

**Memorandum of Understanding between the Central Statistics Office and the  
Royal College of Surgeons in Ireland through the National Office of Clinical  
Audit in relation to the Provision of Mortality Information to support the  
National Paediatric Mortality Register**

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### **List of abbreviations**

CSO	Central Statistics Office
NOCA	National Office of Clinical Audit
MoU	Memorandum of Understanding
RMF	Research Microdata File
NPMR	National Paediatric Mortality Register

14 June 2022 | 10:50 AM BST

**This Memorandum of Understanding is made on the DD day of MM YYYY.**

**Between**

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

***and***

**The Royal College of Surgeons in Ireland, 123 St. Stephen's Green, Dublin 2,  
Ireland, through the National Office of Clinical Audit (NOCA) at 111 St  
Stephens Green, Dublin 2**

## **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 Office of Clinical Audit (NOCA) was established in 2012. NOCA is funded by the Health Service Executive Office of the Chief Clinical Officer, governed by an independent voluntary board and operationally supported by the Royal College of Surgeons 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 Government Order SI 831 of 2007

### **2.3 The National Office of Clinical Audit (NOCA)**

- NOCA was established as a key enabler of clinical effectiveness which in turn is a key component of patient safety and quality. The integration of best evidence in service provision, through clinical effectiveness processes, promotes healthcare that is up to date, effective and consistent. Clinical effectiveness processes include guidelines, audit and practice guidance.
- NOCA establishes and maintains national clinical audits across a number of clinical areas including Intensive Care, Obstetrics, major trauma, hip fractures, arthroplasty and mortality. NOCA is funded by the Health Service Executive Chief Clinical Office and operationally supported by the Royal College of Surgeons in Ireland.

## **3. Context and background**

- 3.1 Mortality data is required to support the functioning of the National Paediatric Mortality Register (NPMR) for Ireland.
- 3.2 This NPMR has developed as an extension of the Irish Sudden Infant Deaths (SIDs) register which was established in 1992 by the Irish Sudden Infant Deaths Association and managed by Temple Street Children's Hospital (now known as CHI Temple Street). In 2020, governance of NPMR was transferred to NOCA.
- 3.3 The overall aim of the NPMR is to provide a centralised system for collection and analysis of all data relating to mortality in the Irish paediatric and adolescent population (currently less than sixteen years) and provide high quality accurate information for development of policy and intervention strategy.

#### **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, NOCA 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 NOCA**

- 5.1 The NPMR 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 NPMR acknowledges the requirement of Section 2 of the Births, Deaths & Marriages 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 NPMR can provide any information.

- 5.3 The NPMR shall be responsible for ensuring the confidentiality of all outputs (reports, publications, presentations, articles etc.). In particular, the NPMR shall apply appropriate Statistical Disclosure Control (SDC) to all tabular and statistical outputs and the NPMR shall not publish data fields with values less than five. The NPMR 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 NPMR 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 (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 in accordance with Section 73.5 of the Civil Registration Act, 2004.

## **6. Data access and responsibilities of NOCA 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 NOCA. 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 be adhere to these given policies which are in force as part of the general CSO RMF access<sup>1</sup>
- 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

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<sup>1</sup> See <https://www.cso.ie/en/aboutus/lgdp/csodatapolicies/dataforresearchers/policies/>

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 NOCA 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 NOCA 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 reported to the Joint Liaison Group immediately.
- 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@csso.ie](mailto:gerard.doolan@csso.ie)

### NOCA

**Name:** Cliona McGarvey, Paediatric Programme Manager,  
**Address:** NOCA, Ardilaun House, Block B, 111 St Stephen's Green, Dublin 2, D02 VN51  
**E-mail:** [clionamcgarvey@nocai.ie](mailto:clionamcgarvey@nocai.ie)

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

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

### ***Signed***

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**Central Statistics Office**  
**Pádraig Dalton**  
**Director General**

**Date 08<sup>th</sup> June 2022**

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**National Office of Clinical Audit**  
**Colette Tully**  
**Executive Director**

**Date 14 June 2022 | 10:50 AM BST**



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

The variables to be provided, on a quarterly basis, shall include the following for persons aged 18 and under (cases relating to ICD-10 external causes of death codes S00 to Y98 shall not include the Underlying Cause of Death code):

**Date of Registration**

**HospitalName**

**Place of Death**

**Place of Death Address**

**Gender**

**monthofdeath**

**yearofdeath**

**Ageatdeath**

**AgeatInfantdeath**

**Infcode**

**Forename**

**Surname**

**Address**

**County**

**Country**

**Coroner District**

**Underlyingcode**

**Certified\_Uncertified**

**Part1A**

**Duration 1A**

**Duration1AUnit**

**Part1B**

**Duration1B**

**Duration1BUnit**

**Part1C**

**Duration1C**

**Duration1CUnit**

**Part2**

**Duration2**

**Duration2Unit**

**MPQualification**

**MPForename**

**MPSurname**

**MPPOBAdd1**

**MPPOBAdd2**

**MPPOBAdd3**

**MPPOBAdd4**

**MPPOBCounty**