Neuroendocrine cancer

1993-2021

(Excluding non-melanoma skin cancer)

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

Northern Ireland Cancer Registry, 2024

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 2021, 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 2024. Neuroendocrine cancer: 1993-2021. 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.

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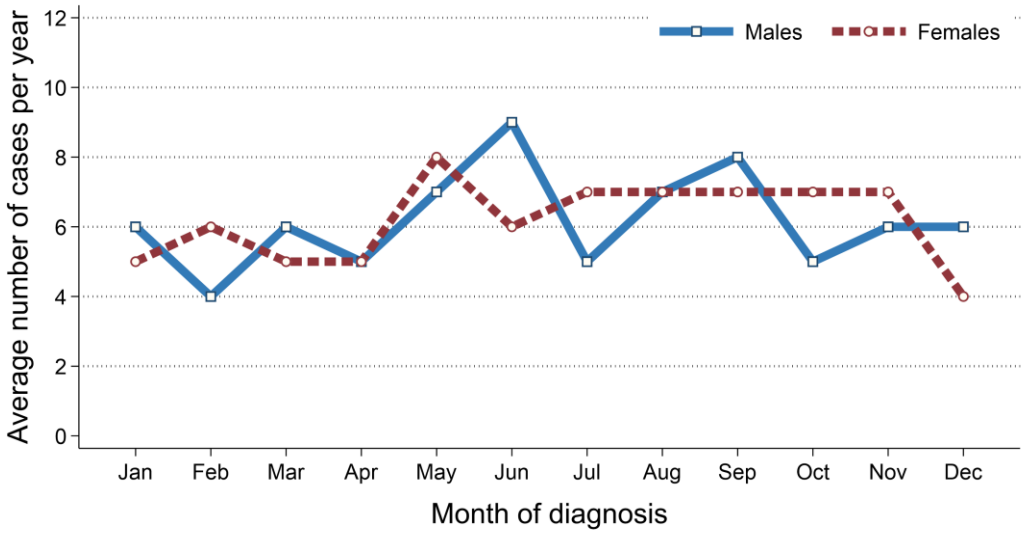
INCIDENCE

- There were 734 cases of neuroendocrine cancer (excluding non-melanoma skin cancer) diagnosed during 2017-2021 in Northern Ireland. On average this was 147 cases per year.
- During this period 48.8% of neuroendocrine cancer cases were among women (Male cases: 376, Female cases: 358). On average there were 75 male and 72 female cases of neuroendocrine cancer per year.
- The most common diagnosis month during 2017-2021 was June among males with 9 cases per year and May among females with 8 cases per year.

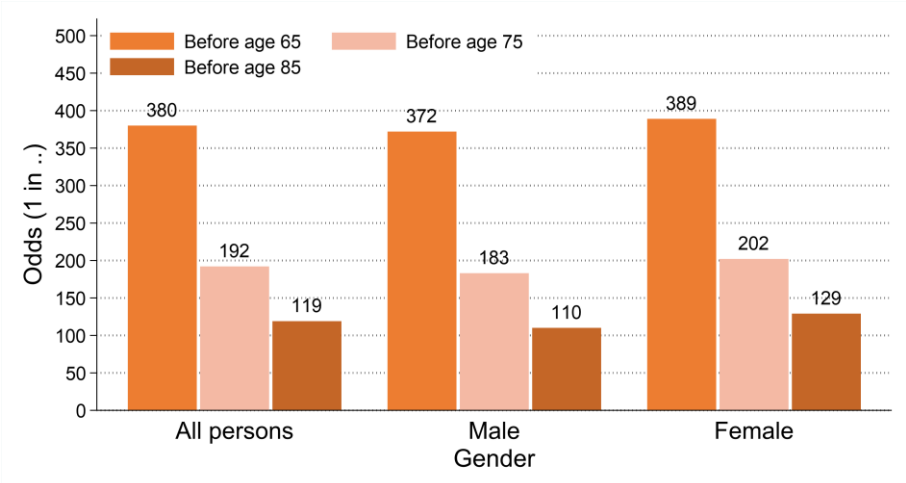
Figure 1: Average number of cases of neuroendocrine cancer per year in 2017-2021 by month of diagnosis



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

- Neuroendocrine cancer made up 1.5% of all male and 1.4% of all female cancer cases (excluding non-melanoma skin cancer).
- The neuroendocrine cancer incidence rates for each gender were 8.1 cases per 100,000 males and 7.5 cases per 100,000 females.
- The odds of developing neuroendocrine cancer before age 85 was 1 in 110 for men and 1 in 129 for women.

