

# REVIEW OF THE WORK OF THE N. IRELAND PRIVACY ADVISORY COMMITTEE 2021

The NI Privacy Advisory Committee (PAC) has the following ongoing responsibilities:

- To oversee the implementation of the recommendations agreed by Minister on Protecting Personal Information;
- To manage a Project Team to complete a Programme of Work to give effect to the recommendations agreed by Minister;
- To report regularly to the Department on progress on implementing the recommendations;
- To keep consent and confidentiality matters in HPSS under continuous review and to provide timely and relevant best practice advice to HPSS bodies; and
- To consider current and new uses to which personal information is put in HPSS bodies and to authorise such uses of personal information, taking particular account of the legal and ethical issues surrounding privacy and confidentiality.

The following is an update on the work of PAC over the past twelve months. The COVID-19 pandemic continued to impact on the work of PAC. All meetings of the Committee were held remotely. Some of the advisory work of PAC was related to COVID.

## **1. Advice and guidance to inform service users and staff**

PAC has continued to participate in discussion around withdrawal of patient opt-out from the NIECR.

## **2. Procedures to improve working practices**

**Personal Data Guardians.** PAC has continued its yearly meetings with Personal Data Guardians. The focus of the 2021 meeting was on the role and responsibilities of Personal Data Guardians. Dr Chris Bunch, Chair of Caldicott Council, participated at the meeting and brought evidence from Caldicott Guardians to the discussion.

**The Health and Care Number.** PAC continues to encourage the use of the Health and Care Number.

## **3. Training to increase awareness and understanding on confidentiality**

**Personal Data Guardian Training.** The training arrangements, introduced in 2013 and organised by the HSC Leadership Centre, continues to work well. The twelfth training day for Personal Data Guardians was provided on-line in October 2021, including top-up training. Participant feedback continues to be very positive. Further training is being arranged for 2022.

**Staff Training.** The E-learning module, based on the Code of Practice on the Protection of Service User Information, is available for all HSC staff through the HSC Leadership Centre.

#### **4. Information and communication technology improvements regarding access and security of personal information**

PAC has continued to promote privacy enhancing technologies, the incorporation of methods to record consent and the use of anonymised data for secondary uses. This has included support for the work of the Honest Broker Service where significant developments include the introduction of the Secure e-Research Platform (UKSeRP). This will enable researchers to remotely access and link data in a secure and governed environment.

#### **5. New legislation**

PAC continues to support the Department in developing a Code of Practice and in establishing the oversight body for the HSC (Control of Data Processing) Act 2016.

#### **6. Advisory Role**

PAC has continued to advise on existing and new uses of personal information and to generally advise on confidentiality issues arising within the HPSS. This year again many requests for advice were related to the COVID-19 pandemic.

PAC provided advice on several national projects where access to HSC (NI) data or service users was being sought, including:

- The National Institute for Cardiovascular Outcomes Research;
- The National Haemophilia Database;
- The Breast and Cosmetic Implant Register.

PAC also provided advice to the DH (NI) and to individual researchers in NI.

**Roy McClelland OBE**  
**Chairman, Privacy Advisory Committee NI**

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