



# Quality Assurance of Administrative Data (QAAD) for Deaths Data in Northern Ireland

Published: May 2022

# Table of Contents

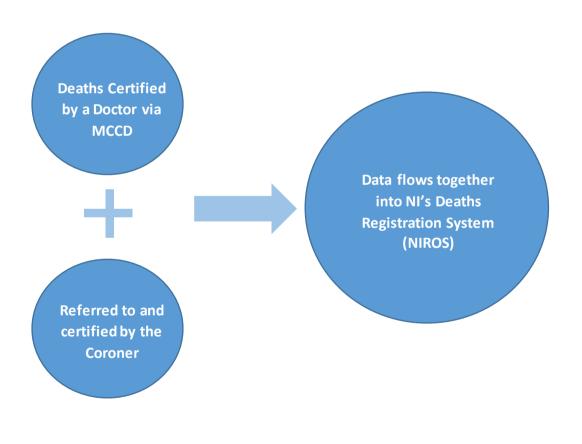
Background		3
Applying the	e Data Quality Assurance Toolkit to Death Statistics in NI	5
Quality Assu	rance of Administrative Data (QAAD) Quality Assurance Matrix	8
Operation	al Context and administrative data collection	8
Communic	cation with Data Suppliers	15
Quality As	surance Principles and checks applied by data suppliers	18
Producer's	s Quality Assurance Investigations and documentation	22
Annexes		26
Annex 1	Flow of Data from Death to Publication of Death Statistics	27
Annex 2	Flow of Data Through the Coroners Service for NI	28

	5	
Annex 3	The Role of Study Categories in Coding of Deaths in NI	29
Annex 4	Sample Coroner's Forms 14, 17 & 21	30

# Background

Deaths in Northern Ireland are certified and registered by a District Registrar under the Births & Deaths Registration (Northern Ireland) Order, 1976. Mortality Statistics are derived from death registrations in Northern Ireland and published by the Northern Ireland Statistics and Research Agency (NISRA) Vital Statistics Unit.

The majority of deaths in NI are certified by a doctor using a Medical Certificate of Cause of Death (MCCD). The MCCD is then taken by a qualified informant<sup>1</sup> to a District Registration Office in order to register the death. Deaths must be registered within five days of the death occurring, but there are some situations where the registration of the death can be delayed, specifically where the death has been accidental, unexpected or suspicious. Under the provisions of Section 7 of the Coroners Act (Northern Ireland) 1959, where a deceased person has died from any cause other than natural illness for which they have been seen and treated by a registered medical practitioner within 28 days prior to the death, the death must be referred to the Coroner. Registration of such deaths take place after the Coroner has completed their investigation and certified the death. The diagram below shows how separate administrative data sources combine and flow into General Register Office, NI's (GRONI), Death Registration System.



#### Figure 1: Overview of sources of data combined to form death statistics

<sup>&</sup>lt;sup>1</sup> <u>Registering a death with the district registrar | nidirect</u>

This document contains information on the quality of the administrative deaths data produced and published by the Northern Ireland Statistics and Research Agency (NISRA) Vital Statistics Unit. It describes the processes involved from data collection to publication, with a focus on quality assurance. It identifies where there are potential areas of risk in the quality and accuracy of deaths data; it also details the checks carried out on the data to mitigate those risks.

This report has been published to help understand the data processing undertaken and provide reassurance and transparency to users on the quality of the data underpinning death statistics in NI. The assessment was carried out using the UK Statistics Authority's <u>Quality Assurance of Administrative Data Toolkit</u>. The toolkit outlines four areas:

- Operational context and administrative data collection
- Communication with data supply partners
- QA principles, standards and checks applied by data suppliers
- Producer's QA investigations and documentation

# Applying the Data Quality Assurance Toolkit to Death Statistics in NI

The UK Statistics Authority introduced QAAD guidance to help statistics producers review their quality assurance arrangements for the administrative data used to produce official statistics. The toolkit comprises -

- Quality Management Actions;
- Quality Assurance Matrix; and
- Risk/Profile Matrix.

The following report aims to apply the requirements of the UK Statistic Authority's Quality Assurance toolkit to the administrative data used by NISRA to produce deaths statistics in Northern Ireland. The aim being to provide reassurance and transparency regarding the quality of the data underpinning these statistics and to give users a better understanding of their reliability and accuracy.

The QAAD toolkit states that the critical judgement about the suitability of the administrative data for use in producing official statistics should be pragmatic and proportionate, made in the light of an evaluation of the likelihood of quality issues arising in the data that may affect the quality of the statistics, and of the nature of the public interest served by the statistics. They recommend that the matrix below is used by producers of statistics to assess the risk profile of the statistics they produce that are derived from administrative sources. The resultant rating then determines the level of assurance required for each of the 4 stages in the Quality Assurance framework.

Level of risk of quality concerns	Public interest profile Lower	Medium	Higher
Low	Statistics of lower quality	Statistics of low quality	Statistics of low quality
	concern and lower public	concern and medium	concern and higher
	interest [A1]	public interest [A1/A2]	public interest [A1/A2]
Medium	Medium Statistics of	Statistics of medium	Statistics of medium
	medium quality concern	quality concern and	quality concern and
	and lower public interest	medium public interest	higher public interest
	[A1/A2]	[A2]	[A2/A3]
High	Statistics of higher quality concern and lower public interest [A1/A2/A3]	Statistics of higher quality concern and medium public interest [A3]	Statistics of higher quality concern and higher public interest [A3]

Note: A0: No Assurance, A1: Basic Assurance, A2: Enhanced Assurance, A3: Comprehensive Assurance.

#### Administrative Data Quality Assurance Toolkit - Risk of Data Quality Concerns:

Level of Risk	Description of Risk
Low risk	The data may have a low risk of data quality concerns in situations in which there is a clear agreement a bout what data will be provided, when, how, and by whom; when there is a good appreciation of the context in which the data are collected, and the producer accepts that the quality standards being applied meet the statistical needs.
Medium risk	The data may be regarded as having a medium risk of data quality concerns when high risk factors have been moderated through the use of safeguards, for example, integrated financial audit and operational checks, and effective communication a rrangements. It is also a ppropriate to consider the extent of the contribution of the administrative data to the official statistics, for example, in cases where the statistics are produced in combination with other data types, such as survey or census data.
High risk	The data may have a high risk of data quality issues when there are many different data collection bodies, intermediary data supplier bodies, and complex data collection processes with limited independent verification or oversight.

#### Administrative Data Quality Assurance Toolkit – Public Interest Profile

Level of Public Interest Profile	Description of Public Interest
Low profile	Politically neutral subject; interest limited to niche user base, and limited media interest.
Medium profile	Wider user and media interest, with moderate economic and/or political sensitivity.
High profile	Economically important, reflected in market sensitivity; high political sensitivity, reflected by Select Committee hearings; substantial media coverage of policies and statistics; important public health issues; collection required by legislation.