Figure 2: Odds of developing neuroendocrine cancer in 2017-2021



INCIDENCE BY AGE

- The median age of patients diagnosed with neuroendocrine cancer during 2017-2021 was 67 years (Males: 67, Females: 67).
- The risk of developing neuroendocrine cancer varied by age, with 26.9% of men and 26.8% of women diagnosed with neuroendocrine cancer aged 75 and over at diagnosis.
- In contrast, 22.6% 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 2017-2021 by age at diagnosis

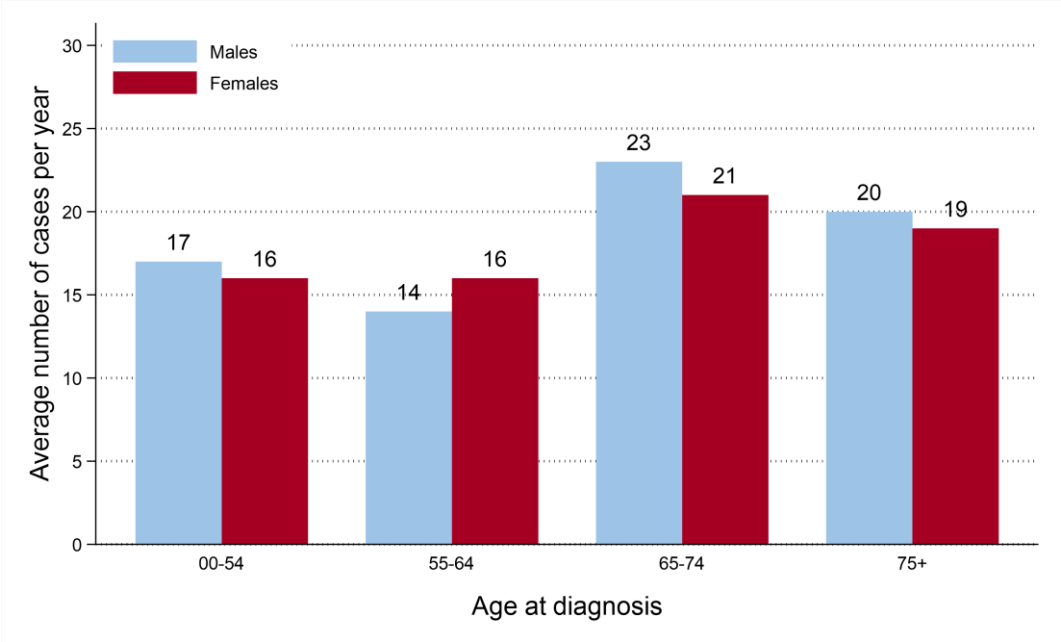
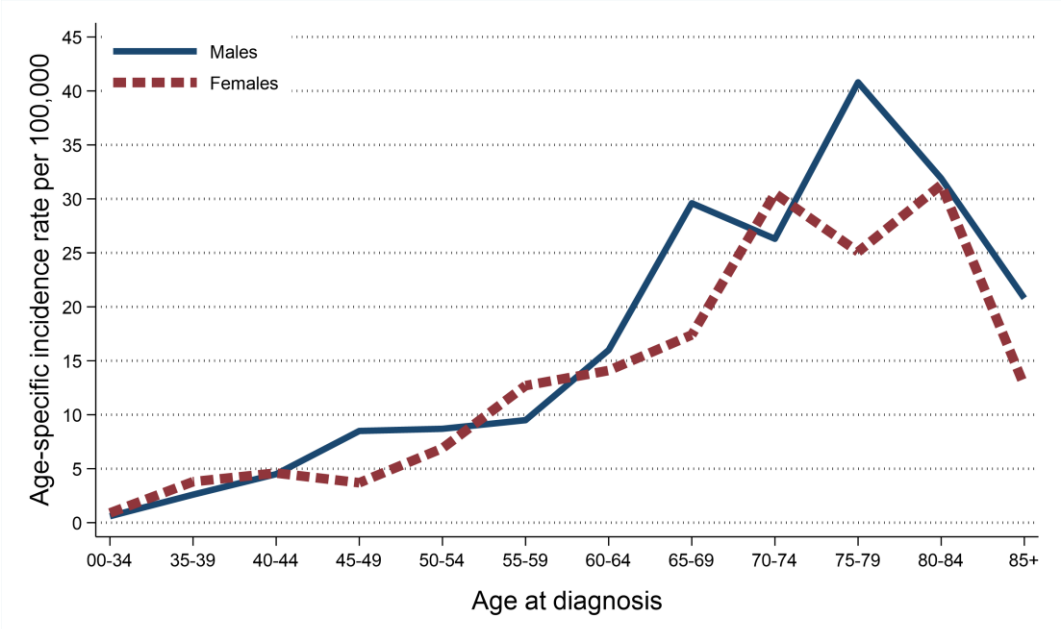


