

41st Meeting of the Privacy Advisory Committee

Wednesday, 24th July 2013 at 10.00am

Venue: Boardroom, NIMDTA, Beechill House

Present: Professor Roy McClelland (Chair), Chris Matthews, Dr Clodagh Loughrey.

1. Apologies

Apologies were received from Dr Jimmy Courtney, Grace Irwin, John Growcott, Roisin Wylie and Brice Dickson.

2. Minutes of the Previous Meeting ~ 16th May 2013

The minutes of the previous meeting held on 16th May 2013 were agreed.

PAC Membership - Dr Clodagh Loughrey

Prof R McClelland (RMCC) welcomed Dr Clodagh Loughrey (CL) to the meeting. Dr Loughrey, Consultant in Clinical Biochemistry, has a specialist interest in the area of confidentiality and secondary uses within health and social care and is a member of REC2.

3. Matters Arising:

i. On-line Training Module

RMCC advised that Colin Harper was progressing the development of the on-line training module in confidentiality and data protection for H&SC staff, based on the Code of Practice for Protecting the Confidentiality of Service User information (COP). The module will provide training for health and social care professional staff, in line with the roll-out of the Electronic Care Record. It is hoped that the module will be finalised prior to the joint meeting with Personal Data Guardians in September 13. PAC will be asked to review and sign-off on the on-line training module prior to roll-out. RMCC advised that he intended to meet with C Harper again this week to discuss further.

4. Chairman's Update

i. Meeting with R&D Office ~ 22nd July 2013

RMCC provided an update on discussions which had been held at a meeting which he had attended with Dr Janice Baillie and Dr Clive Wolsley from the HSC Research & Development Office, Public Health Agency, on 23rd July 2013. RMCC advised that Dr J Baillie is a formal representative of R&D interests at HRA. The benefits of close links between PAC and its counterparts were noted, including the new Confidentiality Advisory Group of the HRA. Given Dr CL's involvement in REC2 and R&D interests, RMCC agreed to facilitate contact between CL and Dr Baillie.

RMCC/CL

ii. The Role of Research Nurses in Primary Care

RMCC advised that he had recently met with Dr Margaret O'Brien, Chair of the Data Quality in Practice Project Board (DQIP), to discuss the issue of research nurses working within primary care and access to patient records for the identification of research participants.

He had also outlined the PAC's support for the development of a secure data extraction system to enable the undertaking of research projects in Northern Ireland.

It is hoped that the development of a data extraction service will facilitate research by providing

more secure access to pseudonymised data. Once established it should provide an exit strategy for the current research nurse role in patient identification, for consent to participate in research.

It was agreed that this item be included on the agenda for discussion at the joint meeting of PAC with Personal Data Guardians in September 2013.

5. NIECR Update

The NIECR is now live. RMcC to ask Dr Courtney to provide an update on progress at the joint PAC/PDG meeting in September.

6. Joint Meeting with PDGs – 19th September 2013

The joint meeting of PAC with PDGs has been confirmed for Thursday, 19th September at 10:00am in Castle Buildings, Stormont. A draft agenda for the meeting was circulated. RMcC requested any further agenda items/issues for discussion to be forwarded to him in advance of the meeting.

RMcC advised that at the previous joint meeting in September 2012, PDGs had suggested input from the Information Commissioners Office (ICO) at future joint meetings. At the time RMcC had advised that this issue would be considered, however on reflection it was not felt that this was within the remit of PAC. PAC would however support DHSSPS in hosting such an event. Chris Matthews (CM) agreed to discuss this possibility with Catherine Vint and Ken Macdonald, ICO to see whether it would be feasible for DHSSPSNI to host an event with PDGs.

C Matthews

7. Legislation for Secondary Uses of Service User Information

CM provided an update on progress in relation to legislation for secondary uses of service user information.

The Minister had approved the Business Case which had been submitted in support of legislation for the secondary use of service user information, to include social care. CM advised that staff have been appointed to assist with this work which is being taken forward in discussion with the Central Policy Team. CM will keep PAC informed of progress.

RMcC advised that he had received a copy of the Primary Legislation Timeline for the Secondary Use of Information as forwarded to him by CM. He agreed to circulate to PAC for information. CM noted that this timeline may be subject to change and the document was not for onward circulation.

RMcC

RMcC highlighted the inclusion of social care within the legislation and the implications this may have on setting aside the common law duty of consent for 'medical purposes' as outlined in PAC's previous paper submitted to the Department.

CM advised that the issue of consent/implied consent in relation to social care was being considered. Legislation in place in the rest of the UK had been reviewed and discussions are ongoing with the Information Commissioners Office.

8. Proposals for Safe Haven Provisions

CM advised that a Memorandum of Understanding (MOU) had been established for the purposes of informing the development of an Honest Broker Service for Health & Social Care (as circulated to PAC by RMcC). Discussion had taken place with various organisations during the production of the MOU, including the Northern Ireland Statistics & Research Agency (NISRA) and the Information Commissioners Office. Ethical opinion had also been sought. The final version of the MOU had been submitted to the Minister and had also been forwarded to the Chief Executives of the relevant HSC organisations, who would be required to sign and return the MOUs by August

2013.

Honest Broker provision will reduce the need for data access agreements to be in place, prior to the sharing of HSC data for secondary purposes. The service should enable the provision of anonymised, aggregated and where necessary, pseudonymised data from the Regional Data Warehouse (held within the Business Services Organisation, BSO), to the DHSSPSNI and relevant HSC organisations. The sharing of data in anonymised/pseudonymised formats will improve data security and patient confidentiality and maximise the benefits of data sharing within health and social care.

The Honest Broker service could also enable the safe provision of anonymised data to researchers for approved HSC related research. It was noted that appropriate application and approvals processes will need to be in place.

It is expected that the Honest Broker service will be trialled internally initially, prior to roll-out to the research community. An Honest Broker Governance Board will also need to be established prior to roll-out. The Honest Broker MOU and associated arrangements will be reviewed annually.

It was highlighted that the development of the Honest Broker Service, along with DQIP, may facilitate the linkage of primary and secondary care data sets, which will be of benefit for the research community.

RMcC advised that at a previous PAC meeting, some members had expressed concern with regards to the information governance arrangements associated with the provision of an Honest Broker Service. Due to the limited attendance at today's meeting, it was agreed that the issue should be discussed further at the November 2013 PAC meeting.

9. Any Other Business

Review of Controls Assurance Standards - CM

CM advised that the DHSSPSNI had recently reviewed a number of Controls Assurance Standards. The Records Management Controls Assurance Standards had been significantly updated, with the number of criteria to be met extended from 6 to 27. The standards had been revised in line with the IGAG Information Governance Toolkit.

CM advised that compliance with the Controls Assurance Standards will be taken forward and managed by the DHSSPSNI. An event, involving representatives from 17 HSC organisations will be held in September 2013, to review the steps which are required in order to meet the criteria within the revised Standards and to assist organisations in achieving this.

RMcC noted the recent Caldicott Information Governance Review paper (March 2013). PAC would support the development of a similar guidance for Northern Ireland and the development of a robust Information Governance Framework. RMcC proposed that this could be addressed by the DHSSPSNI, as part of the ongoing work in relation to the Controls Assurance Standards. CM advised that the recent Information Governance Review paper would be reviewed by the DHSSPSNI and taken forward as necessary.

10. Dates for Next Meetings 2013:

- Thursday, 19th September 2013 (proposed Joint Meeting with PDGs)
- Thursday 21st November 2013.