Neuroendocrine tumours

(Excludes non-melanoma skin cancer)

Patients diagnosed 1993-2019

Further information

Further data is available at: **www.qub.ac.uk/research-centres/nicr**
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e-mail: nicr@qub.ac.uk

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 2015-2019:

▪ There were 71 male and 65 female neuroendocrine tumours (ex NMSC) diagnosed each year.

▪ Neuroendocrine tumours made up 1.4% of all male, and 1.3% of all female cancers (ex NMSC).

▪ The risk of developing a neuroendocrine tumour before the age of 75 was 1 in 182.2 for men and 1 in 199.4 for women, while before the age of 85 the risk was 1 in 112.9 for men and 1 in 141.5 for women.

Incidence by age at diagnosis - *Neuroendocrine tumours, Cases in 2015-2019*

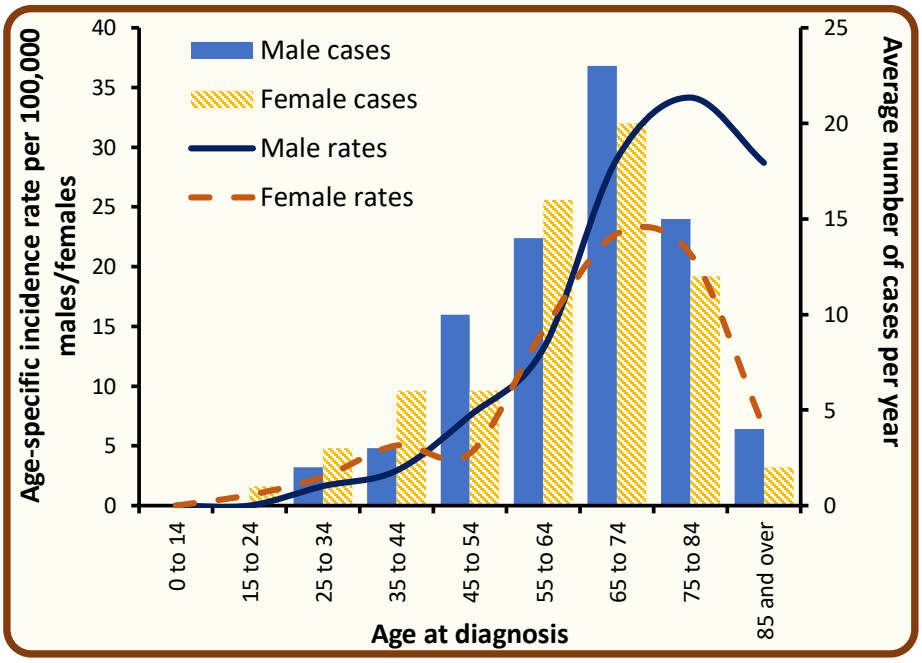
During 2015-2019:

▪ The median age at diagnosis was 67 for men and 65 for women.

▪ Cancer risk increased with age, with 26.8% of men and 21.5% of women aged 75 years or more at diagnosis.

▪ 22.8% of cases were diagnosed among those aged under 55.

Age at diagnosis	Average cases per year		
	Male	Female	Both sexes
0 - 54	15	16	31
55 - 64	14	16	30
65 - 74	23	20	43
75 +	19	14	31
All ages	71	65	136

