

62nd Meeting of the Privacy Advisory Committee
Thursday, 24th November 2022 at 11:00am
School of Law Boardroom, Main Site Tower, Queens University Belfast

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

In attendance: Dr Frances Burns, Programme Lead, HSC NI Trusted Research Environment (NITRE) / Director, NI Public Data Panel (NIPDP)

1. Apologies and Welcome

Apologies were received from Prof Ian Young.

2. Minutes of the Previous Meeting – 7th July 2022

The minutes of the 61st PAC meeting held on 7th July 2022 were agreed.

3. Matters Arising:

i. Ongoing discussion of the Personal Data Guardian role and responsibilities

The role of PDGs and who should fulfil it, was due to be discussed at the joint meeting of PAC with PDGs on 15 September 2022, however the meeting had been stood down.

Prof McClelland referred to his previous discussions on the PDG role earlier this year with both Medical Directors and Executive Directors of Social Work and encouraged PAC to further discuss the matter and communicate with PDGs as soon as possible, ideally prior to a further joint meeting in September 2023.

ii. Independent Neurology Inquiry – confidentiality issues

Prof McClelland advised that further to discussion at the July 22 PAC meeting in relation to the Independent Neurology Inquiry and the associated confidentiality issues, he had written to the Permanent Secretary, on behalf of PAC, and offered PAC's assistance, where relevant, to those leading on the Department's response to the Report's recommendations.

A response had been received from the Permanent Secretary, thanking PAC for its support and the offer of assistance, advising that the Department will be keen to engage with stakeholders, including PAC, and noted that Departmental officials would be in contact in due course. Prof McClelland had shared both letters with PAC members. Item to remain on PAC agenda.

4. Chairman's Update

Chair of PAC

As Prof McClelland had advised at the July 2022 meeting, he would be standing down as Chair of PAC at the end of this year and this would be his last meeting. Colin Harper will take over as the new Chair in January 2023.

Colin thanked Prof McClelland, on behalf of PAC, for his greatly valued contribution to the work of PAC during his time as Chair, since the implementation of the Committee and wished him well in his retirement.

Prof McClelland thanked all PAC members for their wealth of expertise and support to him as Chair in informing the work of PAC and wished all well in the future, particularly in the coming year, in preparation for the implementation of the new HSC legislation.

5. Update on Legislation – Dr Frances Burns, Programme Lead, HSC Trusted Research Environment / Director, NI Public Data Panel

Prof McClelland welcomed Dr Frances Burns to the meeting, who had recently been appointed to the Department of Health to lead a project on the implementation of the Secondary Use Legislation and associated Regulations.

Frances provided an overview of progress on this piece of work to date, including expected timeline and deliverables and the documents and procedures which will require update.

Frances also welcomed feedback from PAC with regards to the work and any recommendations from Committee members.

Update included detail on the following:

- Overview of those from the Department of Health (DOH) who were currently involved in the project delivery;
- The existing DOH Organisational structure:
 - The new Privacy Panel to be developed will report to the newly created Data Co-ordination Board, which in turn reports to the Performance and Transformation Executive Board, which reports to the DOH Top Management Group.
- An overview of the Regulatory Process - work is in progress with an estimated completion date of February 2023;
 - Consultation Phase is underway to agree approach to opt-out processes and penalties, in consultation with the DOH and DHCNI;
 - Work is also underway in relation to update of the existing Code of Practice, including determination of the need for legal review;
 - The next formal stages of the regulatory process were outlined; timeframe to be determined;
- The Terms of Reference of the new Privacy Panel will be agreed (the name for the new Panel/Committee) is yet to be confirmed);
 - An Interim Panel will be established as a pilot;
- The Consultation (socialisation) process with stakeholders will include both with known stakeholders and previous/potential applicants to the new Panel; as well as a public consultation via the NI Public Data Panel (NIPDP). The NIPDP is an existing public forum, piloted in 2022, Frances agreed to forward further detail to PAC.
- The Chair and Deputy Chair of the new Privacy Panel will be appointed via a Public Appointment Process, facilitated by the Data Co-ordination Board and formally agreed by Minister. The Chair/Deputy Chair will then oversee the process for the appointment of the new Privacy Panel members. The new Panel will include an Expert Reference Panel, including clinical expertise.
- Webpage creation, content and publication will be via the existing Data Institute;
- Administrative and communications support for the new Privacy Panel will be included in a Data Institute Business Case.

- The process for requests for access to data was outlined;
 - Initial review undertaken by Ethics and Governance Review, prior to review by Privacy Panel, then to Data Controllers, followed by review by Data Protection Officers. It was noted that requests to access data can be stopped at any stage, by any of the above –

- requests to access data can be declined by Data Controllers and DPOs, even though the request has been approved by Ethics/Governance and Privacy Review.
- PAC agreed that it will be important to ensure the process for obtaining access to data is well communicated, as well as the role and function of the new Privacy Panel. This information needs to be easily accessed.
- It was noted that Data Protection Impact Assessments (DPIAs) will still be required.

Frances noted that her support on this piece of work was time limited to September 2023.

Prof McClelland thanked Frances for the very informative update on this ongoing piece of work. PAC will continue to link with Frances on progress as required.

Colin Harper advised that he would continue to link with Frances and DOH representatives as the project progresses over the coming months and will keep PAC informed of developments.

There was some discussion regarding the provision for opt-out and the importance of respecting the wishes of those individuals who have requested to opt-out, and how this will be communicated when reviewing data access requests. It was noted that the new Panel/Committee will not deal with requests to opt-out of data access/sharing in relation to provision of direct care, or requests to have data removed.

PAC members were in support of progress to date in relation to the implementation of the new legislation/Regulations and look forward to further engagement with DOH colleagues.

6. Any Other Business

i. Early Life Cohort Feasibility Study (ELC-FS)

Prof McClelland provided an overview of a recent request for advice from those involved in the above study, which had received Section 251 approval, and which required further consideration by PAC in relation to N. Ireland's involvement in the study and the associated patient confidentiality issues. For further discussion at the next PAC meeting.

7. Dates for 2023 Meetings of PAC

Dates for 2023 meetings to be advised.