

40th Meeting of the Privacy Advisory Committee

Thursday, 16th May 2013 at 10.00am

Venue: Boardroom, NIMDTA, Beechill House

Present: Professor Roy McClelland (Chair), Dr Jimmy Courtney, Grace Irwin, John Growcott

1. Apologies

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

2. Minutes of the Previous Meeting ~ 22nd November 2012

The minutes of the previous meeting held on 22nd November 2012 were agreed.

3. Matters Arising:

i. On-line Training Module

Prof R McClelland (RMcC) advised that funding had been obtained to proceed with the development of an on-line training module in confidentiality for H&SC staff, to support the Code of Practice on Protecting the Confidentiality of Service User Information (COP). The module will be aimed at professional staff, including those with an interest in/responsibilities for Information Governance. It was agreed that it would be of benefit for this module to be made available to staff to co-incide with the roll-out of the Electronic Care Record, which is expected in June 2013. RMcC agreed to follow up with Dr Colin Harper, who was developing the module, to see if its availability could be expedited. It is expected that the module will assist in promoting awareness of the COP. Grace Irwin (GI) offered assistance to QA the training module.

RMcC

ii. PDG training

Personal Data Guardian training had been provided by Dylis Jones Associates (DJA), and facilitated by the HSC Leadership Centre, Clady Villa, Knockbracken on Tuesday, 23rd April 2013. Arrangements for the training differed from previous years in that delegates had been required to complete invoice forms prior to the event and their organisations were charged individually for the training. Feedback from the training had been positive.

4. Chairman's Update

RMcC advised that the PAC had received a number of queries, seeking guidance on issues relating to consent and confidentiality within health and social care, including:

i. Advisory

NCEPOD

RMcC has provided guidance to the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) in terms of outlining the preferred arrangements for access and linkage to N Ireland patient data for this regional study.

Research Nurse in Primary Care

RMcC advised that he and Dr J Courtney (JC) had discussed the issue of research nurses working within primary care and their access to patient records – options for their compliance with the COP were discussed, including the awarding of honorary contracts and means of ensuring secure data

extraction. RMcC had discussed the issue with Dr Ronnie Atkinson, Chair of REC and Prof Margaret Couples, QUB.

Reference was made to the Scottish Informatics Program (SHIP) research platform used for the collation and analysis of electronic patient records in Scotland, which provides secure access to data for research purposes. It was agreed that a similar system, allowing for access to data in a secure environment, would be the preferred option. It was noted that a Business Case is being prepared for submission to the Department.

RMcC agreed to liaise with Dr Margaret O'Brien, Chair of the Data Quality in Practice Project Board, to outline the PAC's support for the development of a secure data extraction system to enable the undertaking of research projects in Northern Ireland.

RMcC

Looked After Children with Disabilities

RMcC and John Growcott (JG) have been reviewing procedures for accessing data in relation to looked after children with disabilities and the obtaining of consent from a direct care provider, prior to access to data.

ii. *Secondary Uses Guidance (Enc 1)*

RMcC referred to the guidance paper which had been produced by PAC – '*Using Personal Information for Secondary Health & Social Care Purposes*' which was based on the COP.

It was agreed that this guidance paper should be posted on the new PAC website and circulated to Personal Data Guardians for information.

C Murphy

5. The Information Governance Review (Enc 2)

A copy of the Information Governance Review paper (March 2013) had been circulated – it was noted that this paper is applicable to England only. Those present agreed that an equivalent Information Governance Framework is required for health and social care within Northern Ireland, particularly in light of recent discussion in relation to the role of research nurses and their access to personal identifiable information.

It was agreed that further clarity and leadership is required in respect of Information Governance in Northern Ireland and the PAC would support the implementation of a similar framework and principles to this latest Information Governance Review paper.

It was agreed that further discussion should take place at the next meeting with regards to the need for a more robust IG framework, as well as legislation. Item to remain on agenda.

6. The NIECR: Update

The NI Electronic Care Record - Confidentiality and Consent Considerations ~ An Advisory Note prepared by Privacy Advisory Committee (N. Ireland) (Enc 3)

RMcC advised that following discussion on the NIECR at the November 2012 meeting, he had met with Dr Carolyn Harper, Chair of the ECR Project Board, and a number of her colleagues, to discuss the confidentiality issues associated with the roll-out of the NIECR. He had also been invited to attend a meeting of the ECR Project Governance Sub-Committee, by Dr JC, its Chairman.

The above advisory paper had been prepared following these discussions.