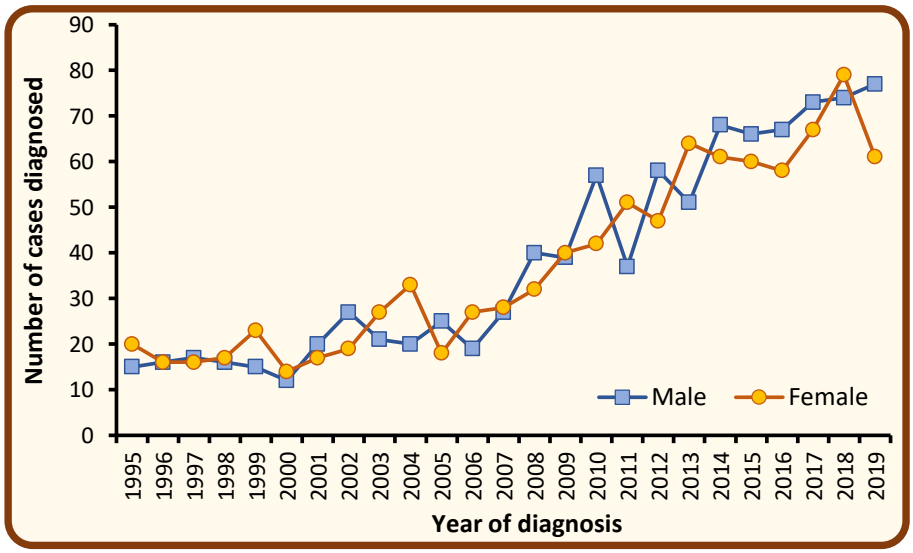


Incidence by year of diagnosis - *Neuroendocrine tumours, Cases in 1995-2019*

▪ Among males the number of neuroendocrine tumours diagnosed increased by 31.5% from an annual average of 54 cases in 2010-2014 to 71 cases in 2015-2019.

▪ Among females the number of cases of neuroendocrine tumours diagnosed increased by 22.6% from an annual average of 53 cases in 2010-2014 to 65 cases in 2015-2019.

Year of diagnosis	Male	Female	Both sexes
2010	57	42	99
2011	37	51	88
2012	58	47	105
2013	51	64	115
2014	68	61	129
2015	66	60	126
2016	67	58	125
2017	73	67	140
2018	74	79	153
2019	77	61	138

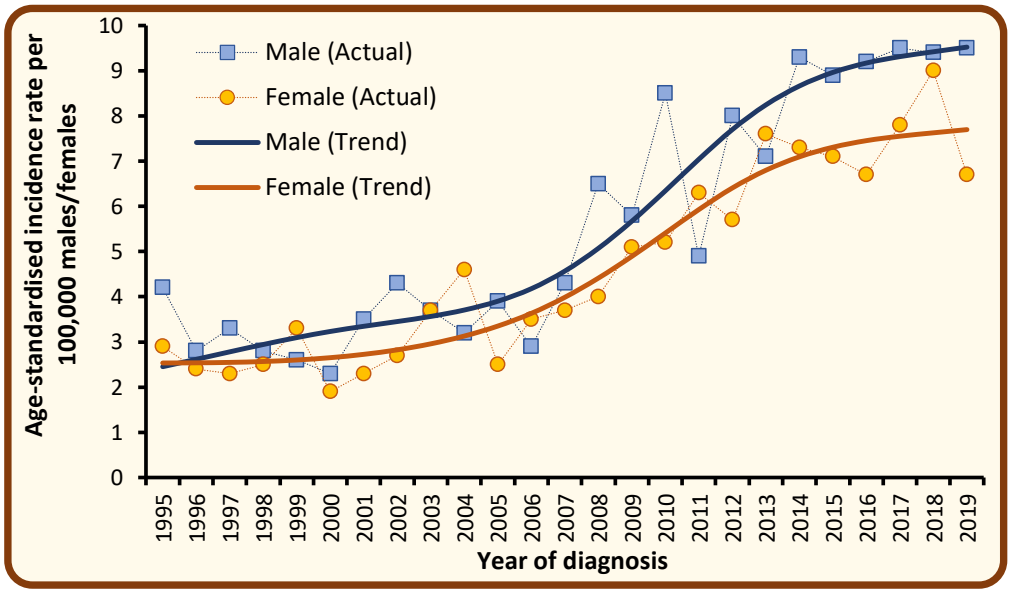


Note: Annual averages based upon several years have been rounded to the nearest integer. Sums of numbers in table rows or columns may thus differ slightly from the given total.
NMSC: Non-melanoma skin cancer

Trends in age-standardised incidence rates - *Neuroendocrine tumours, Cases in 1995-2019*

▪ Among males age-standardised incidence rates for neuroendocrine tumours increased by 22.4% from 7.6 per 100,000 person years in 2010-2014 to 9.3 cases per 100,000 persons years in 2015-2019. This difference was not statistically significant.

