Neuroendocrine cancer

1993-2022

(Excluding non-melanoma skin cancer)

(ICD10 codes: Based upon ICD-O-3 morphology)

Northern Ireland Cancer Registry

Northern Ireland Cancer Registry, 2025

An official statistics publication

ABOUT THIS REPORT

Contents

This report includes information on incidence of neuroendocrine cancer (excluding non-melanoma skin cancer) as recorded by the Northern Ireland Cancer Registry (NICR). Incidence data is available annually from 1993 to 2022, however in order to provide stable and robust figures the majority of information presented in this report is based upon the average number of cases diagnosed in the last five years.

Methodology

The methodology used in producing the statistics presented in this report, including details of data sources, classifications and coding are available in the accompanying methodology report available at: www.qub.ac.uk/research-centres/nicr/CancerInformation/official-statistics.

Official statistics

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. Further information on this code is available at code.statisticsauthority.gov.uk.

Reuse of information

The information in this report (and any supplementary material) is available for reuse free of charge and without the need to contact NICR. However, we request that NICR is acknowledged as the source of any reused information. The following reference is recommended:
Northern Ireland Cancer Registry 2025. Neuroendocrine cancer: 1993-2022. Available at: www.qub.ac.uk/research-centres/nicr

Further information

Further information is available at: www.qub.ac.uk/research-centres/nicr
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Acknowledgements

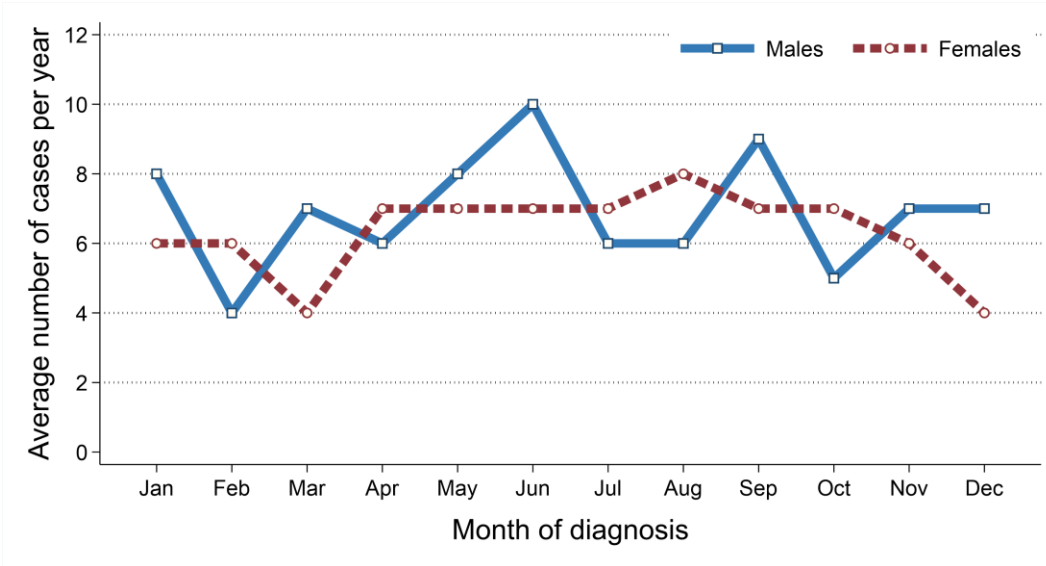
The Northern Ireland Cancer Registry (NICR) uses data provided by patients and collected by the health service as part of their care and support.

NICR is funded by the Public Health Agency and is based in Queen's University, Belfast.

INCIDENCE

- There were 784 cases of neuroendocrine cancer (excluding non-melanoma skin cancer) diagnosed during 2018-2022 in Northern Ireland. On average this was 157 cases per year.
- During this period 47.8% of neuroendocrine cancer cases were among women (Male cases: 409, Female cases: 375). On average there were 82 male and 75 female cases of neuroendocrine cancer per year.
- The most common diagnosis month during 2018-2022 was June among males with 10 cases per year and August among females with 8 cases per year.

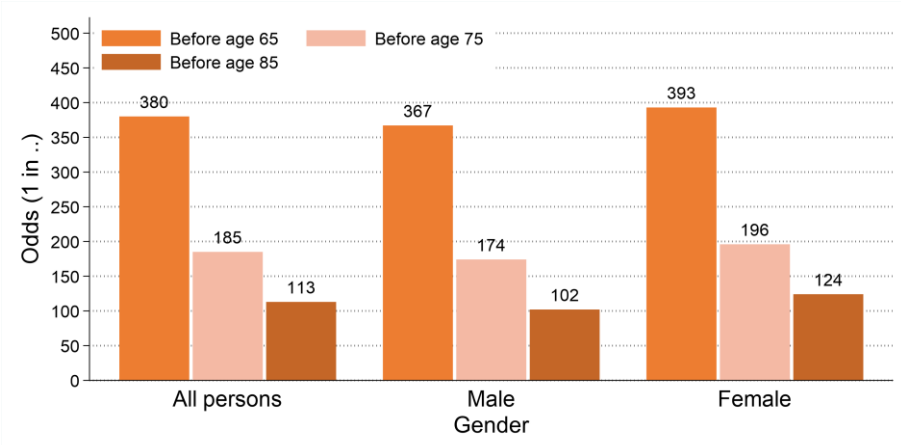
Figure 1: Average number of cases of neuroendocrine cancer per year in 2018-2022 by month of diagnosis



