

64th Meeting of the Privacy Advisory Committee
Thursday, 4th May 2023 at 11:00am

MS Teams Meeting

Present: Colin Harper (Chair), Gillian Acheson, Eileen McKay, 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 Brice Dickson, Dr Clodagh Loughrey and Dr Michael McKenna.

2. Minutes of the Previous Meeting – 19th January 2023

The minutes of the previous meeting held on 19th January 2023 were agreed.

3. Update on Legislation – Colin Harper / Frances Burns

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

- Work is ongoing. Frances had met again with colleagues at the Department of Health, including the Departmental Solicitors Office;
- It was highlighted that there have been significant technological/digital developments since the NI legislation was passed in 2016, which will have implications for the drafting of the Regulations. Clear policy direction is required in relation to prescribed information;
- Frances has also arranged to meet with colleagues at the Public Health Agency;
- Further discussion will also be held with the Information Governance Advisory Group, as well as the Research Directors Forum;
- Frances referred to the UK Data Protection and Digital information Bill, as well as the European Directive on Digital Health, which will also have implications for the drafting of the NI Regulations;
- It was highlighted that further public/stakeholder consultation is required on the drafting of the Regulations and prescribed information - including with data controllers, which provide a service on behalf of the NI HSC organisations, and which may not have responded to the earlier public consultation exercise;
- Frances advised that she had recently worked with Colin and colleagues from DSO, to undertake a mapping exercise in relation to the existing legislation;
- Work is progressing as far as possible.
- It is hoped that recruitment to the new PAC Shadow Committee/Privacy Panel, will

be undertaken soon, and that the new Committee will be established in shadow form in the interim, pending the implementation of the new Regulations and allocation of statutory powers.

PAC were asked to contact Frances directly 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 this agenda and will also be discussed at the forthcoming joint meeting of PAC with PDGs and IGAG members in September.

It was noted that the changing information governance structure within HSC organisations had resulted in contact being made with IG Leads and Information Asset Owners in the first instance, with PDGs being contacted in relation to more complex IG issues.

Colin advised that he intended to join a future meeting of the Caldicott Guardian Council, which Prof McClelland had also attended previously, and would report back on discussions.

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. Colin advised that he had met with a representative from the INI Implementation Team at the end of March, to discuss the various confidentiality issues associated with the Report's recommendations.

There was some PAC discussion regarding the possible use of the new Encompass Programme within the Independent Sector in NI and the requirements for this.

5. Chairman's Update

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

Colin Harper provided an update regarding the above study into child health, wellbeing and development across the UK, following discussion at the previous PAC meeting. He had reported back to the Study Leads regarding the points which had been raised by PAC, in particular regarding the proposed model for obtaining consent from participants (opt-out model as opposed to opt-in); the potential to minimise the detail provided to a third party for facilitation of the study; and whether additional measures could be implemented to increase awareness of the study, prior to participants being contacted.

5. ii NIAS – Out of Hospital Cardiac Arrest (OHCA) in Northern Ireland – a Five Year Review

Colin Harper provided an update on recent discussions with Julia Wolfe, Research &

Development Manager, N. Ireland Ambulance Service (NIAS), regarding confidentiality/privacy aspects on the proposed use of NIAS patient data in research and clinical audits, in particular the above OHCA Baseline study, on which Julia had sought advice from PAC. A draft Study Protocol had been shared with PAC for review and comment.

The study will seek to identify the baseline details and characteristics of OHCA in NI, with the aim to provide a description of OHCA in the NI population.

It was noted that the study would be of significant public interest.

In general, no concerns were raised on the proposed study, however PAC requested further clarity on a number of issues, including:

- The process for the anonymisation of service user data;
- Further detail regarding the exact data which is to be processed; ie: will it be possible to use partial as opposed to full post-code; can age be banded into age groups, or will exact age of individuals be used.
- Whether there are plans for NIAS to participate in a UK-wide study and if there is the potential for service user data to be shared outside of NI at a future time - will only anonymised data be shared, if leaving NI;
- Request for clarity regarding the process for the pseudonymisation of data and if this would include use of the NI H&C number. Also, request for further detail on why it may be necessary to reverse the pseudonymised data; and clarification regarding plans for any long-term/future follow up of study participants;
- Request for clarification regarding reference to minimising the occurrence of missing data.

Colin agreed to feedback on PAC discussions to Julia Wolfe and to request further detail on the above points.

There was some general discussion on the requirement for obtaining ethical approval for research studies and use of the HRA decision-making tools, which may need to be considered further by the new shadow Committee.

6. Any Other Business

PAC Annual Report 2022

The 2022 PAC Annual Review of Progress report had been drafted by Prof McClelland and circulated to PAC and shared with Departmental colleagues.

7. Proposed Dates for 2023 Meetings of PAC

Thursday, 29th June 2023

Thursday, 21st September 2023 (Joint Meeting)

Thursday, 23rd November 2023