How reliably can we use existing routine and ad hoc data sources to evaluate the quality of care for head and neck cancer patients?

M F Roche, J Ridha, S Edwards, G Price, K Lloyd, S Forsey

Cancer Registration

Strengths
- High levels of case ascertainment
- UK wide coverage
- Sole source of population based incidence and survival data
- All head and neck sub sites covered
- Reliable information on tumour type and date of diagnosis
- Reliable information on date and place of initial therapeutic surgery
- Reliable information on date and place of radiotherapy
- Reliable information on date, place and cause of death

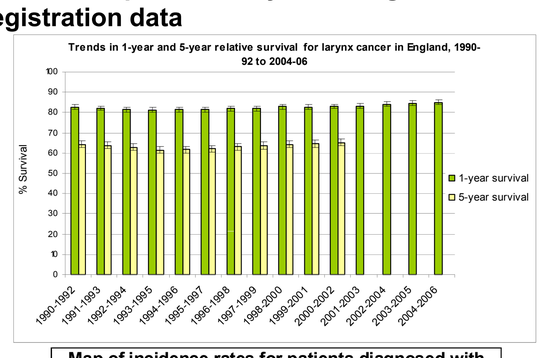
Weaknesses
- Little staging data
- Only (usually) records treatments within six months of diagnosis
- Problems with coding of very complex head and neck cancer surgery
- Lack of clinical detail for radiotherapy treatments
- Incomplete information on chemotherapy
- No information on recurrences
- No information on quality of life or patient experience

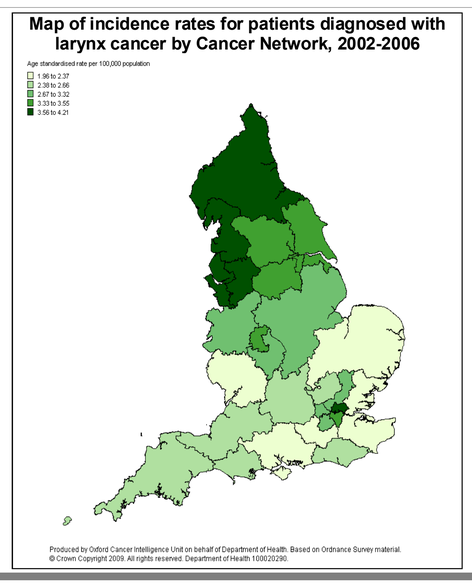
Hospital Episode Statistics (HES)

Strengths
- National coverage (England)
- Mandatory return from NHS hospitals- linked to payments
- Covers all inpatient and day case hospital admissions
- Covers all surgical procedures (diagnostic, therapeutic, palliative)
- Reliable source of information about health service utilisation
- Most complete source of information about ethnicity
- Co-morbidity index can be derived

Weaknesses
- Some issues with accuracy of diagnostic coding
- Problems with coding of very complex head and neck surgery
- No staging data
- No information on quality of life or patient experience
- Outpatient HES has less complete and reliable clinical information

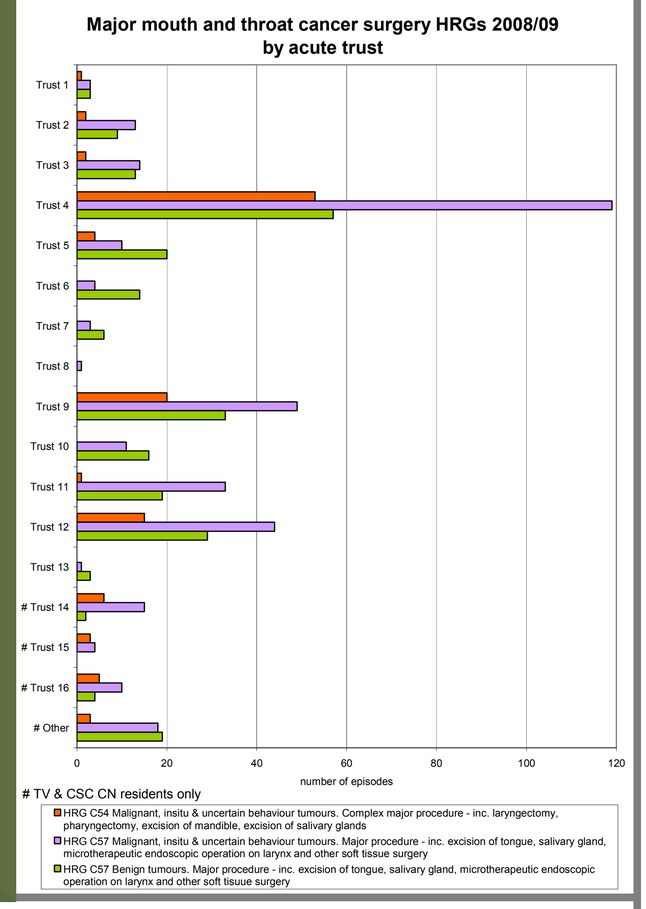
Some examples of analyses using cancer registration data