Month of diagnosis	Average number of cases per year	
	Males	Females
January	8	6
February	4	6
March	7	4
April	6	7
May	8	7
June	10	7
July	6	7
August	6	8
September	9	7
October	5	7
November	7	6
December	7	4

- Neuroendocrine cancer made up 1.5% of all male and 1.5% of all female cancer cases (excluding non-melanoma skin cancer).
- The neuroendocrine cancer incidence rates for each gender were 8.8 cases per 100,000 males and 7.8 cases per 100,000 females.
- The odds of developing neuroendocrine cancer before age 85 was 1 in 102 for men and 1 in 124 for women.

Figure 2: Odds of developing neuroendocrine cancer in 2018-2022



INCIDENCE BY AGE

- The median age of patients diagnosed with neuroendocrine cancer during 2018-2022 was 68 years (Males: 67, Females: 68).
- The risk of developing neuroendocrine cancer varied by age, with 28.6% of men and 27.5% of women diagnosed with neuroendocrine cancer aged 75 and over at diagnosis.
- In contrast, 22.7% of patients diagnosed with neuroendocrine cancer were aged 0 to 54 at diagnosis.

Figure 3: Average number of cases of neuroendocrine cancer diagnosed per year in 2018-2022 by age at diagnosis

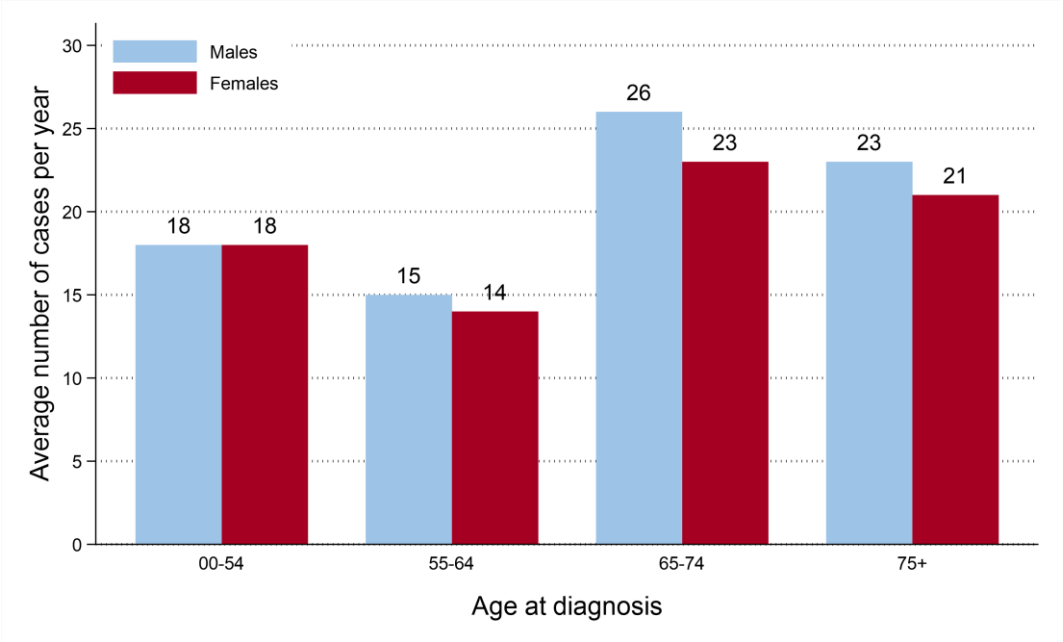
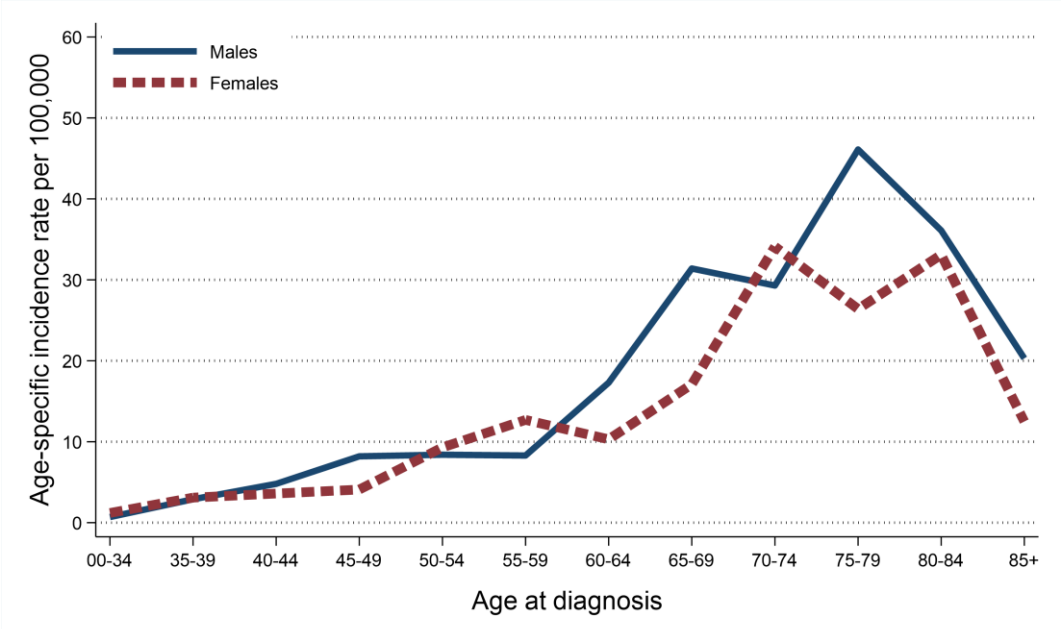


