

25 JAN 2016

MHC

Memorandum of Understanding between Mental Health Commission and the Health Research Board



Memorandum of Understanding

between the

Mental Health Commission

and the

Health Research Board

in relation to

Sharing of Mental Health Data

January 2016

1. Purpose

The Health Research Board (“HRB”) and the Mental Health Commission (“MHC”) share a common requirement for mental health services information. Each agency, operating under its own statutory authority, has specific responsibilities. This agreement sets forth a framework for reciprocal cooperation which will assist each agency in meeting its responsibilities in relation to mental health services information in Ireland. Implementation of this agreement is intended to maintain and enhance agency effectiveness while avoiding duplication of efforts to achieve required mental health services information.

2. Statutory roles and principal functions

2.1 Health Research Board

The HRB is a statutory body with a mission to improve health through research and information. The HRB is responsible for maintaining a number of national surveillance systems on disability, mental health and drug and alcohol use. The National Health Information Systems Unit (the “Unit”) of the HRB manages this function. The National Psychiatric In-Patient Reporting System (“NPIRS”) Team within the Unit has responsibility for maintaining mental health data. This work informs policy, planning and practice in the mental health area. Two data sets are maintained by the NPIRS team.

2.1.1 HRB Mental Health Data

NPIRS records all admissions and discharges to inpatient psychiatric hospitals and units throughout the country as well as related socio-demographic, diagnostic and service-related information. The HRB has an almost fifty years’ unbroken data record for Ireland which is a unique resource world-wide. Annual reports along with national and regional bulletins are provided based on this database.

The HRB provides national Psychiatric Census data relating to in-patient psychiatric facilities. The first of these in-patient censuses was carried out in 1963 and they have been repeated at regular intervals thus providing basic socio-demographic, diagnostic and related information for service planning, monitoring and evaluation. In-patient censuses are traditionally carried out by the NPIRS team every three years and analysis and commentary are published. In addition, annual data are collated on the number of individuals in inpatient psychiatric facilities at the end of each year.

These national mental health data sources are the cornerstone for service planning and development in Ireland and the HRB provides an ongoing service to a wide variety of stakeholders requiring information for such purposes. In addition, external users are provided with access to the HRB information systems in accordance with protocols which assure security, confidentiality of data etc.

In addition to regular publication of research reports and journal articles, outputs from the HRB mental health datasets include the following statistical reports:

- Annual National Activities Reports
- Annual Bulletins

- Census Reports (3 yearly and annually for a smaller data set)
- Quarterly Performance Indicator Reports and Bulletins.

2.1.2 HRB Disability Data

The HRB manages two national-level information systems on disability; the National Intellectual Disability Database (“NIDD”) and the National Physical and Sensory Disability Database (“NPSDD”). The NIDD was established in 1995 and has in excess of 27,000 registrations. The NPSDD was established in 2002. In 2014 there were about 27,000 people registered on the NPSDD.

Both databases were designed as service planning tools and to ensure that the requisite information would be available to the Department of Health (“DoH”), to the Health Service Executive (“HSE”), and to non-statutory agencies to enable them to provide appropriate services designed to meet their changing needs.

Both databases are managed by a National Committee which is chaired by the Department of Health and which has representation for the key stakeholders including the HSE, the voluntary sector and HRB staff. The Committee oversees progress and approves requests from external sources for additional analysis.

2.2 Mental Health Commission

The Mental Health Commission (the “Commission”) is an independent statutory regulatory body which was established in 2002 pursuant to Section 32 of the Mental Health Act 2001 (the “2001 Act”). The mandate of the Commission is derived from the Mental Health Act 2001. The principal functions of the Commission under the 2001 Act are as follows:

- To promote, encourage and foster the establishment and maintenance of high standards and good practices in the delivery of mental health services.(S.33(1))
- To protect the interests of persons detained in approved centres (S.33 (1))
- To appoint persons to be members of mental health tribunals (S.33(3)(a))
- To establish a panel of consultant psychiatrists to carry out independent examinations (S.33(3)(b))
- To develop and maintain a scheme for the granting by the Commission of legal aid to persons detained in approved centres (S.33(3)(c))
- To develop Codes of Practice for the guidance of persons working in mental health services (S.33(3)(e)).
- To appoint an Inspector of Mental Health Services (S.50)
- To carry out inquiries (S.55)

- To make rules regarding specific interventions (S.59 & S.69)
- To establish and maintain a Register of Approved Centres including attaching, amending or revoking registration conditions or refusal or removal of registration (S.64)
- To advise the Minister regarding Regulations for approved centres (S.66)
- To enforce the regulations (S.66 and S.I. No. 551 of 2006).

Data collected by the Commission include:

- Adult involuntary admissions including re-gradings from voluntary to involuntary
- Child admissions (involuntary and voluntary)
- Deaths (all deaths of any resident of an Approved Centre and sudden unexplained deaths of persons availing of community mental health services)
- Electro-convulsive therapy activity data
- Incident reporting
- Inspection data
- Mechanical Restraint activity data
- Mental Health Tribunals activity data
- Physical Restraint activity data
- Register of Approved Centres data
- Seclusion activity data
- Serious Reportable Events data

3. Areas of co-operation

The following areas of co-operation are envisaged between the Commission and the HRB:

- **Data/Statistics:**
 - Exchange of mental health and disability data for cross-referencing and information purposes.
 - Endeavour to align figures published, acknowledge any differences that may exist and provide an explanation regarding why the differences occur.
- **Publications:**
 - Provide copies of relevant publications, reports and articles prior to general circulation.

