



Mental Health Reform

Promoting Improved Mental Health Services

Public consultation on the Privacy Impact Assessment for the Individual Health Identifiers

13th April 2016

Mental Health Reform (MHR) welcomes the HSE's public consultation on a privacy impact assessment for the individual health identifiers. As the national coalition promoting improved mental health services and implementation of the mental health policy *A Vision for Change*, Mental Health Reform is calling on the HSE to ensure that the privacy of individuals with mental health difficulties is adequately protected through this initiative.

Privacy is a fundamental human right and is reflected in a number of international human rights instruments, including the Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights (ICCPR), General Comment No. 16 to the ICCPR and the European Convention on Human Rights. The European Data Protection Directive also provides specific protections for people in terms of the processing of their personal data and reflects key governing principles. These international standards should be considered in the development of the HSE's privacy impact assessment.

Mental Health Reform recognises that there are a number of benefits to individual health identifiers, as set out in the HSE's draft privacy impact assessment. Additional benefits, and of particular relevance to mental health service delivery include the following:

- 1. Promotion of a shared care approach between primary and specialist mental health services**
- 2. Promotion of inter-agency communication and collaboration, for example between mental health and child and family services**
- 3. Provision of data for effective service planning, development and delivery**

Mental Health Reform acknowledges the work of the HSE in identifying the potential privacy risks of individual health identifiers and welcomes its draft privacy impact assessment. However, MHR recommends that in the development of this assessment the HSE take account of the particular concerns that people with mental health difficulties may have with respect to the introduction of IHIs. The added privacy risks for this group of

individuals is largely attributed to the sensitive nature of mental health information, including clinical records, but also the stigma and discrimination that continues to surround mental health difficulties. This is clearly reflected in recent Irish research. The long term consequences of a privacy breach for individuals engaged in mental health services are significant.

It must be acknowledged that previous efforts to establish the WISDOM project (a web based mental health information system) were unsuccessful due in part to concerns by people with mental health difficulties of having their personal data recorded electronically.

HIQA's Information Governance and Management Standards for the Health Identifiers Operator in Ireland provide useful guidance for protecting the privacy of individuals with health identifiers. Mental Health Reform recommends that good practice standards be adhered to in the introduction and development of IHIs. The HSE should also take account of national and international guidelines, including, for example:

- Office of the Data Protection Commissioner (ODPC) guidance on data sharing in the public sector
- OECD guidance on the protection of personal data
- The Australian Privacy Rules

To ensure that all privacy risks associated with IHIs are identified it is imperative that the HSE consults directly with individuals with mental health difficulties, their family members and carers to ensure that their fundamental human right to privacy is adequately respected and protected.

A comprehensive education programme should also be delivered to individuals engaged in mental health services to inform the latter of the associated benefits to IHIs, the potential privacy risks, identified measures to mitigate such risks, as well as information on how their personal data will be recorded and who will have access to it. All information should be communicated in a clear and accessible manner.

Mental Health Reform is available to discuss these comments in further detail. Please contact Kate Mitchell, Policy and Research Officer at 01 874 9468 or via email at kmitchell@mentalhealthreform.ie for further information.