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| **Memorandum of Understanding between the Central Statistics Office and the National Cancer Registry of Ireland (NCRI) in relation to the Provision of Mortality Information Relating to the Incidence and Prevalence of Cancer and Related Tumours in Ireland** |
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**List of abbreviations**

CSO Central Statistics Office

NCRI National Cancer Registry of Ireland

MoU Memorandum of Understanding

RMF Research Microdata File

**This Memorandum of Understanding is made on the 7th day of March 2024.**

**Between**

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

***and***

**The National Cancer Registry of Ireland, Building 6800, Cork Airport Business Park, Kinsale Road, Cork, T12 CDF7**

1. **Establishment of the Parties**

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| 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 National Cancer Registry of Ireland (NCRI) is a publicly appointed body, established in 1991, to collect and classify information on all cancer cases which occur in Ireland. It operates under Statutory Instrument 19/1991, the National Cancer Registry Board (Establishment) Order, 1991 as amended by Statutory Instrument 293/1996, National Cancer Registry Board (Establishment) Order, 1991 (Amendment) Order, 1996. |

1. **The Role of the Parties**

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| 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 Government Order SI 831 of 2007
 |
| 2.3 | The NCRIThe statutory functions of the NCRI, as set out in Statutory Order 19 of 1991, are:* to identify, collect, classify, record, store and analyse information relating to the incidence and prevalence of cancer and related tumours in Ireland;
* to collect, classify, record and store information in relation to each newly diagnosed individual cancer patient and in relation to each tumour which occurs;
* to promote and facilitate the use of the data thus collected in approved research projects and in the planning and management of services;
* to publish an annual report based on the activities of the NCRI;
* to furnish advice, information and assistance in relation to any aspect of such service to the Minister.

The NCRI is active at national and international level in relation to compliance with statutory obligations under a variety of directives, agreements and international protocols. |

In addition to the NCRI Establishing Legislation, and not placing any obligation on the Central Statistics Office, Section 184 of the Data Protection Acts gives a mandate to the NCRI to receive Personal Data and Special *Categories* of Personal Data and process it relating to its functions. S. 184 provides as follows:

1. *The National Cancer Registry Board (established under the Health (Corporate Bodies) Act 1961) may request from any person personal data (including data concerning health and genetic data within the meaning of the Data Protection Regulation) held by, or in the possession of, that person for the purposes of the performance of that Board of its functions.*
2. *Without prejudice to his or her obligations under the Data Protection Regulation and the Act of 2018, the person to whom a request is made under subsection (1) shall provide the personal data requested to the extent it is held by, or in the possession of, that person.*
3. **Context and background**

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| 3.1  | Mortality data is required to support the functioning of the NCRI and the CSO will provide information to the NCRI to support this in line with all relevant legislation. |

1. **Purpose of the Memorandum of Understanding**

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| 4.1 | The purpose of this MoU is to clarify the roles and responsibilities of, as well as the areas of cooperation between, the NCRI and the CSO with regard to the transmission and use of mortality data.  |
| 4.2 | This agreement is a MoU and 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.  |
| 4.4 | Appendix I to this MOU specifies the details, and frequency, of the mortality data to be transferred under this agreement. |

1. **The use of the data by NCRI**

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| 5.1 | The NCRI agrees to get permission from the CSO to analyse CSO data specified in Annex 1 as required by 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) by completing annual requests for access to microdata (RMF) applications.  |
| 5.2 | The NCRI acknowledges the requirement of Section 2 of the Vital Statistics and Births, Deaths & Marriages Act, 1952 that the data supplied by 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 and that a person receiving information pursuant under this section shall not disclose any such information in any form. 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 NCRI can provide any information. |
| 5.3 | The NCRI shall be responsible for ensuring the confidentiality of all outputs (reports, publications, presentations, articles etc.). In particular, the NCRI shall apply appropriate Statistical Disclosure Control (SDC) to all tabular and statistical outputs and the NCRI shall not publish data fields with values less than five. The NCRI 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 NCRI shall not provide CSO microdata to any third parties and any such requests for access to this data must be referred to the CSO. If information on cause of death for individual-level but non-identifiable patients already in the NCRI database is sought by researchers, the requester must obtain permission from the CSO before the NCRI can provide such information. |

