Neuroendocrine cancer

(Excludes non-melanoma skin cancer)

Patients diagnosed 1993-2020

Further information

Further data is available at: **www.qub.ac.uk/research-centres/nicr**
Phone: +44 (0)28 9097 6028
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Acknowledgements

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The incidence, prevalence and survival statistics in this publication are designated as official statistics signifying that they comply with the Code of Practice for Official Statistics.

Incidence

During 2016-2020:

▪ There were 75 male and 70 female neuroendocrine cancers (ex NMSC) diagnosed each year.

▪ The risk of developing neuroendocrine cancer before the age of 75 was 1 in 173 for men and 1 in 195 for women, while before the age of 85 the risk was 1 in 107 for men and 1 in 133 for women.

Incidence by age at diagnosis - *Neuroendocrine cancer, Cases in 2016-2020*

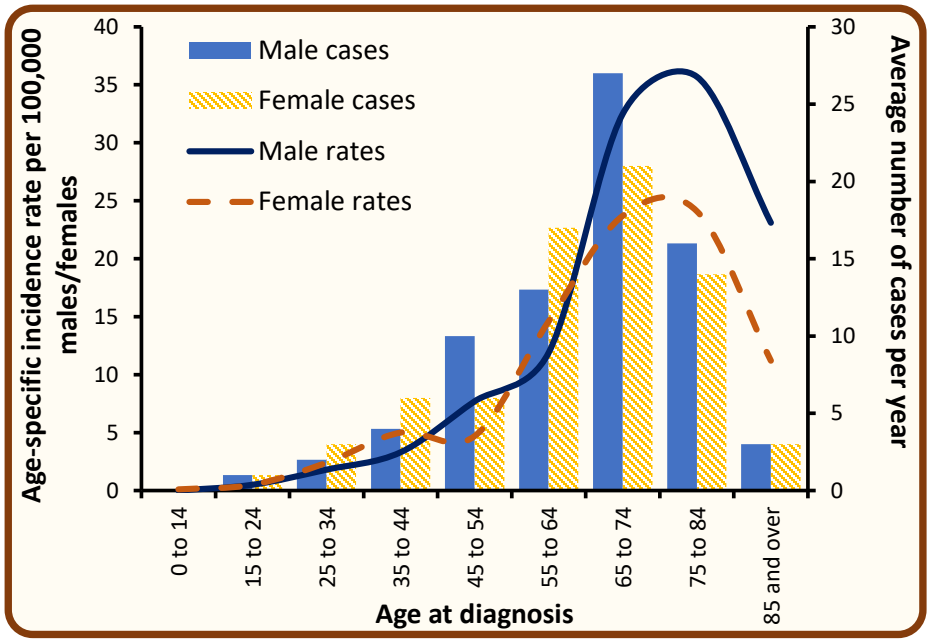
During 2016-2020:

▪ The median age at diagnosis was 67 for men and 66 for women.

▪ Cancer risk increased with age, with 25.3% of men and 24.3% of women aged 75 years or more at diagnosis.

▪ 22.1% of cases were diagnosed among those aged under 55.

Age at diagnosis	Average cases per year		
	Male	Female	Both sexes
0 - 54	17	16	32
55 - 64	13	17	30
65 - 74	27	21	47
75 +	19	17	36
All ages	75	70	145

