

38th Meeting of the Privacy Advisory Committee
Thursday, 19th July 2012 at 10.00am
Venue: Boardroom, NIMDTA Beechill House

MINUTES

Present: Prof Roy McClelland, Brice Dickson, Dr Jimmy Courtney, Roisin Wylie, John Growcott, Chris Matthews.

1. Apologies

Apologies were received from Grace Irwin.

2. Minutes of Previous Meeting

The minutes of the 37th meeting held on 24th May 2012 were agreed, subject to the following amendments:

Attendance/apologies to be inserted

Present: RMCC, JC, GI

Apologies: BD, RW, CM, JG

Page 3 ~ Chairman's Update:

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

- 1) Dr Michael McCormick Power, Consultant Physician, Care of the Elderly and Stroke, Southern Trust regarding the participation of Northern Ireland in the Sentinel Stroke National Audit Programme.*

3. Matters Arising:

PAC Website

C Murphy has e-mailed contact in HSC with regards to the creation of a website for the PAC. Response awaited.

On-line Training

Discussion took place regarding the proposed creation of on-line training material for:

- a) all HSC staff, in relation to confidentiality, information governance/Code of Practice etc;
- b) creation of on-line training material, specifically for Personal Data Guardians.

RMCC advised that he had discussed the development of on-line training material for all HSC staff with Colin Harper, who was willing to assist. It had been proposed that this training module/s could be made available within the existing Beeches Management Centre (BMC) on-line training portal.

Chris Matthews (CM) advised that discussions were ongoing between HSC and the BSO, with regards to the provision of on-line training material for HSC staff in confidentiality/information governance and agreed to obtain update on developments.

It was agreed that the availability of on-line training material would be beneficial in that it would improve access to, and cascading of, training more widely.

The particular requirements of on-line training material were noted:

- training modules would need to be ‘*user-friendly*’;
- Adequate Controls Assurance would need to be in place, with key requirements/fundamental aspects incorporated, to ensure staff attain the required level of training;
- An accountability mechanism would also be essential to ensure uptake/completion of on-line training and this would be required at a local managerial level, given the volume of HSC staff involved;
- Noted that each organisation/Trust needs to take responsibility for the delivery of training (SROs have been appointed within each organisation).

CM advised that Controls Assurance Standards for the HSC are being developed (mapping of existing standards is underway using NHS Toolkit). HSC organisations will be required to provide evidence that they are working to achieve ‘best practice’.

Discussion is ongoing with BSO in relation to standards and the auditing of best practice - policy will be developed and put in place, with an onus on the individual organisations to ensure that best practice is achieved.

PDG training ~

RMcC advised that he had contacted Dylis Jones regarding the possible development of on-line PDG training material and agreed to obtain costings in the first instance (noted that other on-line training providers may be available).

RMcC

RMcC highlighted that Dylis Jones had delivered PDG training in NI in previous years and there may be a benefit in continuity of training provider.

Concern was raised regarding the cost of developing on-line material for PDGs and the requirement for this to be regularly updated, to take account of the constant developments in relation to PDG training eg: particular cases/issues ~ it was noted that this may be difficult to incorporate into on-line training material and may be better delivered via the annual PDG training sessions, as currently delivered by Dylis Jones.

Possibility of on-line PDG training to be discussed with PDGs at the joint PAC/PDG meeting on 13th September 12.

4. Chairman’s Update

i) Meeting with Professor Frank Sullivan

RMcC referred to his discussion with Professor Frank Sullivan, Professor in General Practice, in relation to the extraction and pseudonymisation of personal data from primary care sources, and the challenges faced in relation to data protection as well as ensuring the quality of primary care information, to inform secondary uses effectively (eg: SAIL Project in Wales which had allowed for the safe pseudonymisation of primary care information).

RMcC had highlighted concerns regarding the extraction of data from primary care sources and the pseudonymisation and holding of data in a central location, purely for secondary care uses.

ii) Data Quality in Practice Workshop - 26th June 2012

Dr J Courtney and RMcC provided an update on discussion at the above workshop and the consideration being given to the extraction of information from primary care sources for secondary care purposes.

Dr Courtney also highlighted the need to ensure the quality of primary care data and the methods by which this could be improved eg: improved coding of primary care information by GPs.

iii) Dr Heather Reid re CMACH

RMcC provided an update on further discussions which he had with Dr Heather Reid, NIMACH (Northern Ireland Maternal and Child Health) regarding access to patient information and co-operation with the national Confidential Enquiry into Maternal and Child Health (CMACH).

