

R E P U B L I C OF A L B A N I A

MINISTRY OF HEALTH

THE NATIONAL CANCER CONTROL PROGRAM 2011-2020

WITH THE SUPPORT OF

WORLD HEALTH ORGANIZATION

REGIONAL OFFICE FOR EUROPE

THE WORKING TEAM FOR THE DEVELOPMENT OF THE NATIONAL CANCER CONTROL PROGRAM (NCCP)

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1. EXECUTIVE SUMMARY

Today, cancer is the second leading cause of death in Albania. Most cancer cases are detected at later stages when chances of healing are scarce. But fortunately, today we have the proper knowledge to prevent one third of all cancers, to heal one third of them and to avoid the pain and suffering in most cancer cases. The WHO Strategy for Public Health offers the best approach for transmitting the new knowledge and skills to evidence based effective interventions, which can reach everyone in Albania. Establishment of NCCP enables the setting of priorities and the identification of actions to be taken through a cautious analysis and planning of cancer control activities, in order to use the available resources in the best possible way and to achieve the best possible results to reduce cancer morbidity and mortality. This is particularly essential in a country like Albania, where many critical health issues compete with each-other for having the priority in intervention programs.

The National Cancer Control Program (NCCP) is a product of the National Cancer Control Committee in Albania through close collaboration with the World Health Organization – Regional Office for Europe (WHO-EURO). In 2005, a cooperation agreement was signed between the Albanian Ministry of Health and the World Health Organization for the period 2006-2007 to address, among others, the issue of "Non-Communicable Diseases" which includes cancer. The National Cancer Control Program was developed based on a consultative process with various stakeholders under the principle of the WHO: "…to be integrated into all levels of the Albanian health care system, to be a community property and to include the society through collective and social action".

The National Cancer Control Program relies on the following key moments:

- Regular functioning of the National Cancer Control Committee;
- Law "On health care in the Republic of Albania"
- Law "On public health"
- Law "On obligatory health care insurance in the Republic of Albania"
- National Cancer Control Strategy and the 10-year Action Plan;
- Primary prevention campaign (vaccination against hepatitis B, smoking control, air pollution control programs, programs for cleaning up abandoned industrial hot-spots, etc.);
- Continuing Education Program.

2. INTRODUCTION

2.1. Worldwide Situation

Nowadays, cancer represents an enormous global issue. About 10 million new cases are counted annually, of which over 7 million die from cancer. In the next 10 years, 84 million people will die from cancer if action is not taken. It is estimated that by 2020 there will be 16 million new cancer cases per year and by the year 2050 the today's incidence rate will be doubled to 24 million new cancer cases per year.

A considerable part of the increase in cancer incidence and mortality will be due to dramatic demographic changes towards an aging population. Today there are over 600 million people aged 60 years and over worldwide. In 2025 this number will double up to 1.2 billion and by 2050 to about 2 billion. In 2015, the estimated annual mortality from AIDS will rise to 4 million, and if preventive actions will not properly function, it will rise up to 6 million in 2030 and many of these subjects will suffer from cancer as well.

More than 70% of all cancer deaths occur in low and middle income countries in which available resources for early detection, diagnosis, treatment and palliative care are limited or inexistent. This is tragic in an era when the development level clearly demonstrates that over one third of cancers can be prevented and one third can be cured if early detected and standard therapies are available, and also unnecessary pain and suffering can be reduced for most cancer cases.

Although considerable financial resources for cancer research are allocated worldwide, efforts to implement the data obtained from such work are still lagging behind. Many current activities in the fight against cancer are developed improperly and are lacking overall coordination. Cancer control efforts can be planned and implemented more effectively if they will follow a step by step systematic approach to evaluate the situation, setting health objectives, assessing possible strategies and setting clear priorities.

World Health Organization is committed to develop the health strategy for cancer control in a rational way, to implement the existing knowledge related to cancer control so that even non-optimal resources have a concrete effect. There are guidelines promoted, produced and implemented for setting up the National Cancer Control Programs based on these principles.

A number of concepts have been developed such as reduction of later-stage cancer rate, the obligatory linkage of radiotherapy with the requirement for early referral of treatable cancers to healing centers, essential drugs' policies, pain relief and palliative care as mandatory parts of cancer control and prevention of future cancers, giving priority to smoking control and vaccination, for example against hepatitis B virus (HBV).

2.2. Principles of the National Cancer Control Program in Albania

When designing the summary of NCCP, the working team took into account the following principles recommended by WHO:

- **Focus on the individual:** The final goal of the strategy is to improve the welfare of people, communities, families and individuals.
- **Equity (equality-justice):** The strategy should focus on meeting the needs of all population strata.
- **Ownership:** The strategy should ensure a strong commitment and an active involvement of the key stakeholders at every level of the decision-making process and implementation.
- **Partnership and multi-sectorial approach:** The strategy should ensure a wide participation and the cooperation of all public and private sectors.
- **Continuity (Sustainability):** The strategy should emphasize the need for local governance and partners to struggle together for self-financial and technical support to ensure the continuation of benefits from developed programs after termination of the main assistance.
- **Integration:** The strategy must be placed within the entire framework of chronic diseases prevention and also the control of all other problems (such as problems linked to the environment, transmittable diseases etc.).
- **A step by step approach:** The strategy should consider the step by step implementation of the interventions at the national level (i.e. interventions that follow each other).
- **Based on facts:** The strategy should be based on the research results, program evaluation, economic analysis, bets practices, and lessons learned from other countries).

2.3. Progress Report for the Fight against Cancer in Albania

2.3.1. Cancer Control

- The National Committee for Cancer Control is fully functional and currently leads the National Cancer Control Program (NCCP). For the four key components: prevention, early detection, diagnosis and treatment, and palliative care, responsibilities and specific tasks are designed.
- The National Cancer Control Program document is developed and reviewed by all actors involved in the fight against cancer in Albania.

- The 10-year action plan (2011–2020) which includes activities, timelines and budget is developed based on national priorities.
- To compile the national strategy and the cancer action plan, a series of workshops with the participation of national, regional and international organizations' experts have been organized.

2.3.2. Cancer Registry and Surveillance

- The cancer registry is based on hospital records of the "Mother Teresa" University Hospital Center in Tirana (TUHC). The computerization of data has started in 2008. The data collected from 36 districts are then sent to TUHC.
- The cancer and risk factors surveillance is based on the institutional collaboration between TUHC and the Institute of Public Health.

2.3.3. Prevention and Early Detection of Cancer

- Measures have been taken for the formulation and effective implementation of the legislation on health protection from tobacco products. Efforts for public awareness about harmful effects of tobacco are intensified through specific campaigns and distribution of informational materials.
- Interventions for the early detection of breast cancer are being implemented nationwide through information, education and training of health workers on clinical breast examination. Although national experts recommend PAP-test for early detection of cervical cancer, efforts to establish lower cost programs for early detection of this pathology are underway.
- There are procured 8 mammography devices, of which 4 are installed in Shkoder, Durres and Tirana districts in the framework of Interreg 3.
- A number of conferences and workshops are held on prevention and early detection of the cervical and breast cancer.
- Informative materials are produced and distributed in order to increase women awareness about the advantages of early detection of breast cancer.
- A national plan is developed to integrate early detection of breast and cervical cancer in primary health care.

