

# Information Governance

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

Friday 18 April 2008 starting at 10:00am

Skipton House, Elephant and Castle, London

<b>Members Present:</b>
Patrick Coyle (PC) – Chair
Ian Goodman (IG)
Manny Deveau (MD)
Terence Wiseman (TW)

<b>In attendance:</b>
Adam Goodwin (AG)
Philip Nicholson (PN)
Karen Thomson (KT) PIAG Secretariat
Melanie Kingston (MK), PIAG secretariat
Alan Bonfield (AB)
Susan Milner (SM)
Gloria Brackett (GB), ONS (for relevant part of meeting)
Mike Catchpole (MC), PIAG member (for part of meeting)

1. Welcome and Apologies.		[AG/71/1]
Apologies had been received for Ros Levenson		
PC welcomed GB and MC who were attending to aid discussion regarding the new NHS Central Register applications.		
2. Minutes of the last meeting.		[AG/71/2]
Minutes of the last meeting on the 4 February 2008 were circulated on the day,		
3. Matters Arising.		[AG/70/3]
AG/69/4/1 [AG/69/4/a] Application for HES extract from Cancer Research UK. AG to liaise with IC regarding concerns with the security policy. Awaiting further clarification. Action carried forward.	C/F	SM/AG
AG/69/4/3 [AG/69/4/c] Application for HES extract from University	C/F	SM/AG

<p><b>College London. Applicant to develop SLSP.</b> Further clarification re security aspects required. <b>Action carried forward.</b></p> <p><b>AG/69/4/4 [AG/69/4/d] Application for HES extract from University of Oxford. AG to confirm appropriate security.</b> Clarification still required. <b>Action carried forward.</b></p> <p><b>AG/69/4/5 [AG/69/4/e] Application for HES extract from Clatterbridge Centre for Oncology.</b> Await PIAG decision. PIAG rejected the application.</p> <p><b>AG/69/4/10 [AG/69/4/j] Any other HES business PHO request – Community Safety Strategic Assessment data.</b> Seek advice from DH team. <b>Advice from Jim Shannon – supports the decision of the Advisory Group. This is an inappropriate use of NHS data.</b></p> <p><b>AG/69/5/1 [AG/69/5/a] Application for NSTS access from In Health Netcare.</b> Clarification of security aspects required.</p> <p><b>AG/69/4/2 [AG/69/4/b] Application for HES extract from Health Protection Agency – Centre for Infections. Applicant to be informed of the Group’s decision and advised to develop SLSP.</b> SLSP submitted and approved by AG. <b>Action Closed.</b></p> <p><b>AG/69/4/6 [AG/69/4/f] Application for HES extract from the University of Nottingham. Applicant to be informed of the Group’s decision and advised to develop SLSP.</b> SLSP submitted and approved by AG. <b>Action Closed.</b></p> <p><b>AG/69/4/7 [AG/69/4/g] Application for HES extract from Clatterbridge Centre for Oncology.</b> Applicant informed of the Group’s decision. <b>Action Closed.</b></p> <p><b>AG/69/4/8 [AG/69/4/h] English Cancer Registries Update application.</b> Applicant informed of the Group’s decision. <b>Action Closed.</b></p> <p><b>AG/69/4/9 [AG/69/4/i] Application for HES extract from Cancer Research UK Million Women Study.</b> Applicant informed of the Group’s decision. <b>Action Closed.</b></p>	<p><b>C/F</b></p> <p><b>Closed</b></p> <p><b>Closed</b></p> <p><b>Closed</b></p> <p><b>Closed</b></p> <p><b>Closed</b></p> <p><b>Closed</b></p>	<p><b>SM/AG</b></p> <p><b>PN</b></p>
<p><b>4. Hospital Episodes Statistics (HES) Business</b></p>	<p><b>[AG/71/4]</b></p>	
<p><b>[AG/71/4/a] Application for HES extract from the Royal College of Surgeons, Clinical Effectiveness Unit.</b> The Advisory Group considered this request to gain approval to receive regular annual refresh extracts of the HES database. They also wish to put in place a system whereby they receive quarterly provisional updates in a routine fashion to ensure that analyses are as up to date as possible</p> <p><b>Data requested:</b></p> <ul style="list-style-type: none"> <li>▪ Census Output Area</li> <li>▪ Consultant Code</li> <li>▪ Patient’s DOB</li> <li>▪ Baby DOB</li> </ul>		