Dr JC provided an update on the roll-out of the NIECR:

- Following the ECR pilot project the consent and governance arrangements had been finalised;
- the ECR will switch to a new platform week beginning 20th May 2013, at which stage the

system will undergo a period of testing. Following this the approximately 1,000 existing ECR pilot users will then be transferred across and it is expected that a further period of testing will be undertaken, prior to the roll-out which is expected to take place in mid-June 2013. The Minister will support the launch of the ECR at an event planned for the end of June;

- At this stage there will be no further variation on the information which will be included in the ECR and it will contain only that which was included in the pilot system;
- Further discussion will be required prior to the inclusion of any additional information eg: community/social care and mental health information;
- JC advised that advice will be sought from the Adult and Children’s Safeguarding Board in relation to consent arrangements and other issues prior to the inclusion of such information within the ECR;
- Engagement with representatives from the Mental Health community will also be required to discuss the sensitivities and issues regarding inclusion of mental health related information (eg: regional Mental Health Co-Directors Group).

Concern was again raised regarding information governance in respect of the increased sharing of social care information and the need for improved leadership and direction in this field.

7. Proposed Joint Meeting with PDGs ~ 19th September 2013

The PAC supports a further joint meeting with Personal Data Guardians, with a proposed date of Thursday, 19th September (AM).

The following issues were raised for possible agenda items:

- The ECR and electronic sharing of personal identifiable health and social care information;
- The Information Governance Review;
- Secondary use of health & social care information.

There had been some previous discussion around involving Data Protection Leads and the Information Commissioner’s Office at future PAC/PDG joint meetings, however it had since been agreed that the two should be kept separate. PAC would support the DHSSPSNI in the facilitation of such a meeting with the ICO.

C Murphy to contact PDGs to determine availability on 19th September and to seek suggestions for possible agenda items.

C Murphy

8. Legislation for Secondary Uses of Service User Information

~ Briefing Paper and Letter to Minister (May 2013) (Enc 4 & 5)

RMCC advised that he had written to the Minister in early May 2013 to outline the PAC’s support for the implementation of legislation for the secondary use of service user information ~ a copy of the above briefing paper had also been submitted.

RMCC advised that Chris Matthews (CM) has informed him that the Minister had replied to the Department’s submission in April 2013, in support of legislation for the secondary use of service user information. The Department has been asked to initiate policy work on the creation of Northern Ireland legislation, similar to Sections 251 and 252 of the NHS Act 2006, but to include the sharing of social care information.

The Department are currently working to secure additional resources to take this work forward.

CM has also advised that the establishment of an honest broker service, to provide anonymised and pseudonymised information within the HSC and for ethically approved health related research, is currently being taken forward within the Business Services Organisation. It is hoped that the service will be available before summer 2013.

RMcC advised that he intended to contact CM, to seek further information on the provision of an honest broker service and it was hoped that the PAC would be consulted on the issue.

RMcC

Legislation and Honest Broker provision to be added to the agenda for further discussion at the next PAC meeting.

9. Information Governance Report

Chris Matthews, Head of Information Management

CM had provided an update to RMcC in relation to legislation and honest broker provision (as above).

10. PACs New Web-site - Clare Murphy

A draft PAC website has been produced with assistance from the Business Services Organisation – the information will be hosted on the existing HSC website. Proposed content had been circulated to PAC for feedback/comment.

It was agreed that the preferred domain name would be

www.privacyadvisorycommittee.hscni.net.

It was also proposed that a link to the PAC website be provided via the Board and HSC Trust websites, to facilitate access. C Murphy to take forward with BSO and to ask for the draft content to be published, if no additional comments were received.

C Murphy

11. Any Other Business

Specialist Services/Medical Representative on PAC

RMcC proposed that Dr Clodagh Loughrey, Consultant in Clinical Biochemistry be invited to attend future meetings of the PAC. Dr Loughrey had a specialist interest in the area of confidentiality and secondary uses within health and social care and had recently completed a MSC in Ethics and Law. She is a member of REC2. Those present agreed that it would be of benefit to have Dr Loughrey's input to the Committee. RMcC agreed to check with other PAC members and if in agreement, to invite Dr Loughrey to future meeting/s.

RMcC

12. Dates for Next Meetings 2013:

- It was proposed that the next meeting scheduled for Thursday, 18th July 2013 be brought forward to Wednesday, 10th July.
- Thursday, 19th September 2013 (proposed Joint Meeting with PDGs)
- Thursday 21st November 2013.