

Central register committee

Joint committee with national chairmen for guiding and assessment of research projects.

- Emelie Styring, Olga Zaikova, Peter Holmberg
- Contact with national registry boards and the SSG board
- Keep track of ongoing projects

Check of the registered variables in each country

- Differences that need adjustment?
- Oncological variables (chemotherapy types... ..)

Routines for validation, different in each country. National routines needed.

Patient reported outcome measures (PROM), joint approach? Find and use the same questions?

Review register, how and where?

Abdominal sarcomas, problematic with registers in most countries. Oslo registers all their cases, none in the rest of Norway, Denmark registers all retroperitoneal but some GISTs are missed. In Sweden problems in most regions, no reporting of cases.

Gynecological sarcomas, find them through gynecological registers?

Joint annual report

Number of cases of STS and BS/center and year

Age at diagnosis

Sex

Tumor size

Referral pattern (FNA, core biopsy, surgery, LR, not referred;
present small and superficial STS separately)

Percentage of patients treated with surgery, chemotherapy, radiotherapy

Metastasis at diagnosis

Emelie Styring

Chairman of central register committee