ISTAT
Istituto nazionale di statistica

Istituto Superiore di Sanità

ALTEG
Associazione per la Lotta ai Tumori nell'Età Giovanile

Cancer in adolescents and young adults

With the ageing of the population, cancer, together with cardiovascular diseases, is now the main cause of death in the developed countries. It is well-known that there is a higher incidence of cancer in the older age groups. This is why, taking a purely quantitative view of the question, most studies focused on older people so far.

Children are also a category that has been thoroughly studied, both because of the particular kind of the cancer affecting this age group and because of the high social impact that the event causes.

The analysis of cancer in adolescents and young adults (15-39 years old) has on the other hand been neglected for the most part. This is in fact the age group with the best health status and as a result attention tends to be focused on those questions that are most linked to lifestyle problems (AIDS and accidents). Between 15 and 39 years of age cancer is relatively less frequent and survival data demonstrate that, in many cases, it is not inexorably fatal. Nevertheless it is a serious illness, with strong implications from a psychological point of view, upsetting the existences of young people at the very moment when they are looking to arrange their lives differently as regards education, work, affections and the family.

Moreover, cancer grows very rapidly in a young person; an early diagnosis is therefore one of the most important factors affecting a favourable outcome. The survival statistics on young adults appear to have some special characteristics. Prognosis for some types of cancers is worse between 15 and 39 years than in the adjoining age groups. On the other hand, it is easier to treat some cancers than at other times of life.

Very little is known about the risk factors associated with cancer in young adults. It is maintained that cancer in the young is due to relatively recent environmental causes or to other ones making their appearance now, such as new professions or lifestyles. Concentrating on the analysis of cancer in 15-39 year olds will therefore allow us to bring to light questions that have not yet been much looked into.

As regards the treatment of these diseases, introducing effective therapies can result in a greater reduction in mortality in young people than in the elderly. This is because the health status of the elderly is generally of a greater complexity and the choice of the right sort of treatment can in many cases turn out to be problematic.

A joint research project

The collection of epidemiological data on illnesses is one of the most important practical aspects in the evaluation of prevention techniques and results of therapies. Before any treatment goes ahead there needs to be solid information on the phenomenon.

Currently there is a deep lack of knowledge on cancers in adolescents and young adults.

In the absence of a unitary frame to assess cancer in young people, ISTAT (Italian Institute of Statistics), ISS (Italian Health Board) and ALTEG (Association for the Fight Against Cancer in the Young Age Groups) have launched a joint research project which aim is to fill the gap in information on such an important topic and to improve the health planning and the awareness of the social problems related to the illness.

Very few data about cancer in young people have been published in Italy, and in the rest of Europe and in the United States as well. The most challenging part of the research was the "combining" of data on cancer originating from a variety of different sources on the basis of the type of statistics being considered, the period and the geographical area. This was the first time that such a considerable effort had been made to render all the information that was available homogeneous and mutually compatible, both at a national and an international level, with the focus of attention on young people.

An integral analysis of the various data on cancer in Italy, the rest of Europe and the United States in the first half of the 1990s, with specific reference to adolescents and young adults, is one among the most remarkable results achieved in this first phase of the project.

For the future this research project aims to build up a data base for the analysis of cancer in young people, to provide a useful tool for both central and local government, for the scientific world and to assist the development of research activities in the medical field.

The main results

Each year in Italy about 11,000 people aged between 15 and 39 years (50 for every 100,000 in the same age group) become ill with cancer. This data reflect the occurrence of a number of cancers with a high rate of successful treatment and cure such as cancer of the testicle and of the thyroid, so that death occurs in about 2,600 cases (12 every 100,000).
Out of a total of 21 million people aged between 15 and 39 years, it is estimated that there are about 100,000 adolescents and young adults suffering from cancer (with a cancer diagnosed in the last five years).

