Cancer incidence, survival and prevalence statistics

Methodology report





ABOUT THIS REPORT

Contents

This report includes information on the methodology used by the Northern Ireland Cancer Registry (NICR) in the production of statistics on cancer incidence, survival and prevalence.

Official statistics

Legislation designating NICR as an official producer of statistics came into place on 1st April 2012 [1], with the incidence, prevalence and survival statistics released by the registry designated as Official Statistics. This designation signifies that the production of these statistics comply with the Code of Practice for Official Statistics as set out by the UK Statistics Authority Code of Practice [2].

The framework for the Code of Practice for Statistics is based on trustworthiness (i.e. having confidence in the organisation that produces the statistics), quality (i.e. using data and methods that produce reliable statistics) and value (i.e. the statistics support user's need for information). As a result, official statistics are produced free from political interference and comply fully with the principles and supporting protocols in the code, including the protocol on release practices.

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 usually provided by NICR alongside the release of cancer incidence data. This report thus includes information on the methodology used in the production of mortality statistics that are produced and released by NICR. Mortality data is provided courtesy of the General Register Office (NI) via the Department of Health.

Reuse of information

The information in this report 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. Cancer incidence, survival and prevalence statistics: Methodology report. Available at: www.qub.ac.uk/research-centres/nicr

Further information

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

Phone: +44 (0)28 9097 6028 **e-mail:** nicr@qub.ac.uk

The Official Statistics on cancer incidence, survival and prevalence are available at: www.qub.ac.uk/research-centres/nicr/Cancerinformation/official-statistics

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. Further information on cancer registration from a patient perspective is available in our patient information leaflet which can be found at: www.qub.ac.uk/research-centres/nicr/AboutUs/Registry

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





CANCER REGISTRATION

The Northern Ireland Cancer Registry (NICR) is part of Queen's University, Belfast and is funded by the Public Health Agency to collate information on all new diagnoses of cancer in Northern Ireland (NI). It was first established in 1994 and uses an automated computer system with multiple information sources from across the National Health Service (NHS) in NI to provide detailed information on cancer incidence in NI from 1993 onwards.

REGISTRY OPERATIONS

The NICR acquires notifications of possible cancer and pre-malignant conditions within the NI population from three main sources:

- Pathology reports from the four pathology laboratories in NI (Belfast, Altnagelvin, Antrim and Craigavon);
- Hospital admissions and discharges recorded in the Patient Administration System (PAS) and supplied by the five Health and Social Care Trusts (HSCT); and
- Death registrations from the General Registrar Office (GRO), which are received via the Department of Health (DoH).

These data sources are loaded and combined electronically, with automatic routines applied which cross check key details and resolve multiple notifications. However, considerable manual work is also required to ensure that key data items (e.g. date of diagnosis, cancer type) are coded to international cancer registration standards and that the final data is as complete and as accurate as possible.

As part of this process, a major focus of the registry's operation is on the verification of any registration which comes from a single hospital admission, a single pathology report or a single death certificate. For these registrations trained Cancer Intelligence Officers (CIOs) examine general practitioners' (GPs) notes for patients who have died from cancer, hospital records for cases identified without histopathology or cytology confirmation and pathology reports where there is conflicting information or other possible errors.

To further check the accuracy of any coding, ensure that no duplicate registrations are present and to separate primary cancers from metastatic disease and recurrences, the CIOs review each cancer registration using a range of health care systems. These include:

- Cancer Patient Pathway System (CaPPS);
- Regional Information System for Oncology & Haematology (RISOH);
- Radiotherapy Information System (ARIA); and
- Theatre Management System (TMS)

As part of this review these data sources are also used to add supplementary information to each cancer registration, including stage of disease and cancer specific information (e.g. ER/HER status for breast cancer, Gleason score for prostate cancer) as the majority of this information is not available as part of electronic downloads and may require reading of pathology reports or hospital notes by the CIOs.

Date of Diagnosis

One of the primary data items recorded as part of the cancer registration process is the date of cancer diagnosis. NICR base the collection of this data item on recommendations from the European Network of Cancer Registries [3], which states that where possible the date of diagnosis should be the date of first histological or cytological confirmation of the malignancy. Given that this process can involve various stages, the date is chosen according to the following priority:

1. Date when the biopsy was taken;

- 2. Date of receipt of the sample by the pathologist;
- 3. Date of the pathology report.

In the scenario where the cancer is not diagnosed pathologically then the date of admission to hospital as a result of this malignancy is used as the date of diagnosis. If no information is available other than the fact that the patient has died as a result of cancer then date of death is used as the date of diagnosis, and the registration is flagged as being death certificate only (DCO).

CANCER CLASSIFICATION AND CODING

Cancer is coded to the tenth revision of the International Classification of Diseases (ICD10) [4]. The ICD10 codes used to classify cancer are C00-C97. Non-melanoma skin cancer (ICD10 code C44) is frequently excluded from the overall cancer count as it is easily treated and rarely fatal.

Cancer Type

The ICD10 codes used to classify each type of cancer are listed in table 1.

Table 1: Classification of cancer type based upon ICD10 code

Cancer type	ICD10 code	Cancer type	ICD10 code
Bladder	C67	Lymphoma	C81-C86
Brain (inc. CNS)	C70-C72, C75.1-C75.3	- Hodgkin's lymphoma	- C81
Cervical	C53	- Non-Hodgkin's lymphoma	- C82-C86
Colorectal	C18-C20	Malignant melanoma	C43
- Colon	- C18	Multiple myeloma	C90
- Rectum	- C19-C20	Non-melanoma skin	C44
Breast	C50	Oesophageal	C15
Gallbladder (inc. biliary)	C23-C24	Ovarian (inc. fallopian tube)	C56-C57.4
Head and Neck	C00-C14, C30-C32	Pancreatic	C25
- Oral	- C00-C14	Prostate	C61
- Laryngeal	- C32	Stomach	C16
Kidney	C64	Testicular	C62
Leukaemia	C91-C95	Thyroid	C73
Liver	C22	Unknown primary	C77-C80
Lung (inc. trachea)	C33-C34	Uterine	C54-C55

