NCDR (2007) Data Quality Report

An evaluation of stage indicators for four types of cancer particularly relevant to Teenagers and Young Adults (TYA)

North West Cancer Intelligence Service
2011

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Background

The Improving Outcomes: A Strategy for Cancer (2011) report, recently published by the Department of Health, outlines clear plans to support commissioners by improving the information available on cancer services and the outcomes they deliver. Particular emphasis has been placed on improving information on stage at diagnosis that can feed into the outcomes framework and support the transparency in outcomes initiative, and also support the ambition to improve mortality and survival rates through prevention and early detection.

It is widely acknowledged that considerable work is needed to improve the stage at diagnosis data captured via regional cancer registration in England to facilitate robust stage related analyses. All cancer registries in England are taking active steps to deliver on these necessary improvements.

To help evaluate progress being made in this area, NCIN and the CTYA site specific clinical reference group (CTYA SSCRG) requested a report on staging data currently available for cancers in teenagers and young adults. Three tumour sites that are particularly relevant to teenagers and young adults (TYA), malignant melanoma of the skin, thyroid cancer and cancer of the cervix, were chosen as a representative group of cancers. The objectives were to evaluate the stage indicators being recorded by cancer registries for each tumour site and compare data for TYA with data for other age groups. An evaluation of histological diagnostic indicators relevant for CNS tumours would also be undertaken. This report aims to provide an insight into the completeness of stage data available for informing cancer services and outcomes for TYA cancer patients.

Aims

To provide an overview of stage indicators in the national cancer data repository (NCDR) for cancer among patients aged 15 ï 24 years and compare these with completeness of data among other age groups. Also, to provide a summary of completeness and specificity of morphology data for CNS tumours.

Methods

Data were extracted from the NCDR (2007) on all patients aged 0 to 30 years who were diagnosed between 2006 and 2007 for each of the tumour sites:

a) Malignant melanoma of the skin
b) Thyroid
c) Cervix
d) CNS

For the first three tumour sites, data were extracted on demography, diagnosis and stage related data items. Morphology and topography data were reviewed for all malignant, borderline and benign primary CNS tumours.

Results

I. Malignant melanoma of the skin

Between 2006 and 2007, there were 1066 cases of malignant melanoma of the skin (ICD10 C43) among the 0 ï 30 year age group. Each of these cases was assessed for stage completeness, using all stage related data provided in the ñoriginal stageò, the ñstage descriptionò, the ñintegrated TNMòfields of the NCDR. By extracting all available data, and including all stage indicators, 0 ï 14 year olds had 70% data completeness, 15 ï 24 year olds had 73% completeness and the 25 ï 30 year olds had 78% completeness (Table 1).

Table 1. Stage recorded by age group

Stage	0 - 14 years		15 - 24 years		25 to 30 years		total cases
	no of cases	% cases	no of cases	% cases	no of cases	% cases	
BRESLOW 0.5MM	1	0.05	6	2%	28	4%	35
BRESLOW 1.0MM	0	0%	19	5%	28	4%	47
BRESLOW 1.5MM	0	0%	3	1%	9	1%	12
BRESLOW 2.0MM	0	0%	2	1%	6	1%	8
BRESLOW 2.5MM	0	0%	1	0%	2	0%	3
BRESLOW 3.0MM	0	0%	1	0%	3	0%	4
BRESLOW 3.5MM	1	5%	0	0%	3	0%	4
BRESLOW 4.0MM	0	0%	0	0%	1	0%	1
BRESLOW 4.5MM	0	0%	1	0%	0	0%	1
BRESLOW 5.0MM	0	0%	1	0%	2	0%	3
BRESLOW 5.5MM	0	0%	0	0%	1	0%	1
BRESLOW 6.0MM	0	0%	1	0%	1	0%	2
BRESLOW OVER 6.5MM	0	0%	0	0%	1	0%	1
BRESLOW UNDER 0.5MM	0	0%	9	2%	25	4%	34
CLARKE1	0	0%	4	1%	13	2%	17
CLARKE2	4	20%	54	14%	80	12%	138
CLARKE3	2	10%	51	13%	93	14%	146
CLARKE4	2	10%	44	11%	57	9%	103
CLARKE5	0	0%	2	1%	1	0%	3
STAGE I	1	5%	57	15%	118	18%	176
STAGE II	1	5%	17	4%	26	4%	44
STAGE III	2	10%	9	2%	6	1%	17
STAGE IV	0	0%	1	0%	5	1%	6
No stage	6	30%	107	27%	147	22%	260
Total	**20**		**390**		**656**		**1066**

If the site specific system was not specified in the stage description we have assumed the stage provided is a stage group based on TNM . Only complete stage data was used from the "integrated TNM" field except for 4 cases recorded as XX1 that were interpreted as Stage IV.

