
Unknown primary cancer

1993-2022

(ICD10 codes: C77-C80)



Northern Ireland Cancer Registry, 2025

An official statistics publication

ABOUT THIS REPORT

Contents

This report includes information on incidence of unknown primary 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.

Cancer mortality data

The NI Statistics and Research Agency (NISRA) is the official statistics provider of cancer mortality data in Northern Ireland. However, for completeness, data on cancer mortality is also provided in this report. While analysis is conducted by NICR staff, the original data is provided courtesy of the General Register Office (NI) via the Department of Health.

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. Unknown primary 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.

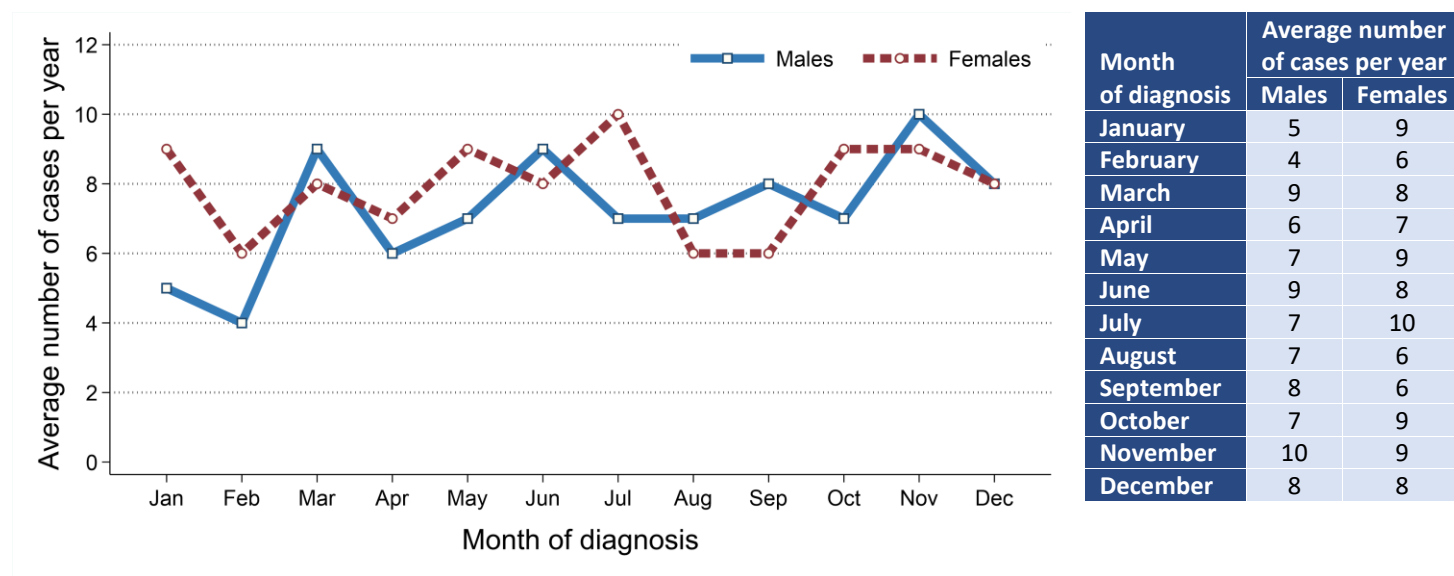
NICR is funded by the Public Health Agency and is based in Queen's University, Belfast.



INCIDENCE

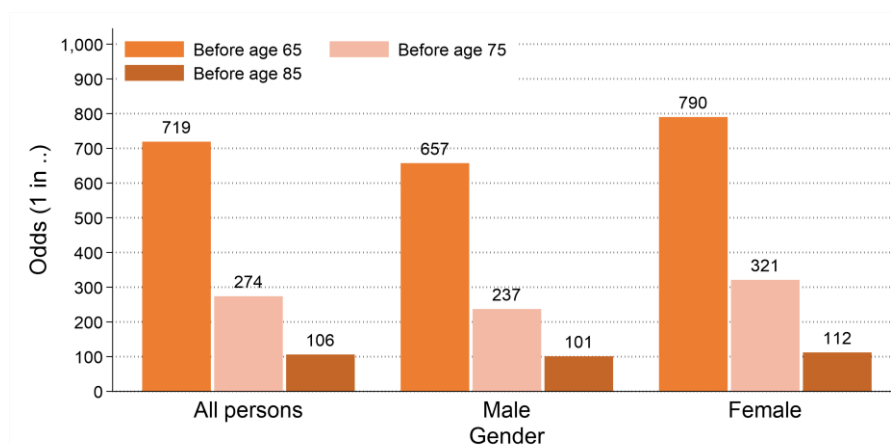
- There were 907 cases of unknown primary cancer diagnosed during 2018-2022 in Northern Ireland. On average this was 181 cases per year.
- During this period 52.1% of unknown primary cancer cases were among women (Male cases: 434, Female cases: 473). On average there were 87 male and 95 female cases of unknown primary cancer per year.
- The most common diagnosis month during 2018-2022 was November among males with 10 cases per year and July among females with 10 cases per year.

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



- Unknown primary cancer made up 1.6% of all male and 1.9% of all female cancer cases (excluding non-melanoma skin cancer).
- The unknown primary cancer incidence rates for each gender were 9.3 cases per 100,000 males and 9.8 cases per 100,000 females.
- The odds of developing unknown primary cancer before age 85 was 1 in 101 for men and 1 in 112 for women.

Figure 2: Odds of developing unknown primary cancer in 2018-2022



INCIDENCE BY AGE

- The median age of patients diagnosed with unknown primary cancer during 2018-2022 was 78 years (Males: 75, Females: 79).
- The risk of developing unknown primary cancer varied by age, with 53.0% of men and 66.2% of women diagnosed with unknown primary cancer aged 75 and over at diagnosis.
- In contrast, 8.2% of patients diagnosed with unknown primary cancer were aged 0 to 54 at diagnosis.

