

The Swedish Head and Neck Cancer Register

SweHNCR

Presentation in English



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Organisation, aim and some data from the 2018 report

The Swedish Head and Neck Cancer Register (SweHNCR) is a nationwide clinical database that contains prospective data collected since 2008. The overall aim of the register is to describe the outcomes of head and neck cancer treatment in Sweden and to create a basis for clinical trials. By December 31, 2018, the register had grown to include 15,452 patients.

Registered data in the SweHNCR

- Patient demographics including age, sex, smoking habits and WHO performance status.
- TNM classification and stage of tumours (UICC 7th ed. and since January 1, 2018: UICC 8th ed.), histology, p16 (HPV-DNA and HPV type optional) and EBV status.
- Date of first visit to an ENT specialist, date of diagnosis, date of multidisciplinary tumour board (MDT) and date of treatment start.
- Planned and given treatment.
- Date and site of recurrence.
- Follow-up data for five years.
- Date of death and tumour status at death.

Aim of the SweHNCR

The aim of the register is to increase knowledge about head and neck cancer in Sweden and identify weaknesses in the diagnostic processes and treatment protocols where improvements can be made. The register should also be hypothesis-generating for research by comparing the outcomes of different treatment modalities. Where there are differences in outcomes, more advanced studies should be initiated. The register strives to have a high coverage ratio compared to the Swedish cancer register and to only include high-quality data. Another aim of the register is to use the data to support the development of national guidelines for head and neck cancer in Sweden. In August 2015, the first edition of the “National Guidelines for Head and Neck Cancer in Sweden” was published and subsequently revised into a second edition in 2019 (Swedish language). The guidelines include actual and relevant data from the SweHNCR.

Organisation of the SweHNCR

The board of the SweHNCR consists of one head and neck surgeon and one oncologist from each of the seven university hospitals in Sweden. Two head and neck cancer specialist nurses and two representatives from the patient’s organisation for head and neck cancer are also members of the board. The Regional Cancer Centre in Gothenburg (RCC-west) supports the register with statistics and administration. Data are registered in the INCA (Information Network for Cancer) database, owned by the RCC organisations in Sweden. The board meets at least twice a year to discuss the development of the register and scientific projects and to give feedback to the reporting clinics. The SweHNCR has financial support through grants from the Swedish Association of Local Authorities and Regions and is free from commercial interests.

Data gathering and the MDT

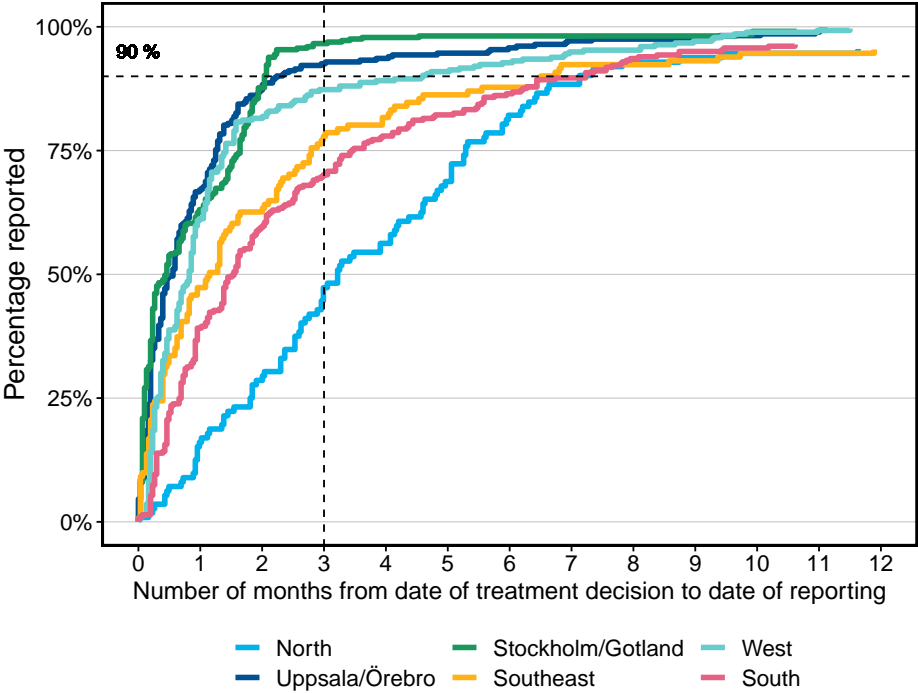
All ENT clinics in Sweden have a duty to submit data from all their patients with head and neck cancer to the SweHNCR. The treatment decision of the multidisciplinary tumour board (MDT) provides the basis for the first report to the SweHNCR. The data from the MDT cover 98 % of the patients with head and neck cancer in Sweden, except for those with small (T1) lip cancers. After

tumour assessment and the screening of comorbidities, a treatment schedule is recommended and presented to the patient. The MDT is held at least once a week at each of the seven university hospitals in Sweden.

