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# Unknown primary cancer

## 1993-2021

(ICD10 codes: C77-C80)

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**Northern Ireland Cancer Registry, 2024**

**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 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](http://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](http://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 2024. Unknown primary cancer: 1993-2021. Available at:*  
[www.qub.ac.uk/research-centres/nicr](http://www.qub.ac.uk/research-centres/nicr)

### Further information

Further information is available at: [www.qub.ac.uk/research-centres/nicr](http://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.

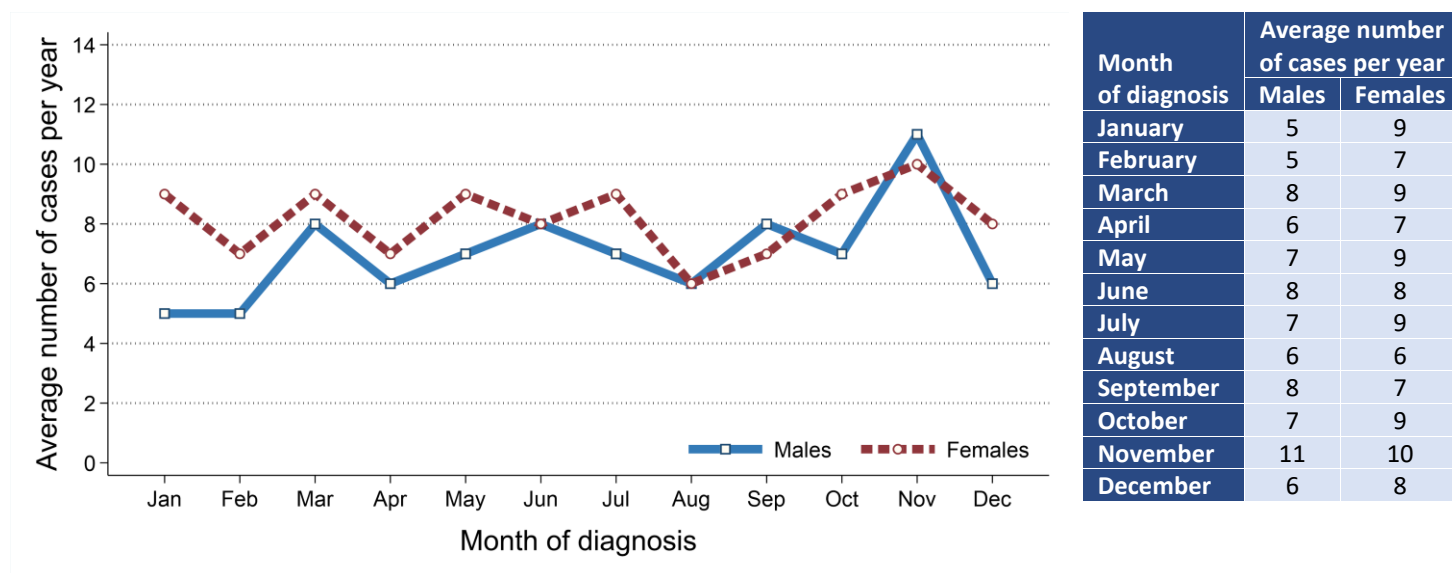
NICR is funded by the Public Health Agency and is based in Queen's University, Belfast.



## INCIDENCE

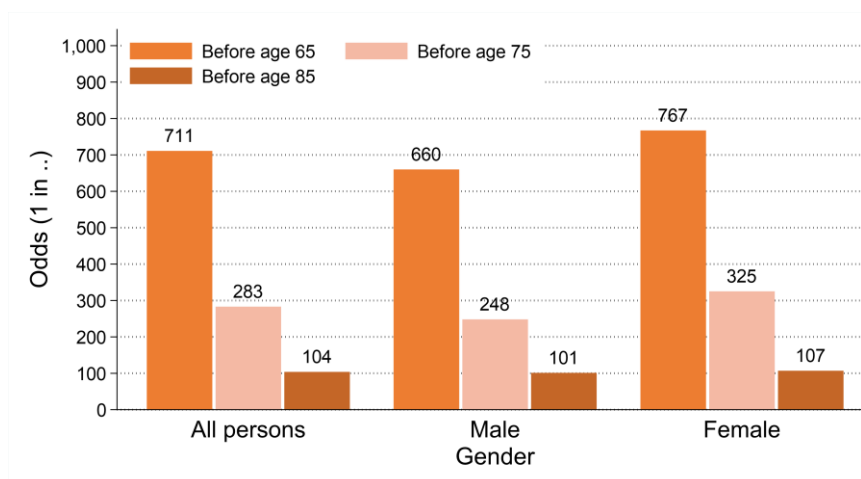
- There were 899 cases of unknown primary cancer diagnosed during 2017-2021 in Northern Ireland. On average this was 180 cases per year.
- During this period 53.7% of unknown primary cancer cases were among women (Male cases: 416, Female cases: 483). On average there were 83 male and 97 female cases of unknown primary cancer per year.
- The most common diagnosis month during 2017-2021 was November among males with 11 cases per year and November among females with 10 cases per year.

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



- Unknown primary cancer made up 1.6% of all male and 2.0% of all female cancer cases (excluding non-melanoma skin cancer).
- The unknown primary cancer incidence rates for each gender were 8.9 cases per 100,000 males and 10.1 cases per 100,000 females.
- The odds of developing unknown primary cancer before age 85 was 1 in 101 for men and 1 in 107 for women.