In 1995 there were about 4,700 males aged 15-39 years with the diagnosis of a cancer, whilst there were about 1,255 deaths. The equivalent figures for females were 6,100 and 1,335. Women therefore appear to be at a disadvantage compared to men (figures 1, 2 and 3).
The frequency with which the disease arises in men in Italy is fairly similar to the rest of Europe and the United States, with figures of around 41 new cases every 100,000 young adults; in women the situation is slightly worse in Italy if compared to the rest of Europe, but substantially better than in the USA, where there are 64 new cases for every 100,000 women versus 52 in Italy.

Figure 1 – **Incidence and mortality between 15 and 39 years old in Italy, Europe and United States by gender**. Year 1995 (standardised rates per 100,000)

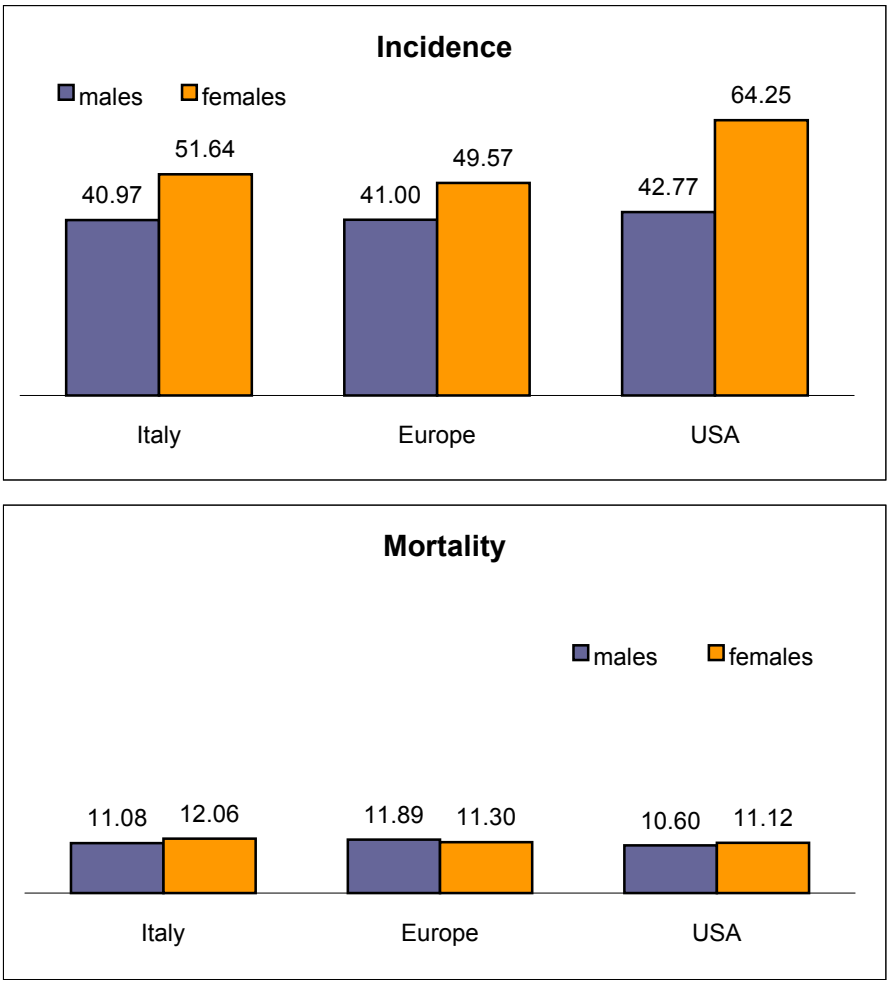


Figure 2 – **Incidence between 15 and 39 years old in Italy of the main categories of cancer by gender.** Year 1995 (standardised rates per 100,000)