Registration of the report from the MDT

The goal is that at least 90 % of the data should be registered in the INCA data system within 3 months from the MDT. Patient data that are not reported within this time frame will be sought. The reporting rate in 2017 for the six Swedish regions is shown in Figure 1.

Figure 1. Reporting rate (%) per region during 2017.

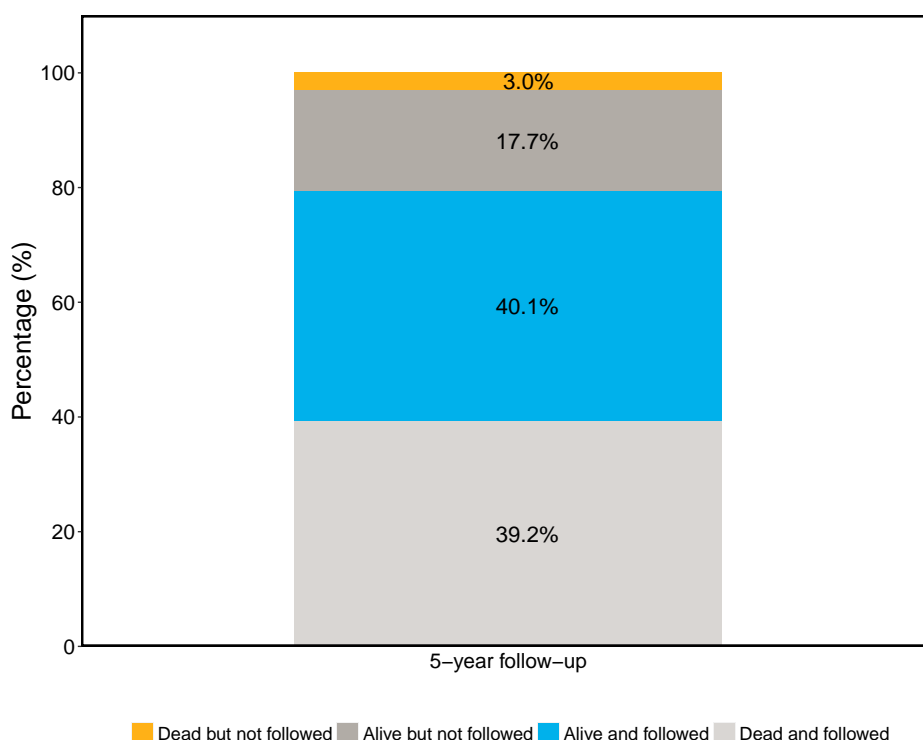


Treatment and follow-up

Most treatments for patients with head and neck cancer in Sweden are centralised to the university hospitals. The clinics that provide the treatment are also responsible for reporting the given treatment to the register. This is performed in two separate reports, one for oncological treatment and one for surgical treatment.

Between 2008 and 2018, 96 % of patients who are included in the SweHNCR had at least one follow-up event registered in the SweHNCR. Follow-up was scheduled for five years. Between 2008 and 2013, 79 % of the cases were properly reported within the five-year follow-up, and 21 % were not (Figure 2).

Figure 2. Proportion of living and dead patients diagnosed from 2008-2013 with and without complete five-year follow-up data.



Validity/Data quality

The initial report to the SweHNCR, which is based on the MDT, has high validity, including patient and tumour data, as well as the process time to the MDT. The follow-up data are incomplete, as a number of visits are not registered in the SweHNCR. As a consequence, the SweHNCR board has decided that all research studies must include the validation of patient data. Consequently, the SweHNCR is validated continuously.

