

Data quality and completeness report: 2010 registrations

Head and Neck Cancer Site Specific Clinical Reference Group

This report has been compiled by

Dr Gabriele Price, Senior Public Health Analyst – Knowledge and Intelligence Team (South East),
Public Health England

With acknowledgements

Dr Monica Roche, Acting Director – Knowledge and Intelligence Team (South East), Public Health
England

Rachel Johnson, Public Health Analyst – Knowledge and Intelligence Team (South East), Public
Health England

Contents

KEY FINDINGS	1
INTRODUCTION	2
METHODS	3
RESULTS	4
1. Patient details	4
1.1 Sex	4
1.2 Date of birth	4
1.3 NHS number	5
1.4 Ethnicity	5
1.5 Postcode	6
2. Tumour details	6
2.1 Tumour site	6
2.2 Morphology system	8
2.3 Morphology coding	8
2.4 Laterality	10
3. Diagnosis details	11
3.1 Basis of diagnosis	11
3.2 Diagnosis date	11
3.3 Death Certificate Only registrations	12
4. Treatment	12
4.1 Surgery	12
4.2 Radiotherapy	13
4.3 Chemotherapy	14
4.4 Hormone therapy	14
5. Death details	14
5.1 Date of death	14
5.2 Cause of death	15
5.3 Place of death	16
6. Stage details	16
6.1 Tumour grade	16
6.2 Tumour size	17
6.3 Nodes examined	18
6.4 Nodes positive	18
6.5 Metastases	19
6.6 Clinical stage	19
6.7 Pathological stage	22
6.8 Integrated stage	24
APPENDIX 1: HEAD AND NECK CANCER DEFINITION	28
APPENDIX 2: PAIRED HEAD AND NECK CANCER SITES	29
APPENDIX 3: QUALITY OF THE HEAD AND NECK CANCER DATASET, ENGLAND 2010	30

Key findings

The National Cancer Data Repository (NCDR) holds merged data from the eight English cancer registries for cancers diagnosed in the years 1990 to 2010. The purpose of this report is to compare the completeness and quality of coding of the main data items held in the NCDR for head and neck cancers diagnosed in 2010.

- **Patient details:** Level of completeness is generally high. Ethnicity coding for North West Cancer Intelligence Service was low in comparison to other registries.
- **Tumour details:** Site was 100% complete for all registries, as was morphology except for West Midlands Cancer Intelligence Unit (99.4% complete). However, 26.1% of site codes were in the unspecified subcategory. All registries used specific morphology codes.
- **Diagnosis data:** Basis of diagnosis was more than 99% complete for all registries. Diagnosis date was 100% complete, but 0.3% of dates were partly imputed.
- **Treatment:** The level of surgical treatment recorded varied from 38.2% to 87.3%. It is not clear why this is but is probably more likely to reflect variations in ascertainment, and in whether diagnostic procedures are counted, rather than treatment practice. Radiotherapy recording ranged from 11.5% to 56.8% and chemotherapy from 5.2% to 23.7%.
- **Cause of death:** Level of completeness was high (over 98%).
- **Place of death:** There were wide variations in the level of completeness, with Thames Cancer Registry not submitting any place of death data.
- **Stage:** Recording of stage remains low, with wide variations between registries. Some improvement has been recorded in recent years.

The recording of tumour grade, size, nodes examined, positive nodes and metastases varied between the cancer registries. Northern & Yorkshire Cancer Registry & Information Service and Oxford Cancer Intelligence Unit had 0% of the head and neck cancers with a recording of size. Trent Cancer Registry had the lowest proportion of tumours with nodes examined and nodes positive (6.1%) and completeness of metastases field was lowest in Trent Cancer Registry (2.1%).

West Midlands Cancer Intelligence Unit showed the highest recording of pathological TNM. Only West Midlands Cancer Intelligence Unit, Northern & Yorkshire Cancer Registry & Information Service and North West Cancer Intelligence Service recorded clinical TNM. Eastern Cancer Registration & Information Centre had over 60% of cancers with integrated TNM, whereas the recording for Thames Cancer Registry, South West Cancer Intelligence Service and Oxford Cancer Intelligence Unit was 0% for this field. As the individual T, N and M components have higher level of completeness, the proportion of overall TNM stage grouping can be increased by integrating all individual components during analysis.

Introduction

The National Cancer Intelligence Network (NCIN) Head and Neck Cancer Site Specific Clinical Reference Group (SSCRG) covers cancers of the head and neck, including the larynx, oral cavity, pharynx, major salivary glands and thyroid gland ([Appendix 1](#)). The Knowledge and Intelligence Team (South East), Public Health England supports the SSCRG's analytical work programme and leads on requests for data on head and neck cancer. The National Cancer Data Repository (NCDR) is often used for analysis. The NCDR holds merged data from the eight English cancer registries for cases diagnosed in the years 1990 to 2010.

Poor quality data or large proportion of missing information in the NCDR can affect the ability to carry out analyses on specific sub-groups of head and neck cancers and also it can potentially lead to inaccurate conclusions to be drawn. Therefore, this report aims to examine:

- the completeness and quality of coding of the main data items held in the NCDR for head and neck cancers diagnosed in 2010; and
- where possible, trends in data completeness for the period 2001 to 2010.

The report uses the cancer registration boundaries and organisational names as in existence in England in 2010 and, therefore, it does not reflect changes in NHS England that took place on 1st April 2013.

Methods

Patients diagnosed with head and neck cancer between 2001 and 2010 were extracted from the NCDR. There were 94,584 new diagnoses recorded in the period with 10,405 tumours diagnosed in 2010 (Table 1). Thames Cancer Registry with over 2,100 new diagnoses registered the highest number of head and neck cancers in 2010, whereas Oxford Cancer Intelligence Unit had the lowest number of registration with over 510 tumours recorded and this reflects the size of the population covered by the registries.

Table 1. Number of head and neck cancers diagnosed in 2010 (England) by cancer registry* of residence

Cancer registry code	Cancer registry name	Numb of cancers
ECRIC	Eastern Cancer Registration & Information Centre	1,046
NWCIS	North West Cancer Intelligence Service	1,576
NYCRIS	Northern & Yorkshire Cancer Registry & Information Service	1,521
OCIU	Oxford Cancer Intelligence Unit	511
SWCIS	South West Cancer Intelligence Service	1,421
Thames	Thames Cancer Registry	2,104
Trent	Trent Cancer Registry	1,074
WMCIU	West Midlands Cancer Intelligence Unit	1,152

* Cancer registries boundaries and names as present in 2010

In 2010 for the first time the NCDR structure was based around the Office for National Statistics (ONS) Cancer Dataset with additional information coming from a merged dataset of cancer registry data. Further information on the 2010 NCDR can be found on the NCIN website¹. This report presents largely analyses based on data fields supplied by the cancer registries. For some data fields combining ONS and registry data fields (date of birth or date of death) provided more comprehensive information. If this was the case, the completeness of data was examined using both fields.

¹ National Cancer Intelligence Network. *National Cancer Data Repository*. [Online]. Available from: http://www.ncin.org.uk/collecting_and_using_data/national_cancer_data_repository/

Results

Analyses were carried using the following sub-categories:

1. patient details (sex, date of birth, NHS number, ethnicity, postcode);
2. tumour details (tumour site, morphology system, morphology coding, laterality);
3. diagnosis details (basis of diagnosis, diagnosis date, death certificates only);
4. treatment (surgery, radiotherapy, chemotherapy, hormone therapy);
5. death details (date of death, cause of death, place of death); and
6. stage details (tumour grade, tumour size, nodes examined, nodes positive, metastases, UICC staging system, TNM clinical, TNM pathological, TNM integrated).

Findings are presented as charts below. Tables with percentages can be found in [Appendix 3](#).

1. Patient details

1.1 Sex

The sex field was 100% complete for 2010 registrations with an average of 60% of cases in males and 40% in females. The sex distribution differed by cancer site (Figure 1.1). Larynx cancer was more common in men (83.1%), whereas women were more frequently diagnosed with thyroid cancers (71.6%).

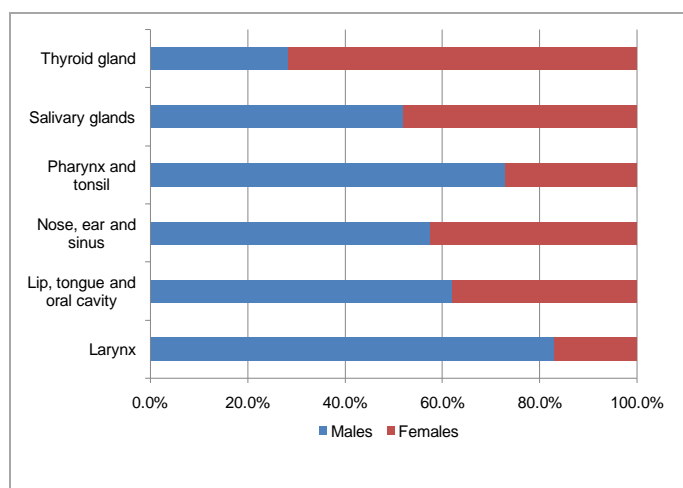


Figure 1.1 Sex distribution by head and neck cancer site

1.2 Date of birth

All records could be allocated a complete recording for date of birth. There were no records with date imputation flag.

1.3 NHS number

NHS number is validated prior to inclusion in the database and a flag is set accordingly. Only 22 registrations (0.2%) had no NHS number reported. Thames had the highest proportion of NHS numbers missing, but this was still under 1% of all registrations (Figure 1.3). Only WMCIU and Trent achieved 100% recording. All NHS numbers were provided in a valid format.

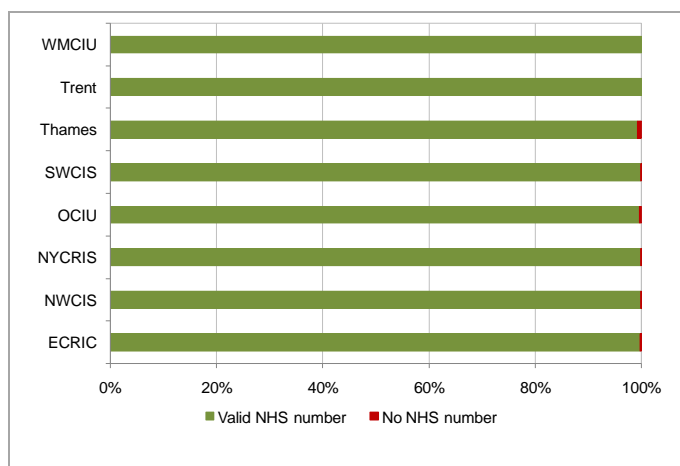


Figure 1.3 Completeness of NHS number

1.4 Ethnicity

Ethnicity is usually derived from HES by matching at patient level and extracting the most recent valid ethnicity code. Average completeness of valid known code was 64.5%, ranging from 12.1% for NWCIS to 91.4% for Trent (Figure 1.4a). The reporting of valid known code between 2001 and 2010 was above 80% for many of the English registries (especially in the latter part of the period examined). For NWCIS the reporting of ethnicity dropped significantly in 2010 to 12% with high completeness recorded for all previous years. Thames showed also a decrease in recent years (32.9% with valid known code). For ECRIC and NYCRIS, the completeness of valid known ethnicity code improved in the last years.

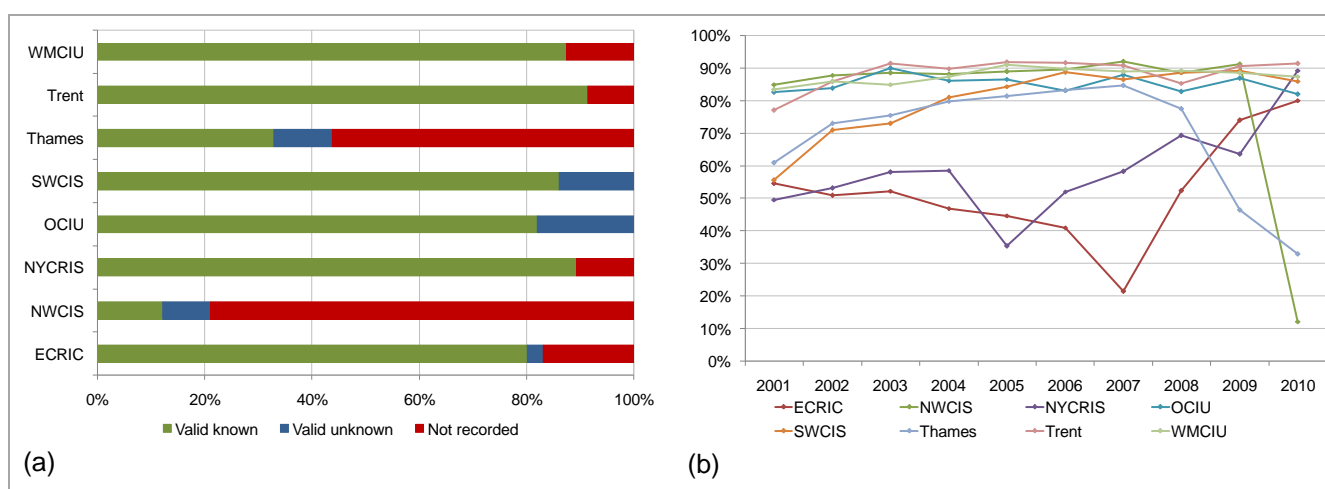


Figure 1.4 Completeness of ethnicity: (a) 2010 registrations (b) trend with valid known code, 2001-2010

1.5 Postcode

The postcode field should be formatted to a length of 7 digits, padded out with spaces if necessary. About 9% of the London postcodes required two spaces in the middle to make the 7 digit format. Thames Cancer Registry has not padded these postcodes to 7 digits.