<ul style="list-style-type: none"> <li>▪ DOD</li> <li>▪ Data years: 1997 – 2007</li> <li>▪ Retention: 2 years + quarterly provisional updates for 2007-8</li> <li>▪ PIAG approval Ref: 2-07(i)2004 Next review 1/6/08</li> </ul> <p>This was a request to extend the dataset to include full DoB, however it was not clear if the existing PIAG approval extends to allow full DoB. It was also noted that the existing application mentioned that data would be retained for 2 years, however the original application was made in 2004 and therefore the 2 year retention period should be up.</p> <p>AG had some concerns with the security documents and requested the corporate security policy be updated with information specific to this study, and requested clarification regarding remote access controls.</p> <p><b>ACTION: Applicant to be informed of the Group's decision. Confirmation required that existing PIAG approval extends to this new data item and clarification of security queries required.</b></p> <p><b>[AG/71/4/b] Application for HES extract from the University of Birmingham</b></p> <p>An application for work involving analysing data for the evaluation of the New Deal for communities (NDC) initiative within the West Midlands region. The study has involved the construction of NDC areas and virtual areas. The virtual areas are similar in demography to the NDC areas and are dispersed West Midlands wide. The areas are also subject to change.</p> <p><b>Data requested:</b></p> <ul style="list-style-type: none"> <li>▪ DOB</li> <li>▪ Census Output area</li> </ul> <p>Data years: 1989 – 2007</p> <p>Data Retention: 2 years</p> <p>The application was referred.</p> <p><b>ACTION: Applicant to be informed of the Group's decision.</b></p> <p><b>[AG/71/4/c] Application for HES extract from NHS South West SHA &amp; University of Bristol</b></p> <p>The Advisory Group considered this application for SWPHO to establish a HES safe haven. General purposes: to supply a local information service for the NHS and academics within the Dept of Social Medicine, University of Bristol and MRC Health Services Research Collaboration.</p> <p><b>Data required:</b></p> <ul style="list-style-type: none"> <li>▪ DOB</li> <li>▪ Postcode</li> <li>▪ Local patient ID</li> <li>▪ NHS Number</li> <li>▪ Ordnance Survey grid ref</li> </ul>		
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- Census Output Area
- Consultant Code
- Code of patient registered/referring general medical practitioner
- Person referring patient
- Augmented care period local ID
- Birth date baby
- Mother DOB
- Detention category
- Legal category of patient
- DOD
  
- Data years: 2006-7
- Data retention: 3 years

PIAG Ref: 4-07(w) 2002 Next review: 1/06/08

**ACTION:**

**[AG/71/4/d] Resubmitted application for HES extract from University of Aberdeen**

This application was submitted to the February 2008 DMSG meeting. The Committee asked for some clarification on the issues below and requested that this application be re-submitted to the April 2008 meeting. The customer has submitted a response to the queries from the Committee (letter enclosed separately).

There were also issues with the security documentation and these have also been addressed by the customer. A system level security policy was requested and this has been submitted.

**Data requested:**

- DOB
- NHS Number
- Postcode of patient
- Birth date baby
- Mother's DOB
  
- Data years: 1993 to 2007 (2007 – 2008 also requested see note below)
- Data Retention: 3 years
- DP registration Z7266585 Expiry date: 21/11/08
- MREC Approval 06/mre10/25

The Advisory Group noted that no specific consent had been obtained to take part in the study, although consent had been implied when an individual returned the questionnaire.

AG requested that an SLSP be developed, and that

The Advisory Group approved the application subject to ..... and clarification of appropriate security as above.