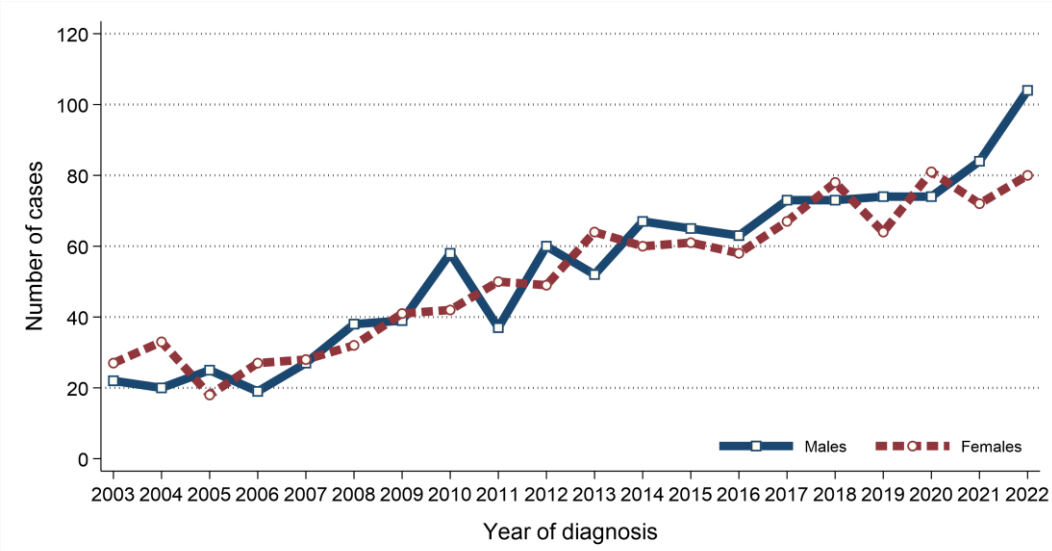
Figure 4: Age-specific incidence rates of neuroendocrine cancer in 2018-2022



INCIDENCE TRENDS

- The number of cases of neuroendocrine cancer among males increased between 2013-2017 and 2018-2022 by 27.8% from 320 cases (64 cases per year) to 409 cases (82 cases per year).
- The number of cases of neuroendocrine cancer among females increased between 2013-2017 and 2018-2022 by 21.0% from 310 cases (62 cases per year) to 375 cases (75 cases per year).

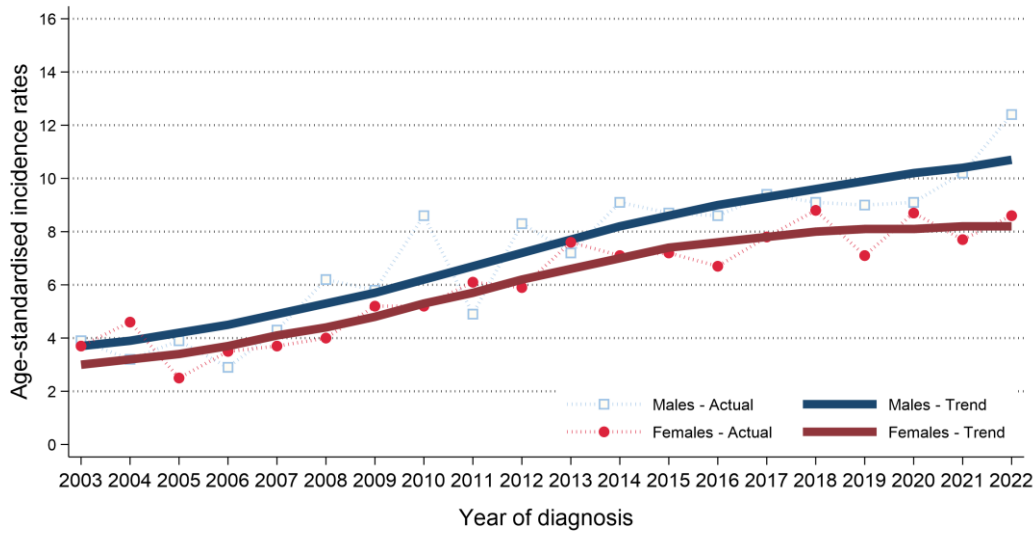
Figure 5: Trends in number of cases of neuroendocrine cancer diagnosed from 2003 to 2022