Across all ages, stage information was recorded either as Clarkes, TNM or Breslow. The most common system recorded for TYA cases with stage information was Clarkes (155 cases, 40%); 84 cases (22%) had a TNM stage and 44 cases (11%) had Breslow data recorded. This distribution of stage system usage was consistent across all ages. The remaining 107 TYA cases (27%) had no valid stage recorded.

For 67 of the cases (all ages) that had a TNM stage group recorded in the ñoriginal stageò field, one registry had also provided additional Clarkes stage entered into the ñstage descriptionòfield.

Analyses on completeness of staging data for the older age groups (Table 2) have kindly been provided by Matthew Iles at South West Cancer Intelligence Service (SWCIS). Note the numbers generated by SWCISôanalyses are slightly different due to differences in de-duplication and cleaning procedures employed by SWCIS and NWCIS.

Table 2. Stage distribution across age groups provided by SWCIS

	Age Band					
Clark Level	**0-14**	**15-24**	**25-44**	**45-64**	**65+**	**Total**
2	5	76	689	976	794	2,540
3	2	54	540	923	827	2,346
4	3	47	408	840	1,215	2,513
5		10	44	208	574	836
Unknown	10	195	1,802	3,391	3,725	9,123
Total	20	382	3,483	6,338	7,135	17,358

	Age Band					
Breslow Thickness	**0-14**	**15-24**	**25-44**	**45-64**	**65+**	**Total**
0-1mm	1	33	340	507	369	1,250
1-2mm		5	65	143	151	364
2.1-4mm	1	2	35	80	171	289
> 4mm		3	19	66	184	272
Unknown	18	339	3,024	5,542	6,260	15,183
Total	20	382	3,483	6,338	7,135	17,358

	Age Band					
TNM Stage	**0-14**	**15-24**	**25-44**	**45-64**	**65+**	**Total**
1					1	1
4			18	66	72	156
Unknown	20	382	3,465	6,272	7,062	17,201
Total	20	382	3,483	6,338	7,135	17,358

Source SWCIS(2010)

We further looked at the cases with no TNM stage group to see what, if any, partial clinical or pathological stage (ie T, N or M) data had been recorded (Table 3). Cases with only partial TNM stage data are usually discounted from stage related analyses. They have been included here only to demonstrate the level of stage information recorded.

None of these cases had sufficient T N and M information recorded to derive any form of stage group. However, 18 cases had primary tumour level information, 9 of which were TYA cases. Two cases (1 TYA) also had regional lymph node data recorded, which could provide some indication of tumour stage if MX is counted as MO.

Table 3. T N and M data recorded for cases with incomplete stage data

no of cases	clinical T N M	pathological T N M	derived summary stage group	derived summary stage group if pathological MX = MO
2		T4 N1	n/a	Stage III
2		T1A	n/a	n/a
8		T1	n/a	n/a
1		T2A	n/a	n/a
1		T2B	n/a	n/a
3		T3	n/a	n/a
1		N1	n/a	n/a
1	T1A		n/a	n/a
241	missing	missing	n/a	n/a

Cases that had either Clarkes or Breslow data recorded in the ñoriginal stageò field but no ñintegrated TNMò stage provided were also assessed for partial T, N and M information. Of those TYA cases with Breslow data, 16 (36%) also had primary tumour data recorded (pathological T). None had data on lymph node involvement. Of those TYA cases with a Clarkes stage, 67 (43%) also had primary tumour data recorded (clinical and/or pathological T), 6 of which had both T and N data but no data on metastases (M).

II. Thyroid

Analysis of completeness of stage for carcinoma of the thyroid needs to take into account rules for staging different thyroid subtypes and age at diagnoses. Analyses presented here are based on all cases with a site code of ICD10 C73.9. Subtypes have then been determined using ICD-0 morphology.

In 2006 to 2007, there were 443 cases diagnosed as thyroid carcinomas among the 0 ï 30 year olds; the majority of cases (89%) were papillary or follicular carcinoma histopathologic subtypes, 6% were medullary carcinomas and 5% were other or unknown subtypes.