#### Risk Profile Rating of Death Statistics in NI and Justification for Matrix Score

The public interest profile has been set to **high** due to the use of death statistics to make decisions on resource allocation by central and local government, along with pandemic response planning and monitoring.

There is significant public interest in the reporting of deaths and this has been heightened by the Covid-19 pandemic. The Department of Health (DoH), Members of the NI Assembly (MLAs), the Public Health Agency (PHA) and members of the public all have an interest in these statistics.

Death statistics receive regular and significant coverage in the Northern Ireland media, on publications such as drug and alcohol related deaths, deaths by suicide and deaths due to Covid-19.

The risk of quality concerns has been set to **medium**. While there is a legal requirement to register deaths and data are collected in a standardised and established way<sup>2</sup>, the review of suicide statistics in 2020-2022 has highlighted the risk in relation to staff changes, multiple data sources and their different systems, all with the potential to present inconsistencies in collation.

As the scores were deemed medium risk of quality concerns and high for public interest profile, the assurance rating was deemed by the Vital Statistics Unit as **A2: Enhanced assurance** (highlighted in matrix below).

Level of risk of quality concerns	Public interest profile		
	Lower	Medium	Higher
Low	Statistics of lower quality concern and lower public interest [A1]	Statistics of low quality concern and medium public interest [A1/A2]	Statistics of low quality concern and higher public interest [A1/A2]
Medium	Medium Statistics of medium quality concern and lower public interest [A1/A2]	Statistics of medium quality concern and medium public interest [A2]	Statistics of medium quality concern and higher public interest [A2/A3]
High	Statistics of higher quality concern and lower public interest [A1/A2/A3]	Statistics of higher quality concern and medium public interest [A3]	Statistics of higher quality concern and higher public interest [A3]

Note: A0: No Assurance, A1: Basic Assurance, A2: Enhanced Assurance, A3: Comprehensive Assurance.

<sup>&</sup>lt;sup>2</sup> www.nidirect.gov.uk/articles/registering-death-district-registrar#toc-2

## QAAD Quality Assurance Matrix

# i) Operational Context and administrative data collection

#### About This Chapter

This chapter provides a description of the administrative systems involved in the production of death statistics in Northern Ireland and provides an overview of how these sources are used for the production of Official and National Statistics. Death statistics are based on a large scale process with multi-agency involvement, where the general public act as the informant. The data are therefore subject to the difficulties inherent in any large scale operational or administrative data recording and collection system - whether this is the consistent application of guidance or standards, for example guidance to clinicians on completing the MCCD or the impact of changes in structures underlying the data collection.

All deaths statistics are sourced from two systems:

- i) NIROS: the Northern Ireland Registration Office System of the GRONI; and
- ii) CLEAR: The information management system of the Coroners Service for Northern Ireland (CSNI)

The same data quality procedures applied to these two IT systems also extend to all deaths statistics outputs. Further details of additional checks applied to each of the individual statistical outputs are covered in later sections of the report. Annex 1 and Annex 2 show the flow of data through the death registration system, the Coronial System and ultimately to the production and publication of death statistics in NI.

In addition, it is essential to consider the death certification process in NI. While this is not an administrative system, it is the prime and unique source of cause of death data by which information (including cause of death) is recorded and flows into NI's registration system and ultimately to the death statistics.

#### Death Certification in Northern Ireland

When someone dies, the death must be registered by the GRONI. Before it can be registered, the Registrar must be provided with notification of the death and either a Medical Certificate of the Cause of Death (MCCD) (Figure 1) from a doctor or authorisation from a Coroner (Annex 4). For most deaths, the doctor who attended and provided care within twenty-eight days of death completes the MCCD. This is delivered to the local Registrar who issues the formal death certificate and an authority for burial or cremation of the deceased. (Form GRO21).

MCCDs can only be completed by a registered medical practitioner who saw and treated the deceased during their last illness. No other person or practitioner may sign the certificate on his/her behalf. It is worth noting that during the Covid-19 pandemic, a number of changes were made to the usual process of certifying and registering a death which were enabled by the Coronavirus Act 2020. More detail is available from the <u>Department of Health</u> website. This includes guidance to medical practitioners on how to complete the Medical Certificate of Cause of Death (MCCD) in Covid-19 related cases. It also provides information on who can complete the MCCD.

The completion of MCCDs is a statutory duty with doctors being subject to regulation of their conduct by the General Medical Council. They must state the cause(s) of death to the best of their knowledge and belief and give<sup>3</sup> the certificate to the Informant or report to the Coroner if necessary.

Figure 1: Medical Certificate of the Cause of Death (MCCD)

		THIS CERTIFICATE MUST BE DELIVERED FIVE DAYS TO A REGISTRAR IN NORTHERN IRELAND FOR INSTRUCTIONS TO INFORMANTS
		SEE OVERLEAF
		MEDICAL CERTIFICATE OF CAUSE OF DEATH FOR USE OF REGISTRAR
		Births and Deaths Registration (Northern Ireland) Order 1976, Article 25(2) Entry No
		To be signed by a Registered Medical Practitioner WHO HAS BEEN IN ATTENDANCE during the last illness of the deceased person and given to some person required by Statute to give information of the death to the Registrar. (SEE OVERLEAF)
		Name of Deceased
		Health + Care Number of Deceased
Patient		Usual Address
details	$\neg$	Place of Death
uetans		Date on which last seen alive and treated by me for the undermentioned conditions
		Whether seen after death by me
		Whether seen after death by another medical practitioner
		CAUSE OF DEATH Agreement a prevent of between I I vesses, days, bears)
		Disease or condition         (a)
Cause of		Antecedent causes
	$\neg$	Morbid conditions, if any, giving rise to the above cause, stating the underlying condition last.
Death		
		II
		tributing to the death, but not related to the death, but not
		causing it.
		"This does not mean the mode of dying og heast failure, asthesia, etc. It means the disease, injury or complication which caused death.
		Coroner's Reference Number
Sign off &		Increase certify that the answerinmed person has need as a result of the hattrar timess or disease for which he has been related by the whith twenty-eight days prior to the date of death, and that the particulars and cause of death above written are true to the best of my knowledge and belief.
Doctor's		Signature GMC Registration No.
	$\neg$	Name (Please print)
Details		Work Address

Details on the MCCD provide the basis of the registration information. The Registrar may update the personal details of the deceased based on the informant's review of these, but the cause of death information is copied verbatim as the doctor has recorded. There are some instances where the Registrar is unable to accept the MCCD (for example, unacceptable terms necessitating report to the CSNI, incomplete form, doctor's credentials & signature omitted, or unacceptable abbreviations used in the Cause of Death fields). In these instances the Registrar would contact the doctor and request an accurately completed MCCD to be re-issued. Registration cannot take place until such errors are corrected.