Figure 2: Odds of developing unknown primary cancer in 2017-2021



## INCIDENCE BY AGE

- The median age of patients diagnosed with unknown primary cancer during 2017-2021 was 78 years (Males: 76, Females: 79).
- The risk of developing unknown primary cancer varied by age, with 53.8% of men and 67.5% of women diagnosed with unknown primary cancer aged 75 and over at diagnosis.
- In contrast, 8.0% 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 2017-2021 by age at diagnosis

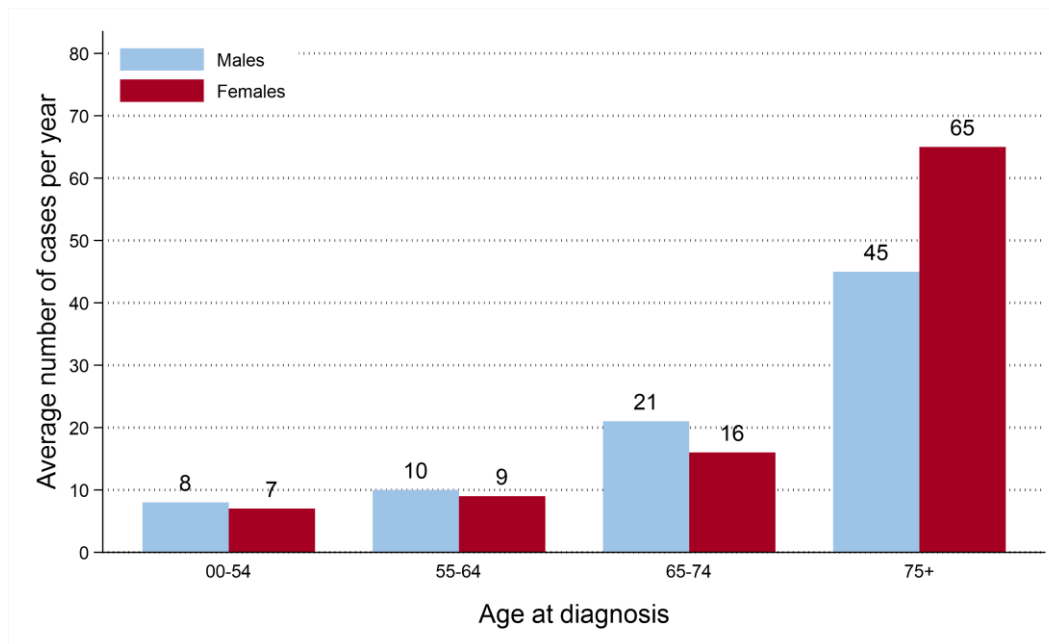
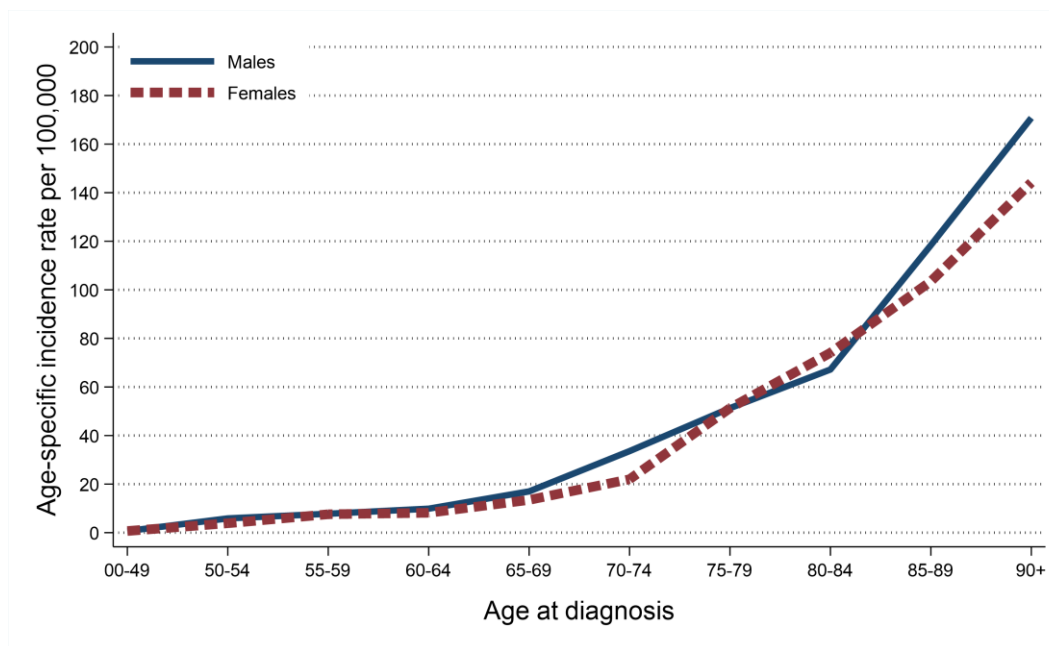


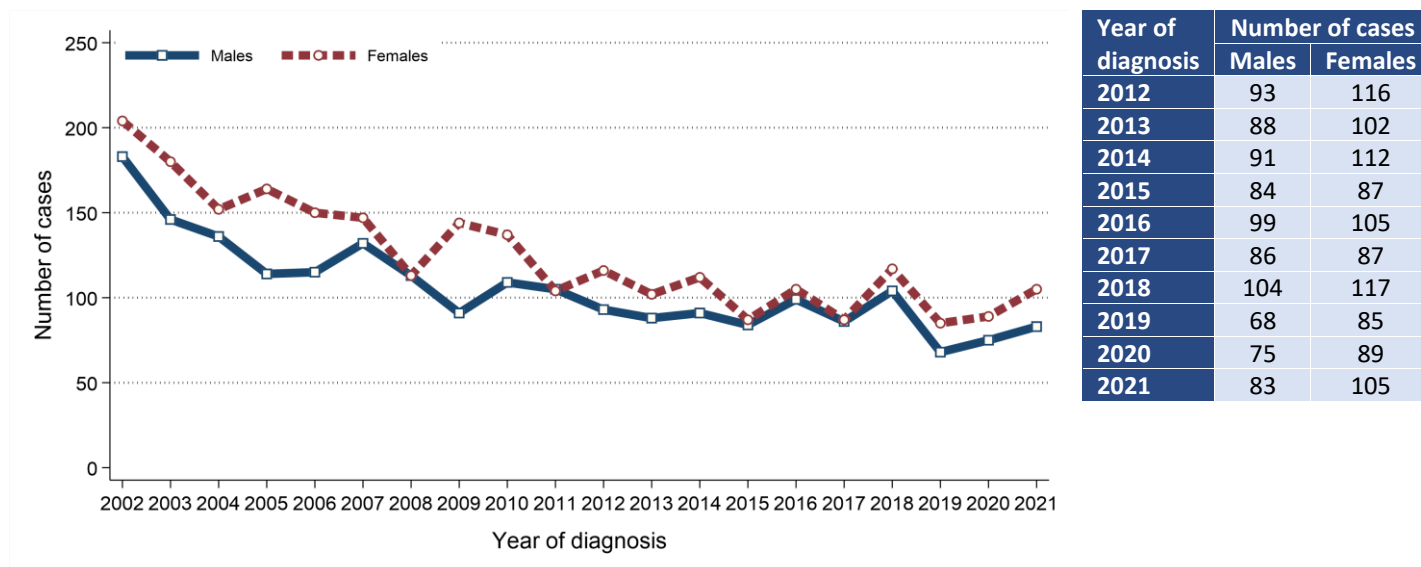
Figure 4: Age-specific incidence rates of unknown primary cancer in 2017-2021



