

45th Meeting of the Privacy Advisory Committee

Wednesday, 14th January 2015 at 10.00am
Boardroom, General Medical Council, 9th Floor, Bedford House,
16-22 Bedford Street, Belfast

Present: Professor Roy McClelland (Chair), Chris Matthews, Dr Jimmy Courtney, John Growcott, Brice Dickson, Geraldine Reynolds.

1. Apologies

Apologies were received from Grace Irwin and Dr Clodagh Loughrey.

Professor McClelland (RMCC) formally welcomed Geraldine Reynolds, Service User Representative, to the Privacy Advisory Committee.

2. Minutes of the Previous Meeting ~11th June 2014

The minutes of the previous meeting on 11th June 2014 had previously been circulated and agreed.

3. Matters Arising:

i. On-line Training Module

The development of the on-line training module in confidentiality, based on the Code of Practice on Protecting the Confidentiality of Service User Information (CoP), has progressed significantly. Susan Lewis, e-Learning Consultant, HSC Leadership Centre has produced a draft module. Logins/passwords have been allocated to all PAC members to enable them to review the module, which has three individual components, based on the layout and format of the CoP.

All members were asked to review the module and to forward any comments to Clare Murphy for collation and response to Susan Lewis, by mid-February 15.

Initial feedback was positive. It was felt that the module was interactive and would be a useful learning tool for HSC staff.

RMCC advised that further work would be required in relation to the roll-out of the module to HSC organisations and possible CPD accreditation.

Action: All

ii. NHS Blood and Transplant (NHSBT) Application

RMCC provided an update following discussion at the previous meeting, in relation to the request for advice from the NHSBT regarding the collection of potential donor audit information from N. Ireland data, in the absence of legislation similar to that in England and Wales and Section 251 approval.

There are currently 12 NHSBT employees working within N. Ireland who are extracting this information from patient data, for forwarding in a pseudonymised form, to NHSBT in England. The potential for data linkage is retained in N. Ireland.

As previously discussed, concern had been raised that although honorary contracts and Memorandum of Understanding were in place for these staff, the data extraction was being undertaken by staff members who were not employees of the HSC in N. Ireland.

RMcC advised that he had initiated discussion with both the PHA and the DHSSPSNI, outlining concerns on the issue regarding data protection and obtaining of consent. However, this initial communication had ceased. It was agreed that he should follow up on the matter with DHSSPSNI.

Action: RMcC

iii. Immunology

RMcC referred to correspondence which he and Dr Clodagh Loughrey had received from an Immunology trainee working in the Belfast HSC Trust, requesting guidance in relation to accessing additional data held on the NIECR for Immunology patients. Access was requested to additional data, only for relevant Immunology patients, which would be used to improve the care provided to those service users.

It was highlighted that a direct care relationship is in place – the trainee is a member of the Immunology Team and would be accessing the information for the purpose of clinical audit/review of care, with the aim of improving the direct care provided to service users; However it was queried whether this use of data was more in line with secondary use.

RMcC referred to Section 3.6 of the Code of Practice on Protecting the Confidentiality of Service-User Information - Review of care

'Review of care, including clinical audit and case review carried out by members of the care team and those supporting them, is for the purpose of improving the direct care of that service user. Such purposes have sufficient connection with that direct care for the sharing of information during the review of care to be justified on the basis of implied consent, provided the individual has been informed'.

It was agreed that the request from Immunology was in sufficient proximity to the above CoP guidance.

RMcC agreed to reply to the request and support access, providing that sufficient measures were in place to protect patient confidentiality ie: access should only be for relevant Immunology patients, with whom a direct care relationship is in place. RMcC agreed to copy Dr J Courtney (Dr JC) and members of the NIECR Project Board into his response.

Action: RMcC

4. Chairman's Update

i. GMC Review of Confidentiality Guidance

RMcC advised that PAC had responded to the GMC in relation to the content and format of the current consultation on the Review of Confidentiality Guidance. The consultation period would end in one week.

ii. Nuffield Council Report

PAC had submitted a response to the Nuffield Council on Bioethics - Biological and Health Data Consultation. The report following this consultation process will be launched in February 2015, following which it will be made available.

RMcC had requested a paper copy of the report.

5. Joint PAC and PDG Meeting – Wednesday, 24th September 2014

The joint meeting of the PAC with Personal Data Guardians (PDGs) had been held on 24th September 2014.

Sandy Fitzpatrick, Head of Information & Registration, Business Services Organisation (BSO) had attended the meeting to provide an update on developments around the Honest Broker Service (HBS) and Safe Haven (SH) provision.

Annual Personal Data Guardian training has been confirmed for Tuesday, 19th May 2015.

C Murphy to forward details to PAC.

6. NI ECR – Mental Health

RMCC referred to communication which he had received from Dr Michael Mannion, Northern HSC Trust, on behalf of the NIECR Project, in relation to the proposals for inclusion of mental health information within the NIECR.

Dr Mannion had been involved in discussions with members of the mental health commissioning team as well as HSC Trust representatives, regarding the proposed linkage of Trusts primary mental health systems to the NIECR. The proposal is to link limited summary information and give limited access to available documents (dependent on access level and clinical area).

Dr Mannion had contacted RMCC to seek the views of the PAC on the proposed incorporation of mental health data.

