

Rarecare project: WP5 (Health indicators: incidence, survival and prevalence) meeting

Utrecht November 7th 2008
Association of Comprehensive Cancer Centers (VIKC)
Gebouw Trindeborch
3e etage Catharijnesingel 55-c
UTRECHT, The Netherlands

Agenda

10.00 Welcome and aim of this meeting (R.Otter)

10.15 Definition and list of rare cancers: state of affairs (Gemma Gatta or Laura Ciccolallo)

10.30 Discussion and agreement on workplan for WP5 deliverable (D11; M24)

TOPICS FOR DISCUSSION

- Content of the report (D11), due in month 24
- Suggestions for layout of the report (i.e. specific chapters on incidence, survival and prevalence or tumour specific chapters. Do we include methodological chapters (i.e estimating complete prevalence, estimating cure/fatality rates)
- Suggestions for standardized table layout for presentation of results
- Presentation of data with confidence intervals (proposal Ellen Benhamou)
- Use of mixture models for survival (cure and fatality rates)?
- Estimation of full prevalence or point prevalence estimates?
- Relation of WP6 (report on data quality) and WP5 deliverable

12.30 Lunch break

13.00 Continuation of discussion

- Availability, quality and usability of Eurochip macro indicators (do we incorporate Eurochip data in the WP5 analysis? (No) relevant information available? (minutes meeting Milan, March 26th 2008)

- Time scheme of analyses, establishing writing committee

15.30 Consensus agreement on content of and workplan for WP5 deliverable (D11)

16.00 End of the meeting