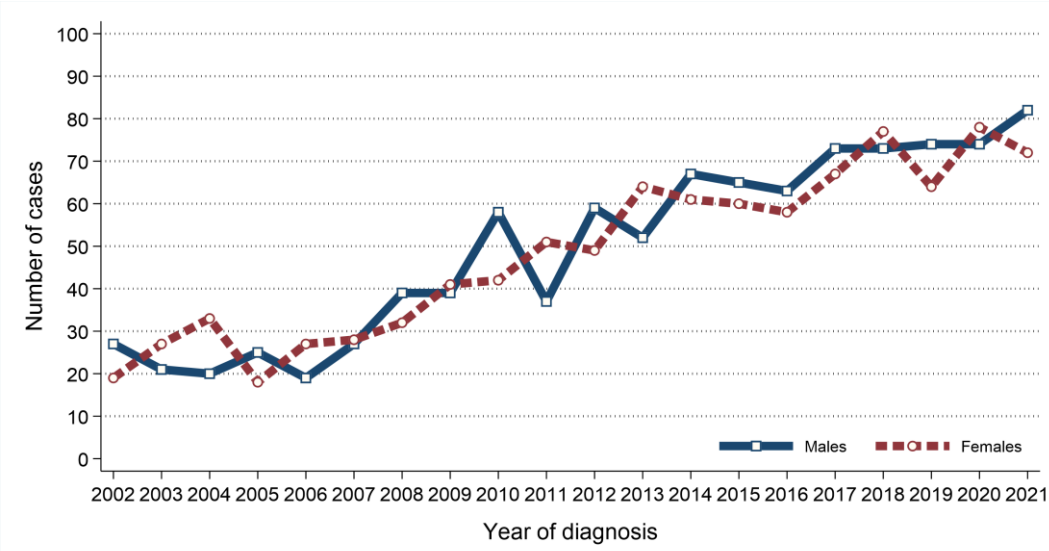
Figure 4: Age-specific incidence rates of neuroendocrine cancer in 2017-2021



INCIDENCE TRENDS

- The number of cases of neuroendocrine cancer among males increased between 2012-2016 and 2017-2021 by 22.9% from 306 cases (61 cases per year) to 376 cases (75 cases per year).
- The number of cases of neuroendocrine cancer among females increased between 2012-2016 and 2017-2021 by 22.6% from 292 cases (58 cases per year) to 358 cases (72 cases per year).

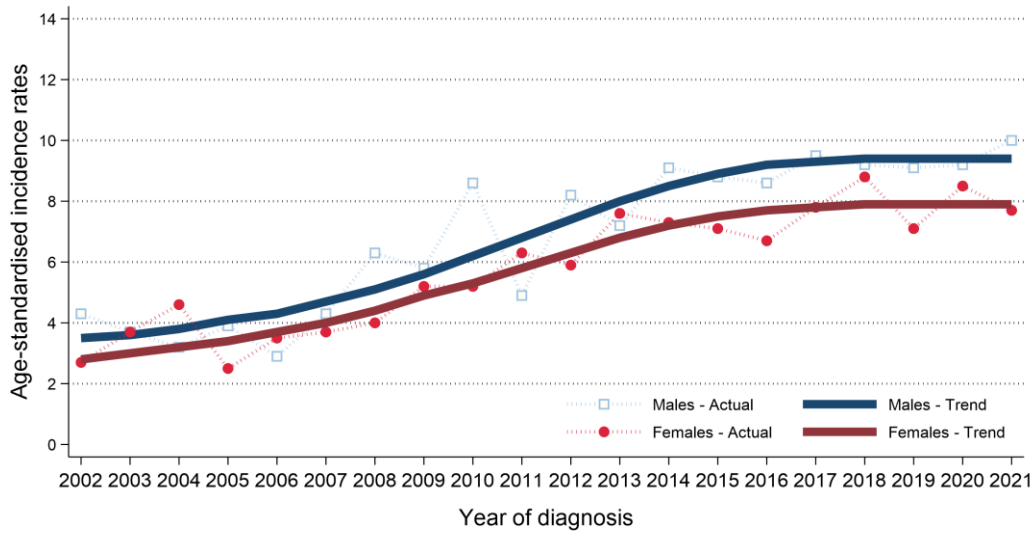
Figure 5: Trends in number of cases of neuroendocrine cancer diagnosed from 2002 to 2021