2.3.4. Cancer Diagnosis and Treatment

- During 2006 and onwards, the following numerous investments have been made to strengthen health services in the field of cancer control, particularly related to diagnosis and treatment.
  1. Purchase of 4 mammography devices (TUHC, Elbasan, Korçë, Fier) with a value of about 2.3 million USD.
  2. Procurement of 3 magnetic resonance devices and 6 computerized tomography scanners for regional hospitals in the country with a value of 5.9 million Euros, expected to be installed by 2011.
  3. Installation and operation of a 128 cutting slices CT (the highest level at the moment) at "Shefqet Ndroqi" University Hospital with a value of 2.2 million Euros.
  4. Purchase of the CT scanner for Saranda Hospital with a value of 300 thousand Euros.
  5. The contraction of the first linear collider with a value of about 2 million Euros, which is expected to be installed by 2011.
  6. The installation of 4 mammography devices in Shkodër, Durrës and Tirana districts, in the framework of Interreg 3.
  7. Investment for reconstruction or infrastructure improvements in the Oncology Service, TUHC, with a value of about 200 thousand USD.
- Annual funding for cytostatic drugs with a value of about 4 million Euros per year.
- Cobaltotherapy device (Equinox Cobalt) in TUHC co-financed by the Albanian Government and donors.
- The brachytherapy equipment funded by IAEA/TC is installed since 2009.
- Training of relevant personnel on the use of high-tech equipment.
- Through the assistance and expertise of the IAEA (technical cooperation projects), the personnel capacity building and training on radiotherapy and nuclear medicine (active projects: ALB/2/012, ALB/6/011) is being enabled.

2.3.5. Palliative Care and Family Support

- Palliative care services are provided by the Center of Oncology Service at Home (funded by the state budget), Ryder Albania Association, Mary Potter Association, and Caritas.
- Currently, family doctors and nurses are being trained about palliative care services.
- A plan for the ongoing education about palliative care issues is developed and covers most of the country. At the same time there is also a partnership with the United Kingdom for international assistance and training.

2.3.6. Activities of the Associations against Cancer

- Albanian Association of Cancer, Ryder Albania, Health Center for Cancer Prevention and Care-at-Home Center are involved in education, prevention, early detection of the breast, uterus and skin cancer, and in palliative care as well.
- *Europa Dona Albania* provides public support and public sensibilization.

2.3.7. Advocacy, Public Education, Legislation

- The Association "For a Tobacco-Free Albania" is active in raising the public awareness about the harms of tobacco and the identification of national legislative priorities for tobacco control.
- *Ryder Albania* Association continues to be active in the palliative care advocacy through publications, TV programs, meetings with the Ministry of Health, non-governmental organizations and other donors.
- *Europa Dona Albania* (a subsidiary of *Europa Dona* international association) is a new active association which supports breast cancer survivors and works to increase the awareness of policy makers and the general public.
- The law "On Public Health" and the Package of Services in Primary Health Care (2009) address issues related to early detection of cancer.

2.3.8. Partners in the Field of Prevention and Early Detection of Cancer

- A value of $100.000 (OFID grant) is allocated to Albania for funding the project "A new model to increase awareness of breast cancer in Albania".

  UNFPA has already allocated to the Institute of Public Health an amount of $40.000 for two years (2009-2010) for activities in the field of primary health care regarding assessment and services mapping, strengthening reproductive health sectors at the local level, including problems of reproductive tract cancers and publications of informative materials. In early 2011, UNFPA allocated a fund to the Ministry of Health and IPH to support the cervical cancer early detection program.
- Current partners: WHO, IAEA, UNFPA, MDS Nordion.
- Full support from WHO.

3. THE SITUATION OF CANCER IN ALBANIA

3.1. General Data for the Republic of Albania

Some important demographic and socioeconomic data for the Republic of Albania are presented in the table below (Table 1):

Table 1. Demographic and socioeconomic data for the Republic of Albania	
Surface	28748 km^2
Population	3 127 263
Males	1 558 376
Population density (people/km2)	108.7
Urban population	1 406 443 (45%)
Fertility rate (per 1000)	13.8
Standardized Mortality Rate, all causes, all ages	847.17 per 100,000
Annual population growth (%)	0.8
Mean age	31 years
Life expectancy	74.0 years (M: 71.7 yrs; F: 76.4 yrs)
Population under 45 years of age (%)	77.9 (5-year average)
Population over 60 years of age (%)	9.2 (5-year average)
Source: INSTAT.	

3.2. Situation of Cancer in Albania

In Albania, as in many other countries of the world, cancer represents a growing concern which needs to be addressed by a Public Health approach. While the number of victims from cancer increases, the health system faces the need to ensure effective drugs and the latest technology equipment.

Based on data from the Ministry of Health, cancer is the leading cause of mortality in the country after cardiovascular diseases (Table 2):

Table 2: Mortality from cancer in relation to other diseases

No.	Cause of Death	Percentage to Total Mortality
1	**Cardiovascular diseases**	50.2 %
2	**Tumoral diseases (cancer)**	**16.6 %**
3	**Causes not well defined**	11.3 %
4	**Accident and injuries**	6.8 %
Source: Ministry of Health		

About 4000-5000 new cases of cancer are reported each year. The available cancer data are partly based on the cancer registry of Oncology Center at the ”Mother Teresa” University Hospital Center in Tirana, and partly from the records of district hospitals and pathology services.

The registered cancer percentage in Albania (approximately 1000 new cases per 100.000 inhabitants) is low compared to other European countries, which may be due to incomplete registration and/or high percentage of youngsters in Albania. Approximately 73% of Albanians or nearly three-quarters of the population are less than 45 years old and the mean age is 31 years old – the lowest in Europe.

But, in the future, as population is ageing, a significant increase in the number of cancer cases is expected in the country.

In our country, cancer is already a serious problem responsible for 17% of all deaths, thus becoming an increasing burden on our health care system (HCS).

Leading forms of cancer in our country in terms of frequency are: skin, lung and urinary tract cancer for males (Table 3.1); and breast, skin and central nervous system cancer for females (Table 3.2):

Table 3.1. Distribution of the 10 most common malignant tumors in males in Albania for the period 1996-2000

No.	ICD 9	Location	No. of cases	Incidence	Frequency (%)
1	162	Lung	306	18.5	18.1
2	173	Skin	291	17.6	17.2
3	188	Urinary tract	129	7.8	7.6
4	140	Lips	104	6.3	6.1
5	151	Stomach	102	6.2	6.1
6	191	Central nervous system	97	5.5	5.3
7	161	Larynx	90	5.5	5.7
8	204	Leukemia	41	2.5	2.4
9	202	Malignant lymphoma	39	2.4	2.3
10	155	Liver	37	2.2	2.2
11		Other tumors	456	27.6	26.9
12		Total	1692	102.2	100
Source: Central Intra-Hospital Registry, University Hospital Center "Mother Teresa"					

Table 3.2. Distribution of the 10 most common malignant tumors in females in Albania for the period 1996-2000

Nr.	ICD 9	Location	No. of cases	Incidence	Frequency (%)
1	174	Breast	301	17.7	27.8
2	173	Skin	147	8.7	13.6
3	191	Central nervous system	69	4.1	6.4
4	180	Cervix uteri	67	3.9	6.2
5	151	Stomach	48	2.8	4.4
6	162	Lung	35	2.1	4.4
7	183	Ovary	34	2.0	3.1
8	202	Malignant lymphoma	24	1.4	2.2
9	154	Rectum	23	1.3	2.0
10	157	Pancreas	22	1.3	2.0
11		Other tumors	314	18.5	29
12		Total	1084	63.8	100
Source: Central Intra-Hospital Registry, University Hospital Center "Mother Teresa"					

As it can be seen in Table 4, out of 9 most prevalent cancers in Albania, 4 of them are clearly preventable, and 3 others are "candidates" for prevention. Four types of cancer can be detected early, which means that in principle they are also preventable, but unfortunately over 75% of breast, uterus and larynx cancers are diagnosed in their later stages meaning that they aren't curable anymore. Despite the therapy, three types of these cancers are incurable. Thus, Table 3 and 4 summarize clearly the priorities that should be addressed by the NCCP in Albania.

