Data Access Advisory Group

Minutes of Meeting held 17th July 2011

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

In attendance: Susan Milner, Kuldeep Sohal, Vanessa Kaliapermall

Apologies: Dawn Foster, Diane Pryce

170711 - a	**Welcome** Dr Mark Davies welcomed everyone to the meeting.
170711 - b	**Minutes of the Previous Meeting** The minutes of the previous meeting were ratified. Actions still open from the previous meeting are: <u>190411 – c – University of Hospitals Birmingham</u> This application was submitted in January and resubmitted to the April meeting. Access was requested to Local Patient Identifier and Consultant Code to enable the users to drill down to internal patient level detail for root cause analysis purposes and to identify areas to improve patient health. The consultant identifier is required to follow up trends for peer review comparisons. Following discussion by the Group at the April meeting, it was agreed that sensitive data could be provided for the hospitals covered by University Hospitals Birmingham, but a pseudonymised HES extract should be provided for the rest of the country. Further information was provided by the applicant for discussion at the May meeting, however, the Group had further queries regarding the provision and use of national consultant data. As agreed at the May meeting, the Chair and CS had a telecon with the customer in which details of the process for providing access to the data were discussed. CS advised the Group that assurances had been given around appropriate access to individual consultant data. Consultants had given consent for their data to be shared with peers, however where consent was not provided, access to the particular Consultant's data will not be provided. CS advised that this is very interesting work around long term survival and cancers. The customer had been requested to submit a protocol providing details of how access to the consultant data would be accessed, however this had not been received yet. The protocol will be reviewed by the Data Access and Information Sharing team who will advise whether the controls are adequate. In the meantime, technical discussions with the HES team had resulted in confirmation that the provision of a table of pseudo Consultant data was feasible and this will be taken forward. **Action: Customer to be asked to submit the Protocol for approval. Technical aspects of providing a pseudo consultant data to be taken forward with HES team. Data Re-Use Agreement will be amended to include the agreed technical aspects together with conditions, and details on how to manage the data regarding deletion if it is no longer appropriate to hold the data.** (c) ECC Statement re MRIS death data, including case study (MR1222) DP had provided an update regarding the current situation with MRIS applications regarding death data following the ECC statement discussed at previous meeting. DP asked for the Group's agreement with the ECC statement that there is no requirement for Section 251 approval and that consent can be reasonably implied. ONS have implied that they are happy that audit applications which have used a third party require ECC Section 251 approval. However, where the clinical care team have been involved in the patient's care then consent is implied. The group agreed that a patient record can be updated with secondary care information as part of

	the patients record but agreed this issue should be discussed further when DP could be present. **Action: DP to provide letter setting out the Group's concerns on behalf of MD which could be sent to ECC (an action from previous meeting). Group will discuss further on receipt of reply from ECC.** **<u>170511 – a – South East Wales Trials Unit</u>** Action: The consent statement to be reworded and explicit consent regained from all the participants in the study. The updated consent statement must be included in both the consent form and the information leaflet. Reworded consent statement to be approved by DAAG.
170711 - c	**Matters Arising** <u>a) Overview of outstanding applications</u> **HES Applications –** <u>190411 – a – University of Kent</u> Outcome letter has been sent to the customer but the customer advised that she has not received it. Letter resent on the 08/07/11. <u>190411 – b – The University of Leeds</u> Outcome letter has been sent to the customer advising that the Group recommended that Section 251 approval be sought. The ECC secretariat have been in contact with the NHS IC and DF provided background information from the discussions at the DAAG meeting for their information. **(b) Decisions Out of Committee - HES applications, June and July 2011** **OC/HES/008 – Queen Mary University, London** **Request for update of HES data extract for data years 2008/8 and provisional 2010/11.** Study to investigate the impact of colposcopy on pre term delivery. The results of this will influence clinical guidelines and advice given to women of reproductive age, who have abnormalities detected by cervical screening requiring treatment. The data flow for this project is: 1. Sites send in cohort data to NHS IC Trusted Data Linkage Service (TDLS) 2. TDLS link to HES maternity data 3. TDLS send pseudonymised data to QMUL 4. QMUL choose sub-cohort and tell sites to collect treatment data on them 5. Sites sent in treatment data to TDLS 6. TDLS add in the HES maternity data, anonymise and send to QMUL Data linkage will be performed by the NHS Trusted Data Linkage Service. **Application approved by Chair.** **OC/HES/009 – Civil Eyes Research Limited** Request for Consultant Code for update of data years provisional 2010-11. Previous application approved by the Database Monitoring sub-Group DMsG Ref: 141010(a). The customer confirmed that the updated data will be used for the same projects and purpose. Data will be used for research projects with healthcare organisations on medical productivity and benchmarking analysis with the objective of improving the quality and delivery of healthcare in the UK. Longitudinal analysis and findings will be provided to medical directors and other senior personnel of the participating organisations. **Application approved by Chair.** **OC/HES/010 – Thames Cancer Registry (on behalf of English Cancer Registries)** Request for an update of HES data extract, including identifiable and sensitive fields, for update of provisional 2010-11 data years. This data will provide essential support to the now accelerated national cancer registration cycle prior to the availability of the 2010/11 HES final annual refresh dataset: the English cancer registries are required to complete registration of diagnosis year 2010 by December 2011.