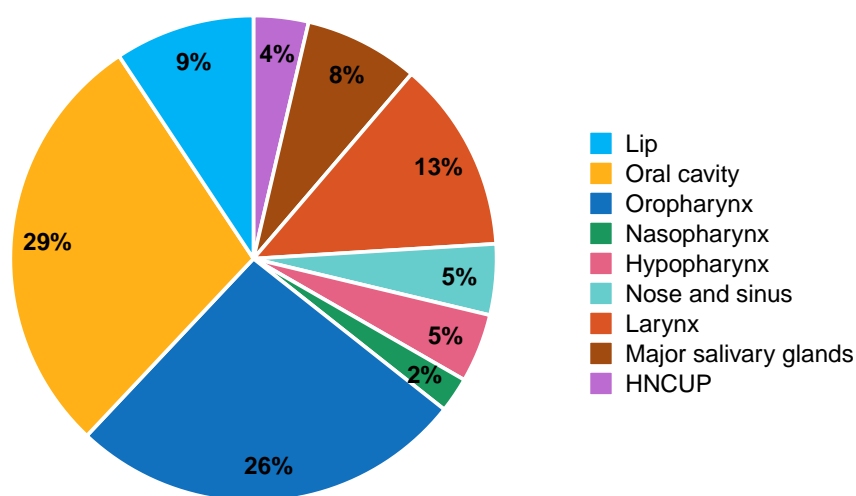
Data from the SweHNCR

The following report is based on the period from 2008-2017 and includes 13,822 patients.

Incidence and trends

Head and neck cancer in Sweden constitutes 2.3 % of all cancers. The incidence is approximately 1,500 cases per year, comprising nine different sites (Figure 3).

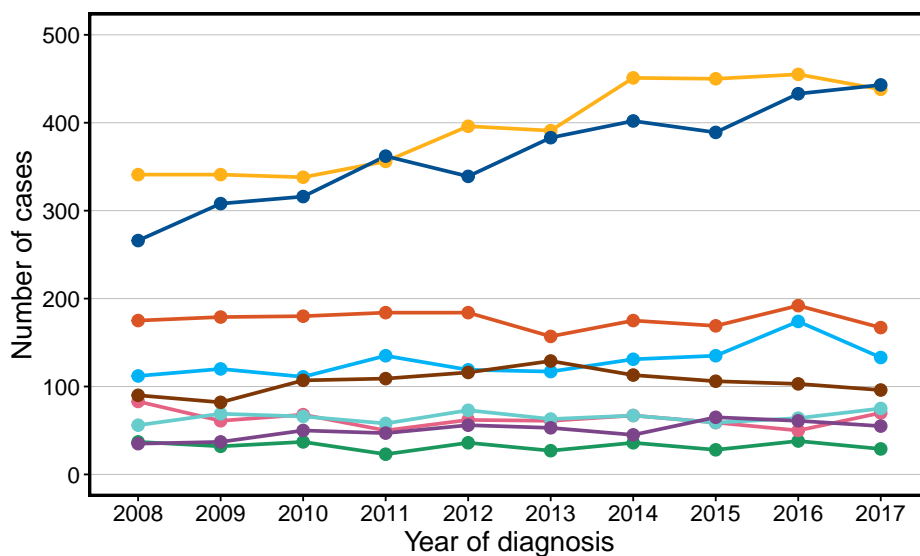
Figure 3. Distribution of head and neck cancer cases in the SweHNCR, 2008-2017.



The incidence of head and neck cancer in Sweden increased by 25 % during the ten-year period from 2008-2017. The incidence of oropharyngeal cancer increased by 65 % and that of oral cancer by 26 %. The incidence of carcinomas of other head and neck cancer sites did not change during the period from 2008-2017 (Figure 4). Human papilloma virus (HPV)-induced oropharyngeal carcinomas are considered the main reason for the increase. In Sweden, there is an on-going vaccination programme against HPV for young girls in order to prevent cervical cancer. The Swedish government has decided to start the same vaccination programme for boys in September 2020.



