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THE BURDEN OF RARE CANCERS IN EUROPE

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Introduction

Rare cancers are a challenge to clinical practice, their burden in Europe is unknown and no accepted definition exists.

Objectives

To provide a definition of *rare cancer*, a list of cancers meeting that definition and rare cancers burden indicators.

Materials and Methods

A multidisciplinary working group developed a definition considering the clinical relevance and the frequency of the tumours. Burden indicators were calculated using data from 65 cancer registries (CRs) in 22 European countries.

Results

This list is structured in 2 layers based on combinations of ICD-O morphology and topography: layer 1) families of tumours relevant for the health care organisation, layer 2) tumours clinically meaningful.

Rare cancers are those with an incidence <6/100,000/year. According to our estimates 2.5 millions of patients are living today with a diagnosis of rare cancers in Europe and every year there are 488,000 new diagnoses (19% of all malignant cancers diagnosed).

Discussion and Conclusions

Our study disclose the burden of rare cancers on the basis of CRs data confirming the importance of CRs to increase knowledge on rare tumours. The list of rare cancers will contribute to address rare cancers challenges.