NIGB

Database Monitoring sub-Group

Minutes of meeting held on Friday 6th February 2009

New King's Beam House, London

11.00am – 1pm

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

In attendance:
Susan Milner (IC, Leeds)
Dawn Foster (IC, Leeds)
Jackie Gallagher (IC, Southport)
Diane Pryce (IC, Southport)
Philip Nicholson (NSTS Security Manager)
Melanie Kingston (ECC Approvals Officer, NIGB)
Vicky Cox (Deputy Policy Manager, NIGB)
Zoë Lawrence (NIGB, Business Manager)

Agenda Number	Item	Actions
060209-01	**Apologies** Mr Manny Devaux (lay member) Harry Cayton (NIGB Chair) Mike Farrell (Security Adviser to NIGB - CFH)	
060209-02	**Harry Cayton (Chair of NIGB) – Welcoming members to NIGB** Due to heavy snow through out the week (2nd – 6th) which had caused widespread disruption across the UK, Harry Cayton was unable to attend the meeting and offer his welcome to members. This has been rearranged for the 24th April meeting.	
060209-03 **a-** **b-**	**Minutes of previous meetings** **Minutes of the meeting on 12th September 2008.** These minutes were agreed as a true and accurate record. **Minutes of the last meeting on 28th November 2008.** These minutes were agreed as an accurate record, with the addition under AOB of the delay to Hospital Episode Statistics (HES) applications. The Information Centre (IC) raised the issue of the delay that had been incurred to outstanding applications awaiting approval of security policies; this followed the change of security advisors. The	

	delay had caused workload issues for the IC team who dealt frequently with frustrated customers. The Chairman asked if the committee could help in anyway to alleviate the situation and it was agreed that the secretariat would draft a letter behalf of DMsG. The Chair of DMsG felt that he should seek agreement for the letter to be sent from the Chair of PIAG. The Chair asked the secretariat to take this forward. **ACTION: Publish minutes on website** **Draft letter of apology on behalf of the DMsG.**	**VC**
060209-04-a	**Matters Arising** Person Based Resource Allocation (PBRA) application (update for 07/08 data) which was brought to the meeting on 13th June 2008 and referred to and subsequently approved by PIAG has been approved by PIAG through a Chair's action.	
060209-05-a	**Secretariat Report** DMsG Website section (http://www.nigb.nhs.uk/ecc/dmsg) The secretariat asked members to look at the website and to comment on how it could be improved. **ACTION: Members to review website and contact Secretariat**	**ALL**
060209-06-a	**NHS Strategic Tracing Service (NSTS)** NSTS was currently scheduled to close in the latter half of 2009[1]. The update paper outlined to the group a number of options for the retention of the NSTS data, post this service's closure. DMsG supported the papers suggest that: ▪ After the end of August 2009, a minimal period of one month would be allowed whilst various closure activities were completed. That the NSTS remained available to the central team, during that month, but not to anyone in the wider user community. ▪ After that first month for contingency and the quick handling of any data queries post-closure and whilst the data is still relatively 'fresh', that a period of six months minimal on-line access capability for NHS Connecting for Health (CFH) be maintained. This access would be available via Atos Origin, if cost allows. ▪ After six months, it would be unlikely that online access would be needed. Therefore the data would be retained, off-line, either as it currently is held, in the NSTS database, or as a number of 'flat files'. ▪ Access after six months would be either via an Atos Origin service (if the database were retained) or dealt with in-house if flat files were retained, possibly stored at the NHS CFH computer suite in Exeter. The DMsG expressed a preference for it to be retained by the NHS rather than a third party. Any future applications for the	**PN**

[1] End August 2009 is the current plan, but depends on successful delivery and implementation of final replacement service for batch tracing and population reporting, plus data feeds to PDS.