Year of diagnosis	Number of cases	
	Males	Females
2013	52	64
2014	67	60
2015	65	61
2016	63	58
2017	73	67
2018	73	78
2019	74	64
2020	74	81
2021	84	72
2022	104	80

- Male age-standardised neuroendocrine cancer incidence rates increased between 2013-2017 and 2018-2022 by 16.3% from 8.6 to 10.0 cases per 100,000 males. This change was not statistically significant.
- Female age-standardised neuroendocrine cancer incidence rates increased between 2013-2017 and 2018-2022 by 12.3% from 7.3 to 8.2 cases per 100,000 females. This change was not statistically significant.

Figure 6: Trends in incidence rates of neuroendocrine cancer from 2003 to 2022



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).

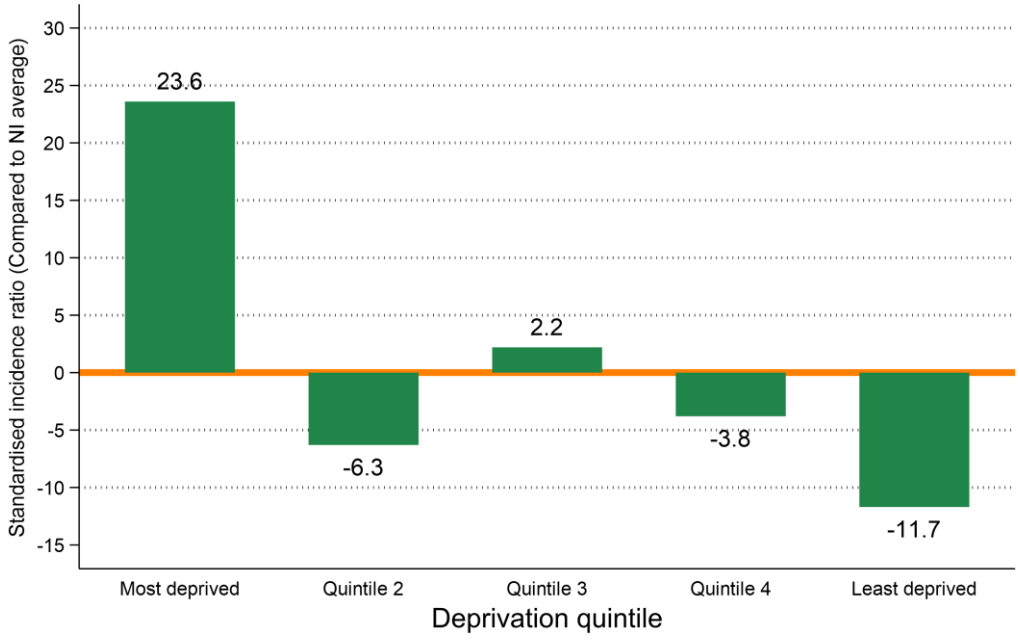
INCIDENCE BY DEPRIVATION

- The number of cases of neuroendocrine cancer diagnosed during 2018-2022 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 23.6% higher than the NI average.
  - in the least socio-economically deprived areas did not vary significantly from the NI average.

Table 1: Number of cases of neuroendocrine cancer diagnosed in 2018-2022 by deprivation quintile

Deprivation quintile	All persons		Male		Female	
	Total cases in period	Average cases per year	Total cases in period	Average cases per year	Total cases in period	Average cases per year
Northern Ireland	**784**	**157**	**409**	**82**	**375**	**75**
	.	.	.	.	.	.
Most deprived	161	32	75	15	86	17
Quintile 2	147	29	87	17	60	12
Quintile 3	169	34	87	17	82	16
Quintile 4	161	32	86	17	75	15
Least deprived	145	29	74	15	71	14
Unknown	1	0	0	0	1	0

Figure 7: Standardised incidence ratio comparing deprivation quintile to Northern Ireland for neuroendocrine cancer diagnosed in 2018-2022



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

A value above 0 means that incidence rates in that deprivation quintile 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.

