

The burden of rare cancers in Italy: the surveillance of rare cancers in Italy (RITA) project

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ABSTRACT

Aims and background. The project Surveillance of rare cancers in Italy (RITA) provides, for the first time, estimates of the burden of rare cancers in Italy based on the list of rare cancers proposed in collaboration with the European project Surveillance of Rare Cancers in Europe (RARECARE).

Methods. RITA analyzed data from Italian population-based cancer registries (CR). The period of diagnosis was 1988 to 2002, and vital status information was available up to December 31, 2003. Incidence rates were estimated for the period 1995-2002, survival for the years 2000-2002 (with the period method of Brenner), and complete prevalence at January 1, 2003.

Results. Rare cancers are those with an incidence <6/100,000/year. In Italy, every year there are 60,000 new diagnoses of rare cancers corresponding to 15% of all new cancer diagnoses. Five-year relative survival was on the average worse for rare cancers (53%) than for common cancers (73%). A total of 770,000 patients were living in Italy in 2008 with a diagnosis of a rare cancer, 22% of the total cancer prevalence.

Conclusions. Our estimates constitute a useful base for further research and support the idea that rare cancers are a public health problem that deserves attention. Centers of expertise for rare cancers that pool cases, expertise and resources could ensure an adequate clinical management for these diseases. Our data also showed that cancer registries are suitable sources of data to estimate incidence, prevalence and survival for rare cancers and should continue to monitoring rare cancers in Italy.

Key words: cancer registries, incidence, prevalence, rare cancers, survival.

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