<sup>&</sup>lt;sup>3</sup> During Coronavirus pandemic, if a MCCD is issued by doctor, it is sent electronically directly to the GRO, bypassing the Informant.

#### Cause of Death Recording

The Cause of Death section of the MCCD is set out in two parts, in accordance with World Health Organisation (WHO) recommendations in the International Statistical Classification of Diseases and Related Health Problems (ICD) as shown below (Figure 2).

#### Figure 2: Cause of Death Recording Format

		These particulars not 1 The entered in Death Registra
Ι	CAUSE OF DEATH	Approximate internal forecast and the statistic states, marthy marily share
Disease or condition directly leading to death*	I (a) IMMEDIATE CAUSE OF DEATH due to (or as a consequence of)	
Antecedent causes Morbid conditions, if any, giving rise to the above cause, stating the underlying condition last	(b) <b>ANTECEDENT CAUSE(S)</b> due to (or as a consequence of)	l
п	(c) UNDERLYING CAUSE(S) OF DEATH	
Other significant conditions contributing to the death, but not related to the disease or condition causing it	OTHER SIGNIFICANT CONDITIONS	

\* This does not mean the mode of dying e.g. heart failure, asthenia, etc. It means the disease, injury or complication which caused death.

#### Part I - Sequence leading to death and underlying cause

This is used to show the immediate cause of death and any underlying cause(s).

Start with the,

- immediate, direct Cause of Death on line I (a); then
- go back through the sequence of events or conditions that led to death on subsequent lines
   I (b) and I (c); until
- you reach the one leading ultimately to death = Underlying Cause of Death.

This should **ALL** be in Part I.

If the certificate has been completed properly, the condition on the lowest completed line of

Part I will have caused all of the conditions on the lines above it.

#### Part II - Contributory causes

Any other significant diseases, injuries, conditions, or events that contributed to the death, but were not part of the direct sequence, should be entered in Part II of the certificate.

How to complete an MCCD is part of all registered medical practitioners in a Northern Ireland training scheme. In addition to this registered medical practitioners should ensure they are competent in MCCD completion by updating their knowledge and regularly reflecting on their practice.

The NI Department of Health (DOH) has done considerable work in recent years to improve the knowledge of medical practioners in this area and have produced <u>several detailed guidance</u> <u>documents on how to complete a MCCD.</u>

In addition to this, work is ongoing to move towards the electronic completion of MCCDs. The creation of an eMCCD using the Northern Ireland Electronic Care Record (NIECR) was introduced in all Health and Social Care (HSC) Trust hospitals in November 2016. While this work has primarily been undertaken in line with DoH policy, the obvious benefit is increased assurance of accurate hospital MCCD data flowing into the death registration system and hence to the NISRA official death statistics.

Handwritten MCCDs remain in primary care, homes, nursing homes, some community hospitals and some hospices although, with the recent Coronavirus pandemic changes, most General Practitioner MCCDs are now in eMCCD format. It is hoped, once the pandemic changes revert, that community-based MCCDs will still be produced electronically and also become available for electronic review of all MCCDs across Northern Ireland.

In addition to the increased awareness of the benefits of accurate cause of death completion, the DoH is currently piloting an Independent Medical Examiner Role, where a random sample of Northern Ireland MCCDs is reviewed. This additional QA process would no doubt further enhance the quality of death data, in particular the cause of death information flowing into the NI registration system and NI death statistics.

### ICD-10 Cause of Death Coding

Coding for cause of death in NI is carried out according to the World Health Organisation (WHO) International Classification of Diseases (ICD tenth revision)<sup>4</sup>.

Historically, ICD 10 coding of deaths in NI was done within GRONI by a dedicated coder, however since 2015, all death data in NI have been coded by the Office for National Statistics (ONS) on behalf of NISRA. The majority of these data (approximately 75%) are coded using automatic cause coding software (MUSE). Specific text terms from the death certificate are converted to ICD codes, and then selection and modification rules are used to assign the underlying cause of death. Using computer algorithms to apply rules increases the consistency and improves the international comparability of mortality statistics. The cause coding of deaths referred to the Coroner is done manually by experienced coders, as the software can not code the additional information supplied by Coroners. This process is informed by a categorisation field held in the Coroners systems referred to as a 'study category' which categorises the death as accidental, undetermined or suicide. This classification in particular has been subject to extensive refinement as part of the 2020-21 review of suicide statistics. See Annex 3 for details on study categories.

The selection of the underlying cause of death is based on ICD rules and is made from the condition or conditions reported by the certifier, as recorded on the certificate. The underlying cause of death is defined by WHO as *the disease or injury that initiated the train of events directly leading to death* or *the circumstances of the accident or violence that produced the fatal injury*.

Deaths attributed to accidents, poisonings and violence are examined, firstly according to the underlying cause of death (external cause) and secondly by the nature of injury or main injury.

<sup>4</sup>www.who.int/classifications/icd/ICD-10 2nd ed volume2.pdf

#### Selection and modification rules

The selection of the underlying cause of death is generally made from the condition or conditions entered in the lowest completed line of Part I of the MCCD. If the death certificate has not been completed correctly - for example, if there is more than one cause on a single line with no indication of sequence or the conditions entered are not an acceptable causal sequence - it becomes necessary to apply one or more of the selection rules in the ICD-10.

Even where the certificate has been completed properly, there are particular conditions, combinations or circumstances when modification rules have to be applied to select the correct underlying cause of death. On some death certificates, for example, when two or more causes are listed and then linked together, these may point to another cause (not mentioned directly on the certificate) as underlying (an inferred underlying cause). This happens in a minority of cases and these are most commonly related to diseases of the circulatory system and late effects of cerebrovascular disease. In other cases, the underlying cause of death can be selected from Part II of the MCCD.

In summary, the purpose behind the selection and modification rules is to derive the most useful information from the death certificate and to do it uniformly so that data will be comparable between places and times and each death certificate produces one, and only one, underlying cause of death.

Further details on ICD coding carried out by the ONS are available in <u>User guide to mortality statistics</u> published on the ONS website.

#### NIROS

The GRONI is primarily concerned with the administration of the registration of births, marriages, civil partnerships and deaths under Civil Registration Legislation (The Births and Deaths Registration (NI) Order 1976, the Marriage (NI) Order 2003 and the Civil Partnership Act 2004).

During registration of a civil event e.g. death, all information is entered by a Registrar onto an electronic system called the Northern Ireland Registration Office System (NIROS). NIROS is an integrated civil registration and certificate production system with direct electronic communication to 26 local District Registrar Offices (DROs) in all 11 council areas. Registration of deaths is therefore consistent across all of NI.