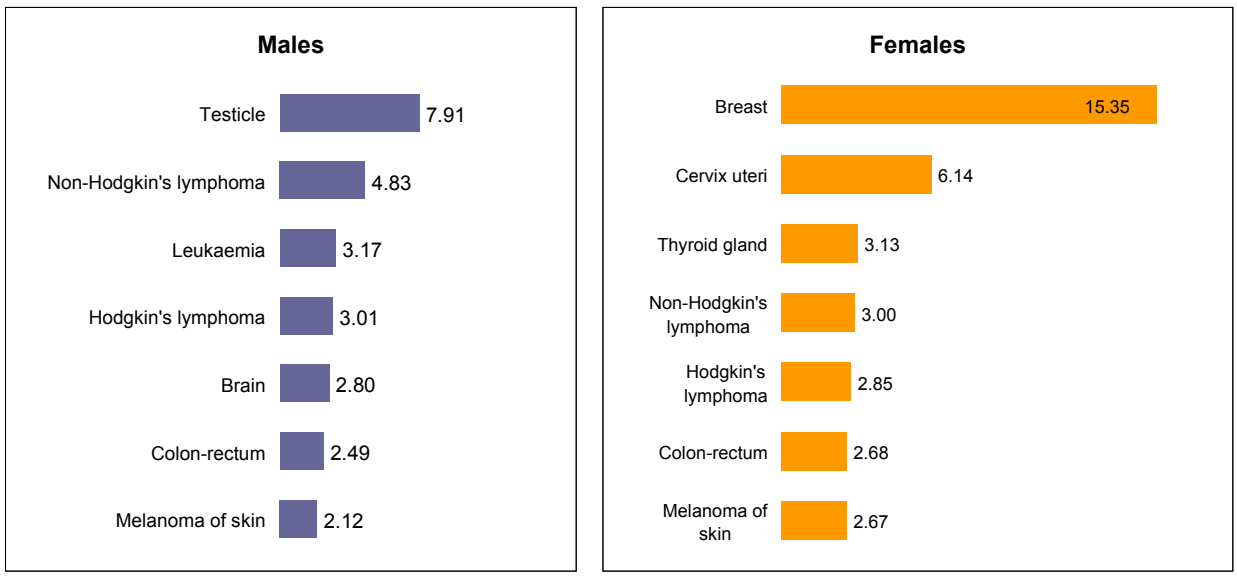


Figure 3 - **Mortality between 15 and 39 years old in Italy for the main categories of cancer by gender**. Year 1995 (standardised rates per 100,000)

