

# Impact of the National Population Register in Improving the Health Information System of Malignant Diseases in Kosovo

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## ABSTRACT

**Introduction:** Malignant diseases are serious socio-medical problem, being that they cause grave problems in terms of health, social and economic perspective to an individual, in particular, and society in general. A proper reporting and monitoring system enables adequate calculation of indicators and evidence based decision making. **Aim:** The study aims to examine the appearance of malignancies diagnosed and reported in Kosovo for a three years period: 2012, 2013, and 2014 by its modalities such as by the years of appearance, gender, age, and most frequent types of malignancies. **Material and methods:** The study is a retrospective cohort research whereas source data we used are reports of malignant diseases from National Cancer Register (NCR) in the Health Information System (HIS) at the National Institute of Public Health of Kosovo (NIPHK). **Results and discussions:** In Kosovo during years 2012, 2013 and 2014 a total of 7437 cases of malignant diseases were reported; in 2012 were 31%, in 2013 were 24.3%, and during 2014 higher number of cases were reported, 3320 or 44.6%. During the reporting period, the appearance of malignant diseases in both sexes is about equal, with a light predominance of male cases with 50.8% (or 3780 cases), while by age group were represented with the elderly, from ages 50 to 79 years with 5111 cases or 68.8% of total malignancies. **Conclusion:** The highest number of malignant diseases was reported during year 2014 due to better reporting through HIS and NCR. Malignancies attacked both genders equally, whereas the most common types of malignancies were: melanoma and other malignant neoplasms of the skin, malignant diseases of the respiratory and intrathoracic organs, digestive tract, breast and female genital tract. The most affected the older ones.

**Keywords:** malignant diseases, year of appearance, gender, age group, diagnose, Kosovo.

## 1. INTRODUCTION

Malignant diseases are serious socio-medical problem, being that they cause grave problems in terms of health, social and economic perspective to an individual, in particular, and society in general. Malignant diseases are mainly characteristic for developed countries, but as well for developing countries and are characterized by high morbidity and mortality rates. According to the WHO, malignant diseases occupy second place as a cause of death in the world (1). Whereas in the United States malignancies are the second cause of death, where half of men and a third of women during their lifetime develop some form of malignant disease (2). They are also the cause of various morbidities and co-morbidities and can be responsible for loss of years of life years as well as loss of years without

disability. The fight against cancer is a major challenge in public health. Public health cancer surveillance data are the crucial for identifying needs, planning interventions, directing public health resources, and evaluating the overall effectiveness of initiatives aimed at preventing or treating cancer and its negative health consequences (3).

The Kosova Cancer Registry (KCR) after long gap in reporting was established by Minister decision (05-6368/2011) in 2011 as the population - based health register in the Department of Health Information System (DHIS) at the National Institute of Public Health of Kosovo (NIPHK). In the 2012 DHIS published first annual report for malignant diseases in Kosovo (4).

Year	N	%	X <sup>2</sup> -test
2012	2308	31.0	X <sup>2</sup> =478.2 P<0.0001
2013	1809	24.3	
2014	3320	44.6	
<b>Total</b>	<b>7437</b>	<b>100.0</b>	

Table 1. Malignant diseases reported in Kosovo for period 2012-2014

## 2. AIM

The study aims to examine the appearance of malignancies diagnosed and reported in Kosovo for a three years period: 2012, 2013, and 2014. In particular, we have analyzed presentation of malignant diseases by the years of appearance, gender, age, and most frequent types of malignancies.

## 3. MATERIAL AND METHODS

The study is a cohort retrospective research whereas source data we used are reports of malignant diseases of national cancer registry in the DHIS at the NIPHK. Data processing is done with the statistical program for data processing SPSS 22.0. The data are presented in tables and graphics, relevant statistical parameters are calculated, while testing the data is made with chi square test and cut off for significance was  $p=0.05$ .

## 4. RESULTS

In Kosovo during the years 2012, 2013 and 2014 in total 7437 cases of malignant diseases are reported. During 2012, there are 2308 cases reported or 31 % from total, during year 2013 there are 1809 cases reported or 24, 3 %, and during year 2014 there is the highest number reported, 3320 or 44,6 % from total number. The number of cases reported over three years has significant difference ( $P < 0.001$ ), therefore we can conclude that the number of malignant diseases reported, was the highest during year 2014 (Table 1).