#### CLEAR

Under the provisions of Section 7 of *the Coroner's Act (Northern Ireland) 1959*, where a person has died from any cause other than natural illness for which they have been seen and treated by a registered medical practitioner within 28 days prior to the death, the death must be referred to the CSNI.

Most notifications of death come in from Police Service of Northern Ireland (PSNI), General Practitioners (GPs), Out of Hours GPs & Hospitals, however a death can be reported to CSNI by anyone. On occasion the Registrar (if a death certificate is incorrect) will notify CSNI of a death, although Registrars are encouraged to speak directly to the doctor first to see if it can be rectified without CSNI input. Notifications may also come from a Next of Kin (or their solicitor), or from a

Trust in which there was concern/internal investigation surrounding a death. In all instances, the Coroner will decide if they feel it falls under Section 7 and a case is formally opened.

Once a case has been reported to the Coroner, information is gathered from a range of stakeholders (e.g. next of kin, PSNI, doctors) and is entered centrally on to the CSNI case management system [CLEAR]. The PSNI, acting as the Coroner's Agent, may gather witness statements; the Health Trust gather their own statements from staff on behalf of the Coroners Service. As the case progresses, notes of conversations, witness statements and all communications surrounding the case are all recorded CLEAR. See Annex 2 for further details.

#### Impact of Changes in Systems

There have been three notable changes in systems which have had an impact on death statistics in NI in recent times:

- i) Following a review of the Coroners Service in Northern Ireland CSNI was restructured from seven Coroners Districts to one centralised service between 2005 and 2006. This resulted in a streamlined process for Coroners' investigations and a reduction in registration delays of deaths in Northern Ireland and a welcome improvement to the timeliness of death statistics reporting in Northern Ireland. A dedicated Coroners Service electronic database known as Mountain was installed to accommodate centralisation; this was replaced by CLEAR in 2019.
- ii) On 26 July 2018, as a result of a case<sup>5</sup> in the UK High Court (and confirmed in NI in November 2018), the standard of proof – the evidence threshold – used by Coroners in England and Wales to determine whether a death was caused by suicide was changed from the criminal standard of "beyond all reasonable doubt" to the civil standard of "on the balance of probabilities". In Northern Ireland, confirmation of the civil standard of proof for suicide was provided by a decision by McCloskey J delivered in November 2018. The outcome was that the lower civil standard applies to suicide deaths in Northern Ireland. This has the potential for Coroners to identify more deaths as selfharm, hence reducing the number of accidental deaths and deaths of undetermined intent. NISRA will monitor and report the impact of this change on our data; given the registration delays and the additional impact of the Review of Suicide Statistics, it will take time to gather enough data to assess the impact of the change.
- iii) Prior to 2015, ICD 10 coding of deaths was carried out within GRONI by a dedicated coder which allowed for case by case scrutiny, including a process by which further information could be sought from the Coroner in relation to 'undetermined deaths'. ICD 10 coding was then transferred to ONS, working in conjunction with the NISRA Vital Statistics Unit (VSU). As a result, direct contact between the ICD Coders and CSNI ceased. The 2020-2022 review of suicide statistics has highlighted the need for streamlined collaboration between NISRA, CSNI and ONS. Lessons learned from this review have been incorporated into the routine production and validation of death statistics in NI:

<sup>&</sup>lt;sup>5</sup> <u>R (on the application of Maughan) (AP) (Appellant) v Her Majesty's Senior Coroner for Oxfordshire</u> (<u>Respondent</u>) - <u>The Supreme Court</u>

- 1. As registration of each Coroner's case takes place, Coroner's Forms 14, 17 & 21 are forwarded by the Registrar to VSU, where they are recorded and are made available to VSU staff for further validations.
- In 2019, CSNI introduced a new case management system, within which all deaths must be assigned as either accidental, intentional self-harm or undetermined intent. This in turn ensures, moving forward, that there will be no ambiguity for the deaths coding team (ONS) and statistics production team (NISRA).
- 3. On a monthly basis;
  - CSNI forward a list of closed Coroners cases and associated Study Category to VSU. Study Category is then attached to the corresponding registration as it takes place and is forwarded to ONS for ICD coding.
  - all deaths (with study category appended, where appropriate) are sent to ONS for coding. Upon receipt of coded data all ICD codes are crossreferenced with cause of death text for Coroner's cases to ensure they are aligned. Issues are raised with ONS as appropriate and corrected where necessary. All checks are carried out, documented, peer-reviewed by VSU and signed off by senior management, thus creating a clear audit trail of decision making.

# ii) Communication with Data Suppliers

#### About This Chapter

This section documents communication with the data suppliers involved in the production of death statistics.

#### NIROS Data Sharing Mechanism

NISRA VSU statisticians have a live link to a specifically designed statistical area within NIROS. This is a restricted copy of NIROS' live system designed to meet VSU's specific needs. The VSU team can download bespoke death data extracts as and when required.

The death data requirement from NIROS is now long established with amendments made over the years to ensure that changes to the processes or systems can be included in the statistics. VSU wrote a statistical data specification for NIROS when it was created, ensuring all data and quality needs were met. Periodically, changes are necessary to NIROS following a legislative change e.g. the introduction of same-sex marriage in NI. In these cases adjustments are made to NIROS to capture this information, while ensuring the data captured meet VSU needs.

Although long established, there is still regular communication between GRONI staff, VSU and the NIROS IT contractor regarding the data download process. This is managed through a formal agreement between NICS IT ASSIST and the contractor and ranges from informal telephone/email queries to resolve data or system problems, to routine validation checks, to VSU staff attending formal meetings with the respective organisations to address larger scale projects such as system upgrades using change management processes. Any problems experienced with the completeness of downloads are raised by VSU with colleagues within GRONI and the NIROS IT contractor as soon as they come to light. Most issues are resolved quickly, but larger issues may take longer if they require an update to the system which has to be scheduled.

ESS Enterprise Shared Services (ESS), responsible for providing shared services to the Northern Ireland Civil Service (NICS), hosts the system and provides the infrastructure services liaising with the NIROS IT contractor regarding operational issues. VSU is informed by the GRONI of any changes that could affect the reliability of our statistics or data extracts.

#### Formal agreements detailing arrangements

In terms of the legal basis for data supply, GRONI is deemed the data controller with regard to the data held on NIROS. The information is collected on NIROS in order to meet GRONI's legal obligations and public functions.

NIROS provides the basis for vital statistics in Northern Ireland. NISRA VSU as the producers of statistical data, process the data on behalf of and under the direction of the Registrar General for Northern Ireland to meet their legislative obligations.

The terms of this arrangement are outlined in a Memorandum of Understanding between GRONI and VSU.

#### Data Protection Provision

All data files are stored on secure VSU SQL server with access restricted solely to the VSU team.

