

47th Meeting of the Privacy Advisory Committee

Wednesday, 20th January 2016 at 10.00am
Room 101, 27 University Square, Queen's University Belfast

Present: Professor Roy McClelland (Chair), John Millar, Brice Dickson, Geraldine Reynolds.

1. Apologies

Apologies were received from Grace Irwin, Dr Jimmy Courtney, Dr Clodagh Loughrey and John Growcott.

2. Minutes of the Previous Meeting ~ 24th June 2016

The minutes of the 46th meeting of the Committee held on 24th June 2015 were agreed.

3. Matters Arising:

Joint Meeting of the PAC with Personal Data Guardians ~ Wednesday, 23rd September 2015

The joint meeting of the PAC with PDGs took place on Wednesday, 23rd September 2015. Fionnula Flannery, Standards & Ethics, GMC had attended to provide an update on progress regarding the GMC's review of its confidentiality guidance.

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. All HSC organisations have been advised of the availability of the programme. 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 at the end of March 2017.

NHS Blood & Transplant Application

Prof McClelland advised that he was still in discussions 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. Concern had been raised that although these staff did have honorary contracts and Memorandum of Understanding were in place, the data extraction was being undertaken by staff members who were not employees of the HSC in N. Ireland.

Prof McClelland to follow up on the issue with Dr P Woods.

RMcC

4. Chairman's Update

Meeting with Medical Directors ~ 18th January 2016

Prof McClelland advised that he had been invited by Dr Paddy Woods to a Medical Leaders meeting on Monday, 18th January 16 to discuss data flows and patient consent in relation to information provided from N. Ireland into a number of national audits.

Medical Directors had been asked to review existing information flows from their organisations and were reminded of the need to ensure that data is anonymised at source and that patient

consent is obtained where possible.
Medical Directors had agreed to report back on progress.

5. GMC Review of Confidentiality Guidance

There was discussion regarding the current GMC consultation on the review of its confidentiality guidance – consultation documents had been circulated and were reviewed.

Representation from the PAC would attend the GMC's round-table exercise on Tuesday, 9th February 2016.

Representation to be confirmed.

6. Administrative Data Research Centre NI ~ Dr Dermot O'Reilly/Dr Frances Burns

Dr Dermot O'Reilly and Dr Frances Burns from the Administrative Data Research Centre (ADRC), NI, provided an overview of the background to and work of the ADRC, including its links with the NI Statistics & Research Agency (NISRA), Queens University Belfast and the University of Ulster.

The overarching Administrative Data Research Network (ADRN) is responsible for linking data between government departments. ADRCs have been established within England, Wales, Scotland and N. Ireland. The ADRN will facilitate research access to administrative data and allow linkage between departments to take place more efficiently.

Assurance was provided that the data use is ethical and lawful and for the benefit of the public. Researchers will be trained and accredited to access and use data responsibly. Data is protected within state of the art technology. All data is de-identified and the linked administrative data will be accessed by the accredited researchers within secure settings. All research applications must pass legal and ethical criteria and are required to adhere to specific criteria, which have been approved at the outset. An audit trail/output controls will also be in place to ensure that identities are not disclosed.

Retention and disposal policy – it was highlighted that the ADRCNI does not undertake data warehousing of any kind, unlike the N. Ireland Honest Broker Service. A retention and disposal policy is in place - data output on completed projects is destroyed after 5 years.

Consent:

Dr Frances Burns referred to the issues of consent surrounding the work of the ADRC. Informed discussions have taken place with Mr Ken Macdonald, Assistant Commissioner within the N. Ireland Information Commissioners Office; Disclosure control policies are in line with the principles of the Data Protection Act - ie: fair and lawful processing of data; data must be adequate, relevant and not excessive. The ADRCNI has no capacity to release identifiable information. As well as research projects requiring legal approval, ethical consideration will also be applied to each project.

It was also noted that measures are in place to ensure transparency and public awareness/engagement, including the requirement for researchers to summarise the outcome of their findings in lay terms, with information on outcomes to be published by the ADRN.

There are currently four approved projects within N. Ireland, with a number of others in the

pipeline.