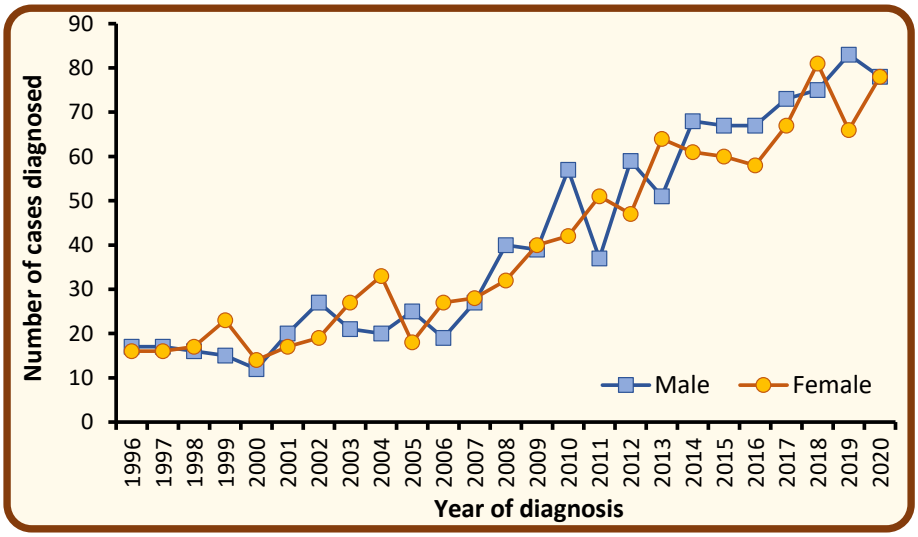


Incidence by year of diagnosis - *Neuroendocrine cancer, Cases in 1996-2020*

▪ Among males the number of cases of neuroendocrine cancer diagnosed increased by 33.9% from an annual average of 56 cases in 2011-2015 to 75 cases in 2016-2020.

▪ Among females the number of cases of neuroendocrine cancer diagnosed increased by 22.8% from an annual average of 57 cases in 2011-2015 to 70 cases in 2016-2020.

Year of diagnosis	Male	Female	Both sexes
2011	37	51	88
2012	59	47	106
2013	51	64	115
2014	68	61	129
2015	67	60	127
2016	67	58	125
2017	73	67	140
2018	75	81	156
2019	83	66	149
2020	78	78	156

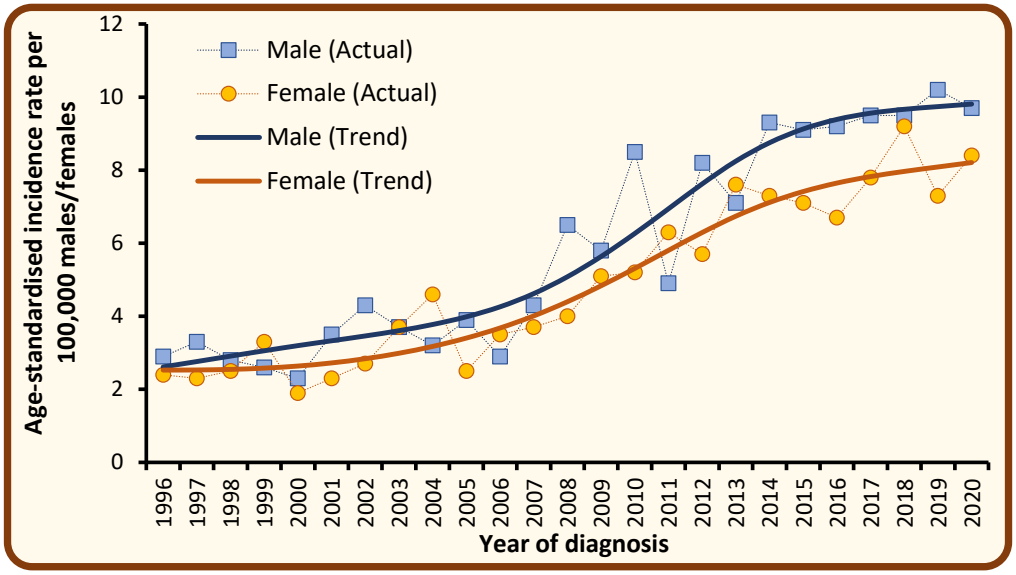


Note: Annual averages based upon several years have been rounded to the nearest integer. Sums of numbers in table rows or columns may thus differ slightly from the given total.
NMSC: Non-melanoma skin cancer

Trends in age-standardised incidence rates - *Neuroendocrine cancer, Cases in 1996-2020*

▪ Among males age-standardised incidence rates for neuroendocrine cancer increased by 23.1% from 7.8 per 100,000 person years in 2011-2015 to 9.6 cases per 100,000 person years in 2016-2020. This difference was not statistically significant.

▪ Among females age-standardised incidence rates for neuroendocrine cancer increased by 16.2% from 6.8 per 100,000 person years in 2011-2015 to 7.9 cases per 100,000 person years in 2016-2020. This difference was not statistically significant.



Age-standardised incidence rates illustrate the change in the number of cases within a population of a fixed size and age structure (2013 European Standard).

