committee.
201211-d	**MHMDS Applications** <u>201211-a – Warwick Medical School</u> Warwick Medical School are requesting access to sensitive MHMDS data in order to study involuntary pathways to mental health care. The sensitive data they require are those fields concerned with compulsion, which is the primary focus of the research. The applicant has been funded by the 'National Institute for Health Research Service Delivery and Organisation programme' to address various research questions. These questions are around geographical variations in involuntary admission rates, and the extent to which this variance can be explained by local socio-economic factors, or the characteristics and status of those using the services. The project also aims to determine whether future needs can be accurately predicted in order to support local NHS managers and services. Longitudinal analysis is a major part of the project, and the main statistical technique employed will be multilevel modelling. The applicants also wish to access other datasets, such as the 2001 census, in the future and then link these to the MHMDS data. They therefore need access to variables that will allow them to detail involuntary admissions, lengths of stay and also the use of other mental health care services. We note that Dr Orla McBride, based at the University of Ulster, will be seconded to the research project and will access the data remotely. The data will be stored on a file server at Warwick University. **Outcome:** Application approved subject to approval of the System Level Security policy. **Action:** SLSP to be submitted to security advisor for approval. Applicant to be advised of the outcome. <u>201211-b – University of Manchester</u> This is an application from the University of Manchester to receive sensitive information from the Mental Health Minimum Data Set. The data will be used for a DH-commissioned project entitled **"The feasibility of developing a person-based approach to the mental health funding formula using the MHMDS".** The project aims to estimate robust equations for the age and additional needs components of the mental health formula at person level. The dataset will be combined with other datasets containing characteristics likely to explain variations in spending across geographical areas and practices. The analysis will generate aggregate descriptive statistics summarising variations in health care spending and usage. The final product will be a set of regression coefficients used to predict expenditure on Mental Health Care for each general practice. The results will be used to derive a formula which will be used to distribute resources between Clinical Commissioning Groups. Findings will be reported to the committee that advises Ministers on the NHS funding formula to enable them to recommend to Ministers improved formulae for distributing NHS resources, so that the accuracy with which NHS financing reflects differences in population needs can be improved. **Outcome:** Application approved subject to approval of the System Level Security policy. **Action:** SLSP to be submitted to security advisor for approval. Applicant to be advised of the outcome. Jo Simpson from the MHMDS team was asked to provide a glossary of terms for the MHMDS data items to assist the members when considering future requests for this dataset.

	HES Applications 201211-c – East Midlands Health Observatory – request for SUS/HES data This application requested the Consultant Code to be provided in clear format from SUS PbR. The field is required to develop a tool in order to explore Consultant level variation and to 'develop value'. The work is being carried out for the 'Right Care' programme. Previously the applicant had requested the clear field which was not approved by DAAG. A pseudonymised SUS PbR extract was subsequently provided. It is not however possible currently for consultant code in pseudo format to be provided from PbR. As the applicant's purpose is to develop a tool which will allow Consultant activity level variation to be explored in order to develop value, there is a requirement for the field to be provided in clear format. The applicant proposed to pseudonymise the consultant identifier and to produce a random set of codes from the raw data to display on the tool. It would therefore not be possible to identify individual consultants. The tool would therefore display results only – no 'raw' data will be provided. In addition, it is proposed that a table could be shared with medical directors of consultants in their own trust only, which would provide them with analysis on the variation levels of their consultants, for internal use only. It was suggested that the applicant be reminded that there is a risk of breaching patient confidentiality in terms of identifying Consultants who deal with sensitive conditions. **Outcome:** The Group were content with the clarification provided with regard to pseudonymisation of the identifier and access control around the data. Application approved, subject to approval of the System Level Security Policy. **Action:** SLSP to be submitted to security advisor for approval. Applicant to be advised of outcome.
201211-e	**NHS Central Register – MRIS Applications** MR1266 - Complete Versus Lesion only Primary PCI Pilot Trial There are no reliable data to determine the best management of patients with ST elevation Myocardial Infarction (STEMI) presenting for Primary-PCI (PPCI) with multi-vessel disease (MVD). Some registries indicate that all lesions should be treated during the PPCI or within that hospital admission, while others support a deferred post-discharge treatment strategy. Various management strategies exist amongst operators with no certainty as to the most appropriate. On admission all patients will be asked to provide a verbal informed "Assent" to participate in the research study which will be documented in the patients' hospital records. Patients will then go to the cardiac catheter lab for angiography and PPCI as per routine clinical care. If more than one artery is blocked they will be randomised to either Group A or Group B. Group A patients will have immediate angioplasty and stent to the artery causing the heart attack ("culprit" vessel) plus angioplasty and stent to other narrowed or blocked arteries and Group B patients will have immediate angioplasty and stent only to the artery causing the heart attack (routine care). Full written informed consent for patients will be obtained <24 hours after PPCI for the recording of simple anonymous data (age, gender, medical history, angiographic results). The MRIS data will help to do a longer term passive follow-up for clinical outcomes in particular vital status using centralised registers for death and hospital admissions. At the moment we do not know the long term prognosis of heart attack patients who have had a primary PCI and this information is vital to understand the longer term consequences of heart attacks and its treatment. **Outcome:** Application approved.

201211-f	**Any other business:** University of Essex – Institute for Social & Economic Research This application to receive month and year of Baby's date of birth was discussed at the November meeting. The data field requested is not a standard field which is provided and therefore the members were asked to consider the request. The applicant required the field for analysis of the effect of seasonality on birth weight. As requested by DAAG, a risk assessment was carried out by the HES analysis team and the results were circulated to members for their consideration, prior to the meeting. The outcome of the assessment concluded that the particular field alone could not be used to identify someone. In order for it to become identifiable, it would need to be combined with a range of other fields or with a field such as full postcode, which in itself would require Section 251 approval. PC had commented that it might be possible to become identifiable if combined with some fields associated with the mother, or less precise geographical fields in thinly populated areas. This particular request does not include any additional fields deemed identifiable or sensitive. The members were assured that all requests for HES data are reviewed by the DAIS team who ensure that appropriate approval is in place before releasing the data. **Outcome:** As the risk assessment had concluded that the request in question would not provide any disclosive or sensitive data, the Group agreed that the data field could be provided in this instance. **Action:** The applicant to be advised that the requested field could be provided.
	Date of next meeting: 31st January 2012