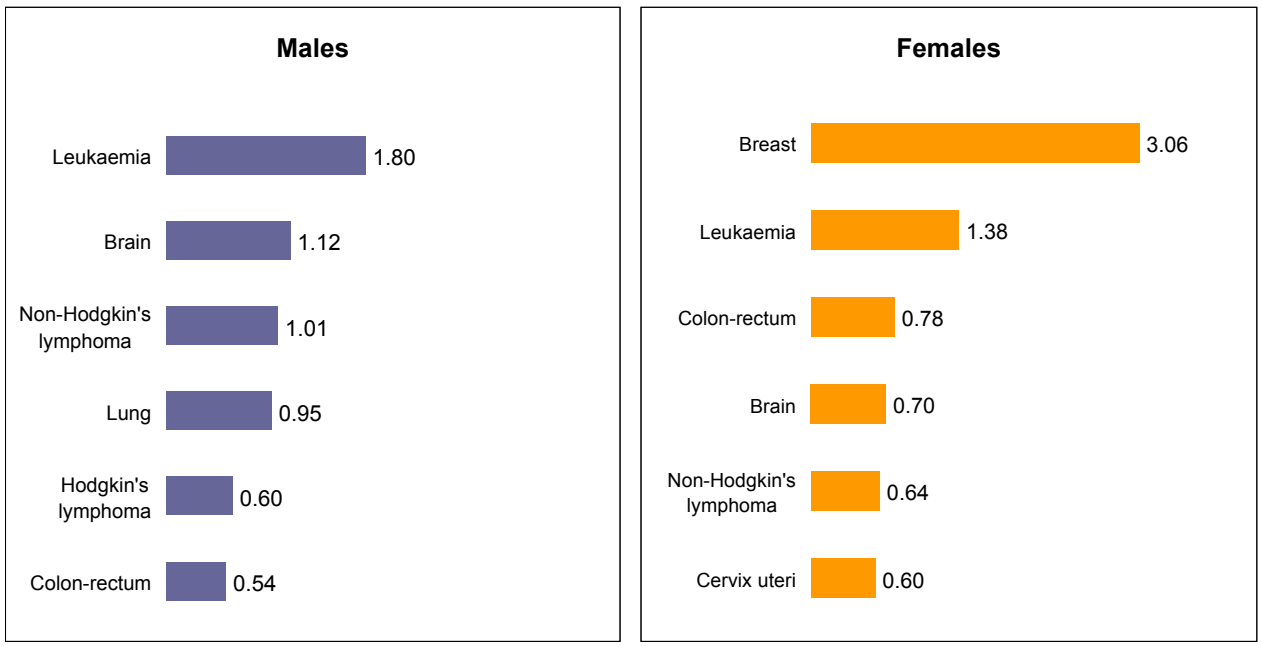
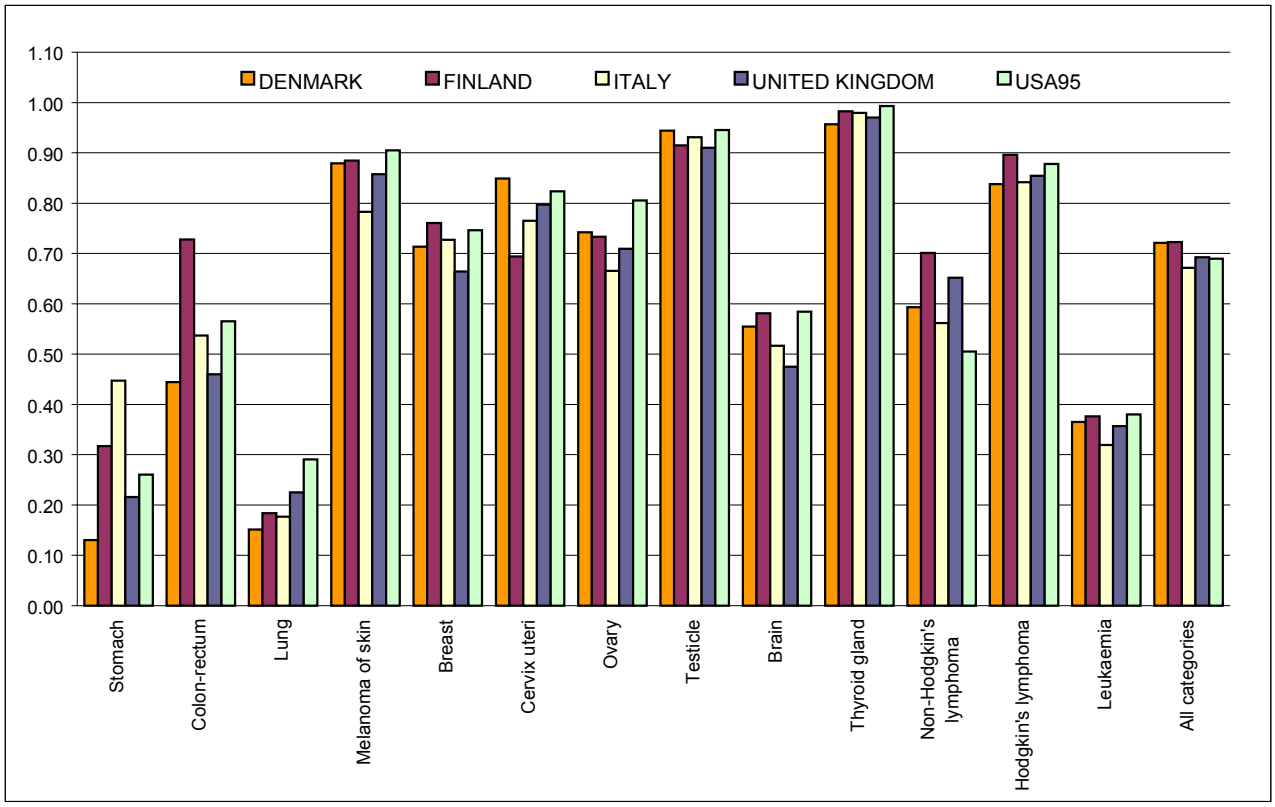


