An Phríomh-Oifig Staidrimh Central Statistics Office

National Cancer Registry Ireland

Memorandum of Understanding

Between

The Central Statistics Office
Skehard Road
Cork
T12 X00E

And

The National Cancer Registry Board
Building 6800,
Cork Airport Business Park,
Kinsale Road,
Cork
T12 CDF7

Dated the day of 2018

1. Preface

This document describes the approach designed to govern the relationship between the Central Statistics Office and the National Cancer Registry Board.

2. Description of collaborating organisations

2.1. Central Statistics Office (CSO)

CSO is Ireland's national statistical office and operates under the Statistics Act, 1993. The CSO fulfils the role specified in accordance with the provisions of 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). The vital statistics are published by the CSO on behalf of the Minister for Employment Affairs and Social Protection.

The functions of the CSO are the collection, compilation, extraction and dissemination for statistical purposes of information relating to economic, social and general activities and conditions in the State.

2.2. National Cancer Registry Board (NCRI)

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.

The 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.

3. Purpose of this Memorandum

The specific purpose of this Memorandum of Understanding ('MOU') is to ensure that there is effective cooperation between the CSO and the NCRI (the Parties) so that both organisations can fulfil their statutory obligations.

This MOU between the CSO and the NCRI relates to the provision of information to NCRI and the NCRI's use of that information, in line 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). This legislation will apply until Section 73 of the Civil Registration Act 2004 is commenced. Information security processes must be applied based on best practice.

4. Terms of the Agreement

It is agreed that the term of this MOU is for a period of 3-year commencing at its execution date. It is further agreed that this MOU will be the subject of a joint annual review (or on a more frequent basis where agreed by the Parties) by the Parties. It is further agreed that on the expiration of the 3 year period this MOU it will continue to have effect as between the Parties until it is formally revoked or renewed by them.

5. Change Management

All changes to the MOU must be agreed to in writing by both parties.

6. Intentions

6.1. Joint Commitments

Both parties agree to make every reasonable effort to fulfil the commitments outlined below. They also agree to establish a CSO/NCRI Liaison Group as a formal high-level mechanism for consultation and communication between both organisations. This Group:

- Shall consider all data matters and related issues of mutual interest.
- Shall address matters of data protection in accordance with the Civil Registration Act 2004 and the Data Protection Acts.
- Shall regularly review the security of data transfer, storage and usage.
- Shall meet on at least one occasion a year.
- Shall review information security standards based on current best practice.

6.2. CSO Commitments

The CSO agree to provide data on mortality to the NCRI on a quarterly basis (based on registration) and annual basis (based on occurrence). See **Annex 1** for details of the data provided.

The mortality data files shall be transferred at quarterly/annual intervals to the NCRI. The transfer of such data will be in line with best data confidentiality and security practice. Metadata, data dictionaries, and other relevant documentation shall be provided for all data.

The CSO agree that the NCRI may use this data to fulfil their statutory requirements, if agreed standards on data confidentiality and security are adhered to. The CSO reserves the right to audit compliance with the MOU.

6.3. NCRI Commitments

The NCRI agrees to get the written permission 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).

The NCRI agrees to adhere to the protocols in relation to the security and use of data as set out in **Annex 1**, the protocols in relation to the use of mobile devices as set out in **Annex 2** and the protocols in relation to access and use of data set out in **Annex 3**. The NCRI recognises the requirement of Section 2 of the 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 General Register Office (GRO) before NCRI can provide cause of death.

NCRI will be responsible for ensuring the confidentiality of all outputs (reports, publications, presentations, articles etc.). In particular the NCRI will apply appropriate statutory disclosure controls to all tabular and statistical outputs.

Any provision of micro-data to third parties for research purposes must respect the procedures of 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 4 of the Civil Registration Act 2004, in relation to the Birth, Deaths and Marriage Registration Act 1972, and the commencement of section 73 (4) and (5) of the Civil Registration Act 2004.

7. Legal Basis

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) and will remain in force, pending commencement of section 4 of the Civil Registration Act 2004, in relation to the Birth, Deaths and Marriage Registration Act 1972, and the commencement of section 73 subsection (4) and (5) of the Civil Registration Act 2004 which subsection 5 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".*

Dated the 4 **day of** Dec **2018**

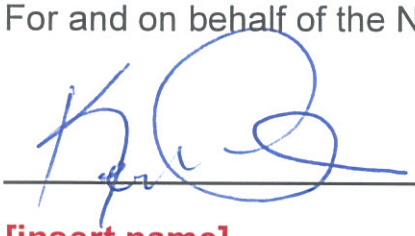
Signed

For and on behalf of the CSO

[insert name]

Signed

For and on behalf of the NCRI



[insert name]

