Data Access Advisory Group

Minutes of Meeting held 17th May 2011

Present

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

In attendance: Diane Pryce, Susan Milner, Kuldeep Sohal, Vanessa Kaliapermall, Olivia Podesta-Atkin (Secretariat)

Apologies: Dawn Foster, Patrick Coyle

170511-a	Welcome Dr Mark Davies welcomed everyone to the meeting. Patrick Coyle sent his apologies and the group received written comments from him in advance of the meeting which were included in the discussion of each agenda item.
170511-b	Minutes of the Previous Meeting The minutes of the previous meeting were ratified.
170511-c	Matters Arising (a) Overview of outstanding applications MRIS Applications – None HES Applications – 190411 – a – University of Kent Outcome letter has been sent to the customer but we have not received a response yet. 190411 – b – The University of Leeds Outcome letter has been sent to the customer but we have not received a response yet. The applicant was advised that they should gain Section 251 approval. 190411 – c – University Hospitals Birmingham This application was submitted in January but the Group requested further information. Access 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

	The application was re-submitted to the April meeting and the Group 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. Action: A telephone call to be arranged between MD, CS and Daniel Ray at UHB to discuss the requirement for national consultant data. (b) Decisions Out of committee - HES applications, May 2011 The following applications were approved out of committee by the Chair of the Data Access Advisory Group: OC/HES/001 - Cambridge CardioResource Study Group (University of Cambridge) This request is for approval to supply NHS number and a unique study number to the NHS IC Trusted Data Linkage Service for linkage to HES. Cambridge CardioResource is being established by researchers at the University of Cambridge and the NHSBT (NHS Blood and Transplant) for use in ethically approved biomedical research to test the feasibility and scalability of recruiting blood donors to take part in research protocols during their routine donation. The applicant has ethical permission to pilot the feasibility of tracking participants' future health outcomes through existing health databases and to examine how these relate to participant characteristics. As such the applicant proposes to establish: 1) The feasibility of linkage through participants' NHS number 2) The number of outcomes that accrue over time 3) How outcomes relate to participants' genetic, clinical and lifestyle characteristics The intention is to link the study information to various external data sources. The consent wording and request were approved by the Chair. OC/HES/002 - North Bristol NHS Trust Request for Local Patient ID and Consultant Code Section 251 approval is in place, however the customer has requested the sensitive data fields Local Patient ID and Consultant Code in order to enable data validation exercises to be completed. These sensitive data fields had not

	been mentioned in the Section 251 application. This application for data is requested to help ensure that complete data is submitted to the National Vascular Database (NVD). The project will ensure a more complete and representative dataset in order to validly assess patient outcomes and inform improvements in practice. This will result in a baseline indicator of performance in relation to current clinical practice and mortality rates reported by centre. Application approved by Chair. OC/HES/003 - University of Oxford The following encrypted identifiers are sought; NHS number (NEWNHSNO), date of birth (DOB), postcode (HOMEADD), sex (SEX). Mothers date of birth (MOTDOB), Baby date of birth (DOBBABY), HESID and Local patient identifier. These fields are encrypted by Northgate Information Solutions before supply to UHCE. Northgate use an encryption algorithm and keys known only to them and never supplied to UHCE. Using this method it is impossible for UHCE to reverse the encryption to obtain the plain text values. Previous approval has been granted by DMSG as the applicant will not be receiving any identifiable data as this is encrypted by Northgate prior to being passed to the applicant. The data set will be matched to the existing pre-linked HES and ONS mortality records, to extend the coverage and time span of the file. With the receipt of this data it is planned to extend the linked file from 1998 to 2011. With the extension of the UHCE programme of work to 2012 the applicant will request further data for the years 2010 to 2012. The applicant plans to continue developing the methodology and test the efficiency of person record linkage of hospital episodes (HES extract data) and death registrations (ONS death extracts) without the use of names and addresses or other plain text identifiers. Instead the matching process uses a group of data items which have been encrypted to generate a unique person number. Permission is also being sought to retain the existing and new data to 2014 in support of further development and analyses. The results of this work are published in the form of academic papers in refereed journals. Application approved by the Chair. OC/HES/004 - Kings College London - OC/HES/004; Request for approval of consent form wording which is in line with the recommendation from DAAG. Study into acute stroke outcomes relating to cumulative length of hospital stay, number of readmissions, recurrent strokes and mortality at different stages post stroke.