A. Papillary and Follicular Carcinomas

For papillary and follicular carcinomas in the under 45 year age group, tumours are classified as either stage I (where there is no distant metastasis) or stage II (where there is distant metastasis). Therefore staging of this thyroid carcinoma subtype in teenagers and young adults is heavily reliant on the capture of metastasis data at the point of cancer registration. The non-capture of this information is the primary reason for poor stage completeness for this diagnoses in this age group.

Among 396 cases of papillary or follicular carcinoma among the 0 ï 30 year olds, 95% of cases had insufficient metastasis information to allow an allocation of a stage group (Table 4). Among the 15 to 24 year olds, only 7 out of 153 cases (4.5%) had information on metastasis in the pathological M and/or the clinical M field which is a similar level of completeness as the other age groups in the dataset analysed.

Table 4. Metastasis data recorded by age group

Mestatisis	0 - 14 years		15 - 24 years		25 - 30 years		Total
	no of cases	% cases	no of cases	% cases	no of cases	% cases	
M0	0	0%	6	4%	7	3%	13
M1	1	6%	1	1%	1	0%	3
MX	3	17%	13	8%	29	13%	45
no entry	14	78%	133	87%	188	84%	335
Total	18		153		225		396

Table 5 shows the clinical and/or pathological TNM stage data that have been recorded for the papillary and follicular carcinomas of the thyroid. Among the 15 to 24 year olds, 26 of the 153 cases (17%) had information recorded on the primary tumour (T), compared with 21% for all ages up to 30 years. Twenty (13%) of these TYA cases had information recoded on both primary tumour and lymph node involvement (N) (compared with 14% of all ages assessed). However without complementary information on metastasis these data are rendered invalid for stage related analyses.

Table 5. T N & M data recorded by age group. Cases with complete metastasis data are highlighted in red.**

T	N	M	0-14	15-24	25-30
T1	N0	MX	0	1	4
T1	N1	M0	0	1	0
T1	N1	MX	0	2	2
T1	N1A	MX	0	0	1
T1	N1B	MX	0	1	1
T1	NX	MX	0	2	3
T2	N0	M0	0	2	5
T2	N0	MX	0	2	6
T2	N1	M0	0	0	1
T2	N1	MX	1	2	3
T2	N1B	MX	0	1	3
T2	N2	M0	0	1	0
T2	NX	MX	1	2	11
T2B	N0	M0	0	0	1
T2B	N1B	MX	0	0	1
T3	N0	M0	0	1	0
T3	N0	M1	0	0	1
T3	N0	MX	0	2	0
T3	N1	MX	0	1	1
T3	N1B	M0	0	1	0
T3	N1B	MX	1	2	1
T3	NX	MX	2	2	6
T4	N0	MX	0	0	1
T4	N1	MX	0	0	1
T4A	N1B	MX	0	0	1
TX	N1	M1	1	1	0
TX	N1	MX	0	1	0
TX	NX	MX	12	125	171
total			18	153	225

***T, N and M data have been taken from either the clinical or the pathological T, N and M fields in the NCDR, using the most complete collective group of TNM fields (ie clinical or pathological). Where a single case had both clinical and pathological completed, the pathological fields are used here. Blank M fields have been counted as "MX"*

B. Medullary carcinomas of the thyroid

Staging of medullary carcinomas of the thyroid follows a more typical staging system, based on a combined assessment of the primary tumour (T), involvement of lymph nodes (N) and metastasis (M).

There were only 25 cases of medullary carcinoma diagnosed among the 0-30 year olds between 2006 and 2007, six cases among the 15 ï 24 years. Across all ages, no cases had information on metastasis recorded; for each case both the clinical and pathological M

fields were either empty or contained ñMXò to indicate ñdistant metastasis cannot be assessedò. Thus no case of medullary carcinoma aged 30 years and below could be considered to have a complete stage.

We then looked at cases of medullary carcinomas with T and N data but either missing M data or M recorded as MX. Among the 15 to 24 year olds, two cases (33%) had information recorded on the primary tumour and the lymph nodes (ie T1N1 and T2N0) and a further case had only lymph node involvement recorded (N1B). Among the 25 to 30 year olds 4 out of 14 cases (28%) had primary tumour and the lymph node data recorded. None of the 5 cases aged 0 ï 14 years had any TNM data recorded at all.

Again, we would emphasise that cases with only partial TNM stage data would usually be discounted from stage related analyses. They have been included here only to demonstrate the level of stage information recorded for thyroid tumours in teenagers and young adults.