OBJECTIVES: To describe the strengths and weaknesses of the available national data sources covering the quality and outcome of head and neck cancer care.
To show examples of analyses from the main national data sources including the National Head and Neck Cancer Audit (DAHNO), national cancer registration system and HES (Hospital Episode Statistics).
To show how more detailed radiotherapy and chemotherapy data collected within one cancer network can supplement the national sources.
METHODS: The completeness and quality of information in DAHNO, the national cancer registration system and HES will be compared and contrasted. Examples will be given of how the different data sources can be used to contribute to the understanding of variations in the quality and outcome of care for head and neck cancer patients. The added value of the data on radiotherapy and chemotherapy which has been collected in one Cancer Network will be reviewed.
RESULTS: The routine national data sources (cancer registration and HES) provide information about almost all patients with a diagnosis of head and neck cancer but are incomplete for some key data items (e.g. stage) and are not sufficiently accurate for others (e.g. complex surgery). The DAHNO audit on the other hand has less complete case ascertainment (although it is improving year on year) but has more information on stage and more accurate recording of complex surgery. None of the national sources currently has detailed information about radiotherapy and chemotherapy.
CONCLUSIONS: The routine and ad hoc data sources available at national level have different strengths and weaknesses. By combining data from these sources, we get a more complete and accurate picture of care. The lack of detailed standardised information on radiotherapy and chemotherapy at national level will be addressed within the next few years.

An analysis of surgical data from HES

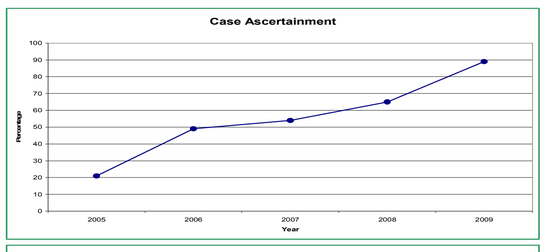


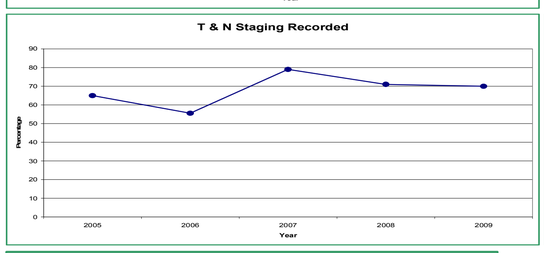
National Head and Neck Cancer Audit (DAHNO)

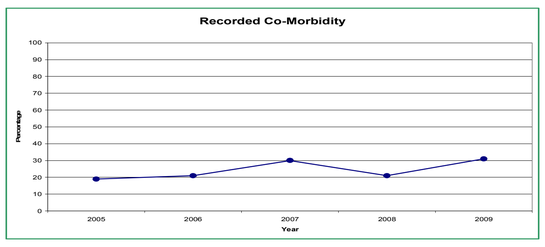
Strengths
- 90% case ascertainment in most recent year
- Best source of staging information
- Surgical data coded by clinical teams