The Head of Vital Statistics Unit is the Information Asset Owner for the branch and is required to ensure that branch security procedures are in place and staff are adequately trained in data protection requirements. As a minimum, all VSU staff must complete mandatory on-line data protection and information security training on joining the branch and complete further annual refresher training in line with NICS policy.

VSU applies statistical disclosure control to all data sourced from NIROS to ensure that no one is identifiable from the data or any sensitive information relating to them.

#### CLEAR Data Sharing Mechanism

In addition to CSNI information flowing from CLEAR to NIROS as part of the Registration process, on a monthly basis the Coroners Service pass details of closed cases (including Study Category) to VSU containing additional information on each case to ensure all deaths are fully and accurately coded (according the WHO ICD-10 rules) before any analysis can take place. See Annex 3 for further details on the role that study category plays in death coding in NI.

#### Formal agreements detailing arrangements

CSNI is the data controller for data held within CLEAR, as outlined in an information sharing agreement between Coroners Service and VSU. This document details the schedule, specification and security arrangements for the provision of data to VSU from CLEAR.

#### Data Protection Provision

Information is transmitted electronically by CSNI to NISRA VSU via Secure File Transfer Protocol (SFTP). All data files and scanned Coroners forms are stored on TRIM (the NICS central record management system) with access restricted solely to VSU.

#### User Engagement

In winter 2021 VSU published the <u>Vital Statistics User Engagement Strategy</u> outlining the approach and action plan for engagement with users for 2021/22. This aims to build on both formal and informal engagement with known users and increase user driven input across all VSU statistics. In addition to closed media briefings which have proven very useful during the Covid-19 pandemic, the team has established a new user group, newsletters and enhanced has its use of social media and explanation videos.

VSU has an ongoing user survey, circulated annually to users via email and social media. The most recent survey results can be seen in Table 1.

#### Table 1 Results of VSU User Survey 2021

N=17	Very Satisfied /Satisfied	Neither Satisfied nor Dissatisfied	Dissatisfied /Very Dissatisfied
How satisfied or dissatisfied are you with the quality of Vital Events statistics?	71%	18%	12%
How satisfied or dissatisfied are you with the extent to which the statistics you use are accurate?	82%	6%	12%
How satisfied or dissatisfied are you with the extent to which the statistics you use meet your needs?	76%	6%	18%

In general, the most frequently stated reasons for using death statistics were policy making/monitoring, performance monitoring, research and media related/informing public/public interest.

In addition to the user survey, VSU liaise and meet with the expert users of the statistics on a regular basis throughout the year. In practice this tends to be in the form of small ad hoc meetings with relevant policy staff or User Group Meetings. Examples of issues raised by users and the VSU response are available from our most recent User Group meeting <u>Issues Raised at the 2021 User</u> <u>Group Meeting</u>. Additionally, NISRA forms part of the UK Mortality Theme Group, chaired by ONS, which is vital to ensuring consistency across the four nations.

In addition to these meetings, VSU staff also have regular telephone and email contact with key users to respond to urgent queries or to provide policy colleagues with relevant statistics or associated advice and guidance. Contact details are also provided in all publications and on the NISRA website where users are also invited to provide feedback. Death statistics are used to inform policy decisions across Government and to answer NI Assembly questions, Freedom of Information requests and general queries from the public.

# iii) Quality Assurance Principles and checks applied by data suppliers

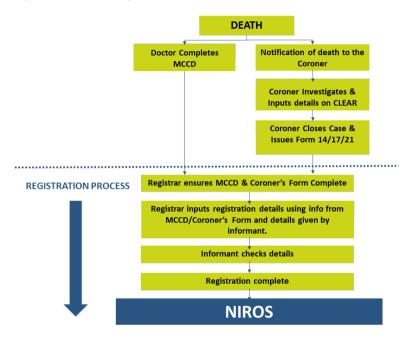
#### About This Chapter

This section documents the quality assurance procedures applied by data suppliers.

The death registration process begins when either

- a doctor completes a MCCD; or
- death is referred to the Coroner

#### Figure 3: Death Registration Process, Northern Ireland



#### Registration Using a MCCD

For ¾ of deaths a doctor completes a MCCD detailing personal details of the deceased along with the cause of death. The completion of MCCDs is a statutory duty with doctors being subject to regulation of their conduct by the General Medical Council (GMC).

Upon completion of the MCCD, the certifying doctor passes it to the next of kin/qualified informant to allow them to register the death.

Before commencing the registration, the Registrar will check that the MCCD is completed with nothing omitted or errors; sometimes these are checked by contacting the certifying doctor. There are certain situations where a Registrar will not register the death if the MCCD is completed incorrectly. All three sections need to be correct i.e. patient and doctor details along with the cause of death. The first two sections are basic factual checks which can be verified with the informant. The cause of death section, prior to the institution of an Independent Medical Examiner (IME) service, was restricted to a check that the MCCD did not contain:

- terms that necessitated a report to the CSNI; and
- use of abbreviations.

DoH is currently piloting an IME whereby approximately 30 per cent of all hospital deaths are now reviewed by an IME and are subjected to a much more in-depth review of whether the formulation:

- 1. conforms to Chief Medical Officer guidance with respect to sequencing, use of inappropriate terms and unqualified terms; and
- 2. contains the terms used in the Cause of Death section that do not reflect the **actual** Cause(s) of Death, determined from the clinical evidence, as determined by an examination of NIECR and a discussion with the certifying doctor.

The cause of death details completed on the MCCD by the certifying doctor are based on clinical judgement. They are required to state the cause(s) of death to the best of their knowledge and belief. The DoH has guidelines in place which cover the accurate completion of the MCCD. All registered medical practitioners completing MCCDs should update their knowledge regularly in this area.

Until the commencement of the Independent Medical Examiner service there was no formal quality assurance of the MCCD formulation. A regional audit, performed retrospectively in 2016, of 1,000 deaths occurring in 2014 revealed that 38% of MCCDs had errors of the type mentioned in category 1, as above. Error type 2 (not the actual cause of death) have been determined in subsequent audits which indicate about 5% of hospital deaths have an incorrect underlying cause of death. Until a formal IME service is fully operational, (timescales for this are not yet known) reviewing both hospital and community deaths, quality assurance of the MCCD formulation will not be possible. There is an obvious need to have quality assurance of this prime data as being the original and only data source of the cause of death.

#### QA checks and quality indicators for input data to NIROS

During the death registration all required information is sourced from both the MCCD and the qualified informant. A provisional copy of the information is shared with the informant before the registration is finalised and the informant is asked to check the information supplied and verify that it is both complete and accurate (e.g. to check that all spellings/dates are correct). Any further errors can be addressed at this stage, before being finalised on GRO's electronic system (NIROS). Information at this stage is reliant on the best knowledge of the informant about the deceased, for example, their knowledge of 'occupation' which may have been some years previous following a period of retirement. In other cases occupation may be provided as 'retired'.