They thus represent changes other than those caused by population growth and/or ageing.

Trends can also be influenced by changes in how cancer is classified and coded. (e.g. the move from ICD-0-2 to ICD-0-3 in 2019).

Incidence by deprivation quintile - *Neuroendocrine cancer, Cases in 2016-2020*

The annual number of cases during 2016-2020 varied in each deprivation quintile due to variations in population size and age.

After accounting for these factors, incidence rates:

▪ in the least socio-economically deprived areas did not vary significantly from the NI average.

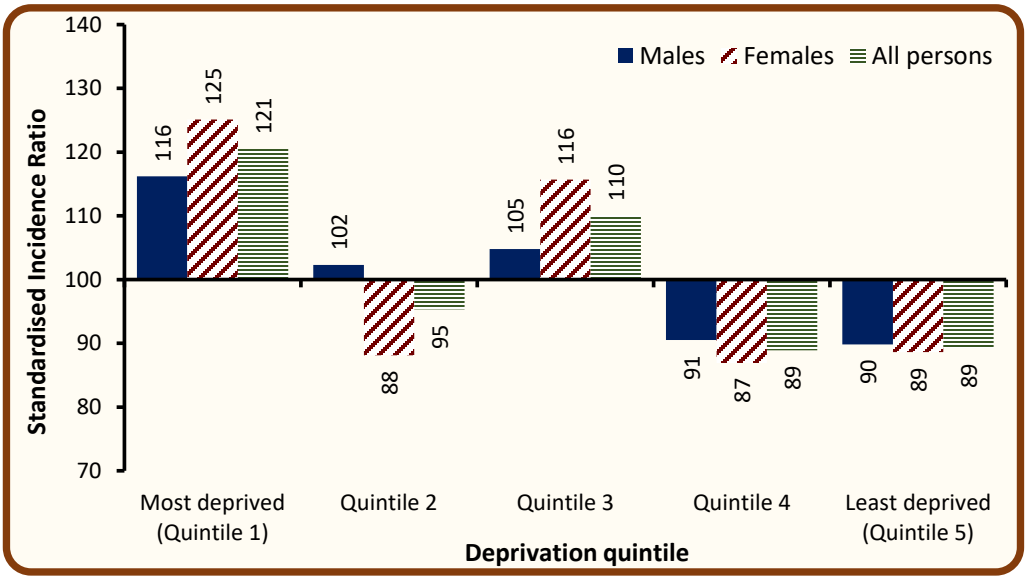
▪ in the most socio-economically deprived areas were 20.5% higher than the NI average.

Deprivation quintile	Average cases per year		
	Male	Female	Both sexes
Most deprived (Quintile 1)	14	15	29
Quintile 2	15	12	28
Quintile 3	17	17	34
Quintile 4	15	13	27
Least deprived (Quintile 5)	14	13	27
Northern Ireland	75	70	145

Standardised incidence ratios compare incidence rates in each deprivation quintile with the Northern Ireland incidence rate.

A value above 100 means that incidence rates in that deprivation quintile are greater than the Northern Ireland average.

This measure takes account of population size and age structure. Differences are thus not a result of these factors.



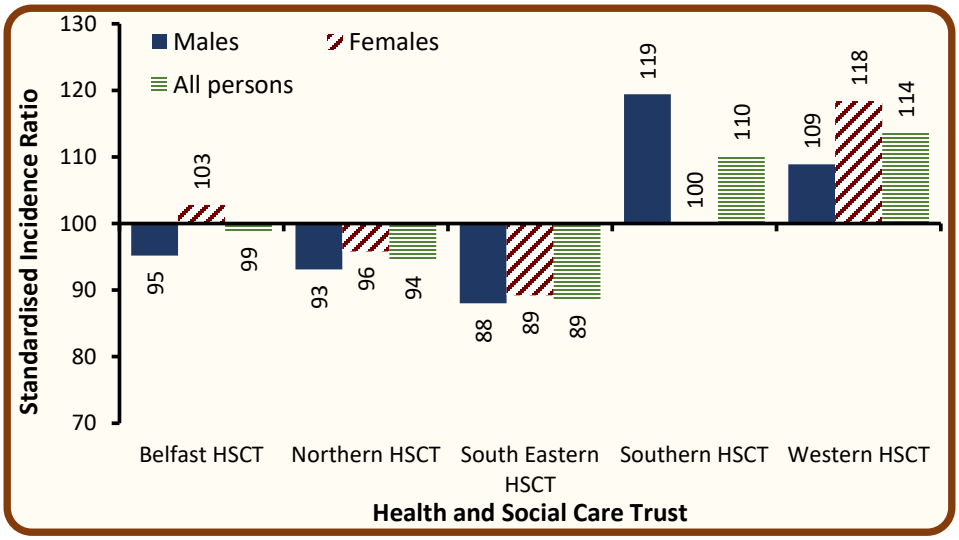
Incidence by Health and Social Care Trust (HSCT) - *Neuroendocrine cancer, Cases in 2016-2020*

