Memorandum of Understanding between the Central Statistics Office and the National Kidney Disease Surveillance System in relation to the Provision of Mortality Information to support the Kidney Disease Surveillance Programme

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An Phríomh-Oifig Staidrimh
Central Statistics Office

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List of abbreviations

CSO	Central Statistics Office
NKDSS	National Kidney Disease Surveillance System
MoU	Memorandum of Understanding
RMF	Research Microdata File
KDSP	Kidney Disease Surveillance Programme

This Memorandum of Understanding is made on the 28th of November 2022.

Between

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

and

The National Kidney Disease Surveillance System, University of Limerick, Limerick

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 National Kidney Disease Surveillance System was established in 2013 and is dedicated to improving knowledge of kidney disease in Ireland.

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 National Kidney Disease Surveillance System (NKDSS)

- The overall goal of the National Kidney Disease Surveillance System (NKDSS) is to improve the delivery, quality and outcomes of care provided to patients with chronic kidney disease (CKD) or at risk of kidney disease in the Irish health system.

3. Context and background

3.1 Mortality data is required to support the functioning of the Kidney Disease Surveillance Programme (KDSP) for Ireland.

3.2 The programme is also addressing disparities in health outcomes of Chronic Kidney Disease between men and women in the Irish Health System.

3.3 The programme is also evaluating the transitions of care to advanced Kidney Disease in the Irish Heath system

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 NKDSS 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.

5. The use of the data by the NKDSS

5.1 The NKDSS 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 NKDSS acknowledges the requirement under Section 2 of the Births, Deaths and Marriages Registration Act, 1972 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 received 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 NKDSS can provide any information.

5.3 The NKDSS shall be responsible for ensuring the confidentiality of all outputs (reports, publications, presentations, articles etc.). In particular, the NKDSS shall apply appropriate Statistical Disclosure Control (SDC) to all tabular and statistical outputs and the NKDSS shall not publish data fields with values less than five. The NKDSS 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 NKDSS shall not provide CSO microdata to any third parties and any such requests for access to this data must be referred to the CSO.

6. Data access and responsibilities of the NKDSS 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 NKDSS. 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]

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".

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

8. Joint Liaison Group

8.1 A NKDSS 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 NKDSS and 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 the Joint Liaison Group.

8.4 The contacts for the management of this JLG are:

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

NKDSS
Name: **Dr Leonard Browne,** Research Fellow**,**
Address: CERC Building, University Hospital Limerick, Limerick, V94 F858
E-mail: Leonard.Browne@ul.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 NKDSS website (www.nkdss.ie).

9.2 This MoU shall remain in force until a new one is entered into or until either body revokes this MOU. Depending on events, this MoU may be amended, subject to the mutual agreement of the NKDSS and CSO.

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

Signed

Central Statistics Office

Pádraig Dalton
Director General

Date 28/11/22

National Kidney Disease Surveillance System
Professor Austin Stack
Principal Investigator

Date 30/11/2022

University of Limerick

Prof Norelee Kennedy
VP Research

Date 7/12/2022

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 excluded):

RegDate
SourceRef
HospitalName
PODline1
PODline2
PODline3
PODline4
County
Country
PlaceOfDeath
Gender
DateOfBirth
MaritalStatus
DayOfDeath
MonthOfDeath
YearOfDeath
AgeAtDeath
AgeAtInfantDeath
InfCode
RegStamp
SpousesOccupation
ParentGuardian1Occupation
ParentGuardian2Occupation
SocialClass
PES
Seg
Forename
Surname
AddressLine1
AddressLine2
AddressLine3
AddressLine4
CountyOfResidence
CountryOfResidence
CountyCode
RDistrict
Pregnant
Underlying_Cod

ManualSuppCode
Certified_Uncertified
Part1A
DurationOfIllness1
Part1B
DurationOfIllness2
Part1C
DurationOfIllness3
Part2
DurationOfIllness4
MPQualification
MPForename
MPSurname
MPPOBline1
MPPOBline2
MPPOBline3
MPare