**6. Data access and responsibilities of the NCRI in relation to access**

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| 6.1 | Mortality data, as per the detail and frequency in Appendix I, shall be made available by the CSO to the NCRI. Changes to the frequency of 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 adhere to these given policies which are in force as part of the general CSO RMF access[[1]](#footnote-2) |
| 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**

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| 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”.*7.2 This MoU is made in accordance with the National Cancer Registry Board (Establishment) Order, 1991 which laid out the functions of the National Cancer Registry Board as follows:* to identify, collect, classify, record, store and analyse information relating to the incidence and prevalence of cancer and related tumours in Ireland;
* to collect, classify, record and store information in relation to each newly diagnosed individual cancer patient and in relation to each tumour which occurs;
* to promote and facilitate the use of the data thus collected in approved research projects and in the planning and management of services;
* to publish an annual report based on the activities of the NCRI;
* to furnish advice, information and assistance in relation to any aspect of such service to the Minister.
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**8. Joint Liaison Group**

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| 8.1 | A NCRI 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 NCRI and the Central Statistics Office. 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 immediately reported to the CSO’s Data Office (dataoffice@cso.ie) and to the Joint Liaison Group.  |
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| 8.4 | The contacts for the management of this JLG are: **Central Statistics Office****Name: Sean O’Connor,** Statistician,**Address:** Central Statistics Office, Skehard Road, Cork, T12 X00E**E-mail:** sean.oconnor@cso.ie**National Cancer Registry Ireland****Name: Fiona Dwane, Data Integration Manager,** **Address:** NCRI, Building 6800, Cork Airport Business Park, Kinsale Road, Cork, T12 CDF7**E-mail:** f.dwane@ncri.ie |

**9. Duration and Review of the Memorandum of Understanding**

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| 9.1 | This MoU shall be published on the CSO website ([www.cso.ie](http://www.cso.ie)) and the NCRI website ([www.ncri.ie](http://www.ncri.ie)). |
| 9.2 | This MoU shall remain in force until a new one is entered into or until either the CSO or the NCRI revokes this MOU. Depending on events, this MoU may be amended, subject to the mutual agreement of the NCRI and the CSO.  |
| 9.3 | This MoU shall be reviewed biennially by both the NCRI and the CSO. Any changes to the MoU shall only be made with the mutual agreement of the NCRI and the CSO. |

***Signed***

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**Central Statistics Office National Cancer Registry Ireland**

**Pádraig Dalton Director**

**Director General**

**Date 07/03/2024 Date 11/03/2024**

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

The CSO agree to provide data on mortality (including late registrations) to the NCRI on a quarterly basis. The cause of death code (ICD-10) will also be included, and codes for all conditions listed in parts 1A, 1B, 1C or 2 of the death certificate (cases relating to ICD-10 external cause of death shall be included but will have the Underlying Cause of Death variable redacted). Codes in the range U00-U49 (“Provisional assignment of new diseases of uncertain etiology”) will also be provided:

Dayofreg

monthofreg

yearofreg

sourceref

HospitalName

PODAddress

PODCounty

PODCountry

PlaceofDeath

Typeinstcode

Gender,

dayofdeath

monthofdeath

yearofdeath

Ageatdeath

Forename

Surname

Date of Birth

Address

Address County

Country

CountyCOD

Underlyingcode

Part1A

Duration1A

Duration1AUnit

Official code 1A

Part1B,

Duration1B,

Duration1BUnit,

Official code 1B

Part1C

Duration1C

Duration1CUnit

Official code 1C

Part2

Duration2

Duration2Unit

Official code part2

The CSO agree to provide annual mortality data, based on year of occurrence, for each neoplasm (ICD10 codes range C00 – D48) cause of death to allow the NCRI to replicate statistics published by the CSO in the Annual Report on Vital Statistics or examine patterns/trends in greater detail:

dayofdeath

monthofdeath

yearofdeath

institution code (both older Placeofdeath and newer Typeinstcode)

county code

Gender

Ageatdeath

social class

economic code

underlying code

Date of Registration

1. See https://www.cso.ie/en/aboutus/lgdp/csodatapolicies/dataforresearchers/policies/ [↑](#footnote-ref-2)