

**37th Meeting of the Privacy Advisory Committee
Thursday, 24th May 2012 at 10.00am
Venue: NIMDTA, Beechill House, Belfast**

MINUTES

Present: Prof Roy McClelland, Grace Irwin, Dr Jimmy Courtney

1. Apologies

Apologies were received from Brice Dickson, John Growcott, Roisin Wylie, Chris Matthews.

2. Minutes of Previous Meeting

The minutes of the 36th meeting held on 17th November 2011 were agreed.

3. Matters Arising:

i. Medical Directors' Meeting ~ 20th February 2012

RMcC provided an update on a meeting he attended with Medical Directors on 20th February 2012 at which there had been discussion around the revised Code of Practice, the need to increase awareness re the COP at Trust level, as well debate regarding Safe Haven and Honest Broker provision.

ii. PDG Training ~ 21st February 2012

RMcC reported on the PDG training held on 21st February 2012. Unfortunately there had been a number of apologies on the day due to other health related issues which had taken precedence. Dr John Simpson to attend alternate training to be provided by Dylis Jones Associates.

RMcC proposed that PAC funding, which had in the past been used for PDG training, be used towards the creation of on-line training material. It may be possible for the Beeches Management Centre to host this on their existing portal. It was noted that an information governance on-line training module is currently available on the BMC portal, however this does not adequately cover wider patient confidentiality issues or PDG training.

JC and GI agreed that this would be beneficial and would improve accessibility for training for a wider group of staff. It was suggested that options might be developed for PDG training, as well as a module in relation to the Code of Practice.

RMcC advised that he had had a preliminary discussion regarding the development of on-line material with Colin Harper, who had assisted in the development of a similar on-line training module for the Royal College of Psychiatrists. It was felt that an interactive model, similar to that in use by the GMC, be developed.

It was agreed that this on-line training option be pursued.

RMcC to follow-up with C Matthews.

Discussion followed regarding the benefit in the creation of on-line material in relation to the role of the Privacy Advisory Committee (as was the case for the

Scottish PAC). GI agreed to look into this and to forward contact details for the relevant staff within the HSC to C Murphy for follow-up ~ it was hoped that this information, including reference to proposed on-line training material, could be made available and regularly updated on the existing HSC website.

GI/CM

iii. Revised Code of Practice, Staff Guidance leaflet, Service User Leaflet

RMcC advised that the revised COP and updated Staff Guidance leaflet had been issued in March 2012. The first section of the staff guidance leaflet refers to the updated COP. RMcC had written to PDGs to request that they raise the profile of the leaflet and COP in their organisations.

GI advised that the COP had been posted on the Northern HSC Trust intranet for staff to access and had also been referred to in an information governance leaflet for staff, as well being placed on the IG forum agenda.

RMcC had proposed the distribution of hard copies of the leaflet along with staff payslips.

The updated Service User leaflet had also been distributed.

iv. PAC and ICO roles in relation to Health and Social Care

RMcC referred to discussion with Ken Macdonald, ICO at the November 2011 PAC meeting. Concern was raised regarding possible perverse consequences of increased awareness of ICO penalties on the wider issues in relation to patient confidentiality within health and social care.

4. Chairman's Update

i. MARAC Consultation

RMcC referred to discussion at a recent MARAC meeting, attended by Clare Simmonds, regarding the issues around the rights of an alleged perpetrator. Catherine Vint, ICO had referred RMcC to new ICO guidance on dealing with appeals at employee tribunals and to the sharing of 3rd party information, in particular, with reference to child protection and vulnerable adults and recent changes in case law.

RMcC agreed to forward his correspondence to Sheila Simons and the link to the new ICO guidance to PAC.

RMcC

ii. Meeting with R&D Office, Workshop ~ 24th April 2012

RMcC advised that he and Chris Matthews had attended an R&D workshop held on 24th April 2012. The R&D community is keen to access patient information in relation to public health related research. At the workshop CM had provided an update on the revised COP and the recently issued DHSSPSNI Information Sharing Protocol. RMcC had given a presentation on confidentiality and the need for anonymisation of data or obtaining consent, as well as the opportunity for Safe Haven provision.

The workshop had also been attended by Brian McKeown (BSO), Dermot O'Reilly and David Marshall.

Debate had taken place around the need for further legislation in NI.

iii. Meeting with NICR

RMcC had met with representatives from the NI Cancer Registry and had discussed the need for legislation, which they were also keen to see developed

further. RMcC had been invited to attend the NICR Council meeting in the autumn and he had suggested that C Matthews be invited to provide an update on legislative developments.

iv. Meetings with BSO re Safe Haven and Honest Broker Provision

RMcC advised that there had been some progress with regards to the consideration of the development of Safe Haven/Honest Broker provision by the BSO. Steve Pavis, Head of Programming for Information Scotland had met with Mr Brian McKeown and colleagues to discuss possible developments.

v. Data Quality in Practice Workshop ~ 26th June 2012

Dr J Courtney (JC) advised that he was a member of the new Electronic Care Record Project Board and Chair of the Information Governance Sub-committee. He provided an update on the consideration being given to the extraction of information from GP records for secondary care purposes. Preliminary discussions had taken place on how this could be actioned and the stipulation that the data be appropriately anonymised. A workshop had been arranged for 26th June to consider how this could be taken forward.