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

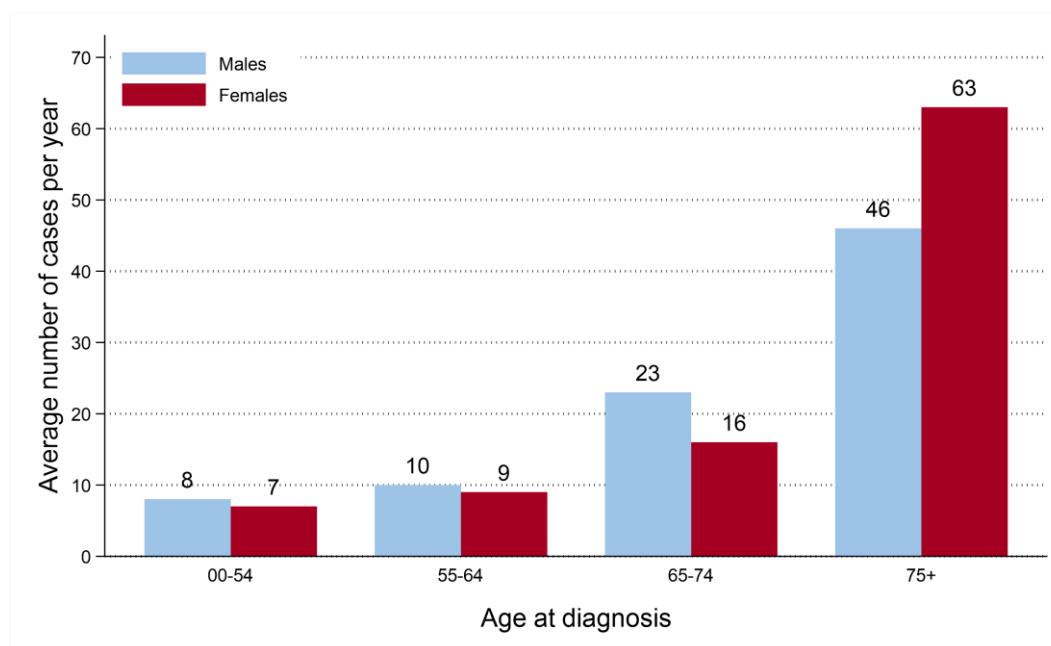
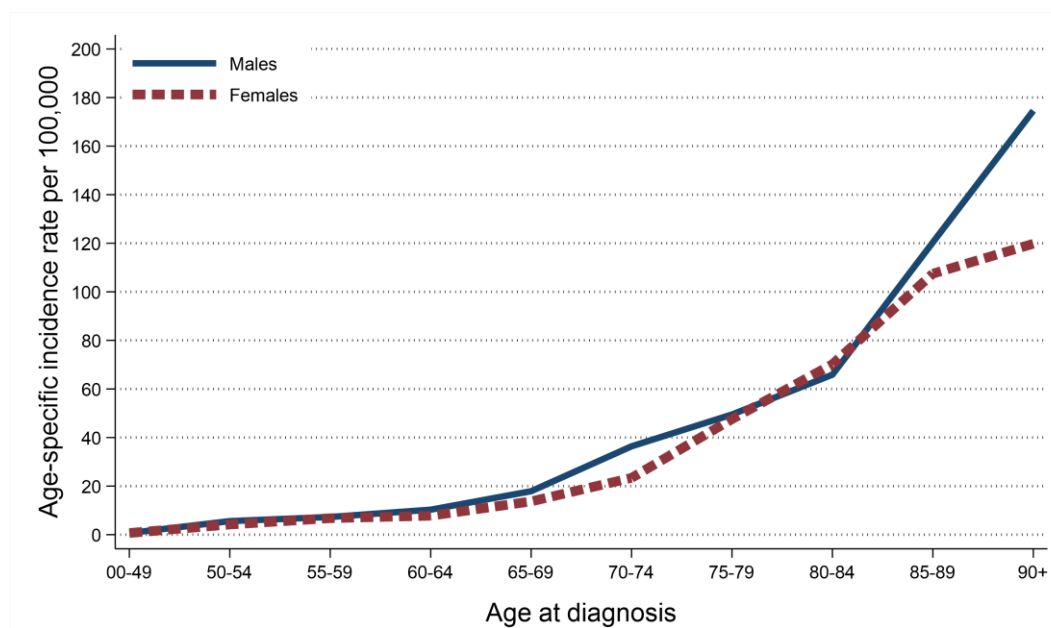


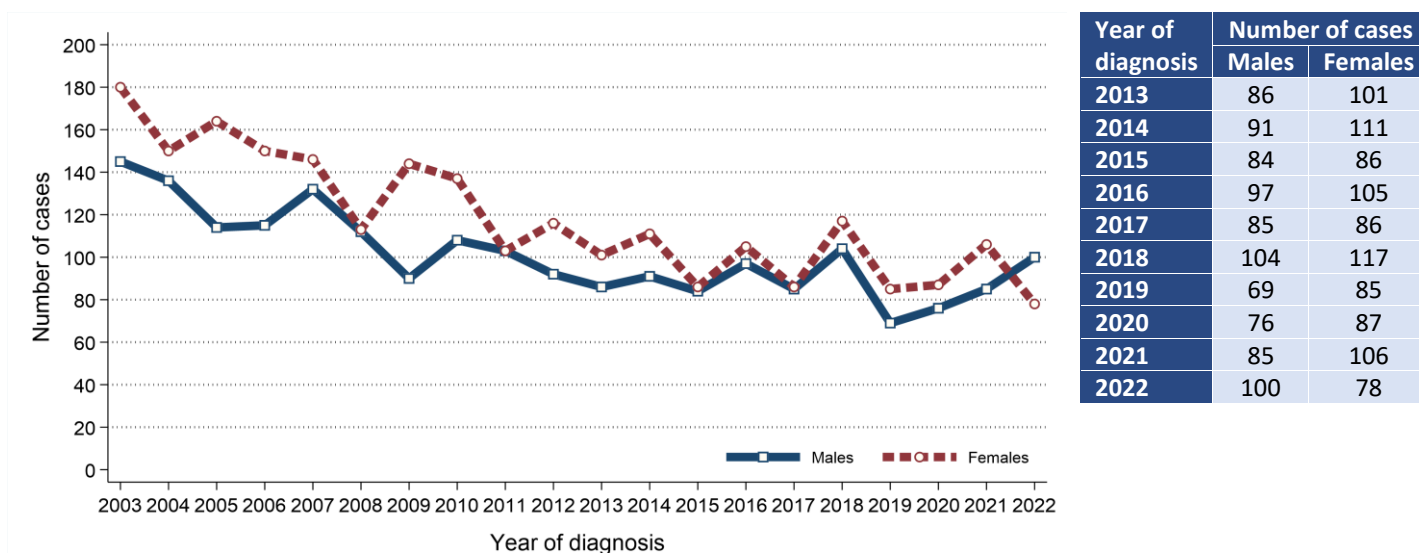
Figure 4: Age-specific incidence rates of unknown primary cancer in 2018-2022



