

54th Meeting of the Privacy Advisory Committee

Wednesday, 10th April 2019 at 10:00am

Venue: Meeting Room 1, A-Floor, Belfast City Hospital

Present: Prof Roy McClelland (Chair), Prof Brice Dickson, Dr Colin Harper, Gillian Acheson, Brendan O'Neill, Liam Carr

In Attendance: Dr Dominic Trainor, Regional Lead for Organ Donation in N. Ireland / Clinical Lead for Organ Donation, Belfast HSC Trust

1. Apologies

Apologies were received from Dr Clodagh Loughrey, Dr Michael McKenna and Geraldine Reynolds.

2. Minutes of the Previous Meeting

The minutes of the previous meeting held on 21st November 2018 were agreed.

3. Matters Arising:

i. Joint meeting with PDGs and IGAG

Prof McClelland referred to the 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.

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.

Prof McClelland advised that he had subsequently written to PDGs to seek their views on the proposal to invite IGAG representatives to attend future joint meetings and there had been majority support for this.

IGAG members would be invited to attend the joint meeting in September 2019 and future joint meetings.

ii. Updated Code of Practice

Given the likely timeframe for the implementation of new legislation, PAC had undertaken an interim 'light' review of the existing Code of Practice on Protecting the Confidentiality of Service User Information (COP), in particular compliance with GDPR/DPA18.

This review had included edits to the relevant chapters 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*.

Brendan O'Neill advised that the revised COP had since been approved by the Department of Health and would be circulated to relevant parties, including to the

Chief Executives of the HSC Trusts and to Personal Data Guardians.

Prof McClelland agreed to review PAC's existing secondary uses guidance to take account of the recent updates to the COP.

Action: Prof McClelland

iii. NHS Blood and Transplant (NHSBT) Application

Prof McClelland welcomed Dr Dominic Trainor, Regional Lead for Organ Donation in N. Ireland & Clinical Lead for Organ Donation, Belfast HSC Trust.

Prof McClelland advised that further to discussion at the Medical Leaders Forum in late 2018, he had met with Dr Paddy Woods (Deputy CMO, Department of Health), Monica Hackett (Regional Lead, NHSBT) and Dr Trainor in February 2019, to discuss the ongoing work of NHSBT in relation to organ donation and the collection of potential donor audit information within N. Ireland.

Dr Trainor had been invited to attend to update PAC on this work and to provide further clarification on a few issues, including:

- The work of the Specialist Nurses for Organ Donation (SNODs) within the clinical team; and
- The status of patients being considered for inclusion in the Potential Donor Audit (PDA)/Referral database, whose records would be the subject of review and data extraction by the Specialist Nurses.

Prof McClelland referred to Enclosure 1, NHSBT Application Summary: Referral of Possible donors to Specialist Nurses, Organ Donation – Collection of Referral information (November 2013).

PAC had previously raised concern in relation to data extraction being undertaken by the Specialist Nurses, who are not employees of the HSC in N. Ireland, and who therefore do not have a direct care relationship with potential donors.

Dr Trainor provided an overview of the work of the dedicated Specialist Nursing team and their role in the complex organ donation process, also highlighting their close involvement with the clinical team in the provision of end of life care to patients within the ICU. Dr Trainor provided numerous examples of direct care delivery to patients by the Specialist Nurses.

PAC noted the strong public interest in the work of NHSBT, including national audit activity, and the need for the Specialist Nurses to access relevant patient identifiable information. It was also noted that in relation to data collected within N. Ireland, all patient identifiers are removed prior to uplift of the data to the national database and that only a partial postcode is used.

Discussion followed in relation to the physiological status of the patients within the critical care setting, whose data may be accessed by the Specialist Nursing team, as well as the inability to obtain patient consent.

PAC recognised the need for a balancing between maintaining patient confidentiality and facilitating disclosure of patient data to the NHSBT. The strong public interest in enabling NHSBT to undertake its valuable work in relation to organ donation was highlighted.

It was agreed that the NHSBT data sharing arrangements should, as soon as reasonably practicable, be brought within the remit of the HSC (Control of Data Processing) Act 2016.

Prof McClelland agreed to draft a letter to NHSBT, to outline PAC's deliberations of the above application and would circulate to PAC for final review and comment.