Figure 4 – **Survival after five years of persons aged 15-39 with a cancer diagnosed between 1985 and 1989**. Italy, United Kingdom, Denmark, Finland and United States (percentages)



As regards mortality, for both sexes the situation in Italy looks similar for the most part to that of Europe and of the USA.

This work evidenced the high level of certain types of cancers, in particular breast cancer and testicle cancer. Figures on these types of cancers are well-known but have never been

analysed specifically for this age group.

In Italy breast cancer (see table 1) is the cancer occurring most frequently, including young women, with a higher level from 30 years onwards. In 1995 in the 15 to 39 age group the average number of new cases diagnosed was 1,931, i.e. in a year over 30% of new cases involved breast cancer. In comparison with 1990 the number of new cases in this age group passed from 11.61 to 15.35 every 100,000 women. An important result is the reduction in mortality from this cause in young women: from 2.83 deaths every 100,000 women in 1992 to 2.55 in 1995. Whilst incidence with this cancer occurs slightly more than in the rest of Europe, the mortality rate is in line with those recorded in the rest of Europe and in the USA. In terms of survival our country is in an intermediate position with 73 surviving for every 100 female patients five years after diagnosis, compared with 66 in the United Kingdom and 75 in the United States (figure 4).

Table 1 – **Epidemiological figures on breast cancer in women aged 15-39 years.** Year 1995

	Incidence	**Mortality**
Absolute numbers		
Italy	1,931	323
Standardised rates (per 100,000)		
Italy	15.35	2.55
Europe	14.38	2.71
USA	15.76	2.67

Survival rates	
Italy	73%
United Kingdom	66%
Denmark	71%
Finland	76%
USA	75%

Among men, cancer of the testicle is the most widespread category in the 15-39 age group: it is calculated that there are 910 new cases annually (1995) among the young, i.e. 19% of all new cases of cancer (see table 2). Moreover cancer of the testicle is the only case in which the incidence rate is significantly higher in this age group than in those that follow: 7.91 new cases every 100,000 persons between 15 and 39 years old in 1995 versus 3.76 new cases for 40 years and over. With the data available it is possible to note an increase in the rate in which it was occurring: only five years earlier the figure was 5.5 new cases every 100,000 men. Nevertheless, this increase is to be regarded with extreme caution, in that we do not possess the data for the intervening years. However, the hypothesis that there has been an increase appears to be confirmed by an estimate for 1996 showing 11.15 new cases every 100,000 men. The mortality rate for this type of cancer is decreasing, in line with a trend already underway over the last few decades in almost all western countries. It should be added that Italy in 1995, when compared to Europe, is in an advantageous position as regards both incidence and mortality rates. Moreover, the particular features of cancer of the testicle make it easy to treat and cure it: the survival rate five years after diagnosis is equal to 93%.

