Data Access Advisory Group

Minutes of meeting held 29 May 2012

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

In attendance: Dawn Foster, Tom Latham, Diane Pryce, Chris Quinn, Frances Hancox (Secretariat)

Apologies: None

290512-a	**Welcome** Mark Davies welcomed everyone to the meeting.
290512-b	**Minutes of the Previous Meeting** The minutes of the previous meeting, 24 April 2012, were ratified.
290512-c	**Matters Arising** **a) Overview of Outstanding Applications** <u>240412-a – University Hospitals Birmingham</u> This application was approved at the previous DAAG meeting on 24 April. It was noted that the outcome letter for this application had been approved by Clare Sanderson, and would be sent to the applicant. **(b) Decisions Out of Committee** <u>OC/HES/018 – University of Oxford</u> This application was an update of an application previously approved by DAAG in 2011 to allow the University of Oxford to construct a file of English national HES data in which each baby's record is linked to their mother's record. The additional data requested would be matched to the existing pre-linked HES and ONS mortality records to extend the coverage and time span of the file. Identifiable and sensitive data items would be provided to the applicant in an encrypted format by Northgate Information Solutions, using an IC-agreed encryption algorithm, meaning that the applicant would not receive any identifiable data. The application was approved by the Chair out of committee. <u>OC/HES/019 – Care Quality Commission</u> This was an update of a previous CQC request. CQC had requested sensitive and identifiable HES data on a monthly managed basis for its function of regulating health and adult social care services in England. With respect to HES, CQC's principal aims were to provide patients and users of services

with clear assessments of the safety, quality and effectiveness of the services they receive. They also aimed to give patients, the public and professionals sound and fair information about health and social care.

CQC had the statutory power to access and use the information for its regulatory functions under Section 64 and Section 78 of the Health and Social Care Act 2008. The application was therefore approved by the Chair.

OC/HES/016 – Thames Cancer Registry

Thames Cancer Registry had requested 2011-12 HES data in addition to the data years already approved out-of-committee in December. This is to support the analytical functions of the English Cancer Registries.

The data originally requested had not yet been supplied due to delays in the applicant obtaining ONS approval, and since the original application was submitted the 2011-12 data had become available. This request was simply to add an additional data year and as such was approved by the Chair.

MR1290 – Putting Life In Years (PLINY): Telephone Friendship Groups

This was a small study requesting flagging for cause of death. The consent materials contained the current recommended wording and no issues were identified.

(c) Other

MR1113 – Study of Heart and Renal Protection (SHARP)

DMsG had reviewed the original SHARP application in 2008 and did not consider the consent sufficient to cover data sharing, processing and provision. SHARP was therefore at the time given S251 support by ECC Chair's action.

As the original study had now ended, the customer requested an extension until 2016. ECC had informed the customer that S251 support might not be required as consent had been taken for the study, and that DAAG should review this request to determine whether the consent would be considered sufficient.

The Group agreed that it did not seem reasonable to provide data to a study which previously required S251 support.

Action: Mark Davies to write to ECC explaining DAAG's concerns regarding providing data to a study which previously required S251 support.

(d) Outstanding Actions:

240412-c1: Diane Pryce confirmed that she had responded to the query about web based consent and informed the customer that a technical assessment would be required.

240412-c2: It was noted that the letter regarding application security assessments and the IG Toolkit had been sent to Phil Walker some time previously, and that a response was awaited.

Action: Secretariat to circulate copy of letter to DAAG for information.

240412-c3/4: Clare Sanderson confirmed that the DAAG Terms of Reference did not require

	EDG approval as only minor changes had been made. The final ToR had been sent to ECC for information. 240412-e1: MR1280 had been discussed with ONS, who commented that consent had been fairly obtained at the time; therefore it would not be useful or appropriate to require the customer to renew consent. 240412-e2: MR1287 had been discussed with the ECC Secretariat, but this action was ongoing as a formal response had not yet been received from the ECC Chair or full committee.
290512-d	**MHMDS Applications** <u>290512-a – London SHA MHMDS</u> Clare Sanderson chaired this part of the meeting while Mark Davies stepped out briefly. London Strategic Health Authority had requested access to sensitive MHMDS data for benchmarking, in order to better understand patterns of detention under the Mental Health Act within the London Region, and between London and other Regions. The SHA wanted to look into why London had a much higher use of detention under the Mental Health Act than other regions, in addition to examining demographic data to assess whether minority ethnic groups were disproportionately detained in London. It was noted that the applicant was willing to work closely with the Information Centre in the development of their report. **Outcome:** Approved <u>290512-b – Care Quality Commission MHMDS</u> The Care Quality Commission had requested sensitive MHMDS fields relating to activities under the Mental Health Act to monitor patients' pathways through the mental health system, in particular where the Mental Health Act had been used to place restrictions on individuals. It was noted that the Care Quality Commission had a statutory duty to monitor how providers of healthcare exercise their powers under the provisions of the Mental Health Act, and had the statutory power to access and use the information required for its regulatory functions. This was the first application CQC had submitted for MHMDS data, and so the application had been brought to a full DAAG meeting rather than being considered out of committee. It was agreed that it was good practice for DAAG to be informed of CQC's request, and that members had no issues with their application. **Outcome:** Approved
290512-e	**NHS Central Register – MRIS Applications** <u>MR1259 - Triple Antiplatelets for Reducing Dependency after Ischaemic Stroke or Transient Ischaemic Attack (TARDIS)</u> This application was for flagging for deaths, exits, re-entries and NHS number where missing. The consent materials and protocol were slightly out of date and referred to MRIS as part of ONS; amendments to this had been suggested to the customer but not carried out. The Group agreed that even without this amendment the wording made it clear that records from