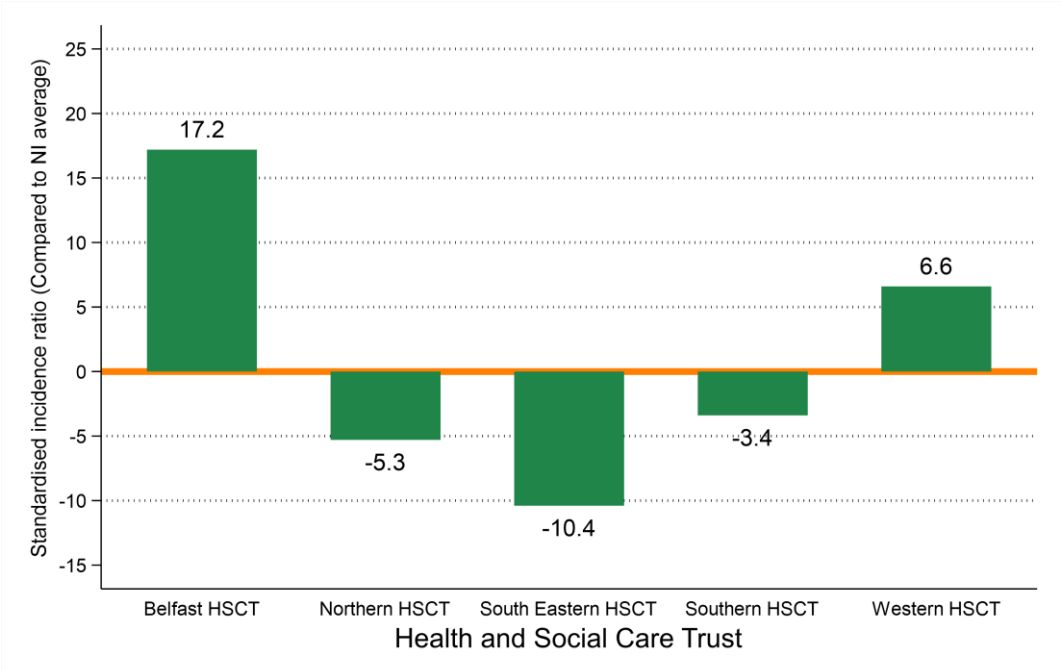
INCIDENCE BY HEALTH AND SOCIAL CARE TRUST

- The number of cases of neuroendocrine cancer diagnosed during 2018-2022 varied in each Health and Social Care Trust 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.

Table 2: Number of cases of neuroendocrine cancer diagnosed in 2018-2022 by Health and Social Care Trust

Health and Social Care Trust	All persons		Male		Female	
	Total cases in period	Average cases per year	Total cases in period	Average cases per year	Total cases in period	Average cases per year
Northern Ireland	**784**	**157**	**409**	**82**	**375**	**75**
	.	.	.	.	.	.
Belfast HSCT	163	33	79	16	84	17
Northern HSCT	196	39	98	20	98	20
South Eastern HSCT	147	29	75	15	72	14
Southern HSCT	145	29	85	17	60	12
Western HSCT	132	26	72	14	60	12
Unknown	1	0	0	0	1	0

Figure 8: Standardised incidence ratio comparing Health and Social Care Trust to Northern Ireland for neuroendocrine cancer diagnosed in 2018-2022