Table 2 - **Epidemiological figures on cancer of the testicle in men aged 15-39 years.** Year 1995

	Incidence	Mortality
Absolute numbers		
Italy	910	36
Standardised rates (per 100,000)		
Italy	7.91	0.32
Europe	10.54	0.41
USA	8.97	0.33

	Survival rates
Italy	93%
United Kingdom	91%
Denmark	94%
Finland	92%
USA	95%

Melanoma of skin (see table 3) arises more frequently in women than in men and this is found in every country and in every year analysed in our study. However, women appear to have a better chance of being cured. As regards survival the rates in Italy for both sexes are lower than in the other countries looked at: 73% among men and 83% among women, with a difference of over 10 percentage points compared to the United States. This would suggest there should be more campaigns promoting the need for prevention and early diagnosis.

Table 3 - **Epidemiological figures on melanoma of skin in persons aged 15-39 years by gender.** Year 1995

	Males		Females	
	Incidence	**Mortality**	**Incidence**	**Mortality**
Absolute numbers				
Italy	258	57	317	56
Standardised rates (per 100,000)				
Italy	2.12	0.47	2.67	0.46
Europe	2.85	0.49	4.26	0.38
USA	4.75	0.58	7.80	0.42

	Survival rates	
Italy	73%	83%
United Kingdom	77%	90%
Denmark	81%	92%
Finland	84%	92%
USA	86%	94%

Hodgkin's disease (see table 4) is in general less frequent and with a lower mortality rate than non-Hodgkin's lymphoma. Nevertheless, it affects more the 15-39 age group than those that follow. This finding is in line with data from the United States where, over the last 40 years, incidence has doubled among 25 to 30 year olds, whilst there has been a 20-30% reduction in the 60-70 age group. In 1995 the incidence rate among Italian young adults is higher than the European average, but substantially lower than in the United States. This better performance by Italy is not, however, reflected in terms of survival, especially among women. From an international comparison it can be seen that five years after diagnosis there is a survival rate of 85 women out of 100 in Italy, compared to 91 in the USA.

Table 4 - **Epidemiological figures on Hodgkin's disease in persons aged 15-39 years by gender.** Year 1995

	Males		Females	
	Incidence	**Mortality**	**Incidence**	**Mortality**
	Absolute numbers			
Italy	328	62	299	47
	Standardised rates (per 100,000)			
Italy	3.01	0.54	2.85	0.43
Europe	2.61	0.38	2.52	0.28
USA	4.43	0.51	4.11	0.29

	Survival rates	
Italy	83%	85%
United Kingdom	85%	86%
Denmark	82%	87%
Finland	87%	92%
USA	84%	91%

Looking at leukaemia (see table 5), the incidence rate in the 15-39 age group is particularly significant for males: 3.17 new cases per 100,000 men, compared to 2.22 per 100,000 women. The situation in Italy is in a mid-way position when compared to other countries, with data that are higher than the European average but lower than in the USA. As regards mortality there has been a slightly diminishing trend over time, which reflects the success that there has been in the treatment of young people over recent years; nevertheless, in 1995, amongst men leukaemia was still the cancer causing the largest number of deaths. The survival rates in Italy are lower for both sexes than in other countries.

Table 5 - **Epidemiological figures on leukaemia in persons aged 15-39 years by gender.** Year 1995

	Males		Females	
	Incidence	**Mortality**	**Incidence**	**Mortality**
	Absolute values			
Italy	341	141	233	109
	Standardised rates (per 100,000)			
Italy	3.17	1.30	2.22	0.99
Europe	2.49	1.60	1.64	1.11
USA	3.18	1.57	2.58	1.12

	Survival rates	
Italy	32%	31%
United Kingdom	32%	41%
Denmark	35%	38%
Finland	37%	39%
USA	40%	36%

Emerging questions and prospects for analysis

Much attention has been dedicated hitherto to the questions of AIDS and road accidents involving young people, in particular males. Nevertheless, the number of individuals aged 15-39 becoming ill with cancer each year is significantly higher than the number of AIDS cases (about 11,000 versus 6,055 in 1995, and the latter have now decreased to about 1,400 p.a.).