▪ Among females age-standardised incidence rates for neuroendocrine tumours increased by 17.2% from 6.4 per 100,000 person years in 2010-2014 to 7.5 cases per 100,000 persons years in 2015-2019. 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 tumours, Cases in 2015-2019*

The annual number of cases during 2015-2019 varied in each deprivation quintile due to variations in population size and age.

After accounting for these factors, incidence rates:

▪ in the most socio-economically deprived areas were 28.5% higher than the NI average.

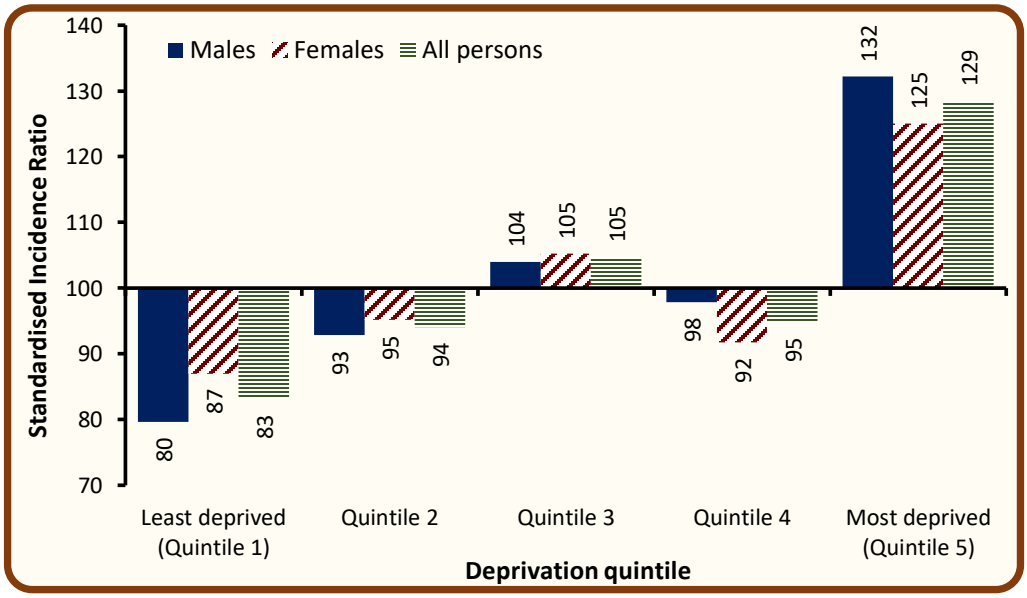
▪ in the least socio-economically deprived areas were 16.9% lower than the NI average.

Deprivation quintile	Average cases per year		
	Male	Female	Both sexes
Least deprived (Quintile 1)	12	12	24
Quintile 2	14	13	27
Quintile 3	16	14	30
Quintile 4	14	12	26
Most deprived (Quintile 5)	16	14	30
Northern Ireland	71	65	136

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.



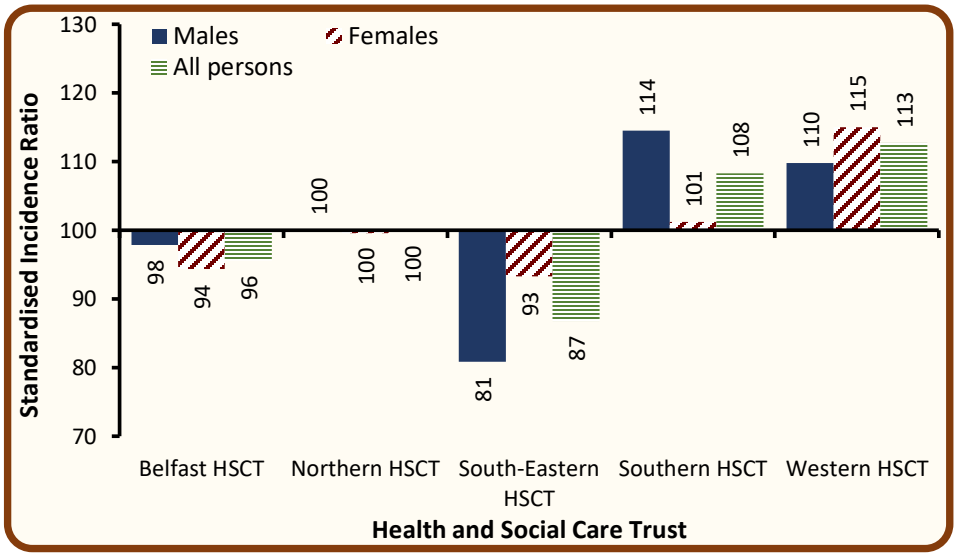
Incidence by Health and Social Care Trust (HSCT) - *Neuroendocrine tumours, Cases in 2015-2019*