## INCIDENCE TRENDS

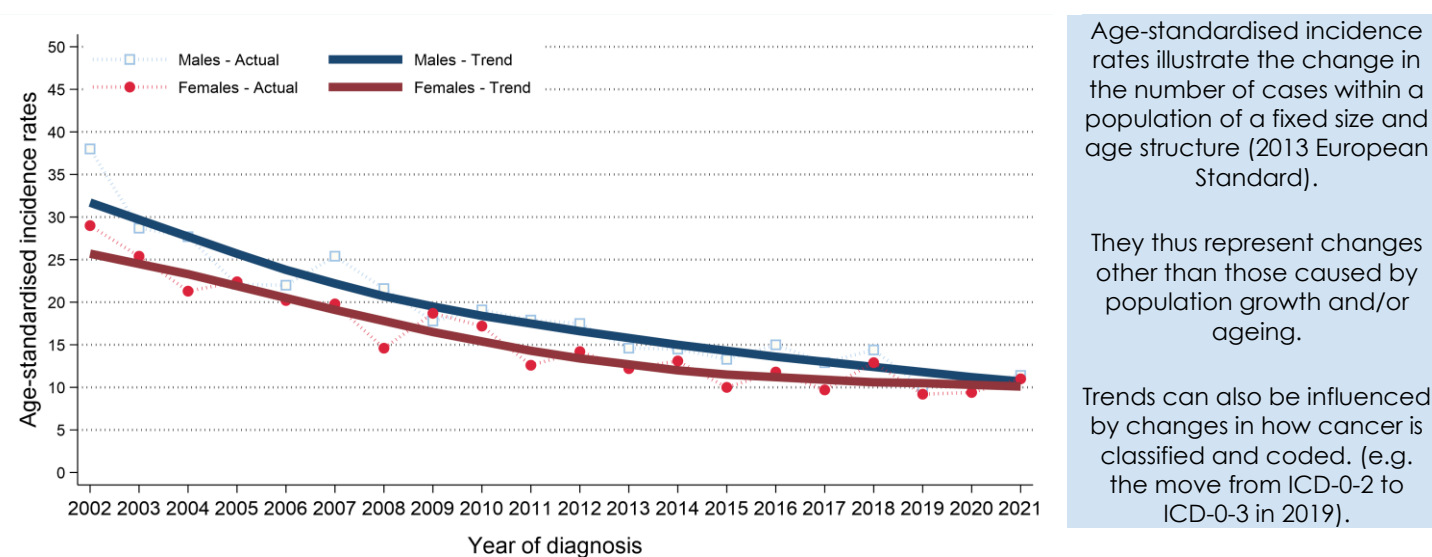
- The number of cases of unknown primary cancer among males decreased between 2012-2016 and 2017-2021 by 8.6% from 455 cases (91 cases per year) to 416 cases (83 cases per year).
- The number of cases of unknown primary cancer among females decreased between 2012-2016 and 2017-2021 by 7.5% from 522 cases (104 cases per year) to 483 cases (97 cases per year).

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



- Male age-standardised unknown primary cancer incidence rates decreased between 2012-2016 and 2017-2021 by 20.8% from 14.9 to 11.8 cases per 100,000 males. This change was statistically significant.
- Female age-standardised unknown primary cancer incidence rates decreased between 2012-2016 and 2017-2021 by 14.8% from 12.2 to 10.4 cases per 100,000 females. This change was not statistically significant.

