

Report from the SSG Central Registry Group

Malmö nov 30th-dec 1st 2015

Regarding the extremity and trunk wall sarcoma register:

The reorganizations of the registers in Sweden, Norway, Denmark and Iceland were presented by the national coordinators. The new data platforms allow for combined registration in the sarcoma register and in each national cancer register.

Once the separate online and data base systems are updated technical legal solutions to ensure increased and/or continued merging of the registers will be applied. Clear agreements on the forms of collaboration are needed. The variables in Sweden, Norway and Iceland are harmonized and work to ensure compatibility with the Danish variables is planned.

The completeness of the register is high in Sweden (controls have been performed in Stockholm and Lund) and Norway. The follow up rate is high, above 90%. Most of the patients missing follow up data are from the past 3 years and data is expected to be reported.

Concerning the new Swedish online system (INCA) the included parameters were discussed and the following will be added.

Date of arrival of the referral letter.

Date of pathology report from both preoperative diagnostics and the excised tumor specimen after surgery.

Also, some adjustments of other parameters were agreed upon.

The follow up form is planned to be up and running in December 2015.

In Sweden, an online automatic presentation of the data will begin the first quarter of 2016.

Concerning the Norwegian online sarcoma registers they have been available in 4 sarcoma centers since 2012. A National Quality Sarcoma Register within the National Cancer Register is under construction now and will be available for online registration in 2016. The format of the collected data will be compatible with the SSG format allowing merging of data for collaborating projects in future. This register will include patients with sarcomas at all sites.

Regarding the visceral and retroperitoneal sarcoma register in Sweden:

From some centers the reporting of cases is continuous. Other centers have not established a routine for reporting their patients. This problem was discussed and pending the potential reorganization of abdominal sarcoma care in Sweden no measures were taken.

In Sweden, an online automatic presentation of the data will begin the first quarter of 2016.

A new chairman of the Central register was elected: Emelie Styring, Lund University/Skåne University Hospital Lund.

/Emelie Styring