2. Tumour details

2.1 Tumour site

Tumour site is coded using the tenth revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10). Tumour site was 100% complete for head and neck cancers diagnosed in 2010 in residents of the English cancer registries. Figure 2.1.1 lists the head and neck tumour site groups in decreasing order of diagnosis, as percentages of all head and neck cancers. The registries show a similar distribution of the most diagnosed tumour sites.

ICD-code	Cancer registry								
	ECRIC	NWCIS	NYCRIS	OCIU	SWCIS	Thames	Trent	WMCIU	England
C73 Thyroid gland	22.2	21.2	21.7	26.4	18.7	23.8	16.0	18.9	21.0
C32 Larynx	17.6	19.2	18.6	15.5	17.2	14.4	17.9	20.6	17.5
C02 Other & unspec. parts of tongue	11.6	8.9	10.2	9.8	10.1	11.3	10.9	11.2	10.5
C09 Tonsil	9.7	8.5	7.6	9.8	9.3	9.9	10.4	11.0	9.4
C01 Base of tongue	5.6	5.2	5.0	4.5	6.5	4.9	5.2	5.7	5.4
C06 Other & unspec. parts of mouth	4.2	4.9	3.7	3.9	4.9	5.1	4.6	4.8	4.6
C07 Parotid gland	3.1	3.2	3.7	5.5	5.5	4.2	5.5	3.6	4.2
C04 Floor of mouth	3.3	5.3	4.4	3.9	3.4	3.0	4.0	3.3	3.8
C05 Palate	3.1	3.4	3.7	3.7	3.4	4.2	3.8	3.2	3.6
C03 Gum	3.8	1.6	1.6	1.2	3.2	3.4	4.7	3.2	2.9
C30 Nasal cavity & middle ear	3.4	2.4	3.5	1.8	3.0	2.5	2.2	2.0	2.7
C00 Lip	3.9	1.9	3.5	4.5	2.3	1.4	1.7	1.9	2.4
C10 Oropharynx	1.1	3.3	2.5	1.8	1.4	2.6	2.1	2.2	2.2
C12 Pyriform Sinus	1.1	2.9	2.2	1.2	2.1	1.9	2.7	3.0	2.2
C11 Nasopharynx	1.3	1.8	1.6	1.8	2.3	2.3	2.0	1.5	1.9
C14 Ill-def. lip/oral cavity/pharynx	1.1	1.7	2.2	2.2	2.8	2.1	1.4	0.9	1.8
C13 Hypopharynx	1.7	2.0	2.0	1.0	1.0	1.0	2.4	1.0	1.5
C08 Unspec. major salivary glands	0.8	1.5	1.4	1.0	1.5	1.2	1.1	1.0	1.2
C31 Accessory Sinuses	1.4	1.2	0.9	0.8	1.5	0.8	1.3	1.1	1.1

Figure 2.1.1 Most commonly diagnosed tumours (percentage of total number of cases)

The proportion of head and neck cancers registered in England examined by broad ICD-10 cancer type group remained relatively unchanged between 2001 and 2010 for most sub-types (Figure 2.1.2). There was a drop in the proportion of larynx cancers registered (from 24.0% in 2001 to 17.5% in 2010). Thyroid cancer registrations as percentage of all head and neck cancers increased from 16.2% in 2001 to 21.0% in 2010).

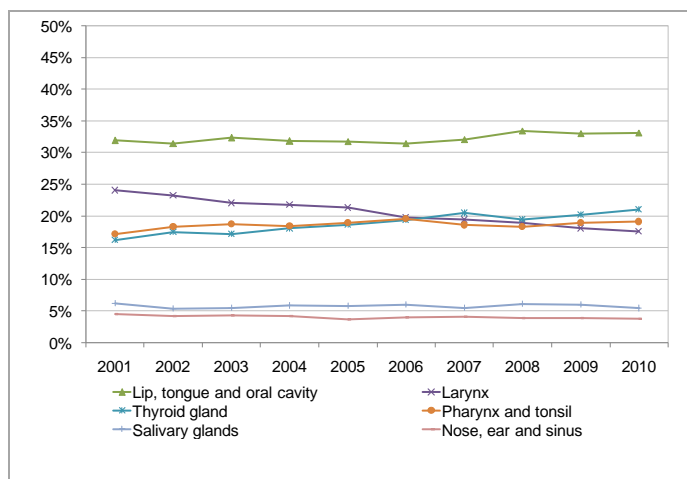


Figure 2.1.2 Proportion of registrations by head and neck cancer type, 2001-2010

The unknown anatomical sites included patients with ICD-10 four digit codes coded of Cxx.8 and Cxx.9. On average 26.1% of all head and neck cancers in 2010 were reported using unknown anatomical site. This ranged from 22.4% in Trent to 33.7% in Thames (Figure 2.1.3).

	All tumours	Numbers		Percentage	
		Known anatomical site tumours	Unknown anatomical site tumours	Known anatomical site tumours	Unknown anatomical site tumours
ECRIC	1046	806	240	77.1	22.9
NWCIS	1576	1202	374	76.3	23.7
NYCRIS	1521	1136	385	74.7	25.3
OCIU	511	385	126	75.3	24.7
SWCIS	1421	1065	356	74.9	25.1
Thames	2104	1396	708	66.3	33.7
Trent	1074	833	241	77.6	22.4
WMCIU	1152	870	282	75.5	24.5

Figure 2.1.3 Unknown and known anatomical sites, 2010 registrations

Between 2001 and 2010 the proportion of head and neck cancers coded as Cxx.8 and Cxx.9 in the NCDR decreased from 30.9% in 2001 to 26.1% in 2010 (Figure 2.1.4).

	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
All tumours	7,630	7,324	7,850	7,962	8,216	8,941	9,069	9,606	10,025	10,405
Unknown anatomical site tumours (numbers)	2,355	2,157	2,497	2,469	2,605	2,757	2,780	2,799	2,746	2,712
Unknown anatomical site tumours (%)	30.9	29.5	31.8	31.0	31.7	30.8	30.7	29.1	27.4	26.1

Figure 2.1.4 Proportion of unknown anatomical sites, 2001-2010

2.2 Morphology system

The International Classification of Disease for Oncology (ICD-O) coding system is used to code the morphology of the cancer. ICD-O-03 was mainly used by ECRIC, NWCIS, NYCRIS and WMCIU for registration of head and neck cancer tumours in 2010. OCIU, SWCIS and Thames reported all cases in ICD-O-02. Trent had a small proportion of 2010 tumours recorded in ICD-O-03 (Figure 2.2).

Cancer registry	ICD-O-02	ICD-O-03	Not coded	Total
ECRIC		1,046		1,046
NWCIS	1	1,575		1,576
NYCRIS		1,521		1,521
OCIU	511			511
SWCIS	1,421			1,421
Thames	2,104			2,104
Trent	1,049	25		1,074
WMCIU		1,150	2	1,152
England	5,086	5,317	2	10,405

Figure 2.2 Morphology coding system used in 2010

2.3 Morphology coding

All registries except WMCIU were 100% complete in coding morphology. WMCIU had 2 cases (0.2%) with no morphology recorded. WMCIU also had 5 (0.4%) cases with a morphology code that relates to a secondary tumour. All other registries used specific morphology codes for 100% of head and neck tumours recorded in 2010. Figure 2.3 shows the most common morphology codes recorded (accounting for 91% of all registrations) by cancer registry.

The top five most common morphology codes recorded include 77% of all head and neck cancers. The two most commonly reported morphology codes were the same for all the registries; 80703 squamous cell carcinoma, NOS and 80713 squamous cell carcinoma, keratinising NOS.

Code	Description	Cancer registry								
		ECRIC	NWCIS	NYCRIS	OCIU	SWCIS	Thames	Trent	WMCIU	England
80703	Squamous cell carcinoma NOS	54.6%	54.3%	55.9%	53.2%	51.6%	52.2%	53.9%	59.4%	54.2%
80713	Squamous cell carcinoma, keratinising NOS	7.6%	10.0%	8.7%	6.3%	11.9%	5.7%	11.4%	9.8%	8.9%
82603	Papillary adenocarcinoma NOS	9.8%	2.9%	9.5%	9.6%	6.6%	10.5%	7.7%	5.5%	7.7%
80103	Carcinoma NOS	4.2%	3.9%	2.0%	3.3%	3.2%	5.1%	2.1%	2.3%	3.4%
83303	Follicular adenocarcinoma NOS	3.1%	1.3%	3.2%	3.1%	2.6%	4.2%	2.3%	1.6%	2.7%
83403	Papillary carcinoma, follicular variant	1.2%	4.1%	4.1%	5.1%	2.0%	0.9%	2.4%	3.6%	2.7%
80003	Neoplasm, malignant	0.8%	2.6%	2.0%	5.9%	4.9%	2.5%	1.7%	0.9%	2.5%
80503	Papillary carcinoma NOS	0.3%	6.2%	0.0%	2.2%	3.2%	2.6%	0.2%	0.1%	2.1%
80723	Squamous cell carcinoma, large cell, nonkeratinising	1.7%	1.3%	0.9%	0.2%	2.2%	2.0%	5.0%	0.0%	1.7%
81403	Adenocarcinoma NOS	1.0%	0.8%	1.6%	2.2%	1.6%	2.2%	2.1%	1.2%	1.6%
84303	Mucoepidermoid carcinoma	1.7%	1.1%	1.2%	1.2%	1.2%	1.1%	1.3%	1.1%	1.2%
82003	Adenoid cystic carcinoma	1.4%	1.4%	1.1%	0.4%	1.1%	1.3%	0.8%	1.3%	1.2%
82903	Oxyphilic adenocarcinoma	0.8%	0.7%	1.9%	1.6%	1.0%	1.1%	0.6%	0.4%	1.0%
Total for most common types		88.1%	90.7%	92.0%	94.1%	93.0%	91.4%	91.6%	87.2%	91.0%
Total for five common types		79.3%	72.4%	79.4%	75.5%	75.9%	77.7%	77.5%	78.6%	77.0%

Figure 2.3 Most common morphology codes (percentage of total number of cases)

2.4 Laterality

For paired sites, for example the tonsils, if there is a tumour in one side, the laterality of that side, left or right, is recorded. For some paired sites, if there is a tumour in both sides then two tumours are registered, one left and the other right. If there is a tumour in both sides (and they have other factors such as morphology the same) then only one registration is made and the laterality is coded as bilateral. If the site of the primary cancer is not part of a pair then laterality is coded as not applicable. A definitive list of paired cancer sites has been produced as part of the UKACR Information and Training Manual for Cancer Registration in England and Wales ([Appendix 2](#)).

Figure 2.4 shows the completeness of laterality coding for cases with paired sites only (1,842 cases diagnosed in 2010). Average completeness was 86.7%, ranging from 76.3% for OCIU to 95.3% for Trent (Figure 2.4a).

For the majority of the cancer registries the recording of laterality for paired site fluctuated during the period examined between about 70% and 90% of cases with valid known code (Figure 2.4b). SWCIS and NWCIS had a lower recording in the earlier period, with completeness considerably improving for more recent head and neck cancer registrations.

Cases with an unpaired site should be coded 100% “not applicable”. Thames Cancer Registry had about 50% and WMCIU 40% of unpaired tumour sites coded as left, right or bilateral.

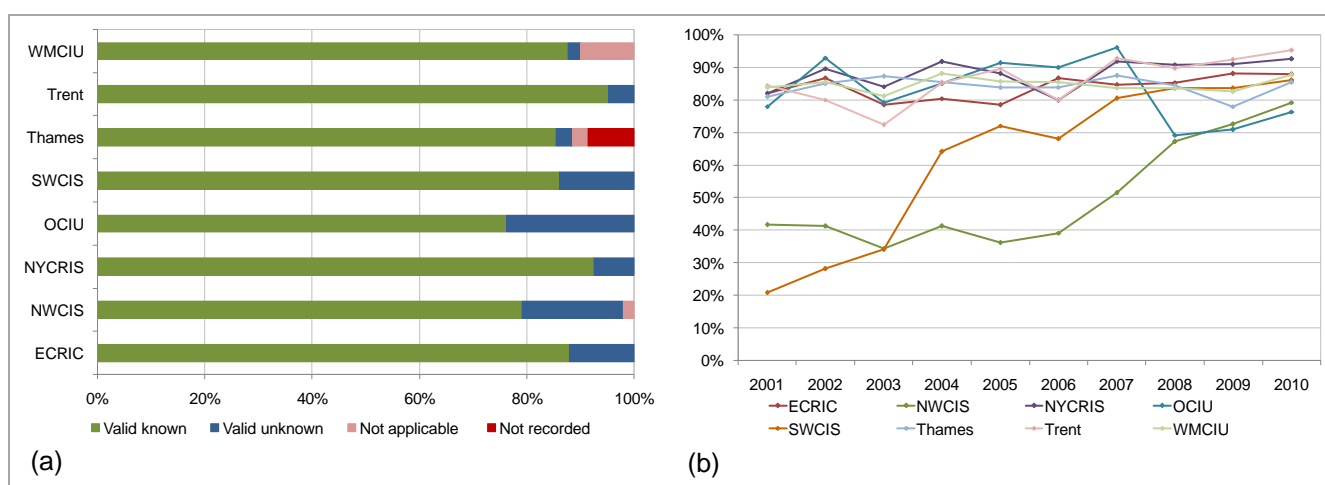


Figure 2.4 Completeness of laterality for paired sites only: (a) 2010 registrations (b) trend with valid known code, 2001-2010

3. Diagnosis details

3.1 Basis of diagnosis

Completeness of basis of diagnosis in 2010 was on average 99.5%. NYCRIS, Thames and WMCIU had basis of diagnosis recorded for 100% of registrations (Figure 3.1a). Although still high, Trent had the lowest percentage completeness at 98.3%. Histology was the most common basis of diagnosis with on average 94.5% of head and neck cancers with valid known code diagnosed this way. Histology as basis of diagnosis ranged between 91.9% for OCIU and 97.2% for Trent (Figure 3.1b). Clinical diagnosis was reported for 3.1% of all head and neck cancer diagnoses with valid known code. The highest proportion of clinical diagnoses was recorded by OCIU (5.5%) and the lowest by Trent (1.8%).

