43rd Meeting of the Privacy Advisory Committee

Wednesday, 9th April 2014 at 10.00am Boardroom, General Medical Council, 9th Floor, Bedford House, 16-22 Bedford Street, Belfast

Present

Professor Roy McClelland (Chair), Brice Dickson, Dr Clodagh Loughrey, Chris Matthews, John Growcott

1. Apologies

Apologies were received from Dr Jimmy Courtney and Grace Irwin.

2. Minutes of the Previous Meeting ~ 27th November 2013

The minutes of the previous, 42nd Meeting of the Privacy Advisory Committee, held on 27th November 2013 were agreed.

3. Matters Arising:

i. On-line Training Module

Prof McClelland referred to the most recent version of the on-line confidentiality training module, forwarded by Dr Colin Harper. In the absence of any further comments, the module would be finalised and made available for on-line publishing by the HSC Leadership Centre. Prof McClelland/Clare Murphy to take forward with Dr Harper and Paul Comac at the HSC Leadership Centre.

Prof McClelland agreed to contact Dr J Courtney to query the possibility of making the module available for medical staff, via the local branch of the BMA and/or Royal College of Physicians.

Prof McClelland advised that he had enquired on the possibility of awarding CPD accreditation on completion of the module and would follow-up on this with the HSC Leadership Centre.

RMcC

ii. PDG Training - 14th March 2014

Feedback from the annual Personal Data Guardian training provided by Dylis Jones Associates, had again been positive and it was agreed that the existing arrangements for the provision of annual training should continue.

4. Chairman's Update

Prof McClelland advised that the PAC continues to receive a steady flow of requests for advice, both at a local and national level:

i. NHS Blood and Transplant Application

Prof McClelland advised that he had been contacted by Alison Gane, Information Manager, NHS Blood & Transplant (Organ Donation and Transplantation Directorate) regarding the information collected in relation to potential transplant donors.

There are currently 12 full-time Specialist Nurses (Organ Donation), working within Northern Ireland, who are affiliated with NHS Blood & Transplant.

The compiling of information into a central potential donor register facilitates organ donation and also enables the auditing of donation.

Approval is sought for the collection of information on potential donors in Northern Ireland, similar to the arrangements in place within England and Wales. The implications of this, in relation to consent and the balance between maintaining patient confidentiality and the sharing of information in the public's interest were highlighted and discussed.

Prof McClelland advised that he would further discuss the issue with Alison Gane and the Manager who is responsible for the SN(OD)s working within NI, in respect to the differing situation in NI and the absence of statutory legislation on capacity and consent.

It was agreed that consideration needs to be given to the threshold for collection of information on potential donors.

Prof McClelland to share further information on the issue with Dr C Loughrey and Brice Dickson – for further discussion.

RMcC

ii. Regional Risk Stratification Activity

Prof McClelland advised that he and Chris Matthews had met with Rosemary Farrell, with regards to the ongoing pilot on Regional Risk Stratification Activity. The pilot involves extraction of data at source, within primary care and does not involve the exposure of identifiable information within any secondary domain. Work is ongoing. Prof McClelland to keep PAC informed of developments.

5. PDG Issues and Needs Questionnaire

Feedback from the questionnaire which had been circulated to Personal Data Guardians was reviewed. C Murphy to follow up with those PDGS who had yet to submit a response. Overall feedback had been positive — a number of comments and suggestions had been identified, including the need to review the existing definition of the role of the PDG and other factors which affected the role today eg: the role of the SIRO; Caldicott 2; honest broker/safe haven developments etc.

It was agreed that the further development of links with Caldicott Guardians in England and Wales, would be of benefit to PAC & PDGs and should be given further consideration.

Feedback from the questionnaire to be forwarded to PDGs and would be discussed further at the next joint meeting of the PAC with PDGs in September 2014.

6. Legislation for Secondary Uses of Service User Information

The draft public consultation for legislation for secondary uses of Service user information had been circulated and was reviewed.

PAC made a number of proposed amendments to the draft consultation. PAC were asked to forward any further comments to Prof McClelland no later than Friday, $11^{\rm th}$ April.

ΑII

7. Safe Haven/Honest Broker provisions- Update ~ John Growcott

John Growcott and Chris Matthews agreed to circulate an update to PAC on developments in relation to Safe Haven and Honest Broker provision, for further discussion at the next meeting.

JG/CM

8. Information Governance Report

~ Chris Matthews, Head of Information Management

Chris Matthews provided an update on Information Governance:

- Legislation work is ongoing in relation to the Legislation for Secondary Uses of Service User Information – the draft public consultation document is being finalised.
- SIRO and IAO training is now available on an ongoing basis, via the Beeches HSC Leadership Centre;
- Work is also ongoing in relation to the Child Health System.

9. Any Other Business

Care.Data

Prof McClelland referred to a recent article published in the BMJ in relation to the planned launch of Care.Data (paper circulated).

It was agreed that the article provided a useful insight into ongoing work in other parts of the UK regarding the link between primary and secondary care records and the ongoing issues in relation to patient confidentiality, which are of relevance to future developments in Northern Ireland.

10. Dates for 2014 Meetings:

Wednesday, 11th June 2014 – venue to be confirmed.