

Report from the SSG central register coordinators meeting

All listed coordinators were specifically called for the meeting.

They include:

Alvegård Thor, Lund	Johansson Ingela, Umeå
Bauer Henrik, Stockholm	Jonsson Haldor Jr, Reykjavik
Bergh Peter, Gothenburg	Kalén Anders, Linköping
Vult von Steyern Fredrik, Lund	Knobel Heidi, Trondheim
Åhlén Jan, Stockholm	Laitinen Minna, Tampere
Blomqvist Calle, Helsinki	Lausten Gunnar, Copenhagen
Kivioja Aarne, Helsinki	Lindholm Paula, Åbo
Eriksson Sigvard, Gothenburg	Löfvenberg Rickard, Umeå
Erlanson Martin, Umeå	Olofsson Eva-Mari, Lund
Hall Kirsten Sundby, Oslo	Rydholm Anders, Lund
Hesla Asle, Stockholm	Smeland Eivind, Tromsø
Holmberg-Jørgensen Peter, Aarhus	Styring Emelie, Lund
Isaksen Vidar, Tromsø	Trovik Clement, Bergen
	Zaikova Olga, Oslo

Following a great effort on the part of coordinators, only 522 (6%) of 8844 orthopaedic oncology cases still have missing key variables. An overview of trends concerning referral and treatment and based on the 8322 complete cases was given. It was decided to write an scientific paper summarizing these trends.

It was further decided to keep the 522 cases with missing key variables in a separate space in the register, to be completed and transferred to the register proper, if missing information should surface in the future, No additional inquiries will be initiated from the registry, but it was noted that at least 154 patients from Helsinki could be expected to be updated shortly.

A year ago it was decided to delete records with missing histology after one more round of inquiries. 234 were still missing, but it was now decided to keep these in another separate space of the register and not delete them completely. No further inquiries concerning these patients will be sent to the coordinators.

About 600 cases with missing reporting hospital, reported incomplete from departments never represented at SSG meetings and not responding to inquiries, will be deleted.

A year ago it was discussed to discontinue mandatory registration of reason for death Following a lecture by SSG- statistician we understood that calculation of death reason probabilities based on population data was possible and might be more reliable than coordinator registered death reasons. Population data was only reliable on a national level though, and no regional quality comparisons could be done. It was decided to keep the death reason variable as a key variable, and to do both types of calculation when relevant.

The register contains 2041 cases of Visceral/Retroperitoneal/Gynecological/HeadandNeck sarcomas. These cases will be verified when more centres start entering patients on a regular

basis. We were informed that the INCA soft-ware for this purpose are now functional in Sweden, and that many new cases are soon to be expected.

The cases of Dermatofirosarcoma protuberance and Aggressive Fibromatosis/Desmoids will not be verified by registry initiative. 689 cases are registered and could be verified in the context of a scientific study.

Work on defining the variables in the Danish sarcoma register according to the values in the SSG register are progressing and data transfers are expected in 2012.

In 2012 inquiries concerning inconsistent data will proceed:
The following list was agreed upon:

- $\text{Diagdat} \leq \text{Fopdat}$
- $\text{Diagdat} < \text{Raddat}, \text{Chedat}$
- $\text{Diagdat} < \text{Fudat}$
- $\text{Lopdat} - \text{Fopdat} \leq 90 \text{ days}$
- $\text{Fopdat} - \text{Diagdat} \leq 180 \text{ days}$

- $\text{Refpat}/\text{Fopdat}/\text{Diagdat}/$
center/outside

Operation and Margins if Numop >0

- At least one Follow-up date and State at follow-up if
> 1 year since date of diagnosis

It was agreed to publish an annual report at the SSG web-site. The report should contain reporting figures and trends in referral, diagnosis and treatment practice for the Nordic countries. It should be based on the three previous years, and be published before the annual working committee-meeting. Olga Zaikova, Emelie Styring, Calle Blomqvist and Clement Trovik were appointed to the annual report publication committee