The highest incidence and prevalence in Kosovo was registered in 2014 and 2012 while in 2013 were reported less diseases, so we see the positive trend of malignant diseases. (Table 2, Chart.1). Presentation of malignant diseases as per gender and years is roughly equal, but with slight variations in 2013 and 2014. Thus, in 2012 we have the participation of females with 49.7% (or 1146 cases) and male with 50, 3% (or 1162 cases). In 2013, more cases of malignancies were presented to females with 52.7% (or 953 cases), and male gender were presented with 43.7% (or 856 cases). In 2014, also slight variations were observed, with higher number of cases presented for males - 53.1% (or 1762 cases), and females were presented with 46.9% (or 1558 cases) (Table 3). However, after testing all cases with chi square test the result has not acquired significant difference ( $P > 0.05$ ), which means that the number of patients by gender and years is not different and that the malignant diseases has attacked

both genders equally (Table 3 and Chart 2).

Based on the results that derived from the processing of data's by age group of the patients, the study reveals that for three years reporting period, 5111 cases or 68.8% of reported malignancies were presented at ages from 50 to 79 years old, and the proportion between ages groups was as follows: group age from 60 to 69 years was presented with 1931 cases or 26% , group age from 50 to 59 years was presented with 1707 cases or 23% and group age from 70 to 79 years old was presented with 1473 cases or 19.8% of cases (Table 4, Chart 3).

Cases	2012		2013		2014		Total	
	N	%	N	%	N	%	N	%
New	1588	68.8	1483	82.0	2989	90.0	6060	81.48
Old	720	31.2	326	18.0	331	10.0	1377	18.52
<b>Total</b>	<b>2308</b>	<b>100</b>	<b>1809</b>	<b>100</b>	<b>3320</b>	<b>100</b>	<b>7437</b>	<b>100</b>
Incidence/100.000 inh.	93.4		83.3		167.9			
Prevalence/100.000 inh.	135.8		101.6		186.5			

Table 2. Incidence and prevalence of malignant diseases reported in Kosovo for period 2012-2014

Gender	Year						Total	
	2012		2013		2014		N	%
	N	%	N	%	N	%		
F	1146	49.7	953	52.7	1558	46.9	3657	49.2
M	1162	50.3	856	47.3	1762	53.1	3780	50.8
<b>Total</b>	<b>2308</b>	<b>100.0</b>	<b>1809</b>	<b>100.0</b>	<b>3320</b>	<b>100.0</b>	<b>7437</b>	<b>100.0</b>
X <sup>2</sup> -test, P-value	X <sup>2</sup> =0.11, P=0.654		X <sup>2</sup> =5.20, P=0.023		X <sup>2</sup> =12.5, P=0.000		X <sup>2</sup> =2.03, P=0.153	

Table 3. Malignant diseases reported in Kosovo per gender and years, period 2012-2014

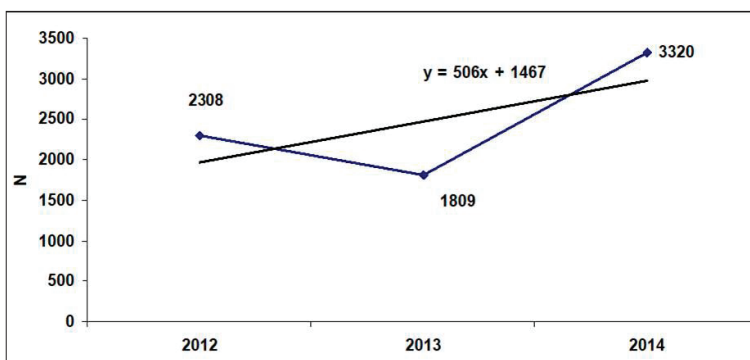


Chart 1. Number of malignancies reported as per years, 2012-2014

The data reported for malignant diseases for the reporting period of three years, are analyzed by presenting them combined as per diagnosis and gender. Based on the results obtained, we found for men these types of malignant diseases as the most common: Melanoma and other skin malignant neoplasms (C43-C44), Malignant diseases