INCIDENCE TRENDS

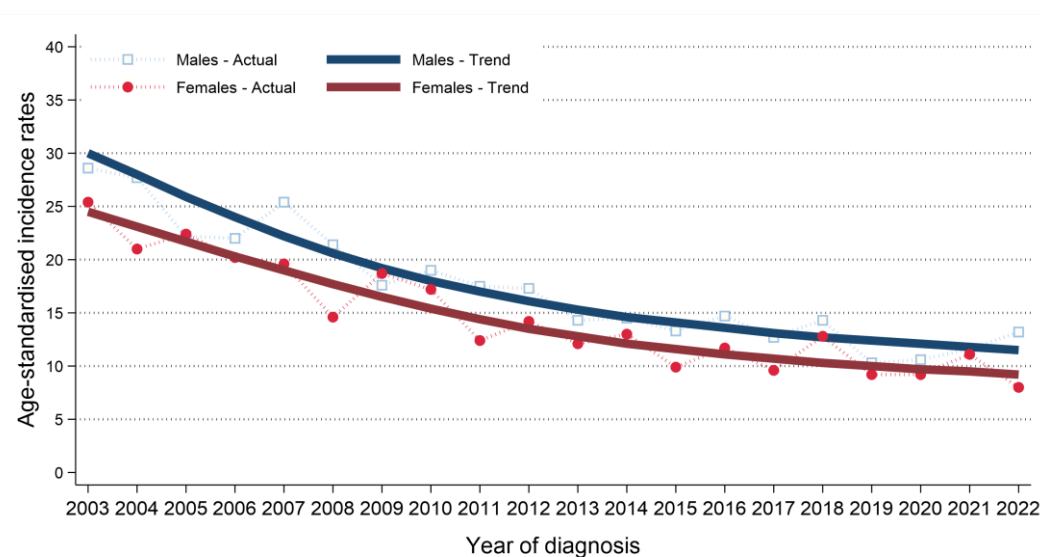
- The number of cases of unknown primary cancer among males decreased between 2013-2017 and 2018-2022 by 2.0% from 443 cases (89 cases per year) to 434 cases (87 cases per year).
- The number of cases of unknown primary cancer among females decreased between 2013-2017 and 2018-2022 by 3.3% from 489 cases (98 cases per year) to 473 cases (95 cases per year).

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



- Male age-standardised unknown primary cancer incidence rates decreased between 2013-2017 and 2018-2022 by 13.7% from 13.9 to 12.0 cases per 100,000 males. This change was not statistically significant.
- Female age-standardised unknown primary cancer incidence rates decreased between 2013-2017 and 2018-2022 by 10.7% from 11.2 to 10.0 cases per 100,000 females. This change was not statistically significant.

Figure 6: Trends in incidence rates of unknown primary 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).

