

REVIEW OF THE WORK OF THE NORTHERN IRELAND PRIVACY ADVISORY COMMITTEE 2022

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, with the first two meetings continuing to be held remotely. PAC's yearly meeting with Personal Data Guardians was postponed following the death of our Queen.

1. Advice and guidance to inform service users and staff

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

PAC agreed to carry out a review of the Code of Practice on the Protection of Service User Information in the context of the requirements of the new HSC (Control of Data Processing) Act 2016.

2. Procedures to improve working practices

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 thirteenth training day for Personal Data Guardians was provided on-line in November 2022, including top-up training. Participant feedback continues to be very positive. Further training is being arranged for 2023.

Staff Training. The E-learning module, based on the Code of Practice on the Protection of Service User Information, continues to be 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.

PAC has continued to facilitate discussions aimed at providing a solution that will enable NI's cardiologists to participate in a series of National Cardiac Audits. The anticipated solution will involve the HBS and as such should provide a model solution for staff across all specialties wishing to participate in national audits and related service improvement initiatives.

5. New legislation

PAC continues to support the Department in introducing the HSC (Control of Data Processing) Act 2016, including the establishment of the oversight body for the Act.

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.

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

- Proposed BPSU study: NEOPOX;
- PANORAMIC trial;
- The National Cardiac Arrest Audit;
- The National Institute for Cardiovascular Outcomes Research;
- Early-Life Cohort Feasibility Study.

PAC continues to provide advice to the Department of Health (NI) and to individual researchers in NI.

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