CNS: Central Nervous System

For head and neck cancer a further breakdown into specific cancer types is also provided. This breakdown is also derived using the ICD10 classification

Table 2: Classification of head and neck cancer type based upon ICD10 code

Cancer type	ICD10 code	Cancer type	ICD10 code
Lip cancer	C00	Nasopharyngeal cancer	C11
Tongue cancer	C01-C02	Hypopharyngeal cancer	C12-C13
Mouth cancer	C03-C06	Other mouth/pharyngeal cancer	C14
Cancer of the salivary glands	C07-C08	Laryngeal cancer	C32
Oropharyngeal cancer	C09-C10	Cancer of the nasal cavity or sinuses	C30-C31

Cancer Morphology

In addition to the ICD10 classification, the more detailed International Classification of Diseases for Oncology, version 3 (ICD-O3) [5] is used in the coding of tumour site (topography), histology (morphology) and behaviour. This information is usually obtained from the pathology report and allows cancer registries to distinguish between the likes of adenocarcinoma and squamous cell carcinoma of the lung, which would both use the same code in the ICD10 classification.

Neuroendocrine cancer

Neuroendocrine tumours and neoplasms develop in endocrine and/or nerve cells and can thus occur in most of the body's organs. Neuroendocrine cancer has malignant characteristics, meaning that it can spread beyond the original location that it developed. To identify neuroendocrine cancer, we use the ICD-O3 and ICD10 combination of codes specified by Genus et al [6] in the first population-based study of these cancers conducted in the UK. The codes used are tabulated below.

Table 3: Classification of neuroendocrine cancers based upon ICD10 and ICD-03 codes

ICD10 code	ICD-0-3 morphology code
C34, C78	8150, 8151, 8152, 8153, 8154, 8155, 8156, 8157, 8158, 8240,
	8241, 8242, 8243, 8244, 8245, 8246, 8247, 8249, 9091
C00-C32, C37-C77, C79-C80	8013, 8041, 8042, 8043, 8044, 8045, 8150, 8151, 8152, 8153,
	8154, 8155, 8156, 8157, 8158, 8240, 8241, 8242, 8243, 8244,
	8245, 8246, 8247, 8249, 9091

Sarcomas

Sarcomas are cancers that develop either in the connective and supporting tissues of the body (such as muscles and nerves) or in the bone. Given that sarcomas can occur in any part of the body, the ICD-O3 classification is used to identify these types of cancer. The codes used are based upon those identified by the National Disease Registration Service as part of their 'Get Data Out' programme [7]. The codes used are tabulated below.

Table 4: Classification of sarcoma based upon ICD-03 code

Sarcoma type	Behaviour code	Topography code	Morphology code
Bone	3	C00-C80	9195, 9221, 9230, 9364
	3	C00-C80, ex. C51-C58	9260, 9365, 9370, 9371, 9372
	3	C40	8902, 8910
	3	C40-C41	8003, 8800, 8801, 8802, 8803, 8804, 8805, 8806, 8810, 8811,
			8812, 8813, 8815, 8825, 8830, 8832, 8833, 8840, 8850, 8851,
			8852, 8853, 8854, 8855, 8857, 8858, 8860, 8890, 8891, 8894,
			8896, 8897, 8901, 8921, 8982, 8990, 8991, 9044, 9120, 9130,
			9133, 9150, 9170, 9180, 9181, 9182, 9183, 9184, 9185, 9186,
			9187, 9192, 9193, 9194, 9220, 9231, 9240, 9242, 9243, 9250,
			9251, 9252, 9540, 9560, 9561, 9571, 9580
	6	C00-C80	9180, 9181, 9185, 9194, 9220, 9221, 9230, 9242, 9243
	6	C00-C80, ex. C40-C41	9364
	6	C00-C80, ex. C51-C58	8812, 9260, 9365, 9370, 9371, 9372
	6	C40-C41	9182, 9184, 9186, 9187, 9192, 9193, 9231, 9240, 9250, 9364
	9	C40-C41	8800, 8890, 9120
Soft tissue	3	C00-C80	8821, 8822, 8933, 9040, 9041, 9042, 9043
	3	C00-C80, ex. C40-C41	8711, 8800, 8801, 8802, 8803, 8804, 8805, 8806, 8810, 8811,
			8813, 8814, 8815, 8824, 8825, 8830, 8832, 8840, 8841, 8850,
			8851, 8852, 8853, 8854, 8855, 8857, 8858, 8860, 8890, 8891,
			8894, 8895, 8896, 8897, 8900, 8901, 8902, 8910, 8912, 8920,
			8921, 8930, 8931, 8935, 8940, 8963, 8964, 8982, 8990, 8991,
			9044, 9120, 9130, 9133, 9150, 9170, 9180, 9181, 9185, 9194,
			9220, 9231, 9240, 9242, 9243, 9251, 9252, 9540, 9560, 9561,
			9571, 9580, 9581
	3	C00-C80, ex. C51-C58	8812
	3	C00-C80, ex. C52-C58	8833
	3	C49	8003, 8004
	3	C50, C61	9020
	3	C77	9250
	6	C00-C80	8711, 8800, 8801, 8802, 8803, 8804, 8805, 8806, 8810, 8811,
			8813, 8814, 8815, 8821, 8822, 8825, 8830, 8832, 8840, 8841,

			8850, 8851, 8852, 8853, 8854, 8855, 8857, 8858, 8860, 8890, 8891, 8894, 8896, 8897, 8900, 8901, 8902, 8910, 8912, 8921, 8930, 8931, 8933, 8935, 8940, 8963, 8964, 8982, 8990, 8991, 9040, 9041, 9042, 9043, 9044, 9120, 9130, 9133, 9150, 9170, 9251, 9252, 9540, 9560, 9561, 9571, 9580, 9581
	6	C00-C80,ex. C40	8895
	6	C00-C80,ex. C40-C41	9231, 9240
	6	C00-C80,ex. C51-C58	8920
	6	C00-C80,ex. C52-C58	8833
	6	C40-C41	9020, 9183
	6	C50, C61	9020
	9	C00-C80,ex. C40-C41	8800, 8890, 8920, 9120
Gastro-intestinal stromal	3,6	C00-C80	8936

Other classifications of sarcoma also exist which may result in slightly different number of cases. Variations are usually a result of how cancers with a mixed sarcoma/epithelial nature are treated (e.g. Mullerian mixed tumour, ICD-O3 morphology 8950).

