42nd Meeting of the Privacy Advisory Committee

Wednesday, 27th November 2013 at 10.00am

Venue: Specialty Schools Room, NIMDTA, Beechill House

Present: Professor Roy McClelland (Chair), Chris Matthews, Dr Clodagh Loughrey, Grace Irwin, Brice Dickson, Dr Jimmy Courtney.

1. Apologies
Apologies were received from John Growcott.

2. Minutes of the Previous Meeting ~ 24th July 2013
The minutes of the 41st meeting held on 24th July 2013 were agreed.

3. *Matters Arising*
i) *Joint Meeting with Personal Data Guardians – September 2013*
Prof Roy McClelland (RMcC) provided feedback on discussion at the joint meeting of the PAC with Personal Data Guardians (PDGs) on 19th September 2013. It was agreed that the annual meeting was a valuable forum for both PAC and PDGs and should continue.

One issue which had been raised by PDGs was the exact role of the PDG today. PAC had agreed to revisit the role, the initial guidance for which was first issued by the Department of Health in 2006 and there have been a number of personnel changes since then. Concern had been raised by PDGs regarding the increasing volume of paperwork/documentation requiring sign-off by PDGs and of their reliance on SIROs and Information Governance Committees.

RMcC advised that he had since written to Dylis Jones Associates for guidance on the issue and to ask if the situation had some parallels with the role of the Caldicott Guardians in England and Wales. The issue would also be taken into account in future provision of PDG training, for which PAC is responsible.

The increasing information governance agenda and volume of the documentation required were noted and it was queried whether all PDGs are fully aware of the implications of this wider, fast-moving agenda.

The increasing volume of Data Access Agreements required to be signed-off for the transfer of information between HSC organisations and the HSCB and Department of Health was also noted – it was noted that this should diminish with the development of the Honest Broker Service and Safe Haven.

It was highlighted that each HSC Trust should have an Information Governance Department/Committee in place which should be in a position to provide support and guidance to the PDGs.

The need for an equivalent to the PDG within primary care was highlighted (each GP practice should have its own Information Governance Lead in place – this is an issue which may need further consideration).

It was agreed that the PAC should write to all PDGs, to re-iterate the existing guidance on the role of

the PDG and to seek feedback on the exact issues/difficulties which they feel they require clarification on.

RMcC agreed to draft a letter and short survey to be circulated to PDGs and to forward to PAC for comment:

RMcC

Suggestions for inclusion in the survey included:
o How effective PDGS feel their role is and how comfortable they are in undertaking this role within their organisation;
o Whether they feel that the role of the PDG has changed significantly in recent years and if the outline of the role, as previously circulated, requires updating;
o Do they feel sufficiently involved in, and aware of, the wider Information Governance agenda in relation to privacy and confidentiality matters;
o Do they feel supported by an Information Governance Committee/Department and/or by the SIRO?
o Do they attend meetings of other Information Governance forums?
o Do they feel that the Privacy Advisory Committee can provide further clarification or support and are the existing arrangements for the annual PDG training considered to be sufficient?
o Are they aware of the role of REC2, and do they feel that the support provided by REC2 is sufficient?
o Any other main concerns/issues.

ii) On-Line Training Module
The most recent Version (1.4) of the on-line training confidentiality module, drafted by Dr Colin Harper had been circulated to PAC for comment.
It was agreed that the target audience for the on-line module was for those HSC staff who would be required to use the Code of Practice on Protecting the Confidentiality of Service User Information (COP) and who would have responsibility for decision-making as to whether service user information should be shared; eg: Senior Social Work staff, Care Home Managers, Information Governance Leads, consultant medical staff etc. The module will not be suitable for all HSC staff.
It was agreed that the content of the module met the required level, was robust and sufficiently detailed, however it was also proposed that the length of the module be reduced where possible, to retain key information/fundamental aspects, without restricting overall content and relevant information. Links can be included to the COP (which already contains additional information/references) however it was highlighted that the module still needs to be a stand alone document.

It was also proposed that the module be modified to make it more 'user-friendly' ie: inclusion of symbols, graphics, possible scenarios; and that the Introductory Section be summarised.
The module contains 6 Sections (in line with the structure and content of the COP) including an Introduction as well as a 'Self-Assessment Section' at the end of the module.
Whilst some sections of the module may be more applicable to certain groups of staff (eg: sections 5 & 6 in relation to social care), it was noted that all those accessing the training should be aware of and have covered all sections.
PAC agreed to review the module within the next few weeks and to provide feedback, indicating where they feel the content can be reduced.

All

RMcC agreed to contact the HSC Leadership Centre, who will host the on-line module, to see what CPD accreditation can be allocated on completion.