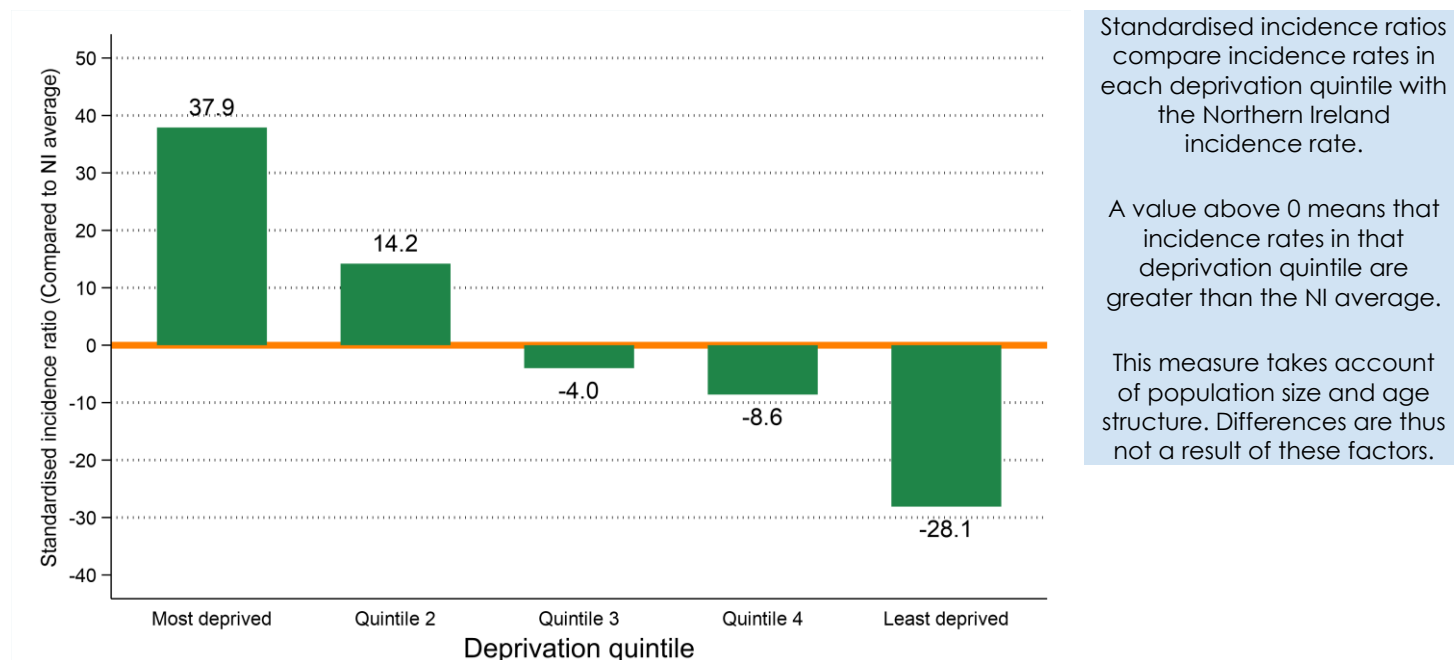
INCIDENCE BY DEPRIVATION

- The number of cases of unknown primary 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 37.9% higher than the NI average.
 - in the least socio-economically deprived areas were 28.1% lower than the NI average.

Table 1: Number of cases of unknown primary 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	907	181	434	87	473	95
Most deprived
Quintile 2	198	40	94	19	104	21
Quintile 3	206	41	91	18	115	23
Quintile 4	184	37	100	20	84	17
Least deprived	176	35	83	17	93	19
Unknown	143	29	66	13	77	15
Unknown	0	0	0	0	0	0

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



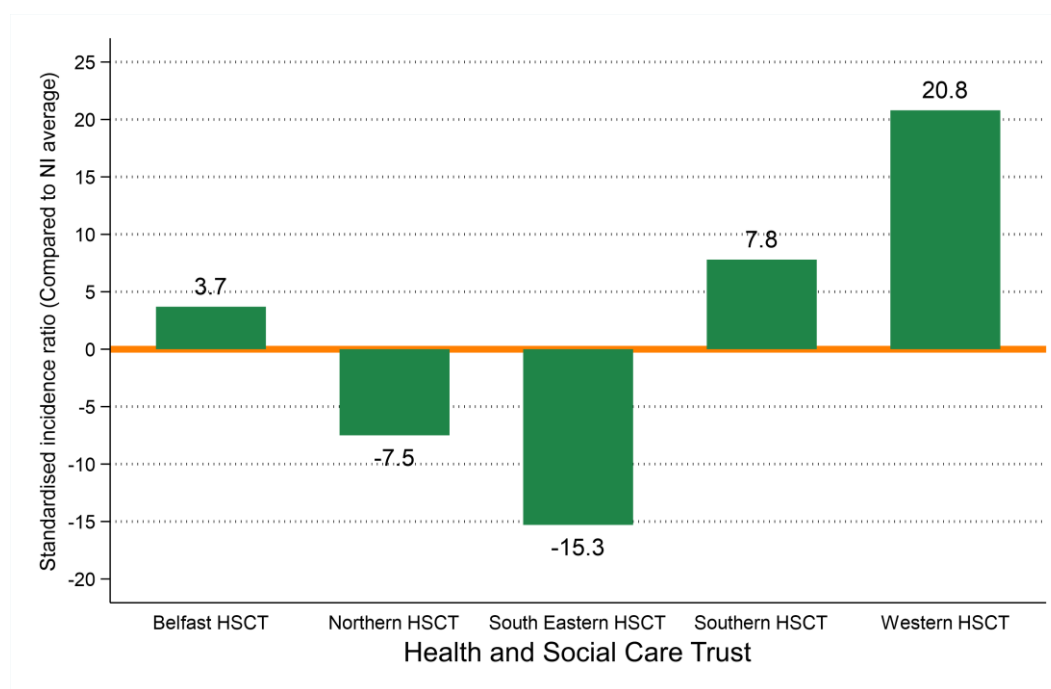
INCIDENCE BY HEALTH AND SOCIAL CARE TRUST

- The number of cases of unknown primary 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 were 15.3% lower than the NI average.
 - in Southern HSCT did not vary significantly from the NI average.
 - in Western HSCT were 20.8% higher than the NI average.

Table 2: Number of cases of unknown primary 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	907	181	434	87	473	95
Belfast HSCT	172	34	79	16	93	19
Northern HSCT	224	45	106	21	118	24
South Eastern HSCT	164	33	75	15	89	18
Southern HSCT	181	36	85	17	96	19
Western HSCT	166	33	89	18	77	15
Unknown	0	0	0	0	0	0