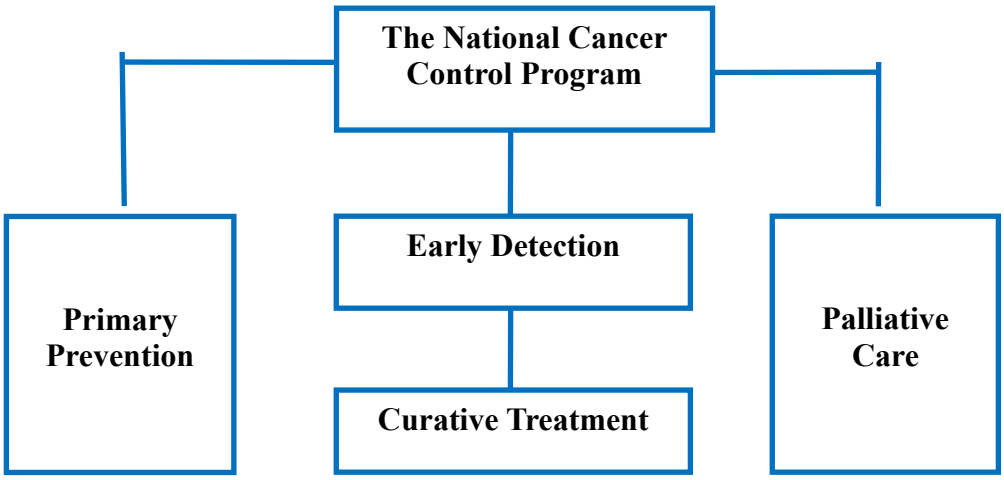
Therefore, cancer therapy must necessarily be linked with early detection efforts, as illustrated in Figure 1, which shows the four main pillars of the NCCP.

Table 4. Advantages of early detection for the nine most common cancers in Albania

No.	Type of cancer	Primary prevention	Early detection	Curative treatment	Palliative care
1	Skin*	++	++	++	++
2	Lung	++	-	-	++
3	Breast	-	++	++	++
4	Central nervous system	-	-	-	++
5	Stomach	+	-	-	++
6	Urinary tract	+	-	+ -	++
7	Larynx	++	++	++	++
8	Rectum	+	+	+	++
9	Uterus	++	++	++	++

* *Including basal and squamous cell carcinoma, excluding melanoma.*

Figure 1. The Pillars of a National Cancer Control Program



4. THE NATIONAL CANCER CONTROL PROGRAM (NCCP)

4.1. Cooperation with the International Atomic Energy Agency (IAEA)

The International Atomic Energy Agency (IAEA) assisted Albania through the Program of Action for Cancer Therapy (PACT). Albania is considered as a pilot country of PACT program. The IEAE assistance in the health field in Albania has started in 2000, while the PACT program started in 2005. Besides concrete assistance in equipment, an added value of the cooperation with IAEA is catalyzing the reform processes in the field of cancer control in our country. IAEA's actions are in harmony with the actions of the WHO.

Specific contribution of the IAEA's for cancer treatment in Albania consists of the following equipment:

- Year 2000: Orthovoltage radiotherapy device for skin cancer and superficial tumors treatment (value: 150.000 USD)
- Year 2005: Cobalt device (value: 600.000 USD)
- Year 2009: Cobalt device (value: 600.000 USD)
- Year 2009: HDR Brachytherapy device (value: 220.000 USD)
- Other devices in process: CT simulator, diagnostic device for radiotherapy (value: 350.000 USD), and 3D Computerized System for treatment plans (value: 150.000 USD).

Also, the IAEA is currently supporting the Nuclear Medicine with devices such as Gamma Camera (value: 600.000 USD). Also, other dosimeter equipment and accessories worth over $100.000 for Radiotherapy and Nuclear Medicine are expected to be installed.

In addition, a variety of different trainings have been carried out with the support of the IAEA. This way, training for the period 2010-2012 amounts to a total value of $350.000.

Programs for prevention and early detection of cancer supported by IAEA consist of increasing women awareness about self-examination of breast, clinical breast examination at all levels of the system starting from primary care, and radiological examination. For the period 2011-2012, the total value of funding for this program will be $100.000. The donor is OFID (OPEC Fund for International Development) through the IAEA.

Also, the integration of screening and early diagnosis of cervical cancer in primary care is being supported financially by UNFPA (2011 and onwards).

4.2. Logistics of the National Cancer Control Program (NCCP)

The National Cancer Control Program is a necessity based on the specific epidemiological situation in our country as well as existing resources. This program, developed under a long-term perspective and serving broad purposes, constitutes a mechanism through which all cancer control activities will be organized and coordinated. Limited resources will not be a discouraging factor.

According to WHO recommendations, the implementation of the NCCP will be completed step by step, by first identifying and implementing those activities that are most urgent and promise greater benefits. The first most necessary steps have already been taken: the gathering together of national and international partners.

4.3. Primary Prevention

4.3.1. Risk Factors

At least one third of all cancers can be prevented through the control of risk factors. Tomorrow's cancers can be prevented today, therefore, primary prevention of cancers of the future is already an absolute priority.

Some of the major risk factors for development of various types of cancer are discussed below:

- ***Smoking:*** smoking is a major risk factor for several cancers and numerous other diseases. Smoking, as a single factor, is one of the most preventable causes of ill-health. In Albania, the smoking epidemics seem to be still in their first half, where the majority of men are smokers and the percentage of smoking among women is low (less than 10%). But this phenomenon (smoking) is increasing steadily and constantly. Whereas in males, there are no significant differences in the prevalence of smoking among different socioeconomic strata, these differences among women are significant and vary greatly. Smoking is very prevalent among women residing in Tirana and in urban areas in general compared with rural area women, and among highly educated, employed or high-income women. Prevalence of smoking increases with age, particularly among men, but trends among youngsters are also of great concern as one in four young people tries to start smoking.

  Albania has in place a contemporary program of tobacco control with a full time coordinator working in the premises of the Institute of Public Health that has implemented a contemporary plan of tobacco control.

  The NCCP cannot and must not create a separate approach, but should join its efforts with this program. Regular tests to check knowledge, attitudes, and practices in order to monitor the effects of the interventions should be performed and also periodic reporting about smoking prevalence and its related factors must be documented.