The annual number of cases during 2015-2019 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	11	24
Northern HSCT	19	17	36
South-Eastern HSCT	12	13	25
Southern HSCT	16	12	28
Western HSCT	13	12	24
Northern Ireland	71	65	136



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

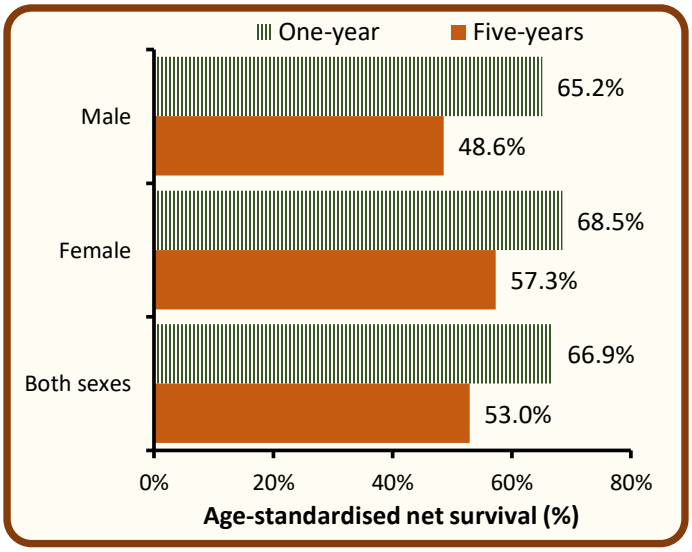
Survival

- 68.1% of patients were alive one year and 51.9% were alive five years from a neuroendocrine tumour diagnosis in 2010-2014. (observed survival)
- Age-standardised net survival (ASNS), which removes the effect of deaths from causes unrelated to cancer, was 66.9% one year and 53.0% five years from a neuroendocrine tumour diagnosis in 2010-2014.
- Five-year survival (ASNS) for patients diagnosed in 2010-2014 was 48.6% for men and 57.3% for women.

Gender	Observed survival		Age-standardised net survival	
	One-year	Five-years	One-year	Five-years
Male	65.4%	46.0%	65.2%	48.6%
Female	70.9%	58.1%	68.5%	57.3%
Both sexes	68.1%	51.9%	66.9%	53.0%

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.

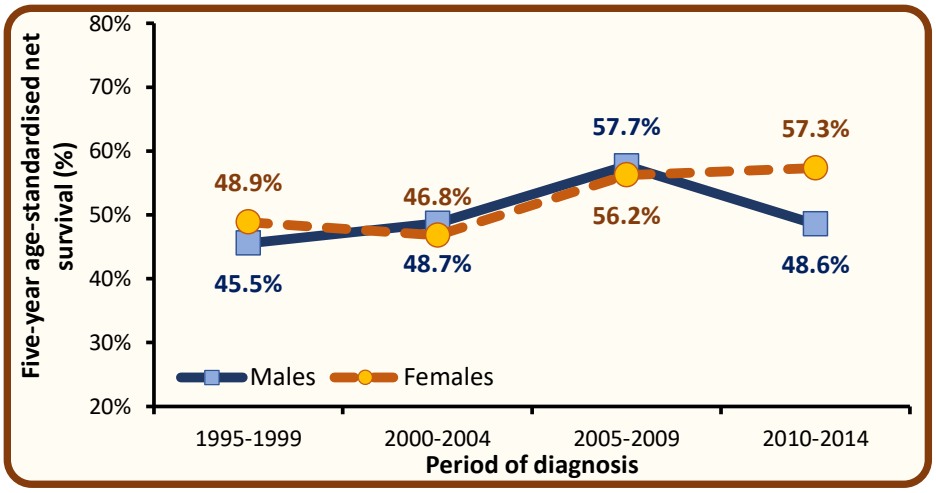
Age-standardised net survival is the proportion of patients who would survive if the patient could not die from causes unrelated to their cancer. This measure is more typically used in studies of cancer survival.



