Announcement of methodological changes to Cancer registration in England

Background

Most official statistics reporting on cancer use cancer sites that are based only on where the cancer started growing in the body. This can be a helpful way to summarise cancers but, for certain cancers, may hide the different types of cancer that grow in the same place. These different types of cancer can need different treatments even though they are found in the same part of the body. From 2013, cancers have been registered by the National Disease Registration Service using ICD-O-3, these were previously coded in ICD-10 and ICD-O2. The ICD-O-3 coding system allows for better reporting by type of cancer.

To better reflect the variety of cancers that patients are diagnosed and treated with, this publication introduces new cancer groupings. The different groupings introduced have been consulted upon with patient representatives, charities and clinicians. These groupings will gradually evolve to reflect changes in medical knowledge and clinical practice; some parts of the body have yet to mapped in detail and these will be added to over time.

Some common cancers have a single detailed level of cancer grouping. Examples of this include breast and prostate cancer. Instead of grouping by individual cancer cell types, the Gleason score (a measure of how aggressive a diagnosis of prostate cancer) has been included as counts and rates. For breast cancer, a series of counts and rates by hormone receptor statuses is included.

Integrated Care Systems were legally established on 1 July 2022, covering all of England. Each ICS has an Integrated care board (ICB) which are NHS organisations responsible for planning health services for their local population. ICBs, NHS trusts and NHS foundation trusts are working in collaboration with Cancer Alliances to deliver approaches to help achieve the NHS Long Term Plan ambition of diagnosing 75% of patients at stage 1 or 2 by 2029. To help ICBs and Cancer Alliances monitor cancer activity and groups facing inequalities, this publication will now present cancer incidence at and England, ICB and Cancer Alliance level, grouping by gender, deprivation quintile and stage at diagnosis, where possible.

Methodological changes

A new way to present cancers

The main report and tables will report on tumours grouped into clinically relevant groups which are based on site or type of cancer, as appropriate. There are two levels of grouping employed, a primary level of up to 35 cancer groups cover every registerable diagnosis

(Main group), 31 of which are used for analysis in this publication. The secondary level groupings, where they exist, can be more precise groupings (Detailed group). For example, the detailed level of blood cancers contains 16 subtypes. The groupings are listed in Appendix A. The codes used to define the groupings can be found as an Appendix to the Cancer registration in England publication (this may change over time to reflect changes in medical knowledge and clinical practice).

Cancer deaths are still registered using ICD-10. Therefore, to enable a comparison between incidence and mortality the publication will also present a tables for incidence and mortality by ICD-10 3-digit code. These figures will be grouped by gender and age group for England only. We will no longer report by ICD-10 4-digit code.

Grade group of prostate cancer

The grade group is the system doctors use to grade prostate cancer; it was previously known as the Gleason score. There are 5 Grade Groups. Grade Group 1 is the least aggressive and Grade Group 5 is the most aggressive. The Grade Group, along with other factors, is used to determine what treatment pathway a patient should be on. How aggressive a tumour is and the treatment they receive is likely to affect survival. This publication now includes prostate cancer incidence figures by Grade Group. Table 1 shows the combinations of Gleason scores which make up each Grade Group.

Table 1: Gleason score combinations used with prostate cancer.

Grade Group	Gleason scores (the two most common scores added together)
1	6 (3+3)
2	7 (3+4)
3	7 (4+3)
4 & 5	8, 9 or 10 (4+4, 4+5, 5+4 or 5+5)
Unknown	Not recorded
All	Scores 6 to 10 and not recorded

Hormone receptor status

Some breast cancers cells are hormone-sensitive, they contain proteins on their surface called hormone receptors. When a hormone binds to these receptors it can cause the cells to grow faster. The hormone receptors associated with breast cancer are Oestrogen receptor (ER), Progesterone receptor (PR) and Human epidermal growth factor receptor 2 (HER2). When there is a higher level of these receptors on the breast cancer cells surface, these are known as positive (e.g. ER-positive). If there are normal levels of hormone receptor, they are known as negative (e.g. ER-negative). This publication now presents breast cancer by hormone status. Table 2 provides the combinations of hormone receptor status presented in this publication.

Table 2: Hormone receptor status combinations presented for breast cancer

Oestrogen (ER)	Progesterone (PR)	Human epidermal growth factor receptor 2 (HER2)	Sometimes called
Any	Any	Any	
Borderline Negative Positive Unknown	Any	Any	
Any	Borderline Negative Positive Unknown	Any	
Any	Any	Borderline Negative Positive Unknown	
Negative	Negative	Negative	Triple negative

Geographical breakdowns

This publication previously presented cancer incidence for England and for Government Office Regions. This will now be replaced with cancer incidence for England, ICBs and Cancer Alliances to better reflect health care systems and monitoring of services. We will present breakdowns of cancer incidence by:

- Cancer group, age group, gender and deprivation quintile for England, ICBs and Cancer Alliances (where numbers allow)
- Age group, gender, deprivation quintile and Gleason group for prostate cancers in England
- Age group, gender, deprivation quintile and hormone receptor status for breast cancers in England
- Cancer group, age group, gender and stage at diagnosis for England, ICBs and Cancer Alliances (where numbers allow)
- Age group, gender, stage at diagnosis and Gleason group for prostate cancers in England
- Age group, gender, stage at diagnosis and hormone receptor status for breast cancers in England

Timing

The first publication to be affected by this change will be the May 2024 release, which will cover the period:

- Adults diagnosed with cancer in 2021

Impact

The impact of the above changes on Cancer registrations in England is expected to be minimal. We are still providing a table with ICD-10 groups so that comparison can be made to mortality statistics as well as incidence statistics outside of England.