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



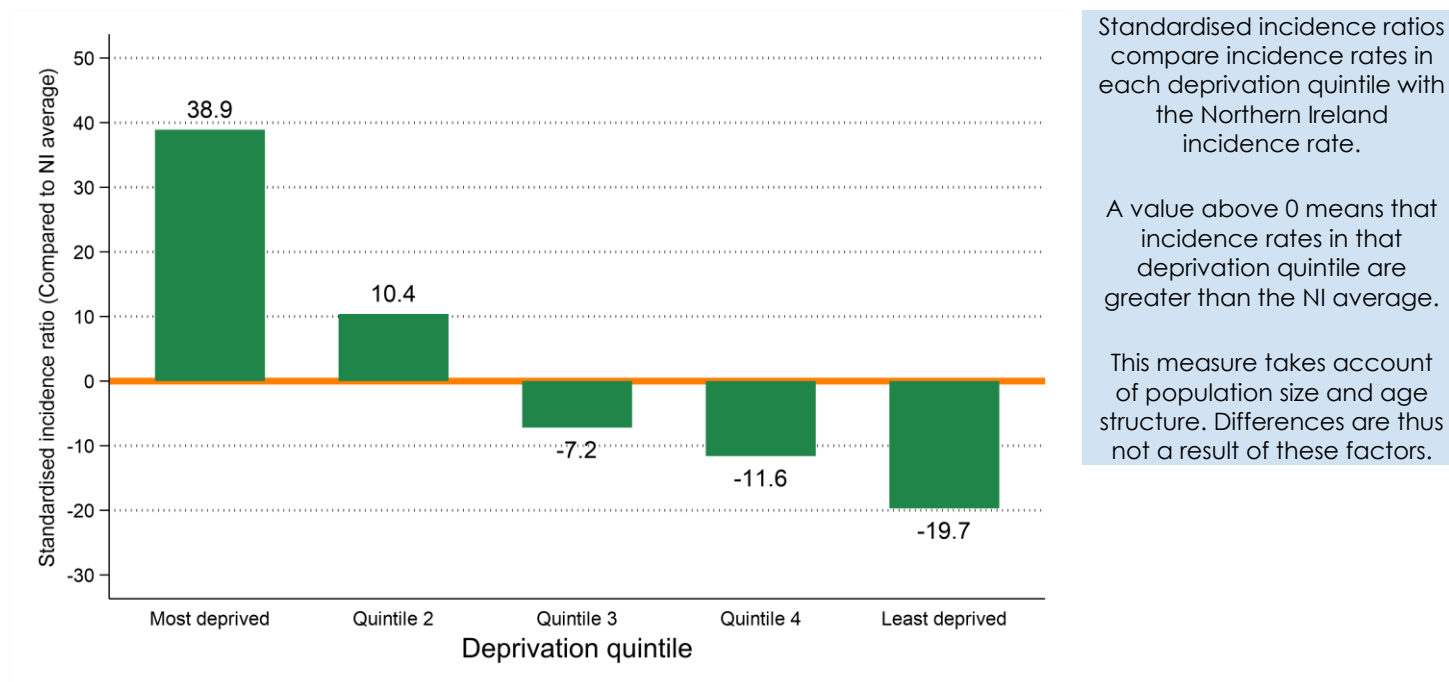
## INCIDENCE BY DEPRIVATION

- The number of cases of unknown primary 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 38.9% higher than the NI average.
  - in the least socio-economically deprived areas were 19.7% lower than the NI average.

*Table 1: Number of cases of unknown primary 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	899	180	416	83	483	97
Most deprived	.	.	.	.	.	.
Quintile 2	199	40	87	17	112	22
Quintile 3	198	40	90	18	108	22
Quintile 4	176	35	91	18	85	17
Least deprived	168	34	81	16	87	17
Unknown	158	32	67	13	91	18
Unknown	0	0	0	0	0	0

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



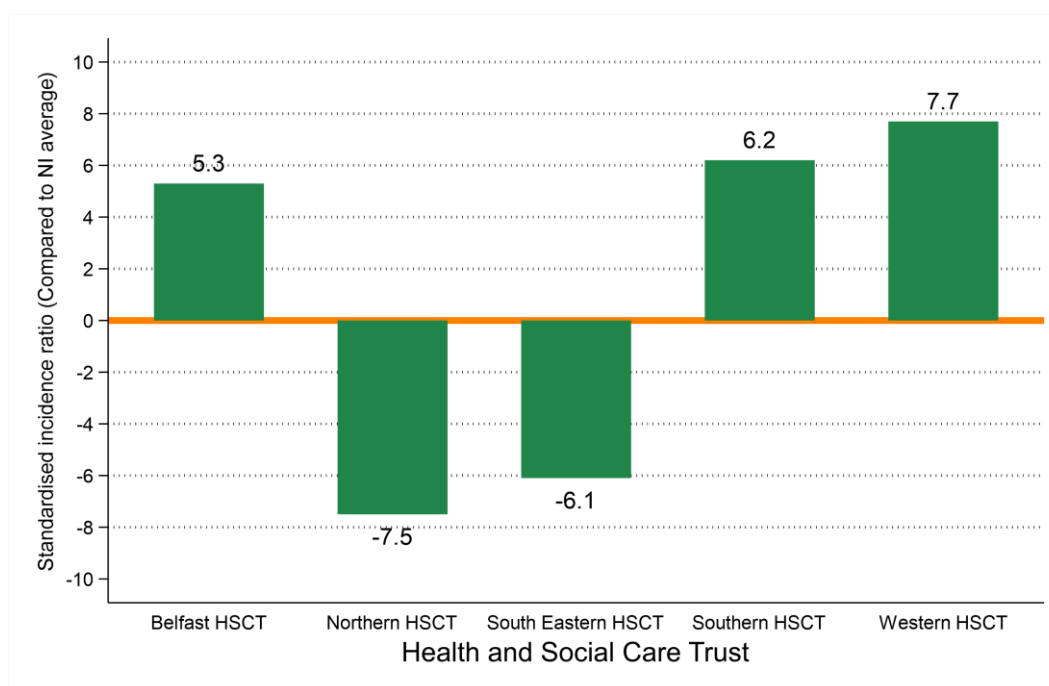
## INCIDENCE BY HEALTH AND SOCIAL CARE TRUST

- The number of cases of unknown primary 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 unknown primary 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	899	180	416	83	483	97
Belfast HSCT	177	35	80	16	97	19
Northern HSCT	222	44	106	21	116	23
South Eastern HSCT	179	36	78	16	101	20
Southern HSCT	175	35	81	16	94	19
Western HSCT	146	29	71	14	75	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 2017-2021*



