

48th Meeting of the Privacy Advisory Committee

Wednesday, 22nd June 2016 at 10.00am
Room 101, 27 University Square, Queen's University Belfast

Present: Professor Roy McClelland (Chair), Dr Clodagh Loughrey, John Growcott, Brice Dickson, Colin Harper

1. Apologies & Welcome

Apologies were received from Grace Irwin, Dr Jimmy Courtney, John Millar, Geraldine Reynolds and Dr Michael McKenna.

Prof McClelland welcomed Dr Colin Harper to the Committee and introductions took place.

It was noted that Dr Jimmy Courtney had stepped down from his role as BMA NI representative to the PAC. Prof McClelland advised that he had written to Dr Courtney on behalf of PAC, to extend thanks and appreciation for his valuable input to the Committee over the last number of years. Dr Courtney continues to provide input to the BSO on information issues, including the NIECR and Prof McClelland had asked him to alert PAC to any new developments which may be of interest to the work of this Committee.

Dr Michael McKenna had been appointed as the new BMA NI representative to the PAC and will attend the joint meeting with PDGs in September 2016.

2. Minutes of the Previous Meeting ~ 20th January 2016

The minutes of the 47th meeting of the Committee held on 20th January 2016 had been agreed and posted on the PAC website.

3. Matters Arising:

3.1 NHS Blood and Transplant Application

Further to discussion at previous meetings, Prof McClelland advised that discussions were ongoing with Dr Paddy Woods, Personal Data Guardian, DHSSPSNI, regarding the work of the NHS Blood & Transplant staff who are involved in the collection of potential donor audit information from N. Ireland data.

3.2 On-Line Confidentiality Training Module

The on-line training module in confidentiality, based on the Code of Practice on Protecting the Confidentiality of Service User Information, had been launched in July 2015, hosted on the HSC Leadership e-learning portal. Uptake will be monitored by the HSC Leadership Centre and PAC will be provided with a report on uptake, by organisation, with the initial report due at the end of March 2017.

4. Chairman's Update

4.i Meeting with Medical Directors on Data Contribution from Northern Ireland to National Clinical Audits

Prof McClelland referred to the meeting which he had been invited to attend with Dr Paddy Woods, Deputy Chief Medical Officer/Personal Data Guardian, along with the Medical Directors of the HSC Trusts, in January 2016, to discuss data flows and patient consent in relation to information provided from N. Ireland to a number of national audits.

Medical Directors had agreed to undertake a programme of work to review the existing arrangements in place within their organisations, in relation to their participation in regional clinical audits and the flow of information.

Medical Directors had been referred to the guidance contained within the Code of Practice on Protecting the Confidentiality of Service User Information.

Following this review, Dr Woods had written to the Healthcare Quality Improvement Partnership (HQIP) and NICOR, in May 2016, to provide an update on the work being undertaken by HSC Trusts, to address any outstanding issues in terms of flow of information to national audits and to advise that work is ongoing to develop a standardised approach across N. Ireland, in line with the Code of Practice and the DHSSPSNI Data Sharing Protocol.

N. Ireland HSC Trusts will continue to participate in the existing regional studies.

Copies of the two letters had been circulated to PAC for information.

Dr Woods had also met with Information Governance Leads within the HSC Trusts to request that work is undertaken to ensure that the flow of information is in line with the COP and the DHSSPSNI Data Sharing Protocol.

Grace Irwin had provided Prof McClelland with an update on progress in relation to the work being undertaken by IG Leads:

- Each HSC Trust had compiled a list of the information flows to national audits and this had been consolidated into a single regional list;
- Each Trust is now working through the list, checking that there are safeguards in place eg: pseudonymisation of data, confidentiality clauses, Data Access Agreements etc.
- Work is ongoing within each Trust to ensure that all contribution of N. Ireland data to regional audits have been identified and this is a work in progress.

Prof McClelland to seek further clarification from Grace Irwin on the ongoing work.

Prof McClelland

John Growcott also agreed to seek an update on progress from Gillian Acheson, Information Governance Lead, Belfast HSC Trust.