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



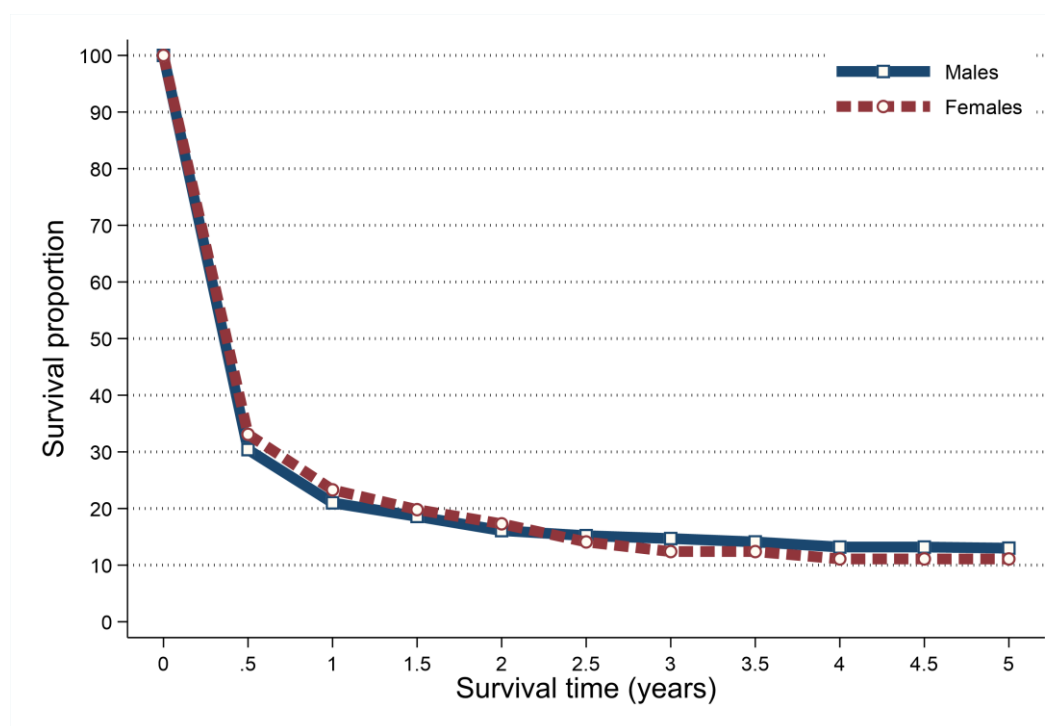
SURVIVAL

- 14.9% of patients were alive one year and 7.1% were alive five years from a unknown primary cancer diagnosis in 2013-2017. (observed survival)
- Age-standardised net survival (ASNS), which removes the effect of deaths from causes unrelated to cancer, was 22.2% one year and 12.0% five years from a unknown primary cancer diagnosis in 2013-2017.
- Five-year survival (ASNS) for unknown primary cancer patients diagnosed in 2013-2017 was 13.0% among men and 11.1% among women.

Table 3: Survival from unknown primary 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	22.6%	31.8%	21.6%	30.4%	23.6%	33.1%
One year	14.9%	22.2%	14.4%	21.0%	15.4%	23.3%
Two years	10.8%	16.7%	10.7%	16.1%	10.8%	17.3%
Five years	7.1%	12.0%	8.1%	13.0%	6.3%	11.1%

Figure 9: Age-standardised net survival from unknown primary 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.

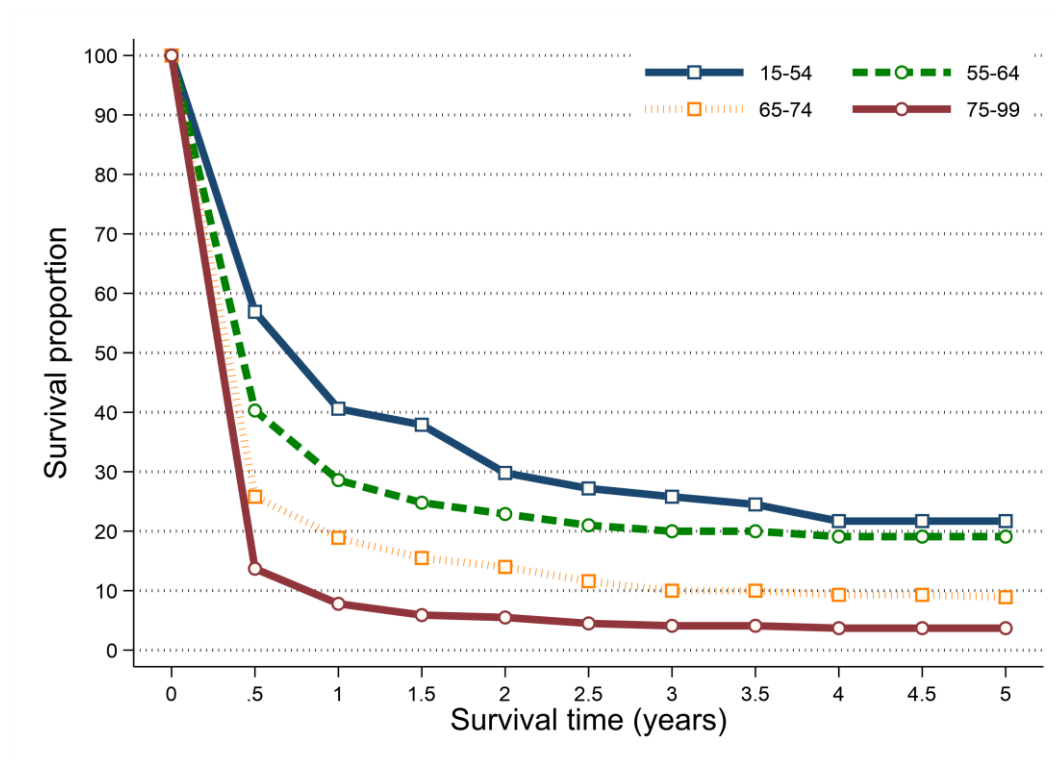
SURVIVAL BY AGE

- Survival from unknown primary 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 21.7% among patients aged 15 to 54 at diagnosis to 3.7% among those aged 75 to 99.

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

Age group	All persons	
	One-year	Five-years
15 to 54	40.6%	21.7%
55 to 64	28.6%	19.1%
65 to 74	18.9%	8.9%
75 to 99	7.8%	3.7%