Age group	N	%
0 to 9	56	0.8
10 to 19	64	0.9
20 to 29	131	1.8
30 to 39	360	4.8
40 to 49	974	13.1
50 to 59	1707	23.0
60 to 69	1931	26.0
70 to 79	1473	19.8
over 80	448	6.0
Not known	293	3.9
<b>Total</b>	<b>7437</b>	<b>100</b>

Table 4. Malignant diseases reported in Kosovo as per group ages for period 2012-2014

of the respiratory and intrathoracic organs (C30-C39), and Malignant diseases of digestive tract (C15-C26). Whereas, for women these types of malignant diseases are found as the most common: Breast malignancies (C50-C50), Malignant diseases of the female genital tract (C51-C58), Melanoma and other skin malignant neoplasms (C43-C44), and Malignant diseases of digestive tract (C15-C26) (Chart 4).

### 5. DISCUSSION

The statistics used to assess the importance (burden) of cancer and of different types of cancer in the population either quantify the disease itself (the “need” for services) or the demand that it places upon them (5). Incidence, the number of new cases occurring, can be expressed as the annual number of cases (the volume of new patients presenting for treatment) or as a rate per 100,000 persons per year. Incidence data are produced by population-based cancer registries (6). Registries may cover national populations or, more often, certain regions. In developing countries in particular, coverage is often confined to the capital city and its environs. It was estimated that, in 1990, about 18% of the world population were covered by registries, 64% of developed countries and 5% of developing countries, although the situation is improving each year (7). Incidence rates provide a measure of the risk of developing specific cancers in different populations. Changes in incidence are the appropriate indicator of the impact of primary prevention strategies. Prevalence, as the number of persons ever diagnosed with cancer (lifetime prevalence), does not have much apparent utility. The data can be derived from cancer registries that have very long-term registration of cases and complete follow-up for vital status over many years (8, 9). Population surveys are another approach, although they underestimate true prevalence (10). In Kosovo, for the year 2012, based on the reported cases the incidence was 93.4/100.000 inhabi-

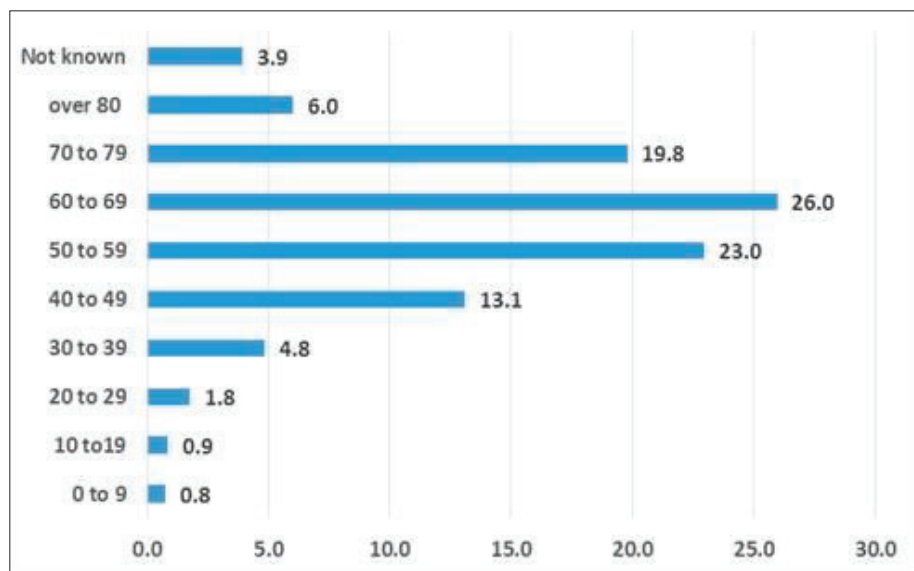


Chart 3. Malignant diseases reported in Kosovo as per group ages for period 2012-2014

