

53rd Meeting of the Privacy Advisory Committee

Wednesday, 21st November 2018 at 10:00am

Venue: Meeting Room, Post Graduate Centre, Belfast City Hospital

Present: Prof Roy McClelland (Chair), Prof Brice Dickson, Dr Colin Harper, Gillian Acheson, Geraldine Reynolds, Dr Michael McKenna, Dr Clodagh Loughrey, Brendan O'Neill, Liam Carr

Prof McClelland welcomed Liam Carr, who had recently taken up post within the Information Management Branch, Department of Health and would be assisting Brendan O'Neill in progressing the development of Regulations for the implementation of the HSC (Control of Data Processing) Act NI 2016.

1. Apologies

None.

2. Minutes of the Previous Meeting

The minutes of the previous meeting held on 12th April 2018 were agreed. A file note of the joint meeting of PAC with Personal Data Guardians and members of the Information Governance Advisory Group held on 13th September 2018, had been retained by PAC for future reference.

3. Matters Arising:

i. Joint meeting with PDGs and IGAG - Future Meetings

Prof McClelland referred to the recent joint meeting of PAC with Personal Data Guardians (PDGs) in September 2018, to which members of the Information Governance Advisory Group (IGAG) had been invited for the first time.

Ken Macdonald and Roisin Kerr from the Information Commissioners Office (ICO), had attended the meeting to discuss the recently implemented General Data Protection Regulation (GDPR) and the Data Protection Act 2018.

Members of PAC who had attended the meeting agreed that it had been beneficial to have IGAG representatives present, with valuable input in relation to Information Governance issues and shared learning. It was agreed that if PDGs were in agreement, IGAG members should be invited to attend future joint meetings of PAC/PDGs.

Prof McClelland agreed to write to PDGs to seek their views on this proposal.

ACTION: Prof McClelland

Following the September joint meeting, Ken Macdonald, ICO, had forwarded a detailed response to the individual queries which PDGs/IGAG had raised in advance of the meeting, as circulated (Enc 1). This response had been circulated to PDGs and IGAG members.

There was some further discussion regarding the implications of GDPR/DPA18 implementation for HSC organisations, including primary care. Dr McKenna

highlighted the increase in the number of Subject Access Requests.

The need to move away from reliance on 'consent' as well as the requirements for 'opt out' provision were also discussed, particularly in relation to the existing NIECR and ongoing work on the encompass Programme, the HSC-wide initiative that will introduce a digital integrated care record to N. Ireland.

Brendan O'Neill advised that he would contact Gary Loughran, Director of the encompass Programme, in relation to information governance implications for the programme, following the implementation of GDPR/DPA18.

ACTION: Brendan O'Neill

ii. Updated Code of Practice

Prof McClelland noted that given the likely timeframe for the new legislation, it had been agreed that PAC undertake an interim 'light' review of the existing COP.

This review had included edits to Chapter 3B of the Code, relating to the use and disclosure of personal identifiable information for purposes of health and social care not directly related to care of that service users ie: secondary uses.

Following the in-house review undertaken by PAC, the updated version had been shared with colleagues within the Childcare Branch of the Department of Health, and a number of additional changes had been recommended, in light of recent judicial reviews.

Prof McClelland had shared these proposed changes with PAC and requested feedback. Lengthy discussion took place regarding the proposed amendments to Chapter 5 of the document re '*Decision-making about whether to use or disclose personal information relating to children*'. A number of comments were noted:

- Para 5.14 - it was felt that additional guidance/clarification was required in relation to referrals to the 'Gateway Service', possibly a footnote to explain the role of the Service and further detail on how it operates. Concern was also raised regarding the wording of this paragraph in relation to the 'threshold' for disclosure of information. The need to consider the variable threshold for disclosure of information between 'medical' and 'social care' professionals was also highlighted;
- PAC agreed that the edits proposed by Childcare colleagues within the Department of Health, should be considered further;
- Prof McClelland agreed to review the edits, in line with other available guidance in relation to sharing of information of children and to share with PAC colleagues, for further comment and discussion via e-mail.

Action: All

iii. NHS Blood and Transplant (NHSBT) Application

Prof McClelland advised that discussions were ongoing regarding the work of NHSBT staff involved in the collection of potential donor audit information within N. Ireland. PAC had previously raised concern in relation to data extraction being undertaken by NHSBT staff, who are not employees of the HSC in N. Ireland, and who therefore do not have a direct care relationship with potential donors.

Dr Paddy Woods, PDG/Deputy CMO, had invited Prof McClelland to attend a recent meeting of the N. Ireland Medical Leaders Forum, to discuss how the issue could be addressed, to ensure practice is consistent with the COP.