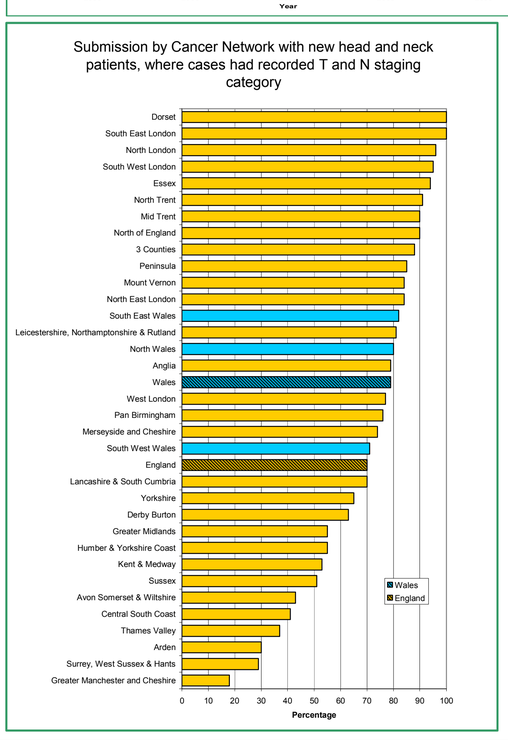
Weaknesses
- Completeness of key data items still varies by Trust and Network
- Only covers some head and neck cancer sub-sites
- Limited information on radiotherapy and chemotherapy
- Incomplete information on co-morbidity and performance status
- Incomplete information on care provided by dieticians, speech therapists, clinical nurse specialists
- Incomplete information on status at follow up

Quality indicators for DAHNO data









An analysis of surgical data from DAHNO

Percentage receiving each category of surgical procedure (including surgery to neck, and flap repair)		
Oral cavity patients - surgery summery	**Count**	**Percentage of 635 patients with surgical procedure recorded**
Floor of mouth excision	**108**	**17.0**
- of these 108, the number having neck dissection	55	8.7
Buccal mucosa excision	**68**	**10.7**
-of these 68, the number having neck dissection	26	4.1
Patients having tongue procedures	**255**	**40.2**
- of these 255, the number having neck dissection	116	18.3
patients having total glossectomy	9	1.4
patients having partial glossectomy	130	20.5
patients having excision lesion of tongue	121	19.1
Patients having mandible procedures	**62**	**9.8**
- of these 62, the number having neck dissection	30	
patients having extensive mandibulectomy	7	
patients having hemimandibulectomy	12	
patients having marginal mandibulectomy	28	
patients having mandibulotomy or excision lesion	18	
Total maxillectomy	**0**	**0.0**
Partial maxillectomy	**29**	**4.6**
Neck dissections (includes those mentioned with procedures above)	**318**	**50.1**
Radical neck dissections (includes those listed previously)	**66**	**10.4**
Modified neck dissections (includes those listed previously)	**29**	**4.6**
Selective neck dissections (includes those listed previously)	**227**	**35.7**
Recontsruction mouth	**126**	**19.8**
with flap	48	
with primary closure	5	
with buccal flap	2	
with pectoralis major	8	
with radical forearm	66	
with SSG	6	
Recontsruction mouth by cancer site		
tongue	40	
lip	11	
gum	8	
mouth floor	35	
palate	3	
cheek mucosa	15	
mouth vestibule	9	
retromolar trigone	5	
Reconstruction mandible	**7**	
with other	3	
with fibula	4	