The annual number of cases during 2016-2020 varied in each HSCT due to variations in population size and age.

After accounting for these factors, incidence rates:

- in Belfast HSCT did not vary significantly from the NI average.
- in Northern HSCT did not vary significantly from the NI average.
- in South-Eastern HSCT did not vary significantly from the NI average.
- in Southern HSCT did not vary significantly from the NI average.
- in Western HSCT did not vary significantly from the NI average.

Health and Social Care Trust	Average cases per year		
	Male	Female	Both sexes
Belfast HSCT	12	13	26
Northern HSCT	19	18	36
South Eastern HSCT	14	13	27
Southern HSCT	17	13	30
Western HSCT	13	13	26
Northern Ireland	75	70	145



Standardised incidence ratios compare incidence rates in each HSC Trust with the Northern Ireland incidence rate. A value above 100 means that incidence rates in that HSC Trust are greater than the NI average.

This measure takes account of population size and age structure. Differences are thus not a result of these factors.

Data for Local Government Districts and Parliamentary Constituencies are available at www.qub.ac.uk/research-centres/nicr

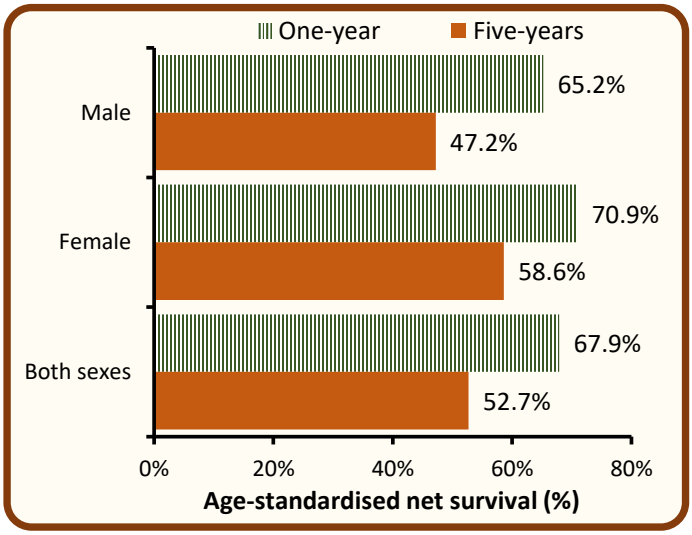
Survival

- 69.7% of patients were alive one year and 52.7% were alive five years from a neuroendocrine cancer diagnosis in 2011-2015. (observed survival)
- Age-standardised net survival (ASNS), which removes the effect of deaths from causes unrelated to cancer, was 67.9% one year and 52.7% five years from a neuroendocrine cancer diagnosis in 2011-2015.
- Five-year survival (ASNS) for patients diagnosed in 2011-2015 was 47.2% for men and 58.6% for women.

Gender	Observed survival		Age-standardised net survival	
	One-year	Five-years	One-year	Five-years
Male	66.4%	46.4%	65.2%	47.2%
Female	73.0%	59.1%	70.9%	58.6%
Both sexes	69.7%	52.7%	67.9%	52.7%

Observed survival is the proportion of patients still alive one/five years after diagnosis. However, in this measure patients may have died from causes unrelated to their cancer.