C. Other stage used

In 33 cases, (30 papillary or follicular and 3 medullary) stage had been recorded in the ñintegrated TNMò field as A, B C and D but the stage system used was unclear. Nine of these cases were aged 15 ï 24 years, the remaining aged 25 ï 30 years.

III. Cervix

In 2006 and 2007, there were 656 cases of cervical cancer (ICD10 C53) diagnosed among the 15 ï 30 year olds. No cases were diagnosed among patients less than 15 years of age.

Of 111 cases aged 15 ï 24 years, 89 cases (80%) had a valid stage group recorded in the 2007 NCDR. This is comparable to 78% of cases aged 25 to 30 years.

Table 6. Stage recorded by age group

summary stage	15 - 24 years		25 - 30 years		Total
	No of cases	% cases	No of cases	% cases	
FIGO I	7	6%	17	3%	24
FIGO IA	7	6%	41	8%	48
FIGO IA1	13	12%	44	8%	57
FIGO IA2	0	0%	6	1%	6
FIGO IB	6	5%	34	6%	40
FIGO IB1	5	5%	36	7%	41
FIGO IB2	2	2%	6	1%	8
FIGO II	1	1%	3	1%	4
FIGO IIA	1	1%	1	0.2%	2
FIGO IIB	5	5%	17	3%	22
FIGO III	1	1%	1	0.2%	2
FIGO IIIA	0	0%	1	0.2%	1
FIGO IIIB	5	5%	8	1%	13
FIGO IV	0	0%	2	0.4%	2
FIGO IVB	0	0%	3	1%	3
STAGE I	12	11%	124	23%	136
STAGE IA	5	5%	17	3%	22
STAGE IA1	1	1%	4	1%	5
STAGE IA2	0	0%	1	0%	1
STAGE IB	4	4%	15	3%	19
STAGE IB1	1	1%	0	0%	1
STAGE II	3	3%	7	1%	10
STAGE IIA	0	0%	1	0.2%	1
STAGE IIB	3	3%	1	0.2%	4
STAGE III	2	2%	8	1%	10
STAGE IIIB	0	0%	3	1%	3
STAGE IV	5	5%	23	4%	28
STAGE IVB	0	0%	2	0.4%	2
No stage	22	20%	119	22%	141
Total cases	111		545		656

Among 15 ï 24 year olds, Figo stage was used in 48% of cases, compared with 40% of 25 ï 30 year olds. The remaining cases had a TNM derived summary group. In cases where Figo was not indicated as the stage system in either the ñstage descriptionò or the ñoriginal stageò fields, we assumed the stage was TNM derived. This may not be a valid assumption as the format of the 2007 NCDR provided a single field for the definitive ñoriginal stageò as well as a field for an ñintegrated TNMò stage but no separate field for a site specific stage. Therefore a mixture of stage systems was recorded in the ñoriginal stageòfield. This issue has now been resolved in the 2008 NCDR. This does not affect the measure of stage completeness in any way. Where cases had both a Figo stage and an

integrated TNM stage recorded, the Figo stage has been counted in Table 6. Where cases had no stage entered in the ñoriginal stageò field or the integrated TNM field, we created a TNM stage group from the individual pathological and clinical T, N and M fields if sufficient information was available.

For the 141 cases with no valid stage group, we assessed the level of primary tumour (T) and lymph node (N) data that was available in the NCDR. The majority of these cases (93%) had no T,N or M data either clinical or pathological. One of the TYA non-staged cases had primary tumour information recorded, the remaining 20 had no TNM information at all. Nine of the un-staged cases aged 25 to 30 years also had some information on the primary tumour and/or lymph node involvement.

This gives an indication of the level of stage information provided for carcinomas of the cervix diagnosed in 2006-2007 and how close cancer registries in England are to obtaining 100% stage for this tumour site.

IV. CNS

In 2006 and 2007, there were 1103 cases with an ICD10 site code that indicated a malignant neoplasm of the brain or other part of the CNS (ICD10 C70 ï C72) or a malignant neoplasm of the pituitary gland (C75.1) or of the pineal gland (C75.3). An additional 351 cases were diagnosed as either borderline or benign CNS tumours.

Here, we have grouped each of these cases into histological types to demonstrate the level of specificity that can be derived for CNS tumours in the NCDR based on ICD-0 morphology. Table 7 shows the distribution of broad histological groupings and the number of cases that could not be allocated to any particular group.

