National Head and Neck Cancer Audit (DAHNO)

Analysis of completeness of follow-up and outcomes data

National Head and Neck Cancer Audit (DAHNO) - Analysis of follow-up and outcomes for audit cohort.

The purpose of this report is to describe the quality and quantity of any follow-up and outcomes data available within the DAHNO audit.

The DAHNO (Data for Head and Neck Oncology) system, which supports the National Head and Neck Cancer Audit, began a phased roll out and started receiving cases in 2004 on larynx and oral cavity cancers. Initially restricted to English cancer networks and subsequently eligible to Wales, all cancer networks in England and Wales now submit data to the audit, but not all eligible networks and trusts participated in the timeframe studied. Some organisations submitted a broader range of tumour site groups (in addition to larynx and oral cavity) at inception whilst others have retrospectively populated the DAHNO database in these site group areas. Formal national collection on pharynx and major salivary gland cancer began in 2008.

The data used for these analyses was uploaded from Trusts to the DAHNO audit and supplied to OCIU in 17 files of cumulative data. The data cover cases diagnosed from 1st January 2004 to 31st October 2008. DAHNO sites include larynx and oral cavity for all years and oropharynx, hypopharynx and nasopharynx mainly from October 2007, but some in earlier years. These files are analysed in an access database.

Overall, the quality of the data has improved over the time period and the quantity has increased with more trusts submitting in later years. However, the inclusion of duplicate records within the data for all years remains a concern and complicates the analysis.

Figure 1: Numbers of records and patients in DAHNO for 2004 to 2008

Cancer group	Number	2004	2005	2006	2007	2008*	total
larynx	records	374	638	987	1129	1227	**4355**
	patients	358	582	944	1079	1120	**4083**
oral cavity	records	381	626	980	1009	1197	**4193**
	patients	356	587	937	978	1109	**3967**
oropharynx	records	166	227	247	208	986	**1834**
	patients	156	215	225	194	913	**1703**
hypopharynx	records	39	60	74	52	261	**486**
	patients	39	55	70	49	243	**456**
nasopharynx	records	14	26	22	33	100	**195**
	patients	14	26	21	28	96	**185**
major salivary	records	24	42	47	43	274	**430**
glands	patients	24	40	44	40	250	**398**
Total	records	**998**	**1619**	**2357**	**2474**	**4045**	**11493**
	patients	**947**	**1505**	**2241**	**2368**	**3731**	**10792**

*2008 data are for January to October only

Figure 1 shows the numbers of records and patients in the DIAGNOSIS table that contains the main information about the tumour such as the cancer site, diagnosis date, stage and hospitals. The DIAGNOSIS table is linked to other tables that hold more specific information such as treatment, nutrition and diet.

Initially, 12 data items that give information on the condition of the patient at different dates were checked for completeness. All patients that are included in the DIAGNOSIS table should also have entries in the CAREPLAN and STATUS tables. Other tables (such as SURGICAL VOICE RESTORATION (SVR)) may not be relevant to all patients.

Figure 2: Numbers of records with outcome related information in selected tables (out of 10792 patients)

Table name	Field name	Patients with entry in table	% of patients with entry in table	Patients with entry in field	% of entries in table with this field coded
CAREPLAN	Recurrence indicator	9224	85.5	5536	60.0
CAREPLAN	Co-morbidity index	9224	85.5	2554	27.7
CAREPLAN	Performance status at present	9224	85.5	5025	54.5
STATUS	Metastatic status	3260	30.2	2174	66.7
STATUS	Nodal status	3260	30.2	2141	65.7
STATUS	Primary tumour Status	3260	30.2	2476	76.0
MORTALITY	Death date	1508	14.0	1507	99.9
NUTRITION	Nutritional Support Type (Phase II)	518	4.8	163	31.5

Figure 2 shows that while basic information on tumours and their treatment may be entered into DAHNO tables, often the details of disease progression and patient status outcomes are not recorded. Figure 2 shows that that the CAREPLAN does contain entries for over 85% of the cases and details of any recurrence and the performance status on about 60% of cases.