- Quality improvement in relation to mental health data:
 - Work collaboratively to progress a mental health minimum data set.
 - Ensure that data collected by both organisations are in line with data definitions in the minimum dataset.
 - Work collaboratively to ensure that mental health data meet national and international data standards.
- Mental Health Catchment populations:
 - Liaise regarding the consistent and appropriate use of population figures
 - Align figures for mental health using most up-to-date Census of Population figures.
- Research collaboration
 - Work collaboratively to identify and execute mutually relevant research projects using mental health data.

4. Information Sharing

4.1 *Commission's requirements*

- NPIRS Data: including data on child admissions and deaths. Sharing of NPIRS and Census data will be governed by NPIRS Privacy and Confidentiality Policy and Procedures including general procedures for the request and release of data.
- Performance Indicator (PI) Reports: The HSE has authorised HRB to provide the Commission with quarterly PI reports. Annual aggregate Independent Service Provider data will be provided (both provisional and final) to the MHC.
- Census reporting: The HRB currently captures timely in-patient data on NPIRS and also carries out a census on a regular basis. To avoid duplication of effort and to reduce the burden of data collection on services the HRB agrees to carry out an inpatient census every three years subject to resources. The HRB will also carry out an annual in-patient census, again subject to resources, reporting on basic statistics from this dataset in the annual activities report.
- National Intellectual Disability Database ("NIDD"): aggregate summary data:
 - Number and type of residential services
 - Service user information
 - Other data as may be identified in any requests for information.

This will be provided following prior approval by the NIDD National Committee.

4.2 *Health Research Board's requirements*

- Register of Approved Centres: The MHC will advise on amendments or additions to the statutory list of in-patient facilities to ensure consistency between organisations
- Information collected by the Inspectorate of Mental Health Services function within the Commission

- Involuntary admission data from the Commission's System for Involuntary Admissions and Tribunals ("SIAT").
- Child data to be cross-referenced using monthly breakdowns.
- Deaths in approved centres data to be cross-referenced using monthly breakdowns.

During the period of the memorandum of understanding each agency should advise of any additional data being collected. If there is agreement by both parties, that it is deemed relevant and appropriate it may also be included in the data shared by mutual agreement.

5. Governance

5.1 Data Protection

The Commission and the HRB shall both adhere to the rules prescribed under the Data Protection Act 1988 and the Data Protection (Amendment) Act 2003 and shall ensure that data is processed fairly.

5.2 Confidentiality

Data will be exchanged via agreed channels to specified contacts and shall be appropriately processed in a manner that ensures confidentiality.

5.3 Timeframes for Data Exchange

The Commission and the HRB agree to provide each other with data in a timely manner.

5.4 Duration of agreement

The Commission and the HRB intend for this memorandum of understanding to commence upon signature by the Chief Executive Officers, and to remain valid for a period of five years commencing on 01/01/2016.

This memorandum of understanding will be reviewed on an annual basis to ensure it is operating efficiently and effectively.

5.5 Settlement of Difference

The Commission and HRB will strive to resolve, by mutual decision, any differences that might arise from the interpretation or application of this memorandum of understanding. Either organisation may discontinue this memorandum of understanding upon written notice to the other. Discontinuation of this memorandum of understanding does not affect the completion of co-operative activities agreed in writing prior to discontinuation.

5.6 No Partnership

This MoU represents the intentions of the partners, made in good faith, to collaborate in respect of the sharing of mental health data. This Memorandum of Understanding is intended to be legally non-binding in nature and is not intended to have the intention of creating legal relations between the signing parties or any other body or committee set up in accordance with the terms of the Memorandum of

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Understanding (the "Joint Venture") notwithstanding the provisions contained herein. No party shall represent the Joint Venture or hold itself out in any way as being able to bind the Joint Venture to any arrangement unless agreed by the other Parties. No Party shall represent any other Party or hold itself out as being able to bind that Party to any arrangement concerning the Joint Venture unless the said Party agrees. This Memorandum of Understanding shall not be deemed to create a legal relationship or any other form of partnership between the Parties.

The Freedom of Information Act 2014 applies to the Commission and the HRB separately.

5.7 Intellectual Property Rights

All Intellectual property created by the HRB prior to the commencement of the MOU shall remain in the ownership of the HRB and all intellectual property created by the MHC prior to the commencement of the MOU shall remain in the ownership of the MHC which rights shall include any enhanced Intellectual Property arising from the provision of the services set out in the MOU.

Health Research Board

Name (printed): _____
Graham Love

Signed:  Date: 20 / 01 / 2016

Mental Health Commission

Name (printed): Patricia Gilheaney
Patricia Gilheaney

Signed:  Date: 22 / 01 / 2016