We found 97% of cases had a morphology or a combination of morphology and ICD10 site code that was sufficiently specific to allow the case to be allocated to one of the histological groups. Most of the cases (71%) were classified as a neuroepithelial histological type, with gliomas dominating across all ages. The majority of cases with a non-specific morphology were benign tumours. of the unspecified malignant CNS tumours.

Table 7. Number and percent of cases by histology type and age group.

	Histological type	0 - 14 years		15 - 24 years		25 - 30 years		Total	
		No of cases	% cases	No of cases	% cases	No of cases	% cases	No of cases	% cases
Neuroepithelial	Gliomas: astrocytomas, glioblastomas, ependymomas, oligodendroglial tumours, mixed gliomas	406	60%	209	53%	199	53%	**814**	**56%**
	Medulloblastomas and other PNET	122	18%	29	7%	10	3%	**161**	**11%**
	All other neuroepithelial tumours: choroid plexus, pineal parenchyma, neuronal-glial tumours	32	5%	15	4%	7	2%	**54**	**4%**
Other CNS tumours	Tumours of the meninges & tumours of the cranial and spinal nerves	21	3%	48	12%	84	22%	**153**	**11%**
	Tumours of the sellar region: Pituitary and craniopharyngioma	25	4%	51	13%	61	16%	**137**	**9%**
	Specified Other: germ cell tumours, hematopoietic tumours, non-menigothelial tumours of the meninges, malignant mesenchymal, local extensions from regional tumours, tumours of uncertain histogensis	49	7%	23	6%	9	2%	**78**	**5%**
	Unspecified CNS: Malignant	9	1%	5	1%	3	1%	**17**	**1%**
	Unspecified CNS: Benign	17	2%	13	3%	6	2%	**36**	**2%**
	Unspecified other	1	0.1%	0	0%	0	0%	**4**	**0%**
total		**682**	**0**	**393**	**0**	**379**	**0**	**1454**	

Conclusions

Two of the three tumour sites we assessed (cervical cancer and malignant melanoma of the skin) had over 70% completeness among teenagers and young adults based on all stage indicators. Furthermore, for cervical cancer, all staged cases were staged using either TNM or the site specific system Figo. However, for malignant melanoma, the Clarkes and Breslow systems were commonly used in the place of TNM stage. Of all three tumour sites assessed for stage, thyroid cancer had the lowest level of stage completeness with just 4.5% of teenagers and young adults having a complete stage record although the level of completeness was not less than other age groups evaluated.

One limitation to our assessment was the way stage data captured by cancer registries was transferred into the 2007 NCDR. At the time this report was initiated, the most current NCDR dataset was complete to 2007; the format of this early version played an influential role in how regional stage data was uploaded from individual cancer registry systems into the NCDR, often with registries taking very different approaches. This factor has made a systematic review of stage completeness and quality difficult. The new NCDR, complete to 2008, has addressed many of these issues, making much clearer distinctions between different staging systems used and allowing for more than one stage. Also fields to record TNM version number and a neoadjuvant therapy flag have been added, which will allow summary stages to be generated and for integrated TNM stage to be validated using the individual T, N and M fields. A further assessment of the 2008 NCDR may reveal very different results to those presented here, even without any real changes to staging capture methods.

It should also be noted that staging completeness is dependent on assessment methods used. Here we have attempted to provide an indication of the type and level of stage recorded by cancer registries by assessing all information contained within the NCDR and by looking at partial stage as well as complete stage. The value of this approach is particularly well illustrated by cases of papillary and follicular carcinoma of the thyroid. Among teenagers and young adults, less than 5% of cases could be classed as having a complete stage and yet 17% of cases had some information recorded on the primary tumour and 13% had information on both the primary tumour and lymph node involvement. While partial stage data cannot usually be used for robust stage related analyses, we hope our inclusion of an assessment of partial stage data capture will help to provide some insight into how the collection of stage data can be improved.

For CNS tumours, the majority of cases had sufficient topography and morphology information to allow cases to be broadly classified into histological groups.

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FIND OUT MORE:

North West Cancer Intelligence Service (NWCIS)

NWCIS is the lead Cancer Registry for cancer in teenagers and young adults.

http://www.nwcis.nhs.uk

Other useful resources within the NCIN partnership:

Cancer Research UK CancerStats – Key facts and detailed statistics for health professionals

http://info.cancerresearchuk.org/cancerstats/

The National Cancer Intelligence Network 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. Sitting within the National Cancer Research Institute (NCRI), the NCIN works closely with cancer services in England, Scotland, Wales and Northern Ireland. In England, the NCIN is part of the National Cancer Programme.