International Classification of Childhood Cancer

The International Classification of Childhood Cancer (Third edition) [8] was modified and expanded in the UK childhood cancer report [9] to accommodate morphology codes that have been introduced in the first and second revisions of ICD-O3; and to cover the most common sites for tumours in the teenage and young adult age range thereby allowing it's use for a broader age group. The codes used are detailed in table 5.

Table 5: International classification of childhood cancer based upon ICD-O3 code

Cancer type	Topography code	Morphology code
01. Leukaemia, myeloproliferative di	sease, and myelodyspl	astic disease
01a. Lymphoid leukaemia	C00-C80	9820, 9823, 9826, 9827, 9831-9836, 9940, 9948
	C42.0-C42.4, C80.9	9811-9819, 9837
01b. Acute myeloid leukaemia	C00-C80	9840, 9861, 9865-9874, 9877-9879, 9891, 9895-9898, 9910-9912,
		9920, 9931
01c. Chronic myeloproliferative	C00-C80	9863, 9875, 9876, 9960-9964
disease		
01d. Myelodysplastic syndrome and	C00-C80	9945, 9946, 9975, 9980-9989, 9991-9993
other myeloproliferative disease		
01e. Unspecified and other	C00-C80	9800, 9801, 9805-9809, 9860, 9930, 9965-9968
specified leukaemia		
02. Lymphoma and reticuloendothel	ial neoplasm	
02a. Hodgkin's lymphoma	C00-C80	9650-9656, 9659, 9661-9665, 9667
02b. Non-Hodgkin's lymphoma	C00-C80	9698-9702, 9705, 9591, 9597, 9670, 9671, 9673, 9675, 9678-9680,
(excluding Burkitt lymphoma)		9684, 9688-9691, 9695, 9708, 9709, 9712, 9714-9719, 9724-9729,
		9731-9735, 9737, 9738, 9740-9742, 9750, 9751, 9754-9759,
		9760-9762, 9764-9769, 9970, 9971
	C00-C41, C42.2,	9811-9819, 9837
	C44-C77	
02c. Burkitt lymphoma	C00-C80	9687
02d. Miscellaneous lymphoreticular	C00-C80	9740-9742, 9749, 9750, 9755-9759
neoplasm		
02e. Unspecified lymphoma	C00-C80	9590, 9596
03. Central nervous system and misc	ellaneous intracranial a	and intraspinal neoplasm
03a. Ependymoma and choroid	C00-C80	9383, 9390-9394, 9396
plexus tumour		

03b. Astrocytoma	C00-C80	9384, 9400-9411, 9420-9425, 9440-9442, 9445
	C72.3	9380
03c. Intracranial and intraspinal	C00-C80	9470-9478, 9480, 9508
embryonal tumour	C70-C72	9501-9504
03d. Other glioma	C00-C80	9381, 9382, 9385, 9430-9432, 9444, 9450, 9451, 9460
	C70, C71, C72.0-	9380
	C72.2, C72.4-C72.9,	
	C75.1, C75.3	
03e. Other specified intracranial	C00-C80	8270-8281, 8300, 9350-9352, 9360-9362, 9395, 9412, 9413, 9492,
and intraspinal neoplasm		9493, 9505-9507, 9509, 9530-9539, 9582
03f. Unspecified intracranial	C70-C72, C75.1-C75.3	8000-8005
and intraspinal neoplasm		
O4 Novemblestone and other posi-		
04. Neuroblastoma and other peri 04a. Neuroblastoma and	C00-C80	
ganglioneuroblastoma	C00-C80	9490, 9500
04b. Other peripheral nervous	C00-C80	8680-8683, 8690-8693, 8700, 9520-9523
cell tumour	C00-C69, C73-C76,	9501-9504
cen turnour	C80	9501-9504
	000	1
05. Retinoblastoma		
05. Retinoblastoma	C00-C80	9510-9514
os. Netinobiastoma	C00-C00	2210 2214
06. Renal tumour		
06a. Nephroblastoma and other	C00-C80	8959, 8960, 8964-8967
non-epithelial renal tumour	C64.9	8963, 9364
06b. Renal carcinoma	C00-C80	8311, 8312, 8316-8319, 8361
OOD. Kenai carcinoma		
	C64.9	8010-8041, 8050-8075, 8082, 8120-8122, 8130-8141, 8143, 8155,
		8190-8201, 8210, 8211, 8221-8231, 8240, 8241, 8244-8246,
		8260-8263, 8290, 8310, 8320, 8323, 8401, 8430, 8440, 8480-8490,
OC - Harristin dan dina art	664.0	8504, 8510, 8550, 8560-8576
06c. Unspecified malignant renal tumour	C64.9	8000-8005
Teriai turiloui		
07. Hepatic tumour		
07a. Hepatoblastoma	C00-C80	8970
07b. Hepatic carcinoma	C00-C80	8160-8180
07b. Hepatic carcinoma	C22.0, C22.1	8010-8041, 8050-8075, 8082, 8120-8122, 8140, 8141, 8143, 8155,
	C22.0, C22.1	8190-8201, 8210, 8211, 8230, 8231, 8240, 8241, 8244-8246,
		8260-8264, 8310, 8320, 8323, 8401, 8430, 8440, 8480-8490,
		8504, 8510, 8550, 8560-8576
07c. Unspecified malignant	C22.0, C22.1	8000-8005
hepatic tumour	C22.0, C22.1	0000 0003
nepatic tamour		
08. Malignant bone tumour		
08a. Osteosarcoma	C40, C41, C76, C80	9180-9187, 9191-9195, 9200
08b. Chondrosarcoma	C00-C80	9221, 9230, 9241-9243
	C40, C41, C76, C80	9210, 9220, 9240
08c. Ewing tumour and related	C40, C41	9363-9365
sarcoma of bone	C40, C41, C76, C80	9260
08d. Other specified malignant	C00-C80	8812, 9250, 9261, 9262, 9270-9275, 9280-9282, 9290, 9300-9302,
bone tumour		9310-9312, 9320-9322, 9330, 9340-9342, 9370-9372
	C40, C41	8810, 8811, 8814, 8823, 8830
08e. Unspecified malignant	C40, C41	8000-8005, 8800, 8801, 8803-8805
bone tumour	010, 041	0000, 0000, 0000, 0000
	ı	
09. Soft tissue and other extraosse	ous sarcoma	
09a. Rhabdomyosarcoma	C00-C80	8900-8905, 8910, 8912, 8920, 8991
09b. Fibrosarcoma, peripheral	C00-C80	8820, 8822, 8824-8827, 9150, 9160, 9491, 9540-9571, 9580
nerve sheath tumour, and other	C00-C39, C44-C76,	8810, 8811, 8813-8815, 8821, 8823, 8834, 8835
nerve sheath tumour, and other	1 000 033, 044-070,	0010, 0011, 0013 0013, 0021, 0023, 0034, 0033

