



Report from

Business meeting Central register coordinators

As agreed at the working groups meeting in Copenhagen nov. 2010 there will be a revival of the central register coordinators meeting in conjunction with the SSG Malmö meeting:

**Wednesday May 4th 2011 in “Nya Börssalen”, Börshuset, Malmö
13.00 – 14.30**

Agreeing on key-variables.

The formerly discussed key variables

Hospital

Age at Diagnosis

Sex

Date of Diagnosis

Referral pattern

Metastasis at Diagnosis

Histology = Sarcoma/GCT

Malignancy grade/MGNA

Size

Site

Location

Number of operation for primary.

Opdate

Other treatment or protocol number

Follow-up date. State at follow-up

(> 1 year since date of diagnosis)

Death date.



were revisited. It was agreed that if these can not be supplemented for cases already in the register, the case will be marked as incomplete and not be included in material released from the register for studies.

"Reason for death" is a variable that may not be needed as a key variable if reason for death can be calculated by statistical methods. It was agreed to invite a statistician from Lund to give a presentation of this method at the working committee meeting in Copenhagen December 2011.

Criteria for sufficiently complete reporting for an institution to be included in studies? , - and have their number of incomplete cases cited in studies?

It was agreed that such criteria would vary depending on the type of study in question and that the researcher in question must decide if data from institutions reporting less than population based, - or reporting completely only a fraction of their cases could be of value in that particular study

Agreeing on local and central control runs.

It was agreed that coordinators should run the following checks before submitting the case to the register:

- $Diagdat \leq Fopdat$
- $Diagdat < Raddat, Chedat$
- $Diagdat < Fudat$
- $Lopdat - Fopdat \leq 90$ days
- $Fopdat - Diagdat \leq 180$ days
- Refpat/Fopdat/Diagdat/center/outside

Operation and Margins if Numop >0

Isolated cases with more than 90 days between 1. and 2. operation for primary tumor could be included if the treating surgeon specifically do not suspect an early local recurrence



Registration of Desmoids/Aggressive Fibromatosis

It was agreed not to reopen registration of these tumours in the regular central register

Clement Trovik
chairman, Central register subcommittee