# 34<sup>th</sup> Meeting of the Privacy Advisory Committee

## Tuesday, 28<sup>th</sup> June 2011 at 10:00am

## NIMDTA, Beechill Road, Belfast

**Present**: Professor Roy McClelland (Chair), Roisin Wylie, Terry McMurray, Brice Dickson, Chris Matthews John Growcott, Jan Maconachie

1. **Apologies**

   Apologies were received from Grace Irwin (GI) and Dr J Courtney.

   (GI attending the ICO Code of Practice launch).

2. **Minutes of the previous meeting**

   The minutes from the previous meeting held on 15 March 2011 were approved subject to the following amendment:

   Dr J Courtney to be added to the list of attendees.

   **PAC Membership**

   Prof McClelland (RMcC) provided an update on the membership of the PAC:

   Jan Maconachie (JM) would be standing down from the Group as from today and would be replaced by Mr John Growcott (JG). Terry McMurray (TMcM) was also welcomed to the group. Brief introductions took place for the benefit of those new to the Committee:

   Chris Matthews (CM) ~ Lead in Information Management, DHSSPSNI, dealing with Information Governance issues and liaising with health & social care.

   Roisin Wylie (RW) – representative from the Patient Client Council ~ previous background in health service.

   John Growcott (JG) ~ Co-Director, Social Work & Social Care Governance, Belfast HSC Trust with a background in child care.

   Terry McMurray (TMcM) ~ Post Graduate Dean and Chief Executive, NIMDTA with a background in Anaesthesia and ICU.

   Jan Maconachie (JM) ~ Assistant Director of Social Care Governance & Workforce Development, Northern HSC Trust.

   Brice Dickson (BD) ~ School of Law, Queens University, Belfast.

   Clare Murphy would replace Joanna McDowell in the provision of administrative support to the PAC.

   RMcC advised that Grace Irwin was Information Governance Lead for the Northern HSC Trust, and Dr J Courtney was the representative from primary care and also Chair of BMA IT Committee.

3. **Matters arising:**

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

   RMcC advised that a letter had been drafted on the above and would be issued to local stakeholders ~ for further discussion under Item 7.

   ***MARAC Agreement***

   As agreed at the last meeting, RMcC and BD had examined the draft MARAC agreement and responded to the consultation:

   ~ See below Item 4.c) Chairman's Business.

4. **Chairman's Update**

   a) **Meeting with BMA**

   RMcC advised that he had attended a recent meeting with the BMA to provide an update on the work of the PAC.  Discussion had centred on confidentiality and there had been keen interest in issues relating to the secondary use of information, including the increasing demand for information disclosure and the need to ensure adequate privacy controls in access to central databases.

   b) **Meeting with Louise McMahon on Secondary Uses**

   RMcC reported on a meeting which he had attended with Louise McMahon, Director of Performance Management, HSC Board, Brian McKeown (BSO), David Bryce and Carolyn Harper (Public Health Agency) regarding the secondary use of information for HSC purposes.  The electronic care record project had been discussed.  RMcC had highlighted key concerns, particularly in relation to the process of consent, as well as the benefits to be achieved in the use of pseudonymisation of data.  C Harper had agreed to contact the Chief Medical Officer regarding this issue and Louise McMahon had agreed to raise the matter with the DHSSPSNI.

   JM stressed the importance of the inclusion of community social services and child care in respect of secondary use of information and recommended further discussion with Sean Holland, Chief Social Services Officer.

   It was acknowledged that future ICT development and the secondary use of information within health & social care needs to be mindful of the Code of Practice.  It was felt that more could be done if pseudonymisation was implemented.

   c) **MARAC: PAC Response to PSNI and Departments advice letter**

   As agreed at the last meeting, RMcC and BD had responded to the draft MARAC agreement ~ a copy of the response was circulated to the Group.  Particular concern had been raised with regards to confidentiality and consent.  The relevant sections of the Code of Practice on Protecting the Confidentiality of Service User Information were noted.  Members agreed that it was disappointing to note that the Code of Practice, the purpose of which being to provide support and guidance for all those involved in health and social care, had not been referenced in the letter issued by the Joint Chairs of the MARAC Steering Group (Christine Jendoubi, DHSSPS and Declan McGeown, Department of Justice).

   Discussion followed regarding the difficulties presented in achieving a balance between protection of vulnerable adults and children and the need to ensure maintenance of confidentiality of service user information.  It was also noted that each case should be considering individually.  It was felt that the importance of achieving this balance had not been referenced within the context of the MARAC guidance letter.

   Concern was raised regarding the failure to include the issue of consent within the letter.

   It was agreed that these concerns should be raised in a letter from the PAC to the Joint Chairs of MARAC Steering Group.  RMcC agreed to draft this letter and to circulate to the group for comment.

   **ACTION: RMcC**

5. **Information Governance Issues**

   *Progress Report on Information Governance Review - Chris Mathews, Head of Information Management*

   CM provided an update on policy development within the DHSSPSNI and the wider information governance agenda:

   1. *Protocol for Sharing  Information for Secondary Purposes*

      Strategy for the launch of the protocol currently being finalised ~ it would be issued to those responsible for Information Governance within health and social care.

      The Data Access Agreement (DAA) is also at a final stage and it was expected that it would be issued within the next week to 10 days.