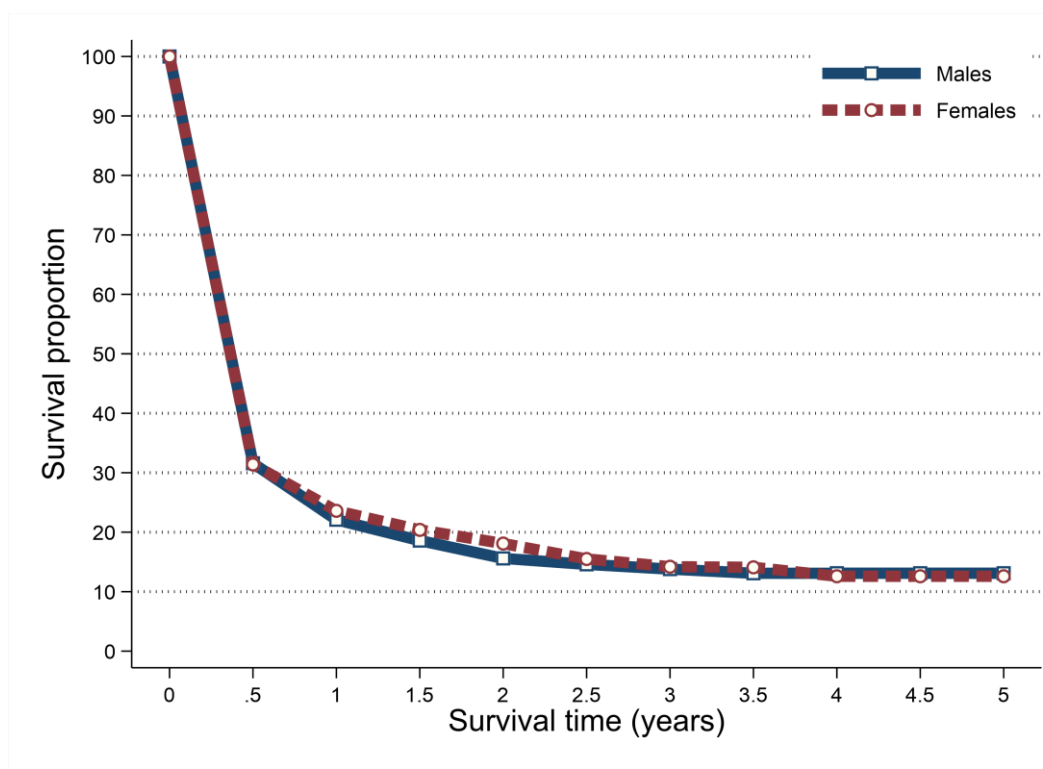
## SURVIVAL

- 15.9% of patients were alive one year and 7.8% were alive five years from an unknown primary cancer diagnosis in 2012-2016. (observed survival)
- Age-standardised net survival (ASNS), which removes the effect of deaths from causes unrelated to cancer, was 23.0% one year and 13.0% five years from an unknown primary cancer diagnosis in 2012-2016.
- Five-year survival (ASNS) for unknown primary cancer patients diagnosed in 2012-2016 was 13.1% among men and 12.6% among women.

*Table 3: Survival from unknown primary 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	23.1%	31.4%	22.6%	31.6%	23.5%	31.4%
One year	15.9%	23.0%	15.1%	22.1%	16.6%	23.6%
Two years	11.2%	17.0%	10.6%	15.6%	11.8%	18.1%
Five years	7.8%	13.0%	8.3%	13.1%	7.3%	12.6%

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



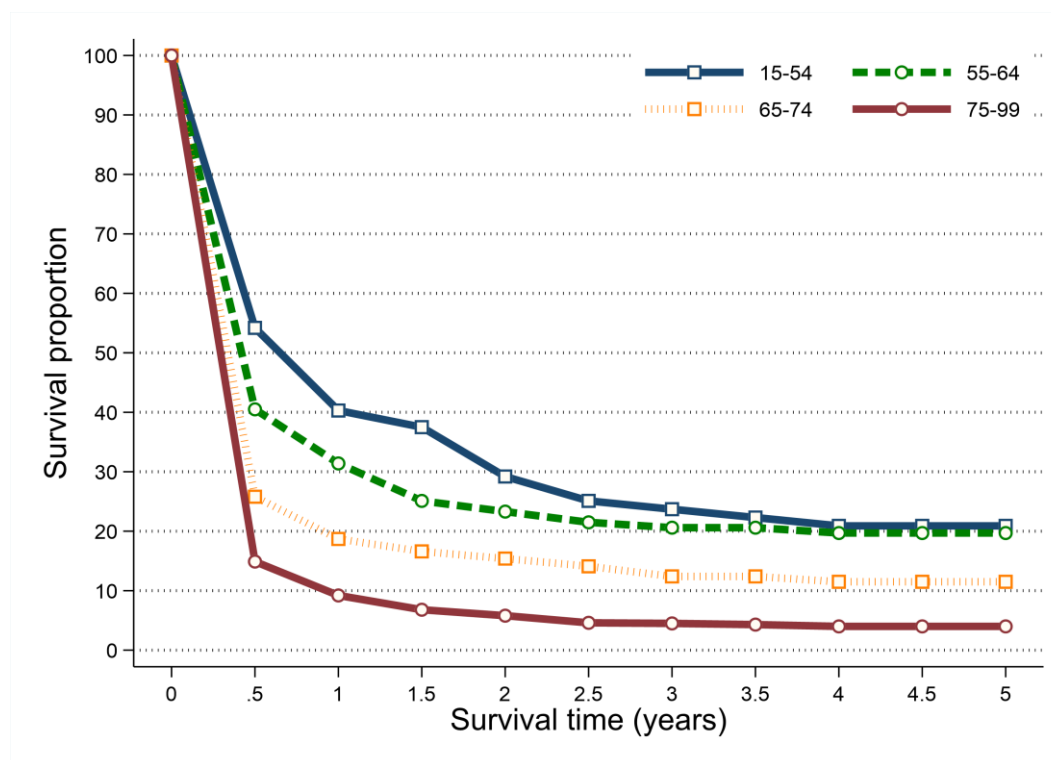
## SURVIVAL BY AGE

- Survival from unknown primary 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 20.9% among patients aged 15 to 54 at diagnosis to 4.0% among those aged 75 to 99.

