

REVIEW OF PROGRESS ON THE IMPLEMENTATION OF RECOMMENDATIONS BY THE PRIVACY ADVISORY COMMITTEE – DECEMBER 2012

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:

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

The Revised Code of Practice on Protecting the Confidentiality of Service User Information (Code of Practice) was issued in March 2012 together with revised staff guidance on confidentiality and a revised Service User Leaflet.

2. **Procedures to improve working practices**

Personal Data Guardians ~ PAC has continued its yearly meeting with Personal Data Guardians and Executive Directors of Social Work, or their representatives, to share and discuss current issues relating to Service User Confidentiality.

The NIECR ~ PAC issued a Position Statement on the NIECR and has participated in discussions with members of the ECR Project Board with the aim of ensuring that informational privacy issues, including consent, are appropriately managed within this new and developing environment.

Primary Care Data Extraction ~ PAC participated in the BSO workshop – *Data Quality in Practice* - which centred on the extraction of Service User Primary Care data and linkage for secondary uses.

The Health and Care Number ~ PAC continues to encourage the use of the Health and Care Number which should facilitate arrangements for pseudonymisation.

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

A fourth training day for Personal Data Guardians has been provided. This included top-up training. Given the on-going need for yearly training, PAC in discussion with the Department and with Personal Data Guardians, has agreed new training arrangements.

Training will now be overseen by the HSC Leadership Centre, The Beeches, with training planned for 2013.

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

PAC has maintained regular contact with the Board's ICT Unit to promote privacy enhancing technologies, the incorporation of methods to record consent and the use of anonymised databases for secondary uses.

PAC has had further discussions with Board staff on the development of Safe Havens and Honest Broker provisions to help address the need for specific secondary uses of HSC information.

5. Consideration of legislative changes

PAC has provided the Department with a Position Statement on the need for new legislation. PAC remains persuaded that this is required to enable the appropriate and limited use of identifiable service user information for essential health and social care purposes which are not directly related to the care of individual service users. We believe that parallel considerations should be given to the development of Safe Haven and Honest Broker services.

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. To this end PAC invited the Assistant Information Commissioner to an exploration of the complementary roles of the IC and PAC with respect to health and social care.

PAC provided advice on several national projects approved by the National Information Governance Board (NIGB) for England and Wales where access to HSC (NI) data or service users was being sought. These included an anaesthetic audit and a paediatric diabetes audit. Advice has also been provided on national service evaluations co-ordinated locally by the NIMARAC Office in relation to maternal deaths, child deaths, epilepsy and head injury.

PAC has also provided advice to:

- a) the NI Leukaemia/Lymphoma Register;
- b) the HSC R&D Division, Public Health Agency and NI MRECs; and
- c) individual researchers.

Roy McClelland OBE
Chairman, Privacy Advisory Committee
December 2012