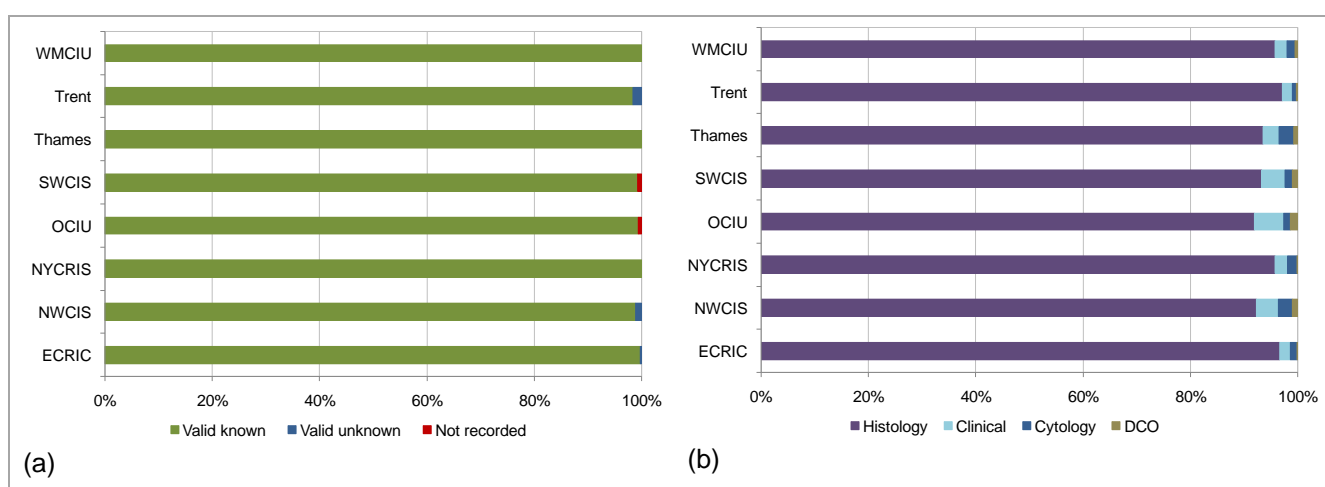


Figure 3.1 Basis of diagnosis coding, 2010 registrations: (a) completeness (b) by type, valid known code only

3.2 Diagnosis date

Diagnosis date was complete for all head and neck cancers diagnosed in 2010. Thames had 1.1% of head and neck diagnosis dates partially imputed, WMCIU had 0.7% and ECRIC 0.2% (Figure 3.2).

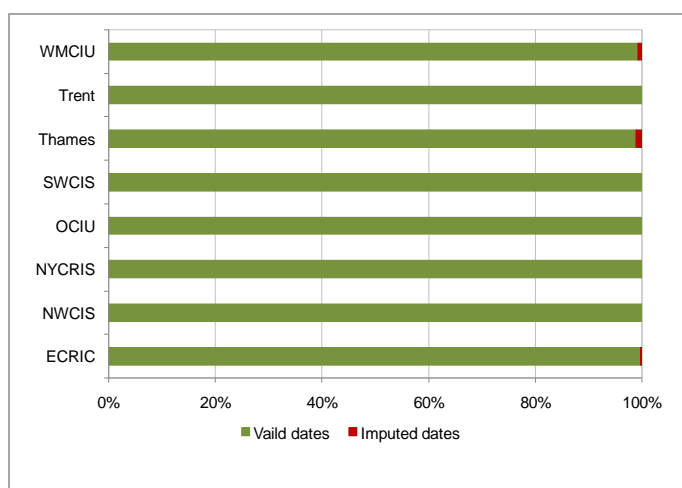


Figure 3.2 Accuracy of recording of diagnosis date

3.3 Death Certificate Only registrations

The proportion of cancers registered from a Death Certificate Only (DCO), with no corroborating information found when followed-up, is often used as a measure of the quality of the data. A high proportion of DCOs indicates that data may be of poor quality, with low ascertainment. The UKACR Quality and Performance Indicators Report gives a target of less than 2% for DCOs. Figure 3.3a shows that all registries have achieved this. Between 2001 and 2010 most registries met the target of less than 2% of head and neck cancer registrations as DCOs. Thames, Trent and SWCIS recoded less than 2% of DCOs from 2004 onwards (Figure 3.3b).

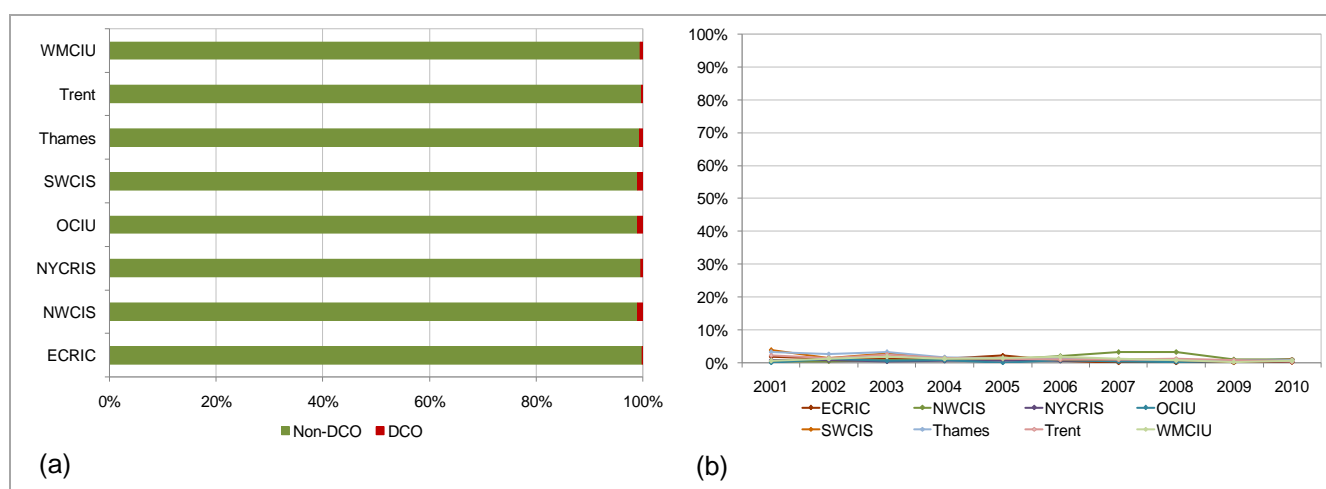


Figure 3.3 Death Certificate Only registrations: (a) percentage in 2010 (b) trend, 2001-2010

4. Treatment

The NCDR records whether or not a tumour received treatment - curative surgery, radiotherapy, chemotherapy or hormone therapy - within six months of the date of diagnosis.

Clarification is required as to what each registry means by “no treatment”. “No treatment” should be recorded when it is known that the patient definitely had no treatment in the six months following diagnosis. If it is not known whether or not a patient had any treatment, this field should be left blank.

4.1 Surgery

An average of 63.1% of all head and neck cancers were reported as having curative surgery. This ranged from 38.2% for Trent to 87.3% for Thames. This difference is more likely to reflect variations in what is counted as curative surgery rather than real variations in treatment (Figure 4.1a). Analyses of major surgical resection treatment in England revealed that about 50% of head and neck cancers receive curative surgery².

² Price G, Roche M, Wight R, Putnam G and Watson M. *Major surgical resections in England: head and neck cancers*. Oxford Cancer Intelligence Unit. 2012.

Thames Cancer Registry recorded surgery as curative treatment for a high proportion of head and neck cancers between 2001 and 2010 (Figure 4.1b).

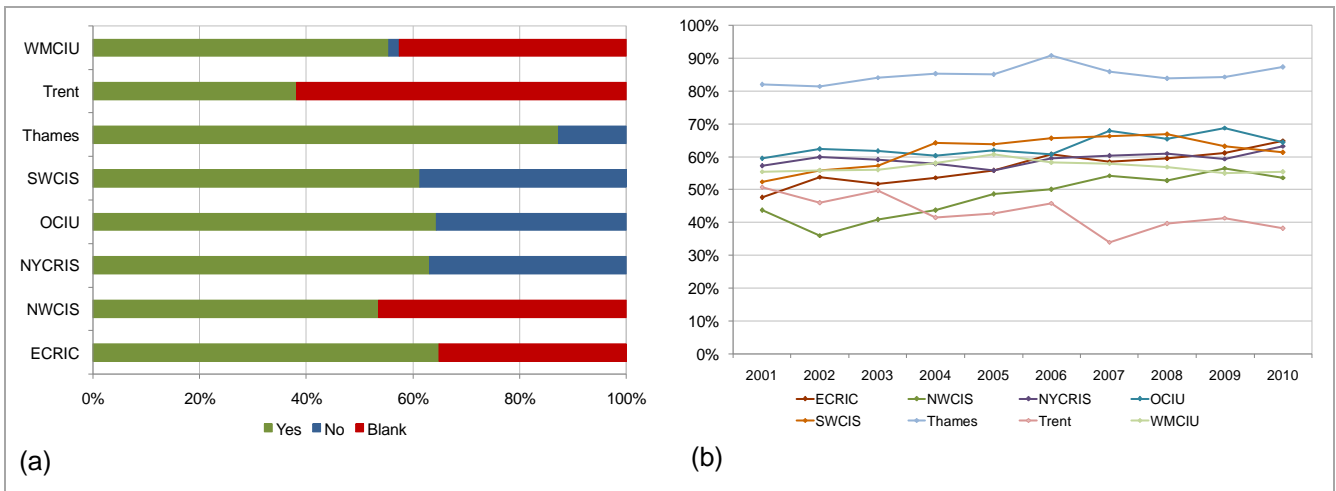


Figure 4.1 Cancers receiving curative surgery: (a) percentage in 2010 (b) trend, 2001-2010

4.2 Radiotherapy

An average of 47.8% of all head and neck cancers received radiotherapy, ranging from 11.5% for Trent to 56.8% for NYCRIS (Figure 4.2a). Between 2001 and 2010, NYCRIS had consistently high, and Trent low, proportion of the head and neck cancers with recording of radiotherapy treatment (Figure 4.2b).

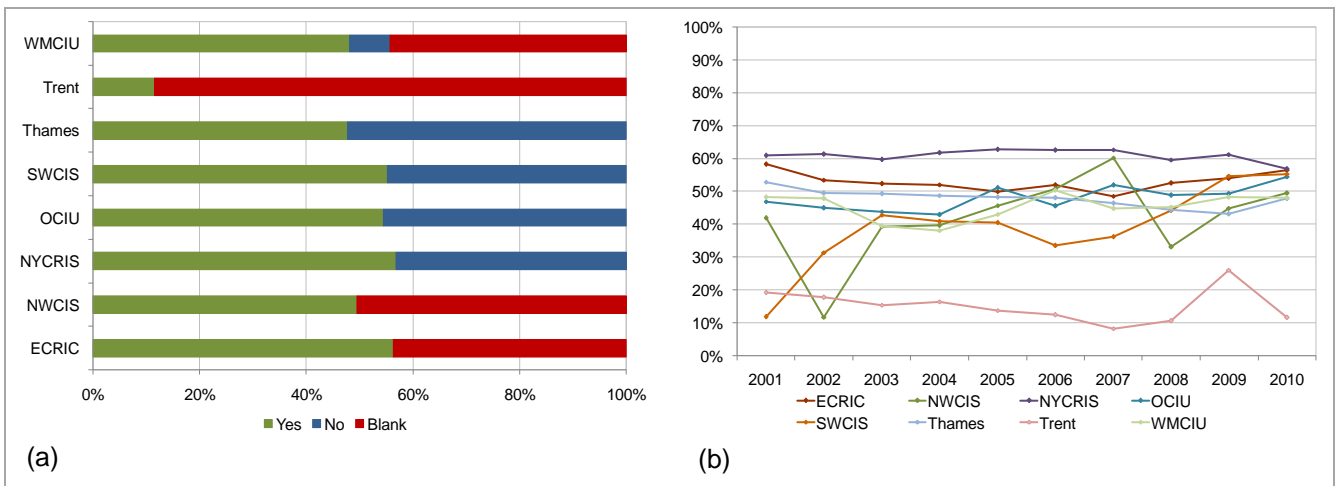


Figure 4.2 Cancers receiving radiotherapy: (a) percentage in 2010 (b) trend, 2001-2010

4.3 Chemotherapy

An average of 19.9% of all head and neck cancers diagnosed in England in 2010 had a recording of chemotherapy treatment. Trent at 5.2% had the lowest proportion of recording for chemotherapy and NYCRIS at 23.7% the highest (Figure 4.3a). As chemoradiotherapy is also a treatment option for head and neck cancers, the recording of chemotherapy and radiotherapy could for some cases reflect the combined therapy rather than individual treatment types. The reporting of chemotherapy as treatment has been generally increasing between 2001 and 2010, with Trent showing a drop from 2009 to 2010 (Figure 4.3b).

