

Database Monitoring sub-Group

Minutes of meeting held on Friday 24th April 2009

New King's Beam House, London

10.00am – 1pm

Members Present:
Dr Patrick Coyle – (Chair)
Ms Ros Levenson
Mr Terence Wiseman

In attendance:
Susan Milner (IC, Leeds)
Louise Dunn (IC, Leeds)
Jackie Gallagher (IC, Southport)
Diane Pryce (IC, Southport)
Melanie Kingston (ECC Approvals Officer, NIGB)
Zoë Lawrence (NIGB, Business Manager)

Agenda Number	Item	Actions
240409-01	Apologies Mr Manny Devaux Dr Ian Goodman Mike Farrell (Security Adviser to NIGB - CFH)	
24049-02	Harry Cayton (Chair of NIGB) – Welcoming members to NIGB Harry Cayton attended the meeting to welcome DMsG members as part of the NIGB structure.	
240409-03 a-	Minutes of previous meetings Minutes of the meeting on 6th February 2008. These minutes were agreed as a true and accurate record subject to 3 minor amendments. ACTION: Office to correct minutes and publish on website	
240409-04-a	Matters Arising The office confirmed that the apology letter regarding delays to applications as part of the change over in security advisor had been sent to all applicants affected.	
240409-05-a	NIGB Office Report Zoe Lawrence provided an update from the NIGB Office. This covered the following -	

	<p>Review of administration procedures – The final report will be presented to the ECC at the meeting in May and a summary will be circulated to DMsG before its meeting in June.</p> <p>ECC Terms of Reference – These have now been approved and published.</p> <p>GRO hold up with releasing data to non-NHS organisations – This has now been resolved.</p> <p>IRAS branding update – The re-branding exercise is complete and the problem with the HES forma enabling has been fixed, so we should start to receive HES applications through IRAS now.</p> <p>Appeals and Complaints process – A draft document was circulated for information. It was noted that there had been comments from both NIGB and ECC members so this was still a draft version.</p>	ALL
240409-06-a	<p>NHS Strategic Tracing Service (NSTS)</p> <p>There were no applications for this meeting. Philip Nicholson provided a written update regarding the closure of NSTS. This explained that contract was planned to terminate on 31 August 2009 as previously noted. This also advised that online tracing replacement and batch tracing replacement have both been rolled out. The population reporting replacement is still undergoing user testing.</p> <p>ACTION: NSTS Security Manager to keep DMsG updated.</p>	
240409-07 240409-07-a 240409-07-b	<p>Hospital Episode Statistics (HES) Business</p> <p>The Information Centre provided an update on previous applications considered by the DMsG meetings in 2008 and tabled an update of applications received in 2009. This report will be circulated with these minutes.</p> <p>ACTION: IC to share update report for circulation.</p> <p>Application from Dr Foster Intelligence Ltd – Mental Health Minimum Dataset</p> <p>The aim of the MHAT tool is to supply mental health trusts with an enhanced range of performance and benchmarking information. The tool has been designed for NHS organisations that provide or commission mental health services to:</p> <ul style="list-style-type: none"> ▪ analyse information about inpatient and community activity, ▪ plan and monitor service improvements ▪ drive more effective allocation and commissioning of resources. <p>MHAT was designed to replace the Department of Health's PICS system using an enhanced range of user designed reports and analyses.</p> <p>User privileges and access to data within the MHAT tool will be designated by local Trust Caldicott Guardians and will be regulated</p>	<p>MK & SM</p> <p>Conditionally Approved.</p> <p>LD to forward IC small numbers policy</p>

via logon access permissions.
Sensitive Data requested:

- Legal Status Classification
- Legal Status Restrictiveness
- Code of GP Practice (Registered GMP)
- Mental Health Care and Legal Status History

Members noted that Dr Foster Intelligence (DFI) does not have section 251 support and therefore is not permitted to receive patient identifiable data.

Whilst the mental health minimum dataset does not contain identifiers due to the nature of the information and the way the data would be analysed there was the potential that this could lead to identification of an individual because of small numbers.

The IC representatives confirmed that there was a small numbers policy in place to prevent disclosure of small numbers onwards from disclosure to the customer. LD agreed to forward this to the NIGB office after the meeting.

Members also queried the statement in the application “Our customers are almost exclusively NHS organisations” and requested clarification of the types of non-NHS organisations that may have access to the data.

The application was approved subject to clarification of the following:

- 1) Which non-NHS organisations data may be released to
- 2) Justification for retaining the data beyond 3 years
- 3) Confirmation that DFI are not permitted to link this dataset with any other information they hold.

It was agreed this could be dealt with by Chairman's action.

