

66th Meeting of the Privacy Advisory Committee
Thursday, 1st February 2024
MS Teams Meeting

Present: Colin Harper (Chair), Gillian Acheson, Eileen McKay, Brendan O’Neill, Geraldine Reynolds, Prof Ian Young, Dr Clodagh Loughrey, Brice Dickson.

In Attendance: Dr Frances Burns, Programme Lead, HSC Trusted Research Environment/
Director, NI Public Data Panel
Dr Michael Quinn, Encompass IG Advisory Council

1. Apologies and Welcome

Apologies were received from Dr Michael McKenna and Geraldine Reynolds.

Colin extend thanks and appreciation to both Brice Dickson and Dr Clodagh Loughrey who had advised that they would be stepping down from the PAC and this would be their last meeting. Colin thanked them both for their contribution to the Committee over the last number of years.

2. Minutes of the Previous Meeting – 29th June 2023

The minutes of the previous meeting held on 29th June 2023 were agreed.

3. Matters Arising:

i. Ongoing discussion of the Personal Data Guardian Role and Responsibilities

No further update at this time. Colin advised that he had recently attended a meeting of the Caldicott Guardian Council. It was agreed that the issue should be discussed further to see how the PDG role could be updated. The importance of the PDG role in relation to social care in NI was also highlighted.

ii. Independent Neurology Inquiry (INI) Report Recommendations - Overarching INI Implementation Plan, July 2023

Colin referred to the above Recommendations, as circulated.

He advised that he had recently met with the INI Implementation Programme Team.

Reference was made to the list of 76 Recommendations, as detailed in Annex A, in particular to those below:

12. The NI Department of Health should ensure that all healthcare providers, both NHS and independent sector, will have full and unhindered access to the integrated Electronic Care Record, having sought the relevant permissions from the patient (with an appropriate division of costs).

13. The NI Department of Health should ensure that until the electronic care record is available, then there should be direct access to patient notes and records between the NHS and the independent sector to facilitate patient safety, having sought the relevant permissions from the patient.

Brendan advised that the implementation of the above two recommendations were being considered by the Chief Digital Information Officer. The challenges in taking this forward were discussed, in terms of both cyber security and information governance arrangements. Further engagement with the Independent Sector providers will be required.

35. Healthcare organisations should share necessary data to ensure patient safety. Data protection concerns should be subordinate to patient safety.

PAC were in agreement that it would not be necessary to formally respond to the Department of Health in relation to the implementation of the Recommendations at this time.

4. Chairman's Update

2023 PAC Annual Report

Colin advised that he is currently drafting the PAC's 2023 Annual Report and will share at the next meeting.

There continues to be a steady flow of requests for advice to PAC in relation to requirements for research involving N. Ireland data, which Colin will detail in the Annual Report.

The current challenges in relation to N. Ireland's participation in UK-wide research studies were discussed. In the absence of legislation in N. Ireland, researchers are often required to develop elaborate workarounds to facilitate the inclusion of N. Ireland data, which it was noted, often involves a cost and may act as a deterrent to researchers.

5. Encompass: Work of the Information Governance Advisory Council ~ Dr Michael Quinn

Dr Michael Quinn, Chair of the Information Governance Advisory Council, joined the meeting to provide an update on the work of the Council in supporting the Encompass Programme Board with the implementation of Encompass throughout N. Ireland.

Dr Quinn provided an overview of the role of the Council and outlined a number of the issues and challenges in the implementation of Encompass, including:

- N. Ireland does not have one Data Controller, with differing processes in place for the management of data within the five HSC Trusts and NIAS; as well as within primary care (over 300 GP practices); complex situation with a large number of technical companies involved and multiple systems in place throughout the HSC;
- Implementation of encompass will result in improved audit functionality in relation to access to personal records; it was noted that additional safeguards are in place for certain specialties, including Mental Health and Social Care;

- The benefits of the My Care patient portal were highlighted;
- It is planned that in future patients will be able to register their interest in participating in clinical trials, this functionality is available within Encompass, although has not yet been implemented;
- Discussions have been ongoing between the IG Advisory Council and IGAG members, which have been very helpful in trying to resolve issues;
- It was noted that there had been some concerns regarding access to information for looked after children. Dr Quinn advised that this would be discussed at the next meeting of the Council and he would provide an update to PAC following this;
- Existing governance strategies will need to be adapted to support the new technology;
- There was some discussion regarding allocation of proxy access to service user information for carers and the need for a process for this;
- The benefit of having one over-arching Data Access Agreement for all of N. Ireland was also highlighted – there are currently differing agreements and processes in place within the Trusts/HSC organisations. An over-arching policy would also avoid un-necessary repetition and duplication of work; it was noted that there is a need for a more ‘patient-centered’ approach to data access and management;
- Gillian Acheson noted that the existing Information Governance Network, which involves IG representatives from all Trusts, is currently working towards streamlining data sharing agreements between Trusts as far as possible.

Colin thanked Dr Quinn for updating PAC on progress to date. It was agreed that it would be of benefit for PAC and IGAG to link again in future regarding ongoing progress in the implementation of Encompass.

6. Update on Legislation – Frances Burns

Frances provided an update on progress regarding the legislation and drafting of Regulations.

As discussed at the previous meeting, an error/mis-reference had been identified within Section 1.11 of the primary legislation passed in 2016. Discussions had been held with the Department of Health and the Departmental Solicitors Office regarding options going forward. A Bill of Amendment will be required and it is anticipated that this will be taken forward in-year, alongside the drafting of the new Regulations.

A degree of public consultation will be required.

Frances to update on progress at the next meeting.

7. Development of Privacy Advisory Committee

There was further discussion regarding the development of the existing Privacy Advisory Committee, in preparation for the implementation of the new Statutory Committee, in line with the new legislation.

Frances advised that in the interim, given the delay with the new legislation and pending the drafting of the new Regulations, she had undertaken a review of the existing documentation, which is submitted in applications to the Confidentiality Advisory Group (CAG) in England/Wales, including research applications submitted via the Integrated Research Application System (IRAS). Frances has prepared a new set of documents, as well as a flowchart to outline the information which will be required to be submitted to the new Statutory Committee.

It is anticipated that the existing PAC will be reconfigured into a new non-statutory Pilot Committee, for which a Terms of Reference will be required.

Frances has drafted a set of recommendations, including an overview of the expertise which will be required for the make-up of the new Pilot Committee.

Frances proposed that representatives from PAC form a small working group to review these draft recommendations, TOR and paperwork required for the new non-statutory Pilot Committee, the outcome of which would then be brought back to the entire PAC for consideration and approval.

PAC were asked to consider this request and to contact Frances directly if they would be interested in participating in this small working group.

PAC were also asked to consider whether they would be willing to participate in the new Pilot Committee, in preparation for the implementation of the new Statutory Committee.

8. Any Other Business

No further business.

9. Proposed Dates for 2024 Meetings of PAC

Thursday, 11th April 2024

Thursday, 13th June 2024

Thursday, 19th September 2024 (Joint Meeting with PDGs/IGAG)

Thursday, 14th November 2024