- ***Ultraviolet Radiation:*** although skin cancer is the most common cancer, there is no prevention program in place for it, probably because of the benign nature of basal cell carcinomas. However, both these cancers and squamous cell carcinoma of lip (which is also relatively common) can be traumatic in cosmetic terms and malignant melanoma (still not so common) can be expected to increase in the near future. As a result, for many malignant tumors early detection represents the best opportunity for treatment and recovery.

  Therefore, an awareness program for the early detection of skin cancers, embedded in the public awareness educational program about early signs of treatable cancers, should be established.

- ***Sexual Behaviors:*** amongst sexually transmitted infections, particularly amongst human papilloma viruses (HPV), 16/18 of them cause uterine cancer. Despite of social and political conditions, Albania is still considered a country with low prevalence of sexually transmitted diseases. The period 1970-80, was characterized by a zero prevalence of syphilis and a delayed start of HIV/AIDS epidemic (after 1994). Recently, the epidemiological surveillance and some specific studies have shown a steady increase of these diseases in the country. Numerous studies have shown the existence of herpes virus in pregnant women, while the prevalence of Chlamydia Trachomatis among a group of reproductive age women in Tirana district is reported to be over 20%. In the 2002 Reproductive Health Survey in Albania, approximately 1% of reproductive age women said they were diagnosed with sexually transmitted diseases such as syphilis, gonorrhea, genital herpes, trichomoniasis and genital acne. As sexual behaviors are changing very quickly it is expected that the incidence of uterine cancer will increase as well.

  In the future joint program of sexually transmitted infections and HIV/AIDS, an integrated educational health approach should be engaged, including sensibilization about the risks of uterine cancer. Also, the step by step building up of a national program of vaccination against HPV should be investigated.

- ***Hepatitis B:*** primary liver-cell carcinoma is the most common cancer worldwide, in the context where there is a vaccine against HBV, and a consensus reached in early '80s about the need of mass vaccination of infants in countries where the population is dense. Hepatitis B virus (HBV) is the primary cause of liver cancer. Albania lies amongst European countries with the highest prevalence of this infection. Studies on seroprevalence conducted in '90s in different population groups, showed a prevalence of 11% to 17%. Massive introduction of single use syringes after 1992 and early immunization of children in 1995 seems to have greatly influenced the prevalence rate, as studies conducted in 2000 showed a decrease in the prevalence rate of Hepatitis B.

  WHO recommends vaccination with HBV vaccine of all newborns if the prevalence of HBV carriers is greater than 10%. In Albania, the vaccination with HBV vaccine started in 1995 with about 50.000 vaccinated persons per year, representing a coverage of about 90%. So, currently there is a national program of HBV vaccination in place.

  The NCCP should establish an active partnership with the national vaccination program (HBV vaccine) and provide a long-term monitoring of changes in rates of chronic carriers and primary liver-cell carcinoma incidence.

- ***Chemical Substances:*** industry uses or produces in various technological processes a vast number of chemical substances, which are tested for carcinogenic effects in animal trials and proven by other studies. In the last 10 years, the phenomenon of uncontrolled waste of various industrial plants is observed, at a time when new industrial plants are spreading rapidly. Population exposure to carcinogenic agents is different in both cases: in the first case the population historically living there or recently moving near hazardous industrial

areas is threatened and in the second case employees who are currently working in these industrial plants are endangered.

The map of hazardous areas in Albania includes the population of the outskirts of Durres (former chemical plant), outskirts of Vlora (former chemical plant), Patos-Ballsh area (oil extraction and refining), particular areas in Berat (former battery plants), Rubik (metallurgical industry) and some areas near the coal mines. Among the new raising industries, the one with the highest risk is the shoe manufacturing industry, in which currently thousands are employed. The total number of population exposed to risks from this industry (both workers and community) is estimated to be around 300.000 inhabitants.

It is necessary to gather facts and data about a possible geographical distribution of "hot spots" of these industries that expose their employees and surrounding populations to carcinogenic agents. Based on this information and comprehensive education, protective and legislative measures should be taken.

- ***Alcohol:*** is another risk factor for several cancers including those of the pancreas and liver. In Albania, the population distribution of alcohol consumers is similar to that of smokers and a significant increase is observed among women and youngsters in general. The prevalence of female alcohol users (almost daily) is increasing. Women with high socioeconomic status and those living in large urban areas consume more alcohol. Teenage girls consume roughly the same amount as adult females (over 40%) and this percentage is high even among young people. One in five youngsters is a regular consumer of alcohol.

Increasing risks of cirrhosis, pancreatic cancer and primary liver-cell carcinoma must be included in the national public awareness program about possible risk factors.

4.3.2. General Overview of Primary Prevention

Top priority should be given to the primary prevention and health education in particular and, when necessary, to appropriate legislation as well, even when the expected benefits can be received many years later.

Health education should cover all aspects related to cancer (in general and in particular), emphasizing primary prevention measures, research for early detection of disease and the advantages of early treatment. It is necessary to familiarize and to increase the public awareness about the methods of prevention and early detection of the disease through increasing the knowledge about risk factors and causes of most forms of cancer (smoking, lifestyle, diet, genetic factors etc.), early symptoms and signs, searching for early diagnosis and advantages of prompt treatment. As a consequence it will be increased, for instance, the percentage of Albanian citizens who recognize signs and symptoms of cancer in an early curable stage and an increasing

part of the population will be aware that surgical treatment, radiotherapy and chemotherapy are effective in treating cancer detected at an earlier stage.

Amongst the most common cancers in Albania, 6-7 of them can be prevented. These are lung cancer (smoking), cervical cancer (sexual behavior, life style and vaccination), liver cancer (vaccination against hepatitis B, EPI), skin cancer (sun exposure), colorectal cancer (diet, smoking), larynx and oropharyngeal cancer (smoking and HPV vaccination) and stomach cancer (helicobacter pylori, smoking).

Primary prevention should include health education, should use the media, legislation, supporting policies etc., and also use the potentially reviewed HPV vaccination programs. It is entirely possible to take action towards smoking, diet, alcohol, factors related to working conditions, environment, vaccination against hepatitis B and awareness of a healthy lifestyle, thus avoiding known risk factors. The newly initiated contemporary program of tobacco control is a priority not only for cancer control but also for the prevention of cardiovascular diseases (which are the number one “killer” in Albania) and respiratory diseases.

Approximately 50.000 children are vaccinated against hepatitis B each year. The Government of Albania will continue to support this vaccination according a scheme included in the expanded program of immunization.

Exposure of the Albanian population to carcinogenic pollutants may be considerable. The most urgent objective is to gather convincing facts and identify the areas/industries and populations with the highest risk in Albania. Coordination is needed between the ministries in order to adopt the legislation/regulations on the basis of which high risk industries must function, and for the protection of employees and other exposed populations.

In addition to informing the general public, an aspect which will be included in the smoking prevention action plan, parallel programs to inform the public about other risks associated with cancers and ways to avoid them, particularly exposure to ultraviolet light, alcohol consumption and balanced diet should be established. These programs will focus on mass-media work and also reviewing and evaluating the education of children in schools.

