FOREWORD
PREFAZIONE

I am extremely pleased to introduce the Italian Cancer Figures Report 2015, completely devoted to the assessment of the burden of rare cancers in Italy.
This report is the latest valuable contribution to knowledge and policy development in the country by the Italian Association of Cancer Registries (AIRTUM).
The Ministry of Health, through its Centre for Prevention and Disease Control, has systematically supported AIRTUM, making careful use of the wealth of information provided by AIRTUM to orient national policies and monitor their implementation.
AIRTUM reports have been the main source of information and the benchmark for all health professionals and patient associations over the past ten years, as the share of Italian population screened by the cancer registries has increased from 23% to 51% so far, and is set to reach 70% in the next few years.
This year's report is the first in Italy to analyse rare tumours from an epidemiological perspective. It shows that one out of four diagnosed cancer cases belongs to the category of rare cancers; this proportion is similar to other European estimates (24%). This means that the affected population is more than significant and calls for highly specific care, based on cancer patterns, as well as individual needs.
Cancers defined as "rare" challenge clinical decision making, health care organisation and clinical research due to their low frequency in the population and the resulting limited expertise available. In their daily life experience, rare cancer patients and their families must overcome a wide range of obstacles, such as:

- misdiagnosis and delay in diagnosis;
- lack of scientific knowledge due to the small number of patients that may not allow for traditional clinical trial design, and limited availability of registries and tissue banks;
- difficulties in developing therapeutic tools and defining therapeutic strategies, and shortage of therapeutic products;
- low-quality healthcare due to poor, not experienced-based protocols, inappropriate referral procedures by general practitioners and misdiagnoses by inexperienced laboratories.

The most striking figure in this report relates to patient survival, which is shorter than for patients affected by more common cancers, at any evaluated period: at 1, 3, and 5 years. This is a particularly challenging figure for the National Health Service, health care professionals, and, of course and above all, patients and their families.
Italy is already committed to improving its health service delivery system in order to provide these patients with high-quality, more effective, and fairer care.
This effort will take on concrete form in a National Network for Rare Cancers which will include the most experienced cancer centres and professionals. This task is not trivial, given the current devolution and the federal structure of our national health system. This report underlines the need to overcome local interests, and provides sound, evidence-based, powerful tools to enhance scientific research and elicit new and non-traditional epidemiological, clinical, and public health analyses.
Thanks to this report we can expect an improvement in the understanding of rare tumours that will be useful not only for Italy, but also for a broader international scientific and medical audience, while supporting patient associations, strengthening their links with scientific associations, whose accountability will be key in forging a new alliance between providers and beneficiaries.
In conclusion, I would like to congratulate and thank all those who actively carried out this work and those who enthusiastically contributed to it.
To their commitment we will continue to add our own, making sure that our decisions and the related resource allocation process are based on a careful, comprehensive need assessment, so as to generate equitable care for those who might otherwise be neglected.

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