Moreover, in this age group cancer represents the principal cause of death in females (almost 32% of total deaths) and the second cause after road accidents among men (11.5% compared to 27.3% for accidents).

If we look at the details regarding the various types of cancer, we discover a number of important aspects requiring special attention. There are categories of cancer that are characteristic of young adults. One example is cancer of the testicle in men and Hodgkin's disease in both sexes, which occur with a greater frequency in individuals aged 15-39 years than in those with 40 years and over.

There are also cancers that, even if they happen more frequently in old age, also strike young people in significant numbers. An example is breast cancer in women aged 15-39 years, which is the main cause of death and the type of cancer occurring most in this age group.

International comparisons and the analysis of the evolution of the phenomenon over time highlight a number of situations deserving an in-depth study, because they demonstrate that young adults in Italy are in a worse position than those in the rest of Europe or in the United States.

Lung cancer in men occurs more frequently than in Europe or in the USA, both before and after 40 years of age. Moreover, among young women an increase in mortality caused by this was recorded in only three years (between 1992 and 1995), in contrast with what is happening with young US women of the same age and also with the decreasing trend to be found among men.

Moreover, Italy would seem to have the potential to make significant improvements as regards melanomas of skin among men, ovary cancer among women and leukaemia in both sexes. In fact, the survival rate five years after diagnosis of these cancers is for an Italian of 15-39 years lower than that recorded for persons of the same age in other European countries and in the USA. This suggests that an investment could be made in better prevention, earlier diagnoses and more effective therapies, so as to improve the survival prospects and health situation of many of the young people.

With the work that has been carried out so far we have been able to delineate the principal characteristics of cancer arising in young adults during the first half of the 1990s. However, on the one hand, we are not in a position to confirm the trends observed over the short term with ones covering a longer period; and on the other it has not been possible to draw up a picture relating to the last few years. Nevertheless it is the intention of the authors of this study to continue the task of monitoring and appraising more thoroughly the question of cancer in individuals aged 15-39 years, as regards both incidence and the relationship between this measure and the other epidemiological measures.

To give an idea of how important it is to have statistics that are recent and data on trends over a long period one should consider some figures from the United States, showing scenarios that it would be desirable did not continue (Bleyer W.A. et al., 2001). From 1975 to 1995 in the USA there was an increase in the incidence rates in patients aged between 15 and 35

years, which was higher than that for other age groups. The mortality rates fell more slowly than among people below 15 or above 35 years of age, and there was less of an improvement in the survival rate five years after diagnosis than for younger individuals.

In spite of the significant publicity given to these findings, only about 5% of patients aged between 15 and 25 have been enrolled to take part in clinical tests versus 60-65% of younger patients.

An aspect that is not secondary in the study of cancer in young adults is the question of quality of life during and after therapies. In young patients the toxicity of some treatments results frequently in vomiting, nausea, being over-weight or under-weight, alopecia and haemorrhaging of an almost chronic nature. Such situations often have repercussions at a psychological level: using the US data again it emerges that, among 41 adolescents that completed their treatment between 2 and 8 years of age and were examined at 17 years old, there was a shortfall in global physiological functions in 27% of cases, while more than a quarter showed symptoms of hypochondria, depression or dissatisfaction with their physical appearance as a result of the treatment. After the therapy there also needs to be an evaluation of the consequences and possible treatment as regards sexuality and fertility, obesity, etc., to achieve a new psycho-physical balance and to facilitate reinsertion in the family and in society. These are objectives that can be pursued on a wide scale and that are justified by the high number of people surviving among sufferers in this age group, with their life before them and aims to be achieved that are to the benefit of society in general.

For any information or clarification regarding the research please contact:

Istituto nazionale di statistica
Roberta Crialesi +39 06 8522 7395
Alessandra Burgio +39 06 8522 7388

Istituto superiore di sanità
Riccardo Capocaccia +39 06 4990 2541
Arduino Verdecchia +39 06 4990 2230