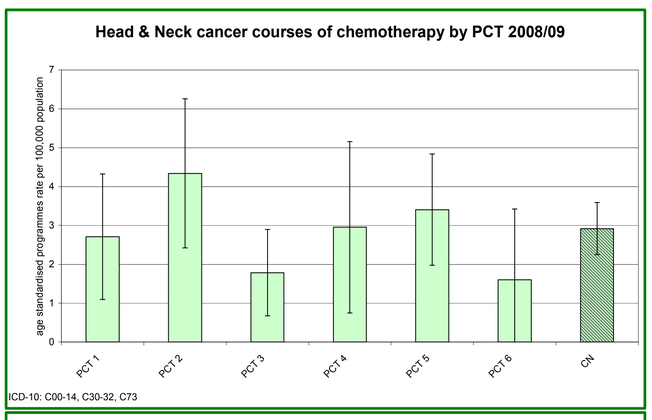
Radiotherapy and Chemotherapy

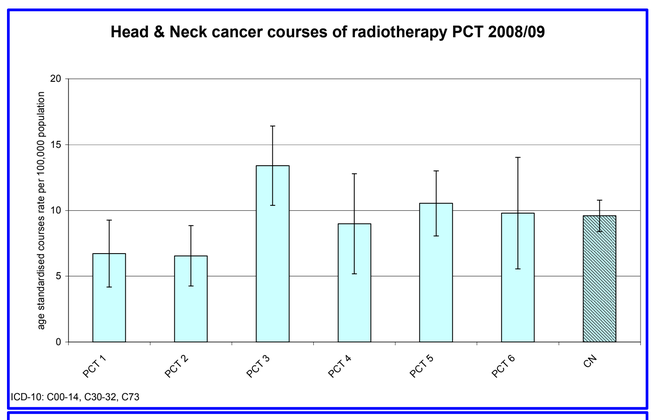
Radiotherapy
From 1 April 2009, all providers of radiotherapy to NHS patients are required to submit the Radiotherapy Data Set (RTDS), linked to the Out Patient Commissioning Dataset, for every fraction of radiotherapy delivered to their patients. This will enable progress against the National Radiotherapy Advisory Group guidelines to be assessed, as well as providing an insight into variations in radiotherapy treatment across England. Ultimately the data will be a new source for cancer registration and will be included in the national cancer data repository.

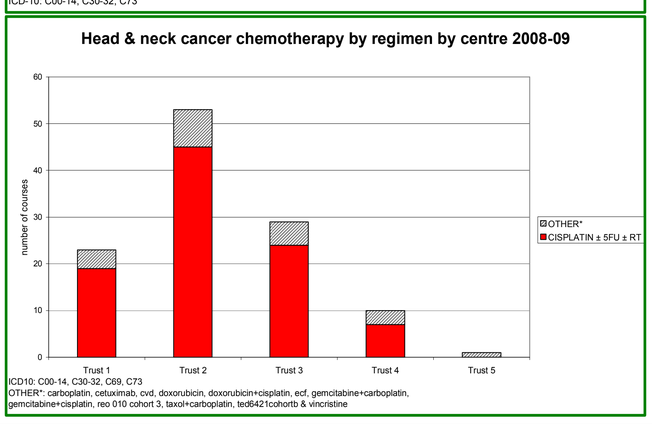
Chemotherapy
NCIN have been working towards the delivery of an agreed chemotherapy dataset for England. The dataset needs to be approved by the Information Standards Board and, if approved, would become a mandatory return from April 2012. The aim is to capture the agreed dataset from e-prescribing systems.

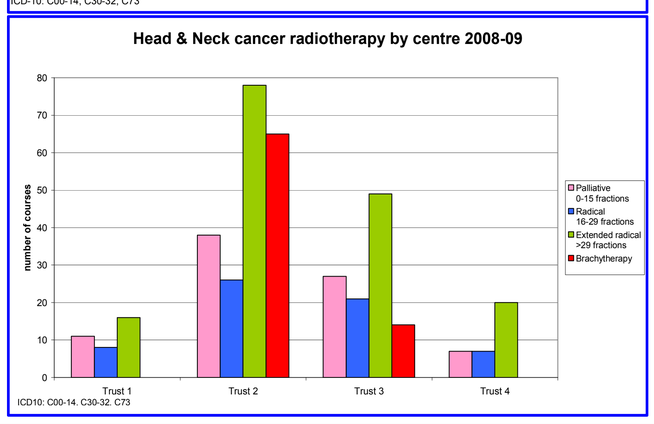
Trusts within Thames Valley Cancer Network have been collecting clinically relevant data on radiotherapy and chemotherapy treatments for more than a decade. The locally agreed datasets are very close to the newly mandated Radiotherapy Dataset and the proposed dataset for chemotherapy though less detailed. The types of analyses that can be undertaken include analyses of radiotherapy and chemotherapy regimes by cancer site, provider and PCT, showing variations between providers and temporal trends.

Some examples of analyses of radiotherapy and chemotherapy data for Thames Valley Cancer Network









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