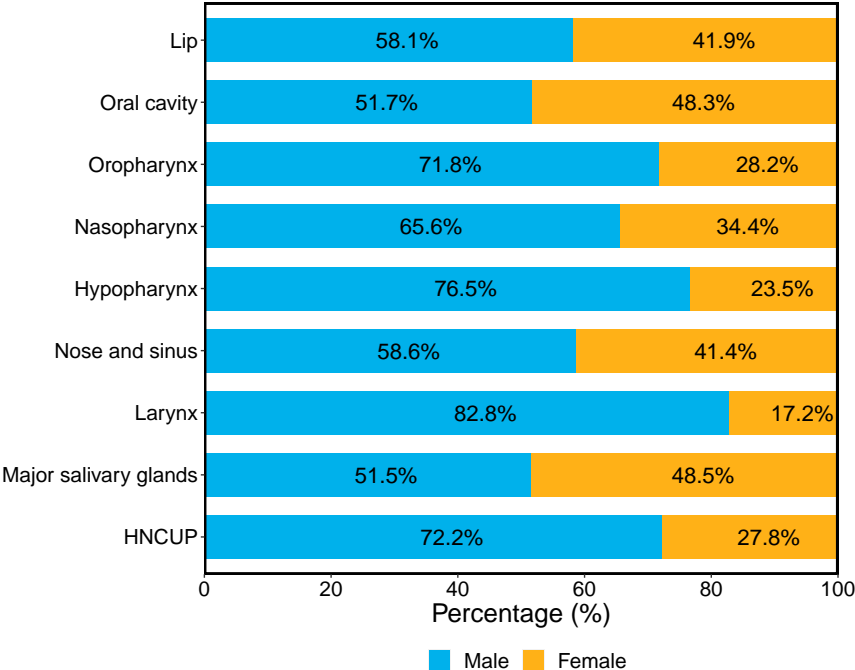
Figure 4. Number of cancer cases per diagnosis group during the years 2008-2017.



Sex and age distribution

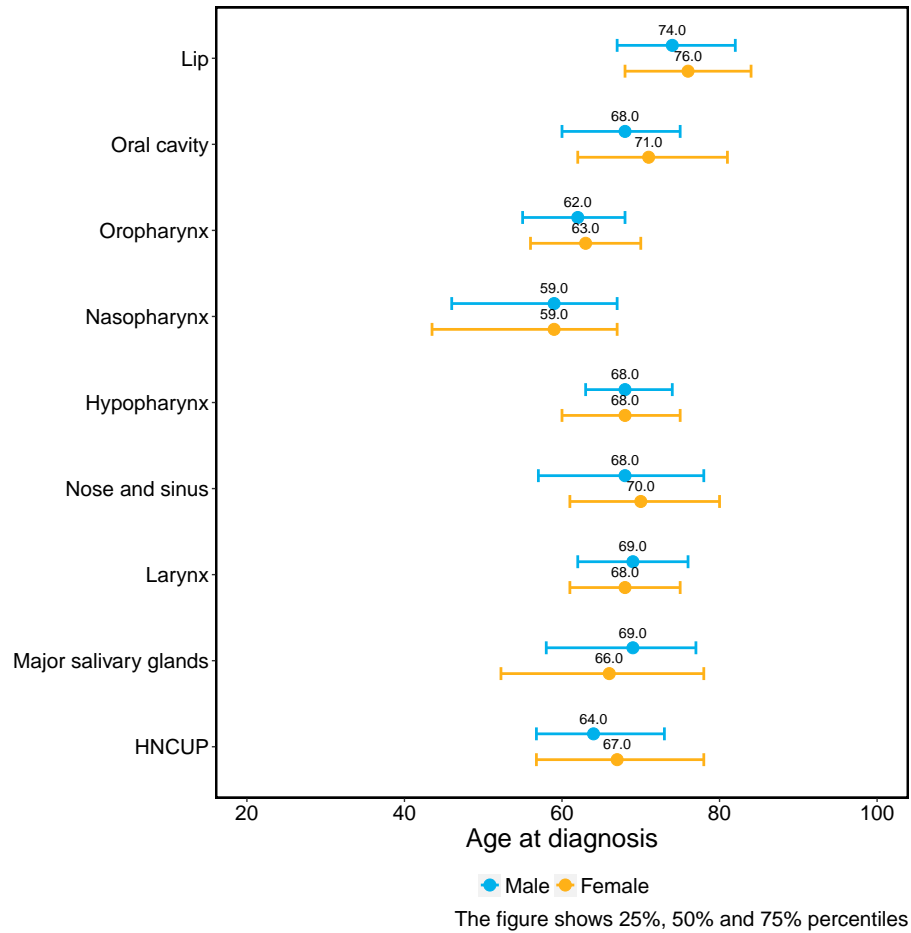
Oral cavity cancer and cancer of the large salivary glands show an almost equal sex distribution. For sinonasal cancer and lip cancer, there is a slight male predominance. There is a high male predominance for the other five sites, with hypopharynx and laryngeal cancers being the most pronounced (Figure 5).

Figure 5. Sex distribution in the diagnosis groups. SweHNCR 2008-2017.