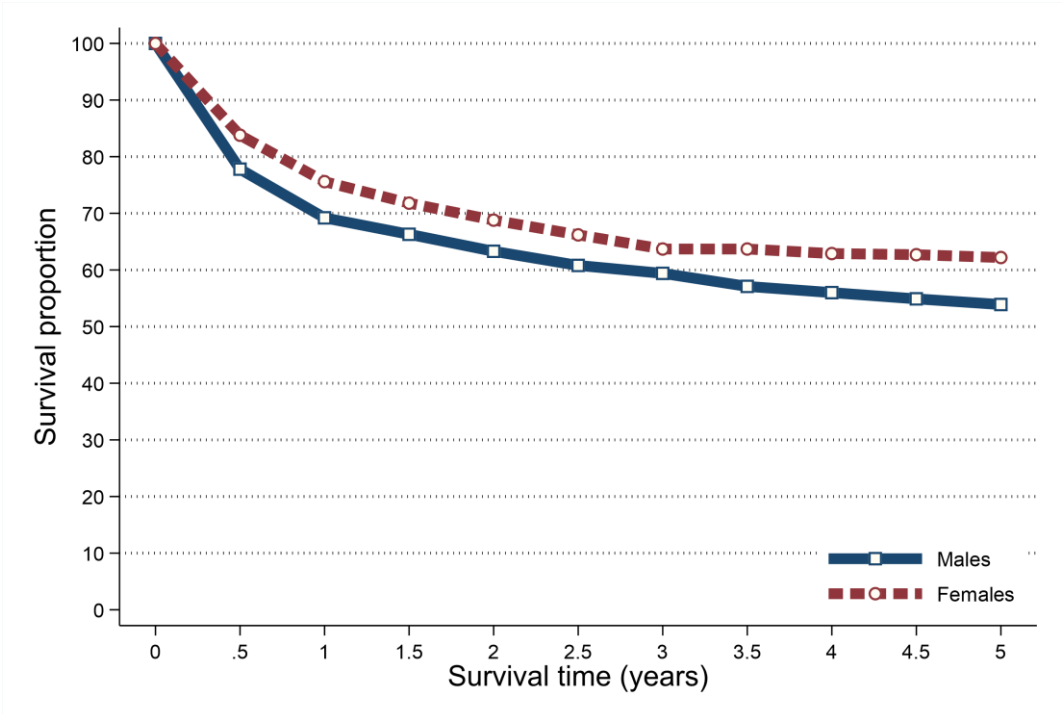
SURVIVAL

- 72.1% of patients were alive one year and 54.6% were alive five years from a neuroendocrine cancer diagnosis in 2013-2017. (observed survival)
- Age-standardised net survival (ASNS), which removes the effect of deaths from causes unrelated to cancer, was 72.3% one year and 57.9% five years from a neuroendocrine cancer diagnosis in 2013-2017.
- Five-year survival (ASNS) for neuroendocrine cancer patients diagnosed in 2013-2017 was 53.9% among men and 62.2% among women.

Table 3: Survival from neuroendocrine cancer for patients diagnosed in 2013-2017

Time since diagnosis	All persons		Male		Female	
	Observed survival	Age-standardised net survival	Observed survival	Age-standardised net survival	Observed survival	Age-standardised net survival
6 months	81.1%	80.7%	77.7%	77.8%	84.8%	83.8%
One year	72.1%	72.3%	68.6%	69.2%	75.8%	75.6%
Two years	64.8%	66.0%	61.6%	63.3%	68.1%	68.8%
Five years	54.6%	57.9%	50.3%	53.9%	59.1%	62.2%

Figure 9: Age-standardised net survival from neuroendocrine cancer for patients diagnosed in 2013-2017



Observed survival examines the time between diagnosis and death from any cause, however, due to the inclusion of non-cancer deaths it may not fully reflect how changes in cancer care impact survival from cancer.

Age-standardised net survival provides an estimate of patient survival which has been adjusted to take account of deaths unrelated to cancer. It is more widely used to assess the impact of changes in cancer care on patient survival.

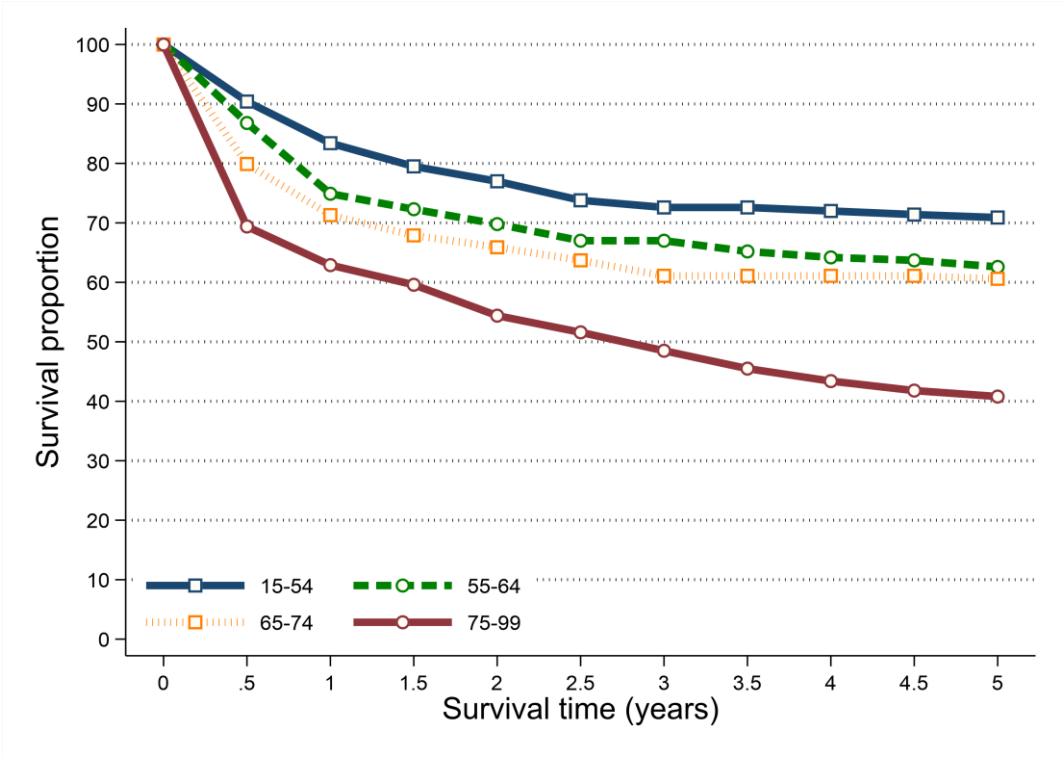
SURVIVAL BY AGE

- Survival from neuroendocrine cancer among patients diagnosed during 2013-2017 was related to age with better five-year survival among younger age groups.
- Five-year net survival ranged from 70.9% among patients aged 15 to 54 at diagnosis to 40.8% among those aged 75 to 99.