The process by which an informant registers a death has been adapted during the Covid-19 Pandemic. Usual practice is that the informant attends their local Registration Office to register a death, bringing the MCCD with them. During the pandemic, the MCCD can be sent to the General Register Office (GRO) electronically, directly from the hospital or General Practitioner certifying the death. Information required from the informant can be provided to GRO by telephone and no signature is required from the informant.

#### Quality Assurance within NIROS

A suite of quality assurance checks is embedded within NIROS in the form of both mandatory and 'soft' checks. The VSU was an integral part of the specification and design of NIROS with IT Contractor & GRO in the run up to its launch in 2016. Quality assurance within NIROS takes the form of

- Mandatory checks & compulsory fields e.g. date of birth & date of death parameter checks
- **'Soft' checks and warnings to Registrars** e.g. *display a warning to Registrars to check the date of death as deceased is over 100. Ask Registrar to confirm this is correct.*
- Automatic generation of fields e.g. age at death

#### Errors identified following registration

Any errors identified in registrations may be rectified at any point and a new death certificate issued. All amendments are verified against the evidence supplied, recorded in TRIM, updated in NIROS by GRO staff and approved at management level.

#### Back-Up Schedule in NIROS

NIROS has full IT Health Check accreditation, most recently completed in 2022. As part of the accreditation, an independent contractor must carry out an IT Health Check. Any issues identified and remedial action required are taken forward by GRONI.

#### Role of operational inspection and internal/external audit

GRONI is scrutinised by DoF Internal Audit every five years. The most recent audit was carried out in 2018 and found that all controls were 'adequate and operating effectively' for the registration of deaths to ensure they are correctly recorded, amended and held securely.

#### Registration Using a Coroner's Form.

The remainder of deaths are registered when the Coroner has completed their investigation and has forwarded the relevant forms (Forms 14, 17 or 21) to the District Registrar Office. District Registrars invite a qualified informant to register the death. Coroners forms contain personal information on the deceased along with cause of death details.

As with MCCD registrations, the CSNI checks forms 14, 17 and 21 to ensure that they have been completed accurately, following which the Coroner reviews the cause of death details contained within Coroner's Forms.

#### QA checks and quality indicators for input data to CLEAR

Similar to MCCDs generated in hospital, Coroners proforma letters (and clinical summaries required for Post-Mortem) for deaths occurring is hospital are now also generated and provided to CSNI via NIECR, providing a higher level of data assurance than handwritten equivalents.

Proforma letters provided by GPs and in the community remain as handwritten submission at present but, similar to MCCDs, this may be reviewed as systems are updated.

Information entered on to CLEAR is provided initially from a range of trusted third parties (GPs/hospital doctors/Out of Hours doctors/PSNI. This information is received from trusted partners who are reporting the death to the Coroner. A sense check is completed by the Death Reporting Team where obvious errors are highlighted (such as an obviously incorrect date of birth) and cross-referenced between all sources. Where follow up information regarding the death is required an additional verification may sometimes be facilitated with the trusted partner.

For cases that progress to post mortem, information is checked by the Coroner's Liaison Officer (CLO) with the Next of Kin (e.g. to check that all spellings/dates are correct). Any further errors or insufficient information can be addressed at this stage.

The system has a design feature that provides an alert to the user to input data in a certain order to ensure that correct closure processes have been completed.

A data check is routinely completed by staff running a view report, to ensure that full case details have been updated.

#### Quality Assurance within CLEAR

The system has inbuilt features where a post code address locator automatically populates an address and place of death. Additionally separate field selections allow the transfer of already populated information which removes duplication of data entry. The system automatically calculates the age of the deceased based on the year of birth entered.

The system has a number of fields (such as age, case number and certain name fields) that are automatically locked to ensure data protection.

Additionally CLEAR has a quality assurance check tab which reflects instances where a management check has been completed on the case.

#### *Errors identified following input into CLEAR*

Where CSNI is advised of amendments to data, or where an error has been identified the case record will be updated with the appropriate details. All updates to a case can be viewed in the case audit history. The case is then reviewed to determine any other impact of such changes to check, for example, whether any amendments are required to previous records.

#### Back-Up Schedule in CLEAR

CLEAR has been fully accredited by the DOJ Accreditation Panel. As part of the accreditation, an independent contractor must carry out an IT Health Check on an annual basis, any issues identified and remedial action required are taken forward by NICTS. It is classified as an OFFICIAL solution, complying with all GDPR and Information Assurance standards.

#### Role of operational inspection and internal/external audit

The Department of Justice undertakes an annual audit of Validation of Reported Performance against Agreed Standards for the CSNI. These include:

• 97% of all deaths investigated that do not require a post mortem examination will have the certificate of registration issued to the Registrar of Deaths within three working days of the relevant documentation being received by the Coroner;

 $\cdot$  95% of all deaths where a post mortem examination reveals a natural cause of death, will have the certificate of registration issued to the Registrar of Deaths within five working days of the Coroner making the decision to close the case following receipt of the post mortem report; and  $\cdot$  In 95% of inquests the administrative listing arrangements will be completed within 28 working days of the Coroner's direction to list.

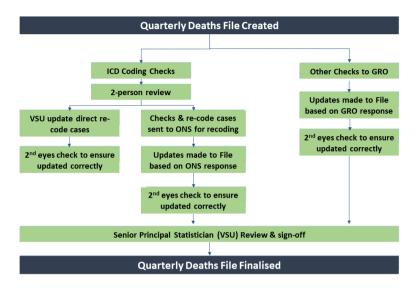
The last audit of Validation of Reported Performance against Agreed Standards was completed in 2021 where audit opinion found that overall there is a satisfactory system of governance, risk management and control.

Additionally, in 2018/19 the Department of Justice completed an Internal Audit Review of the Operation of Coroners Service which found that overall there is a satisfactory system of governance, risk management and control.

# iv) Producer's Quality Assurance Investigations and Documentation

#### About This Chapter

This section documents the additional series of quality assurance checks applied to the deaths data in preparation for publication as a statistical output by NISRAVSU.





Additional quality assurance checks are carried out by VSU using trend analysis, bounds checking, internal within- and across- record consistency and also visual analysis of data to further assess data quality. VSU liaises with staff in GRO, CSNI & ONS over any anomalies found in the data.

#### Individual Record Check

On a quarterly basis, key validation checks are run, to ensure that any potential errors detected are checked at source and corrected when needed. Figure X outlines this process for death validations.

Details of specific checks carried out by VSU are detailed in <u>vital stats QA 0.pdf (nisra.gov.uk)</u>. In addition to this, annual checks are also completed by VSU when creating the final annual file. Three percent of records typically require further investigation by VSU, resulting in death records being updated in around two percent of all deaths.