JC referred to similar work undertaken by the GP Extraction Service run by the Information Centre in England - a set of principles had been agreed with the BMA to oversee this work.

Reference was made to the SAIL Project in Wales, which had also allowed for the safe pseudonymisation of primary care information.

JC highlighted the importance of the quality of data retained in primary care records and that improved coding of information was required which would be best implemented on a phased basis.

vi. RMcC advised that he continued to deal with requests for advice from the PAC. Recent requests received from:

- 1) Dr Michael Power, Consultant Physician, Care of the Elderly and Stroke, Southern Trust regarding the participation of Northern Ireland in the Sentinel Stroke National Audit Programme;
- 2) Dr Heather Reid, PHA regarding maternal and child deaths.

He advised that the volume of work and the number of requests for advice was increasing, which could be attributed to both an increased awareness of the Code of Practice and the increasing number of national initiatives which were seeking NI compliance.

5. DHSS Advice “The Data Protection considerations associated with the electronic processing of personal data for direct care purposes” [Encs 1-4]

Discussion took place regarding the above document, as recently issued by the DHSSPSNI. The PAC had not been consulted on the document prior to its publication.

RMcC referred to the correspondence forwarded to Mr Brian McKeown, Chairman of the ICT Programme Board in July 2010 on behalf of the PAC (Enclosure 3),

which had specifically requested that the Programme Board consider the offer of an 'opt-out' to patients, as well as for arrangements for obtaining express consent.

It was felt that the data protection considerations document could have taken a firmer approach with regards to obtaining the service-user's express consent.

It was noted that the document did not address the issue regarding the sharing of information for purely social care purposes.

Concern was also expressed regarding the issue of consent in relation to the wider distribution of data via the Electronic Care Record, as opposed to consent obtained in the pre-electronic data processing arrangements. It was queried whether this consent was sufficient, given the wider distribution of data.

GI raised concern regarding the failure of the document to address specific issues including both the control of access to 'pooled' information and consideration of common law in relation to confidentiality, alongside the Data Protection Act.

It was agreed that the PAC should develop a position statement with regards to the electronic processing of personal data for direct care purposes, based on the correspondence which had been forwarded to B McKeown in July 2010. RMcC agreed to draft this statement, as well as a supporting letter to Louise McMahon, Chair of the ECR Project Board. For agreement and sign-off by the PAC.

RMcC

JC provided an update on the work of the NI Electronic Care Record Project Board. He confirmed that the ECR was for direct care purposes only. Following the initial pilot, it was now hoped that the ECR would be rolled-out towards the end of 2012.

Consideration had been given to the inclusion of audit software in the ECR to control access to data ie: tailoring access to information according to the role and position of the individual accessing the data.

A consultation exercise would be undertaken prior to the roll-out of the ECR across NI, including with the PCC.

As was the case with the pilot exercise, JC advised that communication would be forwarded to patients - consideration would be given to the process for this ie: whether the communication would be forwarded from the patient's GP and whether it would be addressed to the individual patient or household. RMcC advised that for the offer of opt-out, it would be preferable to address correspondence to all named individuals, as opposed to households.

Discussion took place regarding the length of time for which a patient's consent would remain active, following their initial period of treatment.

It was agreed that consideration also be given to controlling access to data, in relation to multi-disciplinary team access, as well as to the need for an adequate

auditing process to be incorporated into the ECR.

GI advised that she had already contacted the BSTP Project Board, regarding the possibility of access control being incorporated into the new HR system. It was also agreed that a strong regulatory framework should be in place.

6. Matters Arising from Review of the Code of Practice [Enc 5]

Discussion took place regarding an issue raised by the PAC during the review of the COP, specifically the processing of personal data within an organisation so that it can be presented in an anonymised form. Should access be restricted to those involved in a patient's direct care, including audit clerks and the full multi-disciplinary team.

It was agreed that advice on this issue should be given in any future review of the COP.

7. Legislation for Secondary Uses of Service User Information [Enc 6]

RMCC referred to Enclosure 6 - correspondence forwarded to Susan Foster, DHSSPSNI in July 2008 with regards to the advice offered from the PAC with regards to the need for legislation in relation to the processing of health and social care information in Northern Ireland.

Following discussion it was agreed that the PAC should give further consideration to proposals for legislation and produce a position statement, outlining specific recommendations.

All

8. Information Governance Report

~ Chris Matthews, Head of Information Management
Deferred to the next meeting.

9. For Information:

Human Genomics Strategy Group [Enc 7]

(http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_132369)

Caldicott Review of Confidentiality and Information Sharing [Enc 8]

10. Any Other Business

JC advised that the Department of Health in England had recently published an information strategy with regards to health and social care. He agreed to forward to CM for circulation to PAC.

JC/CM

11. Dates for Next Meetings

- Thursday, 19th July 2012
- Thursday, 13th September 2012
- Thursday, 22nd November 2012

It was agreed that PDGs should be contacted to gauge the level of interest in a further joint meeting with the PAC at the 13th September meeting. CM to contact PDGs.

CM