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

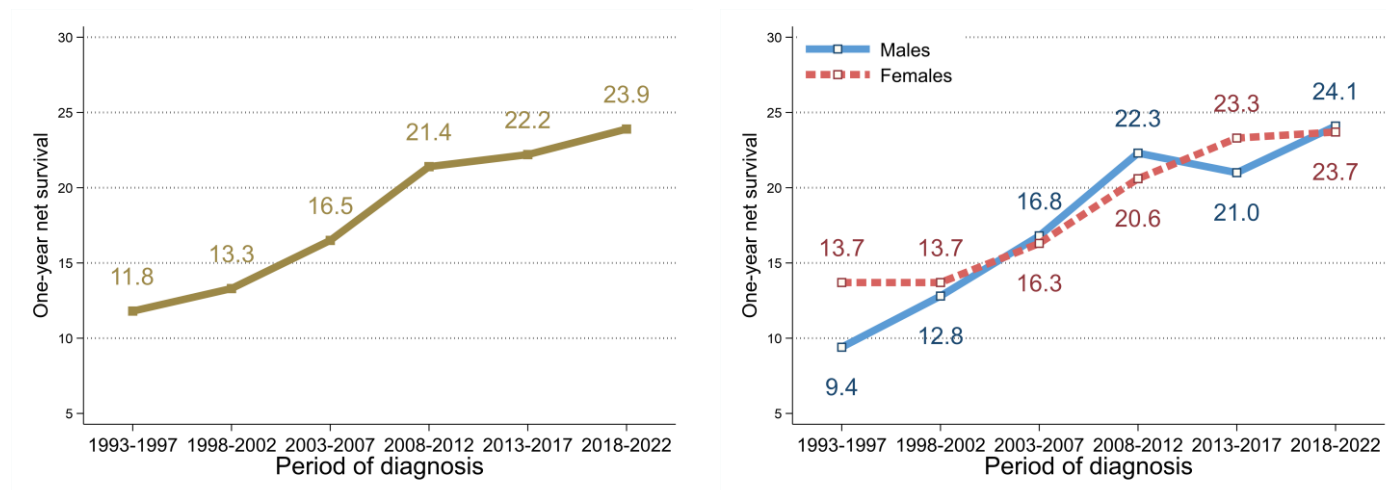


SURVIVAL TRENDS

ONE-YEAR NET SURVIVAL

- Between 2013-2017 and 2018-2022 there was no significant change in one-year survival (ASNS) from unknown primary cancer.
- Compared to 1993-1997 one-year survival (ASNS) from unknown primary cancer in 2018-2022 increased significantly from 11.8% to 23.9%. This increase was significant for males (9.4% to 24.1%) and females (13.7% to 23.7%).

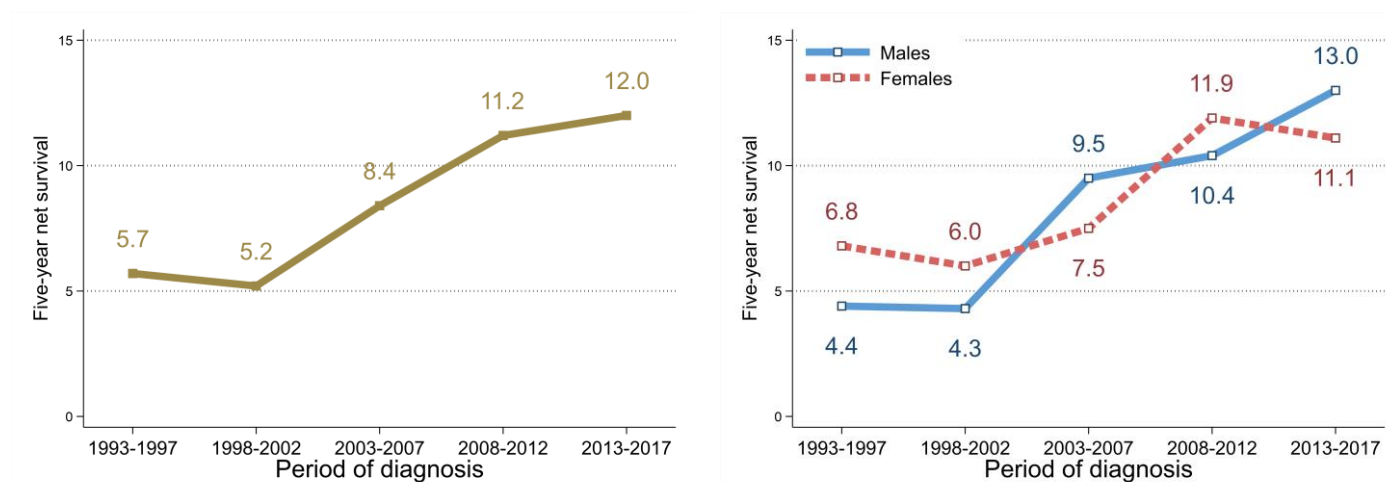
Figure 11: Trends in one-year age-standardised net survival from unknown primary cancer in 1993-2022



FIVE-YEAR NET SURVIVAL

- Between 2008-2012 and 2013-2017 there was no significant change in five-year survival (ASNS) from unknown primary cancer.
- Compared to 1993-1997 five-year survival (ASNS) from unknown primary cancer in 2013-2017 increased significantly from 5.7% to 12.0%. This increase was significant for males (4.4% to 13.0%) but not females.

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



PREVALENCE

- At the end of 2022, there were 275 people (Males: 151; Females: 124) living with unknown primary cancer who had been diagnosed with the disease during 1998-2022.
- Of these 19.3% had been diagnosed in the previous year (one-year prevalence) and 64.7% in the previous 10 years (ten-year prevalence).
- 34.9% of unknown primary cancer survivors were aged 75 and over at the end of 2022.