Year of diagnosis	Number of cases	
	Males	Females
2012	59	49
2013	52	64
2014	67	61
2015	65	60
2016	63	58
2017	73	67
2018	73	77
2019	74	64
2020	74	78
2021	82	72

- Male age-standardised neuroendocrine cancer incidence rates increased between 2012-2016 and 2017-2021 by 11.9% from 8.4 to 9.4 cases per 100,000 males. This change was not statistically significant.
- Female age-standardised neuroendocrine cancer incidence rates increased between 2012-2016 and 2017-2021 by 14.5% from 6.9 to 7.9 cases per 100,000 females. This change was not statistically significant.

Figure 6: Trends in incidence rates of neuroendocrine cancer from 2002 to 2021



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).

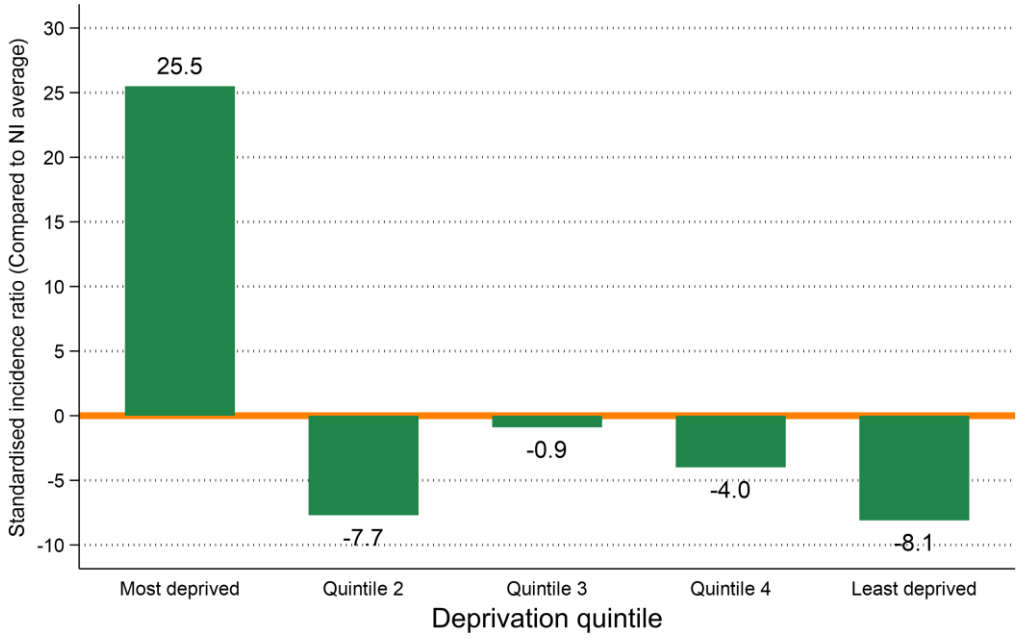
INCIDENCE BY DEPRIVATION

- The number of cases of neuroendocrine cancer diagnosed during 2017-2021 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 25.5% 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 2017-2021 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	**734**	**147**	**376**	**75**	**358**	**72**
	.	.	.	.	.	.
Most deprived	154	31	76	15	78	16
Quintile 2	136	27	76	15	60	12
Quintile 3	153	31	74	15	79	16
Quintile 4	150	30	79	16	71	14
Least deprived	141	28	71	14	70	14
Unknown	0	0	0	0	0	0

Figure 7: Standardised incidence ratio comparing deprivation quintile to Northern Ireland for neuroendocrine cancer diagnosed in 2017-2021



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.