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

Age group	All persons	
	One-year	Five-years
15 to 54	40.3%	20.9%
55 to 64	31.4%	19.7%
65 to 74	18.7%	11.5%
75 to 99	9.2%	4.0%

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

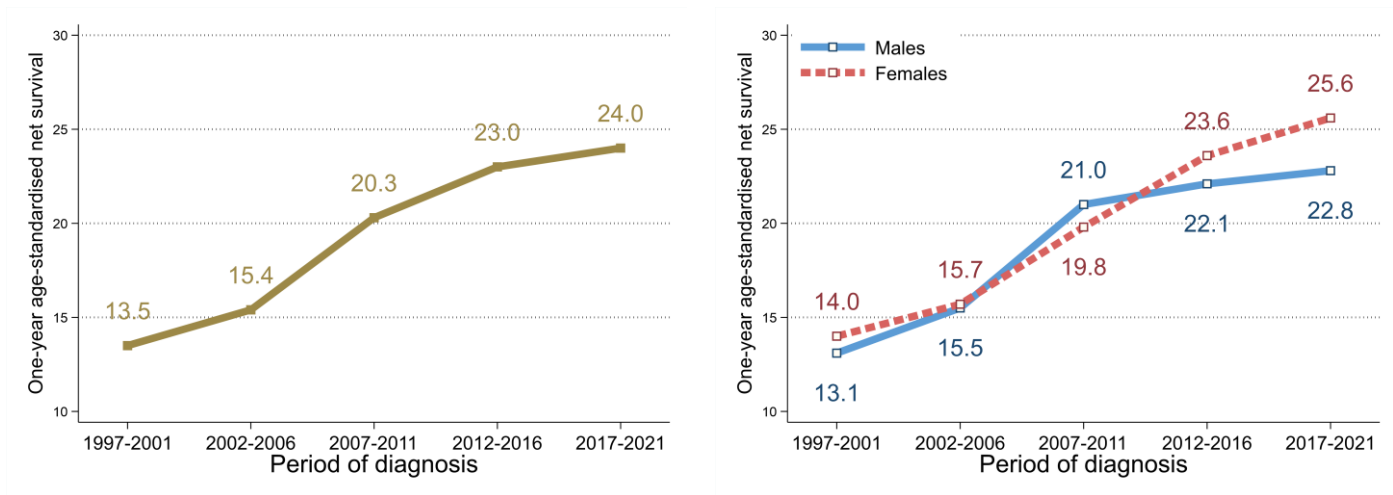


# SURVIVAL TRENDS

## ONE-YEAR NET SURVIVAL

- Between 2012-2016 and 2017-2021 there was no significant change in one-year survival (ASNS) from unknown primary cancer.
- Compared to 1997-2001 one-year survival (ASNS) from unknown primary cancer in 2017-2021 increased significantly from 13.5% to 24.0%. This increase was significant for males (13.1% to 22.8%) and females (14.0% to 25.6%).

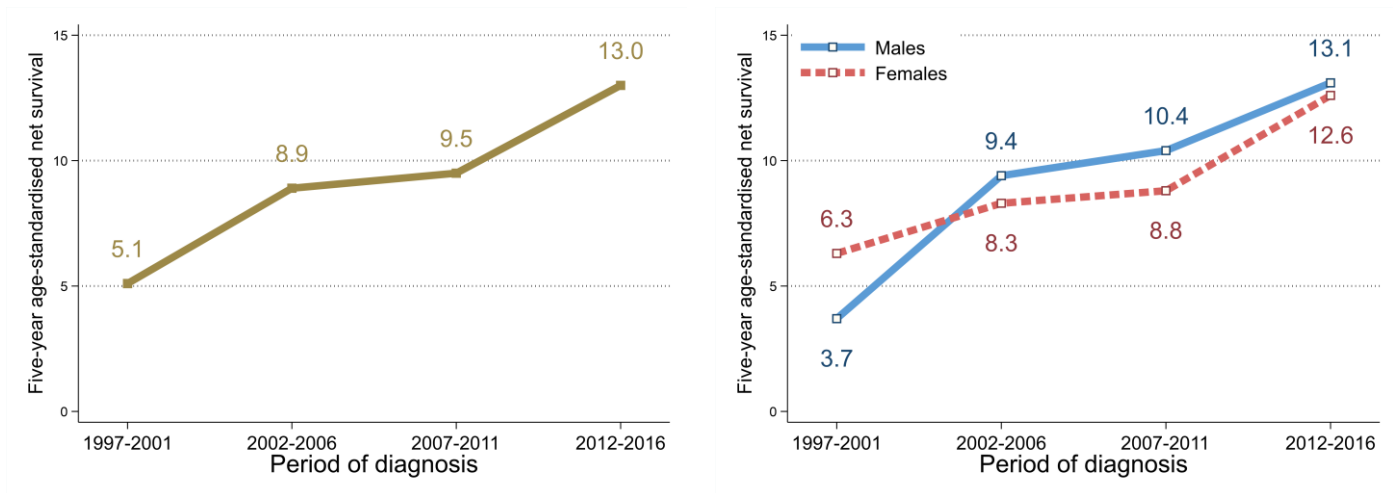
Figure 11: Trends in one-year age-standardised net survival from unknown primary cancer in 1997-2021



## FIVE-YEAR NET SURVIVAL

- Between 2007-2011 and 2012-2016 there was no significant change in five-year survival (ASNS) from unknown primary cancer.
- Compared to 1997-2001 five-year survival (ASNS) from unknown primary cancer in 2012-2016 increased significantly from 5.1% to 13.0%. This increase was significant for males (3.7% to 13.1%) and females (6.3% to 12.6%).

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



## PREVALENCE

- At the end of 2021, there were 264 people (Males: 134; Females: 130) living with unknown primary cancer who had been diagnosed with the disease during 1997-2021.
- Of these 14.8% had been diagnosed in the previous year (one-year prevalence) and 64.0% in the previous 10 years (ten-year prevalence).
- 34.8% of unknown primary cancer survivors were aged 75 and over at the end of 2021.

