Memorandum of Understanding between the Central Statistics Office and the Health Research Board in relation to the Provision of Mortality Information to support the National Drug-Related Deaths Index

Table of Contents

Section 1	Establishment of the Parties
Section 2	Role of the Parties
Section 3	Context and Background
Section 4	Purpose of the Memorandum of Understanding
Section 5	The use of the data by the HRB
Section 6	Data access and responsibilities of the HRB in relation to access
Section 7	Legal Background
Section 8	Joint Liaison Group
Section 9	Duration and Review of the Memorandum of Understanding
Appendix I	Details of Mortality Data to be made available by the CSO

List of abbreviations

CSO	Central Statistics Office
HRB	Health Research Board
MoU	Memorandum of Understanding
RMF	Research Microdata File
NDRDI	National Drug-Related Deaths Index

This Memorandum of Understanding is made on the 8th December, 2022.

Between

The Central Statistics Office, Skehard Road, Cork, T12 X00E.

and

The Health Research Board, Grattan House, 67-72 Lower Mount Street, Dublin 2, D02 H638

1. Establishment of the Parties

1.1 The Central Statistics Office was first established in 1949 and was subsequently established on a Statutory Basis in 1994, pursuant to the Statistics Act, 1993.

1.2 The HRB is a statutory body with a mission to improve health through research and information. The HRB was established under the Health (Corporate Bodies) Act 1961 by S.I. No. 279/1986 - The Health Research Board (Establishment) Order, 1986. There were minor modifications to this founding statutory instrument with S.I. No. 452/1986 - The Health Research Board (Establishment) Order, 1986 (Amendment) Order, 1986. In June 2007, S.I. No. 305/2007 - The Health Research Board (Establishment) (Amendment) (No. 3) Order 2007 came into effect and this amended the Board composition, reducing it from a 16-member Board to a ten member one.

2. The Role of the Parties

2.1 The roles of the parties are summarised below:

2.2 The Central Statistics Office

- The functions of the Office, as detailed in Section 10 of the Statistics Act, 1993, are the collection, compilation, extraction and dissemination for statistical purposes of information relating to economic, social and general activities and conditions in the State.

- The Central Statistics Office publishes Vital Statistics data for the Minister for Social Protection in accordance with the provisions of Section 2 of the Vital Statistics and Births, Deaths and Marriages Registration Act, 1952 and Civil Registration (Transfer of Departmental Administration and Ministerial Functions) Order 2007 (S.I. No. 831 of 2007).

2.3 The Health Research Board (HRB)

- 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, drug and alcohol use and drug-related deaths.

- The national surveillance system to which this MOU refers is the National Drug-Related Deaths Index (NDRDI).

3. Context and background

3.1 The NDRDI is an epidemiological database which records cases of death by drugs and/or alcohol poisoning, deaths among people who use drugs and deaths among alcohol dependent persons in Ireland.

3.2 The NDRDI is maintained by the National Health Information Systems Unit of the HRB and is jointly funded by the Department of Health and the Department of Justice and Equality. The NDRDI was established in 2005 to comply with Action 67 of the National Drugs Strategy (Building on Experience: National Drugs Strategy 2001-2008). That action called for the development of a system for recording drug-related deaths and deaths among people who use drugs to enable the State agencies to respond in a timely manner, with accurate data.

3.3 The objectives of the NDRDI also include identifying and prioritising areas for intervention and prevention and measuring the effects of such interventions. The remit of the NDRDI was further expanded in January 2006 to include alcohol-related deaths and deaths of people who were alcohol dependent.

4. Purpose of the Memorandum of Understanding

4.1 The purpose of this MoU is to clarify the roles and responsibilities of, as well as the areas of cooperation between, the HRB and the CSO with regard to the transmission and use of mortality data.

4.2 This MoU is not intended to create binding or legal obligations on either Party. The MoU is entered into on the understanding that it is subordinate to the relevant legislation governing each body.

4.3 This MoU also sets out a shared understanding of the parties in relation to data protection issues that may arise and roles relating to the compilation, transfer and use of this data. It is the common understanding of the parties that mortality data does not constitute personal data for the purpose of the General Data Protection Regulation, since it relates to individuals who are deceased.

4.4 Appendix I to this MOU specifies the details, and frequency, of the mortality data to be transferred under this MOU.

5. The use of the data by the HRB

5.1 The HRB agrees to seek permission from the CSO to analyse CSO data specified in Annex by completing annual requests for access to microdata (RMF) applications.

5.2 The HRB acknowledges the requirement under Section 2 of the Vital Statistics and Births, Deaths and Marriages Registration Act, 1952 that the mortality data obtained by the HRB from the CSO may not be disseminated, shown or communicated to any other person or body in a form that can be related to an identifiable person or undertaking. If information on cause of death for identifiable patients is sought by hospitals/screening programmes or (with patient consent) researchers, the requester must obtain permission from the CSO and the General Registration Office (GRO) before the HRB can provide any information.

5.3 The HRB shall be responsible for ensuring the exclusion of information relating to an identifiable person from of all outputs arising from its use of the mortality data provided to it under this MoU (reports, publications, presentations, articles etc.). In particular, the HRB shall apply appropriate Statistical Disclosure Control (SDC) to all tabular and statistical outputs and shall not publish data fields with values less than five. The HRB shall also consult with the CSO, through the Joint Liaison Group, for the purposes of ensuring that any additional SDC requirements are applied to all outputs.