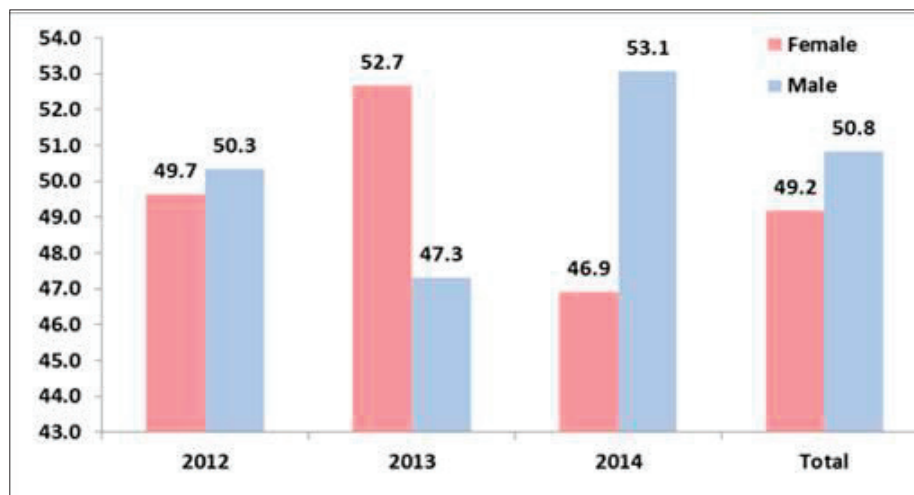


Chart 2. Malignant diseases per years and gender

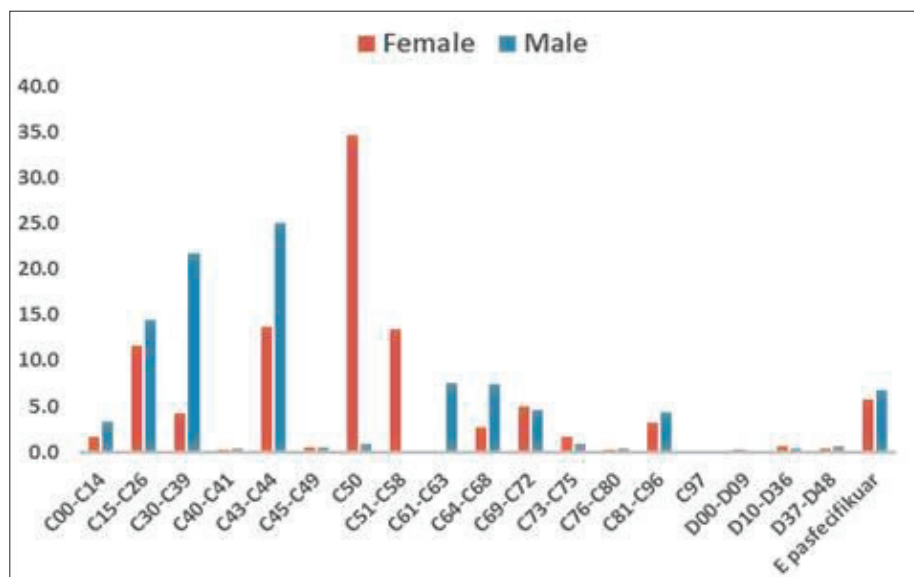


Chart 4. Most common malignant diseases by gender

tants, while for 2014 was 167.9/100.000 inhabitants and the prevalence in 2012 was 135.8/100.000 inhabitants while for 2014 was 186.5/100.000 inhabitants. Even we found that the highest incidence and prevalence in Kosova was registered in 2014, there made be an explanation that this happened due to better reporting through the NCR combined with training with health personnel for filling the forms for malignant diseases, which happened in 2012 and 2014.

In Kosovo, during 2012-2014, the most common malignancies diagnosed in men are melanoma and other skin neoplasms, malignant diseases of the respiratory tract and intra thoracic organs, malignant diseases of digestive tract; while among women the most common types during the same reporting period are: breast malignancies, malignant diseases of the female genital tract, melanoma and other skin malignant neoplasms, malignant diseases of the digestive tract. During previous years, data reveal almost same findings.

In Kosovo, during 2013 first time diagnosed with malignancies, were mostly malignant melanoma and other malignant neoplasms of the skin with 19% of cases, breast malignant disease with 15.1%, and malignant diseases of the digestive organs by 11.9%. Among most common ten types of malignancies were: breast with 18.0%, skin with 15.5%, and bronchial and lung malignancies with 9.2% (11).