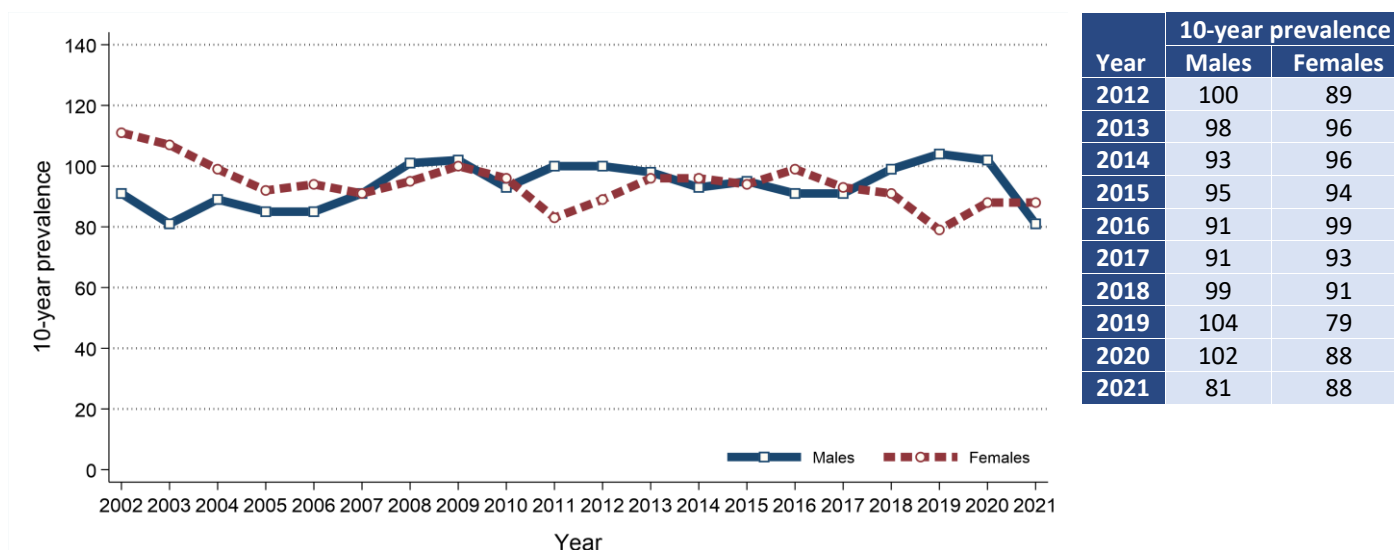
Table 5: 25-year prevalence of unknown primary cancer by age at end of 2021

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	264	39	65	65	95
	0 to 74	172	24	49	40	59
	75 and over	92	15	16	25	36
Male	All ages	134	16	33	32	53
	0 to 74	93	10	27	21	35
	75 and over	41	6	6	11	18
Female	All ages	130	23	32	33	42
	0 to 74	79	14	22	19	24
	75 and over	51	9	10	14	18

## PREVALENCE TRENDS

- 10-year prevalence of unknown primary cancer among males decreased between 2016 and 2021 by 11.0% from 91 survivors to 81 survivors.
- 10-year prevalence of unknown primary cancer among females decreased between 2016 and 2021 by 11.1% from 99 survivors to 88 survivors.

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



## MORTALITY

- There were 1,157 deaths from unknown primary cancer during 2017-2021 in Northern Ireland. On average this was 231 deaths per year.
- During this period 51.6% of unknown primary cancer deaths were among women (Male deaths: 560, Female deaths: 597). On average there were 112 male and 119 female deaths from unknown primary cancer per year.
- Unknown primary cancer deaths made up 4.7% of all male cancer deaths and 5.6% of all female cancer deaths.
- The median age of patients who died from unknown primary cancer during 2017-2021 was 77 years (Males: 75, Females: 78).
- The risk of dying from unknown primary cancer varied by age, with 53.4% of men and 64.0% of women who died from unknown primary cancer aged 75 and over at death.
- In contrast, 6.8% 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 2017-2021 by age at death

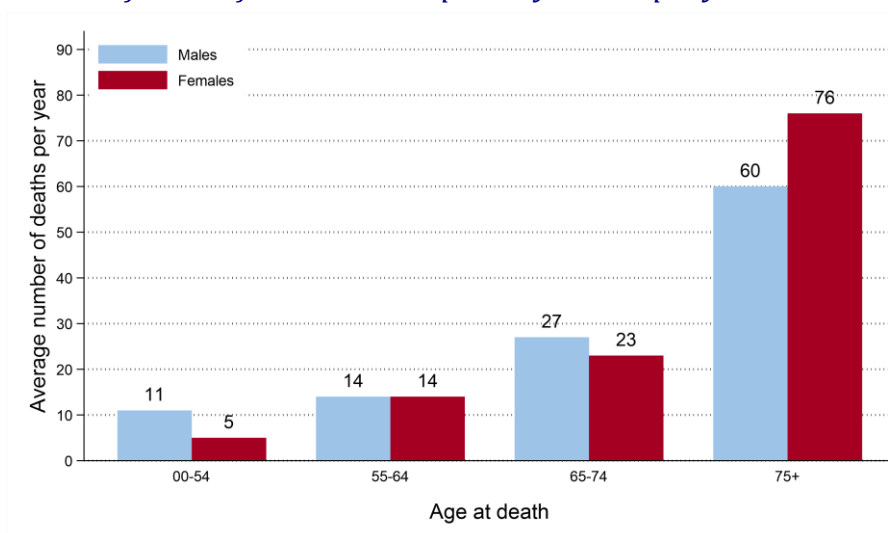
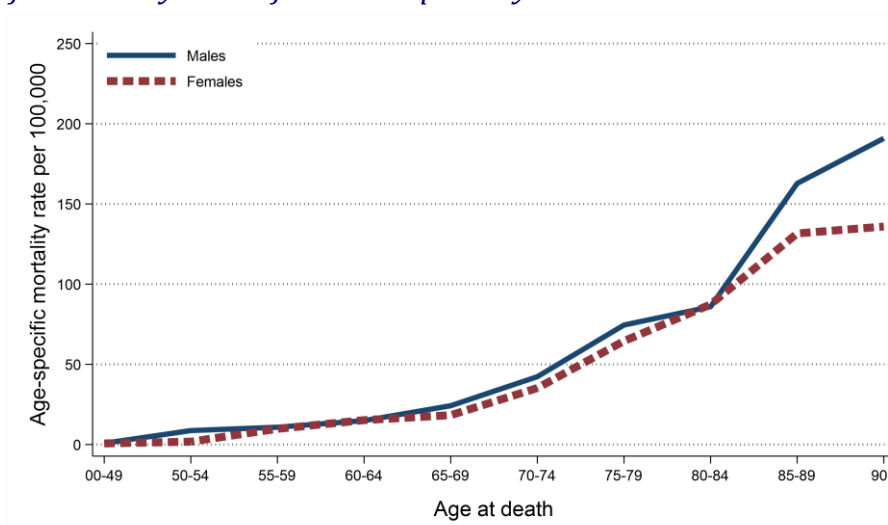