#### Higher Level Checks

In addition to the checks carried out at individual record level, trend analysis is carried out on key statistics e.g. overall death figures, geographic areas and specific causes of death. There is no set measure of tolerance in terms of quarterly/annual percentage change which triggers a query with the VSU team, but back series comparisons help in the assessment of whether data are consistent with historical trends and to query notable changes. Changes to legislation, operational procedures or external factors e.g. pandemic, may impact on future trends but VSU is usually aware of possible impacts to trends before headline counts change and the estimated impact is documented.

#### Comparisons with Other Data Sources

Where possible, VSU also uses external sources of data to validate the finalised statistics, for example to compare with UK and ROI. However, there are limitations for this in respect of death

registration statistics as GRO is the only body carrying out this function within NI and there can be legislative differences between jurisdictions which mean comparisons are not like-for-like. Nonetheless, such comparisons with other jurisdictions can help indicate where NI is on a different trajectory to other areas and support investigation to understand why this may be the case.

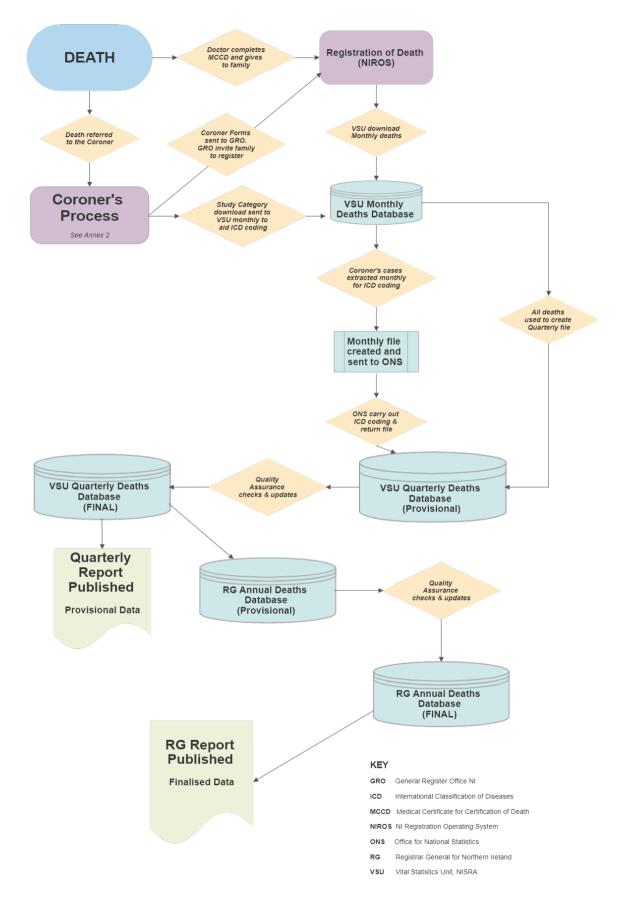
	Strengths	Weaknesses/Limitations	Risks	Mitigation
	-lt is a well established process -Standardised form (MCCD) used to certify death -Certification carried out by qualified medical practitioner	- There are many medical practitioners providing info which may lead to inconsistency in reporting. No checks on standardisation of approach until the full introduction of IMES -There is some scope for clerical error as	-Deaths in NI are not certified resulting in death not being registered -Inaccurate details recorded by medical practioner on MCCD	-It is a legal requirement for all deaths to be certified by a medical practitioner/ Coroner -Many MCCDs are printed directly from hospital systemsPlans to
Certification of Death		information is transferred manually from hospital/GP system forms into paper copy of MCCD	- No guarantee that doctors read the guidance i.e. no mandatory training	move to similar process for community deaths -Medical Practitioners provided with training in completing MCCD during university -DoH provide guidance to Medical Practioners on how to complete MCCD
NIROS	<ul> <li>-Full geographic coverage regionally</li> <li>-Same registration processes and software in place across District Registration Offices</li> <li>-Statisticians have direct access to NIROS</li> <li>-Data suppliers and producers work in close proximity aiding understanding of processes and facilitating resolution of issues.</li> <li>-An agreed MOU between GRONI and VSU outlines procedures and processes for data transfer and resolving data quality issues.</li> </ul>	-There is some scope for clerical error as information is transferred manually from paper forms into NIROS	-Deaths in NI are not registered resulting in no record in NIROS. -Inaccurate details recorded by Registrars on NIROS	<ul> <li>-It is a legal requirement for all deaths to be registered with GRO.</li> <li>-Mandatory checks &amp; 'soft' checks built into NIROS</li> <li>-Informant asked to check details before final registration</li> <li>-Registrar trained on importance of accurate information &amp; common errors.</li> </ul>

	Strengths	Weaknesses/Limitations	Risks	Mitigation
	-Full geographic	- Reliance on trusted	-Inaccurate details	-Management
	coverage regionally	partners to accurately	collated by	checks are carried
		collate information	trusted partners	out including;-
	-Collation of data			Personal details
	recording carried out	-There are many trusted	-Inaccurate details	checked with Next
	by a small, very	partners providing info	recorded by staff	of Kin
	experienced team	which may lead to	on CLEAR	Cause of Death
	(Death Reporting	inconsistency in		checked against
	Team) held centrally	reporting. No checks on	-Inaccurate details	Coroner's
	within CSNI	standardisation of	recorded by staff	Directive/Medical
		approach are carried out	on Form 14/17 or	Adviser advice
	-An agreed SLA		21	Further
	between CSNI and	-There is some scope for		management checks
	VSU outlines	clerical error as		are carried out and
	procedures and	information is collected		documented at case
	processes for data	manually and entered		closure
CLEAR	transfer.	on to CLEAR.		
CLEAN				- Death Reporting
	- CSNI staff have	-Each Coroner interprets		Team provided with
	access to Medical	a case based on the		training in recording
	Advisor	information available to		of deaths and
		them at that time.		appropriate
				information
				- Medical Adviser on
				hand in CSNI to
				advise on cause of
				death recording.
				- Coroners are

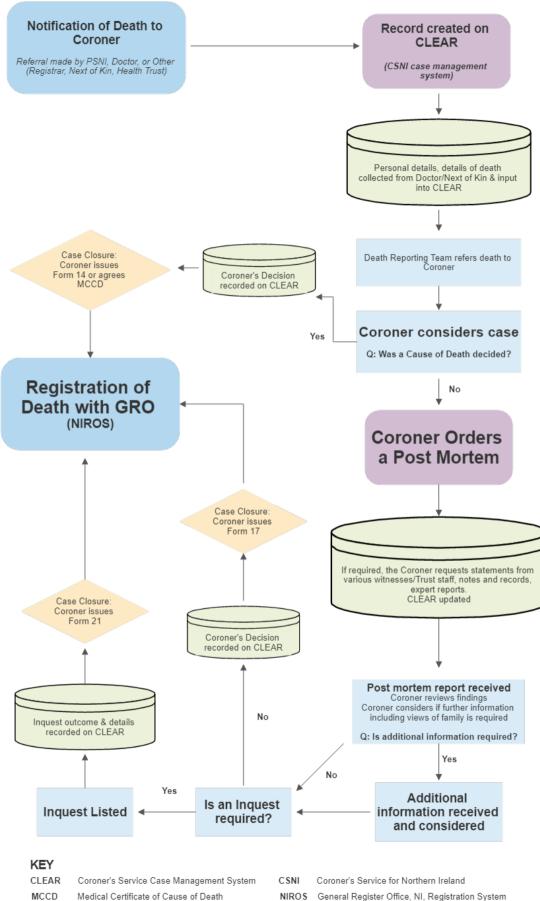
Independent Judicial Officers and are bound by The Coroners Act 1959.