Action: All

Prof McClelland would also request that PAC be provided with the most recent PIAG approval for the work undertaken by NHSBT.

Discussion followed in relation to the information provided to patients as to how their data may be accessed and shared without their consent. It was agreed that this guidance should be reviewed to consider the work undertaken by NHSBT in relation to organ donation. PAC to consider further via e-mail correspondence. Prof McClelland agreed to circulate proposed amendments, for comment.

Action: All

iv. Advisory Committee for New HSC Act

Discussion took place regarding the possibility of PAC acting as a shadow committee to the new Advisory Committee, which is to be established under the HSC (Control of Data Processing) Act 2016. There was agreement on the benefit of this arrangement in order to ensure continuity of provision and experience during the transition to the establishment of the new Committee. The merit in appointing a deputy-Chair for PAC was also recognised.

Prof McClelland agreed to seek expressions of interest among existing members of PAC in undertaking the role of deputy-Chair.

Action: Prof McClelland

Prof McClelland advised that Dr Tony Calland, Chair of the Confidentiality Advisory Group (CAG), and Natasha Dunkley, Head of Confidentiality Advice Service, had accepted his invitation to attend the joint meeting of PAC with PDGs and IGAG members in September 19, to discuss the activities and processes of CAG.

Brendan O'Neill advised that representatives from the Department of Health also intend to meet separately with Dr Calland and Ms Dunkley to discuss the proposed role and function of the new Committee to be established under the new legislation.

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

Prof McClelland advised that he had written to Sasha Korniak, Head of Data and Business Technology, ICNARC, following his attendance at the joint meeting in September 2018, to request an update on the work being undertaken by ICNARC, in respect of N. Ireland's participation in this national audit.

ICNARC had been working towards a technical solution 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.

An update from ICNARC is awaited.

Brendan O'Neill advised that work is progressing to further utilise the existing Honest Broker Service to facilitate N. Ireland's participation in such national audits.

4. Chairman's Update

i) NISRA's Administrative Data Research Centre (ADRC-NI) and Health Projects

Prof McClelland referred to the circulated correspondence between himself and Orla Bateson, NISRA's Administrative Data Research Centre (ADRC-NI), regarding the use of secondary health data for research purposes.

ADRC-NI had forwarded guidance prepared by NISRA, clarifying the existing paths available for health research within the current legal framework. This guidance meant that the proposed ADRC health research could no longer proceed in its current form. ADRC are currently liaising with the Department of Health, to see if a path can be identified to allow this work to proceed.

Brendan O'Neill advised that Departmental colleagues were in the process of seeking legal advice in relation to this.

5. Proposed Retirement of the 'DHSSPS & HSC Protocol for Sharing Service User Information for Secondary Purposes (2012)

Brendan O'Neill advised that further to initial discussion at the joint meeting with PDGS/IGAG in September 2018, the Department of Health had formally written to PDGs in relation to the proposed retirement of the above Protocol, given recent legislative change and the implementation of GDPR/DPA 18.

PDGS had been in agreement with this proposal and the Protocol would be retired.

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.

Work is ongoing on the draft Terms of Reference for the new Advisory Committee. Department officials will discuss further with CAG in September.

Work is also progressing in relation to the impact of GDPR/DPA18 on the new legislation, including consideration of 'opt-out' provision.

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

7. Information Governance Update

Brendan O'Neill provided an update on Information Governance:

There had been a focus on preparation for Brexit, including cross-border data flows, and the formalising of MOUs and data contracts.

Work is also in progress in relation to Information Asset Registers – internal audits are ongoing.

8. Joint Meeting with PDGs and IGAG – Wednesday, 18th September 2019

The annual joint meeting of PAC with PDGS/IGAG representatives is scheduled for Wednesday, 18th September 2019.

Dr Tony Calland, Chair of the Confidentiality Advisory Group (CAG), and Natasha Dunkley, Head of CAG Admin, will be in attendance to discuss the activities and processes of CAG.

9. Any Other Business

None.

10. PAC Annual Report 2018

Prof McClelland referred to the circulated PAC Annual Report 2018.

11. Dates for 2019 PAC Meetings

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