

65th Meeting of the Privacy Advisory Committee
Thursday, 29th June 2023 at 11:00am
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

1. Apologies and Welcome

Apologies were received from Dr Michael McKenna.

2. Minutes of the Previous Meeting – 4th May 2023

The minutes of the previous meeting held on 4th May 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.

An error/mis-reference had been identified within Section 1.11 of the primary legislation passed in 2016. Discussions will be held with the Department of Health and the Departmental Solicitors Office regarding options going forward. It is anticipated that either a repeal of the primary legislation or a Bill of Amendment will be required. It will not be possible to amend the error within the Regulations, the legislation will need to be revised.

A full public consultation exercise will be required for either option and it is expected that PAC will be asked for advice on the matter.

The point in question refers to those in receipt of health and social care;

‘Alive’ – therefore implications for the retrospective use of data for deceased patients, which would impact significantly on the operation of the Disease/Cancer Registries in N. Ireland.

‘In receipt of care’ – it was queried whether this would include those service users who have not received care in recent years, or are those service users with an existing H&C number considered to be in receipt of care?

Work will progress as far as possible with the drafting of the Regulations.

Concern was raised with regards to the implications for the research community if it would not be possible to utilise patient data retrospectively, for deceased patients. PAC felt that it was important to clarify with regards to the use of data for deceased patients. It was queried whether a panel of researchers should be asked to review the legislation in relation to the future use of retrospective data for deceased patients.

PAC will be required to review the legislation again to check for any other areas of ambiguity.

Colin agreed to keep PAC updated on the outcome of future discussions with the DOH

and the proposals to amend the existing legislation.

PAC were in agreement that the legislation is not currently fit for purpose and will need to be amended;

It was highlighted that the discussions and work to date will assist in informing the revised legislation, which should expedite the process.

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 23.

ii. NIAS – Out of Hospital Cardiac Arrest (OHCA) in Northern Ireland (NI); a Five year review

Further to discussion at the previous meeting, Colin advised that he had been in contact again with Julia Wolfe, Research & Development Manager, N. Ireland Ambulance Service (NIAS) and Study Lead for the above review, to provide feedback on the confidentiality issues surrounding the draft study protocol. Colin agreed to forward a formal letter of support to NIAS on behalf of PAC, in relation to the proposed study.

Action: Colin Harper

5. Chairman's Update

No other business.

6. AspECT Excel Study (UCL: Comprehensive Clinical Trials Unit (CCTU)) ~ Enc 1: Study Overview

The Study overview for the above had been shared with PAC. The study is an extension of the AspECT clinical trial, published in 2018. The aim is to continue to follow up on the AspECT study participants to investigate long-term benefits, which will enhance the original study.

The plan is to analyse the original cohort of participants via remote consent. The study plans to seek approval from the UK Confidentiality Advisory Group and NHS Digital, to obtain the information required for this follow up study, for participants who are now deceased.

Colin had advised the Study Leads to contact the relevant HSC Trusts in N. Ireland.

It was queried whether the follow up study could be facilitated via the N. Ireland Honest Broker Service (HBS), which should be able to assist with the identification of participants of the original study who are now deceased, and also to confirm current addresses to enable obtaining of consent from those still alive.

Colin agreed to feedback on discussion to the Study Leads.

Action: Colin Harper

7. UK Prospective Diabetes Study (UKPDS) Long term follow up ~ See Encs 2.1-2.3

Colin provided an overview of the above long-term follow up study and referred to the associated enclosures, as circulated to PAC.

Colin had discussed the study with Dr William Whiteley, Centre for Clinical Brain Sciences, University of Edinburgh, regarding the proposed inclusion of the N. Ireland patients who had participated in the original study, which ran from 1977-1997, in this follow-up study.

Approval for the follow-up study had been obtained from both the Confidentiality Advisory Group (CAG) for England and Wales, as well as from the Public Benefit and Privacy Panel (PBPP) for Scotland.

It was noted that CAG had not considered the use of the consent obtained for the original study to be feasible for the required wider data linkage for the follow-up study.

CAG had also considered that the requested confidential patient information was required to facilitate the data linkage process, which would be undertaken by NHS Digital and could not be otherwise achieved.

It is proposed that the trial identifiers for the NI patients are shared with the Belfast HSC Trust, who would then consider the request and return any matching hospital records. All analysis would be conducted within the Data Security and Protection Toolkit compliant environment at the University of Oxford, Nuffield Department of Population Health, as had already been undertaken for data held by NHS England and was in progress for Public Health Scotland.

PAC were in agreement that it would be of importance and public benefit for the N. Ireland cohort of patients to be included in this follow up study if possible.

Colin agreed to draft a letter of support on behalf of PAC, which the study leads could then share with BHSCT in their request to share the data they hold on the relevant patients.

Action: Colin Harper

8. Recruitment of New Members to PAC

The possibility of inviting new members to join the current Privacy Advisory Committee was discussed, in advance of the implementation of the new Committee/Advisory Body in line with the new legislation. It was agreed that this would be of benefit, particularly in relation to research expertise and the matter would be further discussed.

Brendan O'Neill agreed to circulate a draft document which had been prepared regarding the skills/expertise which would be required for the new Advisory body.

Action: Brendan O'Neill

9. Joint Meeting with PDGs/IGAG ~ Thursday, 21st September 2023

There was some discussion regarding possible agenda items for the joint meeting of PAC with PDGs and IGAG members, scheduled for 21st September. It was proposed that PDGs/IGAG members be invited to put forward suggested items for discussion. PAC to also consider and forward any suggestions in advance.

10. Any Other Business

No further business.

11. Proposed Dates for 2023 Meetings of PAC

Thursday, 21st September 2023 (Joint Meeting)

Thursday, 23rd November 2023