Dr Reid who did not have a direct care relationship with the patients, would be undertaking the anonymisation of data at Trust level. In these circumstances, where consent was not an option, the proposed anonymisation arrangements were considered to be reasonable, in terms of balancing public health interest with the maintaining of patient confidentiality. It would be possible to extract information and ensure that the anonymisation process was undertaken securely.

However, discussion had also taken place regarding the extraction of data in relation to epilepsy, on live patients. RMcC had advised Dr Reid that in these circumstances an adequate process for the obtaining of patient consent should be in place.

iv) National Health Service (Venereal Diseases) Regulations

RMcC referred to a recent enquiry as to whether there is equivalent NI legislation to the National Health Service (Venereal Diseases) Regulations 1974, in place in England and Wales, and the reference to this legislation in the recently revised Code of Practice. CM advised that he had asked the DHSSPS solicitors to look into this issue and to advise accordingly.

5. Consent and the ECR

RMcC referred to the circulated draft paper "The Electronic Care Record including the Emergency Care Summary - A Position Statement Prepared by PAC".

This paper had been drafted to provide advice on the confidentiality obligations applicable to the ECR and to document what the PAC consider to be the most appropriate pre-conditions for the roll-out of an ECR in N Ireland. The paper has referenced the 'Article 29 Data Protection Working Party' and the recently issued DHSSPS and HSC Protocol for Sharing Service User Information for Secondary Purposes.

The draft PAC paper recommends the provision of an 'opt-out' and also that express consent should be sought, at the point of contact with the patient, for any subsequent proposed use of the ECR, for any new episode of hospital specialist direct care (other than emergency care).

Discussion followed regarding particular aspects of the ECR, including:

Pilot Exercise

- JC advised that during the pilot of the ECR, all patients were written to, to advise of the creation of the Emergency Care Summary (ECS), a component of the ECR, which includes details of patient medications and allergies, and the provision of the option to 'opt-out';
- Explicit consent for access to their ECR was sought from patients at the time of contact with their GP. Consent to access applied to the entire ECR;
- The pilot ECR was implemented in two practices - JC advised that he was unaware of an instance when a patient had actually 'opted-out' of the sharing of their ECR for specialist care purposes.

Consent:

- JC highlighted that no new information is being added to the ECR ~ it simply brings together information which already exists;
- Discussion followed as to whether consent can be obtained by the GP/practitioner who is arranging the onward referral to secondary care and whether 'implied consent' can be assumed if a patient agrees to their onward referral;
- It was also queried how long does consent last:
JC advised that a number of options can be set eg: 24 hour access for out-patient purposes, access for a number of weeks for in-patients which would be required to enable staff to complete delivery of care in particular episodes. Discussion is ongoing on this issue;
- JC advised that currently if a patient presents to a practice for medical care, it can be assumed that they are consenting to all staff within their practice accessing their records, including locum GPs;
Patients have an understanding/expectation that their medical practitioner can view their information, in order to deliver the appropriate care.

Keeping Service Users Informed:

- As stated in the COP, service users must be kept informed about the uses and disclosures of their information;
JC advised that discussions on this issue are ongoing and there are points which require further clarification;
- The importance of the patient's perception of what information is made available and to whom, was noted, particularly in relation to sensitive information;
- It was agreed that it is vital that appropriate communication takes place with patients in relation to the implementation of the ECR, and this should happen via a number of channels/forums;
RW proposed that the PCC membership scheme, including 5k members, should be contacted to seek advice/opinion on the proposed roll-out of the ECR;
JC advised that the BMA had held a workshop with their Patient Liaison Group and a variety of feedback had been obtained;
- Contact would also be made with a variety of organisations in advance of the roll-out, including PCC, PAC, ICO etc;
- The communication plan to patients is yet to be finalised.

Provision of Ability to 'Opt-Out'

- JC stated that the ECR has already been created - the provision of an 'opt-out' to patients refers to the onward sharing of their information and who can access their records. It would not be possible to provide patients with the option to 'opt-out' of the actual creation of the electronic record.