A detailed overview of the strategy and action plan for primary prevention of cancer will be presented in subsequent sections, while Table 6 presents a general picture of the cancer primary prevention strategy in our country:

Table 6. Overall picture of Cancer Primary Prevention in Albania

Goal	Strategy	Approach
• Public and professionals	• Education • Increasing of awareness	• Media campaigns • Educational materials for the schools and public • Training and study tours
• Evidence	• Monitoring and evaluation	• Periodic studies to assess the prevalence of risk factors in the population, level of awareness, and use of services • Program evaluation and technical reports
• One third of all cancers	• Relationship with the existing program of tobacco control	• Ongoing and in close cooperation
• Uterine cancer	• Lifestyle, associations with STI / HIV/ AIDS • Public awareness campaign • Educational program • Vaccination	• Creation of public education materials • Preparing the policy document for the Ministry of Health and donors
• Skin cancers	• Increase of public awareness	• Development of education materials and public awareness campaign
• Liver-cell cancer	• HBV vaccination program	• Ongoing
• Urinary bladder • Central nervous system • Leukemia	• Beginning of cancer occupational hazards control program	• Collection of evidence and, if positive, to negotiate with industries, draft legislation and educate the public

4.3.3. General Recommendations for Cancer Primary Prevention

- Based on current knowledge, it seems that *environmental factors* and those associated with exposure due to *lifestyle* are involved in most cancers, independently or combined with different genetic factors. Numerous measures and activities can and should be taken to minimize the population exposure to these factors.
- Activities aiming at primary prevention of cancer should be harmonized with the strategies and other relevant sectorial policies, such as the strategy of disease prevention and health promotion strategy, the strategy of preventing alcohol damages, national nutrition guidelines, HIV/AIDS and STI prevention strategy, immunization strategy etc.
- The NCCP cannot and should not create a separate approach from *tobacco control*, but it should complement it. To monitor the knowledge, attitudes and practices regarding smoking in the population, periodic surveys should be carried out. At the same time, the effects of interventions and undertaken programs should be monitored, evaluated and documented. But, for all these activities financial resources are required.
- An awareness program for early detection of *skin cancers* should be created, which has to be embedded in the public awareness educational program about early signs of treatable cancers.
- An integrated health education approach should be created by including *uterine cancer* awareness in future joint programs between sexually transmitted infections and HIV/AIDS. Also, the step by step building up of a national program of vaccination against HPV should be considered.
- The NCCP should establish an active partnership with the national program of *vaccination against HBV* and provide a long term monitoring of changes in the rate of chronic carriers and the incidence of primary liver-cell carcinoma.
- Facts and data about a possible geographical distribution of "hot spot" industrial areas that may expose their employees and surrounding residents to cancer causing agents should be collected. Based on this information and education of all concerned actors, protective measures, including legislative measures, should be introduced.
- Increased risk of liver cirrhosis, primary liver-cell carcinoma and pancreas cancer, imposes their involvement in the multi-faceted Albanian public awareness program to prevent non-communicable diseases.

  Health education should cover all aspects related to cancer (in general and for some particular types of cancer), emphasizing the current preventive measures, provisions for early detection of disease and the advantages of early treatment.

4.3.4. Action Plan for Cancer Primary Prevention

The main activities to be implemented in order to prevent exposure to risk factors for cancer and decrease cancer incidence in the general population are briefly listed below:

- ***Recommended activities against smoking (estimated to be responsible for about 30% of cancers):***
  - Strengthening capacities of the health system to help anyone who wants to quit smoking. Training and provision of auxiliary materials for doctors and nurses of Primary Care Services (PCS) first and then to the staff of Hospital Service. Identifying and counseling patients about quitting smoking should be provided for free.
  - Activities in support of law enforcement to prevent passive smoking in public areas (awareness campaigns, administrative measures).
  - Public campaigns to prevent smoking, particularly among increasingly high risk groups, such as women and youngsters.
  - Campaigns in schools and workplaces.
  - Further efforts are needed to increase tobacco excise tax within the national tax policies.
  - Warnings on tobacco packages should be made more effective.
- ***Recommended activities against unbalanced nutrition and overweight (estimated to be responsible for about 30%-35% of cancers):***
  - Strengthening capacities of the health system for screening and treatment of faulty nutrition and overweight. Training and provision of auxiliary materials for doctors and nurses of PHC. Identifying and counseling patients regarding nutrition and overweight should be provided for free.
  - Awareness campaigns in the general population to promote the fruits and vegetable intake (at least 5 per day) and control of daily calories. Campaigns in schools and workplaces.
  - Advocacy activities with policy makers in order to introduce restrictions on the marketing of sweets, high fat foods, foods high in salt/preservatives and drinks for children.
- ***Recommended activities against sedentary lifestyle (estimated to be responsible for up to 5% of cancers):***
  - Strengthening capacities of the health system for screening and counseling on sedentary lifestyle. Training and provision of auxiliary materials for doctors and nurses of PHC. Identifying and counseling patients regarding physical activity should be provided for free.

- Awareness campaigns in the general population to promote physical activity. Campaigns in schools and workplaces.

- ***Recommended activities against exaggerated alcohol consumption (estimated to be responsible for about 3% of cancers):***
  - Strengthening capacities of the health system for screening and counseling on alcohol abuse. Training and provision of auxiliary materials for doctors and nurses of PHC. Identifying and counseling patients regarding alcohol abuse should be provided for free.
  - Activities in support of the law preventing alcohol consumption by children and youngsters (awareness campaigns, administrative measures).
  - Public campaigns to prevent alcohol abuse, particularly among young people. Campaigns in schools and workplaces.
  - Further efforts are needed to increase alcohol excise tax within the national tax policies.

- ***Recommended activities against viruses and other biological agents (estimated to be responsible for about 5%-10% of cancers):***
  - Activities within and outside the national immunization program to increase hepatitis B vaccine population coverage.
  - Safe sex promotional activities in the general population and in specific risk groups, including youngsters.

- ***Recommended activities against ionizing radiation and ultraviolet radiation (estimated to be responsible for up to 3%of cancers):***
  - Strengthening capacities of the health system for counseling on the risks of exposure to ultraviolet radiation and healthy practices related to sun exposure. Training and provision of auxiliary materials for doctors and nurses of PHC.
  - Public information through systematic campaigns on healthy practices related to sun exposure, particularly focusing on young women.
  - Raising awareness of the public and responsible authorities for construction standards on radon risks. Advocacy for appropriate construction standards related to protection from radon.
  - Awareness campaigns focusing on health professionals about the proper use of diagnostic and treatment technologies that emit radiation.
  - Inspection activities supporting the enforcement of law on radiation.

- ***Recommended activities against environmental pollution and occupational factors (estimated to be responsible for 2% and 5% of cancers, respectively):***
  - Review of standards, based on EU experience, regarding the monitoring of exposure and carcinogenic substances in the workplace.

