

# Information Governance

## Minutes of the fourth Database Monitoring Sub-Group (DMSG)

Friday 13 June 2008 starting at 10:00am

Skipton House, Elephant and Castle, London

<b>Members Present:</b>
Dr Patrick Coyle
Dr Ian Goodman
Mr Manny Devaux
Ms Ros Levenson
Mr Terence Wiseman

<b>In attendance:</b>
Susan Milner (IC)
Simon Howarth (IC)
Philip Nicholson
Melanie Kingston
Karen Thomson

<b>1. Welcome and Apologies.</b>	<b>[AG/72/1]</b>
<b>2. Minutes of the last meeting.</b>	<b>[AG/72/2]</b>
<b>3. Matters Arising.</b>	<b>[AG/72/3]</b>
<p>KT advised the Group that James Wood's team at CFH was now responsible for reviewing the security aspects of the applications. Adam Goodwin is no longer involved in reviewing applications. PN queried how we would ensure consistency in the process, and ensure that the same checking measures were in place. This is something that needs to be monitored.</p> <p>SM circulated the paper 'review of sensitive HES items'. The Group agreed this should be an agenda item at the next meeting, so that members have sufficient time to review the document. Members also requested that a rep from the IC attend the meeting in order to answer any queries.</p> <p><b>ACTION: HES sensitive items to be an agenda item on the next meeting.</b></p>	

<p><b>IC HES rep to be invited to attend the next meeting.</b></p> <p>AG/71/4/a Need to check if the PIAG approval [2-07(i)/2004) allows them to collect DoB.</p> <p><b>ACTION: PIAG secretariat to confirm.</b></p> <p>NSTS query – Avon Longitudinal Study are requesting full address. This was not covered in the original PIAG application and therefore they need to request an extension.</p> <p>MR1119 – Congenital Adrenal Hyperplasia – PC approved this study by chairman’s action following clarification of queries from the applicant.</p>		
<p><b>4. Hospital Episodes Statistics (HES) Business</b></p>	<p>[AG/72/4]</p>	
<p>[AG/72/4/a] Application for HES extract from University College, London, Gynaecological Cancer Research Centre -UKCTOCS (United Kingdom Collaborative Trial of Ovarian Cancer Screening) programme.</p> <p>The Advisory Group considered this request for HES extract. Data is required to identify which participants of the UKCTOCS</p> <p>Sensitive Data requested:</p> <p>Inpatient data:</p> <ul style="list-style-type: none"> <li>▪ Consultant Code</li> <li>▪ Code of patient’s registered or referring general medical practitioner</li> <li>▪ Person referring patient</li> <li>▪ Augmented care period local ID</li> <li>▪ Data years: 2001 -2007</li> </ul> <p>Outpatients data:</p> <ul style="list-style-type: none"> <li>▪ Consultant Code</li> <li>▪ Code of patient’s registered or referring general medical practitioner</li> <li>▪ Person referring patient</li> <li>▪ Data years: 2003- 2006</li> </ul> <p>This work is covered under the ONS Section 60 approval. The PIAG Secretariat confirmed to UCL that ONS registration and letter of support from Peter Goldblatt would sufficient.</p> <p>UKCTOCS is a Randomised control trial of Ovarian Cancer screening involving 202638 volunteers. The main outcome of trial is to compare morbidity due to Ovarian Cancer between screened and non-screened arms. Data from HES will be used to identify participants who have been admitted for cancer-related treatment. Although the primary cancer of interest is ovarian and fallopian-tube, the study is also looking at Endometrial and Breast cancer.</p> <p>Whilst members agreed that this was a valuable study, there were some queries with the application, and therefore the application was approved subject to the following conditions –</p>		

- Confirmation that the ethical approval covers obtaining information relating to endometrial and breast cancer
- That the consent forms contained sufficient information about the use of information (Members requested to see the consent forms)

**ACTION: Applicant to be informed of the Group's decision.**

**[AG/72/4/b]** Application for HES extract from the Nuffield Trust.

Sensitive data requested:

Admitted patients

- Census Output Area
- Consultant Code
- Code of patient's registered or referring general medical practitioner
- Person referring patient
- DOD
- Data years 2001 to 2007

Outpatient

- Patients Census Output Area, 2001
- Consultant Code
- Code of patient's registered or referring general medical practitioner
- Person referring patient
- DOD
- Data years 2003-2007

The background to this request is that extracts of HES data have previously been approved for Jennifer Dixon at the King's Fund. She has recently moved to Nuffield and is now requesting the same extracts to continue work on the projects. The request covers the following 5 projects which the Trust are working on, most of the projects are DH funded:

- 1) Person based resource allocation (PBRA)
- 2) BME access monitoring project
- 3) Analysis of admission rates COPD: a time series analysis
- 4) Whole system demonstrator project
- 5) Patient flows

Ros Levenson declared an interest in this application and did not take part in the discussion.

