

Database Monitoring sub-Group
Minutes of meeting held 4th November 2009

Present

Members: Dr Patrick Coyle (Chair), Dr Ian Goodman, Ms Ros Levenson, Mr Terence Wiseman

In attendance: Ms Kathryn Anderson (IC, Southport), Ms Natasha Dunkley (Approvals Manager), Ms Louise Dunn (IC, Leeds), Ms Claire Edgeworth (Approvals Officer), Mr Paul Eveson (Department of Health), Ms Melanie Kingston (Deputy Approvals Manager), Ms Zoë Lawrence (NIGB Business Manager), Ms Susan Milner (NHS IC), Ms Diane Pryce (IC, Southport), Kuldeep Sohal (IC, Leeds).

041109-01 Welcome and apologies for absence

Apologies were received from Mr Manny Devaux.

041109-02 Minutes of the previous meeting

Minutes of the previous meeting were approved subject to minor amendments.

041109-03 Matters Arising

Staff Changes at the NHS Information Centre (NHS IC)

The Group was informed of recent staff changes at the NHS IC and welcomed Kuldeep Sohal who would be working with HES team and Kathryn Anderson who would be working with the MRIS team.

Delays with ONS/HES linked data

The NHS IC informed Members that a delay caused by the ONS approval process for English Cancer Registry HES data had now been resolved and that the extract could be provided to the applicant. The NHS IC clarified that some HES extracts fell under the ONS approved researcher route. Currently there were six applicants waiting for ONS approval before their extracts can be provided. The NIGB Business Manager informed the Group that following a meeting between the ONS and the NIGB office a mutual understanding had been reached regarding each organisations roles when releasing data.

041109-04 NIGB Office Report

Actions closed since the last meeting

All outstanding actions had been closed, apart from

1. ZL to contact NRES regarding wording of consent forms and leaflets. **This meeting has been postponed until 23 November.**
2. IC to provide update regarding sensitivity of mental health data in HES. **(See below)**

NIGB Public Member Awareness meeting

The NIGB Business Manager and Deputy Approvals Manager attended this meeting on 13 October. Representatives from 4 organisations attended; Mind, Royal National Institute of Blind People, Social Care Institute of Excellence, and the Association of Chief Police Officers. The meeting was an opportunity to discuss and share examples of some of the issues around data sharing and confidentiality from a patient/service user perspective.

Terms of reference

These were approved by ECC on 21st September and were published on the NIGB website.

MRIS & HES Registers of approved applications

Members were informed that Registers for both HES and MRIS applications were now published on the NIGB website. This covers applications that had been fully approved by DMsG since 1st April 2008.

NIGB public meeting

The NIGB Public Meeting would be held on 12 November at Westminster Central Hall, Storey's Gate, from 2 pm. Members were invited to attend. The NIGB Annual Report (which includes a section on the work of the ECC and DMsG) would be launched at this meeting.

Social Care Record Guarantee

The Social Care Record Guarantee was launched to social care and health professionals during week commencing 19 October at the Social Care Conference in Harrogate and through other media. It sets out for people how the information they provide to social care is used. It is based on law, best practice and professional guidelines. It complements the NHS Care Record Guarantee so supports information sharing between health and social care. The Guarantee would be launched to the public and service users at the NIGB public meeting on 12 November.

Away Day

A list of action points from the away day had been prepared. Progress towards delivering these would be reported at the February meeting.

New Chair of ECC

The chair informed Members that Dr Andrew Harris had been appointed as chair of the ECC, with effect from 1st January 2010. Dr Harris would also be a NIGB member.

041109-05 Update of ECC discussion about validity of consent

This issue was discussed at the last ECC meeting on 21 September. ECC members agreed in principle that section 251 could be used in certain circumstances where the consent could not be considered valid and re-consenting would be inappropriate.

This should however, be considered on a case by case basis as it was obvious there were a number of issues that could determine if the original consent was valid, and these issues would be different for each application.