	NSTS data after its closure should continue to come to the DMsG. ▪ After eight years, the data would be securely destroyed in line with NHS CFH IG guidelines or be placed with the National Records Office. **ACTION: NSTS Security Manager to keep DMsG updated.**	
060209-07	**Hospital Episode Statistics (HES) Business**	
060209-07-a	The Information Centre provided an update on previous applications considered by the DMsG meetings in 2008. This report will be circulated with these minutes. **ACTION: IC to share update report for circulation.**	**VC & SM**
060209-07-b	IC Application: Consultant Team Summary Report (CTSR) – Application to expand the scope of the Consultant Activity Log Project approved in September 2008 (AG/72/4/d) This application from the Health & Social Care Information Centre (NHS IC) requested agreement to expand the scope of the existing Consultant Team Summary Report Project (CTSR) - (formerly known as the Consultant Activity Log). Further to the submission to the DMsG September 2008 meeting (AG/72/4/d) and approval granted by DMsG to deliver consultant team level activity to consultants, this submission seeks to extend both access to the information and extend the level of information made available. DMsG felt that access for non-medical staff i.e. managers was unclear, and would need this to be better defined. DMsG would like it confirmed that each Trusts' Caldicott Guardian would be involved and take responsibility for 'gate keeping'. DMsG recommended an access audit be carried out. The audit would be designed to assess, who was reviewing which records and how often, and also to monitor trends of access. Members also questioned whether certain sensitive healthcare resource group (HRG) codes could be flagged. DMsG agreed to consider in more detail what the audit should cover for the next meeting, to be able to advise the applicant. **ACTION: members to consider details of recommended audit.** **ACTION: Access audit to be an agenda item at April DMsG meeting**	**APRROVED with the recommendation that an access audit be conducted.** **ALL** **VC**

060209-07-c	Kings Fund Ros Levenson declared a potential conflict of interest in this as she is currently working with the King's Fund on other unrelated pieces of work. Sensitive Data requested: ▪ New NHS No: the NHS number was required for project 5, in order to link patient details to their cause of death in the NSTS database (to which access was being sought separately from the Information Centre). This number was a pseudonymised version of the NHS Number, which had previously been accessed; it was encrypted and linked to the HESID. ▪ Census Output Area ▪ Consultant Code ▪ Code of patient's registered or referring general medical practitioner ▪ Person referring patient ▪ Date of death Data Years: 1989 – 2008 In addition monthly updates of the 2007-08 dataset DP Registration: Z806337X Renewal date: 20 July 2009 Retention of data: 3 years The King's Fund was using HES data to assess the impact of the Quality Outcomes Framework (QOF) on GP practice. The King's Fund was also commencing a project to develop a tool to aid PCTs in forward planning of resource use (The Health Care Atlas for England). The King's Fund's had completed a DH/NHS funded project to develop an algorithm using HES data to enable PCTs to predict patients at high risk of admission. The DH required the King's Fund to provide technical support to users and to update the algorithm into the future. The King's Fund needed as many years of HES data as possible, including recent years, to support and upgrade the algorithm. Each update required data from six continuous years. DMsG expressed concern that this application covered 11 separate projects. It felt that in future, 1 application per project would be better, but was content to approve a single application in this instance.	**APPROVED**
060209-07-d	York University – re-submission of application to November meeting (AG/74/4/a) **Title**: **Exploring and explaining variation in activity rates of hospital consultants: generating and testing**	**APPROVED with recommendations**

	hypotheses about the determinants of consultant productivity in the English NHS. This application was submitted to the November meeting of DMsG. The customer had requested the Consultant Code field from HES data which would be linked with data from the Medical Workforce Census. DMsG raised concerns relating to this linkage and requested clarification on the requirement for country of origin and ethnic group. Justification had been requested for use of these fields linked with Consultant Code particularly whether the data would be used to compare the work and performance of practitioners from different ethnic groups. DMsG considered the response from the applicant that "*while they do not plan specifically to look for differences in the activity rates of practitioners from different ethnic groups, they cannot guarantee that a difference would not emerge from the analysis*" to be insufficient. DMsG suggested that Consultants place of qualification (i.e. UK or International) would be more suitable, than country of origin or ethic group to be linked with consultant code. The group had requested assurance that there would be no possibility of identification through small number disclosure. The response from the customer was that "*all data would be presented in aggregate form and entirely anonymised. As with ensuring patient confidentiality, any published reports would not include cell sizes less than five people and in all probability publications would include at a much more aggregate level*". DMsG members expressed concern at the length of time the data would be held and felt that this should be a maximum of three years not for four as set out in the application. As the HES data was being linked with Medical Workforce Census, which was outside the remit of the DMsG, the DMsG felt that it had taken this application as far as it justifiably could. The application was approved with the above recommendations.	
060209-07-e	Aberdeen University Prolong Study : re-submission of application previously considered (AG/74/4/e) This application was submitted for approval in February 2008 and was resubmitted in April and November 2008 in response to requests for clarification on consent from DMsG. At the November 2008 meeting, it was agreed that the application for 1993 to 2007 data could be released, subject to approval of the security policies. **Note: Confirmation of approval of the security policies has not yet been received; therefore the data has not been released.**	**APPROVED**