fibrous neoplasm	C80	
09c. Kaposi sarcoma	C00-C80	9140
09d. Other specified soft	C00-C80	8587, 8710-8714, 8806, 8831-8833, 8836, 8840-8842, 8850-8858,
tissue sarcoma		8860-8862, 8870, 8880, 8881, 8890-8898, 8921, 8990, 9040-9044,
		9120-9125, 9130-9133, 9135-9137, 9141, 9142, 9161, 9170-9175,
		9231, 9251, 9252, 9373, 9581
	C00-C39, C44-C76, C80	8830
	C00-C63, C65-C69,	8963
	C73-C76, C80	8903
	·	0400 0340 0330 0340
	C49	9180, 9210, 9220, 9240
	C00-C39, C47-C75	9260
	C00-C39, C47-C63,	9364
	C65-C69, C73-C76, C80	
	C00-C39, C47-C63,	9365
	C65-C76, C80	
09e. Unspecified soft tissue sarcoma	C00-C39, C44-C76, C80	8800-8805
10. Germ cell tumour, trophoblastic	· · · · · · · · · · · · · · · · · · ·	
10a. Intracranial and intraspinal	C70-C72, C75.1-C75.3	9060-9065, 9070-9072, 9080-9085, 9100, 9101
germ cell tumour	COO CEE CE7 CC4	0060 0065 0070 0072 0090 0096 0400 0405
10b. Malignant extracranial and	C00-C55, C57-C61,	9060-9065, 9070-9072, 9080-9086, 9100-9105
extragonadal germ cell tumour	C63-C69, C73-C75.0,	
	C75.4-C76, C80	
10c. Malignant gonadal germ cell	C56, C62	9060-9065, 9070-9073, 9080-9085, 9090-9093, 9100, 9101
tumour		
10d. Gonadal carcinoma	C00-C80	8441-8444, 8450, 8451, 8460-8473
	C56, C62	8010-8041, 8044, 8050-8075, 8082, 8120-8123, 8130-8141, 8143,
		8190-8201, 8210, 8211, 8221-8241, 8244-8246, 8249, 8260-8263,
		8290, 8310, 8313, 8320, 8323, 8380-8384, 8430, 8440, 8480-8490,
		8504, 8510, 8550, 8560-8573, 9000, 9014, 9015
10e. Other and unspecified	C00-C80	8590-8671
malignant gonadal tumour	C56, C62	8000-8005
11. Other malignant epithelial neopla	asm malignant melanom	a
11a. Adrenocortical carcinoma	C00-C80	8370-8375
	C74	8010-8158, 8190-8231, 8240-8369, 8376-8440, 8452-8454,
		8480-8589, 8941, 8983, 9000, 9010-9016, 9020, 9030
11b. Thyroid carcinoma	C73	8010-8158, 8190-8231, 8240-8369, 8376-8589, 8941, 8983, 9000,
115. Thyrota caremonia	675	9010-9016, 9020, 9030
11c. Nasopharyngeal carcinoma	C11	8010-8158, 8190-8231, 8240-8369, 8376-8440, 8452-8454,
Tic. Nasopharyngear carcinoma	CII	8480-8589, 8941, 8983, 9000, 9010-9016, 9020, 9030
11d. Malignant melanoma	C00-C80	8720-8780, 8790
11e. Skin carcinoma	C44	8010-8158, 8190-8231, 8240-8369, 8376-8440, 8452-8454,
TIE. Skill Carcillottia	C44	
445.0.1	640, 640, 620	8480-8589, 8941, 8983, 9000, 9010-9016, 9020, 9030
11f. Colon carcinoma	C18, C19, C20	8010-8158, 8190-8231, 8240-8369, 8376-8440, 8452-8454,
(excluding appendix)	ex. C18.1	8480-8589, 8941, 8983, 9000, 9010-9016, 9020, 9030
11g. Breast carcinoma	C50	8010-8158, 8190-8231, 8240-8369, 8376-8440, 8452-8454,
		8480-8589, 8941, 8983, 9000, 9010-9016, 9020, 9030
11h. Cervical carcinoma	C53	8010-8158, 8190-8231, 8240-8369, 8376-8440, 8452-8454,
		8480-8589, 8941, 8983, 9000, 9010-9016, 9020, 9030
11i. Bladder carcinoma	C67	8010-8158, 8190-8231, 8240-8369, 8376-8440, 8452-8454,
		8480-8589, 8941, 8983, 9000, 9010-9016, 9020, 9030
11j. Salivary gland carcinoma	C07, C08	8010-8158, 8190-8231, 8240-8369, 8376-8440, 8452-8454,
		8480-8589, 8941, 8983, 9000, 9010-9016, 9020, 9030
11k. Other head and neck carcinoma	C00-C06, C09, C10,	8010-8158, 8190-8231, 8240-8369, 8376-8440, 8452-8454,
2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2	C12-C14, C30-C32,	8480-8589, 8941, 8983, 9000, 9010-9016, 9020, 9030
	C76.0	
11l. Stomach and upper gastro-	C15-C17, C23,	8010-8158, 8190-8231, 8240-8369, 8376-8440, 8452-8454,
intestinal carcinoma	C24, C26	8480-8589, 8941, 8983, 9000, 9010-9016, 9020, 9030
11m. Pancreatic carcinoma	C25	8010-8158, 8190-8231, 8240-8369, 8376-8440, 8452-8454,

		8480-8589, 8941, 8983, 9000, 9010-9016, 9020, 9030
11n. Lung carcinoma	C33, C34	8010-8158, 8190-8231, 8240-8369, 8376-8440, 8452-8454,
		8480-8589, 8941, 8983, 9000, 9010-9016, 9020, 9030
11o. Carcinoma of other	C18.1, C37-C39, C48,	8010-8158, 8190-8231, 8240-8369, 8376-8440, 8452-8454,
specified sites	C51, C52, C54, C55,	8480-8589, 8941, 8983, 9000, 9010-9016, 9020, 9030
	C57, C58, C60, C61,	
	C63, C65, C66, C68,	
	C69, C75.0, C75.4-	
	C75.9	
11p. Carcinoma of unspecified	C70-C72, C76.1-C80	8010-8158, 8190-8231, 8240-8369, 8376-8440, 8452-8454,
sites		8480-8589, 8941, 8983, 9000, 9010-9016, 9020, 9030
12. Other and unspecified malignan	t neoplasms	
12a. Other specified malignant	C00-C80	8930-8936, 8940, 8950, 8951, 8971-8982, 9050-9055, 9110
tumour	C00-C39, C47-C75	9363
12b. Other unspecified malignant	C00-C21, C23-C39,	8000-8005
tumour	C42-C55, C57-C61,	
	C63, C65-C69, C73-	
	C75.0, C75.4-C80	

TUMOUR CHARACTERISTICS

CANCER STAGE

Staging is carried out using a number of laboratory and clinical tests at diagnosis. The staging classification used throughout the official statistics is the TNM stage [10,11] that includes information on the extent of the primary tumour (T), the absence or presence of lymph node metastasis (N) and the absence or presence of distant metastasis (M). The classification combines these three elements to produce an overall TNM stage for the tumour, although the manner in which the overall TNM stage is derived depends upon the cancer site. Staging is carried out on most cancer sites, although for some cancer sites, specifically non-melanoma skin cancer, brain cancer and leukaemia there is no TNM classification.

For analysis purposes the overall TNM stage for each cancer is coded to four groups, ranging from early tumours (Stage I) to advanced tumours that have distant metastasis (Stage IV).

The TNM classification has changed over time. For most cancer types version 7 is used prior to 2018, with version 8 used from 2018 onwards. The sole exception is for head and neck cancer, which uses version 7 prior to 2019, with version 8 used from 2019 onwards.

HISTOLOGICAL TYPE

The International Classification of Diseases for Oncology, version 2 (ICD-O2) [5] is used in the coding of histology. This information is usually obtained from the pathology reports with tumours diagnosed clinically (or by other means) referred to as non-microscopically verified and typically have an unknown histological type. Histological type allows cancer types to be subdivided between the likes of adenocarcinoma and squamous cell carcinoma of the lung.

Table 6: Classification of histological type based upon ICD-02 codes

Cancer/Histological type	ICD-0-2 morphology code
Colorectal cancer	
Adenocarcinoma	8140-8149, 8190-8230, 8250-8384, 8440-8490, 8500-8552, 8571-8576, 8430-8560
Other specified type	Other codes in range 8010-9992
Unspecified	8000-8005
Oesophageal cancer	
Adenocarcinoma	8140-8149, 8190-8231, 8250-8384, 8401, 8440-8490, 8500-8552, 8570-8576
Squamous cell carcinoma	8050, 8086
Other specified type	Other codes in range 8010-9992
Unspecified	8000-8005
Stomach cancer	
Adenocarcinoma	8140-8149, 8190-8230, 8250-8384, 8440-8490, 8500-8552, 8571-8576, 8430-8560
Other specified type	Other codes in range 8010-9992
Unspecified	8000-8005
Lung cancer	
Small cell carcinoma	8002, 8041-8045
Large cell carcinoma	8010, 8012, 8014, 8031, 8035, 8310
Other non-small cell carcinoma	8011, 8013, 8015-8030, 8032, 8033, 8040, 8046-8239, 8250-8300, 8311-8576
Adenocarcinoma	8140, 8211, 8230, 8231, 8250-8260, 8323, 8480-8490, 8550, 8551, 8570-8574, 8576
Squamous cell carcinoma	8050, 8078, 8082-8084
Other specified type	Other codes in range 8010-9992
Unspecified	8000, 8001, 8003, 8004, 8005

Malignant melanoma	
Nodular melanoma	8721
Lentigo maligna melanoma	8742
Superficial spreading melanoma	8743
Acral lentiginous melanoma	8744
Unspecified	8720
Breast cancer	
Infiltrating duct carcinoma	8500
Lobular carcinoma	8520
Infiltrating duct and lobular	8522
Mucinous adenocarcinoma	8480
Tubular adenocarcinoma	8211
Other adenocarcinoma	8140-8149, 8190-8210, 8222-8230, 8250-8384, 8430, 8440-8479
	8481-8490, 8501-8519, 8521, 8523-8552, 8560, 8571-8576
Other carcinoma	Other codes in range 8010-8576
Other specified type	Other codes in range 8580-9992
Unspecified	8000-8005
Prostate cancer	
Adenocarcinoma	8140-8149, 8190-8230, 8250-8384, 8440-8490, 8500-8552, 8571-8576, 8430-8560
Other specified type	Other codes in range 8010-9992
Unspecified	8000-8005

ADDITIONAL INFORMATION

GEOGRAPHIC AREAS

NICR routinely collects address information, including postcode, allowing geographic areas to be assigned to records of cancer incidence. This is accomplished for each patient through an electronic process that uses the collected postcode along with a lookup file, known as the Central Postcode Directory (CPD) [12], which provides the relationship between each valid postcode in Northern Ireland and a range of higher geographic areas. The key areas derived from the patient's postcode in this manner are Health and Social Care Trusts (HSCT), Local Government Districts (LGD), Parliamentary Constituencies and Super Output Areas (SOA - a small geographic area with a target population of around 2,000 people). Addresses with an unknown, incomplete or invalid postcode cannot be assigned higher geographic areas, however, only a small proportion of records for cancers diagnosed fall into this category.

SOCIO-ECONOMIC DEPRIVATION

The 2017 Northern Ireland multiple deprivation measure (NIMDM) [13] assigns a deprivation score to each Super Output Area (SOA) in Northern Ireland based upon the economic characteristics of all persons usually resident in that area. For the purposes of NICR official statistics publications the SOAs were ranked according to this score and divided into quintiles, with quintile 1 containing the fifth of the population resident in the most deprived SOAs and quintile 5 containing the fifth of the population resident in the least deprived SOAs. Patients were then assigned a deprivation quintile based upon their SOA of residence which was derived for each patient based upon their postcode of residence.

MORTALITY DATA

Mortality data is supplied by the General Registrar Office of Northern Ireland (GRONI) via the Department of Health (DoH). It is supplied on a quarterly basis and is used both to determine annual cancer mortality figures, but also to provide follow up information on cancer patients in survival and prevalence calculations. For the purpose of the production of annual mortality data, cancer type is coded using the same ICD10 codes listed in table 1, while the annual count of number of cancer deaths is based upon the year that death occurs. Figures may thus differ slightly from those produced by the NI Statistics and Research Agency who use the year that deaths are registered.

POPULATION DATA

Population data for each calendar year and for a range of geographic areas is required in the calculation of incidence and mortality rates. Mid-year population estimates are produced by the Northern Ireland Statistics and Research Agency (NISRA) on an annual basis and are the source of all population data used throughout the NICR official statistics publications for Northern Ireland overall and for the five Health and Social Care Trusts (HSCT). They are freely available from the NISRA web site [14] and are downloaded from this site by NICR on an annual basis. Prior to 2021 the HSCT population are based on the 2011 Census, and have thus been weighted to match the 2021 NI Census based mid-year estimates for these years. For Local Government Districts and Parliamentary Constituencies the 2021 Census population [15] is used, however, a reduced range of output is produced for these areas due to the lack of annual data available for the later of these areas.

However, annual population data for Deprivation Quintiles are no longer produced, thus an estimate of the annual population is made. This is done by taking previously available annual population data for these areas, generating the proportion within each gender and five-year age group that reside in each area by year (e.g. the proportion of males aged 40-44 who resided in the least deprived quintile in each year from

2001 to 2020) and projecting that forward to the current year using a Poisson regression model. These proportions are multiplied by the NI mid-year population estimate to give an estimate of the deprivation quintile populations for that year.

MEASURES OF CANCER INCIDENCE AND MORTALITY

The statistical methods used by NICR are those widely used by cancer registries throughout the world in describing the burden of cancer within their catchment area. Consequently, a significant amount of literature is available on these techniques [16,17]. This section thus only provides a very general overview of the techniques utilized and is not meant to supplant the numerous (and better) texts on cancer registration techniques and medical statistics.

DESCRIPTIVE STATISTICS

The most common and useful measure of cancer levels in a population is the absolute number of cases (incidence) or deaths (mortality) in a given period of time. It is these very basic figures that allow planning by the health service and are the fundamental building blocks of any other analysis.

Mean (Average) number of cases/deaths

However, the number of cancer cases/deaths within a year compared to the size of the population of Northern Ireland is relatively small. This can result in the number of events being studied fluctuating each year as a result of natural variation, particularly when data are broken down by smaller geographic areas such as Health Trusts or by patient demographics such as age. In order to introduce more stability into any presented statistics we typically observe the population over five or more years and present a mean number of cases/deaths per year, which should be interpreted as a typical value for the annual number of cases/deaths in the patient group being studied.

Proportions and Rates

In order to properly investigate the distribution of cancer by demographic and tumour characteristics and to make comparisons between different groups, proportions or rates are presented alongside most counts of events. Proportions are used whenever the total being used is a fixed cancer-based population (e.g. total number of cancer deaths, total number of male lung cancer cases) which is derived from the same source data as the number of events. All proportions are multiplied by 100% to provide a percentage value.

Rates are used whenever the population of interest is the general population, most of which is cancer free. The population denominators in this report come from the mid-year population estimates [12] which match the groups of interest (e.g. males aged 40-45 resident in Mid-Ulster Local Government District in 2020). Rates are typically multiplied by 100,000 to provide readable statistics and are referred to as a crude incidence/ mortality rate per 100,000 persons.

AGE-STANDARDISED RATES

When comparing one or more patient groups, crude rates are not always the best measure to use as there is a very strong relationship between cancer and age, thus a younger population is more likely to have a lower number of cancers than an older population of the same size. The most useful and easiest measure to calculate which compensates for differences in the age structures of two populations is a set of age-specific rates, which are calculated in a similar manner to crude rates by dividing the number of events by the population of a specific age group and multiplying by 100,000.

The drawback of the use of age-specific rates is the number of these that must be quoted to give a full picture of the cancer/population being studied, particularly since five-year age-groups are the most commonly used age breakdown. In addition, the small numbers involved can cause very noticeable fluctuations over time, even when several years' worth of data are used.

A widely used technique, which provides a summary measure that allows for the changing or differing population age-structure, is age-standardisation. This does not completely overcome the difficulty in comparing rates between populations and is thus not a replacement for age-specific rates but does provide statistics that are more manageable and lend themselves to further analysis, particularly comparisons of many sets of incidence/mortality rates such as is required in trend and geographic analysis.

There are two methods of age-standardisation, direct and indirect, used in analysis of cancer incidence and mortality. The former provides an absolute measure (i.e. the number of events per 100,000 persons), while the indirect method provides a value relative to some other measure (i.e. the number of observed events compared to the number of expected events).

Direct Standardisation

The result of direct standardisation is known as an age-standardised rate (ASR), which refers to the number of events per 100,000 persons occurring in the population if the population possessed the same age structure as a standard population. The standard population used by NICR in incidence and mortality analysis is the 2013 European standard population which is tabulated below.

Table 7: 2013 European standard population

Age group	Population	Age group	Population	Age group	Population	Age group	Population
0-4	5,000	25-29	6,000	50-54	7,000	75-79	4,000
5-9	5,500	30-34	6,500	55-59	6,500	80-84	2,500
10-14	5,500	35-39	7,000	60-64	6,000	85-89	1,500
15-19	5,500	40-44	7,000	65-69	5,500	90+	1,000
20-24	6,000	45-49	7,000	70-74	5,000		

The calculation of an age-standardised rate is based upon the age-specific rates. These rates are multiplied by the standard population for that age class (also known as the weight), with the products summed and divided by the total standard population. It is typically multiplied by 100,000. This value is the standard measure used for making comparisons between different populations, however, while useful within this context it cannot be interpreted as a measure of the actual number of events within a population due to the removal of the age effect and corresponds to the crude rate in the standard population rather than that being studied.

Indirect Standardisation

The indirect method of age-standardisation is a comparison of the observed number of events within a population and the number of events expected in a reference population of the same size. When considering the incidence of cancer, the expected number is calculated by applying the age specific rates of a reference population to the observed population (i.e. the population being studied). The result is usually expressed as a percentage by multiplying by 100, with 100% referring to the events in the reference population and the result known as the standardised incidence ratio (SIR). This approach is also valid for mortality data using age-specific mortality rates with the result known as the standardised mortality ratio (SMR).

This measure is frequently used for geographic analysis with the reference population being that for an entire country (i.e. Northern Ireland) and SIRs or SMRs calculated for smaller geographic units (e.g. district councils/deprivation quintiles) giving an indication of how cancer levels in these areas compare to that of the entire country.

Cumulative Risk/Odds

Another commonly used measure, which is of particular interest to the general public, but is not as useful as age-standardised rates, is the cumulative risk, which gives the risk of an individual developing cancer during a particular age span (i.e. before ages 75 or 85) assuming the absence of other causes of death. Like age-standardised rates it is based upon age-specific rates but is expressed as a percentage rather than a rate. Dividing 1 by the cumulative risk gives the odds that the event will happen before the given age.

Confidence Intervals and Statistical Significance

However, one important feature of age-standardised rates is that they are only estimates of the true value, as uncertainty exists due to random fluctuations in the number of events between different populations. To quantify this uncertainty any rates are accompanied by 95% confidence intervals to indicate the range within which there is a 95% probability that the true value is likely to fall. The size of the confidence interval depends upon the number of events and the size of the population within which they occur, with rates made up of a small number of observations within a large population being less stable and having large confidence intervals.

Rates for two different time periods or population groups are considered to differ only if the 95% confidence intervals for the two age-standardised rates do not overlap. Alternatively, in the case of ratios, the rates for a population differ from those of the reference population only if the confidence interval does not include 100%. This is known as statistical significance and for significant differences the level of certainty about any difference can be quantified by calculating the p-value. This measure provides the probability that any difference observed between two rates is due to chance. Thus, a p-value of 0.001 indicates a 99.9% probability that differences are genuine and not a result of random factors.

CANCER SURVIVAL

Survival refers to the proportion of patients who survive a given amount of time after a diagnosis of cancer. It is one of the best indicators as to the efficiency of diagnostic and treatment methods in a geographic area and is widely used by cancer registries as a broad indicator as to the effectiveness of health services in the treatment of cancer.

It 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.

OBSERVED SURVIVAL

Observed survival is the proportion of patients who survive a specified amount of time after the point that they are diagnosed with cancer. It is typically presented as the probability of a group of patients surviving a specified amount of time regardless of the cause of death. The observed survival of a group of patients is determined by first assessing whether each patient in the group is alive or dead at a certain date. This date is known as the censor date, while the alive or dead status of each patient at this time is known as the vital status. If a patient's vital status is unknown at the censor date (e.g. if they have moved abroad) the censor date is changed to be the date that the patients' vital status was last recorded. Such patients are referred to as being lost to follow up. The number of patients recorded as lost to follow up in Northern Ireland is small due to the use of the passive follow up method of data collection.

If the patient has been identified as having died between the date of diagnosis and the censor date the observed survival time is calculated as the difference, in days, between the exact date of diagnosis and the exact date of death as recorded by the GRO. If the patient is still alive at the censor date the survival time is the difference between the date of diagnosis and the censor date. Such patients are known as "censored" patients. The calculated survival time and vital status are then used in the Kaplan-Meier approach to produce survival estimates at various points after diagnosis, up to a maximum of five years.

While all patients are typically included in incidence calculations, survival calculations are restricted to adults aged 15 to 99 at the time of diagnosis with patients aged 100 and over excluded due to problems with data quality and interpretation of the results. Survival among children aged 0 to 14 is studied and presented separately. In addition, death certificate only (DCO) registrations are excluded as these registrations have the same date of diagnosis as their date of death with a resultant zero survival time which would bias survival rates downward. In situations where a patient has multiple tumours of the type being studied only the first tumour diagnosed is included in the survival analysis.

NET SURVIVAL

Observed survival for cancer patients includes death from causes other than cancer, some of which may be related to cancer or its cause (e.g. other smoking related illnesses) or may even be completely unconnected to the disease (e.g. accidental death). It is thus not the best survival measure for monitoring the effectiveness of treatment of the disease or its impact on society. Instead measures that remove other causes of death from survival figures are preferred. The most commonly used of these types of measures, but not the only one, is net survival, which is the difference between the observed survival of a

given group of patients and the expected survival for a group of persons in the general population with the same characteristics (usually sex and age).

The expected survival can be calculated using several different techniques. The method used in this report is the Pohar-Perme method [18] and is calculated using the stns module in the Stata statistical software package [19]. This requires the use of background mortality rates by calendar year, sex and single year of age. These are derived from mortality data provided by GRO, but are smoothed using Poisson regression in order to remove fluctuations caused by the small number of events recorded.

Age-standardised Net Survival

Survival from cancer is dependent upon age at diagnosis. Thus when comparing survival from different populations the same difficulties that occur when comparing incidence and mortality rates are also apparent, with populations having high percentages of younger people having better survival that those with high percentages of older people. To compensate we thus apply the direct age-standardisation approach that was used with incidence and mortality rates to net survival rates. As before this involves the application of a standard population to age-specific net survival rates. However, it is necessary to bear in mind that the population at risk when investigating survival differs from that for incidence in that the latter refers to the entire population while survival relates only to patients with cancer. Thus different standard populations are required, not only from that used for the age-standardisation of incidence data but also for those cancer sites that have significantly different age distributions for patients than usual, such as testicular cancer which is more predominant in young men and prostate cancer which is more common in the very elderly. In this report we use the same standard populations suggested by Corazziari et al [20] but collapsed to four age groups due to the small number of events in the NI population for specific age ranges.

Table 8: Standard cancer populations used in age-standardisation of net survival

Standard 1		Standard 2		Standard 3		Standard 4				
Age group	Population	Age group	Population	Age group	Population	Age group	Population			
15-54	19,000	15-44	28,000	15-44	60,000	15-64	42,000			
55-64	23,000	45-54	17,000	45-54	10,000	65-74	29,000			
65-74	29,000	55-64	21,000	55-64	10,000	75-84	23,000			
75+	29,000	65+	34,000	65+	20,000	85+	6,000			
Cancer sites										
All except for those requiring		Sarcoma, melanoma, cervix,		Testes, Hodgkin's disease		Prostate				
standards 2-4		brain, thyroid, bone								

Confidence intervals

As with the other statistical measures used in this report observed and net survival values are accompanied by 95% confidence intervals.

PREVALENCE MEASURES

Prevalence refers to the number of people living in a population with a diagnosis of cancer. Most cancer registries have difficulty in providing an exact figure for this value for a variety of reasons. In the context of Northern Ireland the problems are twofold:

- 1. There is no point at which cancer is considered cured. While some people diagnosed with cancer may be cancer free within a few years, others may need treatment for a considerable length of time. Thus in order to develop prevalence figures, either an assumption must be made as to an average "cure" point (sometimes arbitrarily taken as being five or ten years) or all people who have been diagnosed with cancer and are still alive at a certain point must be included.
- 2. NICR have information on people diagnosed with cancer from 1993 onward. Unfortunately with regard to measuring prevalence, this means that there is no information on members of the population who had a diagnosis of cancer prior to 1993. Thus any complete prevalence figures produced is an undercount of the true value.

Figures for complete prevalence are thus not provided by NICR, however, prevalence figures for people diagnosed within a fixed period of time are provided (i.e. those diagnosed within one, five, ten and twenty-five years). These refer to the number of people who are alive at the end of a specified calendar year and have previously been diagnosed with cancer up to one, five, ten and twenty-five years ago respectively.

Cancer prevalence is based upon patients rather than tumours and only the most recent diagnosed tumour of the cancer type under consideration is counted. Thus if a patient has been diagnosed with one colorectal tumour and one breast tumour since 1993 they contribute to both the colorectal cancer and breast cancer prevalence count, however, they contribute only once to the all cancers count. Similarly, a patient with two breast cancers since 1993 contributes only once to the breast cancer count.

REFERENCES

- 1. The Official Statistics Order (Northern Ireland) 2012. Available at https://www.legislation.gov.uk/nisr/2012/2/contents/made
- 2. UK Statistics Authority. Code of Practice for Statistics. Available at https://code.statisticsauthority.gov.uk
- 3. Tyczynski JE, Demaret E, Parkin DM. Standards and guidelines for cancer registration in Europe. IARC Technical Publication No. 40. IARC, Lyon, 2003
- 4. World Health Organisation. ICD10 International Classification of Diseases 10th revision. Geneva: WHO; 1997
- 5. World Health Organisation. International Classification of Diseases for Oncology Third Edition. Geneva: WHO; 2013
- 6. Genus TSE, Bouvier C, Wong K, et al. Impact of neuroendocrine morphology on cancer outcomes and stage at diagnosis: a UK nationwide cohort study 2013-2015. BJC 2019; 121:966
- 7. National Disease Registration Service. Get Data Out: Sarcoma. Available at www.cancerdata.nhs.uk/getdataout/sarcoma
- 8. Steliarova-Foucher E, Stiller C, Lacour B, Kaatsch P. International Classification of Childhood Cancer, third edition. Cancer 2005; 1457-1467
- 9. Public Health England. Children, teenagers and young adults UK cancer statistics report 2021.Available at: http://www.ncin.org.uk/cancer_type_and_topic_specific_work/cancer_type_specific_work/cancer_in_children_teenagers_and_young adults/
- 10. Sobin LH, Gospodarowicz MK, Wittekind C, eds. TNM classification of malignant tumors (7th edition). West Sussex UK: Wiley-Blackwell 2010
- 11. Brierley JD, Gospodarowicz MK, Wittekind C, eds. TNM classification of malignant tumors (8th edition). West Sussex UK: Wiley-Blackwell 2017
- 12. Northern Ireland Statistics and Research Agency. Central Postcode Directory. Available at: www.nisra.gov.uk/support/geography/central-postcode-directory
- 13. Northern Ireland Statistics and Research Agency. Northern Ireland Multiple Deprivation Measure. Available at: www.nisra.gov.uk/statistics/deprivation
- 14. Northern Ireland Statistics and Research Agency. Mid-year population estimates. Available at: www.nisra.gov.uk/statistics/population/mid-year-population-estimates
- 15. Northern Ireland Statistics and Research Agency. 2021 Census. Available at: www.nisra.gov.uk/statistics/census/2021-census
- 16. Boyle P, Parkin DM. Statistical methods for registries. In: Jensen OM, Parkin DM, MacClennan R, et al. Cancer registration principles and methods. Lyon: IARCPress; 1991
- 17. Breslow NE, Day NE. Statistical methods in cancer research, volume II: The design and analysis of cohort studies. Lyon: International Agency for Research on Cancer, World Health Organization; 1987
- 18. Perme MP, Stare J, Esteve J. On estimation in relative survival. Biometrics 2012; 68:113-20
- 19. Clerc-Urmès I, Grzebyk M, Hédelin, G. Net survival estimation with stns. Stata Journal 2014; 14: 87-102
- 20. Corazziari I, Quinn M and Capocaccia R. Standard cancer population for estimating age standardising survival ratios. Eur J Cancer 2004; 40: 2307-16