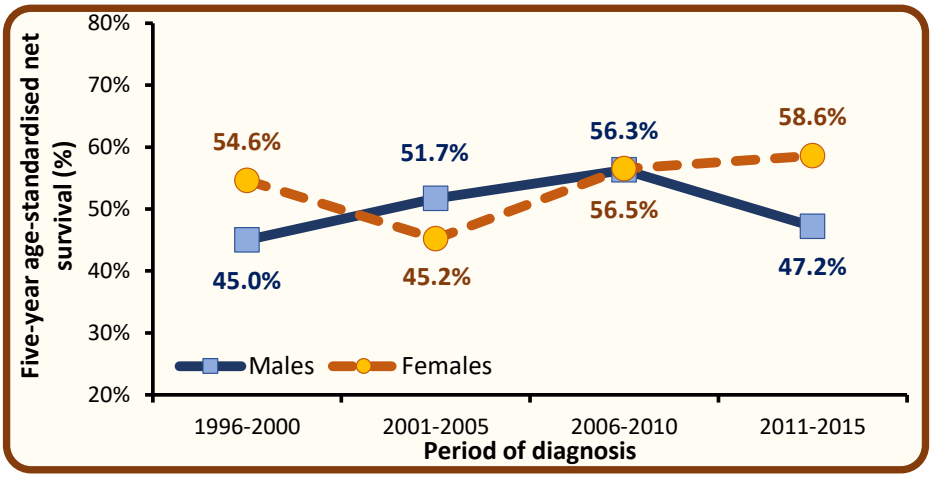
Age-standardised net survival is the proportion of patients who would survive if the patient could not die from causes unrelated to their cancer. This measure is more typically used in studies of cancer survival.



Trends in survival - *Neuroendocrine cancer, Patients diagnosed in 1996-2015*

▪ Among men five-year survival (ASNS) from neuroendocrine cancer decreased from 56.3% in 2006-2010 to 47.2% in 2011-2015. This difference was not statistically significant.

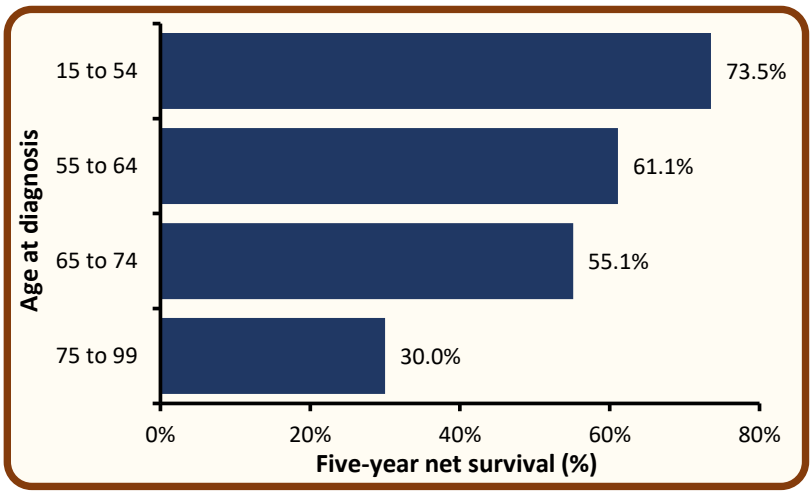
▪ Among women five-year survival (ASNS) from neuroendocrine cancer increased from 56.5% in 2006-2010 to 58.6% in 2011-2015. This difference was not statistically significant.



Survival by age at diagnosis - *Neuroendocrine cancer, Patients diagnosed in 2011-2015*

▪ Survival from neuroendocrine cancer among patients diagnosed in 2011-2015 varied by age at diagnosis with five-year survival decreasing as age increases.

▪ Five-year net survival ranged from 73.5% among patients aged 15-54 at diagnosis to 30.0% among those aged 75 and over.



Prevalence

▪ At the end of 2020, there were 962 survivors (Males: 466; Females: 496) from neuroendocrine cancer who had been diagnosed during 1996-2020. Of these, 28.5% were aged 75 and over.

25-year prevalence refers to the number of cancer survivors who were alive at the end of 2020, and had been diagnosed with their cancer in the previous 25 years (i.e. 1996-2020).

Age at end of 2020	25-year prevalence		
	Male	Female	Both sexes
Aged 0-74	330	358	688
Aged 75+	136	138	274
All ages	466	496	962

Trends in 10-year prevalence - *Neuroendocrine cancer, Patients alive at end of each year from 2011-2020*

▪ Among males the number of survivors from neuroendocrine cancer who had been diagnosed within the previous five years increased by 43.7% from 247 survivors in 2015 to 355 survivors in 2020.