It was queried whether measures are in place for 'opt-out' provision for data subjects who do not wish their information to be shared with the ADRN for research purposes.

Dr Frances Burns advised that this responsibility would rest with the 'data controllers' who would be required to ensure that the information belonging to those individuals who have chosen to 'opt-out', was not released to the ADRN.

At present this is not detailed within the ADRN's guidance. The merit of including this was raised. However, it was noted that the characteristics of individuals who have 'opted out' would need to be shared with researchers, otherwise research outcome may be affected.

Query whether it is currently possible to link educational with health data?

At present there is no common way of linking these data sets and this will be a challenge for future research.

Query whether it will be possible to link data-sets across the UK, between different jurisdictions?

This would be possible, however both data custodians would need to agree on the sharing of data for research purposes.

In summary, the PAC were assured that sufficient policy/controls are in place within the ADRCNI, to ensure that sensitive personal information is processed, in a non-identifiable form and is in line with the principles of the Data Protection Act. Robust and safe controls were considered to be in place.

John Millar referred to the HILS Hub and research work being undertaken by the University of Ulster at the Magee campus, which had been referenced recently by the Health Minister.

Dr Burns agreed to look into this and to report back to PAC on how this work compares to that of the ADRCNI.

Dr Frances Burns

John Millar to enquire, via the Information Governance Committee, to see if there is any current transfer of data from the BSO HBS to the University of Ulster.

John Millar

John Millar referred to the ongoing work within the DHSSPSNI and the consideration by the NI Assembly of the HSC Data Processing Bill (legislation for the secondary use of information).

The need for openness/transparency and the need to keep the public informed of how their data is to be used for research purposes, was highlighted.

7. Safe Haven/Honest Broker Provisions: Update

~ John Millar, Head of Information Management, DHSSPSNI

John Millar provided an update on developments regarding the Safe Haven and Honest Broker Service (HBS);

- Dr Brendan O'Brien, Health & Social Care Board, has been appointed as the new Chair of the HBS Governance Board;
- The HBS is enabling the provision of anonymised, aggregated and in some cases pseudonymised health and social care data to the DHSSPS, HSC organisations; and anonymised data for ethically approved health and social care related research;

- A number of projects have now been completed, and there are 13 current projects, details of which can be viewed on the BSO's website;
- HSC organisations will be encouraged to use the HBS as opposed to having multiple data agreements in place within their organisations. J Millar advised that this work would be taken forward via the HSC Information Governance Group;
- It was noted that the HBS would facilitate N. Ireland's participation in a number of national enquiries and would address any existing difficulties involving the flow of information from N. Ireland HSC organisations.

8. HSC Control of Data Processing Bill ~ Update

John Millar provided an update on progress on the HSC Control of Data Processing Bill:

- Work is now at an advanced stage, the Bill went through the consideration stage by the NI Assembly on Monday, 18th January 16. Legal advice had been sought in relation to 'opt-out' provision, which will be incorporated into the Bill and will be addressed via regulations;
- Final consideration of the Bill by the Assembly is scheduled for Tuesday, 26th January 2016.

9. Information Governance Report

~ **John Millar, Head of Information Management, DHSSPSNI**

John Millar provided an update on Information Governance:

- DHSSPSNI will be undertaking an internal review of its Controls Assurance structure;
- John Millar is also leading on a review of the IT Security Controls Assurance;
- Questionnaires will soon be issued to Senior Information Risk Owners (SIROs) for completion and return;
- The 'Good Management Good Records' consultation has now closed and responses are being reviewed – the DHSSPSNI are engaging with the Information Commissioner's Office (ICO) in this regard.

10. Any Other Business

No further business.

11. Dates for 2016 Meetings:

Dates as circulated:

- Wednesday, 16th March 2016 ~ GMC Office;
- Wednesday, 22nd June 2016 ~ Venue To Be Confirmed;
- Wednesday, 14th September 2016 ~ Joint Meeting with Personal Data Guardians, Castle Buildings, Stormont;
- Wednesday, 16th November 2016 ~ GMC Office.

12. PAC Annual Report 2015

Prof McClelland referred to the PAC's annual report for 2015 which had been circulated and had been submitted to the DHSSPSNI, under the terms of reference of the Committee.