Table 4: Net survival from neuroendocrine cancer for patients diagnosed in 2013-2017 by age at diagnosis

Age group	All persons	
	One-year	Five-years
15 to 54	83.4%	70.9%
55 to 64	74.9%	62.6%
65 to 74	71.3%	60.6%
75 to 99	62.9%	40.8%

Figure 10: Net survival from neuroendocrine cancer for patients diagnosed in 2013-2017 by age at diagnosis

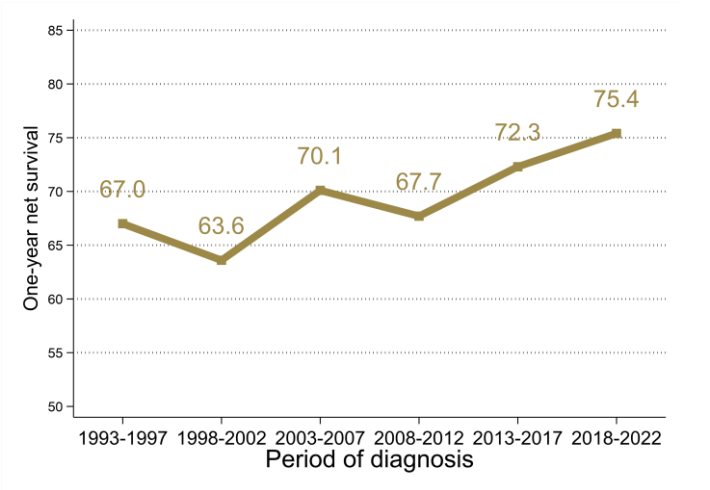


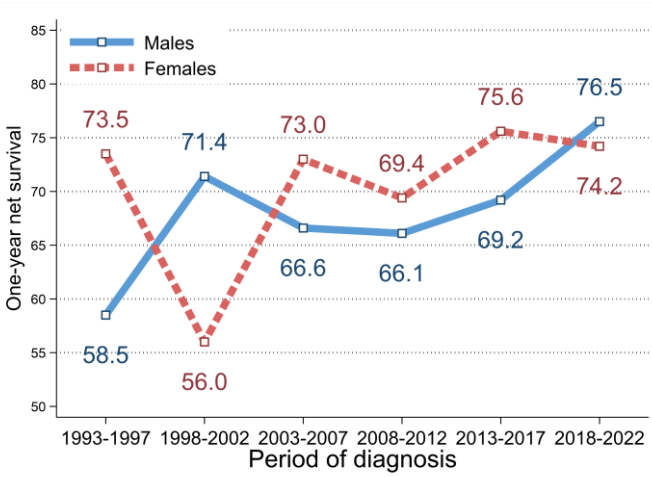
SURVIVAL TRENDS

ONE-YEAR NET SURVIVAL

- Between 2013-2017 and 2018-2022 there was no significant change in one-year survival (ASNS) from neuroendocrine cancer.
- Compared to 1993-1997 one-year survival (ASNS) from neuroendocrine cancer in 2018-2022 did not change significantly.

Figure 11: Trends in one-year age-standardised net survival from neuroendocrine cancer in 1993-2022

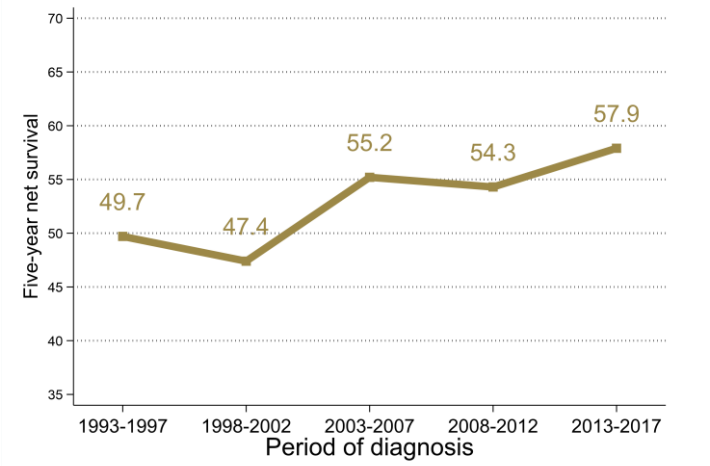


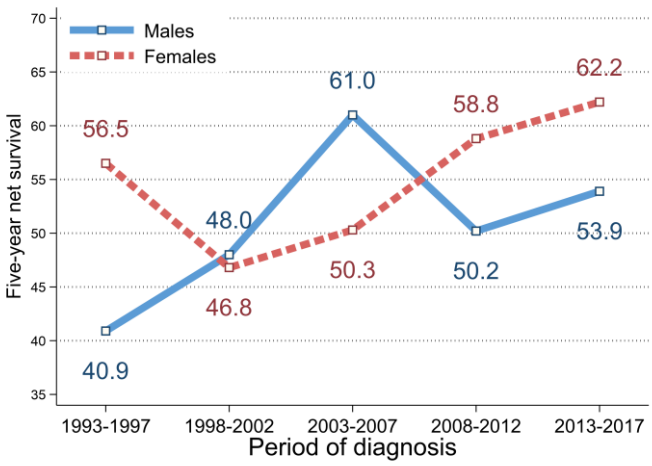


FIVE-YEAR NET SURVIVAL

- Between 2008-2012 and 2013-2017 there was no significant change in five-year survival (ASNS) from neuroendocrine cancer.
- Compared to 1993-1997 five-year survival (ASNS) from neuroendocrine cancer in 2013-2017 did not change significantly.