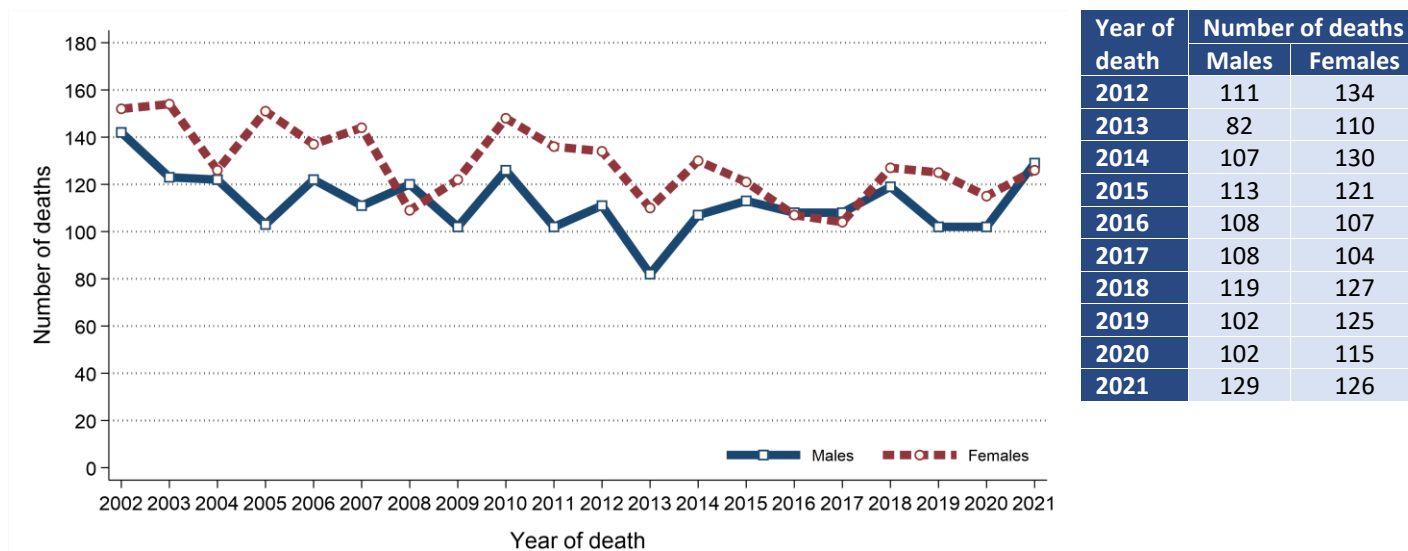
Figure 15: Age-specific mortality rates of unknown primary cancer in 2017-2021



## MORTALITY TRENDS

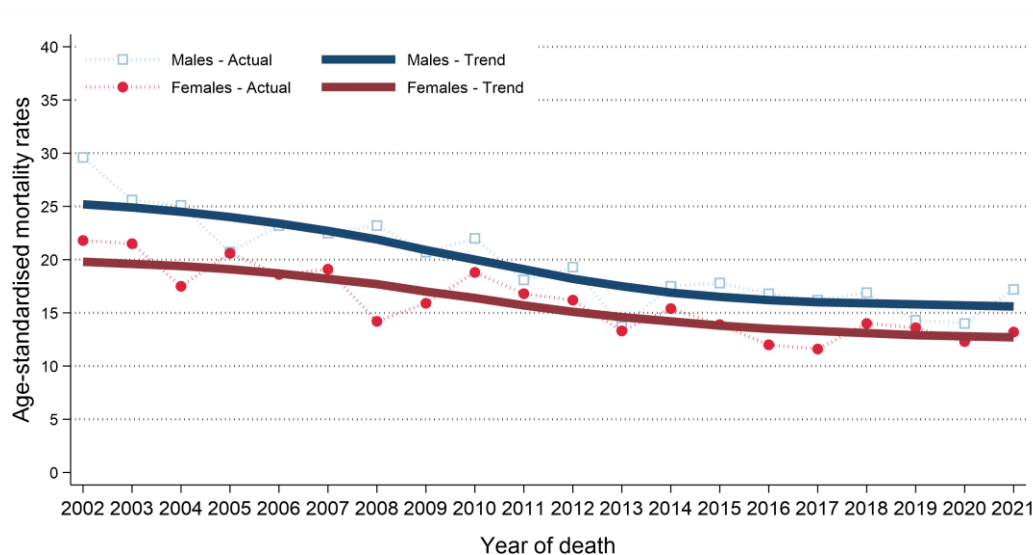
- The number of deaths from unknown primary cancer among males increased between 2012-2016 and 2017-2021 by 7.5% from 521 deaths (104 deaths per year) to 560 deaths (112 deaths per year).
- The number of deaths from unknown primary cancer among females decreased between 2012-2016 and 2017-2021 by 0.8% from 602 deaths (120 deaths per year) to 597 deaths (119 deaths per year).

Figure 16: Trends in the number of deaths from unknown primary cancer from 2002 to 2021



- Male age-standardised unknown primary cancer mortality rates decreased between 2012-2016 and 2017-2021 by 7.6% from 17.0 to 15.7 deaths per 100,000 males. This change was not statistically significant.
- Female age-standardised unknown primary cancer mortality rates decreased between 2012-2016 and 2017-2021 by 7.8% from 14.1 to 13.0 deaths per 100,000 females. This change was not statistically significant.

Figure 17: Trends in mortality rates of unknown primary cancer from 2002 to 2021



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#/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](http://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](http://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](http://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 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.