Dr JC, a member of the NIECR Project Board, provided an overview of the NIECR and its implementation. It was noted that since the launch of the NIECR in July 2013, around 1/2million patient records had been accessed, approx. 28% of the NI population and around 80% of clinical communication now takes place via the NIECR.

Dr JC advised that the NIECR Project Board had been approached by a number of Clinicians as well as Mental Health charities to request the inclusion of mental health information within the NIECR. The importance of access to this information was highlighted, particularly within the unscheduled care setting.

The issue of patient consent was discussed:

- Reference was made to the information leaflet which had been sent to all patients in N. Ireland, in advance of the implementation of the NIECR. The NIECR information leaflets continue to be issued along with medical cards in NI.
- Clinicians are required to obtain express consent from their patients, to enable them to access their records.
- Patients do have the option to have their records ‘locked’, however it was noted that of the small percentage of patients (0.3%) who had requested this, a proportion had subsequently asked for their records to be ‘un-locked’.
- Individual GP electronic systems are components of the NIECR with GPs also having access to hospital data via their NIECR access;
- The access controls which were in place on the NIECR were highlighted ie: role-based access and use of worklists for patients with whom the Clinician has a direct care relationship.
- An audit facility is also in place to monitor inappropriate access.

The paper which had been forwarded by Dr Mannion – *‘Proposals for Accessing Mental Health Information on the NIECR’*, was reviewed, including proposals for role-based access to mental health information.

Dr Mannion had advised that he had also had discussions with the Patient Client Council to seek the views of service-users, as to whether they were in support of mental health information being included in the NIECR. The Bamford Review Group had agreed to facilitate review of the proposals and to provide feedback.

The importance of the views of service-users and the need to ensure that service users were appropriately consulted on future developments was highlighted.

It was noted that there may be circumstances when the absence of mental health information from the NIECR may be detrimental to the care provided to patients in an acute care setting. However, the need for caution was also highlighted in relation to the content of the information provided by Clinicians within discharge summaries, which may be quite detailed, as well as third party information.

The implications of the sharing of sensitive information, including that related to social care, were discussed. It was highlighted that those who have access to view information would be required to have the relevant level of expertise to enable them to interpret that information in an informed way.

In principle, PAC would support the inclusion of mental health data in the NIECR with the specific restrictions and limitations on access stated in the "Proposals" paper. However, PAC's support was subject to the views of service users. It was noted that adequate consultation with service users is required and any concerns they may have should be addressed.

RMCC agreed to formally respond to Dr Mannion on behalf of PAC and to circulate a copy of the response.

Action: RMCC

7. Safe Haven/Honest Broker Provisions: Update - John Growcott

John Growcott advised that the Honest Broker Governance Board (HBGB) were due to meet again in January 15 and he agreed to provide an update on developments regarding Safe Haven and the Honest Broker Service at the next PAC meeting.

8. Legislation for Secondary Uses of Service User Information: Update

Chris Matthews (CM) provided an update on the DHSSPSNI *'Consultation on the Proposal to Introduce Primary Legislation for the Use of Health and Social Care Service User Identifiable Information for Secondary Purposes, in Controlled Circumstances'*.

- The consultation exercise had been undertaken and the responses reviewed.
- CM advised the he had informed the Health Committee of the proposals and was due to provide a further update to the Committee in February 2015.
- The Office of Legislative Counsel had also been consulted.
- CM advised that discussion had also taken place with the Attorney General's Office and he and RMCC had met with the AG on Friday, 9th January to outline the proposals and answer a number of queries. Clear examples in support of the need for legislation had been provided, as well as an outline of the implementation/role of the Honest Broker Service.
- Work is progressing and it is anticipated that the associated bill will be passed by October 2015, following which regulations will be drafted, on which a consultation exercise

will be undertaken.

- CM and RMcC had also discussed the proposals for the structure of the overseeing decision-making body and the associated administrative support which would be required.

There was some discussion regarding the existing processes in place in England and Wales and whether or not N. Ireland would benefit from proceeding with the same arrangements. There was also some discussion on whether applications from cancer and communicable diseases should be outside the remit of the decision-making body, as was current practice in England and Wales.

CM advised that further consideration would be given to the matter and welcomed any further views from PAC.

9. Information Governance Report

~ Chris Matthews, Head of Information Management

CM advised that Information Governance is moving to a steady state within the HSC.

Controls assurance policy is in place and is well established.

Work is ongoing in relation to the development of the HBS.

CM advised that he would be leaving his current post within the DHSSPSNI and would be transferring to another Directorate.

On behalf of the PAC, RMcC extended thanks and appreciation to CM for his valuable input to the work of the Committee and wished him well in his new post.

HSC Data Sharing Event ~ CM agreed to circulate to PAC information on a forthcoming data sharing event within the HSC.

Action: CM

10. Any Other Business

UK Council of Caldicott Guardians Newsletter (August 2014)

RMcC referred to the UK Council of Caldicott Guardians Newsletter, which had been circulated to PDGs and PAC for information.

11. Dates for 2015 Meetings:

- *Wednesday, 1st April 2015*
- *Wednesday, 24th June 2015*
- *Wednesday, 23rd September 2015 (joint meeting with PDGs)*
- *Wednesday, 25th November 2015*