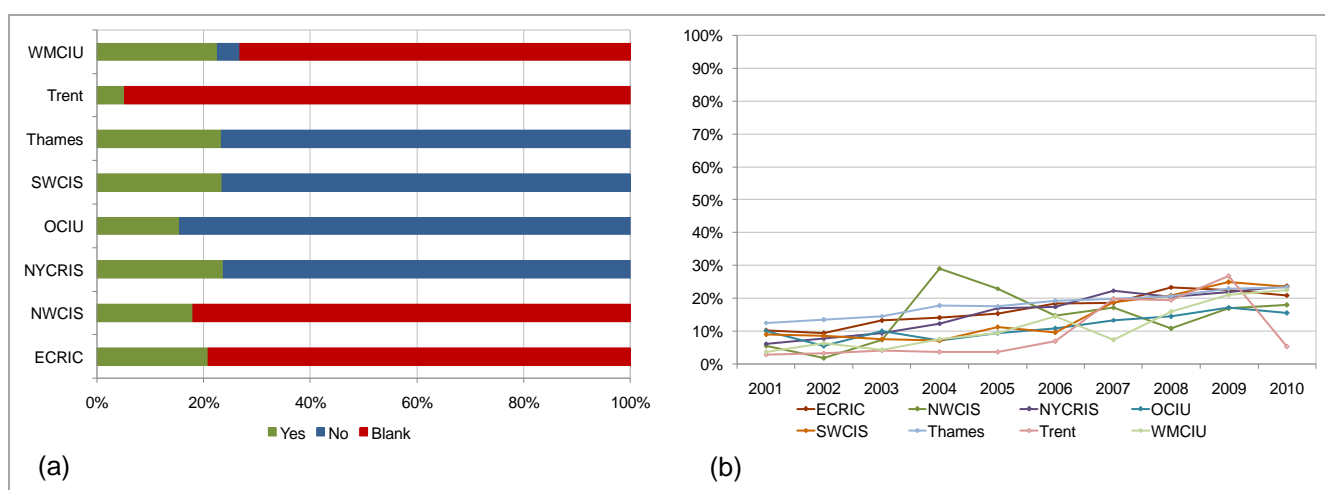


Figure 4.3 Cancers receiving chemotherapy: (a) percentage in 2010 (b) trend, 2001-2010

4.4 Hormone therapy

Only 0.5% of all head and neck cancers diagnosed in 2010 in England were recorded as receiving hormone therapy. WMCIU had the highest proportion at 1.7%.

5. Death details

5.1 Date of death

Figure 5.1 assumes that if there is no date of death recorded the patient is still alive. On average 26% of head and neck cancers diagnosed in 2010 had a death of date recorded (Figure 5.1a).

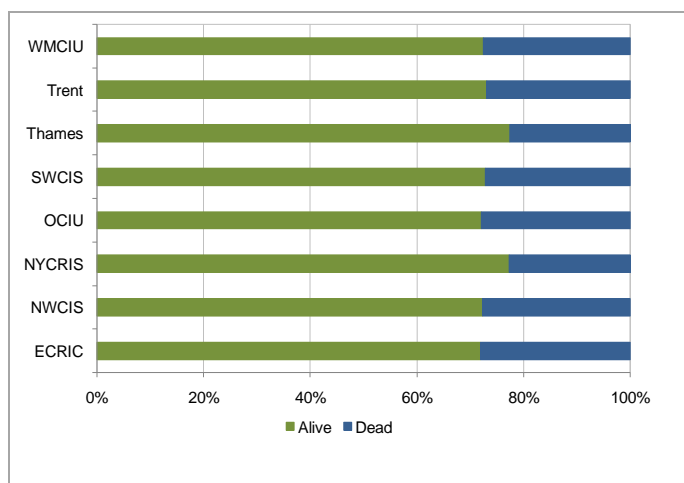


Figure 5.1 Death date recording in 2010

5.2 Cause of death

There are four cause of death fields in the NCDR data, corresponding to the four causes of death given on a death certificate. More than 98% of head and neck cancers with date of death had a cause of death recorded. NYCRIS achieved 100% completeness (Figure 5.2a). Trent and NWCIS had a low completeness of cause of death in the earlier part of the period examined. However, the recording for the registries has been high since 2008 (Figure 5.2b).

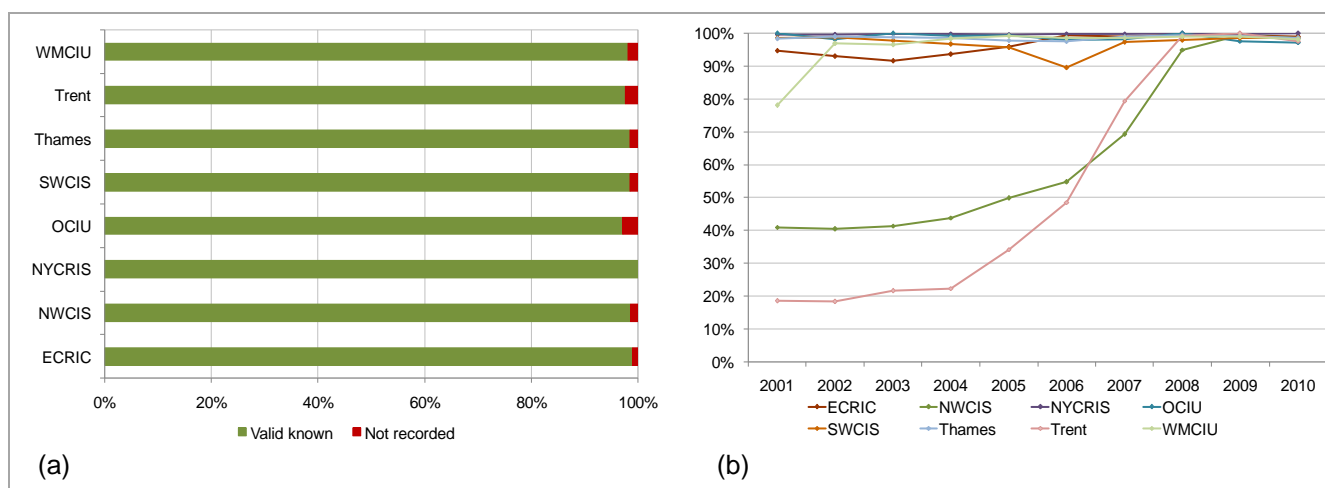


Figure 5.2 Cause of death recording for patients that have died: (a) completeness of in 2010 (b) trend with valid code, 2001-2010

5.3 Place of death

Figure 5.3a/b shows the proportion of records that have a place of death recorded where the patient is known to have died. For 74.1% of head and neck cancer patients in 2010 reported as dead a valid known code for a place of death was reported. NWCIS achieved 100% recording (Figure 5.3a). Four registries were over 90% complete for place of death coding. Thames Cancer Registry does not appear to record place of death. For the latter part of the period examined, SWCIS and OCIU showed a decreasing trend in place of death recording (Figure 5.3b).

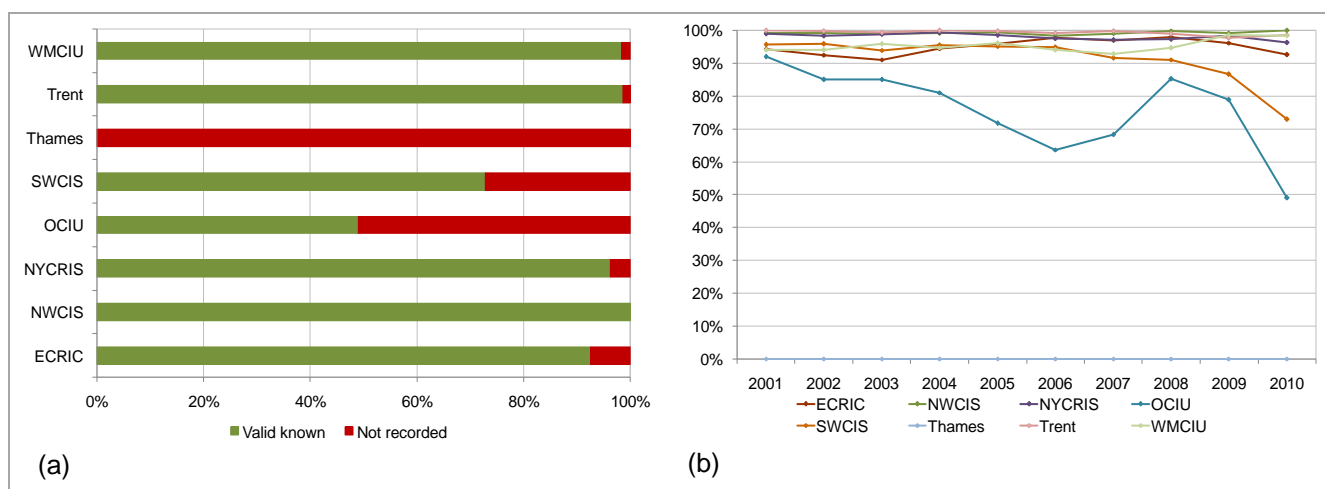


Figure 5.3 Place of death recording for patients that have died: (a) completeness in 2010 (b) trend with valid known code, 2001-2010

6. Stage details

6.1 Tumour grade

Tumour grade was reported on 60.1% of head and neck cases diagnosed in 2010. This ranged from 34.4% for Trent to 69.1% for WMCIU (Figure 6.1a). In the period 2001 to 2010 the recoding of tumour grade using a valid known code varied for most of the cancer registries between 50% and 70%. Between 2001 and 2007 Trent had a low (below 5%) completeness. This considerably increased from 2009 to 2010, but still remained lower than other registries (Figure 6.1b).

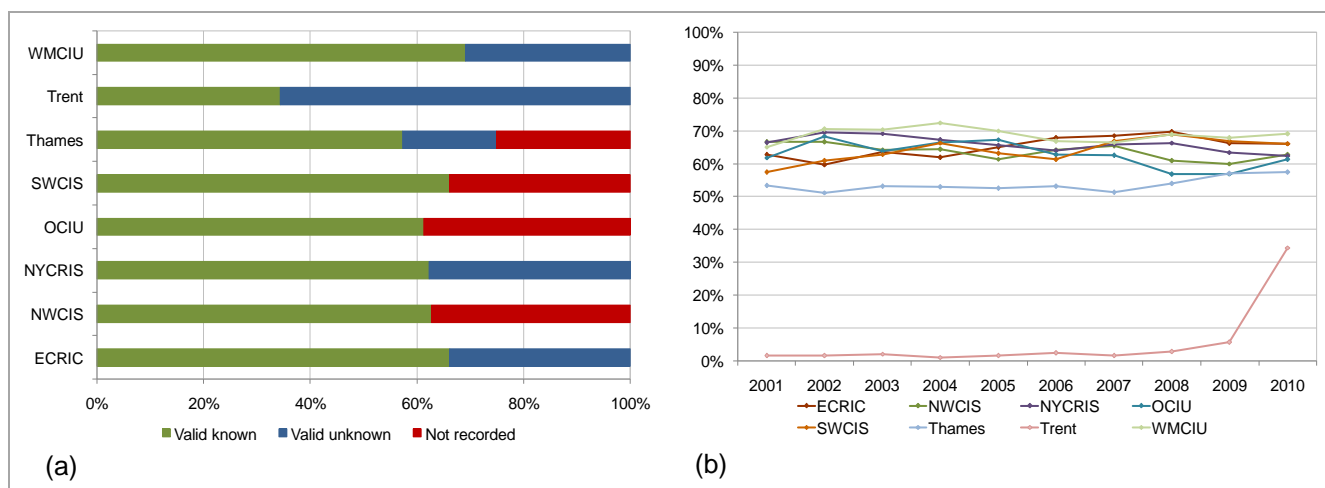


Figure 6.1 Coding of tumour grade: (a) completeness in 2010 (b) trend with valid known code, 2001-2010

6.2 Tumour size

Tumour size relates to the diameter of the tumour measured in millimetres. Recorded tumour sizes for head and neck cancers diagnosed in 2010 ranged largely from 0mm to 150mm. There were three cases with size more than 500mm. Overall tumour size was collected for 22.1% of all head and neck cancers, ranging from 0% for OCIU and NYCRIS to nearly 45% for ECRIC (Figure 6.2a). Tumour size recording has been increasing for many of the cancer registries between 2001 and 2010 (Figure 6.2b). OCIU and NYCRIS had zero (or close to zero) cases with recorded tumour size throughout the period.

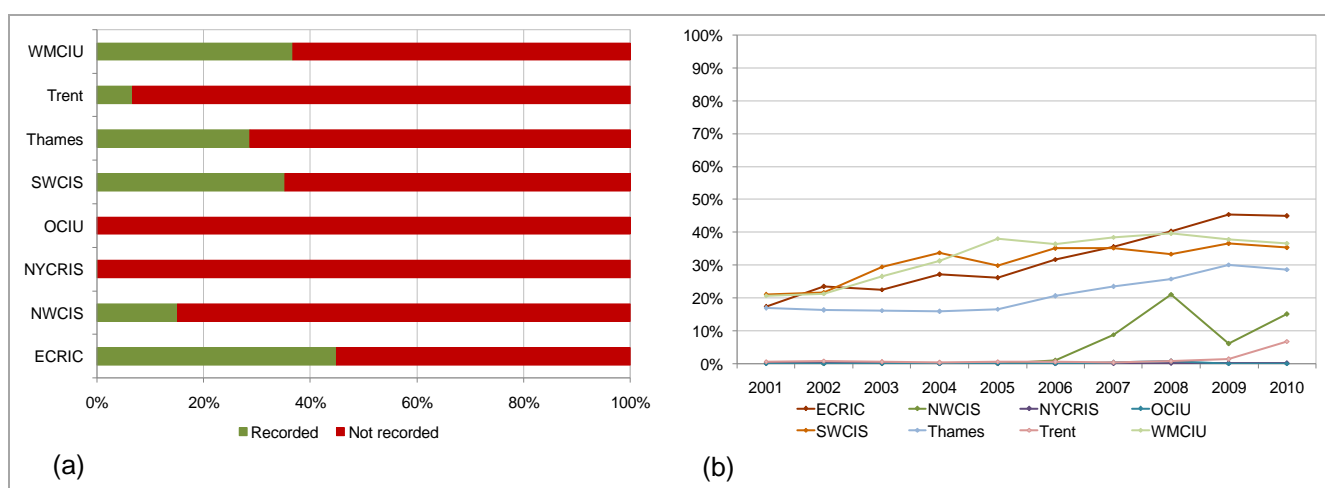


Figure 6.2 Tumour size recording: (a) completeness in 2010 (b) trend with valid known code, 2001-2010

6.3 Nodes examined

Overall, 22.1% of cases had the number of nodes examined recorded. This ranged from 6.1% for Trent and 30.0% for SWCIS (Figure 6.3a). An increasing trend in the number of nodes examined was recorded, with NWCIS, OCIU, NYCRIS and Trent showing most of the improvement from 2007 registrations (Figure 6.3b).