A decision was made to concentrate on the contents of the STATUS table, as it includes information on disease progression, with a date recorded of when the assessment was carried out.
The STATUS table in the DAHNO dataset contains the following data:
- 5890 records for 3275 different patients
- 88 records with the same incorrect patient number caused by an error in the system when patients were entered with no NHS number
- 5387 records with an assessment date (between 21/08/2003 and 25/01/2010)
- 145 records with an assessment date of 01/01/1900
- 1 incorrect date format
- 357 records with no assessment date recorded

A patient may be assessed many times after diagnosis. In the analyses a patient is counted at every assessment recorded in DAHNO and may be counted more than once in an interval (e.g. more than once in a 3 month interval). Analyses were carried out to look at the frequency and intervals of when patients were followed-up after being diagnosed with head and neck cancer. The STATUS table contains the field called 'DatePerformanceAssessment'. This was analysed by taking the difference between this date and the diagnosis date and plotting the number of visits by the number of weeks or months from diagnosis.

There are 73 Trusts that have one or more records with an assessment date and 21 Trusts that have 50 or more records with an assessment date (see Appendix 1 for list of Trusts with more than 50 assessment records).

Results

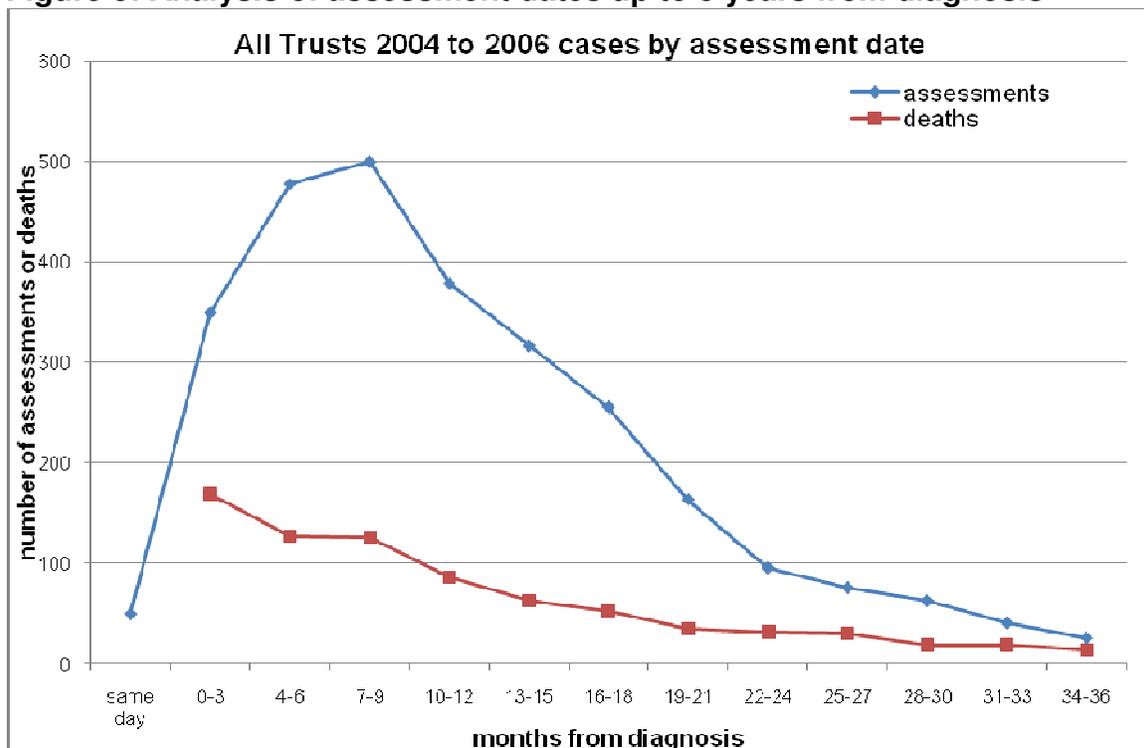**Figure 3: Analysis of assessment dates up to 3 years from diagnosis**

Figure 3 shows the analyses for all cases entered in DAHNO with a diagnosis date in years 2004 to 2006. The blue line shows the number of times they were assessed in intervals of 3 months in the 3 years following diagnosis and the brown line shows the number of patients that died. The assessment curve shows a peak at 7-9 months after diagnosis with a stable decline in these assessments over the next year. The reduction in assessments over time may be due to patients not being assessed, some patients dying within 3 years or details of assessments not being submitted to DAHNO.