**ACTION:**

**[AG/71/4/e] Resubmitted application for HES extract from EPIC Study, University of Oxford**

<p>The Advisory Group noted that this application was also being resubmitted to PIAG, and agreed to approve in line with PIAGs decision, and subject to confirmation of appropriate security arrangements.</p> <p><b>ACTION: Applicant to be informed of the Group's decision.</b></p> <p><b>[AG/71/4/f] Review of Sensitive HES data items.</b></p> <p>PIAG had requested that DMSG review the current list of data items considered sensitive. Members reviewed the whole dataset and advised the following changes.</p> <p>Members suggested the following items to be moved to the sensitive list:</p> <ul style="list-style-type: none"> <li>- Date detention commenced (Psychiatric)</li> <li>- Live or still birth</li> </ul> <p>Some data items are clearly identifiable, for example DoB, NHS number, Postcode, Baby DoB, Mothers DoB. However, a number of 'non identifiable' items could be combined to render the data set identifiable. Members requested to view any applications where there was doubt as to the identifiability of the data. They could also escalate any decision to PIAG if they were unsure.</p> <p>In addition to this, there were a number of data items which the Group requested further clarification of how they are made up</p> <p><b>ACTION: SM to clarify data items as above.</b></p>		
<b>5. NSTS Business</b>		
<p><b>[AG/71/5/a] Application for NSTS access from Fluline</b></p> <p><b>ACTION:</b></p> <p><b>[AG/71/5/b] Resubmitted application for NSTS access from Royal College of Surgeons – Clinical Effectiveness Unit.</b></p> <p><b>ACTION:</b></p> <p><b>Any other NSTS Business</b></p> <p><b>1) Request from Harmoni Clinicentre</b></p> <p>PN had received a request from this Independent Sector Treatment Centre to trace NHS numbers of patients treated. The Centre is responsible for treating elective NHS patients. Members requested to see a full application, however agreed that providing this was for tracing legitimate NHS patients then this could be dealt with via Chairman's action. Security would also need to be checked by AG.</p> <p><b>ACTION: Applicant to be informed to submit full application.</b></p>		

<p><b>2) Request from Scottish researcher.</b> PN had received a request from this researcher to confirm if any of his study participants were deceased. This was a small study of 100 patients and the researcher was requesting vital status of approx 30 individuals. Members agreed the request on the basis that Date of Death is publicly available information. <b>ACTION: PN to inform researcher of the decision.</b></p> <p><b>3) Update on the NSTS migration plan</b> PN gave a quick update regarding the migration plan. He explained that Clinical Spine, the new service replacing online tracing was now active, and that access to this was being managed locally. The Advisory Group will not receive any more applications for online tracing. The service to replace batch tracing is currently still in development, however trials are expected across the NHS in Autumn 2008. The service to replace Reporting is in development but not yet ready for testing.</p>		
<p><b>6. Applications for flagging and tracing on the NHS Central Register</b></p>	<p><b>[AG/71/6]</b></p>	
<p>***** it should be noted that in addition to this approval, the General Register Office in England and Scotland also consider the request to release data*****</p> <p><b>[AG/71/6/a] MR1108 - SIGGAR 1</b> An application to receive cancer data on living patients and to flag for changes in vital status. Members noted that this application had arisen because of an oversight to the study design, where the proper consent had not been requested initially.</p> <p><b>[AG/71/6/b] MR1114 – Cardiovascular magnetic resonance imaging study</b> An application Members also requested that an SLSP be developed.</p> <p><b>[AG/71/6/c] MR1117 – CRISIS study</b></p> <p><b>[AG/71/6/d] MR1118 – Seascale and Dounreay</b> Members agreed that obtaining consent was inappropriate in this instance, and approved the application subject to confirmation that external researchers will only be able to access anonymised/pseudonymised information. <b>ACTION:</b></p> <p><b>[AG/71/6/e] MR1119 – Congenital Adrenal Hyperplasia</b></p>		
<p><b>7. Any other business</b></p>	<p><b>[AG/71/7]</b></p>	

<p><b>[AG/71/6/a] NHS Central Register</b></p> <p><b>[AG/71/6/b] Security review proforma</b></p> <p><b>[AG/71/6/c] DMSG Terms of Reference / Membership</b> Members were asked if they feel the membership could be strengthened in any particular area.</p> <p>The Advisory Group was happy with the draft Terms of reference circulated.</p>		
<p><b>8. Date of next meetings</b></p>	<p><b>[AG/71/7]</b></p>	
<p>The next meetings will take place on:</p> <p>Friday 13 June 2008 Friday 12 September 2008 Friday 28 November 2008 Friday 6 February 2009.</p> <p><b>ACTION: Secretariat to book meeting rooms</b></p>	<p>C/F</p>	<p>MK</p>

Actions arising in the meeting			
Action	Reference	Due Date	Owner
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 issues	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
<b>Closed Actions</b>			