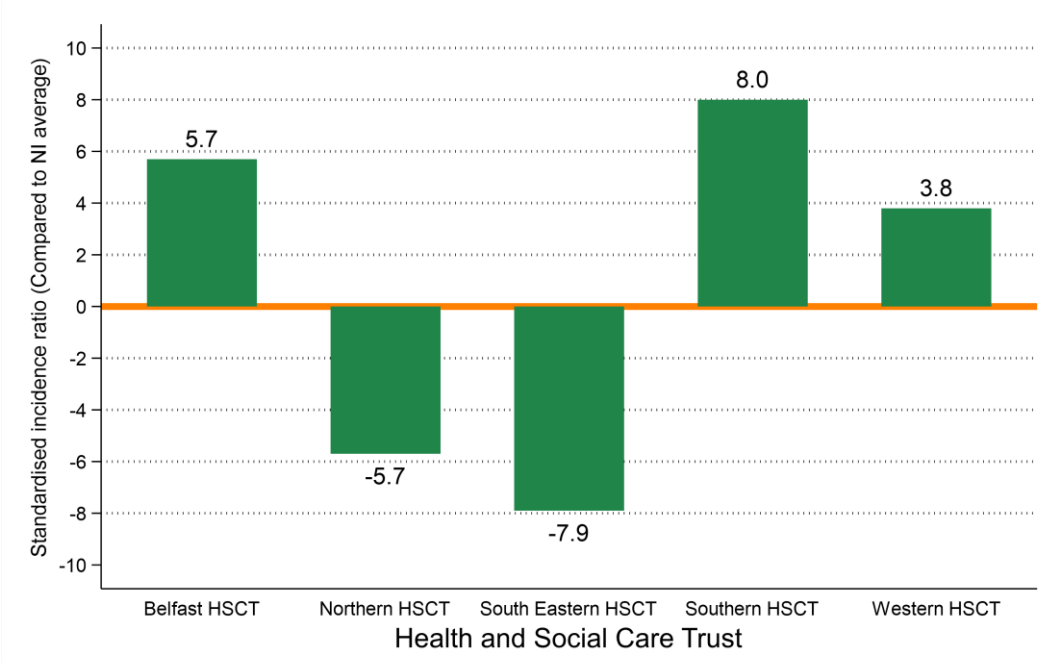
INCIDENCE BY HEALTH AND SOCIAL CARE TRUST

- The number of cases of neuroendocrine cancer diagnosed during 2017-2021 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 2017-2021 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	**734**	**147**	**376**	**75**	**358**	**72**
	.	.	.	.	.	.
Belfast HSCT	139	28	67	13	72	14
Northern HSCT	183	37	90	18	93	19
South Eastern HSCT	141	28	71	14	70	14
Southern HSCT	151	30	88	18	63	13
Western HSCT	120	24	60	12	60	12
Unknown	0	0	0	0	0	0

Figure 8: Standardised incidence ratio comparing Health and Social Care Trust to Northern Ireland for neuroendocrine cancer diagnosed in 2017-2021