Members agreed this request subject to confirmation of appropriate security arrangements for the new location and whilst the information is in transit to the new location.

**Action: Applicant to be informed of the Group's decision.**

**[AG/72/4/c]** North East Public Health Observatory and University of Manchester - Access to HES/MHMDS: Psygrid project

Proposal to permit use of individual patient data from Mental Health Minimum Data Set and Hospital Episode Statistics records for a study cohort of mental health service users. Members considered this request for access to HES and MHMDS (Mental Health Minimum Data Set) data which had been previously submitted to SCAG for approval in 2006. At this time access to the data would have been through NWCS. Access to MHMDS will now be via SUS and will be provided by The NHS Information Centre.

**Data requested:**

- For the year 2006/7, full (all fields) copies of MHMDS and HES records for the 246 members of the first year's cohort through the secondary user service.
- When the data become available, for the years 2007/8, 2008/9 and 2009/10 full (all fields) copies of MHMDS and HES records for all cohort member in respect of the years in and after which they have provided consent.

All individuals have consented to take part in this study.

The Advisory Group approved the application subject to –

- An updated security policy being developed for the 3 year review
- Confirmation that the identifiers are reduced / information is pseudonymised over time

**ACTION: Applicant to be informed of the Group's decision.**

**Any Other HES Business**

**[1] Request from the Audit Commission**

Legal group of patients field. This request was approved.

**[2] Request from Cancer Research UK and LSHTM**

This study evaluating the impact of specialist treatment centres has existing PIAG approval (1-05(c)/2007) SM had received a request to obtain an additional data item - Consultant Code. It was unclear why Consultant code was necessary, and members queried if Hospital code would be sufficient. The Group agreed the request should be forwarded to PIAG for proper consideration.

**ACTION: Request not approved. Applicant. to be advised to contact PIAG.**

**[3] IC access to Consultant Code.**

This request had arisen from the Matthew Swindells IG review. Members did not have enough information at the meeting in order to consider the request, and suggested that a paper be developed that better defines the research question and the justification for requiring the information.

5. NSTS Business	[AG/72/5]
<p>There were no new applications for NSTS access.</p> <p>PN gave an update on the NSTS migration plans. This covered and update on the three replacement parts in development. PN explained that the reporting aspect was now being replaced by a SUS based application that the IC would have responsibility for.</p> <p>Data destruction was also covered, and PN agreed to check legislation requirements regarding how long a copy of the data should be kept for. PN also agreed that data retention policy would be developed and brought to a future meeting for consideration.</p> <p><b>Any other NSTS Business.</b></p> <p><b>[1] UK GRID</b> – PN had received a query regarding NSTS access. It was unclear whether PIAG approval was also necessary. KT agreed to follow up outside of the meeting.</p> <p><b>ACTION: KT and PN to clarify if PIAG application necessary..</b></p>	
6. NHSCR Applications	[AG/72/6]
<p><b>MR1126 – Yorkshire and Humberside Haematology Network</b> Members considered this application to access the NHSCR to receive mortality data from the Central Register. The Register has Section 60 approval which allows the network to identify the suitable cohort in order to seek consent. The application was considered by the DMsG as the consent forms did not explicitly mention the use of the Central Register or ONS/IC in order to follow the patients health status.</p> <p>The application was approved on the basis that this would be a one off approval and proper consent procedures should be in place for future projects.</p> <p><b>ACTION: PIAG secretariat to inform IC at Southport of outcome.</b></p> <p>There were also 2 applications tabled at the meeting.</p> <p><b>MR1113 – Study of Heart and Renal Protection (SHARP)</b> Members agreed this application in principle but requested that the application be circulated round after the meeting in order for them to properly review the application.</p> <p><b>ACTION: Application to be circulated after the meeting for final approval by Chairman’s action.</b></p> <p><b>MR1125 – Three years on...</b> Members did not feel that they had sufficient time to consider this application and requested that it be resubmitted at the September meeting.</p>	