Figure 12: Trends in five-year age-standardised net survival from neuroendocrine cancer in 1993-2017





PREVALENCE

- At the end of 2022, there were 1,085 people (Males: 533; Females: 552) living with neuroendocrine cancer who had been diagnosed with the disease during 1998-2022.
- Of these 13.9% had been diagnosed in the previous year (one-year prevalence) and 74.3% in the previous 10 years (ten-year prevalence).
- 30.9% of neuroendocrine cancer survivors were aged 75 and over at the end of 2022.

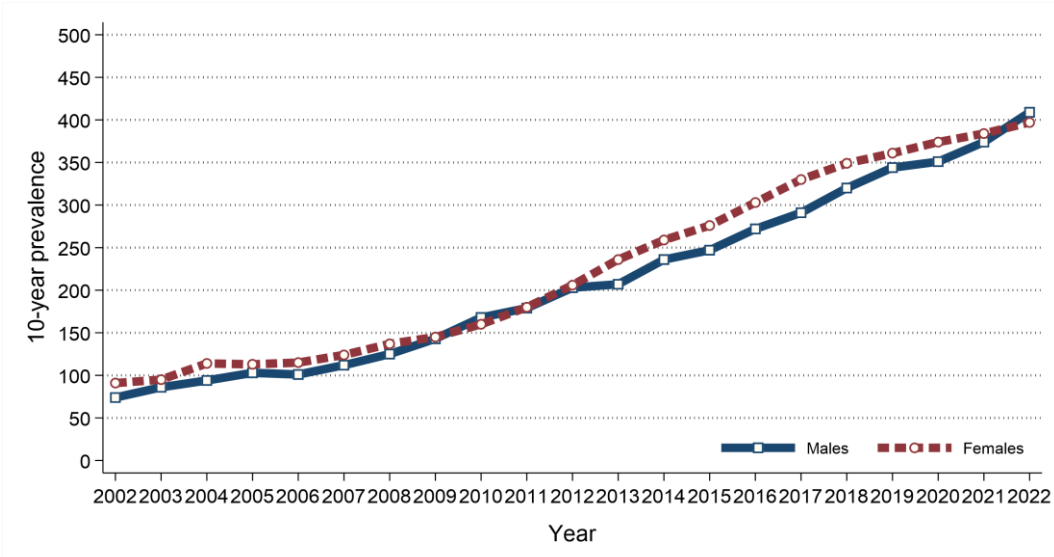
Table 5: 25-year prevalence of neuroendocrine cancer by age at end of 2022

Gender	Age at end of 2022	25-year prevalence	Time since diagnosis			
			0 to 1 year	1 to 5 years	5 to 10 years	10 to 25 years
All persons	All ages	1,085	151	353	302	279
	0 to 74	750	112	244	204	190
	75 and over	335	39	109	98	89
Male	All ages	533	88	177	144	124
	0 to 74	364	61	123	101	79
	75 and over	169	27	54	43	45
Female	All ages	552	63	176	158	155
	0 to 74	386	51	121	103	111
	75 and over	166	12	55	55	44

PREVALENCE TRENDS

- 10-year prevalence of neuroendocrine cancer among males increased between 2017 and 2022 by 40.5% from 291 survivors to 409 survivors.
- 10-year prevalence of neuroendocrine cancer among females increased between 2017 and 2022 by 20.3% from 330 survivors to 397 survivors.

Figure 13: Trends in 10-year prevalence of neuroendocrine cancer in 2002-2022



Year	10-year prevalence	
	Males	Females
2013	207	236
2014	236	259
2015	247	276
2016	272	303
2017	291	330
2018	320	349
2019	344	361
2020	351	374
2021	374	384
2022	409	397

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: 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: Geographic areas are assigned based on a patient's postcode of usual residence at diagnosis using the Jul 2024 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).

Crude incidence/mortality rate: 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.

Age-standardised incidence/mortality rates per 100,000 person years are estimates 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.

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 measure the precision of a statistic (e.g. neuroendocrine cancer 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. neuroendocrine 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 2022 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.

Patient survival is evaluated using two measures. Observed survival examines the time between diagnosis and death from any cause. It thus represents what cancer patients experience, however, due to the inclusion of non-cancer deaths (e.g. heart disease), it may not reflect how changes in cancer care impact survival from cancer. Thus age-standardised net survival is also examined. This measure provides an estimate of patient survival which has been adjusted to take account of deaths unrelated to cancer. It also assumes a standard age distribution thereby removing the impact of changes in the age distribution of cancer patients on changes in survival over time. While this measure is hypothetical, as it assumes patients can only die from cancer related factors, it is a better indicator of the impact of changes in cancer care on patient survival.