Further information

Questions and feedback on the publication are welcomed and should be sent to NDRSenquiries@nhs.net or alternatively call 0300 303 5678.

Appendix A – 31 main cancer groups used in Cancer Registration Statistics, England 2021 publication

Main group	Detailed group
Anus	Not applicable
Bladder	All Bladder Bladder - malignant or in situ Bladder - uncertain or unknown
Blood	All Blood Acute lymphoblastic leukaemia (ALL) Acute myeloid leukaemia (AML) Chronic lymphocytic leukaemia (CLL) or small lymphocytic lymphoma (SLL) Chronic myeloid leukaemia (CML) Chronic myelomonocytic leukaemia (CMML) Diffuse large B-cell lymphoma (DLBCL) and other high grade mature B-cell neoplasms Essential thrombocythaemia (ET) Follicular lymphoma Hodgkin lymphoma Lymphoplasmacytic lymphoma (LPL) or Waldenstrom Mantle cell lymphoma (MCL) Marginal zone lymphoma (nodal, extranodal, MALT) Mature T-cell and NK-cell neoplasms Myelodysplastic syndromes (MDS) Myeloma Other blood cancer Polycythaemia vera (PCV)
Bone Sarcoma	All Bone Bone tumours of intermediate behaviour Chondrosarcoma Chordoma Ewing sarcoma Osteosarcoma Other malignant bone tumours
Bowel	All Bowel Colon Rectosigmoid junction Rectum

Brain	All Brain Benign endocrine Malignant brain Non-benign endocrine Non-malignant brain
Breast	Not applicable
Cancer of unknown primary	All Cancer of unknown primary CUP - Malignant neoplasm, without specification of site CUP - Secondary and unspecified malignant neoplasm of lymph nodes CUP - Secondary malignant neoplasm of other and unspecified sites CUP - Secondary malignant neoplasm of respiratory and digestive organs
Cervix	Not applicable
Endocrine glands excluding brain	All Endocrine glands excluding brain Non-thyroid endocrine glands Thyroid
Eye	Not applicable
Head and neck	All Head and neck Hypopharynx Larynx Major salivary glands Middle ear, and other, and ill-defined head and neck sites Nasal cavity and sinus Nasopharynx Oral cavity Oropharynx
Heart, mediastinum, pleura and ill-defined	Not applicable
Kidney	All Kidney Chromophobe RCC Clear cell RCC Kidney - other Papillary RCC Renal cell carcinoma NOS Wilms (Nephroblastoma)
Liver and biliary tract	All Liver and biliary tract Ampulla of Vater Cholangiocarcinoma Gallbladder

	Liver excluding intrahepatic cholangiocarcinoma
Lung	All Lung Non-small cell lung cancer Small cell lung cancer
Mesothelioma	Not applicable
Oesophagus	All Oesophagus Oesophagogastric junction Oesophagus - overlapping lesion and unspecified Oesophagus lower third Oesophagus upper and middle third
Ovary	All Ovary Ovary - borderline Ovary - malignant epithelial Ovary - miscellaneous and unspecified Ovary - non-specific site Ovary - sex cord-stromal and germ cell
Pancreas	All Pancreas Pancreas - Carcinoma and Other Pancreas - Neuroendocrine
Prostate	Not applicable
Renal pelvis and ureter	All Renal pelvis and ureter Renal pelvis and ureter - malignant or in situ Renal pelvis and ureter - uncertain or unknown
Skin tumour	All Skin tumour Melanoma Non melanoma skin cancer Other skin tumour
Small intestine	Not applicable
Soft tissue sarcoma	All Soft tissue sarcoma Dermatofibrosarcoma protuberans Endometrial stromal sarcoma Gastrointestinal stromal sarcoma (GIST) Kaposi sarcoma Leiomyosarcoma Liposarcoma Malignant peripheral nerve sheath tumour (MPNST) Myofibrosarcomas and other fibroblastic sarcomas

	Myxoid fibroblastic sarcomas Other malignant soft tissue tumours Phyllodes Rhabdomyosarcoma Soft tissue tumours of intermediate behaviour Synovial Tumours of uncertain differentiation Undifferentiated Sarcoma Vascular Tumours
Stomach	All Stomach Cardia GIST located in stomach Non-Cardia Stomach - overlapping lesion and unspecified
Testes	All Testes Non-seminoma Seminoma Testes - other
Thymus	Not applicable
Urethra	Not applicable
Uterus	All Uterus Uterus - endometrial Uterus - non-endometrial
Vagina	Not applicable