Data Access Advisory Group

Minutes of Meeting held 22nd November 2011

Members: Clare Sanderson, Sean Kirwin, Patrick Coyle, Dr Mark Davies

In attendance: Susan Milner, Tom Latham, Dawn Foster, Diane Pryce, Olivia Podesta-Atkin (Secretariat)

Apologies: Vanessa Kaliapermall

221111-a	**Welcome** Dr Mark Davies welcomed everyone to the meeting.
221111-b	**Minutes of the Previous Meeting** The minutes of the previous meeting were ratified. <u>Application security assessments and IG Toolkit</u> Following the workshop on this which was reported at the last meeting, the expected paper from Phil Walker had not yet been received. Concerns were raised at the last meeting of DAAG that using just IGT scores rather than reviewing an SLSP may not be robust, particularly where customers are part of a commercial arm of an organisation that completes the IGT. The use of honorary contracts in universities was also raised as a concern as the NHS would be unable to take disciplinary action should a breach of confidentiality occur. SK advised the Group that he had discussed the above with Phil Walker and advised that a piece of work is starting which will take these issues into account. It was agreed that a formal letter outlining the concerns of DAAG should be prepared and sent to Phil Walker. **Action:** DF to prepare letter for MD's signature. <u>Consent Wording</u> CS has sent a paper to ECC regarding consent wording to agree a way forward with any applications where the consent wording is in question. ECC secretariat have come back to seek clarification on some points and discussions are on-going to finalise the paper in advance of being circulated to ECC members. **Action:** CS will circulate the final version of the consent paper to DAAG members. <u>Future Forum - Consent</u> As discussed at the previous 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 is to be held as an open action as the initial stages of this work will take some time. <u>De-identification standard</u> This work is continuing following the workshop that took place with Phil Walker on 7th October 2011. As things become clearer, this may have an impact on DAAG. **Action:** CS to keep the group updated with progress.

221111-c	**Matters Arising** **a) Overview of outstanding applications** MR1251 - Safety and appropriateness of growth hormone treatments in Europe (SAGHE) At the 23/08/2011 meeting the Group requested clarification about whether the person contacting the patient was appropriate. If this would be a member of the care team then this would be acceptable, however, if contact was to be made by the researcher, then Section 251 support would be required. The Group advised that this application could be approved out of committee, subject to clarification regarding consent. DP confirmed that the researcher has clarified that the initial contact would be made by the patient's current endocrinologist. **Update:** DP advised the group that this application has been delayed due to an ongoing issue with ONS as they do not permit their data to go outside the UK. 180111-d - Brighton and Sussex Medical School (BSMS) The applicant requested the sensitive field Local Patient ID, as well as the identifiable fields Date of Birth – Patient and NHS Number. DAAG previously advised the applicant to amend their consent wording and write to the patients involved in the study asking them to sign the amended consent form. In September Brighton and Sussex Medical School updated DAAG on the consent situation. The applicant said that there had been a few forms coming through to them, but felt that they would not receive any more. About 75% of study participants have returned the amended consent forms. The Group advised that whilst 75% of the cohort has given their consent, there remains 25% who have not responded. It will therefore be necessary to approach ECC for advice regarding whether it would be appropriate to obtain Section 251 support for the remaining 25% of the cohort. **Update:** TL advised the Group that the applicant has confirmed that they are happy not to use the data for the remaining 25% of patients who have not re-consented. The Group were grateful for the clarification and were content to approve the application on that basis. **Action:** Outcome letter to be sent out to applicant. **(b) Decisions Out of Committee** OC/HES/015 - University of Leeds Sensitive and Identifiable data was requested by the Yorkshire Specialist Register of Cancer in Children and Young People, which is based at the University of Leeds. The data was needed to link electronic HES in-patient and out-patient data to a cohort of patients drawn from the Specialist Register. This data would be used to undertake epidemiological and health services research requiring individual records of NHS activity to examine health usage and, in particular, describe late effects of cancer treatment. The applicant has current Section 251 approval to hold identifiable data items, as they are included in the Cancer Registries ECC Approval (ref: PIAG 03-(a)/2001). The application was therefore submitted to the Chair out of committee to gain approval for the applicant to receive the sensitive data items Consultant Code, Person Referring Patient and Census Output Area. **The Chair approved the application.**

