

# REVIEW OF THE WORK OF THE N. IRELAND PRIVACY ADVISORY COMMITTEE 2020

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 impacted significantly on the work of PAC from March 2020. All meetings of the Committee were held remotely. A substantial amount of the advisory work of PAC was related to COVID.

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

PAC contributed to the DH guidance on the disclosure of COVID-19 infection status. Members were also involved in consultations on the Department's contact-tracing app. PAC has participated in the discussion around the proposal to withdraw the option 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 and members of IGAG. At the 2020 meeting Dr Michael Quinn, Head of Clinical Informatics, DHCNI, presented a paper and led discussion on the HSC Data Strategy. The meeting also provided an opportunity to review the experiences and issues arising from the current pandemic in relation to information privacy and patient confidentiality.

**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 eleventh training day for Personal Data Guardians was provided on-line in October 2020, including top-up training. Participant feedback continues to be very positive. Further training is being arranged for 2021.

**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, including the Honest Broker Service. Members provided comments on the *encompass* DPIA report.

#### **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, in fulfilling its responsibilities as outlined in the recommendations provided by the Minister, has continued to advise on existing and new uses of personal information and to generally advise on confidentiality issues in HPSS. This year the majority of requests for advice were related to the COVID-19 pandemic.

PAC provided advice on several national projects approved by the Health Research Authority, where access to HSC (NI) data or service users was being sought. These included the following studies:

- Clinical Characterisation Protocol for Severe Emerging Infections in the UK, through the COVID-19 Clinical Information Network (CO-CIN), to inform the UK government response to this pandemic;
- CAPACITY COVID study, a multi-site clinical database study - cardiovascular data in the COVID-19 population;
- Study of Zanamivir in intensive care patients with influenza infection;
- Pandemic Respiratory Infection Emergency System Triage (PRIEST) study;
- PREPARE-IBD and PROTECT ASUC studies from the UK Irritable Bowel Disease COVID-19 Working Group;
- Neonatal Complications of Coronavirus Disease BPSU COVID-19 study;
- UK SARS-CoV-2 viral sequencing programme – COG-UK.

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