Figure 4 shows the analyses for all cases entered in DAHNO with a diagnosis date in years 2004 to 2008, the number of assessments in the first year following diagnosis and the number of deaths in the first year.

Figure 4: Analysis of assessment dates and deaths up to 1 year from diagnosis
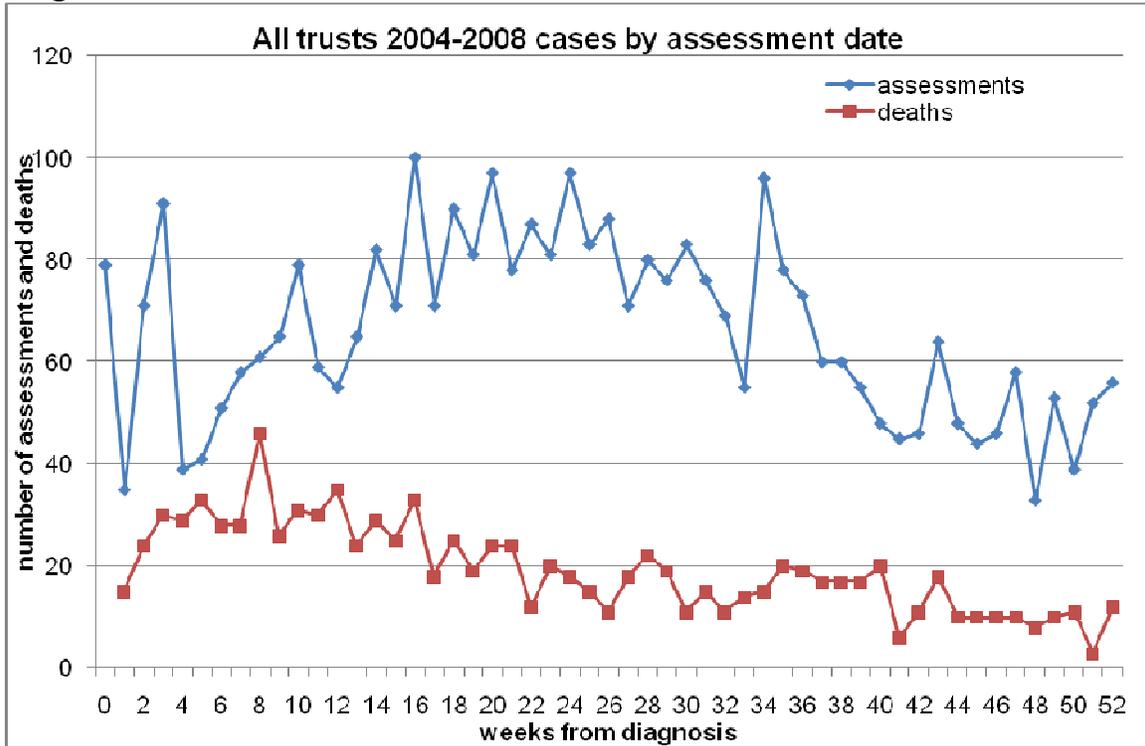
Where there were sufficient cases, this analysis was carried out at Trust level, using Contact hospital if given or else Submitting hospital. Examples are given showing the patterns in the follow-up policies (or recording) of three Trusts.

Figures 5, 6 and 7 show the analysis of assessment dates by week up to 1 year after diagnosis for 3 Trusts. The plotted trendlines show that although the numbers of cases assessed each week is variable the overall policy of case review is similar at all 3 Trusts.