	(c) Other None
221111-d	**HES Applications** <u>221111- a – Clatterbridge Centre for Oncology NHS Foundation Trust</u> This application is in three parts: 1) To receive an update extract of data previously received for data years 1997 to 2010 Admitted patients Cancer, Cardiac and North West Region plus a national dataset which is non-sensitive. In addition the application requests that in future data is provided through business objects. 2) A request for an additional member of staff to be provided with access to restricted HES data fields through the HES business objects function. 3) The application requests that in future data is provided through business objects only. Section 251 is in place for identifiable data. DAAG approval is requested for the sensitive data fields Census Output area, Consultant Code, Code of patients registered general medical practitioner and person referring patient NATCANSAT carry out analysis of HES and other sources of data on behalf of the organisations and individuals listed below. None of the analysis requires identifiers. The identifiers are used as follows: • To provide updates to HES extracts provided by Northgate, to ensure that the most current data is available to DH Cancer Policy Team/NHS Cancer Action Team/National Cancer Director/National Director for Heart Disease and Stroke and their teams • To facilitate updates of the extracts of data received from Northgate when a new procedure or diagnosis is requested to be in the analysis (e.g.: we were requested recently to include congenital heart disease in the cardiac HES analysis, we use a list of relevant procedures for cancer in the cancer HES extract, as new procedures become more commonplace, we receive requests to add these to our extracts. **Outcome:** The request for an update of HES data, previously provided, was approved. However, in view of the current on-going review of access to HES business objects, the Group advised that they were unable to grant approval for any non-standard access through this business function. The Group also had some concerns around the security of receiving data from Business Objects rather than via a bespoke extract. The request for additional access to restricted data fields through the HES Business Objects function was therefore not approved. In addition, the request to receive HES data through HES Business Objects only in the future was not approved. **Action:** Outcome letter to be sent out to applicant. A discussion followed on the merits of DAAG considering applications which have Section 251 support in place, but also require sensitive data fields. CS agreed to discuss with ECC the general issue of clarifying how applications which have Section 251 support but also require sensitive data fields should be dealt with. If sensitive fields are required at the time of the Section 251 application, it was felt that they should be included in the application for Section 251 support as the addition of sensitive fields may have an impact on ECC's decision. **Action:** CS to discuss with ECC.

	221111- b – Centre for Health Economics This application for HES episode records including sensitive data fields is for an NIHR SDO funded project. This study will examine whether better GP practice performance scores on the Quality and Outcomes Framework (QOF) are associated with lower emergency admissions (for both physical and mental health conditions) for persons with serious mental illness (SMI). A key aim of the study is to help inform national policy on the QOF, providing robust guidance on whether the QOF indicators are effective in helping reduce expensive hospital admissions, deaths and costs for this vulnerable patient group. The Group felt that this was a worthwhile study, but raised some concerns around small numbers being released to the applicant. DF confirmed that the applicant would have to sign up to a Data Re-use Agreement before the data was released to them. The Data Re-use Agreement contains a number of standard Terms and Conditions which control the use and release of small numbers. DAAG members were happy to approve the application on that basis. **Action:** Outcome letter to be sent out to applicant.
221111-e	**NHS Central Register – MRIS Applications** MR1263 – BOSS Barrett's Oesophagus Surveillance Study BOSS is a randomised controlled trial, seeking to determine whether patients diagnosed with Barrett's Oesophagus, a pre-malignant condition, should be offered prospective surveillance by endoscopy every two years, as opposed to endoscopy only when prompted by symptoms. Consenting participants will be randomised to being offered surveillance endoscopy every two years, or to no scheduled endoscopy. Participants in both arms will have access to endoscopy whenever symptoms warrant it. Participants will be followed up for 10 years after recruitment. The BOSS trial has been funded to weigh up the costs and benefits of surveillance in as thorough a way as possible, and is likely to remain the only substantial randomised controlled trial in the field. Application approved. MR1265 – National Vascular Database (NVD) and NHS Abdominal Aortic Aneurysm Screening Programme An amendment request was received on 06 January 2011 which requested access to patient data in line with the original approval, where the patient had died and consent could not be obtained in advance and where it was not feasible to seek assent from relatives or next of kin. This was subsequently approved as reassurance had been provided that consent would continue to be sought prospectively, and that the amendment related to emergency clinical situations where it was not initially feasible to seek consent. It was clarified that attempts would be made to seek consent retrospectively if the patient survived, however, where the patient died then views from next of kin, if in attendance, would be sought. This amendment requested that the following data items be provided to the applicant from the Medical Research Information Service (MRIS): cause of death, date of death, GP registration and PCT exit data. The group were advised of comments from the customer about problems obtaining explicit consent prospectively as per the S251 letter of approval. The customer has been requested to discuss this with the ECC secretariat and the customer is seeking approval for a verbal consent model in some instances. The group agreed that the applicant would need to gain consent and record it in the correct way.

221111-f	**Any other business:** Legal Gateway DP confirmed that the email had been sent to CS regarding the 'pre' research project planning advice with ECC and ONS requirements for the release of registration and/or cancer data. CS to discuss with ECC a process for ECC to highlight to the NHS IC any applications for Section 251 support where it would be helpful for the IC to provide some input for example where linkage may be required. University of Essex – Institute for Social & Economic Research This application is for an extract of HES data which requests month and year of Baby birth. As this was a new field the application was brought to the attention of DAAG for their approval. The applicant is analysing the effect of seasonality on birth weight. They advise that several studies have provided evidence of this. Any analysis of birth weight would therefore need to control for potential seasonal variation by taking account of the month of birth The applicant wishes: • to assess the effect on birth weight of the smoking ban introduced in England on 1st July 2007; • to assess the potential increase in utero stress caused by stressful events (such as London bombing attack on 7th July 2005). It is therefore necessary for them to know the month of birth to distinguish between mothers who were and were not affected by such events. **Outcome:** The group requested that a risk assessment be provided for the data requested, to ascertain whether there would be any disclosure issues.
	Date of next meeting: 20th December 2011