	Consent form approved by Chair. OC/HES/005 - Royal College of Surgeons of England - Clinical Effectiveness Unit Request for sensitive field Consultant Code, for an update of data years of HES data extract. This is an update of previous extract which includes identifiable data fields for which Section 251 approval is in place and sensitive fields for which approval has been previously been granted by the Database Monitoring sub-Group. An extension to the Section 251 support has also been granted by the Ethics & Confidentiality Committee for Baby Date of Birth. The studies undertaken by the Clinical Effectiveness Unit (CEU) are concerned with studying the determinants of variation in outcome following surgery. The data will be used for Audit and service evaluation The data will be used for 13 projects most of which are funded by Department of Health and/or Healthcare Quality Improvement Partnership, and NHS Specialist Commissioners. Application approved by Chair. OC/HES/006 - St George's, University of London Request for approval for the NHS IC Trusted Data Linkage Service to receive customer's own version of Local patient identifier for linkage to HES data. Application approved by Chair. OC/HES/007 - University of York, Department of Health Sciences, Request for sensitive fields Census Output Area, Consultant Code and Person Referring Patient NHS number is also requested to enable linkage of HES to data at the Yorkshire & Humberside Haematology Netowrk. ECC approval is in place (PIAG 1-05(h)/2007) for the applicant to record patients' NHS numbers to enable linkage to databases such as the Hospital Episodes Statistics. Partial ECC approval is in place and therefore consent is also required. The consent wording is in line with the DAAG approved consent wording. The applicant intends to use blood and tissue samples from participants for research purposes, as well as examining their medical records and sending them a questionnaire. The applicant will use the samples to make comparisons between people with different types of blood disorders and those who do not have these conditions. The samples and information may also help in the development of new treatments. As well as investigating potential conditions and surgeries that may be

	associated with haematological malignancies, the customer is also interested in referral and treatment patterns for haematological malignancies, and the fields 'person referring patient' and 'consultant code' will be used in these analyses. Little is known about why some people develop certain blood disorders and why people respond differently to treatment. The applicant hopes to find out more about why these diseases occur and what determines response to treatment. This information may also help to improve the organisation of clinical services. Application approved by Chair. (c) ECC Statement re MRIS death data, incluing case study (MR1222) It was not know that MRIS death data was to be discussed by the ECC and therefore the decision was unexpected. The decision does not take ONS requirements regarding the Statistics and Registration Service Act 2007 into account; also it is not evident if ONS have been consulted on the matter. The group decided to wait for a reponse from ECC regarding ONS before approving this as ONS need to be consulted first. Action: Diane to draft a letter for Mark to send setting out the groups concerns for discussion at ECC.
170511-d	Review MHMDS data items New data extracts –Netta Hollings updated the group on the provision of an MHMDS extract service. The NHS IC receives pseudo MHMDS data in order to provide customers with data extracts and produce analysis and statistics. The MHMDS Team have established an extract service based on the HES service which includes the ECC agreed approach to small numbers. The NHS IC will supply extracts to customers who do not have access to extracts directly from SSD. Extracts provided by NHS IC will either include sensitive data items (in which case DAAG approval will be required for the individual customer request) or will NOT include sensitive data items. The IC have approval from ECC to hold the data & provide data extracts, etc but approval is required from DAAG if sensitive data requested. I am not sure how this can be reworded. Hospital Episodes Statistics (HES) 170511 – a – South East Wales Trials Unit HES data was requested in support of the Building Blocks study. The applicant proposes to provide identifiable data items such as NHS number, date of birth

170511 - e	and postcode to enable linkage of the study cohort of teenage mothers to HES data. In addition sensitive information such as deaths, subsequent pregnancies and abortions will be requested, in order to verify information already provided in face-to-face and telephone interviews by women recruited to the study. This data will be summarised over two study groups (intervention and control) using appropriate statistics. The Group felt that the consent statement used in the consent form and participant information leaflet was not explicit enough, as no specific mention is made of national databases, HES, or NHS IC datasets. It is very important that the consent statement used clearly mentions the above, as some of the data being sought is particularly sensitive in an identifiable form. In addition the use of the sensitive data relating to abortions and future pregnancies was not sufficiently identified to the cohort. 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 wording to be approved by DAAG.
170511-f	<u>NHS Central Register – MRIS Applications</u> None
170511-g	<u>Any other business:</u> <u>DAAG Website</u> SM gave an update on progress with the DAAG website which is currently being developed. It is hoped to provide details to the Group for the next meeting. The Group discussed briefly how the website could be more widely publicised to the health community and the possibility of asking key members of the informatics sector to provide opinions on the website.
170511-h	<u>Date of next meeting:</u> 21st June 2011 2-4pm the Snow Room, Leeds