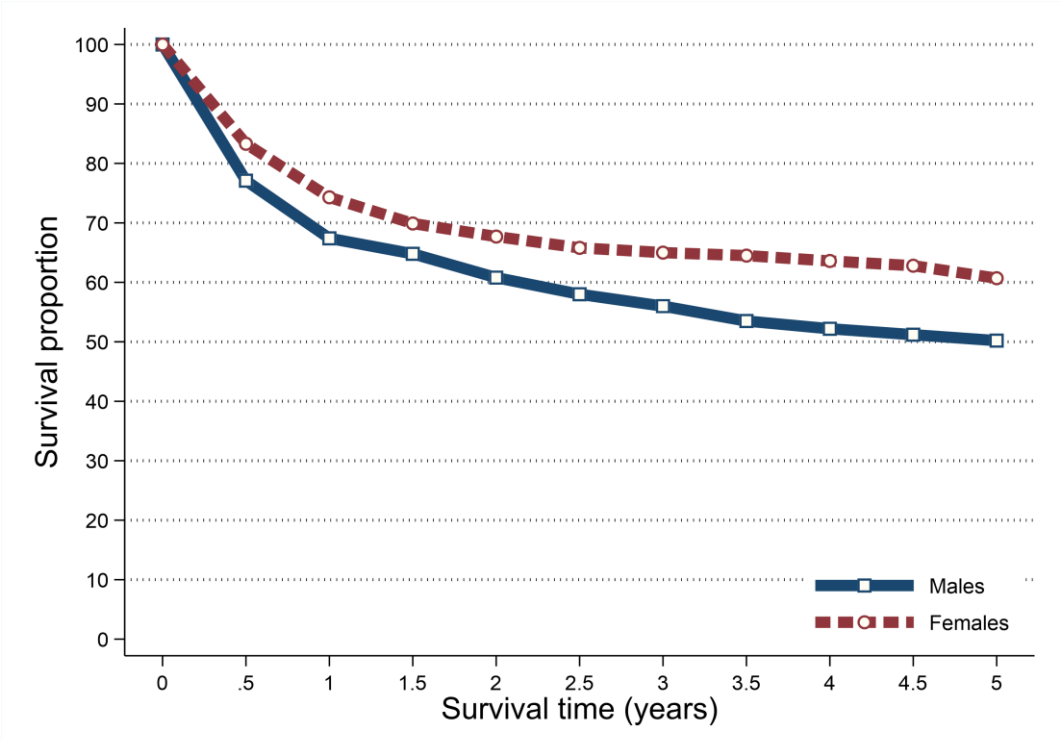
SURVIVAL

- 70.9% of patients were alive one year and 53.0% were alive five years from a neuroendocrine cancer diagnosis in 2012-2016. (observed survival)
- Age-standardised net survival (ASNS), which removes the effect of deaths from causes unrelated to cancer, was 70.3% one year and 54.6% five years from a neuroendocrine cancer diagnosis in 2012-2016.
- Five-year survival (ASNS) for neuroendocrine cancer patients diagnosed in 2012-2016 was 50.2% among men and 60.7% among women.

Table 3: Survival from neuroendocrine cancer for patients diagnosed in 2012-2016

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	80.6%	79.7%	77.3%	77.1%	84.2%	83.3%
One year	70.9%	70.3%	67.1%	67.4%	75.1%	74.3%
Two years	63.6%	63.6%	59.5%	60.8%	68.0%	67.7%
Five years	53.0%	54.6%	47.4%	50.2%	59.0%	60.7%

Figure 9: Age-standardised net survival from neuroendocrine cancer for patients diagnosed in 2012-2016



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.

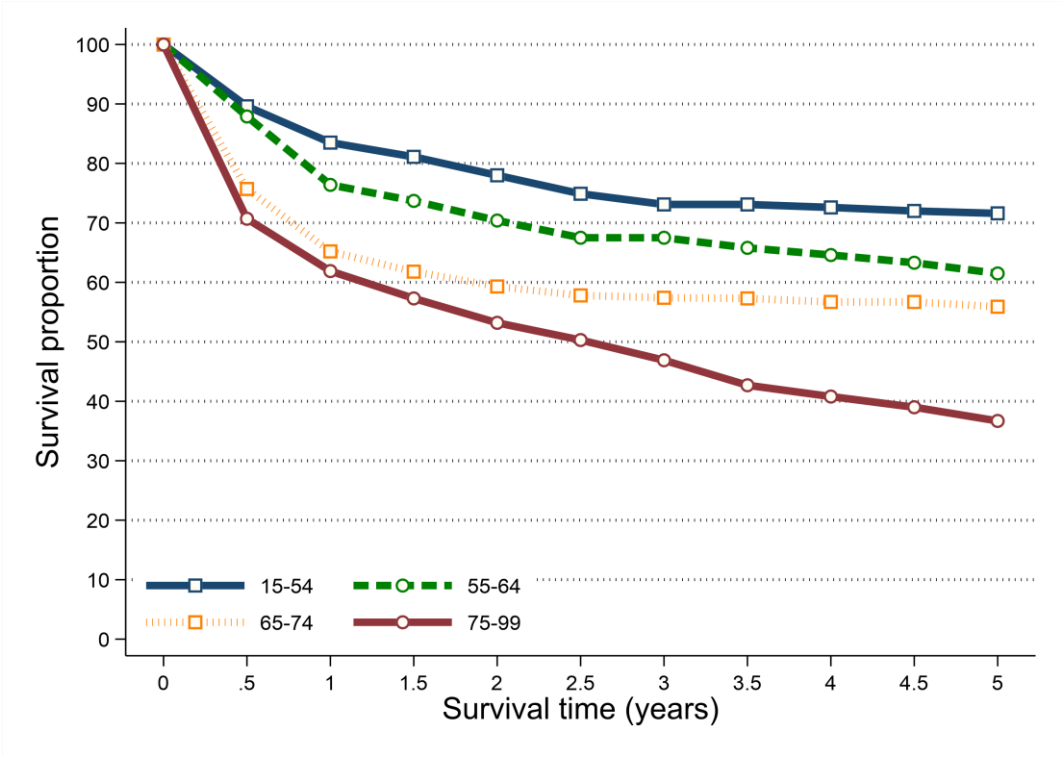
SURVIVAL BY AGE

- Survival from neuroendocrine cancer among patients diagnosed during 2012-2016 was related to age with better five-year survival among younger age groups.
- Five-year net survival ranged from 71.6% among patients aged 15 to 54 at diagnosis to 36.7% among those aged 75 to 99.