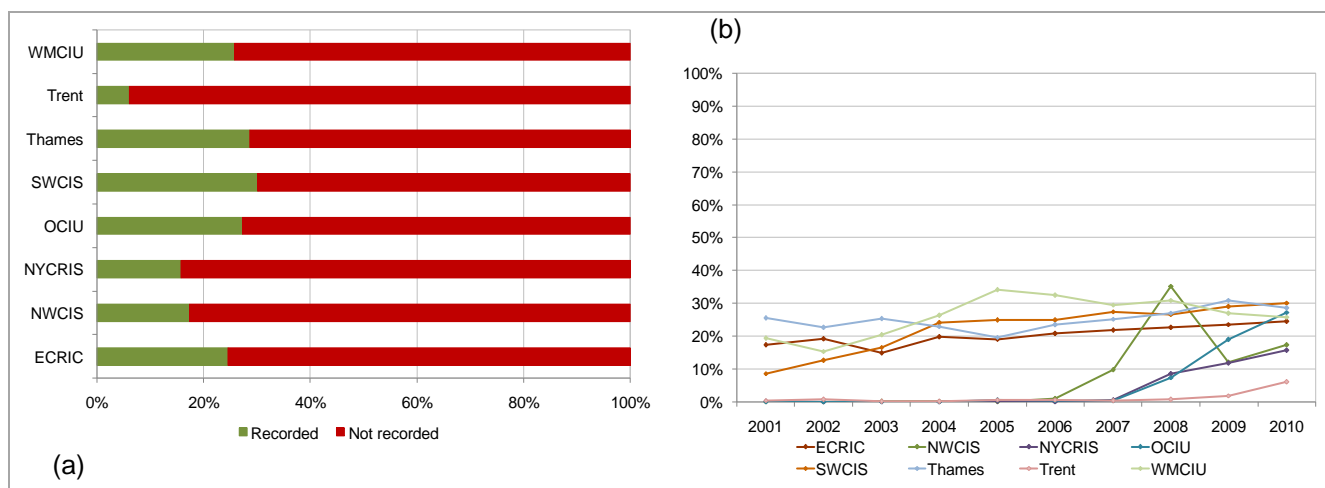


Figure 6.3 Coding of number of nodes examined: (a) completeness in 2010 (b) trend with valid known code, 2001-2010

6.4 Nodes positive

On average 22.9% of head and neck cases diagnosed in 2010 had positive nodes recorded, ranging from 6.1% for Trent and 37.9% for NYCRIS. A valid number of positive nodes, includes zero.

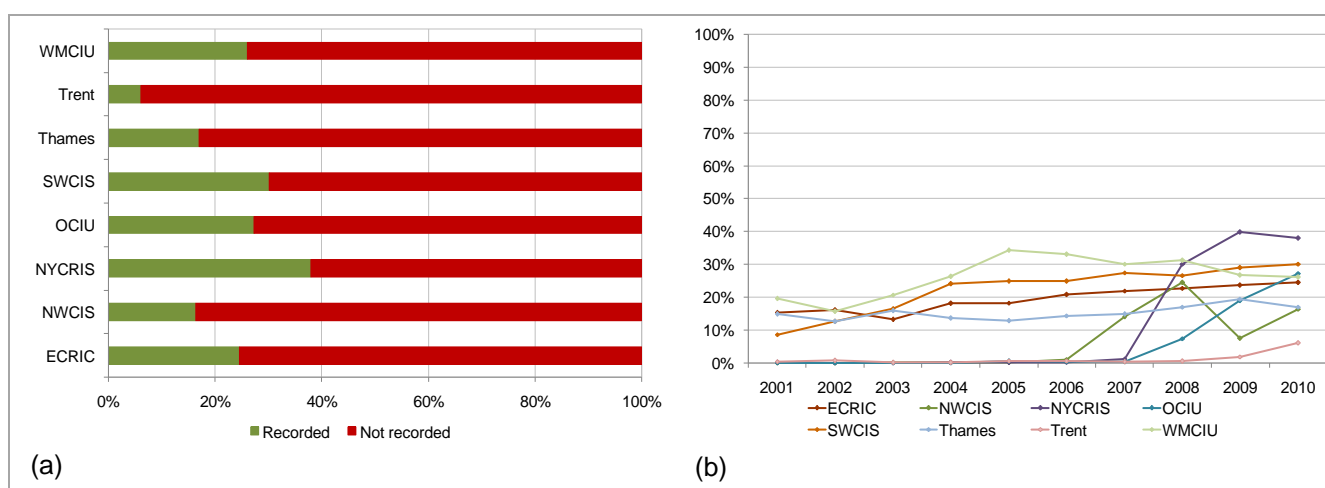


Figure 6.4 Coding of number of positive nodes found: (a) completeness in 2010 (b) trend with valid known code, 2001-2010

Comparing figures 6.3a/b and 6.4a/b, ECRIC, OCIU, SWCIS and Trent only record positive nodes where nodes were examined. NWCIS and Thames have more records with nodes examined than positive nodes recorded. NYCRIS has fewer records with nodes examined than positive nodes recorded.

6.5 Metastases

This field records the presence of distant metastases at diagnosis. On average 33.5% of cases had the presence of distant metastases recorded. This ranged from 2.1% with valid known code for Trent to 57.4% for Thames (Figure 6.5a). Thames showed the highest metastases recording between 2001 and 2010, but this has been decreasing in the later part of the time period (Figure 6.5b).

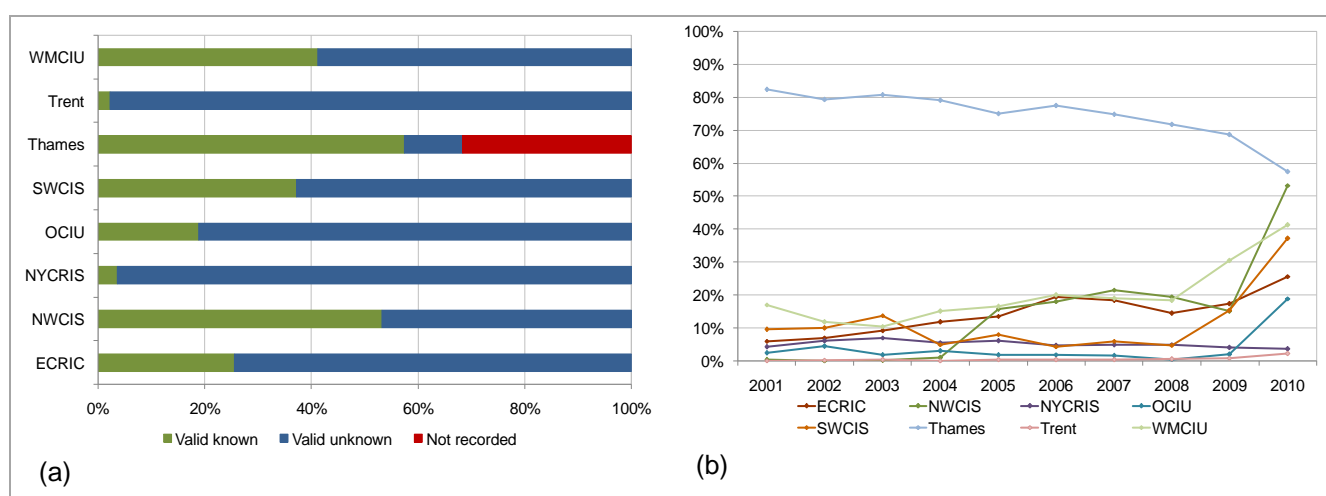


Figure 6.5 Metastases recording: (a) completeness in 2010 (b) trend with valid known code, 2001-2010

6.6 Clinical stage

The staging system used in the NCDR is the Union for International Cancer Control (UICC) TNM Classification of Malignant Tumours. This section relates to clinical stage. Only WMCIU recorded information on the edition of TNM used in clinical stage recording (Figure 6.6.1)

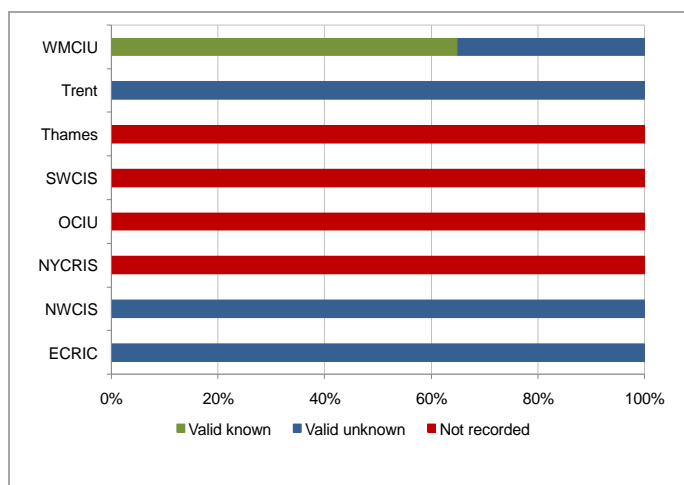


Figure 6.6.1 Completeness in 2010 of UICC staging system (clinical)

All diagnoses of cancer should ideally be confirmed microscopically. A clinical classification is one based on evidence acquired before treatment, for example from physical examination, imaging, endoscopy, biopsy or surgical exploration³. On average the completeness of T component was 25%. NWCIS and Trent recorded the T component for 0% of the head and neck cancers in 2010 (Figure 6.6.2a). WMCIU had the highest percentage recording (58.7%). Between 2001 and 2010 Thames Cancer Registry showed a relatively steady level of T component reporting at around 30% (Figure 6.6.2b).

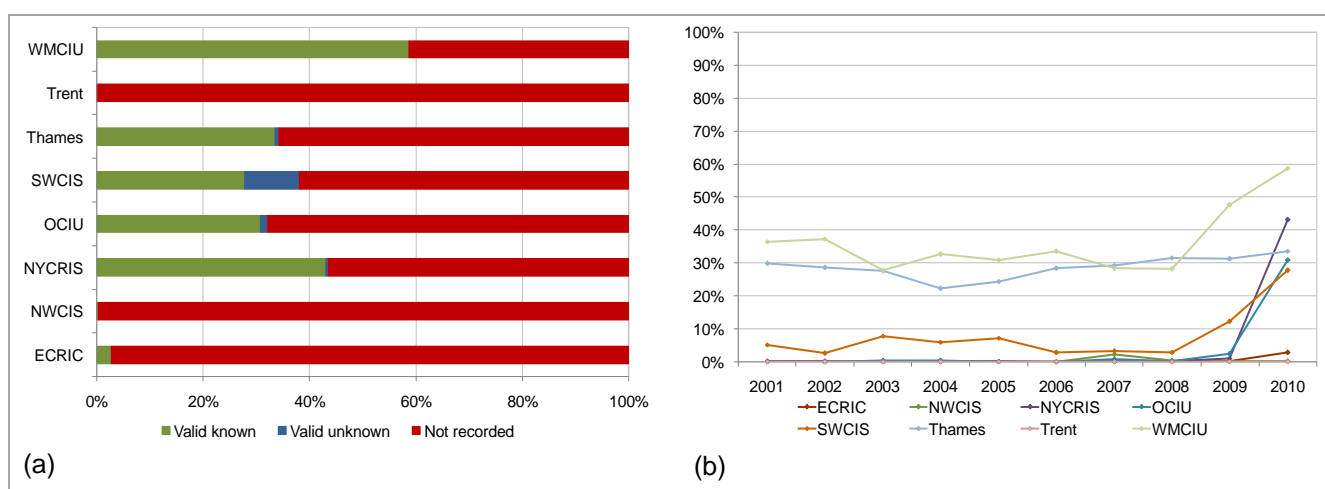


Figure 6.6.2 T component of TNM clinical: (a) completeness in 2010 (b) trend with valid known code, 2001-2010

³ Sobin LH, Gospodarowicz MK, Wittekind C, (eds). *TNM Classification of Malignant Tumours*. 7th edition. Chichester: Wiley-Blackwell; 2009.

On average the completeness of N and M component was 24.5% and 17.7% respectively with trends by cancer registry and by year of diagnosis similar to T component (Figure 6.6.3 and Figure 6.6.4).