	the NHS and NHS IC would be used for contact and follow-up. **Outcome:** Approved <u>MR1275 - The United Kingdom Aneurysm Growth Study</u> At this point Mark Davies resumed Chair of the meeting. The applicant requested flagging and current status for deaths, exits and re-entries. The consent forms previously used had not included data processing, but this had been covered in the patient information. The consent form and patient information had now been amended to include the recommended wording ad verbatim. It was agreed that ideally the consent forms should have included this wording originally, but as this had been updated and patients previously would have seen the patient information leaflet the Group agreed to approve the request. **Outcome:** Approved <u>MR1289 - Adolescents and Adults Living with Perinatal HIV (AALPHI)</u> This application requested flagging for deaths, cancer, exits, re-entries and NHS numbers. The consent literature had been slightly out of date but had now been updated and was considered to be fairly comprehensive. One issue raised was that a statement in the patient literature about not sharing the name and address of individuals could be slightly misleading. The Group agreed that this should be discussed with the customer, but that approval was not contingent on the removal of this statement. **Action:** Diane Pryce to discuss removal of the statement about addresses with the customer. **Outcome:** Approved <u>MR1291 - Clinical Cohorts in Coronary disease Collaboration (4C)</u> The applicant had requested flagging for cause of death. Concerns were raised about the consent materials used, as it was not made clear that personal data would be used outside the study team. A statement in the patient information leaflet advised that access to personal data would not take place outside the immediate study team. This had been discussed with the applicant, who responded that their consent was modelled on Biobank. The Group agreed that the patient information leaflet was inadequate and was not properly balanced by the consent form. There were additional concerns about organisations modelling consent on Biobank as this had been approved several years ago and was not an up to date example of best practice. It was noted that if DAAG required the applicant to amend the patient information, the applicant would then need to go back to the REC. The Group hoped the REC would see this as a minor amendment and that it would not cause substantial delay, and agreed that this should be included in the outcome letter to the applicant. **Outcome:** Not approved **Update:**

	MR1250 - Survival of babies with trisomy 13 or trisomy 18 born in England and Wales since 2004 This application had been discussed at a previous DAAG meeting, and it had been noted that the organisation holding the S251 support was not the same as the organisation making the application for data. This had been followed up, and confirmation had now been received from NIGB that the annual review had approved this study to take place at the new organisation. **Notification to Committee:** MR1288 - The Swine Flu Triage (SwiFT) study and MR1286 - Cohort mortality study of workers occupational exposed to lead in Great Britain (MR33) The Group were notified that these two applications had received S251 approval.
290512-f	**Any Other Business:** Future Forum - Consent It was noted that Dame Fiona Caldicott's review would shortly be beginning to take evidence from stakeholders on a number of themes, but that a report was not yet available. **Action:** Clare Sanderson to keep DAAG updated regarding Dame Fiona Caldicott review. In addition, there was a query regarding dates for subsequent meetings. **Action:** Secretariat to circulate DAAG meeting dates.
290512-g	**Date of Next Meeting:** 26 June 2012 2-3pm

Summary of Actions

Reference	Action	Owner
290512-c1	Mark Davies to write to ECC explaining DAAG's concerns regarding providing data to a study which previously required S251 support.	Mark Davies
290512-c2	Secretariat to circulate copy of Phil Walker letter to DAAG for information.	Frances Hancox
290512-e1	MR1289: Diane Pryce to discuss removal of the statement about addresses with the customer.	Diane Pryce
290512-f1	Clare Sanderson to keep DAAG updated regarding Dame Fiona Caldicott review.	Clare Sanderson
290512-f2	Secretariat to circulate DAAG meeting dates.	Frances Hancox