

# Information Governance

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

Friday 4<sup>th</sup> February 2008 starting at 12:00am

Radisson Edwardian Kenilworth Hotel, London

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

<b>In attendance:</b>
Adam Goodwin (AG)
Philip Nicholson (PN)
Louise Dunn (LD)
Ros Levenson (RL) PIAG member
Melanie Kingston (MK), PIAG secretariat
Susan Milner (SM)

1. Welcome and Apologies.	[AG]	
Apologies had been received for.  PC welcomed RL and MK who were attending on behalf of the Patient Information Advisory Group.		
2. Minutes of the last meeting.	[AG/70/2]	
Minutes of the last meeting on the 9 November 2007 had not been circulated,		
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 College London. Applicant to develop SLSP. Further clarification re security aspects required. Action carried forward.	C/F	SM/AG
AG/69/4/4 [AG/69/4/d] Application for HES extract from University of Oxford. AG to confirm appropriate security. Clarification still required.	C/F	SM/AG

<p><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. Await PIAG decision. PIAG rejected the application.</b></p> <p><b>AG/69/4/10 [AG/69/4/j] Any other HES business PHO request – Community Safety Strategic Assessment data. Seek advice from DH team. 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 InHealth Netcare. Clarification of security aspects required.</b></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. SLSP submitted and approved by AG. 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. SLSP submitted and approved by AG. Action Closed.</b></p> <p><b>AG/69/4/7 [AG/69/4/g] Application for HES extract from Clatterbridge Centre for Oncology. Applicant informed of the Group's decision. Action Closed.</b></p> <p><b>AG/69/4/8 [AG/69/4/h] English Cancer Registries Update application. Applicant informed of the Group's decision. 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. Applicant informed of the Group's decision. Action 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>Closed</b></p>	<p><b>PN</b></p>
<p><b>4. NSTS Business</b></p>	<p><b>[AG/70/4]</b></p>	
<p><b>[AG/70/4/a] Application for NSTS access from Isle of Man Primary Care Services</b></p> <p><b>Papers provided:</b></p> <ul style="list-style-type: none"> <li>▪ Business Justification</li> <li>▪ Information Security Policies (3)</li> </ul> <p>An application from the Isle of Man to access NSTS in order to trace if individuals are already registered before making an NHS number for them. This is proposed as an interim arrangement as the IoM do not currently have permission to access PDS.</p> <p>The application was approved subject to confirmation from Tim Davis that the IG arrangements for the IoM are satisfactory and AG that all security aspects are satisfactory.</p> <p><b>ACTION: Applicant to be informed of the Group's decision. Confirmation required from Tim Davis's team.</b></p>	<p><b>C/F</b></p>	<p><b>PN</b></p>

<p><b>[AG/70/4/b] Application for NSTS access from Interhealth Care Services (UK) Ltd</b></p> <p>Interhealth Care Services (UK) Limited operates two Independent Sector Treatment Centres (ISTC): The Cheshire and Merseyside NHS Treatment Centre and The Kidderminster NHS Treatment Centre. As part of the ISTC Patient Experience Survey programme they require access to NSTS for tracing/confirmation of patient: NHS Number; address; and date of death (check if deceased).</p> <p><b>Special notes:</b></p> <ul style="list-style-type: none"> <li>This is another Independent Sector Service Provider, a number of which the Group has considered for access to NSTS.</li> </ul> <p>The Group agreed that this was a reasonable request, however did not agree that online access should be granted. Approval was given for batch tracing subject to clarification of the security points below.</p> <p>AG noted that the security policies submitted were brief and requested an SLSP be submitted. In addition, he noted a reference to Canada in an email address and requested confirmation that data is not processed outside of the UK.</p> <p>The application was approved (for batch tracing only) subject to clarification of encryption as with the above application.</p> <p><b>ACTION: Applicant to be informed of the Group's decision and be asked to clarify security question above.</b></p> <p><b>Any other NSTS business.</b></p> <p><b>[1] Health Protection Agency – Centre for Infections</b>  A request to utilise the NSTS batch tracing service to enable the HPA to provide PCT-level reporting of <i>clostridium difficile</i> infections to the Department of Health. The patient's NHS number has been made a mandatory field for 2007/08 data. The HPA needs to use the Trust provided data to trace from NSTS details of each reported case's registered GP and associated PCT in order to provide the necessary analyses to the DH.</p> <p>This request was approved subject to the production of an SLSP.</p> <p><b>ACTION: Applicant to submit SLSP.</b></p> <p><b>[2] Royal College of Surgeons – Independent Treatment Sector Audit</b>  This was a late request to access NSTS for the purposes of comparing treatment outcomes between NHS and Independent Sector Treatment Organisations. The consent status of individuals was unknown, therefore consent may have been in place, however, it would also not be known if a patient had dissented.</p> <p>It was noted that an application was being presented to PIAG the next day. Members agreed that this was an important piece of research and agreed to approve the request pending confirmation of PIAG approval.</p>	<p>C/F</p> <p>C/F</p>	<p>PN/AG</p> <p>PN/AG</p>
---	-----------------------	---------------------------

