

**39th Meeting of the Privacy Advisory Committee
Thursday, 22nd November 2012 at 10.00am
Venue: Boardroom, NIMDTA Beechill House**

MINUTES

Present: Prof Roy McClelland, Brice Dickson, Dr Jimmy Courtney, John Growcott, Grace Irwin

1. Apologies

Apologies were received from Roisin Wylie and Chris Matthews.

2. Minutes of Previous Meeting

The minutes of the 38th meeting held on 19th July 2012 were agreed.

3. Matters Arising:

i) Meeting with PDGs ~ 13th September 2012

Prof McClelland (RMcC) provided feedback from the joint meeting between the PAC and Personal Data Guardians (PDGs) on 13th September 2012.

PDGs had welcomed additional 'refresher' training in 2013 and beyond, with support for both group training as has recently been provided by Dylis Jones Associates, as well as for the development of on-line training.

PAC would support and encourage DHSSPSNI in the facilitation of a meeting between PDGs and representatives from the Information Commissioner's Office (ICO), on issues relating to confidentiality and data protection. RMcC agreed to discuss this proposal further with Chris Matthews.

RMcC

John Growcott (JG) requested that a representative from the Children's Safeguarding Board be invited to attend future PDG training events and agreed to forward contact details to C Murphy.

JG

ii) Training

All Staff

RMcC advised that Colin Harper had agreed to develop an interactive on-line training module for all HSC staff, on behalf of PAC, in relation to confidentiality and data protection. The Beeches Management Centre have agreed to host this training module which will form part of their overall Information Governance on-line training material.

PDG Training

RMcC advised that unfortunately, due to budget constraints, PAC would have difficulty in continuing to provide annual PDG training in 2013 and beyond.

RMcC had discussed the issue with Chris Matthews (CM) and Mr Paul Comac at the Beeches Management Centre to explore alternative arrangements. It was agreed that annual training was necessary to enable PDGs to fulfil their role.

The Beeches HSC Leadership Centre have agreed to facilitate and host future training. RMcC advised that he had written to all PDGs, to propose that Trusts and other relevant organisations fund individual PDG attendance at future annual

training which would be likely to require advance payment to the training provider. PDGS had been asked to indicate their support for this proposal and to determine whether their organisation is willing to fund future training. Responses have been requested by 3rd December 12.

C Murphy to forward the communication sent to PDGs to PAC for information.

C Murphy

It was hoped that further PDG training will be provided in spring/summer 2013.

RMcC advised that PDGS had also expressed support for the provision of on-line PDG training material, which would be given further consideration, once the arrangements for face to face group training had been finalised.

At the joint PAC/PDG meeting in September 2012 it had been proposed that PDG and SIRO training be combined, however following discussion with CM, RMcC advised that PDG and SIRO training would continue to be delivered separately.

**iii) Legislation for Secondary Uses of Service User Information
~ Paper and Letter to Minister and HSC Health Committee**

RMcC advised that he had discussed legislation for secondary uses of service user information with CM, who was currently working on a paper for submission to the Minister. Once this had been submitted RMcC would then forward the PAC position paper and accompanying letter to the Minister and to the Chair of the Health Committee, outlining the advice and view of the PAC in relation to legislation for the secondary uses of service user information.

RMcC

4. Chairman's Update

i) Meeting with Dr Carolyn Harper re NI ECR

RMcC provided an update on the outcome of a meeting which he and CM had attended with Dr Carolyn Harper, Chair of the NIECR Project, along with others involved in the Project. Informed discussion had taken place and a number of actions had been agreed.

CM had agreed to consult with his colleagues in DHSSPSNI to consider the development of specific policy in relation to service user controls/consent on the primary use of data in health and social care provision, in anticipation of future developments and the possible flow of more sensitive personal information.

ii) Correspondence with NIMACH (Enc1)

RMcC referred to recent correspondence and advice provided to Dr Heather Reid, Regional Manager and Mrs Joanne Gluck, Clinical Research Midwife, Northern Ireland Maternal and Child Health (NIMACH). The correspondence had related to NIMACH's participation in the national RCPCH Epilepsy Project, involving information on both living and deceased service users. It was felt that adequate consent arrangements were in place for the information on living service users, which will be obtained by a doctor providing direct care to the individual. Pseudonymisation of data on deceased service users will take place within the NIMACH office, which was felt to be proportionate and appropriate in these circumstances.