Table 4: Net survival from neuroendocrine cancer for patients diagnosed in 2012-2016 by age at diagnosis

Age group	All persons	
	One-year	Five-years
15 to 54	83.5%	71.6%
55 to 64	76.4%	61.5%
65 to 74	65.2%	55.9%
75 to 99	61.9%	36.7%

Figure 10: Net survival from neuroendocrine cancer for patients diagnosed in 2012-2016 by age at diagnosis

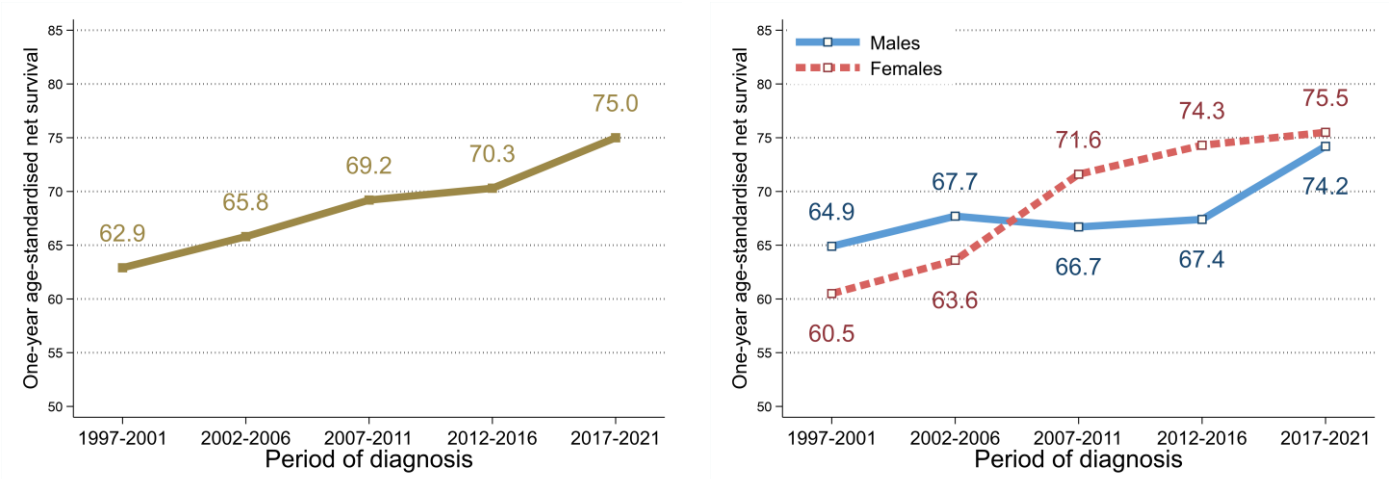


SURVIVAL TRENDS

ONE-YEAR NET SURVIVAL

- Between 2012-2016 and 2017-2021 there was no significant change in one-year survival (ASNS) from neuroendocrine cancer.
- Compared to 1997-2001 one-year survival (ASNS) from neuroendocrine cancer in 2017-2021 did not change significantly.

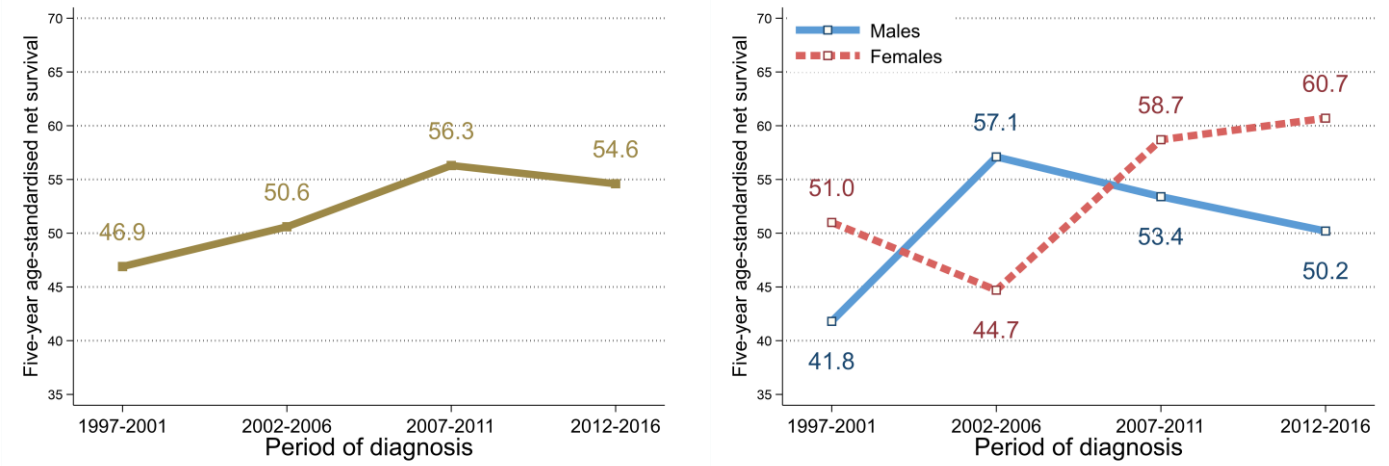
Figure 11: Trends in one-year age-standardised net survival from neuroendocrine cancer in 1997-2021