	The Cancer Registries have ECC support to receive identifiable data fields under Regulation 2 of the Statutory Instrument (SI) on confidentiality – No. 1438, The Health Service (Control of Patient Information) Regulations 2002. **Application approved by Chair.**
190711-d	Hospital Episodes Statistics (HES) **190711 – a – Dr Foster Intelligence** This application by Dr Foster Intelligence (DFI) requests approval from DAAG to allow Dr Foster Unit at Imperial College (DFU) to provide DFI 'Clear Sensitive HES Fields & Diagnosis' which are required in the products/services Dr Foster Intelligence supply to NHS organisations. Currently DFU provide pseudonymised data for the same purpose to DFI in accordance with DFU's current NIGB Section 251 approval. The Group discussed the application and advised that the customer had not made a sufficiently robust case for access to the data requested which is very sensitive and could become identifiable. Full background clarifying why the current data is not sufficient and what has occurred to make the present data no longer suitable was requested. In addition, the issue of potential small number disclosure would need to be addressed with confirmation that strict controls are in place. In view of the fact that the current Section 251 approval is in the name of DFU and that the previous joint application was rejected for DFI to receive the data, the Group agreed that this application should be brought to the attention of the Ethics and Confidentiality Committee (ECC) and a letter outlining the application and the Group's concerns is to be drafted for PC to review. **Action:** **1. DFI to resubmit the application, with full background to the request for access to the data provided under Section 251 support to DFU. This should include:** **a) Why the present data is no longer sufficient and reasons for the requirement for data provided under DFU's approval.** **b) Clarification on whether any of the existing data flows contain sensitive fields.** **c) Details of protocol for dealing with the sensitive data such as abortion statistics.** **d) Clear protocol providing assurance regarding potential disclosure of small numbers to be provided.** **e) What service for the customer will be provided by access to this data that is not currently being provided?** **2. Letter for ECC to be drafted and sent to PC for review.**
	NHS Central Register – MRIS Applications **MR1249 – European Community Respiratory Health Survey III (ECRHS) -** Application for: Flagging and current status: deaths, PCT, exits and re entries & NHS No. DAAG approval requested for release of PCT data and fact of death only to facilitate contact for explicit consent. To be followed by an extension request for death data once consent materials have been through further ethical review and approved by DAAG. The Group discussed the application and approved the tracing of those patients that are alive to contact them and to update consent. The group deferred the decision on fact/form of death in the absence of DP. **ACTION: The Group to discuss fact/form of death in more detail with DP.**