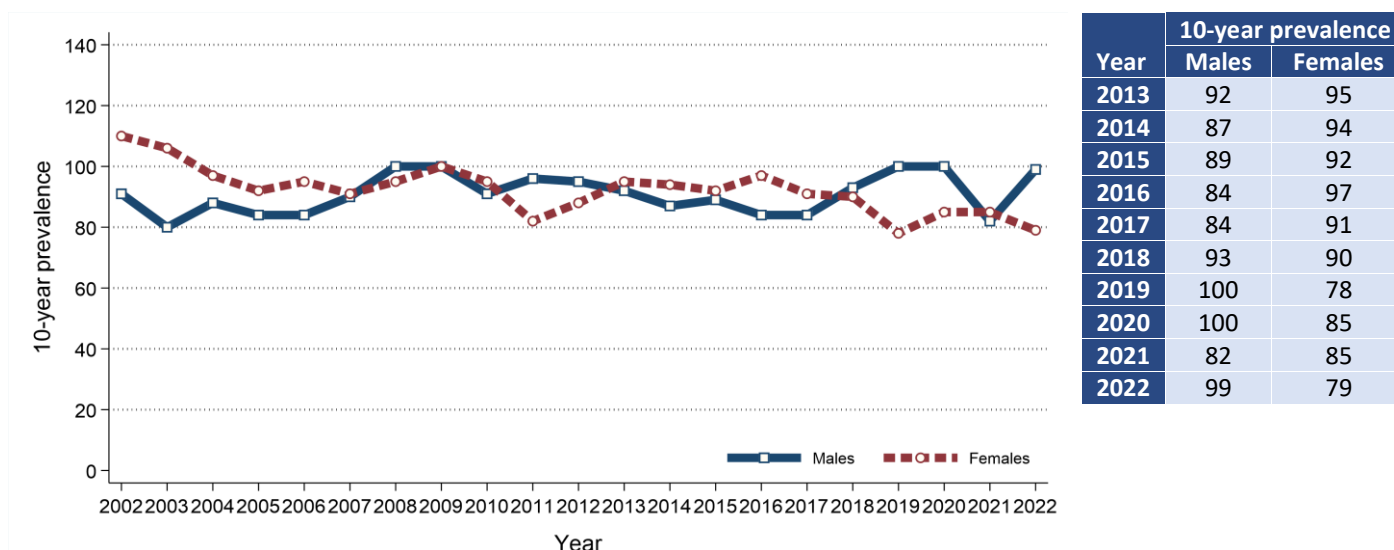
Table 5: 25-year prevalence of unknown primary cancer by age at end of 2022

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	275	53	74	51	97
	0 to 74	179	27	55	36	61
	75 and over	96	26	19	15	36
Male	All ages	151	35	34	30	52
	0 to 74	99	19	25	21	34
	75 and over	52	16	9	9	18
Female	All ages	124	18	40	21	45
	0 to 74	80	8	30	15	27
	75 and over	44	10	10	6	18

PREVALENCE TRENDS

- 10-year prevalence of unknown primary cancer among males increased between 2017 and 2022 by 17.9% from 84 survivors to 99 survivors.
- 10-year prevalence of unknown primary cancer among females decreased between 2017 and 2022 by 13.2% from 91 survivors to 79 survivors.

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



MORTALITY

- There were 1,149 deaths from unknown primary cancer during 2018-2022 in Northern Ireland. On average this was 230 deaths per year.
- During this period 51.1% of unknown primary cancer deaths were among women (Male deaths: 562, Female deaths: 587). On average there were 112 male and 117 female deaths from unknown primary cancer per year.
- Unknown primary cancer deaths made up 4.7% of all male and 5.4% of all female cancer deaths.
- The median age of patients who died from unknown primary cancer during 2018-2022 was 77 years (Males: 75, Females: 78).
- The risk of dying from unknown primary cancer varied by age, with 53.9% of men and 63.0% of women who died from unknown primary cancer aged 75 and over at death.
- In contrast, 6.3% of patients who died from unknown primary cancer were aged 0 to 54 at death.

Figure 14: Average number of deaths from unknown primary cancer per year in 2018-2022 by age at death

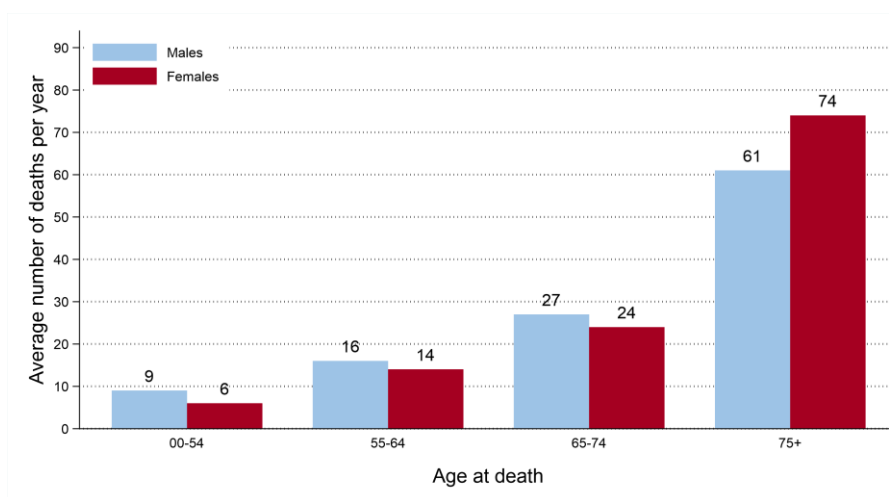
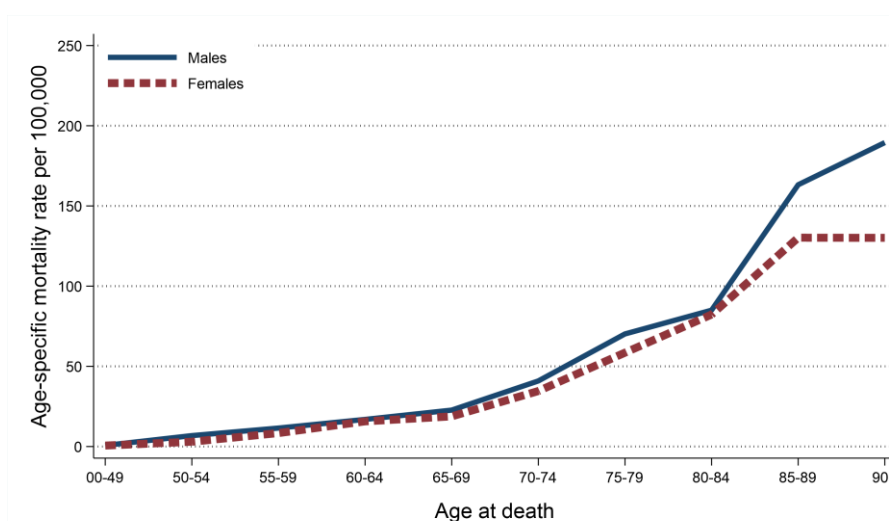