Table 7. Action Plan for Cancer Primary Prevention in Albania

Factors	Activities	Responsibility	Financial resources (in 000 ALL)
Smoking	Strengthening capacities of the health system to help anyone who wants to quit smoking	MoH, IPH, PHD	1 000 /year
	Activities in support of law enforcement to preventing passive smoking in public areas (awareness campaigns, administrative measures)	MoH, IPH, MoI, PHD, Inter-ministerial Committee	1 000 /year
	Public campaigns to prevent smoking	MoH, IPH	4 000/year
	Further increase on tobacco excise tax	Inter-ministerial Committee	-
	Warnings on tobacco packages should be made more effective	Inter-ministerial Committee	-
Unbalanced nutrition and overweight	Strengthening capacities of the health system for screening and treatment of faulty nutrition and overweight	MoH, IPH, PHD	Included in the first raw
	Awareness campaigns in the general population to promote the fruits and vegetable intake (at least 5 per day) and control of daily calories	MoH, IPH	1 000 /year
	Advocacy activities with policy makers in order to introduce restrictions on the marketing of sweets high fat food, foods high in salt / preservatives and drinks for children	MoH, IPH, TUHC	500
Sedentary lifestyle	Strengthening capacities of the health system for screening and counseling on sedentary life	MoH, IPH, PHD	Included
	Awareness campaigns in the general population to promote physical activity	MoH, IPH	500 /year
Alcohol	Strengthening capacities of the health system for screening and counseling on alcohol abuse	MoH, IPH, PHD	Included
	Activities in support of the law preventing alcohol consumption by children and youngsters (awareness campaigns, administrative measures)	MoH, IPH, PHD	500 /year
	Public campaigns to prevent alcohol abuse, particularly in youngsters	MoH, IPH	500 /year
	Further efforts are needed to increase alcohol excise tax within the national tax policies	MoH, MoF	-
Viruses and other biological agents	Activities within and outside the national immunization program in order to hepatitis B vaccine population coverage	MoH, IPH, PHD	1 000 /year
	Safe sex promotional activities in the general population and in specific risk groups, including youngsters	MoH, IPH	1 000 /year
	Strengthening capacities of the health system for		

- Activities supporting inspections related to environmental pollution from hazardous gases and particles.
- Expansion of the air pollution monitoring system with adequate technology and coverage of the territory.
- Improving the monitoring system for arsenic in potable water.

4.4.

4.5. Early Detection of Cancer

4.5.1. Reducing the Rate of Late Stage Cancer

Selection of the types of cancer that will be involved in early detection programs should be based on the following criteria:

- High incidence
- The possibility of detection at an early stage (pre-clinical phase)
- High possibility of healing when detected in an early stage
- The possibility of detection with non-invasive methods (non-aggressive)
- Low cost of screening methods

From the 8 most common cancers in Albania, 4 of them can be detected early by methods that depend on the stage and the level of available resources: breast, uterine, skin and larynx/oropharynx cancer.

The current situation in Albania cannot support mass screening programs of breast and uterus: available resources are scarce, infrastructure is limited and most of the cancers are detected at advanced stages (III/IV). In this situation, reducing the late-stage rate by increasing the public awareness and training of the medical personnel can have a great impact on the disease and, therefore, emphasis should be placed on health education and sensibilization of the population and medical personnel.

Regarding breast cancer, women should acquire knowledge about self-examination of breast and about self-referral to a doctor if they detect any gland. On the other hand, mammography should be focused on case detection, so that screening should be used to confirm the presence of a gland detected by the woman (over 50 years of age) or by a specialist.

Regarding uterine cancer, women should be self-referred to the doctor if they observe warning signs of bleeding after sexual intercourse, bleeding after menopause and bad odors discharges.

Several pilot studies have already been carried out in Albania with the support of the Italian Government (Province of Puglia) for breast and uterine cancer screening. In the context of these pilot studies, free Pap-test was provided to women over 40 years old in Tirana.

As for the larynx cancer, self-referral to the family doctor should be made 1 to 2 weeks after hoarseness whereas regarding skin cancer the subjects should learn to recognize the warning signs of this disease.

4.5.2. Advantages of Cancer Early Detection

Early referral, diagnosis and prompt treatment of breast, uterus and larynx/oropharynx cancer are more important than any kind of therapy applied at a later stage of the disease.

In our country, there must be a quantitative increase in the number of examined women and this should be reflected in the early detection of breast and uterine cancer. Also, there must be an increase in the number of subjects examined for early detection (in pre-clinical phase) of colon and rectum cancer, skin, mouth cancer etc.

It should be mentioned that a concrete proposal for a national screening program for breast and uterine cancer is already in place. A detailed protocol for the screening program is established, taking into consideration issues such as selection of screening pilot areas, target groups, referral system, quality control etc. At the same time, an education and public sensibilization campaign was carried out to mobilize the target population to participate in the screening program. The development of the program is supported through training the staff abroad about the methodology of organizing cytopathology and mammography, as well as visits of foreign consultants in Albania who have offered their assistance since the beginning of the screening program including evaluation of this program as well.

Table 8 summarizes the strategy of early detection of cancer:

Table 8. General overview of the strategy of early detection of cancer

Aim	Strategy	Approach	Costs
Breast and uterine cancer in women, skin cancers in the general population	Public awareness campaign about early signs of cancer and cancer healing opportunities	• International consultancy • Development of informative materials and other approaches that are proven to be effective	• International consultant • Production of educational materials • Follow-up of the campaigns • Monitoring and evaluation
	Development of monitoring and evaluation indicators	Ensuring uniform TNM classification of tumors, targeted before and during the campaign	• Local expert • Use of cancer registry
		Test of knowledge, attitudes and practices before and after the campaign	Local expert
	Pilot studies for mammography screening and	International expertise with the support of the Italian Government	EU and Italian Government

	cytological screening for uterine cancer		
	Preparing the proposal for national screening of breast and uterine cancer	International consultancy	International partners

4.5.3. Action Plan for the Cancers of Reproductive Tract

The full action plan for the cancers of reproductive tract is presented below:

ACTION PLAN FOR THE CANCERS OF REPRODUCTIVE TRACT				
Targets - by 2015 • To maintain breast cancer standardized mortality rate at the level of year 2006 (22/100 000 – estimation) • To reduce by 5% the cervical cancer standardized mortality rate compared with 2006 rate (5.5/100 000 estimation) • To provide preventive and treatment services for reproductive tract cancers in the 12 prefectures of the country • To have in place the National Program for Control and Prevention of Cervical Cancer				
Interventions	**Indicators (to assess interventions)**	**Responsible persons**	**Timelines**	**Budget**
Objective 1: Establishment of a national program that aims to reduce the incidence and mortality of women who develop breast and cervical cancer.				
Coordination of prevention services of the reproductive tract cancers with other programs that provide health services to women, e.g. maternal health programs, family planning etc.	Number of cancer prevention services offered by reproductive health services	MoH IPH TUHC NPOs Donors	2010-2015	No cost
Educate the public about the importance of prevention of these cancers	Number of activities conducted to educate the public	MoH IPH Media NPOs Donors	2010-2015	48050000
Reaching women in	Number of screened	MoH	2010-2015	48050000

most difficult socioeconomic problematic areas to increase access to prevention and screening services of reproductive tract cancers	women for reproductive tract cancer Number of women in socioeconomic problematic areas with that attend cancer prevention and screening services	HII IPH TUHC NPOs Donors		
Education and training of professionals at all levels of care for cancer prevention including communication skills	Number of trained personnel Number of trainings conducted	MoH Continuous education center IPH TUHC NPOs Donors	2010-2015	3 700 000
Screening, case management, quality assurance of screening tests for breast and cervical cancers in primary health care and hospital services	Screening, management, quality assurance system	MoH Continuous education center IPH TUHC NPOs Donors	2010-2015	1 100 000 000
Establishing a surveillance system for capturing, monitoring, and evaluation of cancers	Surveillance system established (in place)	MoH Continuous education center IPH TUHC NPOs Donors	2010-2015	3 800 000
Establishment of coalition and partnership between institutions that provide public and private prevention services, cancer treatment, donors, national and international partners and civil society	Established partnerships	MoH Continuous education center IPH TUHC NPOs Donors	2010-2015	No cost
Review and removal of legal barriers that	Number of preventive and screening services	MoH		580 000