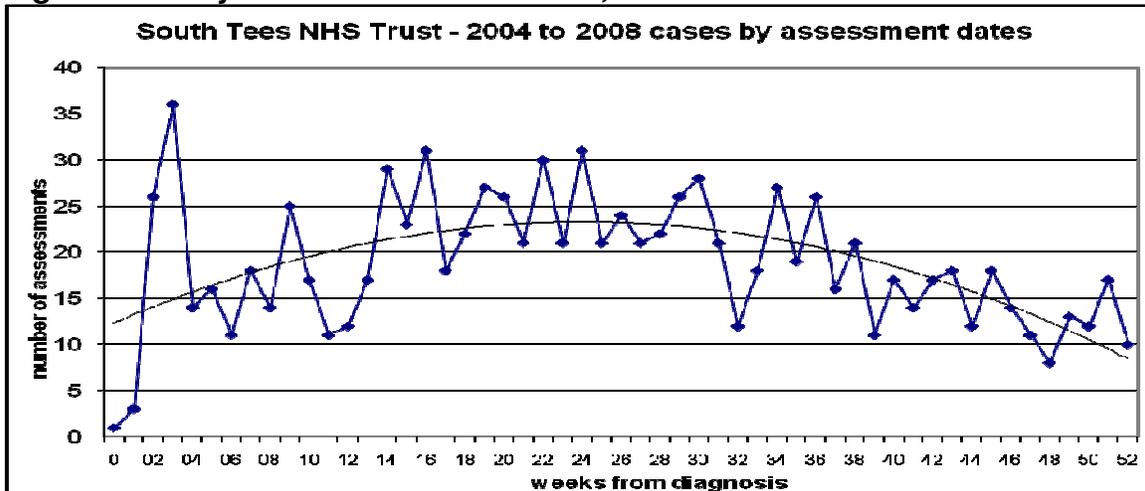**Figure 5: Analysis of assessment dates, South Tees NHS Trust**

Figure 6: Analysis of assessment dates, Norfolk and Norwich NHS Trust
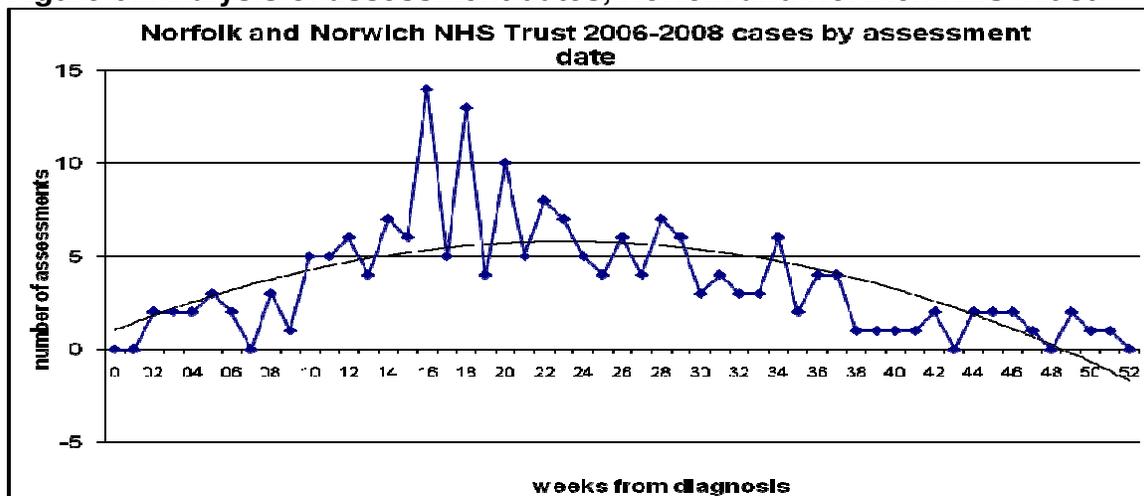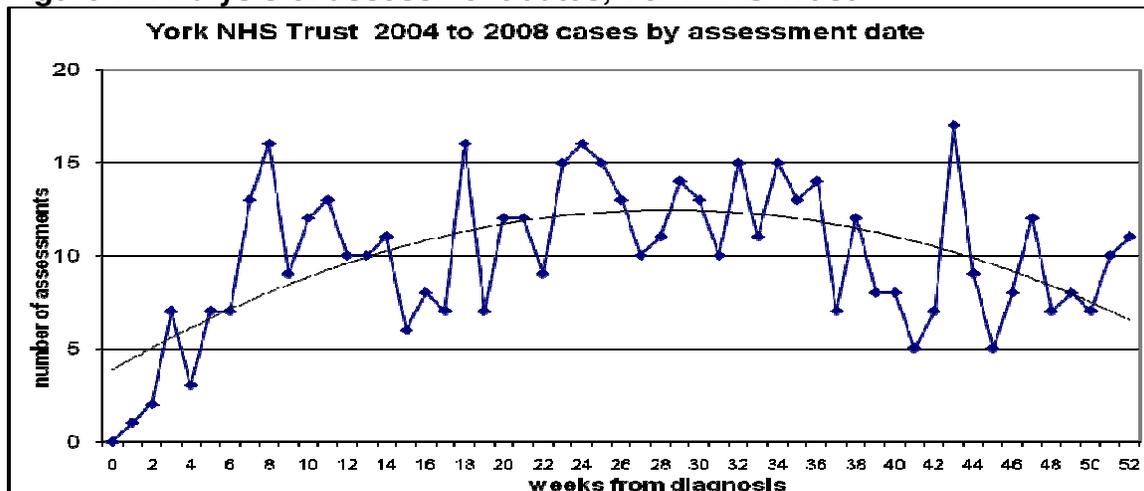