<p><b>ACTION: Await PIAG outcome</b></p> <p><b>Update of the NSTS Migration Plan.</b> PN gave a short update regarding the replacement services for NSTS. He advised that the NSTS contract had been extended until 2009.</p>	C/F	
<p><b>5. Hospital Episodes Statistics (HES) Business</b></p>	[AG/70/4]	
<p><b>HES Business</b></p> <p><b>[AG/70/5/a] Cancer Epidemiology Unit, University of Oxford: The European Prospective Investigation into Cancer and Nutrition, Oxford cohort (EPIC-Oxford)</b></p> <p>The purpose of this application is to increase the scientific value of EPIC-Oxford by obtaining information from the HES database. Follow up of patients has been conducted through questionnaires to the patients and through the collection of data on cancer diagnoses and on deaths through Cancer Registries and ONS. This has enabled results on self-reported health, incident cancer and mortality to be published. The development of HES now provides the opportunity to also conduct analyses on all other diseases diagnosed in hospital and operations performed.</p> <p><b>Data requested:</b></p> <ul style="list-style-type: none"> <li>▪ DOB</li> <li>▪ NHS Number</li> <li>▪ Postcode of patient</li> <li>▪ Data years: 1989 to 2007</li> <li>▪ DP registration Z6256472      Expiry date: 1 January 2009</li> <li>▪ Scotland A research ethics committee approval: MREC 02/0/90</li> </ul> <p>EPIC-Oxford has current PIAG section 60 support Class IV (PIAG 3-09(e)/2003 for research on cancer covering use of name, address, DOB, NHS Number, data on diet and lifestyle from questionnaires, reports from NHS Central Register, plus name of patient's consultant, methods of diagnosis of cancer, stage of disease at diagnosis, pathology report and tissue sample. They are currently checking with PIAG whether this approval would also cover the EPIC-Oxford Study.</p> <p>The Group was generally happy with the request, although was aware that any approval would be dependent on PIAG giving approval also.</p> <p>AG requested clarification that the back up tapes were stored encrypted and confirmation that the security policy submitted also covers the back up information.</p> <p><b>ACTION: Applicant to be informed of the Group's decision and requested to clarify the security points above.</b></p>	C/F	SM/AG
<p><b>[AG/70/5/b] University of Aberdeen – Health Services Research Unit: ProLong Longitudinal Study of pelvic floor dysfunction and childbirth (ProLong Study)</b></p> <p>New application. Pro-Long study is a longitudinal cohort study following</p>		

women's health since an index delivery in 1993-94. The women have been contacted on 3 occasions (initial questionnaire, questionnaire at 6 years and one at 12 years in 2007). The study only contacts women who replied to the initial mailing in 1993-94.

**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
- PIAG not required

Note: 2007-08 data has also been requested. If this application is approved, the customer will be advised that a formal letter requesting the approval to be extended to cover 2007-2008 data should be submitted to the Committee in November 2008 together with any possible updated security details or policy relevant at that time.