The age distribution, illustrated in Figure 6, shows a tendency for younger patients in the nasopharyngeal and oropharyngeal cancer groups and for elderly patients in the lip cancer group.

Figure 6. Age at diagnosis by group and sex, (2008-2017).



Survival

The relative five-year survival rate for all patients with head and neck cancer in the SweHNCR was 67% (95% CI: 66-68%), and the overall survival rate was 59% (95% CI: 58-60%).

There were large differences in the relative survival rates between the different diagnosis groups. Patients with lip cancer had the highest relative survival rate (91 %), while patients with hypopharyngeal cancer had the lowest relative survival rate (25 %), as seen in Figure 7 and Table 1.

Figure 7. Five-year relative survival rates per diagnosis group in the SweHNCR, 2008-2017.

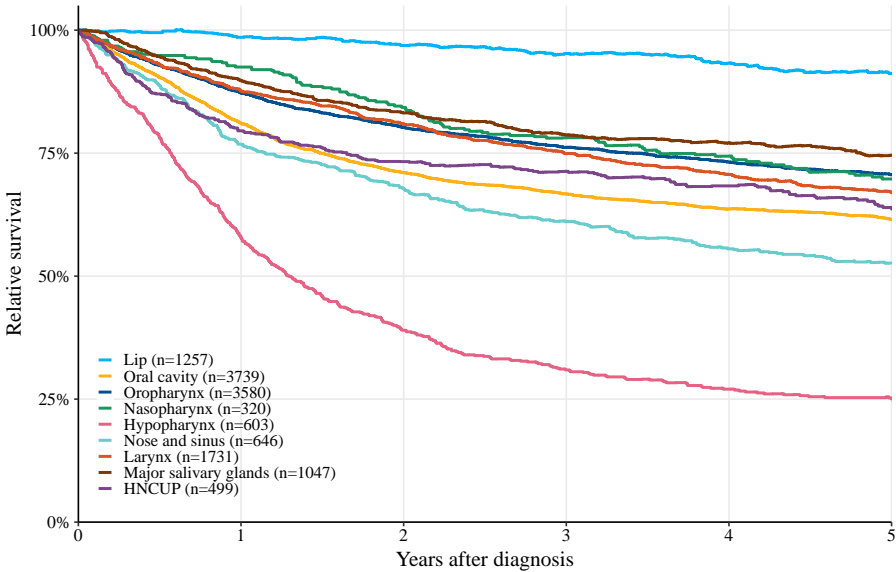


Table 1. Five-year relative survival rates per diagnosis group in the SweHNCR 2008-2017.

| Diagnosis group | Relative 5-year survival | 95% confidence interval |
|-----------------------|--------------------------|-------------------------|
| Lip | 91 | (88 - 95) |
| Oral cavity | 62 | (60 - 63) |
| Oropharynx | 71 | (69 - 72) |
| Nasopharynx | 70 | (64 - 76) |
| Hypopharynx | 25 | (21 - 29) |
| Nose and sinus | 53 | (48 - 58) |
| Larynx | 67 | (64 - 70) |
| Major salivary glands | 75 | (71 - 78) |
| HNCUP | 64 | (59 - 69) |

There were also major differences in relative survival between the stages in the subgroups. An example of this was the relative survival for carcinomas of the mobile tongue and of the tonsils. All patients were treated with curative intention and had a histological diagnosis of squamous cell carcinoma. The difference in relative survival between stage I and IV patients with cancer of the mobile tongue was 55 %, but was only 12 % in patients with oropharyngeal cancer (Figures 8-9 and Tables 2-3).

Figure 8. Relative five-year survival by stage for patients with cancer of the mobile tongue treated with curative intention and with the histopathological diagnosis of squamous cell carcinoma. SweHNCR 2008-2017.