**ACTION: Applicant to be informed of the outcome
LD to forward small numbers policy to NIGB Office**

240409-07-c

CMPO – Bristol University

The sensitive data requested was:
HES data fields – Admitted Patients

- Census Output Area
- Consultant Code
- Code of patient's registered or referring general medical practitioner
- Person referring patient

The data was required to carry out a long term project (to 2009/10) study the effects of patient choice at the point of referral on competition and hospital outcomes. The data would be used in 4 separate studies:

- 1) Analysis of the change in geographical access (travel distance) to

	<p>hospital services over time in the NHS, following recent NHS reforms.</p> <p>2) Analysis of the factors influencing long travel times to providers for inpatient admission.</p> <p>3) Analysis of the impact of increased choice on competition.</p> <p>4) Examination of the impact of mergers.</p> <p>Members questioned if this was replicating research that has already been done in the area and requested further clarification of this. It was agreed this could be dealt with by Chairman's action.</p> <p>It was also noted, that due to geographical analyses, this data, if in small numbers could be potentially identifiable. Again the group was satisfied that the small number policy would prevent disclosure of small numbers and therefore were happy to approve the request.</p> <p style="text-align: center;">ACTION: Applicant to be informed of the outcome.</p>	
240409-07-d	<p>Application from the Information Centre -NCASP Central Cardiac Audit Database</p> <p>The data is requested for comparison with clinical registration data and identification of registration deficits in National Heart Failure Database. Data requested</p> <ul style="list-style-type: none"> ▪ DOB ▪ NHS Number ▪ Postcode ▪ Local patient identifier <p>This application was originally submitted in December 2008 but was not approved due to the issues with the HQIP NCASP Section 251 approval. HQIP were given s251 approval in April 09 and therefore this application had been resubmitted.</p> <p>The Advisory Group approved the application in line with the HQIP Section 251 application and ongoing approval would also be subject to the ongoing 4 monthly review of the HQIP approval.</p> <p style="text-align: center;">ACTION: Applicant to be informed of the outcome</p>	APPROVED
240409-07-e	<p>Update from the Healthcare Commission / Care Quality Commision</p> <p>Members considered a letter received from the Healthcare Commission advising of change of name to Care Quality Commission (CQC) from 1 April 2009. The HC confirm that their statutory responsibilities with regard to hospital acquired infection, performance assessment and investigations will continue into CQC.</p> <p>The Commission confirmed that Ian Horrigan would continue as Data Custodian for HES data and that the internal arrangements for the use, analysis, monitoring and secure storage of HES data will not change. The CQC's location will remain at Finsbury Tower and there will therefore be no changes to external and internal security measures and access and storage of the HES data.</p>	APPROVED

<p>240409-07-f</p> <p>a-</p>	<p>The Commission requested that DMSG retain the same rights of access and storage as currently granted following the change of name.</p> <p>DMSG approved this request.</p> <p>ACTION: Applicant to be informed of the outcome</p> <p>HES - Any Other Business</p> <p>Ongoing query regarding the Dr Foster Unit at Imperial College. Dr Foster already have s251 approval, however this was a request for additional sensitive data fields that were not included in the s251 application. The request had initially be rejected as it contained mental health data fields which PIAG had previously not approved. This had now been resubmitted with the mental health fields removed and the Group approved the request.</p> <p>ACTION: Applicant to be informed of the outcome.</p>	<p>Request approved</p>
<p>240409-08</p> <p>a-</p>	<p>HES Sensitive Items</p> <p>Members again discussed the sensitive data items. The IC had helpfully provided some clarification around the data fields, what type of data is involved and the volume of applications that request a particular data item.</p> <p>The group considered each item in turn as the whether it should be a 'sensitive' data item as they had previously, taking the additional information into consideration.</p> <p>The Group also considered the reasons why an item was sensitive and noted that this was largely linked to the probability of identification. Members agreed that data should not leave HES if it is identifiable.</p> <p>It was clear from discussions that it was difficult to give a definite answer as some fields whilst being sensitive when potentially identifiable, they became less sensitive if only requested in anonymous format.</p> <p>With regard to the mental health fields, members suggested it would be valuable for the IC to undertake some user involvement with mental health organisations, for example Mind, in order to get some views on what information they consider to be sensitive and public attitudes towards.</p> <p>In conclusion DMSG suggested the following items should be made sensitive –</p> <ul style="list-style-type: none"> Ethnic Category Method of discharge Still birth <p>DMSG also noted a number of other fields which they labelled as 'potentially' sensitive, which would require further consideration.</p> <p>ACTION: MK to prepare update paper for July ECC meeting. IC to consult with mental health user groups.</p>	<p>MK/ Information Centre</p>

