Data Access Advisory Group

Minutes of Meeting held 31st January 2012

Members: Mark Davies, Patrick Coyle, Sean Kirwan

In attendance: Tom Latham, Diane Pryce, Olivia Podesta-Atkin (Secretariat)

Apologies: Clare Sanderson, Dawn Foster, Susan Milner

310112-a	**Welcome** Dr Mark Davies welcomed everyone to the meeting.
310112-b	**Minutes of the Previous Meeting** The minutes of the previous meeting were ratified. <u>i) Application security assessments and IG Toolkit</u> DF previously circulated a draft letter to CS and MD outlining the concerns of the members with regard to the move to using IGT scores rather than reviewing an SLSP. MD confirmed that this letter was with him to review. **Action:** MD to review the letter and provide feedback. Once agreed, the letter will be circulated to the group. <u>ii) Future Forum - Consent</u> As discussed at the November meeting, 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. This item was not discussed at the January meeting but is to be held as an open action as the initial stages of this work will take some time.
310112-c	**Matters Arising** **a) Overview of outstanding applications** <u>181011-a – University of Aberdeen</u> This application was originally considered at the October meeting. The applicant wishes to use HES data to supplement data already collected from participants in the Knee Arthroplasty Trial. The applicant believed that they had sufficient consent in place to do this. However, the application was not approved at the October meeting. The main concerns of members at that time were around who would obtain information from patient's notes, whether the study was still ongoing, and the wording of the consent statement itself. The consent statement refers to "NHS information to do with … knee replacement", but the applicant could potentially receive information about other hospital episodes in their extract. In addition, the consent statement does not conform to the DAAG-approved wording. The applicant has now sent a written response to address these concerns which was circulated. Members were content with this response and therefore approved the application. **Outcome**: Approved. **Action:** Outcome letter to be sent to applicant.

	(b) Decisions Out of Committee MR1268: The MRIS request had been approved by Mark outside the group meeting on 19/01/2012. However, HES linkage was mentioned in the supporting papers, although not specifically requested, so this was followed up with the customer. Diane Pryce is now working with Xanthe Hannah to facilitate this; the customer has requested 2 annual HES extracts for this cohort and 3 MRIS reports. The consent wording has been approved by MD for MRIS but it also covers the HES request. This type of MRIS/HES cohort linkage will become part of the proposed Data Linkage Service, however, in the interim Diane is working with Xanthe to facilitate these types of requests. **Outcome**: Diane to inform the group when they receive these bespoke HES Data Linkage applications. **(c) Other** MIDAS – GP Practice Code – Applications with section 251 approval, non sensitive data linkage. The data is in the public domain since last month and there were 260 indicators that went out including GP names and addresses. **Outcome**: Diane to inform the group when these data linkages are happening.
310112-d	**HES Applications** <u>310112-a – BUPA Health Dialog (BHD)</u> Access is requested for the Admitted Patient Care (APC) Consultant code to be supplied in the HES monthly managed extract service data to enable internal BUPA Health Dialog (BHD) to analyse patterns of variation among consultants within a treatment specialty. This will lead to productivity measurements and benchmarking reports that will be used to inform healthcare organisations that are working with BHD in their efforts to improve the quality of healthcare delivered to patients. The actual Consultant Code value is required to enable the NHS recipient of the information to discuss the findings with their local provider if appropriate. Any analysis results that have used the consultant code will be supplied to the requestor at summary level only and not patient level and the 'small number rule' obviously applies. No patient level information will be shared with the requestor. **Outcome:** The Group were of the opinion that more details are required in order to approve the application. They would like clarification around whether patient level data is being supplied to the applicant. In addition, further assurance was requested from the applicant around the purpose for which they will use the data, and that they will only use the data for the specific purpose outlined in their application. **Action:** Outcome letter to be sent to applicant. <u>310112-b – Imperial College London</u> Sensitive HES data was requested and will be used to support Imperial College's research programme, in particular to: (1) evaluate polyclinics in London - to investigate the impact of polyclinics on patient flows, hospital admissions and health outcomes, in areas with and without polyclinics/polysystems; (2) to investigate associations between hospital admission rates and other health outcomes and the quality of primary care services; (3) to investigate trends in admission rates for various respiratory infections in children; (4) to investigate whether public release of information on hospital performance has been associated with changes in patient flows; (5) to investigate the effect of GP-led urgent care centres on short stay emergency hospital admissions. The applicant has requested 2010-11 annual refresh data, having already received approval from