ECC members were happy for DMsG to continue acting as the initial filter for these types of queries and to escalate up to the ECC where appropriate.

041109-06 Hospital Episodes Statistics (HES) Applications

041109-06-a Unit of Healthcare Epidemiology, University of Oxford

This was an application for an update of a previous HES extract which had been approved by DMsG in 2008. The applicant required an extension to the data years requested and permission to extend the retention of data. Members were also informed that a request for legal status had been withdrawn from the applicant and that the method of encryption used had proved extremely effective.

Members discussed the possibility that if the method of encryption was working and prevented the need for identifiable information to be sent to the researcher then there was a chance that this method could be used in other studies. The encryption anonymised information before disclosure but allowed linkages to be made by the researcher.

Members were reassured that the applicant would sign an NHS IC data sharing agreement providing assurance that the data would only be used for the purposes stated in the application.

Members agreed that the application could be approved until 2013.

Action: NIGB Office to inform applicant of outcome.

Action: NIGB Office to consider encryption methods used and whether this could be used in other situations.

041109-06-b Cancer Epidemiology Unit, University of Oxford

This applicant required an extension to the original retention period approved by DMsG. Members were informed that recruitment for the study was now complete. Members agreed to approve this application.

Action: NIGB Office to inform applicant of outcome.

041109-06-c National Centre for Social Research

This application from the National Centre for Social Research required a HES extract containing date of birth, NHS number and postcode. The study was fully consented.

Members enquired whether there was any disclosure of identifiable information for the purposes of identifying a cohort and therefore before consent. It was agreed that the NIGB office would liaise with the applicant to confirm and that, if satisfied with the response, the application could be approved by chair's action.

Action: NIGB office to inform applicant of outcome.

041109-07 NHS Central Register, MRIS applications

MR1171 Getting out of the House study

This application from the University of Nottingham required flagging for deaths for a consented cohort. The study's primary aim was to measure the effectiveness and cost effectiveness of treating people who have had a stroke with a new outdoor mobility rehabilitation intervention.

Members noted that the applicants had made particular effort to inform participants fully about the databases from which they would receive information. Members believed that on the basis of promoting best practice that the information that a person's data will continue to be used in the

study should a person withdraw should be included in both the GP information and the consent form.

Action: NIGB office to inform applicant of outcome.

041109-08 Any Other Business

Department of Health (DH) – Sexual Health and Reproductive Health Activity Dataset (SRHAD)

The DH had submitted a paper to the September ECC meeting. ECC members had been concerned that the level of information within the dataset could lead to the identification of an individual. The response letter from the DH provided more information on the issues raised by the ECC and DMSG members were asked to consider the response to confirm the dataset did not include identifiable information

DMSG members felt that the letter provided convincing justification that there was no identifiable data held and that it would not be possible to link the local identifiers with HES data.

The Subgroup noted that there was an intention to develop an integrated SRHAD / Genitourinary Medicine Clinic Activity Data Set (GUMCAD) data stream in the future and requested that they were kept informed of developments to ensure that any linked data remains anonymous.

HES Business

Members were informed that two applications had been made for sensitive data extracts just after the deadline for the DMSG meeting. It was agreed that these could be forwarded to the secretariat and they could provide an assessment as to whether these could be considered outside of scheduled meetings given that the next DMSG meeting was not until February 2010.

The NHS IC enquired whether the secretariat had received any response from Whipps Cross Hospital regarding an application for a sensitive HES extract. It was confirmed that the applicant has not yet responded to the secretariat's questions.

MRIS Applications

The NHS IC enquired whether there was any flexibility to consider applications outside of meetings. Members felt that if the applications were unproblematic and did not provide too many issues then they could be submitted to the chair for an opinion.

Dates of next meetings

- Tuesday 23rd Feb 2010
- Wednesday 5th May 2010
- Tuesday 20th July 2010
- Tuesday 14th September 2010
- Tuesday 23 November 2010