Control of Access

- JC highlighted that access to the ECR does not necessarily allow for access to all parts of the ECR ~ specific role-based access can be allocated ie: as is current - only certain staff can access certain patient databases;
- As the ECR may contain sensitive personal information, including possible social care information, adequate controls/regulations will need to be in place;
- JC stressed that all access to information contained in the ECR would be auditable and it would allow for greater control than for existing paper records;
- Primary care information will be made available electronically - it is up to the patient as to whether they provide consent for that information to be viewed by other parties in the delivery of their care;
- Governance arrangements are still being considered.

It was agreed that the PAC position paper should make specific reference to the particular version of the ECR and should elaborate on what exactly is included in the ECR:

JC advised that the pilot ECR included the following:

- Emergency Care Summary - detailing patient medications and allergies;
- Laboratory results;
- X-rays;
- PAS - patient demographics and appointments etc;
- ED admissions;
- Patient discharge letters.

Clarification is still required in relation to social care information, which is currently not included in the ECR.

CM and JC agreed to further discuss developments regarding the planned implementation of the Electronic Care Record in NI.

CM/JC

RMcC agreed to update the position paper to take account of the above discussion.

RMcC

6. Anonymisation at Trust Level [Enc 2]

RMcC referred to the circulated draft paper ~ 'Data Anonymisation within Trusts for Secondary Uses'.

Discussion followed regarding the need to ensure the secure 'processing'/anonymisation of personal data for secondary uses and who is actually authorised to undertake this anonymisation of data. Within Trusts this should generally be achievable by those having a direct care relationship with the service user, including the multi-disciplinary teams, audit clerks etc.

It was queried whether this anonymisation of data could be undertaken by temporary staff/external agencies, in specific circumstances eg: data on deceased persons (eg: CMACH), and if the development of a secure pseudonymised extraction

service is an alternative.

As stated in the COP, express consent and/or anonymisation of data is required for secondary use of personal identifiable information, however there may be possible exceptions and there is a need to balance non-disclosure with for example, overriding public interest.

RMcC advised that all advice he had provided recently on behalf of PAC, around this issue has been based on the content of this draft paper.

CM referred to the current ICO consultation on a draft Anonymisation Code of Practice (closing date 23rd August 12), in particular on whether consent is required to produce or disclose anonymised information (page 24).

RMcC welcomed comments on the draft paper and it was agreed that advice on this issue be included in the next review of the COP.

All

7. Legislation for Secondary Uses of Service User Information

Following discussion at the last meeting it had been agreed that the PAC should give further consideration to proposals for legislation and produce a position statement outlining specific recommendations. BD advised that he was currently working on this position statement, which would take account of the previous paper, produced by Colin Harper in 2007 'Does NI Need an Equivalent to Section 60 of the Health & Social care Act 2001'.

It was agreed that the draft paper outlining the PAC's recommendations and concerns regarding the need for adequate legislation, in relation to secondary uses of personal information, should be forwarded to the Minister for Health and possibly also to the Chair of the NI Assembly Health Committee.

Draft paper to be circulated to PAC for comment.

BD

8. Information Governance Report

CM provided an update on information governance:

- Progress is ongoing in relation to the provision of an honest broker function - analysis has been undertaken;
- A meeting had taken place recently between Andrew McCormick (Permanent Secretary), Bernie Hanagan and representatives from BSO in relation to the secondary use/sharing of personal information. CM advised that he would be working with Clive Wolesley and the BSO to consider the options available for the secure anonymisation of personal data in N Ireland, and the policy requirements for this.
- A consultation process will also take place regarding the potential for safe haven provision.
- CM is finalising an options paper in relation to the secondary use of information (including social care) and the associated legislation and resource implications, as well as safe haven/honest broker provision.

It was hoped that this paper would be finalised by the following week and forwarded to Julie Thompson, prior to sending onto the Minister for Health.

- The Regional Information Governance Group, chaired by Julie Thompson, is currently reviewing data quality etc.

9. Joint Meeting with Personal Data Guardians

The joint PAC/PDG meeting has been confirmed for Thursday, 13th September at 10am - Castle Buildings, Stormont, Belfast.

The circulated draft agenda for this meeting was reviewed.

Agenda to be shared with Personal Data Guardians in advance of joint meeting, requesting any additional items for discussion.

RMcC

10. Any Other Business

11. Dates for Next Meetings

- Thursday, 13th September 2012 (Joint PAC/PDGs meeting)
- Thursday, 22nd November 2012