	DAAG to receive provisional data from 2010-11 in February 2011. DAAG approval was granted in 2011 on the condition that the data was only to be used in support of the five studies specified at that time. One of the projects specified appears to have changed from the previous application. However, the applicant has advised us that the new project is an additional objective agreed within project (1). **Outcome:** The Group were content to approve the application. **Action:** Outcome letter to be sent to applicant.
310112-e	**NHS Central Register – MRIS Applications** <u>MR1264 – Study of the Incidence of cancer and mortality in patients from the SEAS Trial</u> The Simvastatin and Ezetimibe in Aortic Stenosis (SEAS) Follow-up study is an observational, multinational, follow-up study to observe the incidence rates of cancer, total mortality, and mortality due to cancer over a 21 month follow-up period (from 4th March 2008 to 31st December 2009) in patients from the SEAS trial. Data will be collected from central cancer and death registries for patients who were randomised to ezetimibe/simvastatin or placebo in the SEAS trial and who were known to be alive at the end of the base study. The aims of the study are to estimate the percentage and rate of patients with newly diagnosed cancer in the group of patients originally allocated to treatment with ezetimibe/simvastatin 10/40 mg/day and the group of patients originally allocated to treatment with placebo. Also to estimate the percentage and rate of patients who died (total mortality) and the percentage and rate of patients who died due to cancer. The initial discussions related to this application centred around the consent, which does not meet current standards, and the issue around data going outside the UK. Some consent was in place for the original study but MRIS did not consider this acceptable therefore the customer approached ECC for advice, subsequently a S251 application has been approved using an 'opt out' model rather than obtaining further explicit consent. The issue around data going outside the UK is ongoing with ONS. **Outcome:** Approved. <u>MR1270 – A study of deaths (including suicides) in the UK Armed Forces who are deployed to the Falklands campaign</u> This study will enable the MOD to address claims made in the press and by charitable organisations that the UK Armed Forces personnel who deployed to the Falklands are experiencing a higher rate of suicide. The primary aim is to ascertain the actual number of suicides (and other causes of death) amongst the Falklands cohort, calculate rates of suicide and other causes of death, and compare these rates to those found for comparable groups in the Armed Forces and UK general population. **Outcome:** Approved. <u>MR1271 – AspECT</u> • To assess whether intervention with a) aspirin and/or b) high dose PPI therapy results in a decreased rate of all causes of mortality, cause-specific mortality, or conversion rate from Barrett's Metaplasia (BM) to adenocarcinoma or high grade dysplasia or any of these when each is considered separately. • To assess whether there are clinical and molecular risk factors which can be identified in BM for the development of Barrett's Adenocarcinoma (BA). • To assess the cost effectiveness of aspirin and/or PPI treatment in the prevention of BA. • To assess whether intervention with PPI and/or aspirin induces changes in the expression of molecular markers for BA. • To investigate new genes important in the progression of BA, as a unique tissue bank will be available with a complete endoscopic, histological, physiology and pharmaceutical history. • To assess inherited genetic factors for predisposition to oesophagitis above BM, BM, LGD HGD and BA • To assess what the biological risk factors are for cardiac disease and aspirin resistance. • To assess gender differences in outcomes.

	Outcome: Approved. MR1272 – The National Dementia and Antipsychotic Prescribing Audit (DAP) – Notification only The DH has undertaken to conduct an audit on the prescribing of antipsychotic medication for people with dementia. This commitment arose as a result of a report by Professor Sube Banerjee that concluded inappropriate prescribing of antipsychotic drugs for people with dementia was resulting in unnecessary deaths. The National Dementia and Antipsychotic Prescribing Audit has been designed to assess whether prescribing of antipsychotics and alternative pharmaceutical interventions for people with dementia are changing with time. It will also evaluate how emerging clinical practice affects outcomes for these patients. **Outcome:** Approved. Dr Mark Davies also requested that it be noted in the minutes his declaration of interest regarding this application.
310112-f	**Any other business:** Terms of reference – The group agreed that the DAAG Terms of Reference need to be updated, specifically with regards to named deputies attending the DAAG meetings in a member's absence. In addition, as it has been over a year since the Terms of Reference were drawn up, the Group agreed that it would be helpful to conduct a general review of them. **Action**: Tom Latham to circulate the Terms of Reference to the group for review at the next meeting. Glossary of terms for MHMDS applications At the December meeting, Jo Simpson from the MHMDS team was asked to provide a glossary of terms for the MHMDS data items to assist the Group in considering such applications. Since the meeting, Jo had asked for clarification about what exactly was required. The Group agreed that details of the sensitive MHMDS data items would be sufficient. **Action**: Jo Simpson to produce a glossary of terms for sensitive data items only for the next meeting. Nomination from ECC for member to participate in DAAG The Ethics and Confidentiality Committee has not identified a suitable representative at this time. DAAG may need to contact NIGB in order to obtain a representative. **Action**: Clare Sanderson to discuss this with Alan Doyle.
	Date of next meeting: 28th February 2012, 2-3pm