

**Minutes of the 33<sup>rd</sup> meeting of the Privacy Advisory Committee (PAC) on Tuesday 15 March 2011 at 10am in Beechill House, Belfast**

**Present**

Professor R J McClelland (Chair)  
Professor B Dickson  
Dr Jimmy Courtney  
Mr C Matthews  
Ms Roisin Wylie  
Dr Grace Irwin  
Ms Joanna McDowell (Secretary)

**1. Apologies and Welcome**

Apologies were recorded from Ms Jan Maconachie.

**2. Minutes of previous meetings**

Minutes of the last meeting which took place on 10 January 2011 were approved.

**3. Matters arising**

**i PDG Training Day - 18 February 2011**

RMcC reported that the training day for PDGs was well attended, there was good engagement from participants and he had received positive feedback. He said there were still some PDGs who had not been trained and he had made organisations aware of training opportunities available in GB.

**ii Update of the Code of Practice on Protecting the Confidentiality of Service User Information (PAC CoP)**

RMcC said he had written to Andrew McCormick, Permanent Secretary, DHSSPS about revisiting the PAC CoP and received a positive response. This is not expected to be a major exercise and PAC will carry out most of the work. The update will be consulted upon and there was some discussion as to whether PAC or the Department would lead on this. It was agreed that a lead by the Department would afford it more weight and CM suggested that the covering letter be worded in such a way that indicates that PAC has been tasked by the Department to carry out this piece of work. This was agreed. RMCC will draft a letter which will be sent to main local stakeholders as well as the BMA and ICO.

**ACTION POINTS**

**RMCC to draft a letter about the update of the CoP which will be sent to main local stakeholders as well as the BMA and ICO.**

**ALL to critically review the PAC CoP**

#### **4. Chairman's Update**

##### **i Request for information about PAC**

RMcC reported that he had received a request from Kuldeep Sohal, the Access and Information Sharing Manager for the NHS Information Centre, asking for information about any mechanism that would approve the use of patient identifiable data in Northern Ireland where consent is not in place. RMcC responded providing information about PAC and confirming that the Committee does not have any statutory powers.

##### **ii Data Access Agreements**

RMcC spoke about communication from Hospital Information Branch, DHSSPS (HIB) about establishing a data access agreement with NHSCT for sharing patient level data. RMcC advised HIB to consult with PAC and Information Management Branch (IMB) in the Department about this. CM confirmed he had discussed this issue with HIB. GI said that NHSCT was not saying that this sharing cannot happen but that it is currently not in line with policy and procedures.

RMcC wishes to pursue this matter and JC commented that information sharing of this type has mushroomed and should be examined to ensure that it is being done in line with policy and procedures. CM confirmed that consideration of secondary use legislation is a priority in the IMB workplan.

##### **iii MARAC agreement**

This agreement is about sharing information regarding vulnerable people (adults and children) in a multi-agency risk assessment committee setting and has been issued for consultation. GI expressed concern that, although the draft agreement had been shared with HSCTs, it was shared through professional groups rather than information governance people. RMcC and BD agreed to examine the draft document and respond to consultation.

#### **ACTION POINT**

**RMcC and BD to examine the draft MARAC agreement and respond to consultation.**

#### **5. Update from Chris Matthews, Head of Information Management, DHSSPS Draft Data Access Agreement (DAA) and progress on information sharing protocols**

The draft DAA has been reviewed and comments made by PAC considered/ incorporated. This was discussed at the last meeting of the Information Governance Advisory Group when more useful input was provided including identifying the need for a step by step "sign off" process to ensure that information governance people were fully involved.

It is hoped that the DAA and Protocol will be finally signed off on 31 March 2011 however the issue of the Protocol may be delayed until a comparison with the ICO CoP on Information Sharing can be carried out to ensure alignment.

## **ii Utilisation of Secondary Uses Guidance**

BD asked if the PAC CoP covered information sharing and said that, if not, this should be considered for the update. RMcC said that the Secondary Uses paper set out the PAC line on information sharing but perhaps it needed to be more explicit.

CM said that BSO may appear to be the obvious place for an “honest broker” function to rest but there are obviously resource implications. There is need to understand the concept and how it will operate – this is on the IMB programme of work. JC agreed that the “honest broker” is a good idea but agreed that we need to be clear how it will operate.

## **6. Information Governance issues**

### **a. Health and Care Number (HCN) and**

#### **(i) its management as a personal identifier**

The Committee agreed that the HCN is relevant to the work of the Committee as it is a personal identifier.

RMcC confirmed he had, as agreed at the last meeting, spoken to Carolyn Harper, PHA, Louise McMahan, BSO, Adele Graham, PHS, Stephen McDowell and Eugene Mooney, DHSSPS. He and IT reps will meet with Carolyn Harper and Louise McMahan at the end of April. There is a clear interest in secondary uses amongst this group of people.

RMcC also met with David Bryce and Brian McKeown BSO ICT to discuss PAC concerns about the use of the HCN number. They suggested that the HCN could be concealed ie the linkage could be carried out inside the data warehouse and only the result published for the purpose of secondary uses within the HSC including the Department – in other words, the information inside the data warehouse would be identifiable but outside it would be unidentifiable.

#### **ii. Health and Care Number (HCN) as a potential means for unauthorised access to service user information**

RMcC reported that his discussion with Brian McKeown and David Bryce widened to include discussion about secondary uses control arrangements including the need for audits. GI said this issue has now made its way on to the ICT agenda.

JC said that an audit function had been incorporated into the Emergency Care Summary Project systems.

BD suggested that the updated PAC CoP should be clear about this – the HCN is a potential identifier and not a pseudoanonymiser.

**b. Managing the boundaries of direct care –**

**(i) who should be able to access service user information**

RMcC said that although the PAC CoP does address this it needs to be more explicit and the definitions need to be clearer. RW pointed out that healthcare is provided by teams these days and asked if care contracted out to agencies would be covered. GI said that the administration teams supporting direct care teams also need to be considered and access should be on a “need to know” basis – so there is a need to consider eg how different levels are protected, role based access. JC said that sharing appropriate information is the important issue.

**(ii) keeping service users informed**

RMcC said that the patient information leaflet should also be revisited .

**c. development of policy, strategy and regional leadership on secondary uses**

RMCC updated the Committee on his attendance at a seminar in QUB where Professor Calhoun, Professor of Public Health at Dundee University spoke about data linkage. She presented the research communities’ side of the argument and drew attention to what could be achieved if good physical and electronic security existed in a “safe haven” environment. RMcC suggested that CM contact Dermot O’Reilly, Frank Kee and Bob Millen on the research side in public health at QUB. JC said that clinical input was also required.

RMcC then spoke about the dangers surrounding the “mushrooming” of data bases. He referred to the report from the Scottish Health Informatics Programme Information Governance Working Group which had been circulated to Committee members and said that Scotland does not have a statutory basis for secondary uses either so the Report may act as a starting point for discussions.

**7. Dates of meeting for remainder of 2011**

Please note change of dates for the remainder of 2011. The Committee will meet on the following dates:

Thursday 19<sup>th</sup> May 2011

Thursday 23<sup>rd</sup> June 2011

Thursday 8 September 2011

Thursday 17<sup>th</sup> November 2011

**8 Any other business**

There was no other business.

**Joanna McDowell**