	The DMsG advised that they could not approve release of the 2007 -08 data until they had reviewed: ▪ A revised patient consent form which reflects the comments raised previously by the DMsG. ▪ Revised questionnaire which would specifically seek consent instead of assumed consent through the completion of the questionnaire. The DMsG had advised that 'opt in' was the preferred method for patients to agree to take part in the study, rather than assumed consent. DMsG had given approval for the use of the data already collected by Aberdeen, however ALL future questionnaires must seek explicit consent. The information sheet MUST be corrected and updated to reflect the level of access and involvement from researchers and IC staff. **ACTION: that advice about the need for consent and correct information sheets could be made available on both the NIGB and HES websites.**	**SM & VC**
060209-07-f	**HES - Any Other Business**	
a-	Briefing note was provided regarding **Dr Foster Intelligence Ltd's** application for data from the Mental Health Minimum Dataset [MHMDS] to enable tool analysis and reporting. From 2008/09, this data would be updated every quarter via the NHS Information Centre. This application was received after the deadlines for the DMsG meeting; however a request from Dr Foster Intelligence Ltd sought approval for this application via Chairman's action's outside of the DMsG meeting. DMsG turned down this request and would like to see the full application at the April meeting. **ACTION: IC to inform Dr Foster Intelligence Ltd of outcome to request.**	**a- Full Application to April meeting** **SM**
b-	Appendix A – Regarding a previous request from Dr Foster Unit requesting additional HES data fields. This had come back with some of the additional fields requested removed, however still requesting NHS number. DMsG queried whether this data would be linked to existing data held by Dr Foster Unit. If so, the S251 currently in place for Dr Foster Unit would be insufficient and a further application to the ECC for S251 support would be needed.	
c-	**ACTION: IC to inform Dr Foster Unit of DMsG query.** IC requested a letter from ECC Secretariat explaining the reason for the delay to applications cause by the security advisors hand-over. This was discussed at previous meetings, but not actioned. **ACTION: Secretariat to write letter within the next 5**	**SM** **VC**

	working days.	
060209-08 a-	**HES Sensitive Items** This item was deferred to the April meeting for a full discussion. The final paper would be taken to the NIGB for approval. **ACTION: IC to write full update/ process paper as well as sharing the changes spreadsheet.**	**SM**
060209-09 **a-**	**NHS Central Register, MRIS Applications:** 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. This paper would form part of DMsG's report to ECC. **ACTION: Sect to share with ECC and circulate with minutes.**	**VC**
MR1136	Study Name: **A research monitoring system of hospital attendances due to self harm: Mortality following self-harm.** This study was for 9,500 patient records in England and Wales to be flagged. Notifications requested for date and cause(s) of death, plus exits from NHS. Self-harm accounts for an estimated 220,000 hospital attendances every year in the UK; a quarter of all suicides are preceded by an episode of non-fatal self-harm in the previous year. This applicant had Section60 approval (given in 2004) to under taken a study into the numbers of hospital attendances due to self harm and the approval was subject to annual reviews. DMsG approved this follow up study and the NIGB Secretariat would pass it on for an extension of S251 support to be approved by ECC Chair's action. **ACTION: Secretariat to request Chair's action for S251 extension and inform IC Southport and applicant of the outcome.**	**APPROVED** **VC**
MR1142	Study Name: **Derbyshire Mental Health Trust – Self-harm monitoring project – Mortality following Deliberate Self-harm** This study required the flagging and current status of 6830 patient records. Notifications requested for date and cause(s) of death plus exits from the NHS. Deliberate self-harm (DSH) was a major healthcare problem in the UK, with at least 200,000 presentations to Emergency Departments per year. This application had S251 approval (given in 2004) to	**APPROVED**

	undertake a self-harm monitoring project and the approval (given again in January 2008) would be subject to annual review. However, the original S251 does not cover the flagging requested in this application, S251 extension was needed. DMsG approved the flagging for this follow up study and the NIGB Secretariat would ask that a S251 extension be approved by ECC Chair's action. **ACTION: Secretariat to request Chair's action for S251 extension and inform IC Southport and applicant of the outcome.**	**VC**
MR1147	Study Name: **E-ECHOES: Ethnic - Echocardiographic Heart of England Screening Study** This study required the flagging and current status of 5,000 patient records to provide NHS Number, Health Area, Fact and Cause of Death, Cancers and other exits from NHS. Heart failure (HF) was a common, chronic disabling condition with high mortality and was also a major cause of healthcare expenditure. Coronary artery disease, the commonest cause of HF, was expected to be more common amongst South Asian (SA) and African−Caribbean (AC) ethnic groups in the UK. DMsG wanted the following changes made before this can be approved: 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 should 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. **ACTION: IC Southport and Sect to work jointing to inform applicant of the outcome of application.**	**NOT APPROVED.** **CHANGES to application requested by DMsG.** **DP & VC**
MR1151	Study Name: **PREPARED-UK: Prospective Registry and Evaluation of Peripheral Arterial Risks, Events and Distribution in the UK** This study requires flagging of 381 patient records in England, Wales and 36 in Scotland. Notifications required for fact and cause(s) of death and embarkations only. Peripheral Arterial Disease (PAD) is a common and important manifestation of atherosclerosis. PAD affects about 5% of western populations aged between 55 and 74 years and usually presents with intermittent claudication (IC). PREPARED was an observational registry of patients with PAD referred to an outpatient clinic at a specialist centre	**APPROVED**