▪ Among females the number of survivors from neuroendocrine cancer who had been diagnosed within the previous five years increased by 38.0% from 274 survivors in 2015 to 378 survivors in 2020.

	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020
Males	178	201	205	235	247	275	292	321	347	355
Females	180	204	234	258	274	301	327	350	363	378
All persons	358	405	439	493	521	576	619	671	710	733

Background notes

Cancer classification: Classification of tumour sites is carried out using ICD10 codes. For a listing and explanation of ICD10 codes see: World Health Organisation at http://apps.who.int/classifications/icd10/browse/2010/en#/II

Population data for Northern Ireland, and smaller geographic areas, are extracted from the NI mid-year population estimates available from the NI Statistics and Research Agency (available at www.nisra.gov.uk).

Geographic areas are assigned based on a patient's postcode of usual residence at diagnosis using the Jan 2021 Central Postcode Directory (CPD) produced by the NI Statistics and Research Agency (available at www.nisra.gov.uk).

Deprivation quintiles: Super output areas (SOA) are assigned to each patient based on their postcode of usual residence at diagnosis. Using the SOA each patient is assigned a socio-economic deprivation quintile based on the 2017 Multiple Deprivation Measure. The 2017 Multiple Deprivation Measure is available from the NI Statistics and Research Agency (available at www.nisra.gov.uk).

A **crude incidence/mortality rate** is the number of cases/deaths per 100,000 person years in the population. Person years are the sum of the population over the number of years included.

An **age-standardised incidence/mortality rate** per 100,000 person years is an estimate of the incidence/mortality rate if that population had a standard age structure. Throughout this report the 2013 European Standard Population has been used. Standardising to a common Standard Population allows comparisons of incidence/mortality rates to be made between different time periods and geographic areas while removing the effects of population change and ageing.

A **Standardised Incidence/Mortality Ratio (SIR/SMR)** is the ratio of the number of cases/deaths observed in a population to the expected number of cases/deaths, based upon the age-specific rates in a reference population. This statistic is often used to compare incidence/mortality rates for geographic areas (e.g. Trusts) to the national incidence/mortality rates (i.e. Northern Ireland). An SIR/SMR of 100 indicates there is no difference between the geographic area and the national average.

Confidence intervals are a measure of the precision of a statistic (e.g. neuroendocrine tumour incidence rate). Typically, when numbers are low, precision is poorer and confidence intervals will be wider. As a general rule, when comparing statistics (e.g. cervical cancer incidence rate in year 2012 vs year 2013), if the confidence interval around one statistic overlaps with the interval around another, it is unlikely that there is any real difference between the two. If there is no overlap, the difference is considered to be **statistically significant**.

Lifetime risk is estimated as the cumulative risk of getting cancer up to age 75/85, calculated directly from the age-specific incidence rates. The odds of developing the disease before age 75/85 is the inverse of the cumulative risk.

Prevalence is the number of cancer patients who are alive in the population on a specific date (31st December 2020 in this report). Since data from the NI Cancer Registry are only available since 1993, prevalence only refers to a fixed term (10 and 25 years in this report). There may be members of the population living with a diagnosis of cancer for more than 25 years.

Observed survival refers to the proportion of patients who survive a specified amount of time from their date of diagnosis. Observed survival considers death from any cause and is not adjusted for the age of the patient. Cause of death may be unrelated to the cancer the patient has been diagnosed with.

Net Survival is an estimate of survival where the effect on survival of background population mortality rates has been removed. It represents the [theoretical] survival of cancer patients if they could only die from cancer-related causes. Age-standardised net survival estimates are the estimates that would occur if that population of cancer patients had a standard population age structure. The age groups and weights used here are those used by international studies such as EUROCARE, an international study group that compares cancer survival among European countries. However, due to the small number of patients in NI, the first two age categories in the standard population are combined.

Mortality: Information relating to cancer mortality is sourced from the General Registrar Office (GRONI) via the Department of Health (NI). Results are based upon the date on which death occurs, and may thus differ slightly than those produced by the Northern Ireland Statistics and Research Agency (NISRA), which produces deaths data based upon the date on which the death is registered with GRONI.