Further to discussion, Dr Woods had agreed to contact the relevant Intensive Care Unit Clinical Leads, to consider how the issue could be resolved and had agreed to provide feedback to Prof McClelland on the outcome of discussions. No further update available at this time. Prof McClelland to follow up with Dr Woods. Item to remain on this agenda.

Action: Prof McClelland.

4. Chairman's Update

i. Intensive Care National Audit & Research Centre (ICNARC) Data Flows

Prof McClelland advised that Sasha Korniak, Head of Data and Business Technology, ICNARC, had attended the joint meeting of PAC with PDGs/IGAG members in September 2018, to provide an update on the work being undertaken by ICNARC, in respect of N. Ireland's participation in this national audit.

Work is ongoing to ensure that the flow of data meets the requirements of DPA18, in the absence of the equivalent of Section 251 legislation in N. Ireland. ICNARC are working towards a technical solution, which will provide a means for the anonymisation of data at source (involving 'privacy by design' and one-way cryptographic hash function of personal information).

The proposed technical solution will involve the use of an algorithm to create additional unique identifiers, which will enable accurate and secure data linkage.

This solution will adhere to data protection regulations, by ensuring that only those who input the patient data within the source organisation, and therefore with a direct care relationship, will have access to the unique patient identifiers.

Prof McClelland advised that he had recently contacted Mr Korniak to request an update on progress and the expected timeframe for the proposed technical solution – further update awaited.

ii. The PIND (BPSU) Study in Northern Ireland

Prof McClelland provided an update on the outcome of e-mail correspondence and discussions with the Principal Investigator involved in a study of progressive intellectual and neurological deterioration in children (the PIND Study) which is being carried out using the British Paediatric Surveillance Unit (BPSU) system. The PIND study has been on the BPSU system since 1997 and has been performing UK-wide surveillance for vCJD in children since then.

Discussions had taken place to look at the options available to facilitate N. Ireland's participation in this UK-wide study, in the absence of the equivalent of Section 251 legislation.

Prof McClelland had also consulted with Consultant Neurology colleagues, to consider the options available to facilitate N. Ireland's participation in this national study ie: consent or anonymisation/pseudonymisation of data.

Further to these discussions, a solution had since been agreed, which will involve the pseudonymisation of data at source (using an agreed set of identifiers (month

and year of birth, partial postcode and gender), along with the creation of unique identifiers to enable follow up and data linkage.

This outcome will ensure maintenance of patient confidentiality as well as ensuring N. Ireland's continued participation in this important national study.

5. Advisory Committee for New HSC Act ~ Reflections on Past Work of PAC and Future Challenges

Prof McClelland referred to the circulated Enclosure 2 - Recent Applications/Communications on On-going Applications to PAC, which provided an overview of the recent work of the Committee, including communications with:

- Intensive Care National Audit and Research Centre (ICNARC);
- PIND (BPSU) Study in N. Ireland;
- National Institute for Cardiovascular Outcomes Research (NICOR) in relation to six national cardiovascular audits as part of the National Cardiac Audit Programme (NCAP);

Prof McClelland provided an update on discussions with James Chal, Chief Operating Officer of NCAP in relation to N. Ireland's participation in the above national studies.

- British Association for Oral and Maxillofacial Surgeons (BAOMS).

There was discussion regarding the existing role of the PAC and the future requirements of the new Committee to be established by the Department of Health, as part of the new legislation.

The possibility of PAC in its present form, given its current work and experience, on taking on the role of a shadow Committee for the new legislation was raised. It was noted that further discussion would be required between DOH and PAC, as if this proposal were to be implemented, it would significantly inform PAC's agenda and preparatory work would need to be undertaken.

It was agreed that it would be beneficial to liaise with the HRA Confidentiality Advisory Group (CAG), as there would be parallels between its work and that of the new Committee.

There was also discussion regarding the future challenges for facilitating important health & social care research, particularly in light of recent technological advances, while at the same time maintaining public confidence in how their personal data is stored and processed.

The need to further develop and maximise the use of the existing NI Honest Broker Service was also noted.

6. HSC (Control of Data Processing) Act 2016

Brendan O'Neill provided an update on the above legislation. Work is progressing as far as possible, pending Ministerial appointment.

The DOH will seek to engage further with all relevant stakeholders, including the research community.

7. Any Other Business

Dr McKenna thanked Prof McClelland for his guidance in developing Privacy Notices for use within primary care, which have now been disseminated widely.

Dr McKenna advised that he would be contacting Prof McClelland in the future in relation to the GPip Project.

8. Dates for 2019 PAC Meetings

- Thursday, 24th January 2019
- Wednesday, 10th April 2019
- Wednesday, 26th June 2019
- Wednesday, 18th September 2019 (Joint Meeting with PDGs)
- Thursday, 14th November 2019