      CM advised that engagement had also commenced with the DHSSPS Policy colleagues in relation

to the consideration of secondary uses legislation.  The existing challenges in relation to information sharing and the action planned will be shared with the Permanent Secretary.

2. **Good Management, Good Records**

'Good Management Good Records' guidance related to the retention and storage of records to be submitted to the NI Assembly for approval in the autumn.

3. **Electronic Care Record** ~ Guidance on the sharing of service user identifiable information through ICT for direct care purposes is being drafted and is currently with the Information Commissioners Office for comment and consideration.   It will then be shared with a wider audience for consideration.

4. **Senior Information Risk Owners (SIROs) / Information Asset Owners (IAOs)**

SIROs and IAOs have been appointed and training would commence in September 2011, co-ordinated by the Information Governance Advisory Group.  Training would be composed of two half-day training sessions, 6 months apart – SIRO and IAOs will be advised of their role and responsibilities within information governance.

**Information Governance Board (IGB)** – CM advised that consideration is being given to the establishment of an Information Governance Board.  Representation is likely to include Trusts, DHSSPSNI and BSO IT.  The Board would review the key strategic issues in relation to information governance.

CM referred to the work of the Information Governance Advisory Group.  The Group meets monthly and current work includes progressing the SIRO/IAO training, development of the protocol for the sharing of information, as well as the recent 3$^{rd}$ data protection review.

5. **General Awareness Training Across HSC Trusts** ~ An on-line training facility is available and is currently in use within several HSC organisations.   CM had contacted Brian McKeown, BSO to ask if this on-line training facility could sit on an HSC platform, making it available to all HSC organisations.

RMcC thanked CM for the update and highlighted the close link between information governance and the remit of the PAC with regards to confidentiality.  He raised concern with regards to the lack of progress on policy development around the secondary use of data, particularly the use of pseudonymisation and emphasised that much more could be done in relation to information governance, with clearer policy direction.

CM advised that at this stage there was a desire to keep direct care and the secondary use of information as separate issues, however the issue of secondary use of information remained on the agenda.  The protocol for information sharing for secondary purposes will shortly be disseminated to all health and social care organisations.

The consideration of 'honest brokers' also remained on the IMB programme of work.

6. **Joint Meeting with PDGs ~ Draft Agenda**

RMcC circulated a draft agenda for the joint PAC/PDG meeting scheduled for 8$^{th}$ September 2011 and welcomed additional items for inclusion.

Revised CoP ~following the consultation exercise on the existing CoP, RMcC advised that it would be anticipated that a revised version, taking account of any feedback, would be prepared by the end of August (stakeholders would be asked to respond to the consultation by 26$^{th}$ August 11).   Comments on the existing CoP had already been requested from the PDGs.  It was intended that the revised version would be circulated to PDGs for consideration and further discussion at the joint meeting on 8$^{th}$ September.  It was expected that feedback from PDGs would be beneficial in identifying any gaps in the existing CoP, given their experience in the issues and challenges regarding information governance and confidentiality.

JM suggested that it may be beneficial to obtain the views of Social Care Governance Assistant Directors.

Update on Regional Information Governance – RMcC asked CM if he would be available to attend the meeting to provide an update on regional information governance.

RW asked if clarification could be sought from the PDG's as to how the Code of Practice is issued if requested by a service user ie: is the full document issued as is or has each Trust developed a separate policy/procedure using the CoP as the foundation document.

Patient information leaflets to be included on the agenda. RW circulated copies of the 'Information About You' leaflet circulated by Blackpool Council. It was queried whether the existing NI patient leaflet outlines how service user information will be used.

CM agreed to liaise with IGAG members to ensure that any changes to the CoP would be reflected in policy.

7.  **Review of Code of Practice**

Update provided by RMcC as above.

RMcC advised that he had taken note of previously requested changes to the CoP in relation to children and the need for clarity regarding secondary use of information had also been noted (as previously raised by JM and BD).

The previous consultation list used for the review of the CoP in 2007 had been reviewed and amended for this consultation ~ the proposed list would be forwarded to PAC members for consideration.

(Requests for the NI Equality Commission and Housing Association to be included).

Agreed that the consultation should be forwarded to the Minister for Health and NI Health Committee.

JM advised that she and JG would be contacting relevant social care workers during the consultation process to ensure that they reviewed the CoP and provided feedback.

A list of the organisations to be included in the consultation, as well as a copy of existing CoP to be distributed along with consultation letter from RMcC.

8.  **Any Other Business**

*PAC Website Development*

It was agreed that it would be beneficial to develop a website for the PAC, which would raise the profile of the Committee and could be used for posting relevant articles/documentation, including previous minutes.

*Jan Maconachie ~ Retirement*

RMcC extended thanks and appreciation on behalf of the Group to JM, for her valuable input and contribution to the work of the Committee, since its creation in 2006. JM advised that JG, who had a background in social care, would be taking over her role within the PAC. She wished the Group well in their future work.

RMcC also extended thanks to Joanna McDowell for the provision of administrative support to the PAC.

9.  **Date of Next Meeting:**

Thursday, 8th September 2011 ~ Joint PDG/PAC meeting – venue to be confirmed.

Thursday, 17th November 2011.