	MR1250 – Survival of babies with trisomy 13 or trisomy 18 born in England and Wales since 2004 - BINOCAR Whilst the application was flagged for notification to DAAG only, the Group discussed the application briefly. The ECC approval was checked and it was noted that the current application is for Barts and The London School of Medicine, London but the Section 251 approval is for University of Leicester. This would need to be checked as Section 251 approval is not transferrable. In addition, it was noted that the annual review for Binocar is due for renewal on 5 August 2011. The Group advised that a decision on this application is deferred until the renewal has been completed and continued approval is in place. **Action: DP to confirm Section 251 support has been extended and to clarify the location. Application to be resubmitted.** **MR1217: Leukaemia and other cancers in teenagers and young adults in England: an aetiological analysis applying new statistical approaches.** **For notification to the committee only. No approval required. Noted by the Group.**
190711-f	<u>Any other business:</u> **i) Time Limit for closure of applications** The Group discussed whether a time limit should be imposed on responses from applicants. It was agreed that a limit of one month should be imposed on applicants who do not respond to any queries or conditions requested by the Group. Applicants would then be advised that their application will be closed due to non-response. The requirement for REC approval was also discussed and it was agreed that where REC approval is in place, the application can be submitted to DAAG. However if an application requires REC approval, it should not be submitted to DAAG until REC approval is granted. **Action: HES/MRIS teams to advise applicants that applications will be closed if they do not respond to DAAG correspondence within one month of provision of the outcome of the Group's decision.** **Action: DP to note that where REC is not in place applications should not be submitted to DAAG.** **ii) IG Toolkit Assessment** VK raised with the Group that Phil Walker (PW) had advised her that in future, Groups such as DAAG must ensure that applicants have completed a successful IG toolkit assessment. PW requested that DAAG consider how this can be incorporated into the application process. Discussion followed relating to the implications of this assessment replacing review of the System Level Security Policy and how the implementation of sourcing and providing results of the IG Toolkit assessment would impact on the application process. It was also agreed that further information on this requirement would be needed in order for the Group to agree how the proposal could be taken forward and made practical for the NHS IC. **Action: SK to discuss with PW and feed back to DAAG what is expected. A meeting will then be arranged to discuss further.** **iii) HES data loss** CS updated the Group on a recent serious loss of HES data by an organisation in London. Local controls at this organisation are being audited. As a result, DH had requested a full audit and review of the end to end process for access to HES data. CS assured the Group that no areas of concern had been highlighted relating to the NHC IC process.

	iv) Health Protection Authority - Request for Access to Sensitive/Identifiable HES data through HES Business Objects This application from HPA requests access to sensitive/identifiable data fields through the HES Business Objects function. Section 251 support is provided under Ref: PIAG 03-(c) /2001 for NHS Number, DOB and Postcode. System Level Security Policy has received approval by the ECC security advisor. Previous request for access were submitted to the Database Monitoring sub-Group for approval. The applicant has advised that access to HES via Business Objects is essential for undertaking matching of surveillance data to hospital episodes for certain vaccine preventable infections, for undertaking analysis of data for examining vaccine safety. This is occasionally required rapidly in response to vaccine safety signals or outbreaks of vaccine preventable disease. Usage and the purpose for access remains as previously requested and approved. Discussion followed on how checking of individuals requiring access could be assessed. The Group requested that a robust process be implemented to assess requests for access to Identifiable/Sensitive fields through HES Business Objects. In the absence of a method to assess individuals requiring access, all applications should be approved by a senior member of the organisation who can provide authorisation for access and confirm compliance to the NHS IC security requirements for access to this function. Applicants to continue to confirm adherence to NHS IC terms and conditions by signing the HES Protocol. The request from HPA was approved by the Group. **Action: Customer to be advised that current request approved.** **Action: DAIS team to put in place robust process to assess requests for access to sensitive data fields through HES Business Objects.** **v) DAAG Website** MD asked for an update on the status of the DAAG website. SM advised that the website was in the final stages and should be available shortly. **Action – URL for DAAG website to be provided in the Minutes of this meeting. Feedback welcome from the Group.**
	Date of next meeting: 23 August 2011