John Growcott

It was agreed that the issue could be included as an agenda item at the joint meeting with PDGs in September, to emphasise the need for compliance with the COP in relation to data sharing, in the absence of current legislation.

4.ii GMC Review of Confidentiality Guidance

Prof McClelland advised that he and representatives from the PAC had attended a round-table exercise with the GMC in February 2016, to discuss the review of its confidentiality guidance. An extensive public consultation exercise had been undertaken by the GMC on the review of the guidance and the opinions of a wide range of groups had been sought. It is expected that the revised guidance will be published by late 2016.

5. Northern Ireland Life & Times Survey of Public Attitudes to Data Sharing ~ ARK Seminar: 7th September 2016

Prof McClelland advised that he had been invited to meet with Professor Helen Dalk, University of Ulster and Prof Gillian Robinson, Director of Access Research Knowledge N. Ireland (ARK), to discuss the outcome of a survey which had been jointly undertaken in relation to public attitudes to data sharing in N. Ireland. A seminar to present the findings of the survey is scheduled for Wednesday, 7th September 2016 in the University of Ulster Belfast Campus. Prof McClelland agreed to circulate details of the seminar to PAC as members may wish to attend.

Prof McClelland

Prof McClelland referred to the content of the survey, which had included scenario-based questions on data sharing, extraction and linkage, as well as the obtaining of consent, in relation to the sharing of health and direct care data.

There was discussion regarding the wider implications of data sharing in relation to health and social care information and the changing public perceptions surrounding this.

6. Joint Meeting with Personal Data Guardians ~ 14th September 2016

A draft agenda for the up-coming joint meeting of the PAC with Personal Data Guardians (PDGs) on 14th September 2016, was circulated and reviewed.

PAC will provide an update on the following:

- On-line Training Module on Confidentiality;
- GMC Review of Confidentiality Guidance;
- Data Contribution from N. Ireland to national clinical audits.

It was agreed that the new Chair of the Honest Broker Governance Board should be invited to attend the joint meeting to provide an update on the Honest Broker Service.

It was suggested that Information Governance Leads from the HSC Trusts/organisations be invited to attend the joint meeting of the PAC with PDGs. Prof McClelland agreed to raise this suggestion with PDGs.

Prof McClelland

Items for discussion will be sought from PDGs in advance of the meeting.

7. Safe Haven/Honest Broker Provisions

Prof McClelland provided an update on the Safe Haven/Honest Broker Service, on behalf of John Millar (copy of report circulated to PAC);

- The HBS had been launched in June 2014 to facilitate access for ethically approved researchers, health planners and policy makers to anonymised and pseudonymised NI HSC data and is now the preferred method for granting organisations access to data – there are

now 45 data sets available from HSC systems and this is expected to increase in the coming year;

- The Honest Broker Governance Board (HBGB) is established and in operation, with an agreed Terms of Reference.
- It was noted that to date 17 research applications and 16 HSC applications have been approved.
- As the HBS is now moving into its third year of operation it is intended that a review should take place, on which PAC will be engaged in the near future.

It was proposed that the Chair of the HBGB be invited to a future PAC meeting to provide an update on progress.

8. HSC (Control of Data Processing Act): Update

Prof McClelland provided an update on the HSC Control of Data Processing Act, on behalf of John Millar:

Primary legislation had received Royal Assent in April 2016.

Final operational policy proposals will be developed, to include provision for opt-out; development of a Code of Practice; provision for annual review; definition of processing; fines and penalties; and the establishment and operation of a Statutory Committee.

John Millar will continue to update PAC on progress on this work and on the timescales involved.

9. Information Governance

It was noted that the EU General Data Protection Regulation (GDPR) officially comes into effect in May 2018. Implementation is being managed as a N. Ireland Civil Service wide project.

10. Any Other Business

No further business.

11. Dates of 2016 Meetings

Wednesday, 14th September 2016 ~ Joint Meeting with PDGs;

Wednesday, 16th November 2016.