5.4 The HRB shall not provide CSO microdata without consulting with the Joint Liaison Group and without the subsequent documented approval of the CSO. In addition, if such approval is granted by the CSO, any provision of microdata to third parties for research purposes must also respect the procedures of Section 2 of the Vital Statistics and Births, Deaths and Marriages Registration Act, 1952 which remains in force, pending commencement of Section 73 of the Civil Registration Act 2004.

5.5 It is acknowledged that anonymised NDRDI coronial data under a strict MOU with ethical approval is provided to academics for research in the drugs area. Original data from other sources is not given to third parties.

5.6 The NDRDI provide aggregated analysis which does not identify the source of the data, for international, national (Department of Health, HSE queries including PQ's and data for policy e.g. the new National Drug Strategy).

5.7 The NDRDI provide aggregated analysis on an annual basis to the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA), WHO and United Nations Office for Drugs and Crime on behalf of the Department of Health. They are frequently asked to collaborate on national and international studies in the area of drug mortality.

5.8 Academics who request aggregated NDRDI data must complete and adhere to HRB data request requirements.

6. Data access and responsibilities of the HRB in relation to access

6.1 Mortality data, as per the detail and frequency in Appendix I, shall be made available by the CSO to the HRB. Changes to the frequency of such data

being made available shall be discussed and agreed at the Joint Liaison Group (Section 8 below).

6.2 The data shall be provided by CSO in an agreed format.

6.3 Metadata and other relevant documentation shall be provided for the mortality data being provided.

6.4 System Access, On-Site Appointments, IT Security and Access to the microdata must be adhere to these given policies which are in force as part of the general CSO RMF access[1]

6.5 Only the personnel named in the annual RMF application may access the microdata and all processes and procedures governing access to CSO RMF data must be fully adhered to.

7. Legal background

7.1 This MOU is made in accordance with Section 2 of the Vital Statistics and Births, Deaths and Marriages Registration Act, 1952 (as amended by section 7 of the Births, Deaths and Marriages Registration Act, 1972) which remains in force, pending commencement of section 73 of the Civil Registration Act 2004 and in accordance with Section 73.5 of the Civil Registration Act 2004 which specifies, in relation to the CSO, that:

"Information referred to in subsection (4) may be disclosed to persons engaged in medical or social research or to medical officers of health boards if the Minister consents in writing to the disclosure and the disclosure complies with such conditions (if any) as are attached to the consent; and the Minister is hereby authorised to attach such conditions as he or she considers appropriate to a consent under this subsection".

8. Joint Liaison Group

8.1 A HRB and CSO Joint Liaison Group (JLG) shall be convened, in accordance with the CSO's standard Data Governance Framework. The JLG shall oversee the data sharing as agreed between the parties and summarised in this MoU and the uses for which the data is required.

8.2 The Terms of Reference (ToR) for the JLG shall be agreed between the HRB and the CSO. The ToR shall cover, amongst other things, membership of the JLG, frequency of meetings and scope of the JLG. Changes to the ToR must be jointly agreed by both parties.

8.3 Any data breach or any issues of interest must be reported to the Joint Liaison Group immediately.

[1] See https://www.cso.ie/en/aboutus/lgdp/csodatapolicies/dataforresearchers/policies/

8.4 The contacts for the management of the JLG are:

Central Statistics Office
Name: **Gerard Doolan**, Statistician,
Address: Central Statistics Office, Skehard Road, Cork, T12 X00E
E-mail: gerard.doolan@cso.ie

HRB
Name: **Ena Lynn**, Research Officer,
Address: National Health Information Systems, Health Research Board, Grattan House,
67-72 Lower Mount Street, Dublin 2, D02 H638
E-mail: elynn@hrb.ie

9. Duration and Review of the Memorandum of Understanding

9.1 This MoU shall be published on the CSO website (www.cso.ie) and the HRB website (www.hrb.ie).

9.2 This MoU shall remain in force until a new one is entered into, and/or both CSO and the HRB agree to revoke it. Depending on events, this MoU may be amended, subject to the mutual agreement of the HRB and CSO.

9.3 This MoU shall be reviewed biennially by both the HRB and the CSO. Any changes to the MoU shall only be made with the mutual agreement of the HRB and CSO.

Signed

Central Statistics Office
Pádraig Dalton
Director General

Date 08/12/22

Health Research Board
Dr Mairéad O'Driscoll
Chief Executive Officer

Date 15/12/2022

Appendix I Details of Mortality Data to be made available by the CSO

The variables to be provided, on an annual basis, shall include the following (cases relating to ICD-10 external causes of death shall be included but will have the Underlying Cause of Death variable redacted):

Forename
Surname
Registrars Stamp
Address
County
Gender
Day of birth
Month of birth
Year of birth
Day of death
Month of death
Year of death
Age at death
Occupation Code
PES Code
Underlying cause of death code (including external causes of death)
Supplementary code
Where Died
Day of registration
Month of registration
Year of registration
Part1A
Part1B
Part1C
Part2