prevent the expansion of screening an preventive services linked to these two cancers among young girls and women of reproductive age	Percentage of screened young girls and women	HII TUHC IPH Donors		
Total				**1 264 389 000**
Objective2: Improving access and quality of preventive, screening and treatment services of the reproductive tract cancers.				
Developing and implementing protocols and clinical standards for diagnosis and treatment of reproductive tract cancers	Completed protocols	MoH Faculty of Medicine IPH TUHC Donors	2010-2013	520 000
Improvement/ expansion of cytological services for screening of reproductive tract cancers	Number of cytological services for screening of reproductive tracts cancers	MoH Faculty of Medicine IPH TUHC Donors	2010-2015	13 000 000
Provision of equipment and tools for PHC institutions for screening of reproductive tract cancers (mammography, pap test)	Number of equipment and tools offered	MoH HII NPOs Donors	2010-2015	1537 000 000
Total				**1 628 046 000**
Objective 3: Education and health promotion on the reproductive tract cancers, particularly breast and cervical cancer, about prevention, diagnosis, treatment, psychological support and rehabilitation in order to increase awareness to seek preventive health care.				
Education, information, counseling and health promotion to encourage women to overcome barriers to screening (including fear of cancer diagnosis, lack of access to health screening services, financial and	Number of education, information, counseling and health promotion activities that encourage women to overcome barriers to screening	MoH IPH TUHC Donors	2010-2015	3100000

social barriers in the family etc.) and to understand the benefits and advantages of early detection of these two cancers				
Increase public awareness about reproductive tract cancers as a priority public health problem	Number of promotional activities to increase public awareness about cancers	MoH IPH TUHC Media Donors	2010-2015	1210000
Creation of support services that meet the unique needs of women affected by breast and cervical cancer	Number of support services to women affected by breast and cervical cancer	MoH IPH HII TUHC Donors	2010-2015	103 680 000
Education and health promotion provided by PHC services about reproductive system organs and related diseases	Number of promotional activities conducted by PHC services	MoH IPH TUHC NPOs Donors		25 500 000
Building a support network/community for women with breast and cervical cancer	Number of communities and groups that support women	MoH IPH TUHC NPOs Donors	2010-2015	900 000
Total				**27 720 000**
Objective 4: Development of a health infrastructure and systems of reference for screening, diagnosis, and treatment of the reproductive tract cancers starting with the primary health care level and other levels of health care later on.				
Building national guidelines and standards for screening, diagnosing and treatment of reproductive tract cancers	Guidelines and standards completed	MoH IPH TUHC NPOs Donors	2010-2015	1 210 000
Determination of	Number of services	MoH	2010-2015	710 000

screening services to be provided in the three levels of care: primary, secondary and tertiary, which should be accessible to all women in need	that meet performance and quality criteria for screening and follow up of reproductive tract cancers	IPH Standards NC TUHC NPOs Donors		
Ensuring the quality of health services related to screening and follow up of reproductive tract cancers	Determined screening services	MoH IPH Standards NC TUHC NPOs Donors	2010-2015	No cost* related to the above objective
Determining ways to finance the required expenditures for services that provide screening, diagnosis and treatment for reproductive tract cancers	Ways of financing the specified costs	MoH IPH HII TUHC NPOs Donors	2010-2015	710000
Total				**2 761 500**
Objective 5: Improving the knowledge, skills and practices of health personnel at all levels of care regarding reproductive health cancers in terms of prevention, screening, diagnosis, treatment, rehabilitation, improved patient quality of life, psychosocial support and palliative care.				
Training of a vast network of health personnel about their role in early detection and diagnosis of breast and cervical cancer, starting with the PHC level – family physicians, nurses, radiologists, laboratory assistants and cytologists.	Number of conducted trainings Number of trained personnel	MoH IPH Continuous Education Center TUHC NPOs Donors	2010-2015	3 500 000
Training of obstetricians – gynecologists about taking a Pap smear sample	Number of conducted trainings Number of trained personnel	MoH IPH Continuous Education Center TUHC	2010-2015	3 540 000

		NPOs Donors		
Total cost				**7 392 000**
Objective 6: Continuous collection, monitoring and analysis of information from public and private health services about the number of new cases, treated cases, deaths from breast and cervical cancer.				
Establishing a regular surveillance system to assess the actual magnitude and gravity of these cancers, their potential future evolution, to provide information on prevalence and risk factors trends, to monitor the effects of prevention, early detection/screening, treatment and palliative care	Established surveillance systems	MoH IPH TUHC NPOs Donors	2010-2015	1500000
Establishing a local and regional monitoring system for data collection through the national cancer registry	The defined system	MoH IPH TUHC NPOs Donors	2010-2015	500 000
Setting national standards and formats to ensure timely and quality data collection in the cancer registry	Number of established standards	MoH IPH NPOs Donors	2010-2013	200000
Total cost				**2 310 000**
Objective 7: To promote, support and develop cooperation between different actors including policy makers, health care personnel, voluntary groups, communities, media and business groups in order to increase their awareness about the reproductive tract cancers.				
Promotional activities in media to increase awareness of all women about screening practices; provision of screening in hard-to-reach population groups (women in rural areas,	Number of conducted promotional activities	MoH IPH TUHC Media NPOs	2010-2015	1 250 000

or in socioeconomic difficulties)		Donors		
Organization of training conferences, scientific meetings with specific interest groups (media, business groups, NPOs, etc.) regarding breast and cervical cancer issues	Number of conducted conferences and scientific meetings	MoH IPH TUHC Media NPOs Donors	2010-2015	10 000 000
Total cost				**11 812 500**
TOTAL CANCERS				**2,932,618,500**

4.6. Cancer Diagnosis and Therapy

4.6.1. Diagnostic Services and Treatment Protocol

Early detection and treatment remains the most promising strategy for achieving the targeted objectives to reduce cancer mortality.

The oncological service in Albania faces problems in meeting the needs due to inadequate technology and insufficient training of medical personnel. These needs are expected to increase as the number of cancer cases in our country grows progressively.

Improved diagnostic and treatment services based on scientific protocols is essential for the effective diagnosis of cancer, possibly at an early stage, as well as in determining the stage and appropriate treatment of cancer (including radiotherapy). It includes both the introduction of appropriate methods and technology (equipment), as well as the appropriate and continuing training of specialists (physicians, technicians, etc.) to get the best out of technology.

Emphasis should be placed to the triage of patients into 3 groups: (i) curable cases (by using standard protocols of therapy, where making available of sufficient quantities of medicines for this group can be a priority); (ii) non-curable cases (soothing care only, avoiding the non-effective expensive therapies) and (iii) other cases (where the usual therapies should not be implemented as there is no proven curative effect and it is often costly and with a high risk of morbidity, but palliative care can be provided).