RMcC

iii) PDG Training
The next annual Personal Data Guardian training will be arranged for Spring 2014, facilitated by the Beeches HSC Leadership Centre - date to be notified to PDGs once confirmed. Arrangements will be as for the 2013 training, with individual organisations funding the training of their PDGs.
PAC members are welcome to attend the training if they feel this is required.

4.   *Chairman's Update*
     i) Congenital Anomaly Register Seminar
     RMcC advised that he had been invited to participate in the Congenital Anomaly Surveillance in Northern Ireland Seminar on 23rd October 13, hosted by the University of Ulster, which co-ordinates a number of Congenital Anomaly Registries throughout Europe.

     In response to a request from the Department of Health, who are currently drafting a consultation paper for submission to the Minister on the need for secondary uses legislation in Northern Ireland, RMcC advised that he had provided a number of examples of recent requests for information sharing for secondary purposes, to outline how Northern Ireland would benefit from such legislation; including the aspiration to establish a NI Congenital Anomaly Registry.

     RMcC has also been in contact, on behalf of PAC, with Dr Heather Reid, Public Health Agency, to provide guidance and advice on confidentiality matters in relation to a number of ongoing National Confidential Enquiries, including maternal and child deaths. Work is ongoing.

5.   *Information Governance Review*
     The Government Response to the Caldicott Review – Information: To Share or not to Share – September 2013, Department of Health, had been circulated to PAC for review.
     It was acknowledged that it would be of benefit for Northern Ireland to have a read across of the Review to outline good practice in relation to information sharing within HSC organisations.
     Dylis Jones had forwarded a copy of the recommendations of the recent Caldicott Review, which RMcC agreed to circulate to PAC for information.

RMcC

6.   *Nuffield Council on Bioethics ~The Linking and Use of Biological and Health Data –*
     Open Consultation – October 2013
     The above consultation document was circulated to PAC for review and it was agreed that PAC should submit a response.
     RMcC agreed to draft a response and to circulate to PAC for comment, prior to the closing date for submissions which is 10th January 2014.

RMcC

7.   *Legislation for Secondary Uses of Service User Information – Update*
     Chris Matthews (CM) provided an update on developments in relation to legislation:
     The Department of Health are currently preparing a consultation document on the need for legislation regarding the secondary use of service user information, for Ministerial submission. It is hoped that this will be finalised within the next few weeks, with a view to undertaking the consultation in March 2014, and hopeful implementation of legislation by 2016.
     CM agreed to forward a copy of the schedule for implementation of legislation to PAC, not for wider circulation.

8. *Safe Haven Provisions Update*

CM provided an update on Safe Haven provision:
The initial stage of the introduction of a Safe Haven facility for the provision of pseudonymised/anonymised information to HSC organisations, hosted by the Business Services Organisation (BSO), had gone live on 4th November 2013, with planned gradual development and implementation. Formal communication had been issued to Chief Executives advising that while they will not be required to review all Data Access Agreements at this stage, the use of the Safe Haven facility should be considered when the Agreements are due for renewal.
It is planned that the Save Haven facility will be available for research purposes as from January 2014 – CM to discuss further with Dr C Loughrey.

Phase 2 of the implementation process, including work on metadata, data-sets and data quality is ongoing. The quality of the data sets will be reviewed by the Regional Information Group (RIG); Requests for information will be submitted to the Safe Haven, processed within and the output, in the form of pseudonymised/anonymised information, will be returned to the requestor.
A Safe Haven Governance Board to oversee the requests has been established, chaired by John Growcott.
An Honest Broker Governance Board has also been established and will review applications.

Concern which had been raised at a previous meeting of the PAC, in relation to information governance arrangements associated with the provision of an Honest Broker service, had been discussed further with CM and the concerns raised had been addressed satisfactorily.

RMcC highlighted that the Safe Haven initiative will enable and optimise the secondary uses of service user information for a range of important health and social care purposes. He added that consideration should also be given to placing the Safe Haven on a statutory footing, in the context of legislative developments.

9. *Information Governance Report*
CM advised that there had been significant changes with regards to the development of Information Management Controls Assurance Standards for HSC organisations, with the number of criteria to be addressed increasing from 7 to 27. The Department of Health are working with HSC organisations to address the information governance challenges which these changes have presented.

10. *Review of Progress*
The PAC Review of Progress for 2013 was circulated to PAC for comment. RMcC asked that the document be reviewed and any suggested amendments be forwarded, following which he would submit to the Department of Health.

RMcC

11. *Any Other Business*
None.

12. *Date of Next Meeting*
2014 dates were circulated, as below:
- *Wednesday, 22nd January 2014*
- *Wednesday, 9th April 2014*
- *Wednesday, 21st May 2014*
- *Wednesday, 23rd July 2014*
- *Wednesday, 24th September 2014*
- *Wednesday, 26th November 2014*