

63rd Meeting of the Privacy Advisory Committee
Thursday, 19th January 2023 at 11:00am

MS Teams Meeting

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

In Attendance: Dr Frances Burns, Programme Lead, HSC Trusted Research Environment/
Director, NI Public Data Panel

1. Apologies and Welcome

Apologies were received from Eileen McKay.

2. Minutes of the Previous Meeting – 24th November 2022

The minutes of the previous meeting held on 24th November 2022 were agreed.

3. Update on Legislation - Frances Burns, Programme Lead, HSC Trusted Research Environment / Director, NI Public Data Panel

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

- Frances and Colin are in the process of drafting the Regulations; work is progressing well;
- Discussions are ongoing with Departmental representatives regarding the legislative requirement for a mechanism for opt-out of data sharing for secondary uses. It was noted that the new regional opt-out process will supersede all other existing opt-out provision for individual Registries in N. Ireland – discussions have been held with the N. Ireland Cancer Registry in this regard;
- It was noted that the roll-out of Encompass will assist in the provision of opt-out functionality via the patient portal;
- It was agreed that it will be essential to ensure that the public are fully aware of the mechanism to request opt-out from the sharing of their data for secondary uses. Opt-out will not be possible in relation to direct care;
- PAC stressed the importance of providing assurance to the public on how their data will be used and protected in order to ensure public confidence is maintained;
- Frances had met with the Departmental Solicitors Office (DSO) regarding the new Code of Practice (COP) to be implemented – the COP will be a regulatory/statutory document which the new Privacy Panel will refer to and will also be accessible to the public; a Lead will be assigned to oversee the drafting and implementation of

the new COP;

- Consideration is being given to the existing UK and EU legislation in relation to penalties/fines as a result of data breaches and to whether any further legislation, specific to N. Ireland, will be required. DSO advice is awaited. It was noted that the requirement for any new legislation will add significantly to the timeline for implementation of the new legislation/Regulations;
- It was also highlighted that there have been significant technological/digital developments since the NI legislation was passed in 2016;
- Work is progressing well on the drafting of the new Regulations and it is anticipated that they should be available by Spring 2023; once finalised the Regulations will be submitted for formal DOH approval;
- Terms of Reference for new Committee will be developed.

PAC were asked to contact Frances if they had any further queries in relation to the drafting of the new Regulations.

4. **Matters Arising:**

- i. Ongoing discussion of the Personal Data Guardian Role and Responsibilities**
No further update at present; item to remain on agenda for future discussion.

- ii. Independent Neurology Inquiry (INI) – confidentiality issues**

PAC had written to the Permanent Secretary to offer assistance, where relevant, to those leading on the Department's response to the INI Report's recommendations. A response had since been received, advising that Departmental officials would be keen to engage with stakeholders, including PAC, and would be in contact in due course. No further update at this time.

5. **Chairman's Update**

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

Colin Harper provided an overview regarding the above study into child health, wellbeing and development across the UK, and a background on previous discussions between himself and Prof McClelland with the study leads. A number of related documents had been shared with PAC prior to the meeting for review and comments were welcomed.

It was agreed that N. Ireland's participation in this UK-wide study would be extremely beneficial. It was noted that the study has been approved by the HRA Ethics Committee; the Confidentiality Advisory Group in England & Wales; and the Public Benefit and Privacy Panel (PBPP) in Scotland.

A number of points were raised by PAC, including in relation to the proposed model for the obtaining of consent from participants (opt-out as opposed to opt-in); whether there was potential to further minimise the level of detail provided to IPSOS in order for them to facilitate the study; and also whether additional steps could be taken to

increase public awareness of the birth cohort study in advance – it was suggested that an initial flyer with detail on the study could be shared by a healthcare provider/member of staff; or for this detail to be made available to the public within healthcare facilities.

Colin agreed to feedback on discussions and PAC suggestions to the study leads and will update PAC on developments.

Action: Colin Harper

6. Any Other Business

PAC Annual Report 2022

Prof McClelland is in the process of drafting the PAC Annual Review of Progress for 2022 and will forward to Colin Harper, for review and sharing with PAC.

7. Proposed Dates for 2023 Meetings of PAC

Thursday, 4th May 2023

Thursday, 29th June 2023

Thursday, 21st September 2023 (Joint Meeting)

Thursday, 23rd November 2023