Permission has been received from the Privacy Advisory Committee of NHS National Services Scotland to obtain the equivalent information for women who were delivered in Aberdeen.

Members requested to see the original consent forms signed. It was unclear whether the original consent mentioned accessing this HES data. The example consent form provided was not considered appropriate and the Group requested confirmation if this was the only information given to patients at recruitment.

AG requested that the SLSP be updated to include the courier process, and confirmation of secure storage and encryption of back up tapes. The relationship between Birmingham University and the University of Aberdeen also requires clarification.

**ACTION: Applicant to re-submit application providing further clarification as above. Also to be advised to submit SLSP.**

**[AG/70/5/c] Health Protection Agency: Extension of Business Objects access to include Identifiers**

Since 1999 HPA have linked NWCS data and immunisation data using NHS Number or an algorithm of sex, DOB and Postcode. This linkage provides them with a complete record for the child with the date and ICD code of the admission to hospital and the date of immunisation. This record linkage has been used to establish an active system for post-marketing surveillance of vaccine safety which covers all vaccinations given during the first five years of life with sufficient power to rapidly identify rare reactions.

Since the closure of the NWCS service this vital monitoring and assessment

C/F

SM/AG

<p>of vaccine safety has been unable to continue hence the request for access via business objects.</p> <p>They intend to retain the fields for the minimum period to allow them to monitor the trend of infectious disease that may have an epidemic cycle of several years.</p> <p>Fields requested to be added to their current Business Objects access:</p> <ul style="list-style-type: none"> <li>▪ NHS number,</li> <li>▪ DOB,</li> <li>▪ Local Patient ID</li> <li>▪ Postcode</li> </ul> <p>This work is covered under the HPA's existing PIAG approval, although the applicant is awaiting written confirmation of this from PIAG.</p> <p>The application was approved subject to receipt of a letter of confidence regarding the security arrangements.</p> <p><b>ACTION: Applicant to be advised to submit a letter of confidence re security arrangements.</b></p> <p><b>[AG/70/5/d] Proposal to collect Attribution Data Set (ADS): The Information Centre / Paul Dixon, Data Translation and Analysis, University of York</b></p> <p>Update of application approved February 2007</p> <p>Request to continue to collect the Attribution Data Set which includes counts of GP's patients by postcode. This application for data to be collected in 2008 is an update of the request approved in February 2007. For 2008 the data collected will primarily be for the purpose of supporting the calculation of weighted capitation targets for the next round of Primary Care Trust allocations from 2009-10. The data will be collected by the IC for finance in the Department of Health.</p> <p>The data from the CfH (Exeter) systems will be analysed by a contractor working for the Department. The contractor, as in previous years, is Paul Dixon of Data Translation and Analysis, University of York. Confirmation has been received that all security information for the previously approved application remains the same.</p> <p>The Group requested clarification of what was meant by GP. Whether this was General Practice or registered General Practitioner. AG requested confirmation that raw data will be encrypted during transfer.</p> <p>The application was approved subject to the above.</p> <p><b>ACTION: Applicant to be informed of the Group's decision and asked to clarify queries as above.</b></p> <p><b>[AG/70/5/e] CCAD – The Information Centre [Application 1]</b></p>	<p>C/F</p>	<p>SM/AG</p>
<p></p>	<p>C/F</p>	<p>SM/AG</p>