Figure 7: Analysis of assessment dates, York NHS Trust

Conclusions

- In the years covered by this report, only limited follow up and outcomes data were recorded for the DAHNO audit cohort.

- No meaningful analyses of follow up strategies or variations in disease free survival are possible given the limitations of the data.

- A small number of hospitals do record much more complete follow up and outcomes data. It will be important to share their experience and approach to capturing follow up data with other Trusts

- Ensuring more complete recording of information on recurrences and performance should be a priority.

Appendix 1

Trusts with 50 or more records having assessment dates

NHS Trust	2004	2005	2006	2007	2008	2004-2008
South Tees Hospital NHS Foundation Trust	350	527	238	105	93	1313
York Hospitals NHS Foundation Trust	16	34	43	176	467	736
University Hospital Birmingham NHS Foundation Trust	69	108	74	28	20	299
The Newcastle Upon Tyne Hospitals NHS Foundation Trust	0	2	120	54	62	238
South Devon Healthcare NHS Foundation Trust	25	31	49	66	56	227
Southend University Hospital NHS Foundation Trust	1	13	70	56	66	206
Norfolk and Norwich University Hospitals NHS Foundation Trust	0	1	29	69	94	193
Blackpool, Fylde and Wyre Hospitals NHS Foundation Trust	0	0	0	70	121	191
Aintree University Hospitals NHS Foundation Trust	25	45	41	20	30	161
Poole Hospital NHS Foundation Trust	13	30	23	47	36	149
Leeds Teaching Hospitals NHS Trust	17	22	39	28	0	106
Derby Hospitals NHS Foundation Trust	6	6	43	27	21	103
Doncaster and Bassetlaw Hospitals NHS Foundation Trust	7	29	34	25	6	101
The Royal Marsden NHS Foundation Trust	37	43	21	0	0	101
North Cumbria University Hospitals NHS Trust	0	21	33	6	26	86
East Sussex Hospitals NHS Trust	0	9	31	21	13	74
Bradford Teaching Hospitals NHS Foundation Trust	18	41	14	0	0	73
Colchester Hospital University NHS Foundation Trust	3	23	25	11	10	72
University Hospitals Of Leicester NHS Trust	23	11	14	1	16	65
Dorset County Hospital NHS Foundation Trust	1	3	3	22	22	51
St George's Healthcare NHS Trust	43	6	0	1	0	50
All Trusts	**736**	**1123**	**1052**	**913**	**1275**	**5099**