

REVIEW OF PROGRESS ON THE IMPLEMENTATION OF RECOMMENDATIONS BY THE PRIVACY ADVISORY COMMITTEE 2014

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 GMC invited PAC to provide initial comments on their proposals to update current GMC guidance on confidentiality.

PAC provided a detailed response to the Nuffield Council on Bioethics Open Consultation on Biological and Health Data: The collection, linking, use and exploitation of biological and health data: ethical issues. The results of this national survey, which should significantly inform the work of all organisations concerned with informational privacy, including PAC, are to be made public in February 2015.

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 to share and discuss current issues relating to Service User Confidentiality and informational privacy.

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: The new training arrangements, introduced in 2013 and organised by the HSC Leadership Centre, The Beeches, have been working well. A sixth training day for Personal Data Guardians was provided in 2014 which included top-up training.

PAC continues to review training arrangements and participant feedback has been very positive. Further training is being arranged for 2015.

Staff Training: An E-learning programme on confidentiality in health and social care has now been developed and is presently being uploaded by HSC Leadership Centre, The Beeches. This is 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 2015 for all HSC staff.

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

PAC has continued to support the Board's ICT Unit in the promotion of privacy enhancing technologies, the incorporation of methods to record consent and the use of anonymised databases for secondary uses. PAC welcomes the recently established Safe Havens and Honest Broker provisions, to help address the need for specific secondary uses of HSC information. To promote this service PAC invited Sandy Fitzpatrick, Head of Information & Registration, Business Services Organisation, to provide an overview of the service at the September joint-meeting with Personal Data Guardians.

5. Consideration of legislative changes

PAC welcomes the Department's issuing for consultation, a proposal to introduce primary legislation which would extend the use of service user identifiable information, to include sharing for secondary use in controlled circumstances. PAC has responded to the consultation invitation and the Chairman has, along with Department Officials, provided evidence to the Health Committee on the proposals.

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 on service users was being sought. These included the NHS Blood & Transplant Service, the National Hip Fracture Database and the Cost-effectiveness of Models of Care for Young People with Eating Disorders study.

PAC has also provided advice to:

- a) NILES Risk Stratification and Proactive Care Management Project;
- a) the HSC R&D Division of the Public Health Agency and the Department; and
- b) individual researchers.

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Chairman, Privacy Advisory Committee
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