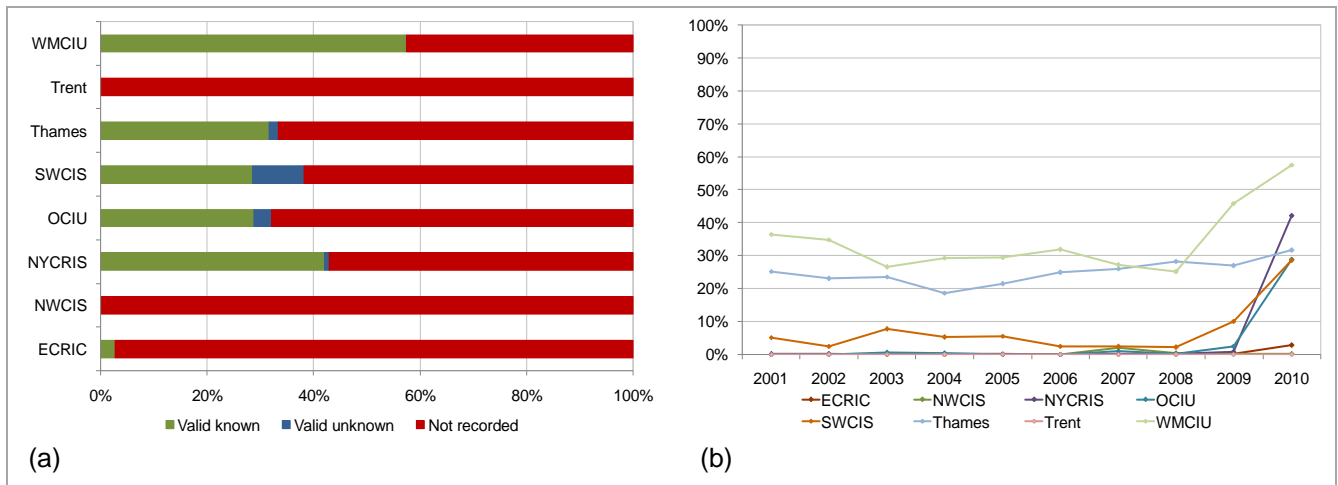


Figure 6.6.3 N component of TNM clinical: (a) completeness in 2010 (b) trend with valid known code, 2001-2010

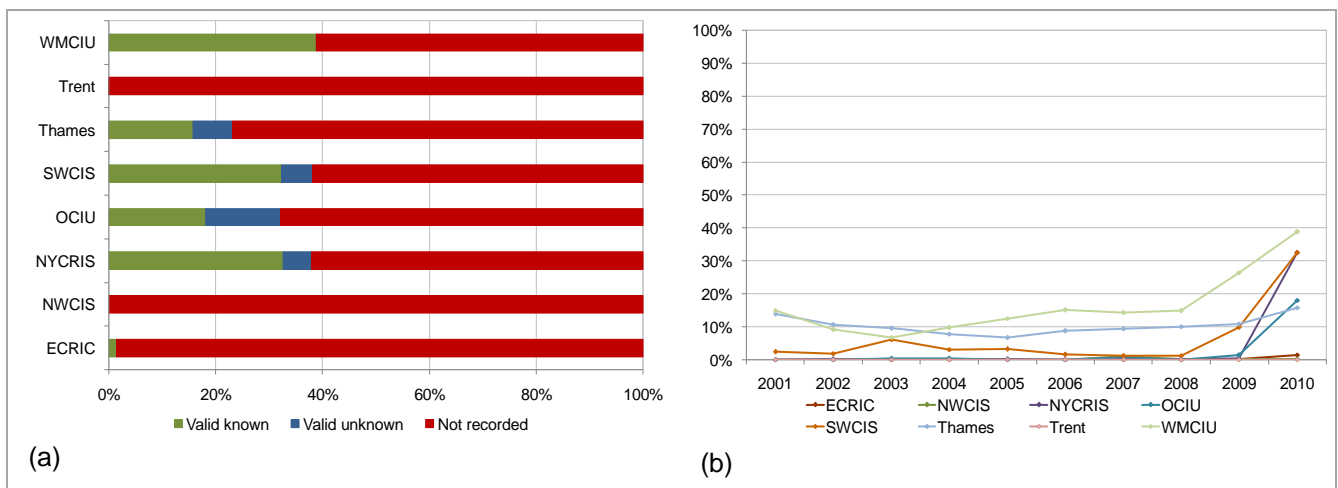


Figure 6.6.4 M component of TNM clinical: (a) completeness in 2010 (b) trend with valid known code 2001-2010

TNM stage grouping is defined by the TNM handbook³. With 2.5% of all head and neck cancers with valid TNM clinical stage recorded the reporting is very low. WMCIU has 20.3% of cases with a stage group and NYCRIS 1.8% (Figure 6.6.5a). WMCIU had generally the highest completeness of TNM clinical stage between 2001 and 2010 (Figure 6.6.5b). As the individual T, N and M clinical components have higher level of completeness, the proportion of overall TNM stage grouping can be increased by integrating all individual components during analysis.

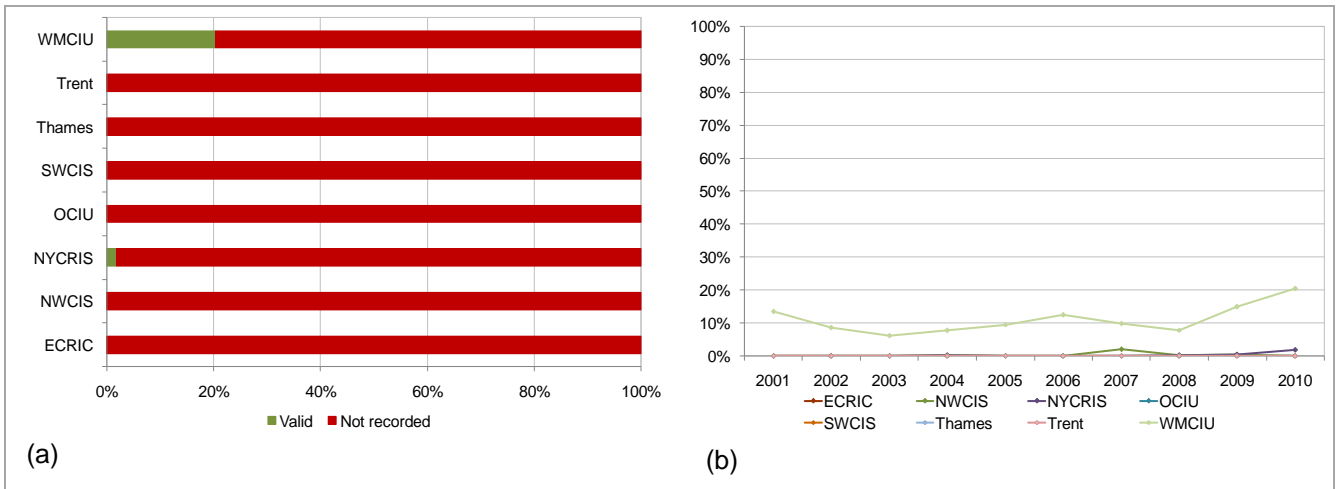


Figure 6.6.5 TNM stage, clinical: (a) completeness in 2010 (b) trend with valid known code 2001-2010

6.7 Pathological stage

WMCIU recorded valid known information (47.4% of all head and neck cancers) on the edition of TNM used in pathological stage recording (Figure 6.7.1). Trent had also some cases with valid known code but the proportion was below 1%.

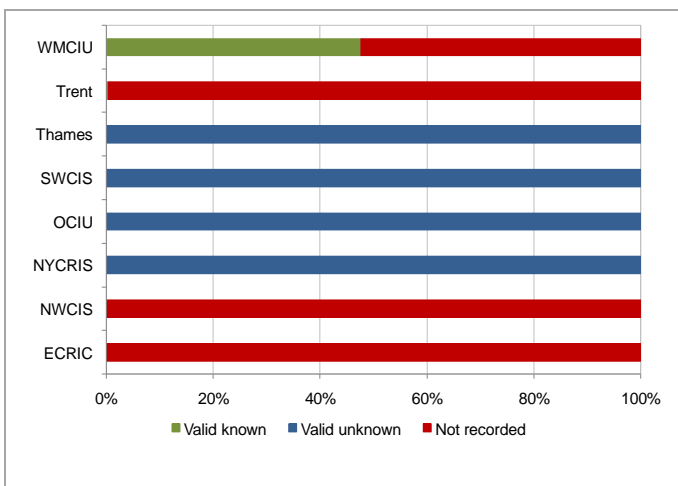


Figure 6.7.1 Completeness of UICC staging system (pathological)

The pathological classification is based on evidence acquired before treatment, supplemented or modified by additional evidence acquired from surgery and pathological examination³. On average the completeness of T component pathological was 24.4%. In 2010, WMCIU had the highest completeness of T component recorded (42.8%), followed by OCIU (38.6%) and Thames (32.4%). Trent with 3.9% of head and neck cancers with T pathological reported achieved the lowest percentage (Figure 6.7.2a). In the later part of the 2001-2010

diagnosis period, there was an increasing trend in the recording of the T component for pathological stage for many of the cancer registries (Figure 6.7.2b).

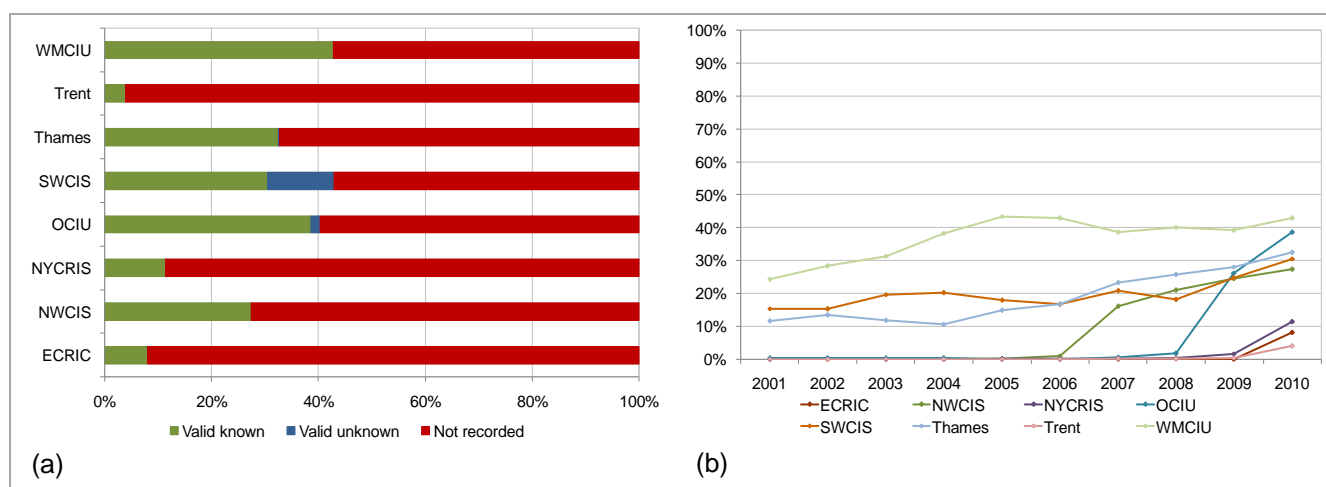


Figure 6.7.2 T component of TNM pathological: (a) completeness in 2010 (b) trend with valid known code, 2001-2010

On average the completeness of valid known N component was 17.6%. SWCIS had the highest percentage of tumour with N pathological recorded (34.1%), followed by OCIU (28.0%) and WMCIU (27.1%) (Figure 6.7.3a). Trent had the lowest proportion (2.9%). Similar to T component, in the later part of the 2001-2010 diagnosis period the recording of the N component for pathological stage increased for many of the cancer registries (Figure 6.7.3b).

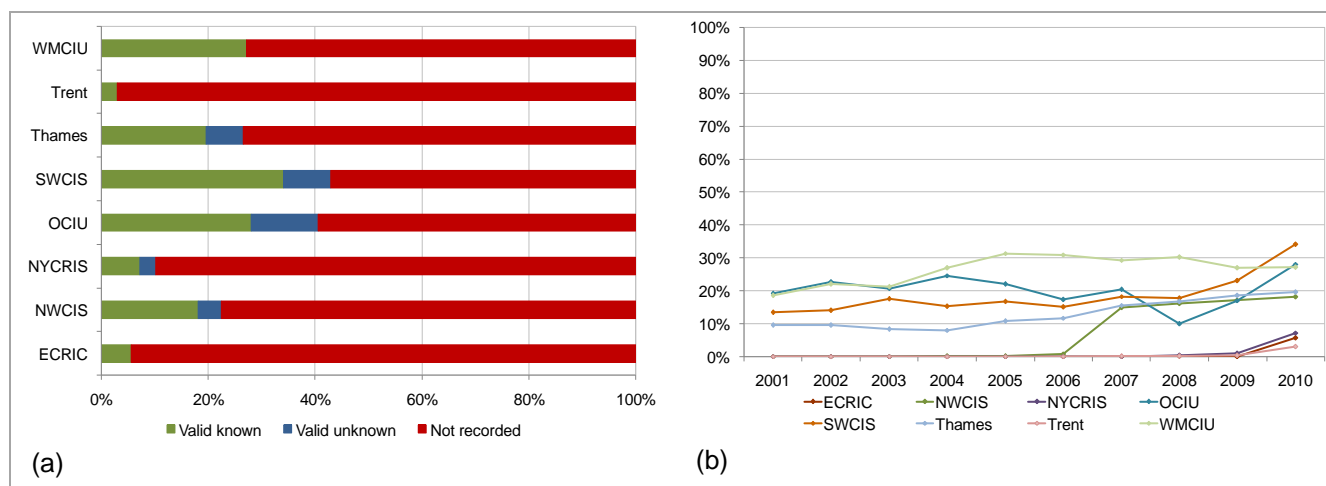


Figure 6.7.3 N component of TNM pathological: (a) completeness in 2010 (b) trend with valid known code, 2001-2010

On average the completeness of valid known M component pathological was low at 3.0%. SWCIS had the highest percentage of tumours with M pathological recorded (9.0%) (Figure 6.7.4a). Trent and NYCRIS had the lowest proportions (0.5%).