In both genders, lung malignant diseases were the most common malignancy around the world, contributing 13% of the total number of new cases diagnosed in 2012. Breast malignancies (women only) were the second most common with nearly 1.7 million new cases in 2012. Colorectal malignancies were the third most common with about 1.4 million new cases in 2012 (12).

More than 60% of new malignant diseases in the world, are presented in Africa, Asia and Central and South America, and in these regions occur about 70% of global deaths from malignant diseases. It is expected that the number of deaths from malignant diseases will increase globally from 14 million in 2012 to 22 million over the next two decades (12). From approximately 14.1 million cases of malignancies worldwide in 2012, 7.4 million cases affected men and 6.7 million affected women. This number is expected to rise to 24 million by year 2035. This increase of malignant disease's burden, as well as the general context of massive non-communicable diseases (NCD), was the main focus of the summit meeting of the United Nations on massive non-communicable diseases (NCD), in New York, September 2011 (13).

Breast malignant diseases is globally the most common type of malignant diseases in women, with about 1.7 million new cases diagnosed in 2012 (and the second type of malignant diseases most common). This represents about 12% of all new malignant diseases cases and 25% of all malignant diseases in women. Breast malignant diseases is associated with hormonal status, and factors that modify the risk of malignant diseases are not the same when diagnosed before and after menopause (12).

In Kosovo, breast malignant diseases are placed as number one type of malignancies in women during the reporting period of three years, 2012-2014. About 22% of breast malignant diseases cases in Brazil can be prevented by not drinking alcohol, having moderate physical activity and maintaining body weight. Belgium had the highest incidence of breast ma-

lignant diseases, followed by Denmark and France. Slightly more cases of breast malignant diseases were diagnosed in less developed countries (53%) (12). In 2014, it was estimated that 191.300 Canadians have developed malignant diseases and 76,600 have died from malignant diseases. More than half of new malignant diseases cases (52%) will be lung, breast, colorectal and prostate malignancies. Lung malignant diseases is the leading cause of deaths from malignancies, causing more deaths among Canadians than three other types of malignant diseases together. Slightly more men than women develop malignancies in Canada, and the majority (89%) of Canadians who develop these diseases are over age 50. However, malignant diseases can develop at any age and its impact on a younger age can be particularly devastating. According to Statistics Canada, in 2009, malignant diseases was the leading cause of death in children under the age of 15 years (14).

Limitations of the study are directed toward data control and link data from NCR with other patient evidences such as patient record disease histories, protocols and other forms of patient registers related to malignant diseases.

## 6. CONCLUSION

On introduction of the NCR improved the system of reporting malignant diseases in Kosova and gave us the possibility to calculate different related indicators. The highest numbers of malignant diseases were reported during year 2014; the reporting is higher in the years where trainings of the health personnel were performed. Malignancies attacked both genders equally, whereas the most common types of malignancies were: melanoma and other malignant neoplasms of the skin, malignant diseases of the respiratory and intrathoracic organs, malignant diseases of digestive tract, malignant diseases of breast and female genital tract. The most affected group ages are the older ones. However, we are not satisfied with the quantity and quality of the reporting. The better the quality of data from the cancer registry, the better the possibilities for effective use of these data in planning and research. Conversely, the more active and research-oriented the registry, the better the possibilities of maintaining good coverage and accuracy. Support reporting of malignant disease consistently and correctly, so that we have no deficiencies in reporting, or we have incomplete data for malignant diseases; Increased political commitment for the prevention and control of malignant diseases; Protocol management for malignant diseases, aiming to unification and standardization of diagnostic and therapeutic protocols; Early diagnosis and treatment of disease, especially important investments in early detection and screening as the most cost effective methods for early detection of several types of malignant diseases; Personal measures for the prevention of malignant diseases-recommended ensuring the ideal weight from childhood and adolescence through the age after 40; Additional care for vulnerable population groups.

- Authors contribution: MB, NR, SG, RH, FB participated in design of the study, methodology part, discussion and corrections of the manuscript. SG, FB and RH conducted and has contributed for statistical analysis. SG, RH, DK has contributed in gathering, discussion and correction of manuscript. All authors have read and approved the final manuscript.
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- Conflict of interest: The authors declare that no conflicts of interest exist.

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