

Swedish National Quality Register of Head & Neck Cancer (SHNC-QR) – A population based register of H& N cancer incidence, treatment and outcome.

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Background: Registries with high coverage can be invaluable for describing patterns of care and outcomes for a population of patients (pts).

We report the initial findings from, a prospective, longitudinal, observational national register of head and neck carcinoma (HNC) pts in Sweden. All ENT and Oncology departments diagnosing and treating HNC are participating

Methods: Pts are eligible for SHNC-QR if they have newly diagnosed HNC. Coverage is double-checked through the Swedish Cancer Registry which receives information from clinical departments and pathology departments.

Data are entered in the register electronically and transferred via protocols in the web-based INCA system. Pts are followed from time of initial diagnosis and for a minimum of 5 years, or until death.

Data collected: Histology, anatomic site, TNM classification and stage, personal data and performance. Type of treatment planned and completed as well as follow-up. When all data has been introduced and verified in the data base, the patient file is locked. Only locked records are summarized and reported.

Results: 1195 pts have been enrolled during 2008 comprising 96% of patients with HNC in Sweden. Until April 2010 2486 patient have been entered into the Register. Oral cavity is the most prevalent site (29 %) followed by oropharynx (22 %) and larynx (15%). Curative treatment is intended in 89%. Treatment comprises surgery alone in 26%, surgery in combination with radiotherapy in 18 % and radiotherapy alone in 47%. After 13 month of follow up 64% of the patients are tumour free.

Conclusions: SHNC-QR is a complete, population based, prospective register of HNC in Sweden with acceptance in all treatment centers and the Swedish National Health Board. It allows population based analysis of incidence, treatment and outcomes. Within a few years this can with accuracy be done by site/sub-site.