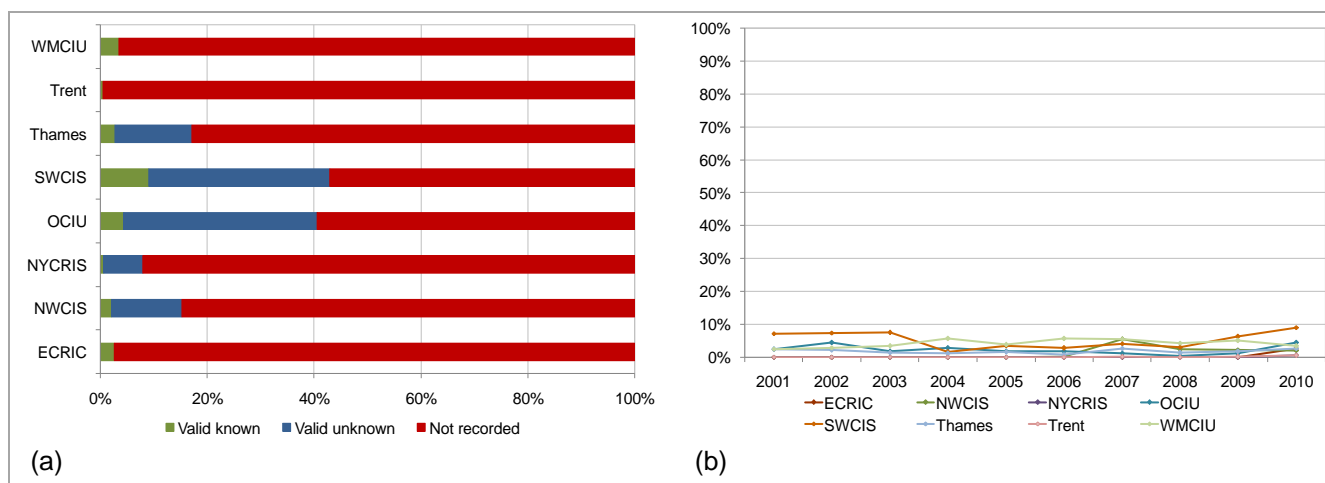


Figure 6.7.4 M component of TNM pathological: (a) completeness in 2010 (b) trend with valid known code 2001-2010

With 0.7% of all head and neck cancers with valid TNM pathological stage recorded, the reporting is very low. WMCIU had 3.4% of cases with a stage group with NYCRIS and NWCIS about 1% (Figure 6.7.5a). The reporting of TNM stage pathological for OCIU, SWCIS and Thames was 0%. As the individual T, N and M pathological components have higher level of completeness, the proportion of overall TNM stage grouping can be increased by integrating all individual components during analysis.

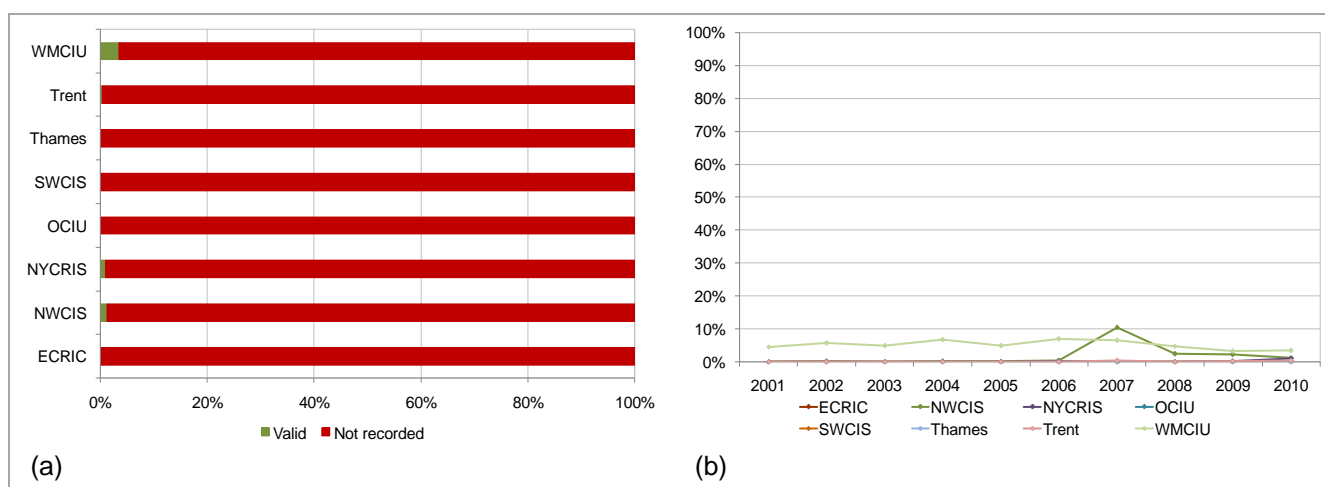


Figure 6.7.5 TNM stage, pathological: (a) completeness in 2010 (b) trend with valid known code, 2001-2010

6.8 Integrated stage

A third classification of stage information is TNM integrated. This is a hybrid of the clinical and pathological T, N and M values. Only WMCIU recorded valid information (84.2% of all head and neck cancers) on the edition of TNM used in integrated stage recording (Figure 6.8.1)

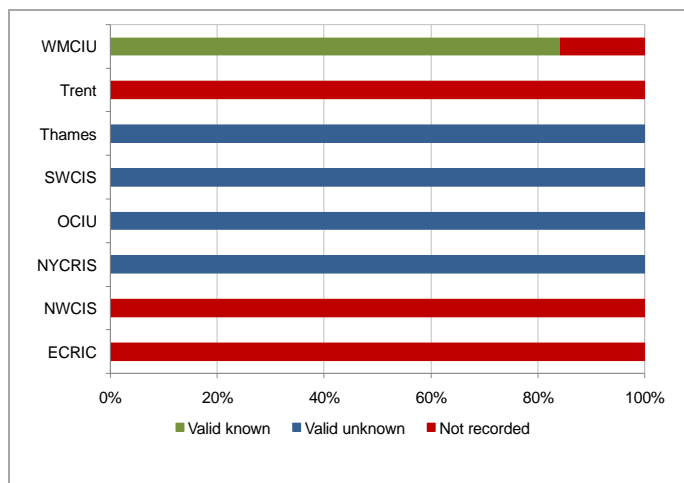


Figure 6.8.1 Completeness of UICC staging system (integrated)

On average the completeness of T component integrated was 34.8%. In 2010, WMCIU had the highest completeness of T component recorded (78.9%), followed by NWCIS (77.0%) and ECRIC (75.6%). OCIU, SWCIS and Thames had 0% completeness for T integrated (Figure 6.8.2a). In the later part of the 2001-2010 diagnosis period there was an increasing trend in the recording of the T component for integrated stage for ECRIC, NWCIS, WMCIU and NYCRIS (Figure 6.8.2b).

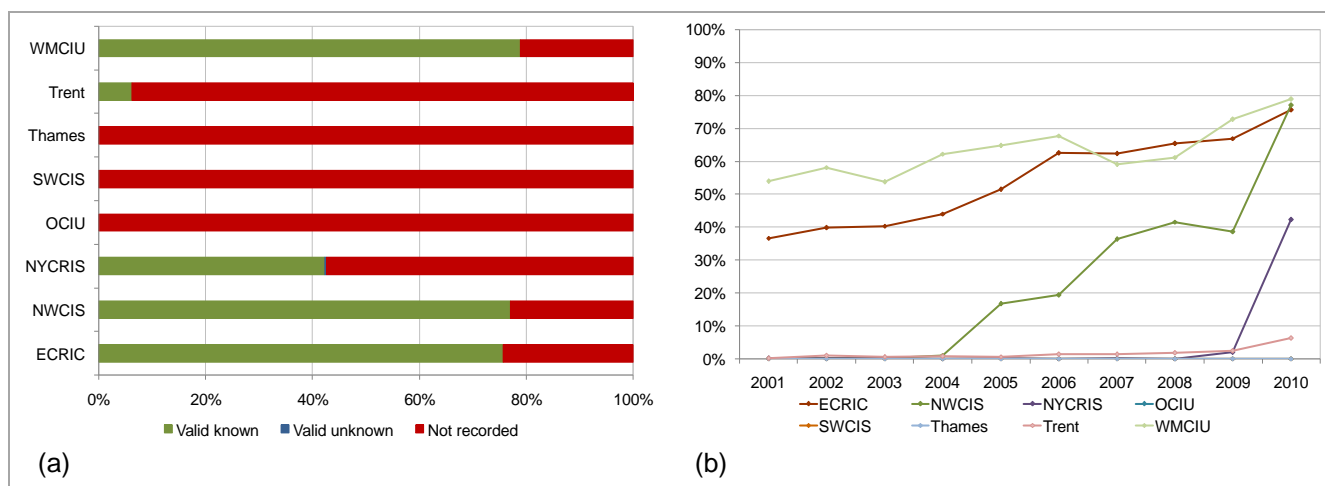


Figure 6.8.2 T component of TNM integrated: (a) completeness in 2010 (b) trend with valid known code, 2001-2010

On average the completeness of valid known N component was 30.5%. NWCIS had the highest percentage of tumour with N integrated recorded (71.1%), followed by WMCIU (68.4%) and ECRIC (58.4%) (Figure 6.8.3a). OCIU, SWCIS and Thames had 0% completeness for N integrated. In the later part of the 2001-2010 diagnosis period there was an increasing trend in the recording of the N component for pathological stage for ECRIC, NWCIS, WMCIU and NYCRIS (Figure 6.8.3b).

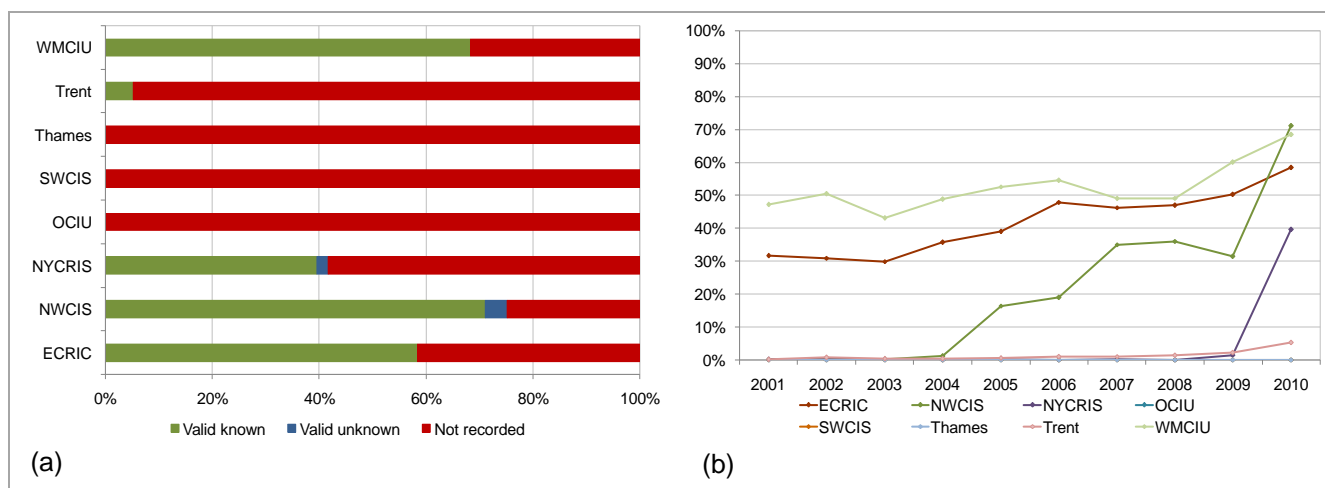


Figure 6.8.3 N component of TNM integrated: (a) completeness in 2010 (b) trend with valid known code, 2001-2010

On average the completeness of valid known M component was 19.4%. NWCIS had the highest percentage of tumour with M integrated recorded (53.2%), followed by WMCIU (41.0%) (Figure 6.8.4a). OCIU, SWCIS and Thames had 0% completeness for M integrated (Figure 6.8.4a).

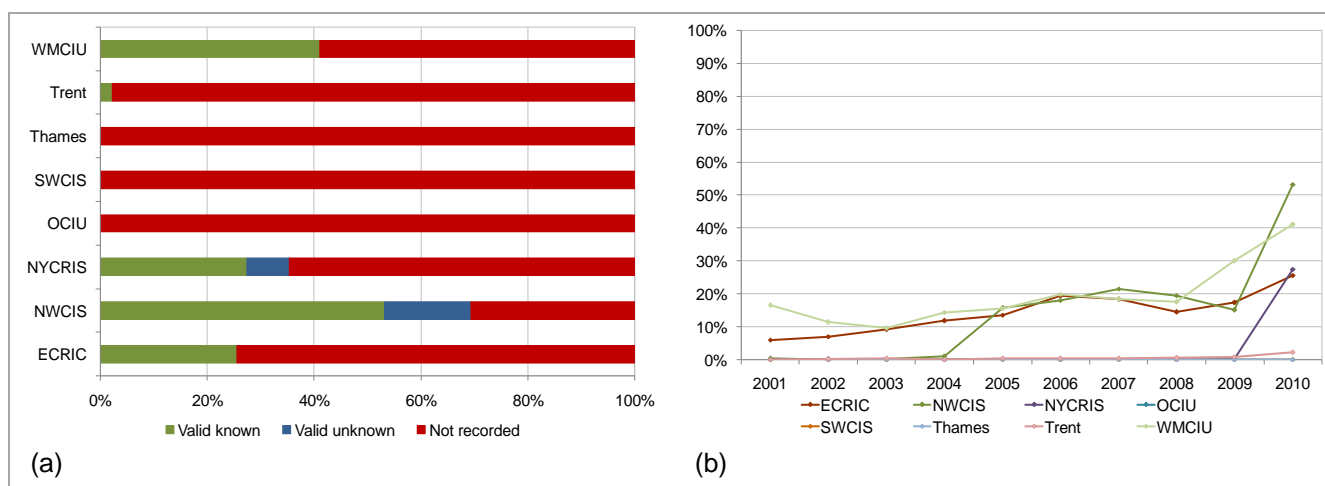


Figure 6.8.4 M component of TNM integrated: (a) completeness in 2010 (b) trend with valid known code, 2001-2010

On average 12.6% of all head and neck cancers had a valid TNM integrated stage recorded. In 2010, ECRIC had the highest reporting of TNM integrated stage recorded (63.8%). OCIU, SWCIS and Thames had 0% reporting for TNM integrated (Figure 6.8.5a). ECRIC had the highest TNM integrated stage reporting between 2001 and 2010 (Figure 6.8.2b). As the individual T, N and M integrated components have higher level of completeness, the proportion of overall TNM stage grouping can be increased by integrating all individual components during analysis.