FIVE-YEAR NET SURVIVAL

- Between 2007-2011 and 2012-2016 there was no significant change in five-year survival (ASNS) from neuroendocrine cancer.
- Compared to 1997-2001 five-year survival (ASNS) from neuroendocrine cancer in 2012-2016 did not change significantly.

Figure 12: Trends in five-year age-standardised net survival from neuroendocrine cancer in 1997-2016



PREVALENCE

- At the end of 2021, there were 999 people (Males: 476; Females: 523) living with neuroendocrine cancer who had been diagnosed with the disease during 1997-2021.
- Of these 12.5% had been diagnosed in the previous year (one-year prevalence) and 75.6% in the previous 10 years (ten-year prevalence).
- 30.1% of neuroendocrine cancer survivors were aged 75 and over at the end of 2021.

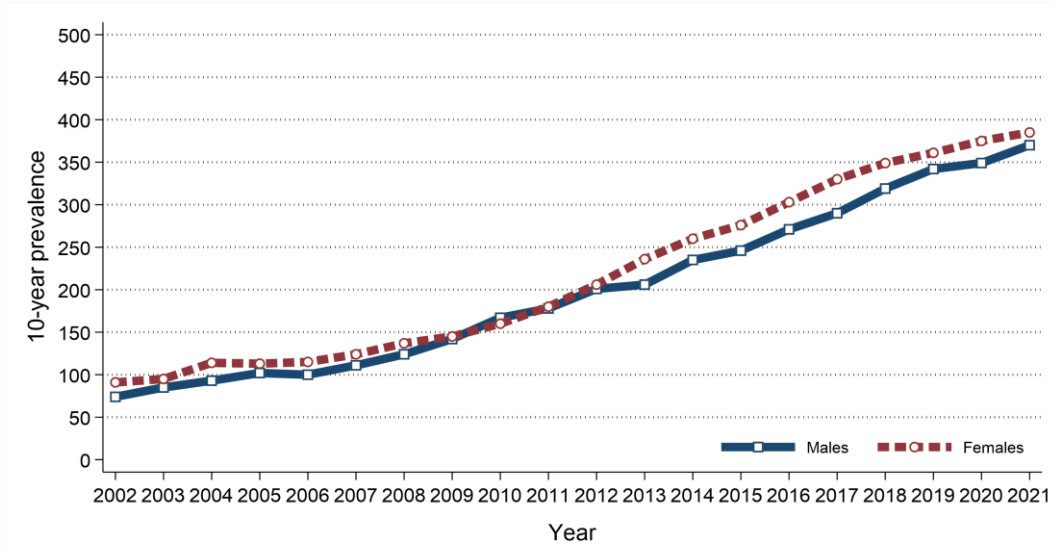
Table 5: 25-year prevalence of neuroendocrine cancer by age at end of 2021

Gender	Age at end of 2021	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	999	125	349	281	244
	0 to 74	698	82	248	200	168
	75 and over	301	43	101	81	76
Male	All ages	476	67	173	130	106
	0 to 74	331	41	127	96	67
	75 and over	145	26	46	34	39
Female	All ages	523	58	176	151	138
	0 to 74	367	41	121	104	101
	75 and over	156	17	55	47	37

PREVALENCE TRENDS

- 10-year prevalence of neuroendocrine cancer among males increased between 2016 and 2021 by 36.5% from 271 survivors to 370 survivors.
- 10-year prevalence of neuroendocrine cancer among females increased between 2016 and 2021 by 27.1% from 303 survivors to 385 survivors.

Figure 13: Trends in 10-year prevalence of neuroendocrine cancer in 2002-2021



Year	10-year prevalence	
	Males	Females
2012	201	206
2013	206	236
2014	235	260
2015	246	276
2016	271	303
2017	290	330
2018	319	349
2019	342	361
2020	349	375
2021	370	385

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 Jan 2023 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 2021 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.