## Annex 1 Death Statistics in NI Data Process



# Annex 2 Coroners Service, for Northern Ireland, Data Process



Medical Certificate of Cause of Death Vital Statistics Unit, NISRA

VSU

NIROS General Register Office, NI, Registration System

## The Role of Study Categories in Coding of Deaths in NI

In some instances Cause of Death text alone does not allow for accurate ICD coding of deaths, for example, an individual may die from a "Head Injury", which is medically correct, but more information on the circumstances is required in order to derive the correct ICD code.

For example, the deceased may have had a fall which caused the head injury, in which case a Study Category of "Fall Accidental" may be assigned by the Coroner when closing the case, or perhaps the deceased was involved in a road traffic accident and would therefore have a Study Category of "RTC-Accidental".

Table A1 below shows a list of study categories available to the Coroner. The Coroner selects the appropriate study category when closing the case. This information is made available to VSU on a monthly basis to allow for accurate coding of deaths and is particularly important for VSU to determine the intent behind a death i.e. whether it was accidental, death by suicide, or in some cases, limited evidence available to the Coroners means the death is of undetermined intent.

This is an evolving list where study categories can be added as required on agreement between NISRA and CSNI

Gunshot- Undetermined Intent
Hanging-Accidental
Hanging-Suicide
Hanging-Undetermined Intent
Hospital death
House Fire- Accidental
House fire- Suicide
House Fire- Undetermined Intent
Industrial accident
Industrial asbestos related
Murder
Natural
RTC- Accidental
RTC- Suicide
RTC- Undetermined Intent
SADS
SIDS
Stillbirth
Unascertained
Volatile Substance- Accidental
Volatile Substance- Suicide
Volatile Substance- Undetermined Intent

#### Table A1 List of Study Categories used by CSNI

Last Updated: February 2022

Sample Coroner's Forms 14, 17 & 21

#### CORONERS ACT (NORTHERN IRELAND) 1959 (Section 24)

#### NOTIFICATION TO THE REGISTRAR OF DEATHS THAT THE CORONER DOES NOT CONSIDER IT NECESSARY TO HOLD AN INQUEST

#### I(a) XXXXXXXXX

A post-mortem examination has not been made and the cause of death was stated by

I do not consider it necessary to hold an inquest and have issued my authority to bury or cremate the body.

Signature:

NOTE: This death should be registered by a qualified informant.

Form 14 Next of Kin Details: Name: Relationship to Deceased: Contact Number: Address: Funeral Director: Study Category:

#### CORONERS ACT (NORTHERN IRELAND) 1959 (Section 28(2))

### CERTIFICATE OF REPORT OF POST-MORTEM EXAMINATION AND NOTIFICATION THAT THE CORONER DOES NOT CONSIDER IT NECESSARY TO HOLD AN INQUEST

I have investigated the death of born, late of which occurred at on and have had a post-mortem examination of the body carried out by Pathologists name

I certify that the cause of death, as disclosed by the report of the post mortem examination was:-

I(a)

I do not consider it necessary to hold an inquest and have issued my authority to bury or cremate the body.

Signature ..... Coroner for Northern Ireland

Date

To: The Registrar of Birth and Death for the District of

NOTE: This death should be registered by a qualified informant.

Form 17 Next of Kin Details: Name: Relationship to Deceased: Contact Number: Address: Funeral Director: Study Category:

#### CORONERS CERTIFICATE

To be sent to the Registrar within FIVE DAYS after the Inquest.

To the Registrar of Births, Deaths and Marriages for the District of

I HEREBY CERTIFY that at an Inquest held at on The Coroner for Northern Ireland touching the death of before

I found as follows:

- 1. Name and Surname:
- 2. Sex:

me

- 3. Date of Death:
- 4. Place of Death: Please enter the content IF your condition is met
- 5. Usual address (if different from place of death): ,
- 6. Marital Status:
- 7. Date and Place of Birth:
- 8. Occupation:
- 9. Maiden Surname (of woman who had married):
- 10. Cause of Death: I(a)
- 11. Findings:

Witness my hand this **05 April 2022**. Signature

Coroner for Northern Ireland

Form 21

Space 3:	(a) If date of death is unknown, enter "Found dead on" followed by the date on which the body was found.
	(b) If the death relates to a child who lived for less than 24 hours, enter after
	the date of death the word "aged" followed by the age in completed hours or if less than one hour, in minutes.
Space 4:	If the place of death is unknown, enter "Found at" followed by the place where
Space 4.	the body was found.
Space 6:	Enter "Single," "Married," "Widowed" or "Divorced," regardless of the sex of deceased. Young children should be described as "Single."
Space 7:	Enter the date of deceased's birth followed by the place of birth. Enter the date in one of four ways as, for example,
	14 April 1930 April 1930
	1930
	About 1930 depending on the nature of the information to hand. Enter the place of birth as
	the name of the town, or townland only; where the deceased was born outside
	Northern Ireland, include the name of the country.
Space 8:	Enter the last gainful occupation, if any. Terms such as "Unemployed," "Housewife," etc. may not be entered in the death register. If deceased was a child under 16 years of age, enter "Son of" or "Daughter of" followed by the name, surname and occupation of the father (or where this cannot be supplied, eg where the child was illegitimate, the name, surname and occupation [if any] of the mother). If deceased was a woman who had married enter her last gainful occupation (if any) followed IN ALL CASES by the words "wife of" or "widow of" and the name, surname and occupation of her (late) husband. If deceased had
	retired, enter "Retired" before the occupation.
Space 9:	Where applicable, enter the surname in use immediately before deceased's (first) marriage.
Space 10	State at I the disease or conditions directly leading to the death followed by any morbid conditions which gave rise to the cause, stating the underlying condition last.
	State at II any other significant conditions contributing to the death, but which were not related to the disease or condition causing it.

Next of Kin Details: Name: Relationship to Deceased: Contact Number: Address: Study Category: