Public Health England

Protecting and improving the nation's health

cancer52
the common voice
for less common cancers

National Cancer Intelligence Network
Rare and less common cancers

Incidence and Mortality in England, 2010 to 2013

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. It does this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. PHE is an operationally autonomous executive agency of the Department of Health.

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The intelligence networks

Public Health England operates a number of intelligence networks, which work with partners to develop world-class population health intelligence to help improve local, national and international public health systems.

National Cancer Intelligence Network

The National Cancer Intelligence Network (NCIN) is a UK-wide initiative, working to drive improvements in standards of cancer care and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research.

National Cardiovascular Intelligence Network

The National Cardiovascular Intelligence Network (NCVIN) analyses information and data and turns it into meaningful timely health intelligence for commissioners, policy makers, clinicians and health professionals to improve services and outcomes.

National Child and Maternal Health Intelligence Network

The National Child and Maternal Health Intelligence Network provides information and intelligence to improve decision-making for high-quality, cost-effective services. Its work supports policy makers, commissioners, managers, regulators, and other health stakeholders working on children's, young people's and maternal health.

National Mental Health, Dementia and Neurology Intelligence Network

The National Mental Health Intelligence Networks (NMHDNIN) brings together the distinct National Mental Health Intelligence Network, the Dementia Intelligence Network and the Neurology Intelligence Network under a single programme. The Networks work in partnership with key stakeholder organisations. The Networks seeks to put information and intelligence into the hands of decision makers to improve mental health and wellbeing, support the reduction of risk and improve the lives of people living with dementia and improve neurology services.

National End of Life Care Intelligence Network

The National End of Life Care Intelligence Network (NEoLCIN) aims to improve the collection and analysis of information related to the quality, volume and costs of care provided by the NHS, social services and the third sector to adults approaching the end of life. This intelligence will help drive improvements in the quality and productivity of services.

Foreword

This project, and the continuing collaboration that it represents between NCIN and Cancer52, marks a milestone in the recognition of the number of people affected by the rare and less common cancers. Incidence and mortality figures have been brought together for many rare and less common cancers for the first time in one place. Details of nearly 280 cancers, the vast majority of them rare cancers (affecting fewer than 6 per 100,000 people in the population) have been recorded and separated out from general site groupings.

As more is learned of the genomic variations and mutations of each specific cancer, and personalised treatments become the way forward, the information in this important report is both necessary and timely.

The enormous initial task of listing as many of these specific cancers as possible, checking and ensuring the correct ICD-10 and morphology coding is used, has now been carried out by NCIN, and the robust incidence and mortality figures shown should enable policy makers to improve strategies and decision-making on awareness, prevention, diagnosis, treatment and clinical outcomes for the patients and the people around them that are affected by these cancers.

Overall, this project can be seen as a vital step in providing more detailed and useful information for the rare and less common cancers community as the work evolves more widely across the UK and into yet more cancers.

Finally, Cancer52 would like to record its thanks and gratitude to the PHE/NCIN team involved in this work for both their skill and commitment to this project and we look forward to on-going collaboration between PHE and Cancer52 to identify yet more data on rare and less common cancers.

Jonathan Pearce

Chair, Cancer52

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Executive summary

Rare and less common cancers make up just under half of all newly diagnosed cancers - 47% for 2013[1] in England for both males and females. As of 2013 there are around 2,700 more deaths annually from rare and less common cancers than in 2010[1]. Counts and crude rates are presented for 278 rare and less common cancer sites for incidence figures and 95 sites for mortality figures. Data covers 2010 to 2013 and is broken down by year and sex for England. Data relating to many of these sites has not been published routinely before. Malignant cancer sites with the highest incidence per 100,000 population include brain, endometrioid adenocarcinoma, Non-Hodgkin Lymphoma, multiple myeloma and pancreas. Sites with the highest mortality include brain, ovary, Non-Hodgkin Lymphoma, pancreas and bladder.

A list of sites and sites codes are included for the incidence and mortality figures. Cancer site groupings were constructed to cover less common (those cancers that are not breast, colorectal, lung or prostate) and rarer cancers (those with an incidence of less than 6 per 100,000). Sites are broken down to cover as many groups as possible while remaining clinically relevant and maintaining a good level of data quality and completeness. All this data, with the addition of breakdowns by year and sex, are available from the NCIN website.

A number of cancer sites stand out as having comparatively high mortality rates considering their incidence rates. Mesothelioma and bone tumours of the head and neck have relatively high mortality rates compared to their incidence rates, 3.90 vs. 4.24 and 0.09 vs. 0.10 per 100,000 population respectively. Upper GI cancers including pancreatic cancer and biliary tract cancers (cholangiocarcinoma/bile duct cancer (intra- or extrahepatic)) also had high mortality rates given their incidence, 13.10 vs. 14.05 and 3.64 vs. 3.58 per 100,000 population respectively. Examining these differences in more detail, and assessing any changes in the quality of cancer registration data over time may help to unpick the variation seen here.

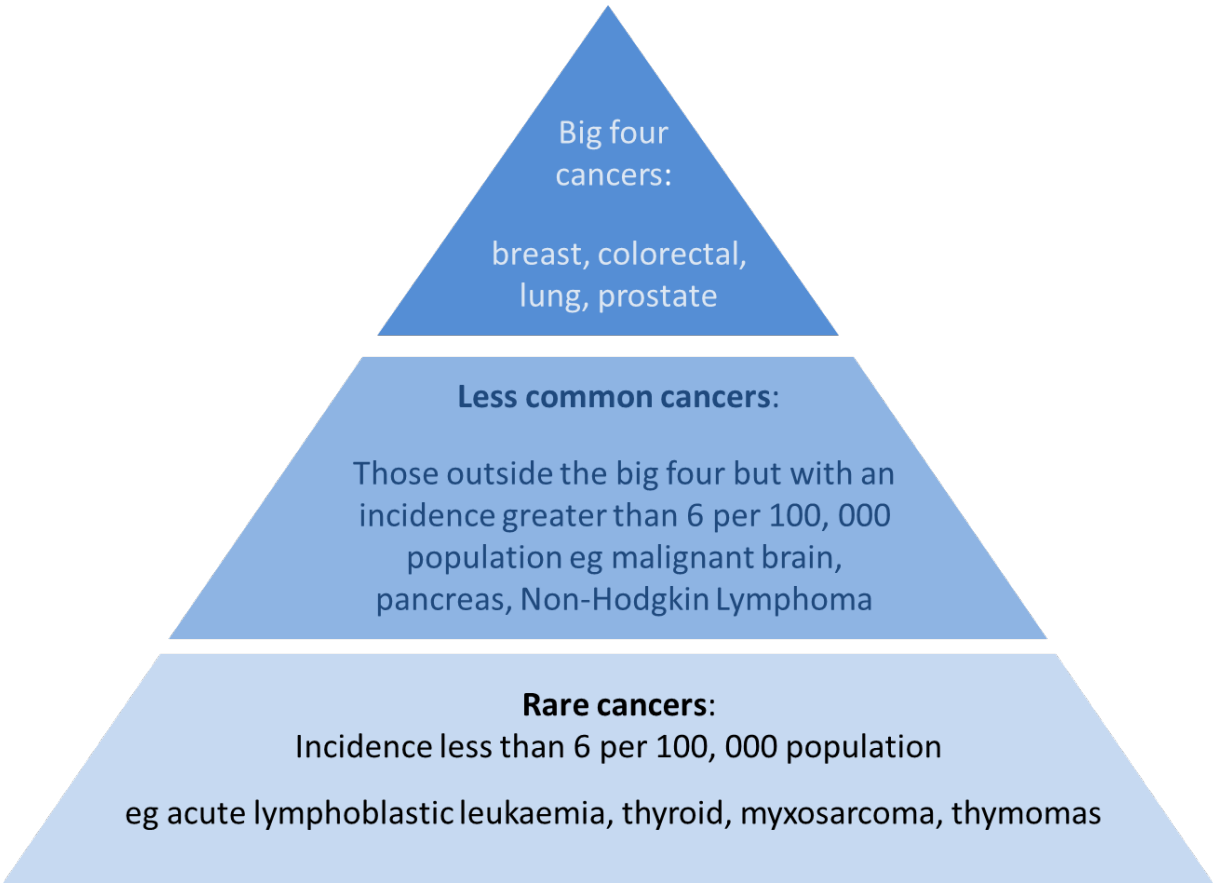
A number of sites show both high incidence and mortality rates. Brain, rarer leukaemia types, multiple myeloma, gallbladder and primary liver (excluding intrahepatic bile duct cancer) all have crude mortality rates above many sites, but also with incidence rates no greater than double that of the mortality rate.

This work illustrates that data on many more less common and rare cancers can be reported routinely than in previous years, but also that a number require more work to break down larger generic groupings with improvements in coding completeness and quality.

Introduction

Cancers sites can be grouped in many ways, including by location, by tumour behaviour, by stage, by route to diagnosis and also by how common they are. The cancers with the highest incidence rates – breast, colorectal, lung and prostate – are considered to be the common cancers. Below these are many less common cancers such as ovarian cancers and Non-Hodgkin Lymphomas, and a final grouping for rare cancers, including any cancers of children, teenagers and young adults, brain tumours and many types of sarcomas. The classifications with some examples can be seen in figure 1.0 below.

Figure 1.0 Common, less common and rare cancer site definitions



Rare and less common cancers make up just under half of all newly diagnosed cancers, 47% for 2013[1] in England for both males and females. While the numbers diagnosed remain in line with the general increase in cancer diagnosis the number of people dying has increased year on year. As of 2013 there are now around 2,700 more deaths annually than in 2010 outside of breast, colorectal, prostate and lung cancers[1]. Rare and less common cancers make up 54% of all cancer deaths, spread equally amongst males and females. Rare and less common cancer deaths in males show a larger increase since 2010 than females where numbers are stable, but represent a slightly

larger proportion of all cancer mortality (54.3% in males compared to 54.6% in females)[2].

The increase in rare and less common cancer incidence has been reported by Gatta et al[3], where analysis of European wide cancer registry data suggested incidence rates were increasing by 108 people per 100,000 population yearly. Five year relative survival was also estimated to be worse for rare and less common cancers, 47% compared to 65% for common cancers (1995 to 1999, follow up 2003). Research from Japan using the RARECARE definitions[4] found 94,800 new rare and less common cases in 2012, 15% of all Japanese cancer diagnosis[5]. Figures from the United States (1995 to 2004) suggested 25% of 9 million incident cancers were rare or less common (albeit with a higher threshold definition of <15 cases per 100,000 population)[6]. The reporting of rare and less common cancers is of growing importance in a large number of countries worldwide.

Much of the literature suggest the establishment of specialist groups and systems to better record and understand rare and less common cancers. While a great amount of data is held on the English National Cancer Registration Services (NCRS) system, specialist databases and groups, such as the EXPeRT Initiative[7], GEM registry[8], Haematological Malignancy Research Network (HMRN)[9] and the Site Specific Clinical Reference Groups (SSCRGs) of the National Cancer Intelligence Network (NCIN) all play a role in recording and analysing data relating to rare and less common cancers. Many of these groups and others have helped improve the quality of data for registrations of rare and less common cancers.

Despite a growing awareness of rare and less common cancers the bulk of literature continues to focus on common cancers. However, in recent years the number of cancer sites reported has increased as data completeness and quality have improved, for example the NCIN's routes to diagnosis study now covers 56 cancer sites for England and much SSCRG work has been done in defining and examining rare and less common cancers in their reports. Much of this work groups cancer sites by ICD-10 coding systems, identifying tumours by position on or within the body. These groupings can obscure some of the detail needed to examine rare and less common sites, for example sarcomas or gynaecological cancers. Cancers can also be identified by morphology codes, detailing a tumour's behaviour, which can give a large amount of granularity in site groupings, but can also lead to every site listed having a very small number of cases that are hard to analyse meaningfully in some circumstances.

Awareness of rare and less common cancers has been championed by Cancer52, an alliance of more than 80 predominantly small patient support group charities. Cancer52 has helped drive the agenda of rare and less common cancers and, together with the National Cancer Intelligence Network (NCIN), aim with this piece of work to:

- define coding classifications for rare and less common cancers, agreed with the NCIN SSCRGs, reflecting the breadth of interests of Cancer52 members. Sites may be constructed using ICD-10 codes or morphology codes
- report incidence and mortality figures (numbers and rates), by age and sex, for all cancers in 2010 to 2013, broken down by rare and less common cancer site at a granular level

The construction of non-standard cancer groupings aims to combine sites that are clinically relevant, small enough to cover a large number of rare and less common sites, but still large enough to maintain data quality and be useful for analysis. The overarching aim is to give a view of the current state of rare and less common cancers being diagnosed and the number of deaths resulting from them.

Almost 280 cancer sites are included in this analysis, some defined using ICD-10 codes and some with morphology codes included. Some groups from the common cancers are also included, for example male breast cancers as it is recognised that there are smaller sub groups within these sites that are relevant to this work. All of this data is available from the NCIN website[10] with greater detail by year and sex.

While this data covers a large number of sites, more work remains to split apart groupings such as 'rarer types' and 'other', and also to examine cancers of children, teenagers and young adults by morphology code groupings. Applying the groupings to data from Northern Ireland, Ireland, Scotland and Wales will also be an important next step in making use of the site lists, helping to build a UK wide picture.

Results

The following tables contain counts and crude rates of rare and less common cancer groupings. The data is for England, 2010 to 2013 combined. The list of codes used to construct these sites can be found in Appendix I.

Further breakdowns of the data by year (2010 to 2013) and sex are available from the NCIN website[10] as a Microsoft Excel workbook.

Crude incidence – numbers and rates

The following tables show the number of cancer cases and the crude incidence rate per 100,000 population for England, 2010 to 2013. For age and sex specific cancers such as the gynaecological or children's cancers the population has been adjusted to match the relevant group. Sites are grouped as per the codes in tables 3.0 to 3.17 found in Appendix I. Highlighted names represent sites that are defined as less common (not breast, colorectal, lung or prostate), those without a highlight are considered rare (incidence <6 per 100,000 population).

Table 1.0 Breast cancer incidence, 2010 to 2013, England

Cancer site 2010 to 2013		Number of incident cases	Incidence rate per 100, 000 population
Breast	Male breast	1,196	1.14
	Nipple and areola (persons)	1,828	0.86

Table 1.1 Central nervous system cancer incidence, 2010 to 2013, England

Cancer site 2010 to 2013		Number of incident cases	Incidence rate per 100, 000 population
Central Nervous System	Meninges	7,921	3.72
	Brain	19,216	9.03
	Spinal cord and Cranial nerves	2,439	1.15
	Intracranial endocrine	3,340	1.57
	CNS unspecified/unknown	137	0.06

Table 1.2 Children's (0 to 14 years old) cancer incidence, 2010 to 2013, England

Cancer site 2010 to 2013		Number of incident cases	Incidence rate per 100, 000 population
Children	Central Nervous System (incl brain) malignant	1,021	2.72
	Central Nervous System (incl brain) non-invasive	285	0.76
	Hodgkin lymphoma	242	0.64
	Kidney	322	0.86
	Leukaemia: acute lymphoblastic	1,279	3.40
	Leukaemia: acute myeloid	253	0.67
	Leukaemia: other (all excluding ALL, AML and CLL)	89	0.24
	Non-Hodgkin lymphoma	308	0.82
	Sarcoma: connective and soft tissue	229	0.61

Table 1.3 Teenagers and young adults (15 to 24 years old) cancer incidence, 2010 to 2013, England

Cancer site 2010 to 2013		Number of incident cases	Incidence rate per 100, 000 population
Teenagers & young adults	Central Nervous System (incl brain) malignant	559	2.03
	Central Nervous System (incl brain) non-invasive	317	1.15
	Cervix	212	1.57
	Cervix (in-situ)	4,858	17.63
	Colorectal	401	1.46
	Female breast cancer	123	0.91
	Head and neck – Thyroid	443	1.61
	Hodgkin lymphoma	1,119	4.06
	Kidney	62	0.22
	Leukaemia: acute lymphoblastic	250	0.91
	Leukaemia: acute myeloid	234	0.85
	Leukaemia: other (all excluding ALL, AML and CLL)	110	0.40
	Melanoma	693	2.51
	Non-Hodgkin lymphoma	456	1.65
	Ovary	348	2.58
	Sarcoma: connective and soft tissue	250	0.91
	Testis	931	6.62

Table 1.4 Colorectal cancer incidence, 2010 to 2013, England

Cancer site 2010 to 2013		Number of incident cases	Incidence rate per 100, 000 population
Colorectal	Anal cancer - Adenocarcinoma	415	0.20
	Anal cancer - Basaloid & cloacogenic carcinoma	73	0.03
	Anal cancer - Squamous-cell carcinoma	3,123	1.47
	Anal cancer - Other	85	0.04

Table 1.5 Gynaecological cancer incidence, 2010 to 2013, England

Cancer site 2010 to 2013		Number of incident cases	Incidence rate per 100, 000 population
Gynae - Cervical	Squamous carcinoma	6,960	6.45
	Neuroendocrine	115	0.11
	Adenosquamous	352	0.33
	Adenocarcinoma	2,053	1.90
	Unclassified epithelial	291	0.27
	Other epithelial	33	0.03
	Other	195	0.18
Gynae - Ovarian	Borderline	3,682	3.41
	Clear cell carcinoma	992	0.92
	Endometrioid carcinoma	1,393	1.29
	Mucinous carcinoma	1,260	1.17
	Serous carcinoma	8,455	7.83
	Sex cord-stromal or germ cell tumours	555	0.51
	Unclassified epithelial	5,442	5.04
	Other classified epithelial and epithelial-stromal tumours	927	0.86
	Miscellaneous and unspecified	1,526	1.41
Gynae - Uterine	Clear cell and papillary serous carcinoma	2,606	2.41
	Endometrioid adenocarcinoma	22,085	20.46
	Mixed epithelial and mesenchymal tumours	1,756	1.63
	Other classified and unclassified carcinoma	861	0.80
	Miscellaneous and unspecified	418	0.39
Gynae - Vulva	Squamous carcinoma	3,431	3.18
	Adenocarcinoma	239	0.22
	Melanocytic	197	0.18
	Other classified and unclassified epithelial	118	0.11
	Miscellaneous and unspecified	97	0.09
Gynae - Vaginal	Squamous carcinoma	525	0.49
	Adenocarcinoma	132	0.12
	Melanocytic	64	0.06
	Other classified and unclassified epithelial	58	0.05
	Miscellaneous and unspecified	39	0.04
Gynae - Placenta	Placenta	101	0.09

Numbers in 2013 relating to malignant neoplasm of placenta (C58) should be treated with caution due to data quality issues.

Table 1.6 Haematological cancer incidence, 2010 to 2013, England

Cancer site 2010 to 2013		Number of incident cases	Incidence rate per 100, 000 population
Haematology	Hodgkin Lymphoma	6,263	2.94
	Non-Hodgkin Lymphoma	42,961	20.20
	Leukaemia: acute lymphoblastic	2,369	1.11
	Leukaemia: acute myeloid	9,822	4.62
	Leukaemia: chronic lymphocytic	11,222	5.28
	Leukaemia: chronic myeloid	2,332	1.10
	Leukaemia: rarer types	3,973	1.87
	Monoclonal Gammopathy of Undetermined Significance	1,961	0.92
	Multiple myeloma	17,630	8.29
	Myelodysplastic Syndromes	9,312	4.38
	Other	6,580	3.09

Table 1.7 Head and Neck cancer incidence, 2010 to 2013, England

Cancer site 2010 to 2013		Number of incident cases	Incidence rate per 100, 000 population
Head & Neck	Bone tumours	208	0.10
	Internal Lip	157	0.07
	External Lip	625	0.29
	Hypopharynx	1,827	0.86
	Larynx	7,410	3.48
	Middle ear and external auditory canal	8,927	4.20
	Nasal cavity (only excluding middle ear)	989	0.46
	Nasopharynx	808	0.38
	Oral cavity	10,129	4.76
	Oropharynx	7,945	3.74
	Palate	1,510	0.71
	Salivary glands	2,301	1.08
	Sinuses	581	0.27
	Thyroid	9,900	4.65
	Head and neck - Other sites	4,976	2.34

Table 1.8 Lung cancer incidence, 2010 to 2013, England

Cancer site 2010 to 2013		Number of incident cases	Incidence rate per 100, 000 population
Lung	Mesothelioma	9,027	4.24
	Pulmonary carcinoids	558	0.26
	Solitary fibrous tumours of pleura	2	0.00
	Thymomas	308	0.14

Table 1.9 Sarcoma incidence, 2010 to 2013, England

	Cancer site 2010 to 2013	Number of incident cases	Incidence rate per 100, 000 population
Sarcoma - Bone Sarcomas (C40-C41)	Adamantinoma of long bones; tibial adamantinoma (C40.2)	10	0.00
	Alveolar rhabdomyosarcoma	2	0.00
	Ameloblastic fibrosarcoma: Ameloblastic sarcoma: Odontogenic fibrosarcoma	1	0.00
	Ameloblastoma	17	0.01
	Central osteosarcoma (C40._, C41._);	5	0.00
	Chondroblastic osteosarcoma (C40._, C41._)	76	0.04
	Chondroblastoma, malignant (C40._, C41._)	1	0.00
	Chondroid chordoma	6	0.00
	Chondrosarcoma	604	0.28
	Chordoma	142	0.07
	Clear cell chondrosarcoma, (C40._, C41._)	5	0.00
	Dedifferentiated chondrosarcoma (C40._, C41._)	28	0.01
	Dedifferentiated chordoma	5	0.00
	Desmoplastic small round cell tumour	3	0.00
	Epithelioid haemangioendothelioma, malignant	8	0.00
	Epithelioid sarcoma, epithelioid cell sarcoma	2	0.00
	Ewing's sarcoma, Ewing's tumour, Extraskeletal Ewing tumour	255	0.12
	Fibroblastic osteosarcoma (C40._, C41._); osteofibrosarcoma (C40._, C41._)	21	0.01
	Fibromyxosarcoma	6	0.00
	Fibrous histiocytoma, malignant; fibroxanthoma, malignant	12	0.01
	Giant cell sarcoma (except of bone M9250/3); pleomorphic cell sarcoma	1	0.00
	Giant cell tumour of bone, NOS	31	0.01
	Haemangioendothelioma, NOS, Kaposiform haemangioepithelioma	1	0.00
	Haemangiopericytoma, NOS	1	0.00
	Haemangiosarcoma, Angiosarcoma of soft tissue	18	0.01
	Infantile fibrosarcoma; congenital fibrosarcoma	1	0.00
	Inflammatory myofibroblastic tumour, Myofibroblastic tumour, NOS	4	0.00
	Intraosseous well differentiated osteosarcoma (C40._, C41._)	3	0.00

Table 1.10 Sarcoma incidence continued, 2010 to 2013, England

Cancer site 2010 to 2013		Number of incident cases	Incidence rate per 100, 000 population
Sarcoma - Bone Sarcomas (C40-C41)	Juxtacortical chondrosarcoma (C40._, C41._)	10	0.00
	Leiomyosarcoma, NOS	9	0.00
	Liposarcoma, NOS; fibroliposarcoma	1	0.00
	Liposarcoma, well differentiated; Liposarcoma, differentiated	1	0.00
	Malignant peripheral nerve sheath tumour MPNST, NOS	1	0.00
	Mesenchymal chondrosarcoma	14	0.01
	Myoepithelioma	3	0.00
	Myxoid chondrosarcoma	24	0.01
	Myxoid Liposarcoma; myxoliposarcoma	3	0.00
	Odontogenic tumour	14	0.01
	Osteochondromatosis	1	0.00
	Osteosarcoma in Paget's disease of bone (C40._, C41._)	10	0.00
	Osteosarcoma, NOS (C40._, C41._)	361	0.17
	Parosteal osteosarcoma (C40._, C41._)	18	0.01
	Periosteal fibrosarcoma (C40._, C41._); periosteal sarcoma, NOS (C40._, C41._)	1	0.00
	Periosteal osteogenic sarcoma (C40._, C41._)	5	0.00
	Peripheral neuroectodermal tumour; neuroectodermal tumour, NOS	1	0.00
	Pleomorphic liposarcoma	2	0.00
	Primitive neuroectodermal tumour	4	0.00
	Rhabdomyosarcoma, NOS; rhabdosarcoma	2	0.00
	Sarcoma, NOS	55	0.03
	Small cell osteosarcoma (C40._, C41._)	2	0.00
	Small cell sarcoma; round cell sarcoma	3	0.00
	Solitary fibrous tumour, NOS	3	0.00
	Spindle cell sarcoma	56	0.03
	Synovial sarcoma, biphasic	1	0.00
	Synovial sarcoma, NOS; synovioma, NOS; synovioma, malignant	4	0.00
	Synovial sarcoma, spindle cell	1	0.00
	Telangiectatic osteosarcoma (C40._, C41._)	15	0.01
	Undifferentiated sarcoma	3	0.00
Sarcoma	Gastrointestinal stromal tumours	2,365	1.11

Table 1.11 Sarcoma incidence continued, 2010 to 2013, England

Cancer site 2010 to 2013		Number of incident cases	Incidence rate per 100, 000 population
Sarcoma - Soft tissue sarcomas	Adamantinoma of long bones; tibial adamantinoma (C40.2)	1	0.00
	Adenosarcoma	139	0.07
	Alveolar rhabdomyosarcoma	117	0.06
	Alveolar soft part sarcoma	24	0.01
	Ameloblastoma	1	0.00
	Angiomyoliposarcoma	3	0.00
	Angiomyosarcoma	28	0.01
	Angiomyxoma	1	0.00
	Askin tumour	1	0.00
	Chondroblastoma, malignant (C40._, C41._)	1	0.00
	Chondroid chordoma	1	0.00
	Chondrosarcoma	67	0.03
	Chordoma	51	0.02
	Clear cell sarcoma (except of kidney M8964/3)	41	0.02
	Clear cell sarcoma of kidney	8	0.00
	Dedifferentiated chondrosarcoma (C40._, C41._)	1	0.00
	Dedifferentiated chordoma	1	0.00
	Dedifferentiated liposarcoma	319	0.15
	Dermatofibrosarcoma, NOS (C44._); dermatofibrosarcoma protuberans, NOS (C44._)	591	0.28
	Desmoplastic small round cell tumour	40	0.02
	Embryonal rhabdomyosarcoma; sarcoma botryoides; botryoid sarcoma	151	0.07
	Embryonal sarcoma	8	0.00
	Endometrial stromal sarcoma (C54.1)	176	0.08
	Endometrial stromal sarcoma, low grade	60	0.03
	Epithelioid haemangioendothelioma, malignant	32	0.02
	Epithelioid leiomyosarcoma	40	0.02
	Epithelioid sarcoma, epithelioid cell sarcoma	87	0.04
	Ewing's sarcoma, Ewing's tumour, Extraskeletal Ewing tumour	107	0.05

Table 1.12 Sarcoma incidence continued, 2010 to 2013, England

Cancer site 2010 to 2013		Number of incident cases	Incidence rate per 100, 000 population
Sarcoma - Soft tissue sarcomas	Fibroblastic liposarcoma	5	0.00
	Fibromyxosarcoma	598	0.28
	Fibrosarcoma, NOS, sclerosing epitheliod fibrosarcoma	112	0.05
	Fibrous histiocytoma, malignant; fibroxanthoma, malignant	325	0.15
	Giant cell sarcoma (except of bone M9250/3); pleomorphic cell sarcoma	419	0.20
	Giant cell tumour of soft parts, NOS	8	0.00
	Granular cell tumour, malignant; granular cell myoblastoma, malignant	19	0.01
	Haemangioendothelioma, NOS, Kaposiform haemangioepithelioma	15	0.01
	Haemangiopericytoma, NOS	47	0.02
	Haemangiosarcoma, Angiosarcoma of soft tissue	571	0.27
	Infantile fibrosarcoma; congenital fibrosarcoma	16	0.01
	Inflammatory myofibroblastic tumour, Myofibroblastic tumour, NOS	61	0.03
	Kaposi sarcoma; Multiple haemorrhagic sarcoma	540	0.25
	Leiomyosarcoma, NOS	2,024	0.95
	Liposarcoma, NOS; fibroliposarcoma	529	0.25
	Liposarcoma, well differentiated; Liposarcoma, differentiated	457	0.21
	Lymphangiosarcoma; lymphangioendothelial sarcoma	3	0.00
	Malignant peripheral nerve sheath tumour MPNST, NOS	246	0.12
	Malignant peripheral nerve sheath tumour with thabdomyoblastic differentiation	13	0.01
	Malignant schwannoma; neurilemoma, malignant	54	0.03
	Malignant tenosynovial giant cell tumour (C49._)	7	0.00
	Mesenchymal chondrosarcoma	4	0.00
	Mesenchymoma, malignant; mixed mesenchymal sarcoma	132	0.06
	Mixed liposarcoma	9	0.00
	Mixed type rhabdomyosarcoma	3	0.00
	Myoepithelioma	52	0.02
	Myosarcoma	6	0.00
	Myxoid chondrosarcoma	47	0.02

Table 1.13 Sarcoma incidence continued, 2010 to 2013, England

Cancer site 2010 to 2013		Number of incident cases	Incidence rate per 100, 000 population
Sarcoma - Soft tissue sarcomas	Myxoid leiomyosarcoma	23	0.01
	Myxoid Liposarcoma; myxoliposarcoma	257	0.12
	Myxosarcoma	80	0.04
	Odontogenic tumour	1	0.00
	Osteosarcoma, NOS (C40._, C41._)	17	0.01
	Perineurioma, malignant; Perineural MPNST	2	0.00
	Peripheral neuroectodermal tumour; neuroectodermal tumour, NOS	39	0.02
	Phyllodes tumour, malignant (C50.) Cystosarcoma phyllodes, malignant (C50.)	220	0.10
	Pigmented dermatofibrosarcoma protuberans; Bednar tumour	51	0.02
	Pleomorphic liposarcoma	140	0.07
	Pleomorphic rhabdomyosarcoma	45	0.02
	Primitive neuroectodermal tumour	93	0.04
	Rhabdoid sarcoma	34	0.02
	Rhabdomyosarcoma with ganglionic differentiation; Ectomesenchymoma	1	0.00
	Rhabdomyosarcoma, NOS; rhabdosarcoma	104	0.05
	Round cell liposarcoma	22	0.01
	Sarcoma, NOS	1178	0.55
	Small cell sarcoma; round cell sarcoma	34	0.02
	Smooth muscle tumour	2	0.00
	Solitary fibrous tumour, NOS	154	0.07
	Spindle cell rhabdomyosarcoma	15	0.01
	Spindle cell sarcoma	622	0.29
	Stromal Sarcoma	36	0.02
	Synovial sarcoma, biphasic	38	0.02
	Synovial sarcoma, epithelioid cell	1	0.00
	Synovial sarcoma, NOS; synovioma, NOS; synovioma, malignant	226	0.11
	Synovial sarcoma, spindle cell	46	0.02
	Undifferentiated sarcoma	155	0.07

Table 1.14 Skin cancer incidence, 2010 to 2013, England

Cancer site 2010 to 2013		Number of incident cases	Incidence rate per 100, 000 population
Skin	Apocrine carcinoma	40	0.02
	Atypical fibroxanthoma (AFX) (superficial malignant fibrous)	72	0.03
	Dermatofibrosarcoma protuberans (DFSP)	537	0.25
	Digital papillary adenocarcinoma	16	0.01
	Eccrine epithelioma (syringoid carcinoma)	59	0.03
	Eccrine porocarcinoma	49	0.02
	Fibro-epithelial tumour of Pinkus	105	0.05
	Haemangioendothelioma	2	0.00
	Hidradenocarcinoma	312	0.15
	Histiocytoma (superficial sarcoma not otherwise specified)	72	0.03
	Malignant cylindroma	46	0.02
	Malignant epithelioid haemangioendothelioma	1	0.00
	Malignant pilomatrixoma	19	0.01
	Malignant spiradenoma	13	0.01
	Microcystic adnexal carcinoma (sweat gland carcinoma)	109	0.05
	Mixed tumour, NOS	7	0.00
	Neuroendocrine carcinoma (Merkel cell tumour/trabecular carcinoma)	1,014	0.48
	Primary adenoid cystic carcinoma	46	0.02
	Primary mucinous carcinoma	44	0.02
	Primary mucoepidermoid carcinoma	12	0.01
	Sebaceous carcinoma	436	0.20
	Skin Appendage	171	0.08
	Tumours associated with Muir–Torre syndrome	436	0.20

Table 1.15 Upper Gastro-Intestinal (UGI) cancer incidence, 2010 to 2013, England

Cancer site 2010 to 2013		Number of incident cases	Incidence rate per 100, 000 population
Upper GI	Ampulla of Vater	1,569	0.74
	Biliary tract cancer (or cholangiocarcinoma or bile duct cancer (intra- or extrahepatic))	7,606	3.58
	Duodenal cancer	1,700	0.80
	Gallbladder cancer	2,714	1.28
	Pancreas	29,892	14.05
	Primary liver (excluding intrahepatic bile duct cancer)	9,902	4.66

Table 1.16 Urological cancer incidence, 2010 to 2013, England

Cancer site 2010 to 2013		Number of incident cases	Incidence rate per 100, 000 population
Urology	Non-TCC bladder	2,580	1.21
	Para-testicular neoplasms (epididymis and spermatic cord)	58	0.03
	Penile cancer	1,850	0.87
	Small-cell prostate	304	0.14
	Testicular (with a subgroup of Sertoli cell - 8640 and Leydig cell - 8650)	7,511	3.53
	Ureter and renal pelvis	5,378	2.53
	Urethral cancer	665	0.31

Crude mortality – numbers and rates

The following tables show the number of deaths and the crude mortality rate per 100,000 population for England, 2010 to 2013 combined. For age and sex specific cancers such as the gynaecological or children's cancers the population has been adjusted to match the relevant group. Sites are grouped as per the codes in tables 4.0 to 4.12 in Appendix I. Highlighted names represent sites that are less common, those without a highlight are rare based on the previous crude incidence rates. Only sites where the codes match with the incidence groups are included for this classification. Sites marked with an asterisk (*) have coding combinations that do not directly map on to the equivalent incidence groupings and should not be directly compared.

Table 2.0 Breast cancer mortality, 2010 to 2013, England

Cancer site 2010 to 2013		Number of deaths	Mortality rate per 100, 000 population
Breast	Male breast	258	0.25
	Nipple and areola (persons)	7	0.00

Table 2.1 Central nervous system cancer mortality, 2010 to 2013, England

Cancer site 2010 to 2013		Number of deaths	Mortality rate per 100, 000 population
Central Nervous System	Meninges	1,288	0.61
	Brain	15,245	7.17
	Spinal cord and Cranial nerves	95	0.04
	Intracranial endocrine	240	0.11
	CNS unspecified/unknown	18	0.01

Table 2.2 Children's (0 to 14 years old) cancer mortality, 2010 to 2013, England

Cancer site 2010 to 2013		Number of deaths	Mortality rate per 100, 000 population
Children	Central Nervous System (incl brain) malignant	293	0.78
	Central Nervous System (incl brain) non-invasive	44	0.12
	Hodgkin lymphoma	5	0.01
	Kidney	25	0.07
	Leukaemia: acute lymphoblastic	99	0.26
	Leukaemia: acute myeloid	75	0.20
	Leukaemia: other (all excluding ALL, AML and CLL)	15	0.04
	Non-Hodgkin lymphoma	28	0.07
	Sarcoma: connective and soft tissue	45	0.12

Table 2.3 Teenagers and young adults (15 to 24 years old) cancer mortality, 2010 to 2013, England

Cancer site 2010 to 2013		Number of deaths	Mortality rate per 100, 000 population
Teenagers & young adults	Central Nervous System (incl brain) malignant	178	0.65
	Central Nervous System (incl brain) non-invasive	21	0.08
	Cervix	21	0.16
	Colorectal	26	0.09
	Female breast cancer	8	0.06
	Head and neck – Thyroid	2	0.01
	Hodgkin lymphoma	40	0.15
	Kidney	13	0.05
	Leukaemia: acute lymphoblastic	79	0.29
	Leukaemia: acute myeloid	87	0.32
	Leukaemia: other (all excluding ALL, AML and CLL)	13	0.05
	Melanoma	28	0.10
	Non-Hodgkin lymphoma	41	0.15
	Ovary	22	0.16
	Sarcoma: connective and soft tissue	62	0.22
	Testis	14	0.10

Table 2.4 Colorectal cancer mortality, 2010 to 2013, England

Cancer site 2010 to 2013		Number of deaths	Mortality rate per 100, 000 population
Colorectal*	Anal cancer	1,041	0.49

Table 2.5 Gynaecological cancer mortality, 2010 to 2013, England

Cancer site 2010 to 2013		Number of deaths	Mortality rate per 100, 000 population
Gynae*	Cervix	2,997	2.78
	Ovary	14,003	12.97
	Placenta	5	0.00
	Uterus	6,491	6.01
	Vagina	319	0.30
	Vulva	1,379	1.28

Numbers in 2013 relating to malignant neoplasm of placenta (C58) should be treated with caution due to data quality issues.

Table 2.6 Haematological cancer mortality, 2010 to 2013, England

Cancer site 2010 to 2013		Number of deaths	Mortality rate per 100, 000 population
Haematology	Hodgkin Lymphoma	1,013	0.48
	Non-Hodgkin Lymphoma	15,333	7.21
	Leukaemia: acute lymphoblastic	756	0.36
	Leukaemia: acute myeloid	8,354	3.93
	Leukaemia: chronic lymphocytic	3,842	1.81
	Leukaemia: chronic myeloid	763	0.36
	Leukaemia: rarer types	1,989	0.94
	Monoclonal Gammopathy of Undetermined Significance	50	0.02
	Multiple myeloma	9,471	4.45
	Myelodysplastic Syndromes	3,781	1.78
	Other	1,489	0.70

Table 2.7 Head and neck cancer mortality, 2010 to 2013, England

Cancer site 2010 to 2013		Number of deaths	Mortality rate per 100, 000 population
Head & Neck	Bone tumours	195	0.09
	External Lip	16	0.01
	Head and neck - Other sites	1,413	0.66
	Hypopharynx	659	0.31
	Larynx	2,525	1.19
	Middle ear and external auditory canal	250	0.12
	Nasal cavity (only excluding middle ear)	88	0.04
	Nasopharynx	408	0.19
	Oral cavity	3,266	1.54
	Oropharynx	1,848	0.87
	Palate	226	0.11
	Salivary glands	642	0.30
	Sinuses	332	0.16
	Thyroid	1,203	0.57

Table 2.8 Lung cancer mortality, 2010 to 2013, England

Cancer site 2010 to 2013		Number of deaths	Mortality rate per 100, 000 population
Lung*	Mesothelioma	8,290	3.90
	Pleura	145	0.07
	Thymomas	166	0.08

Table 2.9 Sarcoma mortality, 2010 to 2013, England

Cancer site 2010 to 2013		Number of deaths	Mortality rate per 100, 000 population
Sarcoma*	Bone sarcomas	900	0.42
	Soft tissue sarcomas	4,048	1.90

Table 2.10 Skin cancer mortality, 2010 to 2013, England

Cancer site 2010 to 2013		Number of deaths	Mortality rate per 100, 000 population
Skin*	Malignant neoplasm of skin, unspecified	771	0.36
	Mycosis fungoides	80	0.04
	Other mature T/NK-cell lymphomas	761	0.36
	Overlapping lesion of skin	2	0.00
	Peripheral T-cell lymphoma, not elsewhere classified	139	0.07
	Sézary disease	22	0.01
	Skin of ear and external auricular canal	240	0.11
	Skin of eyelid, including canthus	12	0.01
	Skin of lip	3	0.00
	Skin of lower limb, including hip	88	0.04
	Skin of other and unspecified parts of face	202	0.09
	Skin of scalp and neck	491	0.23
	Skin of trunk	53	0.02
	Skin of upper limb, including shoulder	35	0.02

Table 2.11 Upper gastro-intestinal (UGI) cancer mortality, 2010 to 2013, England

Cancer site 2010 to 2013		Number of deaths	Mortality rate per 100, 000 population
Upper GI	Ampulla of Vater	352	0.17
	Biliary tract cancer (or cholangiocarcinoma or bile duct cancer (intra- or extrahepatic))	7,743	3.64
	Duodenal cancer	912	0.43
	Gallbladder cancer	1,698	0.80
	Pancreas	27,869	13.10
	Primary liver (excluding intrahepatic bile duct cancer)	6,899	3.24

Table 2.12 Urological cancer mortality, 2010 to 2013, England

Cancer site 2010 to 2013		Number of deaths	Mortality rate per 100, 000 population
Urology*	Bladder	17,170	8.07
	Para-testicular neoplasms (epididymis and spermatic cord)	1	0.00
	Penile cancer	322	0.15
	Testicular	220	0.10
	Ureter and renal pelvis	773	0.36
	Urethral cancer	84	0.04

Methodology

Site groupings

The cancer sites included in this report have been agreed upon by the NCIN Site Specific Clinical Reference Groups (SSCRGs). Twelve SSCRGs were consulted as part of the work, covering central nervous systems, children, teenagers and young adults, gynaecological, haematological, sarcomas, skin, upper GI, urology, colorectal, breast, lung and head and neck cancers. An initial list of site breakdowns from the RARECARE project[4] and the sites previously published as part of the routes to diagnosis work[11] were consulted as part of the grouping construction process. The SSCRGs then discussed the feasibility of breaking down sites in to more granular groupings or combining some if necessary. A number of factors were considered when building the lists, including the clinical relevance of site groups (for example if some sites would be treated in a similar way and by a similar patient pathway), the ease in reporting incidence and mortality for them (as data available for these calculations can differ), data quality (larger site groupings may be used if there are coding issues with some very small sites) and any previously published work. The use of ICD-10 and ICD-O-3 coding was decided by the group dependent upon the feasibility of either coding system to cover the groups they wished to include, and the quality of the data available.

Less common cancers were defined as those that were not breast, colorectal, lung or prostate cancers and had an incidence rate of greater than 6 per 100,000 population. Rare cancers were defined as those that had an incidence of less than 6 per 100,000 population. It should be noted that for the purpose of this work some rare cancers within the general breast, colorectal, lung and prostate groups have been included to recognise that within the big four cancer sites there are rare and less common sub groups not commonly reported.

Not every rare or less common cancer will be included in this report. Some may be excluded due to data quality issues, due to the nature of the group construction or because no expert consultation was available at the time. A comprehensive split exclusively by ICD-10 code groups is available from the Office of National Statistics (ONS) MB1 series[12], which will include some sites not found here. Other site groupings, such as cancer of unknown primary, have been reported in previous reports and can be found on the NCIN website[13].

Data extraction

Code lists returned by the SSCRGs were converted in to 4 digit ICD-10 codes where necessary and checked against the World Health Organization (WHO) ICD-10 10th revision, 2010[14]. ICD-O-3 codes were checked against those from International Agency for Research on Cancer (IARC)[15]. No codes were found to be obsolete, so none were removed as part of these checks.

Incidence counts were extracted from the English Cancer Analysis System for the calendar years 2010 to 2013. No age limitations were applied to the data, save for children (0 to 14 years) and teenagers and young adults (15 to 24 years) for the respective site groupings.

Cancers were excluded from the counts if they:

- were marked as provisional by the registration service
- were from 2010 or 2011 and not marked to be included in the cascade[16] system (with the exception of CNS, male breast cancer and skin tumours, as some of these cases are excluded from the standard cascade cancer sites)
- had an LSOA code that was not for England
- had a null value in their tumour ID or ICD-10 or ICD-O-3 code
- had a duplicated tumour ID

Note that the cascade flag was not applied to the incidence data for 2012 and 2013. This data has undergone a de-duplication process, and comparing 2012 with and without the cascade flag results in minor change. The process to apply the flag to 2013 data has not yet been carried out as of the date of publication of this report.

Mortality counts were extracted from the English Cancer Analysis System, ONS mortality data for 2013. This data is only available by ICD-10 code, so where morphology groupings have been used for incidence relevant groupings have been constructed using ICD-10 codes. This will result in fewer groupings for the mortality data, with less granularity in the codes included. This will mean in some cases the incidence and mortality figures will not directly relate to each other when different groups have been used. Mortality data is from 2010 to 2013, based on registration year. No age limitations were applied to the data, save for children (0 to 14 years) and teenagers and young adults (15 to 24 years) for the respective site groupings.

Cancers were excluded from the counts if they:

- had an LSOA code that was not for England
- had a null value in their ICD-10 code

Crude incidence and mortality

Once counts of cases and deaths were extracted crude incidence and mortality rates were calculated using ONS mid-year population estimates for 2010 to 2013 for England[17]. Populations were split by year, sex, age group (for children, teenagers and young adults) and for the whole 2010 to 2013 cohort. Crude incidence was calculated with the tumour count as the numerator, the relevant population as the denominator and per 100,000 population. Crude mortality rates were calculated in a similar way, but using the number of deaths as the numerator.

When examining and comparing the data a number of factors should be considered. Firstly, site grouping may not match those more commonly published as they have been constructed specifically for the purpose of examining rare and less common cancers and in some cases very specific morphology codes have been included or excluded, which can alter the number of cases in a group quite dramatically. Before comparing to other literature it is recommended checking the codes included to gauge the level of comparability.

As ICD-O-3 codes are not available for the mortality groupings incidence and mortality will only relate when the codes used match up, which will be in cases where the incidence groups are based solely on ICD-10 codes. For example, CNS incidence and mortality codes are the same, whereas sarcoma coding varies greatly between the metrics.

Both incidence and mortality calculations are also crude, and do not take in to account the underlying age structure of a population. This is because the project aims to report on rare and less common cancers as they are in the population, without statistical adjustments. For some sites rates may be high or low, and one of the reasons may be the size of the specific population at risk. For example, cancers that are more likely to effect the older population may have higher rates if the number of older people is a larger portion of the population.

Finally, code lists may be revised and changed as a result of changing clinical practise, research, data quality changes or updates to coding systems.

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Appendix I

Cancer site lists for incidence

The following tables show the cancer sites groupings used, including the ICD-10 codes and morphology codes if used. These are available from a Microsoft Excel workbook on the NCIN website[10].

Table 3.0 Breast cancer groups

General Group	Group or site name	ICD10 codes
Breast - male Breast	Male breast	C50
	Nipple and areola (persons)	C500

Table 3.1 Central nervous system cancer groups

General Group	Group or site name	ICD10 codes
Central Nervous System	Brain	C71, D330-D332, D430-D432
	CNS unspecified/unknown	C728-C729, D337-D339, D437,D439
	Intracranial endocrine	C75, D352-D354, D443-D445
	Meninges	C70, D320, D321, D329, D420, D421, D429
	Spinal cord and Cranial nerves	C72, D333-D334, D433-D434

Table 3.2 Children's (0 to 14 years old) cancer groups

General Group	Group or site name	ICD10 codes
Children (0 to 14)	Central Nervous System (incl brain) malignant	C70-C72, C751-C753
	Central Nervous System (incl brain) non-invasive	D32, D33, D352-D354, D42-D43, D443-D445
	Hodgkin lymphoma	C81
	Kidney	C64
	Kidney and unspecified urinary organs	C64-C66, C68
	Leukaemia: acute lymphoblastic	C910
	Leukaemia: acute myeloid	C920, C924, C925, C930, C940, C942
	Leukaemia: other (all excluding ALL, AML and CLL)	C921, C912-C919, C922, C923, C927, C929, C931-C939, C941, C943-C947, C95
	Non-Hodgkin lymphoma	C82-C85
	Sarcoma: connective and soft tissue	C49

Table 3.3 Teenagers and young adults (15 to 24 years old) cancer groups

General Group	Group or site name	ICD10 codes
Teenagers & young adults (15 to 24)	Central Nervous System (incl brain) malignant	C70-C72, C751-C753
	Central Nervous System (incl brain) non-invasive	D32, D33, D352-D354, D42-D43, D443-D445
	Cervix	C53
	Cervix (in-situ)	D06
	Colorectal	C18-C20
	Female breast cancer	C50
	Head and neck – Thyroid	C73
	Hodgkin lymphoma	C81
	Kidney	C64
	Leukaemia: acute lymphoblastic	C910
	Leukaemia: acute myeloid	C920, C924, C925, C930, C940, C942
	Leukaemia: other (all excluding ALL, AML and CLL)	C921, C912-C919, C922, C923, C927, C929, C931-C939, C941, C943-C947, C95
	Melanoma	C43
	Non-Hodgkin lymphoma	C82-C85
	Ovary	C56-C57
	Sarcoma: connective and soft tissue	C49
	Testis	C62

Table 3.4 Colorectal cancer groups

General Group	Group or site name	ICD10 codes	Morphology codes (where applicable)
Colorectal - Anal Cancer	Adenocarcinoma	C21	8140-8145, 8190-8231, 8260-8263, 8310
	Basaloid & cloacogenic carcinoma	C21	8123-8124
	Other	C21	8010-8034
	Squamous-cell carcinoma	C21	8050-8076

Table 3.5 Gynaecological cancer groups

General Group	Group or site name	ICD10 codes	Morphology codes (where applicable)
Gynae - Ovarian	Borderline	C56-C57	8442, 8444, 8451, 8462, 8463, 8472, 8473
	Clear cell carcinoma	C56-C57	8310
	Endometrioid carcinoma	C56-C57	8380, 8382, 8560, 8570
	Miscellaneous and unspecified	C56-C57	8000-04, 8013, 8041, 8045, 8090, 8200, 8450, 8771, 8800-04, 8830, 8840, 8850, 8852, 8854, 8858, 8890, 8891, 8895, 8896, 8900, 8902, 8920, 8930, 8963, 9220, 9364, 9540, 9580
	Mucinous carcinoma	C56-C57	8144, 8470, 8471, 8480, 8481, 8482, 8490
	Other classified epithelial and epithelial-stromal tumours	C56-C57	8020, 8021, 8050-52, 8070-74, 8082, 8120, 8313, 8323, 8381, 8931, 8933, 8940, 8950, 8951, 8980, 9000, 9013, 9014, 9015
	Serous carcinoma	C56-C57	8441, 8460, 8461
	Sex cord-stromal or germ cell tumours	C56-C57	8240, 8241, 8243, 8244, 8245, 8330, 8340, 8590, 8600, 8620, 8621, 8622, 8623, 8630, 8631, 8640, 8650, 8670, 8810, 9060, 9064, 9070, 9071, 9073, 9080, 9081, 9083, 9084, 9085, 9090, 9091, 9100, 9101, 9110, 9473
	Unclassified epithelial	C56-C57	8010, 8012, 8022, 8030-33, 8040, 8046, 8140, 8141, 8146, 8160, 8201, 8211, 8230, 8246, 8260, 8262, 8290, 8320, 8360, 8401, 8440, 8542, 8550, 8562, 8572, 8574
Gynae - Uterine	Clear cell and papillary serous carcinoma	C54-C55	8310, 8441, 8460
	Endometrioid adenocarcinoma	C54-C55	8022, 8050, 8140, 8141, 8200, 8201, 8210, 8211, 8230, 8255, 8260, 8261, 8262, 8263, 8323, 8380, 8382, 8384, 8440, 8461, 8480, 8481, 8482, 8490, 8550, 8560, 8570, 8574, 9110
	Miscellaneous and unspecified	C54-C55	8000, 8001, 8004, 8442, 8472, 8473, 8730, 8860, 8880, 9071, 9080, 9100, 9105, 9364, 9473
	Mixed epithelial and mesenchymal tumours	C54-C55	8033, 8381, 8933, 8940, 8950, 8951, 8980, 8981, 9014
	Other classified and unclassified carcinoma	C54-C55	8010, 8012, 8020, 8021, 8031, 8032, 8041, 8046, 8052, 8070, 8071, 8072, 8074-76, 8120, 8143, 8221, 8240, 8245, 8246, 8350, 8500

Table 3.6 Gynaecological cancer groups continued

General Group	Group or site name	ICD10 codes	Morphology codes (where applicable)
Gynae - Cervical	Adenocarcinoma	C53	8140, 8141, 8144, 8201, 8210,8255, 8260, 8261, 8262, 8263, 8310, 8323, 8380, 8384, 8440, 8441, 8460, 8461, 8470, 8480, 8481, 8482, 8490, 8570, 8574, 9110
	Adenosquamous	C53	8015, 8560
	Neuroendocrine	C53	8013, 8041, 8240, 8246
	Other	C53	8000-02, 8033, 8720, 8800, 8801, 8803, 8804, 8810, 8890, 8891, 8896, 8900, 8901, 8910, 8920,8930, 8933, 8950, 8951, 8963, 8980,8982, 8990, 9100, 9120, 9364, 9473, 9540, 9581
	Other epithelial	C53	8020, 8021, 8098, 8200, 8230, 8472
	Squamous carcinoma	C53	8050, 8051, 8052, 8070-77, 8082, 8083, 8084, 8120, 8123, 8130
	Unclassified epithelial	C53	8010, 8012, 8022, 8032, 8040, 8046, 8090, 8092, 8094, 8124, 8143, 8147, 8320, 8430, 8550
Gynae - Vulva	Adenocarcinoma	C51	8041, 8140, 8200, 8211, 8260, 8310, 8390, 8400, 8401, 8402, 8407, 8408, 8410, 8480, 8481, 8542, 8560, 8940
	Melanocytic	C51	8720, 8721, 8723, 8730, 8742-46, 8770-72
	Miscellaneous and unspecified	C51	8000-02, 8247, 8800, 8801, 8803, 8804, 8810, 8832, 8833, 8841, 8850, 8851, 8854, 8858, 8860, 8890, 8891, 8900, 8910, 8920, 8950, 8963, 8980, 9120, 9231
	Other classified and unclassified epithelial	C51	8010, 8011, 8012, 8020, 8033, 8147, 8246, 8320
	Squamous carcinoma	C51	8032, 8051, 8052, 8070-76, 8083, 8090-94, 8097, 8123, 8231
Gynae - Vaginal	Adenocarcinoma	C52	8140, 8144, 8260, 8262, 8263, 8310, 8380, 8441, 8450, 8460, 8480, 8481, 8490, 9110
	Melanocytic	C52	8720, 8721, 8730, 8743, 8744, 8770-72
	Miscellaneous and unspecified	C52	8000, 8001, 8004, 8033, 8933, 8935, 8950, 8951, 8980, 9071, 9100
	Other classified and unclassified epithelial	C52	8010, 8012, 8020, 8021, 8041, 8046, 8050, 8090, 8143, 8200, 8230, 8246, 8542, 8560
	Squamous carcinoma	C52	8032, 8051, 8052, 8070-74, 8076, 8083, 8094, 8123
Gynae - Placenta	Placenta	C58	-

Table 3.7 Haematological cancer groups

General Group	Group or site name	ICD10 codes
Haematology	Hodgkin lymphoma	C81
	Leukaemia: acute lymphoblastic	C910
	Leukaemia: acute myeloid	C920, C924, C925, C930, C940, C942
	Leukaemia: chronic lymphocytic	C911
	Leukaemia: chronic myeloid	C921
	Leukaemia: rarer types	C912-C919, C922, C923, C927, C929, C931-C939, C941, C943-C947, C95
	Monoclonal Gammopathy of Undetermined Significance	D472
	Multiple myeloma	C88,C90
	Myelodysplastic Syndromes	D46
	Myeloproliferative	C946
	Non-Hodgkin lymphoma	C82-C85
	Other	D470-D471,D473-D479

Table 3.8 Head and neck cancer groups

General Group	Group or site name	ICD10 codes
Head and Neck	Bone tumours	C410-C411
	External Lip	C000, C001
	Head and neck - Other sites	C00, C14
	Hypopharynx	C12-C13
	Internal Lip	C003, C004
	Larynx	C32
	Middle ear and external auditory canal	C301,C442
	Nasal cavity (only excluding middle ear)	C300
	Nasopharynx	C11
	Oral cavity	C02-C04, C06, C050
	Oropharynx	C01, C09-C10
	Palate	C05
	Thyroid	C73
	Salivary glands	C07-C08
	Sinuses	C31

Table 3.9 Lung cancer groups

General Group	Group or site name	ICD10 codes	Morphology codes (where applicable)
Lung	Mesothelioma	C45	-
	Pulmonary carcinoids	C349	8240-8249
	Solitary fibrous tumours of pleura	C384	8815
	Thymomas	C379	8580-8589

Table 3.10 Sarcoma groups

General Group	Group or site name	ICD10 codes	Morphology codes (where applicable)
Sarcoma - Bone Sarcomas (C40-C41)	Adamantinoma of long bones; tibial adamantinoma (C40.2)	-	9261
	Alveolar rhabdomyosarcoma	-	8920
	Ameloblastic fibrosarcoma: Ameloblastic sarcoma: Odontogenic fibrosarcoma	-	9330
	Ameloblastoma	-	9310
	Central osteosarcoma (C40._, C41._)	-	9186
	Chondroblastic osteosarcoma (C40._, C41._)	-	9181
	Chondroblastoma, malignant (C40._, C41._)	-	9230
	Chondroid chordoma	-	9371
	Chondrosarcoma	-	9220
	Chordoma	-	9370
	Clear cell chondrosarcoma, (C40._, C41._)	-	9242
	Dedifferentiated chondrosarcoma (C40._, C41._)	-	9243
	Dedifferentiated chordoma	-	9372
	Desmoplastic small round cell tumour	-	8806
	Epithelioid haemangioendothelioma, malignant	-	9133
	Epithelioid sarcoma, epithelioid cell sarcoma	-	8804
	Ewing's sarcoma, Ewing's tumour, Extraskeletal Ewing tumour	-	9260
	Fibroblastic osteosarcoma (C40._, C41._); osteofibrosarcoma (C40._, C41._)	-	9182
	Fibromyxosarcoma	-	8811
	Fibrous histiocytoma, malignant; fibroxanthoma, malignant	-	8830
	Giant cell sarcoma (except of bone M9250/3); pleomorphic cell sarcoma	-	8802
	Giant cell tumour of bone, NOS	-	9250
	Haemangioendothelioma, NOS, Kaposiform haemangioepithelioma	-	9130
	Haemangiopericytoma, NOS	-	9150
	Haemangiosarcoma, Angiosarcoma of soft tissue	-	9120
	Infantile fibrosarcoma; congenital fibrosarcoma	-	8814
	Inflammatory myofibroblastic tumour, Myofibroblastic tumour, NOS	-	8825
	Intraosseous well differentiated osteosarcoma (C40._, C41._)	-	9187

Table 3.11 Sarcoma groups continued

General Group	Group or site name	ICD10 codes	Morphology codes (where applicable)
Sarcoma - Bone Sarcomas (C40-C41)	Juxtacortical chondrosarcoma (C40._, C41._)	-	9221
	Leiomyosarcoma, NOS	-	8890
	Liposarcoma, NOS; fibroliposarcoma	-	8850
	Liposarcoma, well differentiated; Liposarcoma, differentiated	-	8851
	Malignant peripheral nerve sheath tumour MPNST, NOS	-	9540
	Mesenchymal chondrosarcoma	-	9240
	Myoepithelioma	-	8982
	Myxoid chondrosarcoma	-	9231
	Myxoid Liposarcoma; myxoliposarcoma	-	8852
	Odontogenic tumour	-	9270
	Osteochondromatosis	-	9210
	Osteosarcoma in Paget's disease of bone (C40._, C41._)	-	9184
	Osteosarcoma, NOS (C40._, C41._)	-	9180
	Parosteal osteosarcoma (C40._, C41._)	-	9192
	Periosteal fibrosarcoma (C40._, C41._); periosteal sarcoma, NOS (C40._, C41._)	-	8812
	Periosteal osteogenic sarcoma (C40._, C41._)	-	9193
	Peripheral neuroectodermal tumour; neuroectodermal tumour, NOS	-	9364
	Pleomorphic liposarcoma	-	8854
	Primitive neuroectodermal tumour	-	9473
	Rhabdomyosarcoma, NOS; rhabdosarcoma	-	8900
	Sarcoma, NOS	-	8800
	Small cell osteosarcoma (C40._, C41._)	-	9185
	Small cell sarcoma; round cell sarcoma	-	8803
	Solitary fibrous tumour, NOS	-	8815
	Spindle cell sarcoma	-	8801
	Synovial sarcoma, biphasic	-	9043
	Synovial sarcoma, NOS; synovioma, NOS; synovioma, malignant	-	9040
	Synovial sarcoma, spindle cell	-	9041
	Telangiectatic osteosarcoma (C40._, C41._)	-	9183
	Undifferentiated sarcoma	-	8805
Sarcoma	Gastrointestinal stromal tumours	-	8936

Table 3.12 Sarcoma groups continued

General Group	Group or site name	ICD10 codes	Morphology codes (where applicable)
Sarcoma - Soft tissue sarcomas	Adamantinoma of long bones; tibial adamantinoma (C40.2)	-	9261
	Adenosarcoma	-	8933
	Alveolar rhabdomyosarcoma	-	8920
	Alveolar soft part sarcoma	-	9581
	Ameloblastoma	-	9310
	Angiomyoliposarcoma	-	8860
	Angiomyosarcoma	-	8894
	Angiomyxoma	-	8841
	Askin tumour	-	9365
	Chondroblastoma, malignant (C40._, C41._)	-	9230
	Chondroid chordoma	-	9371
	Chondrosarcoma	-	9220
	Chordoma	-	9370
	Clear cell sarcoma (except of kidney M8964/3)	-	9044
	Clear cell sarcoma of kidney	-	8964
	Dedifferentiated chondrosarcoma (C40._, C41._)	-	9243
	Dedifferentiated chordoma	-	9372
	Dedifferentiated liposarcoma	-	8858
	Dermatofibrosarcoma, NOS (C44._); dermatofibrosarcoma protuberans, NOS (C44._)	-	8832
	Desmoplastic small round cell tumour	-	8806
	Embryonal rhabdomyosarcoma; sarcoma botryoides; botryoid sarcoma	-	8910
	Embryonal sarcoma	-	8991
	Endometrial stromal sarcoma (C54.1)	-	8930
	Endometrial stromal sarcoma, low grade	-	8931
	Epithelioid haemangioendothelioma, malignant	-	9133
	Epithelioid leiomyosarcoma	-	8891
	Epithelioid sarcoma, epithelioid cell sarcoma	-	8804
	Ewing's sarcoma, Ewing's tumour, Extraskeletal Ewing tumour	-	9260

Table 3.13 Sarcoma groups continued

General Group	Group or site name	ICD10 codes	Morphology codes (where applicable)
Sarcoma - Soft tissue sarcomas	Fibroblastic liposarcoma	-	8857
	Fibromyxosarcoma	-	8811
	Fibrosarcoma, NOS, sclerosing epitheliod fibrosarcoma	-	8810
	Fibrous histiocytoma, malignant; fibroxanthoma, malignant	-	8830
	Giant cell sarcoma (except of bone M9250/3); pleomorphic cell sarcoma	-	8802
	Giant cell tumour of soft parts, NOS	-	9251
	Granular cell tumour, malignant; granular cell myoblastoma, malignant	-	9580
	Haemangioendothelioma, NOS, Kaposiform haemangioepithelioma	-	9130
	Haemangiopericytoma, NOS	-	9150
	Haemangiosarcoma, Angiosarcoma of soft tissue	-	9120
	Infantile fibrosarcoma; congenital fibrosarcoma	-	8814
	Inflammatory myofibroblastic tumour, Myofibroblastic tumour, NOS	-	8825
	Kaposi sarcoma; Multiple haemorrhagic sarcoma	-	9140
	Leiomyosarcoma, NOS	-	8890
	Liposarcoma, NOS; fibroliposarcoma	-	8850
	Liposarcoma, well differentiated; Liposarcoma, differentiated	-	8851
	Lymphangiosarcoma; lymphangioendothelial sarcoma	-	9170
	Malignant peripheral nerve sheath tumour MPNST, NOS	-	9540
	Malignant peripheral nerve sheath tumour with thabdomyoblastic differentiation	-	9561
	Malignant schwannoma; neurilemoma, malignant	-	9560
	Malignant tenosynovial giant cell tumour (C49._)	-	9252
	Mesenchymal chondrosarcoma	-	9240
	Mesenchymoma, malignant; mixed mesenchymal sarcoma	-	8990
	Mixed liposarcoma	-	8855
	Mixed type rhabdomyosarcoma	-	8902
	Myoepithelioma	-	8982
	Myosarcoma	-	8895
	Myxoid chondrosarcoma	-	9231

Table 3.14 Sarcoma groups continued

General Group	Group or site name	ICD10 codes	Morphology codes (where applicable)
Sarcoma - Soft tissue sarcomas	Myxoid leiomyosarcoma	-	8896
	Myxoid Liposarcoma; myxoliposarcoma	-	8852
	Myxosarcoma	-	8840
	Odontogenic tumour	-	9270
	Osteosarcoma, NOS (C40._, C41._)	-	9180
	Perineurioma, malignant; Perineural MPNST	-	9571
	Peripheral neuroectodermal tumour; neuroectodermal tumour, NOS	-	9364
	Phyllodes tumour, malignant (C50.) Cystosarcoma phyllodes, malignant (C50.)	-	9020
	Pigmented dermatofibrosarcoma protuberans; Bednar tumour	-	8833
	Pleomorphic liposarcoma	-	8854
	Pleomorphic rhabdomyosarcoma	-	8901
	Primitive neuroectodermal tumour	-	9473
	Rhabdoid sarcoma	-	8963
	Rhabdomyosarcoma with ganglionic differentiation; Ectomesenchymoma	-	8921
	Rhabdomyosarcoma, NOS; rhabdosarcoma	-	8900
	Round cell liposarcoma	-	8853
	Sarcoma, NOS	-	8800
	Small cell sarcoma; round cell sarcoma	-	8803
	Smooth muscle tumour	-	8897
	Solitary fibrous tumour, NOS	-	8815
	Spindle cell rhabdomyosarcoma	-	8912
	Spindle cell sarcoma	-	8801
	Stromal Sarcoma	-	8935
	Synovial sarcoma, biphasic	-	9043
	Synovial sarcoma, epithelioid cell	-	9042
	Synovial sarcoma, NOS; synovioma, NOS; synovioma, malignant	-	9040
	Synovial sarcoma, spindle cell	-	9041
	Undifferentiated sarcoma	-	8805

Table 3.15 Skin cancer groups

General Group	Group or site name	ICD10 codes	Morphology codes (where applicable)
Skin	Apocrine carcinoma	C43-C44, D23	8401/3
	Atypical fibroxanthoma (AFX) (superficial malignant fibrous)	C43-C44, D23	8830/1
	Cutaneous lymphomas (Cutaneous Cell Lymphoma incl Mycosis fungoides, Sezary disease)	C43-C44, D23	9700/3,9701/3
	Cutaneous malignant nerve sheath tumours (including cutaneous neurofibrosarcoma and malignant Schwannoma)	C43-C44, D23	9540/3
	Dermatofibrosarcoma protuberans (DFSP)	C43-C44, D23	8832/3
	Digital papillary adenocarcinoma	C43-C44, D23	8408/1
	Eccrine epithelioma (syringoid carcinoma)	C43-C44, D23	8407/3
	Eccrine porocarcinoma	C43-C44, D23	8409/3
	Fibro-epithelial tumour of Pinkus	C43-C44, D23	8093/3
	Haemangioendothelioma	C43-C44, D23	9130/3
	Hidradenocarcinoma	C43-C44, D23	8402/3
	histiocytoma (superficial sarcoma not otherwise specified)	C43-C44, D23	8830/3
	Malignant cylindroma	C43-C44, D23	8200/3
	Malignant epithelioid haemangioendothelioma	C43-C44, D23	9133/3
	Malignant pilar tumour	C43-C44, D23	8103/0
	Malignant pilomatrixoma	C43-C44, D23	8110/3
	Malignant spiradenoma	C43-C44, D23	8403/3
	Microcystic adnexal carcinoma (sweat gland carcinoma)	C43-C44, D23	8400/3
	Mixed tumour, NOS	C43-C44, D23	8940/3
	Neuroendocrine carcinoma (Merkel cell tumour/trabecular carcinoma)	C43-C44, D23	8247/3
	Pleomorphic carcinoma of the skin	C43-C44, D23	8022/3
	Primary adenoid cystic carcinoma	C43-C44, D23	8200/3
	primary cutaneous CD30+ T cell lymphoproliferative disorder	C43-C44, D23	9718/3
	Primary mucinous carcinoma	C43-C44, D23	8480/3
	Primary mucoepidermoid carcinoma	C43-C44, D23	8430/3
	Sebaceous carcinoma	C43-C44, D23	8410/3
	Skin Appendage	C43-C44, D23	8390/3
	Tumours associated with Muir–Torre syndrome (Sebaceous carcinoma see above)	C43-C44, D23	8410/3

Table 3.16 Upper gastro-intestinal (UGI) cancer groups

General Group	Group or site name	ICD10 codes
Upper GI	Ampulla of Vater	C241
	Biliary tract cancer (or cholangiocarcinoma or bile duct cancer (intra- or extrahepatic))	C221, C240, C248, C249
	Duodenal cancer	C170
	Gallbladder cancer	C23
	Pancreas	C25
	Primary liver (excluding intrahepatic bile duct cancer)	C220, C222 – C229

Table 3.17 Urological cancer groups

General Group	Group or site name	ICD10 codes	Morphology codes (where applicable)
Urology	Non-TCC bladder	C67, D090, D414	(exclude 8120 - 8130 (TCC) and 8000 and 8021 (unspecific codes))
	Para-testicular neoplasms (epididymis and spermatic cord)	C630, C631	-
	Penile cancer	C60	-
	Small-cell prostate	C61	8041, 8043, 8803
	Testicular	C62	-
	Ureter and renal pelvis	C65, C66, D411, D412	-
	Urethral cancer	C680, D413	-

Cancer site lists for mortality

The following tables show the cancer sites groupings used for mortality calculations. Sites marked with an asterisk (*) have coding combinations that do not directly map on to the equivalent incidence groupings and should not be directly compared.

Table 4.0 Breast cancer groups

General Group	Group or site name	ICD10 codes
Breast - male	Male breast	C50
Breast	Nipple and areola (persons)	C500

Table 4.1 Central nervous system cancer groups

General Group	Group or site name	ICD10 codes
Central Nervous System	Brain	C71, D330-D332, D430-D432
	CNS unspecified/unknown	C728-C729, D337-D339, D437,D439
	Intracranial endocrine	C75, D352-D354, D443-D445
	Meninges	C70, D320, D321, D329, D420, D421, D429
	Spinal cord and Cranial nerves	C72, D333-D334, D433-D434

Table 4.2 Children's (0 to 14 years old) cancer groups

General Group	Group or site name	ICD10 codes
Children (0 to14)	Central Nervous System (incl brain) malignant	C70-C72, C751-C753
	Central Nervous System (incl brain) non-invasive	D32, D33, D352-D354, D42-D43, D443-D445
	Hodgkin lymphoma	C81
	Kidney	C64
	Kidney and unspecified urinary organs	C64-C66, C68
	Leukaemia: acute lymphoblastic	C910
	Leukaemia: acute myeloid	C920, C924, C925, C930, C940, C942
	Leukaemia: other (all excluding ALL, AML and CLL)	C921, C912-C919, C922, C923, C927, C929, C931-C939, C941, C943-C947, C95
	Non-Hodgkin lymphoma	C82-C85
	Sarcoma: connective and soft tissue	C49

Table 4.3 Teenagers and young adults (15 to 24 years old) cancer groups

General Group	Group or site name	ICD10 codes
Teenagers & young adults (15 to 24)	Central Nervous System (incl brain) malignant	C70-C72, C751-C753
	Central Nervous System (incl brain) non-invasive	D32, D33, D352-D354, D42-D43, D443-D445
	Cervix	C53
	Cervix (in-situ)	D06
	Colorectal	C18-C20
	Female breast cancer	C50
	Head and neck – Thyroid	C73
	Hodgkin lymphoma	C81
	Kidney	C64
	Leukaemia: acute lymphoblastic	C910
	Leukaemia: acute myeloid	C920, C924, C925, C930, C940, C942
	Leukaemia: other (all excluding ALL, AML and CLL)	C921, C912-C919, C922, C923, C927, C929, C931-C939, C941, C943-C947, C95
	Melanoma	C43
	Non-Hodgkin lymphoma	C82-C85
	Ovary	C56-C57
	Sarcoma: connective and soft tissue	C49
	Testis	C62

Table 4.4 Colorectal cancer groups

General Group	Group or site name	ICD10 codes
Colorectal*	Anal Cancer	C21

Table 4.5 Gynaecological cancer groups

General Group	Group or site name	ICD10 codes
Gynae*	Cervix	C53
	Ovary	C56-C57
	Placenta	C58
	Uterus	C54-C55
	Vagina	C52
	Vulva	C51

Table 4.6 Haematological cancer groups

General Group	Group or site name	ICD10 codes
Haematology	Hodgkin lymphoma	C81
	Leukaemia: acute lymphoblastic	C910
	Leukaemia: acute myeloid	C920, C924, C925, C930, C940, C942
	Leukaemia: chronic lymphocytic	C911
	Leukaemia: chronic myeloid	C921
	Leukaemia: rarer types	C912-C919, C922, C923, C927, C929, C931-C939, C941, C943-C947, C95
	Monoclonal Gammopathy of Undetermined Significance	D472
	Multiple myeloma	C88,C90
	Myelodysplastic Syndromes	D46
	Myeloproliferative	C946
	Non-Hodgkin lymphoma	C82-C85
	Other	D470-D471,D473-D479

Table 4.7 Head and neck cancer groups

General Group	Group or site name	ICD10 codes
Head and Neck	Bone tumours	C410-C411
	External Lip	C000, C001
	Head and neck - Other sites	C00, C14
	Hypopharynx	C12-C13
	Internal Lip	C003, C004
	Larynx	C32
	Middle ear and external auditory canal	C301,C442
	Nasal cavity (only excluding middle ear)	C300
	Nasopharynx	C11
	Oral cavity	C02-C04, C06, C050
	Oropharynx	C01, C09-C10
	Palate	C05
	Thyroid	C73
	Salivary glands	C07-C08
	Sinuses	C31

Table 4.8 Lung cancer groups

General Group	Group or site name	ICD10 codes
Lung*	Mesothelioma	C45
	Pleura	C384
	Thymomas	C379

Table 4.9 Sarcoma groups

General Group	Group or site name	ICD10 codes
Sarcoma*	Bone sarcomas	C40-C41
	Soft tissue sarcomas	C48-C49

Table 4.10 Skin cancers groups

General Group	Group or site name	ICD10 codes
Skin*	Malignant neoplasm of skin, unspecified	C449
	Mycosis fungoides	C840
	Other mature T/NK-cell lymphomas	C845
	Overlapping lesion of skin	C448
	Peripheral T-cell lymphoma, not elsewhere	C844
	Sézary disease	C841
	Skin of ear and external auricular canal	C442
	Skin of eyelid, including canthus	C441
	Skin of lip	C440
	Skin of lower limb, including hip	C447
	Skin of other and unspecified parts of face	C443
	Skin of scalp and neck	C444
	Skin of trunk	C445
	Skin of upper limb, including shoulder	C446

Table 4.11 Upper gastro-intestinal (UGI) cancers groups

General Group	Group or site name	ICD10 codes
Upper GI	Ampulla of Vater	C241
	Biliary tract cancer (or cholangiocarcinoma or bile duct cancer (intra- or extrahepatic))	C221, C240, C248, C249
	Duodenal cancer	C170
	Gallbladder cancer	C23
	Pancreas	C25
	Primary liver (excluding intrahepatic bile duct cancer)	C220, C222 – C229

Table 4.12 Urological cancers groups

General Group	Group or site name	ICD10 codes
Urology*	Bladder	C67, D090, D414
	Para-testicular neoplasms (epididymis and spermatic cord)	C630, C631
	Penile cancer	C60
	Testicular	C62
	Ureter and renal pelvis	C65, C66, D411, D412
	Urethral cancer	C680, D413

About Cancer52

Cancer52 is an alliance of more than 80 predominantly small cancer charities united by their vision of seeing a better future for everyone affected by rare and less common cancers, which account for more than half of all cancer deaths in the UK. Their aim is to promote improved diagnosis, treatment and support for those affected, leading to improved quality of life and increased survival.

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