Data Access Advisory Group

Minutes of Meeting held 19th April 2011

Present

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

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

Apologies: Kuldeep Sohal

190411-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.
190411-b	Minutes of the Previous Meeting The minutes of the previous meeting were ratified.
190411-c	Matters Arising <u>(a) Update on SLSP Standard</u> Alistair Donaldson from Department of Health gave an update on having an agreed standard for applicants to sign up to rather than complete a SLSP. Alistair advised that he has been working on an agreed standard for Ethics and Confidentiality Committee (ECC) as currently security documentation is taken at face value and there is no opportunity to test claims by applicants. The agreed standard will take the form of a new requirement (335) in version 9 of the IG Toolkit, which is tailored towards research organisations, and will require them to take part in the Toolkit. However completing the Toolkit will be an option and they can still submit an SLSP but additional evidence will also be required. Auditors will be encouraged to take a greater role when dealing with claims being made and applications submitted. It will be the applicant's responsibility to make sure all claims being made are accurate. Actions: The IC would like a set of standards which the group can use and give to applicants to sign up to and confirm they are complying

	with. Then if they are found to be in breach, action can be taken. Dawn to list out the relevant standards from the IG Toolkit and look at some scenarios on the types of customers we have and how we would apply it. To bring a report back to the June meeting. <u>(b) Outstanding Applications</u> MRIS Applications – None HES Applications – 220311-a Nottingham University Hospitals This application was submitted to the March meeting. The applicant had requested access to clear Consultant Code through HES Business Objects in order to support medical appraisal and revalidation of Consultants which would assist Nottingham University Hospital to meet key milestones outlined in the GMC Statement of Intent. The Group had requested further clarification around the reasoning for accessing this information via HES Business Objects together with governance issues around possible benchmarking against Consultants at other Trusts. In response to the Group's queries the customer had responded that they were requesting access to Consultant data through HES Business Objects as they believed there would be a charge for the information in the form of a HES extract. In view of the current financial difficulties facing the NHS, they felt that access through Business Objects would be more cost effective. With regard to benchmarking, the applicant wished to compare indicators for consultants in his Trust against consultants in other Trusts, for the purpose of yearly appraisals. As no identifiable data was required for other consultants, there would not be any governance issues. In addition to the update from the customer, the DAIS team advised that access to clear Consultant Code through Business Objects would provide the applicant with National data and not just their own individual Trust. Following discussion, the Group felt that, whilst they understood the applicant's comments with regard cost of an extract, a more appropriate vehicle for their request would be an extract of HES data which would provide pseudo Consultant Code. There was still a lack of clarification around the issue of benchmarking against other Consultants as the applicant advises that they intend to compare against consultants in other Trusts, but then state that they only need access to their own Trust Consultant data. However, the decision by the Group that an extract of pseudo data would be the best option would ensure that identifiable Consultant data would not be supplied without consent and any benchmarking would be at a non-disclosable level. Action: The applicant to be advised that the request for clear Consultant

	Code through Business Objects was not approved and that an extract of data providing pseudo Consultant Code would be more appropriate. 180111-d Brighton and Sussex Medical School This application was submitted to the January meeting and requested patient identifiable data regarding primary and secondary diagnoses in order to determine whether there is a correlation between comorbidity of oncology patients and the toxicity they encounter to chemotherapy. The study primary objective is "To ascertain if co-morbidity score predicts severe chemotherapy toxicity". The decision of the Group was that the consent statement used was not explicit enough, as no specific mention is made of national databases, HES, or NHS IC datasets. The Group had queried whether it would be possible/feasible for the applicant to reword the consent statement and regain explicit consent from all the participants in the study The applicant had provided an update for the March meeting, advising that ethics approval had now been granted to re-consent the patients in the study. The reworded consent is now: "I give access to any medical information held on me in National Databases (the Hospital Episodes Statistics and NHS Information Centre databases)". The applicant is now carrying out the re-consent exercise. (c) Decisions out of Committee: None (d) Review of appropriate wording for consent statements Diane advised the group that ONS colleagues were not available until early May to discuss this so will be discussed further at the next meeting.
190411-d	Hospital Episodes Statistics (HES) 190411-a – University of Kent (Personal Social Services Research Unit) This request is for Evaluation of the Personal Health Budget Pilots. The aim of the project is to give more control to patients about how they receive their care. The evaluation will assess the cost effectiveness of personal health budgets for different chronic health conditions compared to conventional health service provision. Comparisons will be made for both primary and secondary care. For primary care consent will be requested from participants for information to be taken from their medical records. For Secondary care use NHS number is being requested from HES and informed consent will be obtained from participants.

	This application was not approved. The Group requested the applicant to change the consent statements on the leaflet to match the approved wording which the group recently agreed upon. With regards to the allowing a representative with power of attorney to consent on a patient's behalf, the group would like to ensure that the applicant has fully complied with section 32 of the Mental Capacity Act. Action: DAIS team to provide outcome to applicant. 190411-b – The University of Leeds The applicant requires Local Patient ID, NHS number, DOB and postcode to allow linkage to clinical audit database (MINAP) and the UK Women's Cohort Study. The object of the study was to "establish the relationship of nutrition with the occurrence of certain diseases". The linkage will be carried out by the NHS IC Trusted Data Linkage Service. Ethics approval was obtained in 1993, which was appropriate at the time, however it was not required to complete consent forms. Return of a questionnaire was therefore considered to be consent. The last page of the questionnaire which is included in the papers for the application asks for personal details such as NHS number and GP information to be provided. The application was not approved. As no formal consent form has been completed by participants and the consent for this study was obtained in 1995 they will need to contact the ECC as to whether an application for section 251 authorisations for disclosure is required. Action: DAIS team to provide outcome to applicant. 190411-c – University Hospitals Birmingham This application was submitted in January but the Group requested further information. University Hospitals Birmingham have developed tools which are being used in several acute hospital trusts in the West Midlands for clinical governance readmission and mortality monitoring systems. Access is 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 tool is currently not able to identify consultant activity. The application was approved in principle, but subject to conditions. The Group

	queried why the applicant required so much historic data and why they are asking for data for the whole of England while supplying only a very small number of West Midland hospitals. The Group agreed that sensitive data can be provided for the hospitals covered by University Hospitals Birmingham, but a pseudonymised HES extract should be provided for the rest of the country.
190411-e	<u>NHS Central Register – MRIS Applications</u> MR1206 – Investigating the relationship between tumour & genetic & environmental risk for colorectal cancer – Approved. MR1224 – HPS 3/TIMI 55:REVEAL (Randomized Evaluation of the effects of Ancetrapib through Lipid-modification) – Approved. MR1225 – ExACT-extended anticoagulation treatment for VTE: a randomised trial – Approved, subject to the information leaflet being amended, and the statement 'have names and addresses removed', to be taken out.
190411-f	<u>Any other business:</u> New data extracts – Dawn to invite Netta Hollings to attend the next meeting to discuss the provision of an MHMDS extract service and for the Group to review the current list of sensitive data items.
190411-g	<u>Date of next meeting:</u> 17th May 2011 2-4pm the Snow Room, Leeds