	because of Intermittent Claudication (IC). 479 patients were recruited, and consent obtained for obtaining baseline medical information and to be followed up for 2 years. Consent was also obtained for long-term flagging with the Office of National Statistics (ONS). A baseline report had previously been published exploring associations between baseline co-variates. **ACTION: IC Southport to inform applicant of outcome. Secretariat to request security review and confirm when complete.**	**DP & VC**
MR1152	Study Name: **Exploring the determinants of outcome following major surgery** This study required flagging of 1,621 patient records in England, Wales and 139 in Scotland to provide fact/cause(s) of death and exits from the NHS. The aim was to look at long term outcomes of post-operative complications and those independently associated with a reduction in long term mortality, and consider whether there was a reduction in long term survival for patients who had operative complications as measured by Post Operative Morbidity Survey (POMS). Both the applicant and the REC considered this to be an audit, so did not require ethical approval. DMsG considered this to be research and not an audit and therefore wanted to see the following additional documents before this could be approved: 1) The consent form and patient information leaflet (PIL) from January 2001 that gave general over arching agreement from patients suffering with Post Operative Morbidity Survey (POMS). 2) The full REC application and response letters from that REC. **ACTION: IC Southport and Secretariat to work jointly to inform applicant of the outcome of application.**	**NOT APPROVED.** **CHANGES to application requested by DMsG.** **DP & VC**
MR1153	Study Name: **Pallister-Killian Study** This study required the current status of 70 patient records in England, Wales and 10 in Scotland. Notifications required for fact and cause(s) of death, Health Authority and Exits from the NHS. Pallister−Killian syndrome was caused by having four copies (instead of the usual two copies) of a section of chromosome 12, known as 12p, in some cells of the body. Increasing maternal age had been suggested as a risk factor. This condition was diagnosed using a new technique (assay CGH), which could be performed on blood samples and by FISH analysis of mouth brush samples. The study wanted to investigate whether these could be used for routine diagnostic testing. Each British cytogenetic department in United Kingdom would be asked to identify the live born patients who have been diagnosed with Pallister-Killian syndrome in that	**NOT APPROVED.** **CHANGES to application requested by DMsG.**

	laboratory and to pass the full name, date of birth and NHS number (England & Wales) or CHI number (Scotland) to the researchers. This means that researchers would have access to identifiable data and would need S251. DMsG requested that this application remains in its current state and be considered by ECC. **ACTION: IC Southport and Secretariat to work jointly to inform applicant of the outcome of application. Secretariat to advise applicant on how to improve application.**	**DP, VC & MK**
MR1157	Study Name: **Knee Pain Progression and Risk Factors** This retrospective cohort study requested tracing of 1,023 deceased patient records in England and Wales, to provide fact and cause of death only. Knee pain affected 1 in 4 people over 55 years, and was a leading cause of disability in the elderly. Whilst the prevalence of knee pain had been examined, the natural history of knee pain and associated risk factors for outcome remain unknown. This was publicly available data. **ACTION: IC Southport to inform applicant of outcome. Secretariat to request security review and confirm when complete.**	**APPROVED** **DP & VC**
060209-10 **a-** **b-** **c-**	**Any Other Business** At present ECC Administration processes were being reviewed. The outcome of this review might result in changes to the way administration for ECC and DMsG were delivered. Once the Terms of Reference (ToR) for ECC had been agreed, there would be a need to revise the Terms of Reference of DMsG to reflect the delegated functions. Membership of DMsG would also be reviewed in line with the ToR. Members requested that the number of late submissions of papers for the meeting be kept to a minimum. Where possible all papers should be sent out together 10days before each meeting. **ACTION: Secretariat to draw up and share a timetable for key submissions to DMsG members.**	**VC**
060209-11	**Dates and venue of future meetings** • **All 2009 meetings will take place at New King's Beam House on:** • Friday 24th April 2009 – room 11.1.6 • 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	