Discussion followed with regards to the possibility of obtaining consent on the use of information on deceased children, from their parents or legal representatives and it was agreed that this issue should be given further consideration.

5. The NIECR - Confidentiality and Consent Considerations ~ An Advisory Note Prepared by PAC [Enc 2]

RMcC referred to the paper which he had drafted and circulated on behalf of the PAC, following discussion at the meeting with Dr Carolyn Harper, outlining a number of proposals for consideration by the DHSSPSNI, in relation to the issue of consent and the future provision within the NIECR.

- Discussion followed regarding the possibility of obtaining patient consent at the referral stage, so as express consent has been sought prior to the service user attending a hospital specialist. Dr Carolyn Harper had agreed to discuss this option further with the NIECR Project Board who were due to meet on the afternoon of 22nd November 2012;
- It was highlighted that hospital discharge correspondence has been included in the current proposal for the NIECR, currently uploaded to Patient Centre from PAS. While this differs to existing practice, it was acknowledged that this will not include more sensitive service user information eg: information relating to mental and sexual health;
- It was noted that although such service user information already exists in electronic form, the aggregation of this information into a new database such as the NIECR, does pose an additional risk with regards to access and sharing of personal identifiable information;
- It was agreed that all service users should be made fully aware of the inclusion of such information and the extent of information sharing via the ECR, which will require a public information campaign. Dr J Courtney advised that the NIECR Project Board have developed a Patient Information Leaflet for distribution and service users will also be directed to a website if they wish to obtain further information on how their information will be accessed and used;
- The balance between maintaining patient confidentiality while at the same time ensuring that the relevant service user information is made available to healthcare practitioners via the NIECR was highlighted;
- It was also noted that provision should be made within the NIECR to respect the wishes of a service user who has opted not to have certain information made available on the NIECR such as hospital discharge correspondence. However, it was also acknowledged that it may not be technically possible to selectively exclude certain information;
- Dr Courtney outlined access controls and provision within the NIECR, including role-based access and the proposed on-screen options for consenting to view a patient's information eg: this time only, for a 3 or 12 month period *etc.* The PAC supports the current provision within the NIECR for time-limited consent and access provision;
- It was noted that there would be exceptions to the usual consent to view ie: emergency situations and also where a patient is incapable of consenting due to incapacity - it was agreed that provision should also be made for obtaining consent for a child from a parent/guardian;
- Possible future inclusion in the NIECR of more sensitive service user information eg: mental health and sexual health was also discussed - currently there are no plans for inclusion of this information. It was acknowledged that further

discussion will be required if this were to be progressed to ensure that patient confidentiality is maintained and that sensitive information is appropriately highlighted and access restricted within the NIECR. It was also felt that further consideration should be given to establishing a definition of 'sensitive information' and on the responsibility for the classification of information as sensitive;

- Discussion followed regarding the proposed '*Transforming Your Care*' model and the future delivery of healthcare in a community setting, which would require community-based practitioners to have access to service user information outside of the acute hospital setting eg: information on social care, community nursing and AHPs etc. It was acknowledged that further consideration should be given to the development of a community ECR.

RMcC agreed to update the draft PAC Advisory Paper, to take account of discussion.
RMcC

6. Information Governance Report

Discussion deferred to the next meeting.

7. Any Other Business

PAC Website

BSO have advised that it is possible to host a PAC sub-site on the existing HSC extranet. C Murphy to circulate draft outline structure to PAC for consideration.

8. Dates for Next Meetings

Dates for 2013 meetings as below (dates for January and May meetings have been updated)

~~Thursday, 24th January 2013~~, Wednesday, 16th January 2013;

Thursday, 28th March 2013;

~~Thursday, 23rd May 2013~~, Thursday, 16th May 2013;

Thursday, 18th July 2013;

Thursday, 19th September 2013 (proposed Joint Meeting with PDGs);

Thursday 21st November 2013.