Annex 1: Details of data provided by the CSO to the NCRI

- The CSO agree to provide data on mortality (including late registrations) to the NCRI on a quarterly basis. This data shall consist of data received by the CSO from the GRO. The cause of death code (ICD-10) will also be included, except in cases relating to ICD-10 external causes of death codes S00 to Y98 inclusive. The variables provided shall include:
  Dayofreg,
  monthofreg,
  yearofreg,
  sourceref,
  HospitalName,
  PODAddress,
  PODCounty,
  PODCountry,
  PlaceofDeath,
  Gender,
  MaritalStatus,
  dayofdeath,
  monthofdeath,
  yearofdeath,
  Ageatdeath,
  AgeatInfantdeath,
  Occupation,
  Occupationcode1digit,
  PESCode,
  Forename,
  Surname,
  Address
  Address County
  Country,
  CountyCOD,
  Underlyingcode
  Part1A
  Duration1A
  Duration1AUnit
  Part1B,
  Duration1B,
  Duration1BUnit,
  Part1C
  Duration1C
  Duration1CUnit
  Part2
  Duration2
  Duration2Unit
  MPForename

MPSurname
MPPOBAdd1
MPPOBAdd2
MPPOBAdd3
MPPOBAdd4
MPPOBCounty

- Additional data relating to mortality dataset based on year of occurrence annually. The data includes individual record of:
  (i) each non-external cause of death including the following variables:
  day of death, month of death, year of death, institution code, county code, sex, marital status, age, neonatal, social class, economic code, ICD-10 code, month of registration and year of registration.
  (ii) each external death with information on:
  day of death, month of death, year of death, institution code, county code, gender, marital status, age at death, occupation, economic code and the cause of death narrative (No ICD-10 cause of death code is included).

Annex 2: Procedures for the use of mobile media devices by the NCRI to maintain the cancer registry

The NCRI collect and classify information on all cancer cases that occur in Ireland. This includes onsite data compilation that involves the mortality data provided by the CSO and data collected by the NCRI field staff that use mobile electronic devices to capture cancer data.

For the purposes of this agreement, mobile media includes mobile ICT equipment such as laptop, tablet, mobile phone, PDA, iPod or similar devices; storage media such as CD, DVD, USB stick, memory card, diskette, magnetic tape, external or removable hard drive and any other portable device capable of storing or transmitting information in electronic format.

Regarding the hand-held devices used for accessing the mortality data in the field, the following minimum requirements should be implemented by the NCRI:

- Devices should be allocated to identifiable individuals with individual logins rather than using Generic names
- If possible two factor authentications should be used during login, e.g. Username and pin or Fob
- All devices should be encrypted and should have an automatic lockout after a number of unsuccessful login attempts
- Data should also be encrypted when transmitted to and from the device
- Devices should have up to date end point Anti-Virus protection
- If using windows devices, they should be regularly patched with the latest updates
- Devices should be regularly Audited to ensure compliance
- There should be no differentiation between read or write access
- Lost, mislaid or stolen devices should be immediately reported to the Gardaí and CSO notified if device contains the mortality data
- On receipt of data from the CSO, the NCRI copy the contents to a sequel server table and the CSO data is deleted after 28 days
- The ports are read only for the USB keys and it is not possible to take a copy off their machine and on to a USB stick.
- Regarding back-up: The NCRI can arrange that the data received from the CSO is not backed-up but once it is on the sequel server the NCRI data is backed-up

The information may not be held on or copied onto any other media device, other than the one it is intended for.

By default, USB and other ports on the mobile devices should not be enabled. The reason for this is to protect data security and to reduce the risks from viruses and other malware. They may be temporarily enabled to copy information onto the device but otherwise must be disabled.

The NCRI are requested to ensure that staff (working on-site or off-site) are familiar with and comply with the requirements laid out in this Annex. This compliance should be in the form of a written agreement by the relevant staff to abide by the conditions as laid out in Annex 2. The NCRI to provide this form.

The NCRI should support the compliance of this Annex with the appropriate level of monitoring and the CSO may, from time to time, audit its implementation, to confirm compliance and support good practice.

Any breaches of policy must be notified to the CSO as soon as possible. Such breaches may result in having access to CSO data withdrawn and the NCRI may also be liable to further sanctions, including withdrawal of all CSO data.

Annex 3: Access and use of data

- Access to data under this MOU may be held at the NCRI Head Office at Building 6800, Cork Airport Business Park, Kinsale Road, Cork or at various medical establishments in the State by employees of the NCRI. This off-site access will be governed by the rules and procedures of Annex 2.
- All data disseminated via the NCRI Head Office must clarify that "other researchers must follow processes".
- In relation to data held at the NCRI Head Office:
    - **a)** The CSO must be satisfied that the IT network, protocols and security provisions are in place to protect the network to ensure only those person(s) authorised can access the specified area of the network.
    - **b)** No source data will be retained by the NCRI beyond agreed retention periods. The NCRI will delete all unmatched, non-cancer records 7 years after year of receipt, as previously agreed with the CSO. USB portals and other connectivity should be disabled.
- In relation to both Head Office and "off-site" access, the CSO reserve the right to inspect the procedures in place, without prior notification, to ensure that the appropriate procedures are in place to protect the confidentiality and integrity of the data.
- The analysis/research undertaken must comply or be consistent with the specific purpose for which the access was granted.