<b>ACTION: 1125 to be circulated at the September DMsG meeting.</b>		
<b>7. Any other business</b>	<b>[AG/72/7]</b>	
<b>8. Date of next meetings</b>	<b>[AG/72/7]</b>	
<p>The next meetings will take place on:</p> <p>Friday 12 September 2008  Friday 28 November 2008  Friday 6 February 2009.</p> <p><b>ACTION: Secretariat to book meeting rooms</b></p>	<b>C/F</b>	<b>MK</b>

Actions arising in the meeting			
Action	Reference	Due Date	Owner
HES sensitive items to be an agenda item on the next meeting. IC HES rep to be invited to attend the next meeting.			SM
PIAG secretariat to confirm if PIAG 2-05(i)/2007 has approval to collect DoB			SM/MK
[AG/72/4/a] Applicant to be informed of the Group's decision			SM
[AG/72/4/b] Applicant to be informed of the Group's decision			SM
[AG/72/4/c] Applicant to be informed of the Group's decision			SM
HES AOB [2] Request not approved. Applicant to be advised to contact PIAG.			SM
NSTS AOB [1] KT and PN to clarify if PIAG application necessary..			KT/PN
MR1126 – PIAG secretariat to inform Southport of outcome			MK
MR1113 – Application to be circulated for consideration by Chairman's action			MK/PC
MR1125 – Application to be added to agenda for September meeting.			MK
Actions carried forward from previous meeting's			
[AG/70/4/a] Application for NSTS access from Isle of Man. Clarification required from Tim Davis's team and AG re IG and security aspects	AG/70/4/1	Next meeting	PN/AG
[AG/70/4/b] Application for NSTS access from Interhealth Care Services (UK) Ltd - Applicant to be informed of the Group's decision and be asked to clarify security question re encryption and confirm data not processed outside of the UK	AG/70/4/2	Next meeting	PN/AG
NSTS Any Other Business [1] – Health Protection Agency Centre for Infections. Applicant to submit SLSP	AG/70/4/3	Next meeting	PN/AG

NSTS Any Other Business [2] – Royal College of Surgeons – Independent Treatment Sector Audit. Applicant to await outcome of PIAG discussion	AG/70/4/4	Next meeting	PN
[AG/70/5/a] EPIC Oxford. Applicant to be informed of the Group's decision and clarify that back up tapes are held encrypted.	AG/70/5/1	Next meeting	SM/AG
[AG/70/5/b] University of Aberdeen – Health Services Research Unit. Applicant to be advised to re-submit application and develop SLSP	AG/70/5/2	Next meeting	SM/AG
[AG/70/5/c] Health Protection Agency – Extension of Business Objects to include identifiers. Applicant to submit a letter of confidence re security arrangements	AG/70/5/3	Next meeting	SM/AG
[AG/70/5/d] Proposal to collect Attribution Dataset (ADS). Applicant to be informed of the Group's decision and be asked to clarify security Queries	AG/70/5/4	Next meeting	SM/AG
[AG/70/5/e] CCAD – The Information Centre [1]. Applicant to be informed of the Group's decision and to be asked to clarify that raw data will encrypted	AG/70/5/5	Next meeting	SM/AG
[AG/70/5/f] CCAD – The Information Centre [2]. Applicant to be informed of the Group's decision and asked to confirm that raw data will be encrypted.	AG/70/5/6	Next meeting	SM/AG
HES Any Other Business	AG/70/5/7	Next meeting	SM
Secretariat to book meeting rooms for 2008	AG/70/7	Next meeting	MK
AG/69/4/a Application for HES extract from Cancer Research UK. AG to liaise with the IC regarding concerns with the security policy. LD to seek clarification re Section 60	AG/69/4/1	Next meeting	AG/SM
AG/69/4/c Application for HES extract from University College London. Applicant to be informed of the Group's decision and advised to develop SLSP	AG/69/4/3	Next meeting	AG/SM
AG/69/4/d Application for HES extract from University of Oxford. AG to confirm appropriate security arrangements in place. Applicant to be informed of the Group's decision.	AG/69/4/4	Next meeting	AG/SM
AG/69/4/e Application for HES extract from Clatterbridge Centre for Oncology. Applicant to be informed that the Group has deferred making a decision pending the outcome of the PIAG application	AG/69/4/5	Next meeting	SM
AG/69/4/j Any other business PHO request – Community Safety Strategic Assessment data. ????	AG/69/4/10	Next meeting	SM

AG/69/5/a Application for NSTS access from InHealth Netcare. Applicant to clarify security arrangements.	AG/69/5/1	Next meeting	PN
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