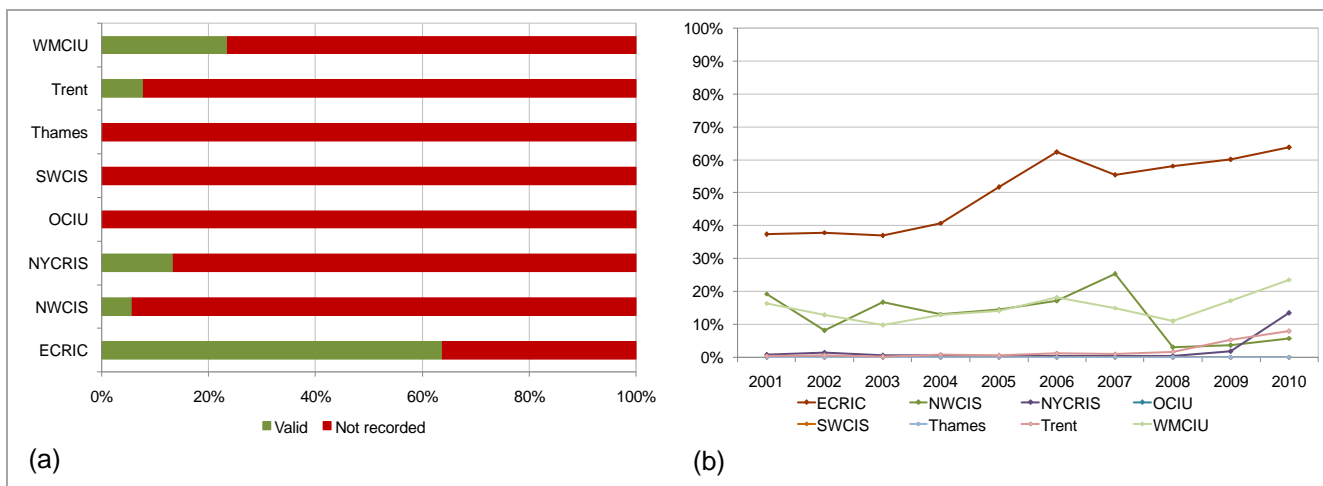


Figure 6.8.5 TNM stage, integrated: (a) completeness in 2010 (b) trend with valid known code, 2001-2010

Appendix 1: Head and neck cancer definition

ICD10 code	Description	Site
C00	Lip	Lip, tongue and oral cavity
C01	Base of tongue	Lip, tongue and oral cavity
C02	Other and unspecified parts of tongue	Lip, tongue and oral cavity
C03	Gum	Lip, tongue and oral cavity
C04	Floor of mouth	Lip, tongue and oral cavity
C05	Palate	Lip, tongue and oral cavity
C06	Other and unspecified parts of mouth	Lip, tongue and oral cavity
C07	Parotid gland	Salivary glands
C08	Other and unspecified major salivary glands	Salivary glands
C09	Tonsil	Pharynx and tonsil
C10	Oropharynx	Pharynx and tonsil
C11	Nasopharynx	Pharynx and tonsil
C12	Pyriiform sinus	Pharynx and tonsil
C13	Hypopharynx	Pharynx and tonsil
C14	Other ill-defined sites lip/oral cavity/pharynx	Pharynx and tonsil
C30	Nasal cavity and middle ear	Nose, ear and sinus
C31	Accessory sinuses	Nose, ear and sinus
C32	Larynx	Larynx
C73	Thyroid gland	Thyroid gland

Appendix 2: Paired head and neck cancer sites

ICD10 code	Description
C06.0	Cheek mucosa
C07	Parotid gland
C08.0	Submandibular gland
C08.1	Sublingual gland
C09.0	Tonsillar fossa
C09.1	Tonsillar pillar
C09.8	Overlapping lesion of tonsil
C09.9	Tonsil unspecified
C30.1	Middle ear
C31.0	Maxillary sinus
C31.1	Ethmoidal sinus
C31.2	Frontal sinus
C31.3	Sphenoidal sinus
C31.8	Overlapping lesion of accessory sinus

Appendix 3: Quality of the head and neck cancer dataset, England 2010

	ECRIC	NWCIS	NYCRIS	OCIU	SWCIS	Thames	Trent	WMCIU
Total number of registrations	1046	1576	1521	511	1421	2104	1074	1152
Patient details								
Sex	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%
Males	59.7%	61.3%	58.4%	55.8%	62.1%	58.2%	63.4%	60.0%
Females	40.3%	38.7%	41.6%	44.2%	37.9%	41.8%	36.6%	40.0%
Date of birth	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%
NHS number								
Valid NHS number	99.8%	99.9%	99.9%	99.6%	99.1%	99.3%	100%	100%
No NHS number	0.2%	0.1%	0.1%	0.4%	0.1%	0.7%	0.0%	0.0%
Ethnicity								
Valid known	80.1%	12.1%	89.3%	82.0%	86.1%	32.9%	91.4%	87.5%
Valid unknown	3.0%	8.9%	0.0%	18.0%	13.9%	10.9%	0.0%	0.0%
Not recorded	16.9%	78.9%	10.7%	0.0%	0.0%	56.2%	8.6%	12.5%
Postcode								
Valid length	100.0%	100.0%	100.0%	100.0%	100.0%	91.2%	100.0%	100.0%
Invalid length	0.0%	0.0%	0.0%	0.0%	0.0%	8.8%	0.0%	0.0%
Tumour details								
Tumour site								
Known anatomical site	77.1%	76.3%	74.7%	75.3%	74.9%	66.3%	77.6%	75.5%
Unknown anatomical site	22.9%	23.7%	25.3%	24.7%	25.1%	33.7%	22.4%	24.5%
Morphology system								
Valid known	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	99.8%
Not recorded	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.2%
Morphology coding								
Valid known	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	99.6%
Not recorded	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.4%

	ECRIC	NWCIS	NYCRIS	OCIU	SWCIS	Thames	Trent	WMCIU
Laterality (paired sites only)								
Valid known	87.9%	79.2%	92.6%	76.3%	86.1%	85.5%	95.3%	87.7%
Valid unknown	12.1%	18.9%	7.4%	23.7%	13.9%	3.1%	4.7%	2.4%
Not applicable	0.0%	1.9%	0.0%	0.0%	0.0%	2.9%	0.0%	9.9%
Not recorded	0.0%	0.0%	0.0%	0.0%	0.0%	8.6%	0.0%	0.0%
Diagnosis details								
Basis of diagnosis								
Valid known	99.8%	98.9%	100.0%	99.4%	99.2%	100.0%	98.3%	100.0%
Valid unknown	0.2%	1.1%	0.0%	0.0%	0.0%	0.0%	1.7%	0.0%
Not recorded	0.0%	0.0%	0.0%	0.6%	0.8%	0.0%	0.0%	0.0%
Diagnosis date								
Valid dates	99.8%	100.0%	100.0%	100.0%	100.0%	98.9%	100.0%	99.3%
Imputed dates	0.2%	0.0%	0.0%	0.0%	0.0%	1.1%	0.0%	0.7%
Death Certificate Only registrations								
Non-DCO	99.9%	99.0%	99.6%	99.0%	99.0%	99.3%	99.7%	99.5%
DCO	0.1%	1.0%	0.4%	1.0%	1.0%	0.7%	0.3%	0.5%
Treatment								
Surgery								
Yes	64.8%	53.6%	63.2%	64.4%	61.2%	87.3%	38.2%	55.4%
No	0.0%	0.0%	36.8%	35.6%	38.8%	12.7%	0.0%	2.1%
Blank	35.2%	46.4%	0.0%	0.0%	0.0%	0.0%	61.8%	42.5%
Radiotherapy								
Yes	56.3%	49.4%	56.8%	54.4%	55.2%	47.8%	11.5%	48.1%
No	0.0%	0.0%	43.2%	45.6%	44.8%	52.2%	0.0%	7.6%
Blank	43.7%	50.6%	0.0%	0.0%	0.0%	0.0%	88.5%	44.4%
Chemotherapy								
Yes	20.8%	17.9%	23.7%	15.5%	23.4%	23.2%	5.2%	22.5%
No	0.0%	0.0%	76.3%	84.5%	76.6%	76.8%	0.0%	4.3%

	ECRIC	NWCIS	NYCRIS	OCIU	SWCIS	Thames	Trent	WMCIU
Hormone therapy								
Blank	79.2%	82.1%	0.0%	0.0%	0.0%	0.0%	94.8%	73.3%
Yes	0.4%	0.4%	0.2%	0.4%	0.1%	0.5%	0.2%	1.7%
No	0.0%	0.0%	99.8%	99.6%	99.9%	99.5%	0.0%	2.1%
Blank	99.6%	99.6%	0.0%	0.0%	0.0%	0.0%	99.8%	96.2%
Death details								
Date of death								
Alive	71.9%	72.3%	77.3%	72.0%	72.8%	77.4%	73.0%	72.5%
Dead	28.1%	27.7%	22.7%	28.0%	27.2%	22.6%	27.0%	27.5%
Cause of death (patients with date of death only)								
Valid known	99.0%	98.6%	100.0%	97.2%	98.4%	98.5%	97.6%	98.1%
Not recorded	1.0%	1.4%	0.0%	2.8%	1.6%	1.5%	2.4%	1.9%
Place of death (patients with date of death only)								
Valid known	92.5%	100.0%	96.2%	49.0%	72.9%	0.0%	98.6%	98.4%
Not recorded	7.5%	0.0%	3.8%	51.0%	27.1%	100.0%	1.4%	1.6%
Stage details								
Tumour grade								
Valid known	66.1%	62.8%	62.3%	61.3%	66.1%	57.3%	34.4%	69.1%
Valid unknown	33.9%	0.0%	37.7%	0.0%	0.0%	17.6%	65.6%	30.9%
Not recorded	0.0%	37.2%	0.0%	38.7%	33.9%	25.0%	0.0%	0.0%
Tumour size								
Recorded	44.8%	15.0%	0.1%	0.0%	35.3%	28.6%	6.7%	36.6%
Not recorded	55.2%	85.0%	99.9%	100.0%	64.7%	71.4%	93.3%	63.4%
Nodes examined								
Recorded	24.5%	17.3%	15.6%	27.2%	30.0%	28.6%	6.1%	25.8%
Not recorded	75.5%	82.7%	84.4%	72.8%	70.0%	71.4%	93.9%	74.2%
Nodes positive								
Recorded	24.5%	16.4%	37.9%	27.2%	30.0%	17.0%	6.1%	26.0%

	ECRIC	NWCIS	NYCRIS	OCIU	SWCIS	Thames	Trent	WMCIU
Metastases								
Not recorded	75.5%	83.6%	62.1%	72.8%	70.0%	83.0%	93.9%	74.0%
Valid known	25.5%	53.2%	3.6%	18.8%	37.2%	57.4%	2.1%	41.1%
Valid unknown	74.5%	46.8%	96.4%	81.2%	62.8%	10.9%	97.9%	58.9%
Not recorded	0.0%	0.0%	0.0%	0.0%	0.0%	31.7%	0.0%	0.0%
Clinical stage (with valid known codes only)								
T	2.7%	0.1%	43.0%	30.7%	27.7%	33.5%	0.0%	58.7%
N	2.7%	0.1%	42.0%	28.8%	28.5%	31.6%	0.0%	57.5%
M	2.7%	0.1%	42.0%	28.8%	28.5%	31.6%	0.0%	57.5%
TNM	0.0%	0.0%	1.8%	0.0%	0.0%	0.0%	0.0%	20.3%
Pathological stage (with valid known codes only)								
T	8.0%	27.3%	11.3%	38.6%	30.5%	32.4%	3.9%	42.8%
N	5.5%	18.0%	7.1%	28.0%	34.1%	19.6%	2.9%	27.1%
M	2.5%	2.0%	0.5%	4.3%	9.0%	2.7%	0.5%	3.4%
TNM	0.1%	1.2%	1.0%	0.0%	0.0%	0.0%	0.4%	3.4%
Integrated stage (with valid known codes only)								
T	75.6%	77.0%	42.3%	0.0%	0.0%	0.0%	6.1%	78.9%
N	58.4%	71.1%	39.6%	0.0%	0.0%	0.0%	5.1%	68.4%
M	25.5%	53.2%	27.4%	0.0%	0.0%	0.0%	2.1%	41.0%
TNM	63.8%	5.7%	13.3%	0.0%	0.0%	0.0%	7.8%	23.5%

For further information on the National Head and Neck Cancer programme, click [here](#).

The National Cancer Intelligence Network (NCIN) is a UK-wide partnership operated by Public Health England. The NCIN coordinates and develops analysis and intelligence to drive improvements in prevention, standards of cancer care and clinical outcomes for cancer patients.

www.ncin.org.uk