Trends in survival - *Neuroendocrine tumours, Patients diagnosed in 1995-2014*

▪ Among men five-year survival (ASNS) from neuroendocrine tumours decreased from 57.7% in 2005-2009 to 48.6% in 2010-2014. This difference was not statistically significant.

▪ Among women five-year survival (ASNS) from neuroendocrine tumours increased from 56.2% in 2005-2009 to 57.3% in 2010-2014. This difference was not statistically significant.

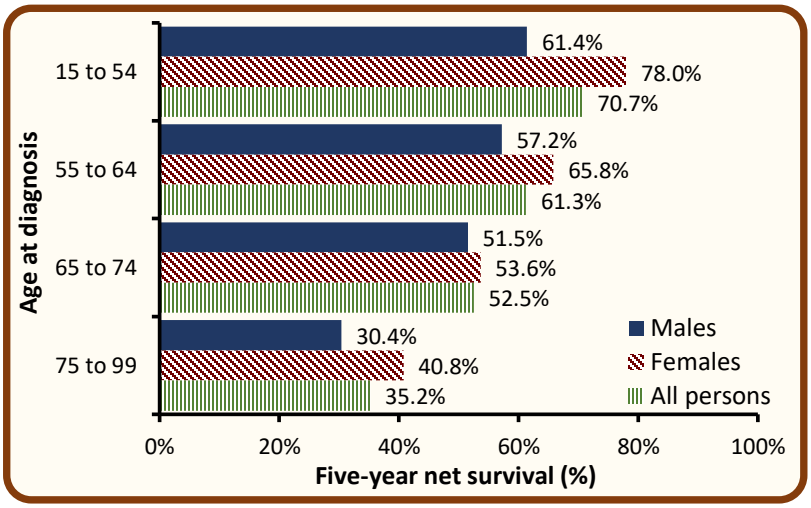


Survival by age at diagnosis - *Neuroendocrine tumour, Patients diagnosed in 2010-2014*

▪ Survival from neuroendocrine tumours among patients diagnosed in 2010-2014 varied by age at diagnosis with five-year survival decreasing as age increases.

▪ Five-year net survival ranged from 70.7% among patients aged 15-54 at diagnosis to 35.2% among those aged 75 and over.

▪ Five-year net survival among patients aged 75 and over was 30.4% for men and 40.8% for women.



Prevalence

▪ At the end of 2019, there were 908 people (Males: 441; Females: 467) living with a neuroendocrine tumour who had been diagnosed during 1995-2019. Of these, 26.5% were aged 75 and over.

25-year prevalence refers to the number of cancer survivors who were alive at the end of 2019, and had been diagnosed with their cancer in the previous 25 years (i.e. 1995-2019).

Age at end of 2019	25-year prevalence		
	Male	Female	Both sexes
Aged 0-74	314	353	667
Aged 75+	127	114	241
All ages	441	467	908

Trends in 10-year prevalence - *Neuroendocrine tumours, Patients alive at end of each year from 2010-2019*

▪ Among males the number of survivors from neuroendocrine tumours who had been diagnosed within the previous five years increased by 44.7% from 235 survivors in 2014 to 340 survivors in 2019.

▪ Among females the number of survivors from neuroendocrine tumours who had been diagnosed within the previous five years increased by 37.2% from 258 survivors in 2014 to 354 survivors in 2019.

	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019
Males	168	179	201	205	235	245	273	290	317	340
Females	160	180	204	234	258	274	301	327	347	354
All persons	328	359	405	439	493	519	574	617	664	694

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 2019 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.