<p>240409-09</p> <p>a-</p> <p>MR1147</p> <p>MR1152</p> <p>MR1145</p>	<p>NHS Central Register, MRIS Applications:</p> <p>CR and Secretariat staff shared an update paper on the current status of all MRIS applications that were made in 2008 and those made so far in 2009. It was noted that some applications were being held up by the General Registers Office.</p> <p>This paper would form part of DMsG's report to ECC.</p> <p>ACTION: Office to share with ECC and circulate with minutes.</p> <p>Study Name: E-ECHOES: Ethnic - Echocardiographic Heart of England Screening Study</p> <p>Resubmitted application from the last meeting. Members had requested the following amendments:</p> <ol style="list-style-type: none"> 1) The PIL and CF needed to be reworded to reflect accurately the involvement of the IC. 2) The plan to keep the data for 50 years must be revised to a maximum of 10 years initially, with re-applications every five years to coincide with the re-screening of the risk factors and heart failure of participants. 3) The invitation letter to participants to come from the General Practitioner (GP) involved in the care of the SA or AC patients. Consent must be gained before researchers be allowed any identifiable data about participants. <p>Members were satisfied with the clarification provided and agreed to approve the application.</p> <p>ACTION: Applicant to be informed of the outcome.</p> <p>Study Name: Exploring the determinants of outcome following major surgery</p> <p>This application was referred at the previous meeting. Members were of the opinion that this was a research application and not audit as the applicant was suggesting. The applicant had previously advised that their Ethics Committee also considered the study to be an audit and therefore did not require REC approval. DMsG therefore requested to see confirmation of this. In addition members also requested that the consent form and patient information leaflet (PIL) from January 2001 was updated to give general over arching agreement from patients suffering with Post Operative Morbidity Survey (POMS).</p> <p>Members were satisfied with the clarification provided and agreed to approve the application.</p> <p>ACTION: Applicant to be informed of the outcome.</p> <p>Study Name: Obtaining standardised follow up and cause of death information for the BRACE memory clinic database</p> <p>Application for list cleaning, flagging and current status for a study,</p>	<p>MK APPROVED</p> <p>APPROVED</p> <p>.</p>
---	---	---

	<p>Patients had already been recruited in 3 separate cohorts. All participants had consented to be part of the study however the initial cohort was recruited before 1994 and the consent forms used did not make clear about this use of their data.</p> <p>There have since been two more recruitment phases. The second had a more detailed consent form and the most recent had a very clear consent form and information leaflet.</p> <p>The Group was happy to provide Section 251 support for the most historical cohort.</p> <p>The application was also requesting cancer notifications and members queried this as it did not appear in keeping with the initial research question.</p> <p>The application was approved subject to clarification of the following:</p> <ul style="list-style-type: none"> • Clarification of the requirement for cancer data • Confirmation that the most recent group was fully consented with appropriate information. <p>ACTION: Applicant to be informed of the outcome.</p>	
MR1149	<p>Study Name: Risk factors for suicide in prisoners: mortality following near-lethal self-harm in custody</p> <p>This study requested flagging of 240 patients in England and Wales. Notifications are required of fact and cause of death only.</p> <p>This is a follow up study of patients who had carried out near fatal suicide attempts. Patients would be flagged for 3 years to allow monitoring of all mortality. This included a cohort of 120 control patients.</p> <p>The Group were willing to approve the application and felt that, given the nature of the research, consent would not be appropriate in this study.</p> <p>ACTION: IC Southport to inform applicant of outcome. Secretariat to request security review and confirm when complete.</p>	APPROVED
MR1158	<p>Study Name: Improving the care pathway for heart failure in residential care (HFinCH)</p> <p>Application for flagging of 500 patients for fact and cause of death. This will be linked to qualitative data collected from professional carers of the patients.</p> <p>It was noted that the researcher intended to retain the data for 15 years. Members questioned this however were happy to approved the application providing the mortality data and qualitative data was held in a linked anonymised format.</p> <p>The application was approved.</p>	

<p>MR1160</p>	<p>ACTION: Applicant to be informed of the outcome of application.</p> <p>Study Name: Parkinsonism: Incidence and Cognitive Heterogeneity in Cambridge. The PICNICS study.</p> <p>Application for flagging of fact and cause of death, registered Health Authority and exits from the NHS.</p> <p>This would only be done after consent had been obtained from participants.</p> <p>It was noted that the researcher intended to retain the study data for 30 years, and members suggested that this was excessive and that data should be retained for a maximum of 15 years.</p> <p>The Group approved the application.</p> <p>ACTION: Applicant to be informed of the outcome of application.</p>	
<p>240409-10</p> <p>a-</p>	<p>Any Other Business</p> <p>Members noted that a large number of MRIS applications were coming for DMSG approval because the consent forms and information sheets were not considered appropriate. It was suggested that the group should produce some recommended wording for consent forms and circulate this to organisations such as NRES.</p>	
<p>240409-11</p>	<p>Dates and venue of future meetings</p> <ul style="list-style-type: none"> • All 2009 meetings will take place at New King's Beam House on: • Wednesday 17th June 2009 - room 11.1.6 • Wednesday 2nd September 2009 - room 11.1.6 • Wednesday 4th November 2009 - room 5.2.1 • January 2010 – as yet unconfirmed 	