



# Now you see them, now you don't

Assessing the impact of switching from routine access to hospital case notes to receipt of electronic data for cancer registration in the Northern and Yorkshire Cancer Registration and Information Service (NYCRIS) area.

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## BACKGROUND

The transition from manual collection to electronic receipt of cancer registration data was a carefully managed process over a number of years within the NYCRIS area. This presented a unique opportunity to compare directly levels of ascertainment, quality of data and effects on reaching timeliness targets of the two methods. We set out to assess and quantify the changes over the period of transition from 2005 to 2010.

## METHODS

To enable changes in numbers of registrations by year to be examined for consistency, details were extracted from the NYCRIS database for tumours diagnosed in NYCRIS residents - **diagnosis years 2005 to 2010, tumour site, treatments received, first trust visited, network of residence.** Apparent anomalies were scrutinised by registration staff.

Registrations from Cancer Waiting Times (CWT) data with no pathological confirmation were identified and a number of unexpected sites were investigated.

Percentages of tumours receiving definitive surgery were compared and a sample of those showing a reduction was linked to Hospital Episode Statistics (HES) to check for any missing procedures.

## RESULTS

### Ascertainment

Overall, and for most sites, the number of cases continued to increase as expected, with registrations for malignant tumours (ICD10 codes C00-C97 excluding C44) diagnosed in 2009 and 2010 being at 104% of the 2005-08 average (Figure 1).

However, the overall position can hide small but significant differences to the trend – for example, the number of registrations where the first trust was in the private sector fell by 58% from 1,130 in 2005 to 475 in 2010 (Figure 2).

### Timeliness

The transition to receipt of electronic data has enabled new shorter timeliness targets to be achieved. At the start of the period, time to completeness was 18 months (after diagnosis year end). This had reduced to 12 months for 2010 registrations (Figure 3).

### Treatment Indicators

The percentages of tumours receiving various treatments remained largely consistent throughout – for example, surgery at 43/44%, chemotherapy at 25/26%, teletherapy at 19/20% (Figure 4). The fall in hormone treatment from 16% to 13% reflects the trend towards more targeted therapy.

### Quality Assurance

The results of the project prompted us to undertake a number of quality assurance exercises.

A sample of C18: Colon and C32: Larynx with no surgery recorded by the registry but with surgery on in-patient HES were checked remotely on trust clinical systems. Of the 1,559 colon tumours, 56 seemed to have relevant surgery coded on HES but only 3 of these were added to the registry data – the others being a mixture of biopsies, cancelled surgeries or removal of polyps. Corresponding numbers for larynx were 159, 21 and 9, with 12 exclusions for similar reasons.

## CONCLUSIONS

- Overall there has been no obvious decline in data quality.
- It can be difficult to separate genuine trends from those caused by changes in registration process.
- Significant changes in small areas can easily be missed by concentrating on the overall picture.
- Examination of details is proving that without remote access to trust systems it would be difficult to make sense of some electronically-received data needing amendment.
- Supplementing surgery from HES is not necessarily accurate when checked remotely on hospital systems.

Figure 1 - Registrations for all NYCRIS Residents

ICD10 Site code and description	2005	2006	2007	2008	2009	2010	Average 2005-08	% of 05-08	Average 2009-2010
Grand Total	53,515	54,625	56,340	58,564	59,088	59,258	55,761	106%	106%
C00-C97: All Malignant Sites	45,446	46,543	47,963	49,593	49,372	49,932	47,386	104%	105%
C00-C97 excl C44	34,991	35,725	36,368	37,358	37,509	37,698	36,111	104%	104%
All D codes	8,069	8,082	8,377	8,947	9,691	9,282	8,369	116%	111%
C00: Lip	43	55	43	30	54	53	43	126%	124%
C01: Base of tongue	33	43	51	79	78	77	52	151%	150%
C02: Other and unspecified parts of tongue	104	147	140	130	130	156	130	100%	120%
C03: Gum	25	25	19	21	29	25	23	129%	111%
C04: Floor of mouth	67	47	74	64	72	67	63	114%	106%
C05: Palate	34	34	40	58	33	56	42	80%	135%
C06: Other and unspecified parts of mouth	51	68	67	74	65	57	65	100%	88%
C07: Parotid gland	46	54	43	58	42	58	50	84%	115%
C08: Other/ unspecified major salivary glands	14	15	11	28	21	22	17	124%	129%
C09: Tonsil	102	106	126	116	135	117	113	120%	104%
C10: Oropharynx	22	27	16	26	40	38	23	176%	167%
C11: Nasopharynx	25	29	29	27	26	25	26	102%	91%
C12: Pyriform sinus	32	45	47	37	26	36	40	65%	89%
C13: Hypopharynx	17	24	15	17	19	31	16	104%	170%

Figure 2 - NYCRIS residents - 1st trust XR or non-NHS (C00-C97 ex C44)

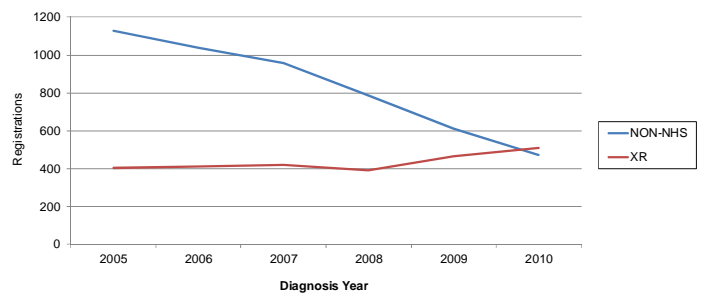


Figure 3 - Timeliness of Northern & Yorkshire Cancer Registrations 2006-11

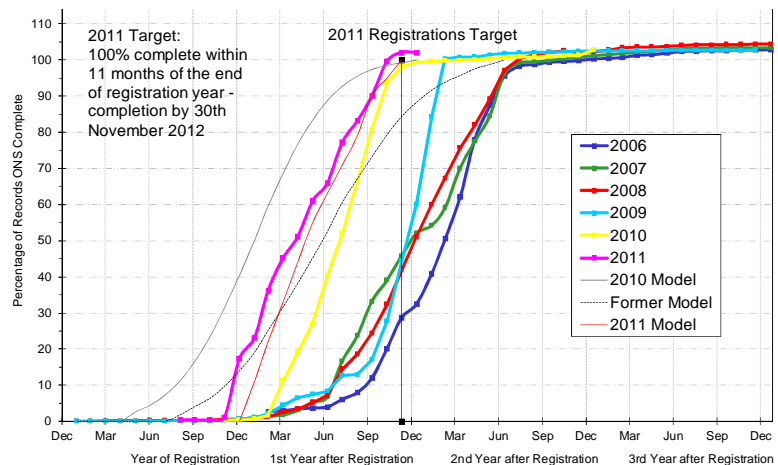


Figure 4 - Percentage of tumours receiving definitive treatment

Treatment	2005	2006	2007	2008	2009	2010
All Malignant Tumours (C00-C97 ex C44)	34,991	35,725	36,368	37,358	37,509	37,698
Surgery	43%	43%	43%	44%	44%	44%
Chemotherapy	25%	25%	26%	26%	27%	26%
Hormone	16%	15%	15%	15%	14%	13%
Immunotherapy	0.5%	0.7%	0.8%	0.9%	0.8%	0.9%
Brachytherapy	1.0%	1.1%	1.1%	0.9%	0.9%	1.2%
Teletherapy	19%	20%	19%	19%	20%	20%