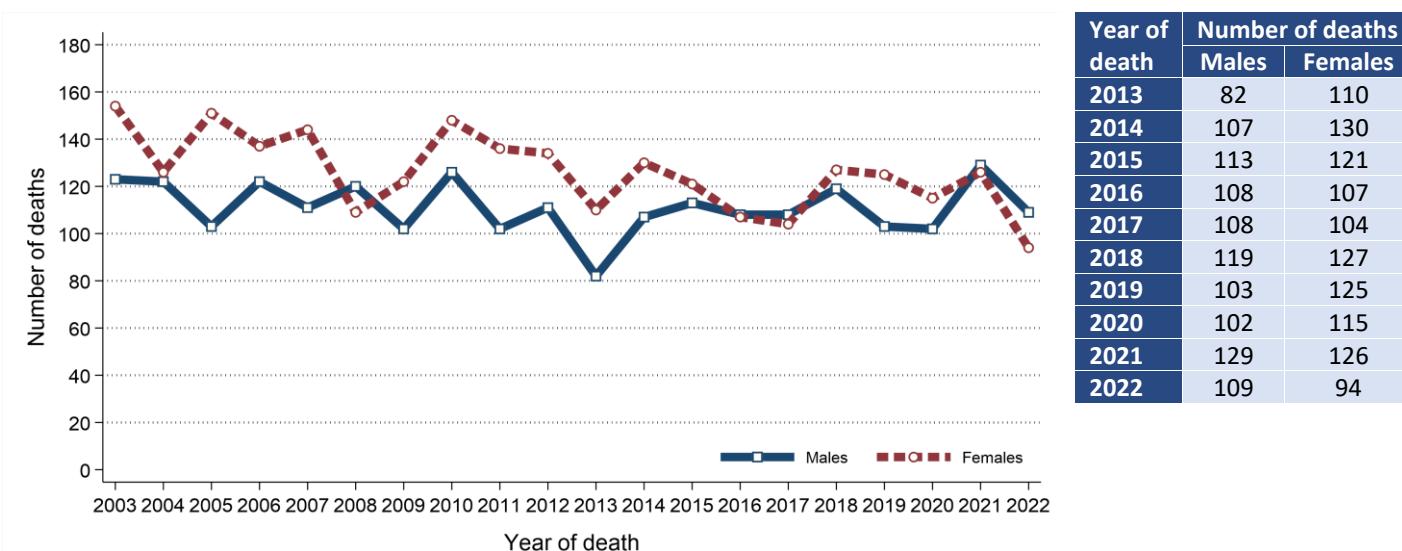
Figure 15: Age-specific mortality rates of unknown primary cancer in 2018-2022



MORTALITY TRENDS

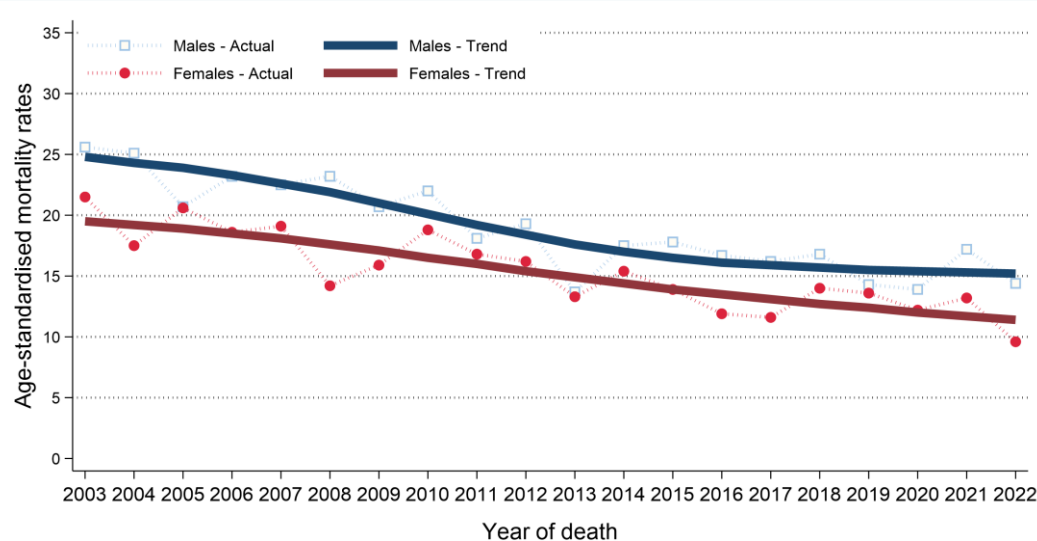
- The number of deaths from unknown primary cancer among males increased between 2013-2017 and 2018-2022 by 8.5% from 518 deaths (104 deaths per year) to 562 deaths (112 deaths per year).
- The number of deaths from unknown primary cancer among females increased between 2013-2017 and 2018-2022 by 2.6% from 572 deaths (114 deaths per year) to 587 deaths (117 deaths per year).

Figure 16: Trends in the number of deaths from unknown primary cancer from 2003 to 2022



- Male age-standardised unknown primary cancer mortality rates decreased between 2013-2017 and 2018-2022 by 6.7% from 16.4 to 15.3 deaths per 100,000 males. This change was not statistically significant.
- Female age-standardised unknown primary cancer mortality rates decreased between 2013-2017 and 2018-2022 by 5.3% from 13.2 to 12.5 deaths per 100,000 females. This change was not statistically significant.

Figure 17: Trends in mortality rates of unknown primary cancer from 2003 to 2022



Age-standardised mortality rates illustrate the change in the number of deaths 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.

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#/I>

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. unknown primary 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. unknown primary 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.