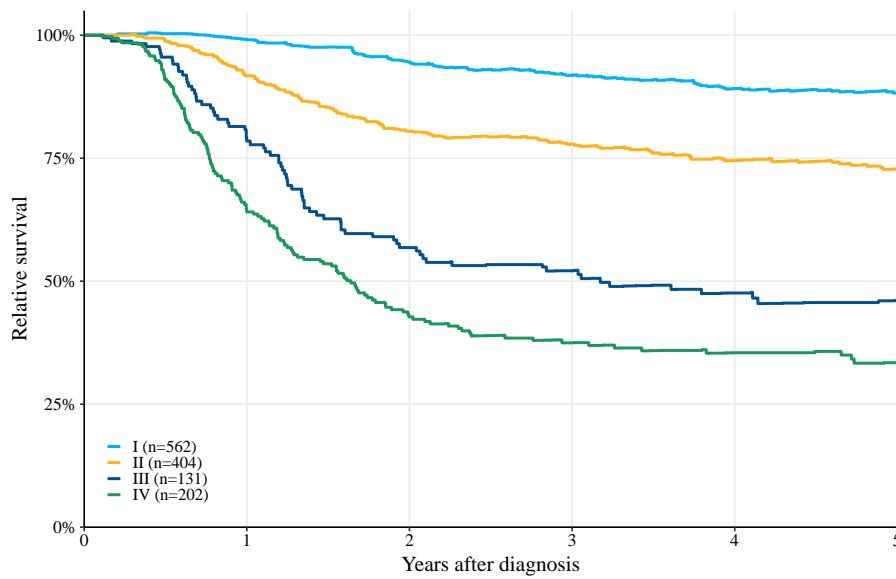


Table 2. Relative five-year survival by stage for patients with cancer of the mobile tongue treated with curative intention and with the histopathological diagnosis of squamous cell carcinoma. SweHNCR 2008-2017.

| Stage | Relative 5-year survival | 95% confidence interval |
|-------|--------------------------|-------------------------|
| I | 88 | (84 - 92) |
| II | 73 | (68 - 78) |
| III | 46 | (38 - 57) |
| IV | 33 | (27 - 41) |

Figure 9. Relative five-year survival by stage for patients with tonsillar cancer treated with curative intention and with histopathological diagnosis of squamous cell carcinoma. SweHNCR 2008-2017.

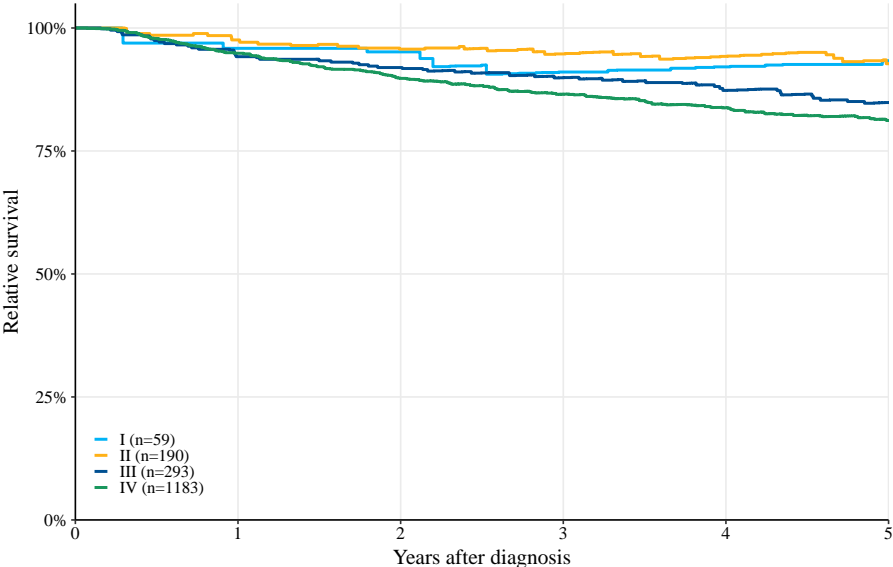


Table 3. Relative five-year survival by stage for patients with tonsillar cancer treated with curative intention and with histopathological diagnosis of squamous cell carcinoma. SweHNCR 2008-2017.

| Stage | Relative 5-year survival | 95% confidence interval |
|-------|--------------------------|-------------------------|
| I | 93 | (85 - 103) |
| II | 93 | (87 - 99) |
| III | 85 | (80 - 90) |
| IV | 81 | (79 - 84) |



Summary

The Swedish Head and Neck Cancer Register (SweHNCR) is a national population-based register comprising the following ICD-10 codes: C00-C14, C30-C32 and C77.0. The register has high patient coverage and data validity. The register has made it possible to develop the “National Guidelines for Head and Neck Cancer”, which are supported by both oncologists and ENT physicians, as well as by all the university hospitals in the country.

Head and neck cancer represents a low-incidence cancer type consisting of nine different sites and several subsites. Therefore, the SweHNCR will enable studies with not only larger groups but also smaller subgroups with a low incidence. The register is and will be a great asset for research and for developing future diagnostic and treatment modalities for head and neck cancer.

For the SweHNCR National Steering Committee

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