44th Meeting of the Privacy Advisory Committee Wednesday, 11th June 2014 at 10.00am Room 101, 1st Floor, School of Law, 27 University Square, Queen's University Belfast

Present:

Professor Roy McClelland, Dr Jimmy Courtney, Brice Dickson, Grace Irwin, John Growcott, Dr Clodagh Loughrey.

1. Apologies

Apologies were received from Chris Matthews.

2. Minutes of the Previous Meeting ~ 9th April 2014

The minutes from the previous meeting on 9th April 2014 were agreed.

3. Matters Arising:

i. On-line Training Module

Prof McClelland (RMcC) provided an update on the development of the confidentiality on-line training module.

The module is now in final draft with a few minor additions to be included – John Growcott (JG) agreed to follow up with Dr Colin Harper in relation to some additional information regarding decision-making on the sharing of children's information. C Murphy (CM) to forward contact details.

Action: JG/CM

RMcC advised that he had made initial enquiries with various organisations, including NIMDTA, the HSC Leadership Centre and DHSSPSNI, in relation to the awarding of CPD accreditation for staff who complete the on-line training module.

It was noted that the training module on confidentiality and information sharing will supplement the existing Information Governance training, which is mandatory for some staff within HSC organisations.

Further discussion is required to determine whether or not it will be possible to allocate CPD accreditation to the training module, as well as the roll-out of the module to individual organisations and whether or not it will become mandatory for particular groups of staff. The module is aimed at senior professionals and those involved in Information Management within health and social care.

Dr J Courtney (JC), Dr C Loughrey (CL) and JG agreed to discuss further with colleagues within the Business Services Organisation (BSO), Health & Social Care Board (HSCB) and Belfast HSC Trust, to see how similar on-line training modules had been implemented and to provide feedback to RMcC.

It was noted that it may be beneficial to include a link to the training module on the BMA and Royal College of Physicians websites – issue for further discussion.

ii. NHS Blood and Transplant Application

RMcC referred to correspondence received from Ms Alison Gane, Information Systems Security Manager, NHS Blood & Transplant (NHSBT), requesting advice/approval from PAC in relation to the collection of potential donor audit information from Northern Ireland data, by the NHSBT. RMcC had discussed with Ms Gane, the

particulars in relation to the collection of Northern Ireland data, in the absence of legislation similar to that in England & Wales and Section 251 approval.

Further to these discussions, RMcC had also had separate discussions with members of the NHSBT team based in Belfast, who had outlined the process for collection of information and had agreed to formally detail the information flows which are in place between NHSBT staff in NI and the UK.

Arrangements are in place in relation to the access of information, however a number of issues require further consideration.

The process for the flow of information and the pseudonymisation of patient data by the NI NHSBT staff means that no patient identifiable information is leaving N. Ireland. However, concern was raised that paper-based records are currently held by the NHSBT, outside of an HSC organisation in NI; and access to this information is undertaken by staff who are not directly employed by a HSC organisation. It was noted that collection of NI data has been ongoing since 2003.

Honorary contracts are in place for Specialist Nurses: Organ Donation (SNODs) to collect the data and Memorandum of Understanding (MOUs) are also in place with individual organisations, which RMcC had been advised, are in the process of being signed-off for 2014.

Grace Irwin (GI) agreed to enquire regarding the existence of an MOU within the Northern HSC Trust and to provide feedback to RMcC.

Action: GI

RMcC advised that he would be seeking further clarification and advice on the processes from Dr Martin Donnelly, Chief Medical Officer Group, DHSSPSNI, and Dr Eddie Rooney, PHA; and would also enquire with his counterpart in Scotland to determine what arrangements are in place there.

RMcC to keep PAC informed of further discussion and developments via e-mail.

Action: RMcC

CL agreed to make further enquiries with colleagues in the Belfast HSC Trust (Transplant Co-Ordinator and Organ Donation Lead) and to provide feedback to RMcC.

Action: CL

4. Chairman's Update

i. GMC Review of Confidentiality Guidance

RMcC referred to communication from the GMC, who are planning to begin a review of their guidance for doctors on confidentiality in the autumn of 2014 and have welcomed comments from PAC on the content and format of the current guidance.

RMcC asked PAC to review the existing guidance and to forward any comments to him by Friday, 20th June, to allow a formal response to be submitted to GMC, by 25th June 14.

Action: All

5. Safe Haven/Honest Broker provisions: Update - JG

JG, Chair of the Honest Broker Governance Board (HBGB), provided an update on the development of a Safe Haven/Honest Broker Service (HBS), to be hosted within the BSO. A briefing paper was circulated outlining the aims of the HBS, the role of the BSO, governance issues, Terms of Reference and the procedure for processing of requests for information etc.

A number of workshops etc are ongoing to promote the development of the HBS and to

outline its proposed role and uses.

The HBS will initially focus on health data, however it will eventually include social care data as well.

Applications made to the HBGB will require to be initially approved by the Research Ethics Committee (REC).

The HBGB will seek to recruit a number of service-users to join the Board.

JG advised that the HBGB would forward regular updates to PAC, once the Board was fully implemented.

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

RMcC advised that he had received an update from Chris Matthews 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.

Work is ongoing to incorporate the initial feedback and comments received from PAC into the consultation document.

It was noted that an advisory group will be a key element in the proposed legislation – similar to the PIAG/CAG approval process. Work is ongoing.

7. Information Governance Report

~ Chris Matthews, Head of Information Management Discussion deferred to next meeting.

8. Joint PAC and PDG meeting – Wednesday, 24th September 2014 (Enc 1)

The draft agenda for the joint meeting of the PAC with Personal Data Guardians on Wednesday, 24th September 2014, was circulated and reviewed.

PAC were asked to consider and to forward any additional items for discussion. It was agreed that it would be beneficial to PDGs to invite a speaker to attend the joint meeting, to facilitate learning and discussion regarding child protection and decision-making about the sharing of confidential children's information, given a number of ongoing judicial reviews and enquiries. JG agreed to inform PAC of the outcome of recent child protection enquiry. The importance of shared learning was highlighted.

Action: JG

9. Any Other Business

No further issues.

10. Dates for 2014 Meetings:

- Wednesday, 24th September 2014 (Joint Meeting with PDGs)
- Wednesday, 26th November 2014