<p>This application is a modification of previously approved extract and requests local identifiers but not dates of death as previously. Additional ICD code request to enable the checking of completeness of data submissions.</p> <p>This request is to allow linkage to clinical audit database (MINAP) to assess case ascertainment rates by NHS trust in England, as requested by Prof. Roger Boyle (National clinical director for Heart Disease) and others.</p> <p>Data requested:</p> <ul style="list-style-type: none"> <li>▪ DOB</li> <li>▪ Local patient ID</li> <li>▪ NHS NUMBER</li> <li>▪ Postcode of patient</li> <li>▪ DP registration: IC: X8959110 expiry date 10 March 2008</li> <li>▪ Healthcare Commission: Z8498881 expiry date 1 April 2008</li> <li>▪ NCASP has Section 60 exemption.</li> <li>▪ Data retention: 12 months</li> <li>▪ Data years: 2005 to 2007</li> </ul> <p>AG requested clarification that raw data would be encrypted.</p>		
<p><b>ACTION: Applicant to be informed of the Group's decision and asked to clarify security as above.</b></p> <p><b>[AG/70/5/f] CCAD - The Information Centre [Application 2]</b></p> <p>Update application of previous extract approved November 2007. This application refers to a different type of pace maker.</p> <p>Data requested:</p> <ul style="list-style-type: none"> <li>▪ DOB</li> <li>▪ Local patient ID</li> <li>▪ NHS NUMBER</li> <li>▪ Postcode of patient</li> <li>▪ DP registration: IC: X8959110 expiry date 10 March 2008</li> <li>▪ Healthcare Commission: Z8498881 expiry date 1 April 2008</li> <li>▪ NCASP has Section 60 exemption.</li> <li>▪ Data retention: 12 months</li> <li>▪ Data years: 1989 to 2007</li> </ul>	C/F	SM/AG
<p>The application was approved subject to clarification of encryption as with the above application.</p> <p><b>ACTION: Applicant to be informed of the Group's decision and asked to confirm that raw data will be encrypted.</b></p> <p><b>Any other HES business.</b></p> <p><b>1. Public Health Observatories</b></p> <p>Request to receive a national extract of what they already hold on HES Business Objects. Members requested clarification how long they intend to hold the data for, how the data is transferred, and how regularly they intend</p>	C/F	SM/AG

<p>to receive updates.</p> <p><b>ACTION: Clarify issues above – ok for Chairman’s action.</b></p> <p><b>2. Kings Fund</b> The Group was informed that the Data Custodian had left the organisation. All work had been undertaken specifically for the Kings Fund and not for the individual but some of the projects started may be transferred from the Kings Fund at a later date. The Group agreed that further approvals should be obtained if the applicant wishes to transfer the data from any existing studies.</p> <p><b>3. Eastern Public Health Observatory – Community Safety Strategic Assessment.</b> Follow up from previous meeting – Advice had now been sought from Jim Shannon at the Department of Health, who agreed with the views of this Group. If approved, this request would allow NHS data to be used for non-NHS purposes, which the Group does not consider appropriate.</p> <p><b>4. Security update.</b> LT advised that, in light of the recent security breaches highlighted in the press, a note had gone round all HES applicants reminding them of the need to hold HES extracts securely. This note had also been published on the HES website.</p>	<b>C/F</b>	<b>SM</b>
<b>6. Any other business</b>	<b>[AG/70/6]</b>	
<p>No other general business.</p>		
<b>7. Date of next meetings</b>	<b>[AG/70/7]</b>	
<p>The next meetings will take place on:</p> <p>Friday 18 April 2008 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>	<b>C/F</b>	<b>MK</b>



<b>Actions arising in the meeting</b>			
<b>Action</b>	<b>Reference</b>	<b>Due Date</b>	<b>Owner</b>
[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 be 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
<b>Actions carried forward from previous meeting's</b>			

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
<b>Closed Actions</b>			
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	AG/69/4/2	Next meeting	AG/SM
AG/69/4/f Application fro HES extract from the University of Nottingham. Applicant to be informed of the Group's decision and advised to develop SLSP	AG/69/4/6	Next meeting	AG/AM
AG/69/4/g Application for HES extract from Clatterbridge Centre for Oncology. Applicant to be informed of the Group's decision	AG/69/4/7	Next meeting	SM
AG/69/4/h English Cancer Registries update application. Applicant to be informed of the Group's decision.	AG/69/4/8	Next meeting	SM
AG/69/4/l Application for HES extract from Cancer Research UK Million Women Study. Applicant to be informed of the Group's decision.	AG/69/4/9	Next meeting	SM