

## REVIEW OF PROGRESS ON THE IMPLEMENTATION OF RECOMMENDATIONS BY THE PRIVACY ADVISORY COMMITTEE 2013

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

#### **Data anonymisation within Trusts and Primary Care for Secondary uses (2012).**

Service user information held within hospitals and primary care is often required for a range of Secondary uses. To achieve this secure and effective anonymisation arrangements are required. While this should generally be achievable by those having a direct care relationship with that service user, exceptionally an external agent appointed or with an appropriate contract may be able to carry out this function. The advice statement explores such exceptions while advocating the development of secure pseudonymised extracting services.

**Using Personal Information for Secondary HSC Purposes (2013).** This guidance should be of particular interest and relevance for those staff who have specific responsibilities for information management in the health and social care sector. It should also be useful for staff dealing with requests for access to service user information for secondary purposes and for implementing data sharing protocols. The guidance is based on the DHSSPS Code of Practice on Protecting the Confidentiality of Service User Information (2012). This guidance replaces Consent and Secondary Uses of Service User Information in Northern Ireland (2009).

### 2. Procedures to improve working practices

**Personal Data Guardians.** PAC has continued its yearly meetings 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 has participated in discussions with members of the ECR Information Governance Committee with the aim of ensuring that informational privacy issues, including consent, are appropriately managed within this new and developing environment.

PAC issued an Advisory Note on the Northern Ireland Electronic Care Record (NIECR). The purpose of the paper was to provide comment and advice on the confidentiality and related consent obligations applicable to the NIECR and, from a confidentiality perspective, what were considered to be appropriate preconditions for current and potential future developments in the NIECR.

**The Health and Care Number.** PAC continues to encourage the use of the Health and Care Number which should, among other things, facilitate arrangements for pseudonymisation.

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

**PDG Training.** Given the on-going need for yearly training PAC, in discussion with the Department and with Personal Data Guardians, has assisted with new training arrangements. Training is now organised by the HSC Leadership Centre, The Beeches. A fifth training day for Personal Data Guardians was provided in 2013 which included top-up training. PAC continues to review training arrangements. Further training, under the new arrangements, has been agreed for 2014.

**Staff Training.** PAC is currently developing an E-learning programme on confidentiality in health and social care. This will be based on the Code of Practice on the Protection of Service User Information. It should also support the promulgation of the NIECR. The aim is to make the module generally available by early 2014.

### **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. The decision to establish Safe Havens and Honest Broker provisions, to help address the need for specific secondary uses of HSC information, is particularly welcomed.

### **5. Consideration of legislative changes**

PAC welcomes the decision of the Minister to develop new legislation and has written to the Minister and to the Health Committee in support of the initiative.

### **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.

PAC provided advice on several national projects approved by the National Information Governance Board (NIGB) for England and Wales, now Confidentiality Advisory Group of the

Health Research Authority, where access to HSC (NI) data or service users was being sought. These included initiatives under the National Confidential Enquiries into Patient Outcome and Death (NCEPOD) and into Suicide and Homicide (NCISH). Advice also continues to be provided on national level service evaluations/clinical outcome reviews, co-ordinated locally by officers within the PHA, in relation to maternal deaths and child deaths (MBRRACE), epilepsy, head injury, suicide and homicide (NCISH).

PAC has also provided advice to:

- a) the Child Death Overview Panel;
- b) the HSC R&D Division of the Public Health Agency and NI MRECs; and
- c) individual researchers.

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