Diagnosed patients should be checked thereafter by a multi-disciplinary team of trained specialists, including palliative care professionals. Doctors must learn to "break the bad news", to start as soon as possible to communicate patients their diagnosis, thereby telling the truth (currently, our physicians feel uncomfortable with this and it is culturally unacceptable for them) as well as applying effective principles of pain relief. For the physicians, particularly family doctors and the oncologists, it is necessary to achieve a good university education and to learn from patients.

Building of new capacities in radiotherapy should be linked with the research on early detection/diagnosis of curable cancers. A list of essential cytostatic drugs for cancer should be established, which must be rigorously implemented and also reviewed and improved over time. Sophisticated ways of treatment without proven results or ambiguous ones should be carefully reviewed by a group of multi-disciplinary and collaborative physicians, because they can lead to loss of resources and lack of funds, and therefore should be avoided.

National efforts to improve therapy must necessarily relate to early detection and referral of patients, reduction of the rate of cancers diagnosed at later stages to increase healing opportunities, step by step improvement of radiotherapy and palliative care, thus paying special attention to diagnosis setting and to patients in incurable stages of the disease as well.

4.6.2. Current Resources in the Fight against Cancer

Based on the last decade data (obtained from the Central Registry of "Mother Teresa" University Hospital Center in Tirana), there are about 4000-4500 new cases of cancer per year. Currently, the available resources to fight cancer in our country include the following:

- ***Institutions:*** The National Oncology Service is part of "Mother Teresa" Hospital and the only specialized public institution in the country, with a multi-disciplinary team which deals with cancer diagnosis and treatment. This service has 111 beds, 31 physicians and consists of surgery pavilion (where surgery of breast, colon and rectum, soft tissues and bones, testicles, skin and melanoma is performed), radiotherapy, chemotherapy, pathological anatomy and diagnostic radiology pavilions. University Clinics within "Mother Teresa" Hospital are: General Surgery, Urology, Surgery of the Thorax, Otorhinolaryngology, Maxillofacial Surgery, and Neurosurgery. These services provide primarily surgical treatment for tumors of the stomach, urinary tract, lung, head, neck and brain.
    - *Regional hospitals:* generally are not equipped in a modern way and have less qualified medical personnel to diagnose and treat cancer.
    - *Primary Health Care Centers and Specialties' Policlinics:* in Tirana and other districts across the country there are such centers for patients who initially go there for cancer diagnosis. These centers also include other sections for ambulatory patients diagnosed and treated for cancer (Oncology centers). These services are available in the main districts of the country (Tirana, Durres, Shkoder, Fier, Vlore, Lezhe, Elbasan, Kruje, Kavaja and Korca).
    - *Private services:* there is only one private complex hospital center in Tirana, Hygeia hospital, which provides a high quality multi-disciplinary complex service in oncology including radiotherapy with 2 linear accelerators, but every service is provided against direct payment from the patient. The American hospital also provides modern diagnostic service, as well as surgery and chemotherapy treatment, also against direct payments from the patients.
- ***Medicaments:*** count for a very large part of our health care system expenses. Moreover, currently it is still unclear whether their use pays back the desired healing effects, since most of patients are diagnosed at an advanced stage of disease. Therefore, clear policies should be compiled for the use of these drugs and which of these should be used by choosing, whenever possible, the most cost-effective ones and giving priority to drugs with proven curative effects. The cost of cytostatic drugs for cancer treatment currently represents one of the biggest costs to the government, about 4 million USD, and results of this major expenditure are not clear. Cancer drugs, according to priority can be divided into the following groups:
    - Curable cancers and those cancers where the cost-benefit rate clearly favors the treatment with anti-tumor drugs and that can be managed properly with basic treatment

regimen, based on relatively few drugs, which can be found in the market at relatively low cost as generic medicines. The widespread availability of these drugs should be the number one priority of health policy.

- The second group of drugs may have some advantages in certain clinical situations.
- Based on current evidence, the third group of drugs (new drugs) is considered as not essential to real effectiveness in cancer care. Numerous new drugs are "aggressively" introduced into the market, but most of them are expensive and of limited benefit. To resist the pressure to "the latest drugs", there should be compiled clear policies which would initially guarantee the existence of essential approved drugs.

4.6.3. Proper Development of Therapy

Drugs represent a major financial burden for our health system. Moreover, it is not certain whether their use achieves effective curative effects due to the advanced stage of diagnosis in most patients. Therefore, there should be compiled clear policies for the use of these drugs with absolute priority the use of cost-effective generic drugs, giving priority to curative proven drugs. To resist the pressure to "the latest drugs" (very expensive) aggressively advertised by the pharmaceutical industry and international conferences, and also demanded by Albanian citizens who are treated abroad and then return home to continue treatment, there should be compiled clear policies to not use these drugs until essential approved drugs are available. Meanwhile, palliative care should be provided immediately at the moment of establishing the diagnosis.

4.6.4. Recommendations

- Rapid development of human resources with adequate professionals.
- Improvement of technology for pathology (anatomy and pathology), radiology and laboratory diagnostics, as well as radiotherapy.
- Standardization of therapy through the adaption and dissemination of selected protocols (for diagnosis and therapy) for highest incidence cancers in the country.
- Provide opportunities for physicians to use the main diagnostic and curative manuals issued by the most prestigious regional anti-cancer institutions, and Balkan, Mediterranean, European and American Oncology Associations.
- Establishment of clear methods of referral, focal points and potential triage.
- Development of indicators and systems for measuring the impact of improved cancer care.
- Development of a clear cost-effective drug policy and the provision of selected drugs for all patients and throughout the year.

The recommended action plan for the treatment of cancers in our country is presented in detail below:

Goal	Strategy	Approach	Costs	Timelines
Development of human resources	Update the post graduate curricula. Gradual creating of positions for appropriate men power not only in Tirana but also in other districts, and continuous training.	Developing special curricula for radiotherapy and medical oncology for 5 years, and laboratory technician in radiotherapy Increase the number of trainees and people trained in the following positions: radiotherapy technicians, medical oncologist, medical physicist, palliative care physicians, anatomopathologists. Radiotherapy technicians, nurses for CT, palliative care nurses, social workers. Study tours and training in various diagnostic and treatment methods.	No cost Involved in projects with IAEA and Albanian Government Search for sponsors to cover costs	2011-13 2011-15
Equipment	TUHC- Nat. Ca. Inst. - 2Linac+2 Bunkere -1 CT Sim Big Bore -1 IMR -2 Second 3 D- T.P.S. -Improvement of techn. per sect, Pat. Anat. Introduction of Rec.Horm. and IHC Establishment of two competent centers for cancer treatment in two regional hospitals, eventually in Durres and Shkodra. They include: Medical Onc. Surgery, Radiotherapy, Pat. Anat., Palliation	Projects with IAEA and Albanian Government, and other potential supporters. Projects with IAEA and Albanian Government, and other potential supporters.	4.5 million Euro 500.000 Euro 1.5million Euro 230.000 Euro 200.000 Euro 100.000 Euro About 10 million Euro	2012 2012 2012 2011 2011 2011 2013 - 2015
Availability of drugs	Establishment of an essential drugs list with the use of generic drugs whenever possible.	Involvement in the national list of drugs	7 million Euro	2012
Careful policy towards aggressive	Providing funds for national quotas of essential drugs which	Providing accurate evidence for the Ministry of Health regarding cancer morbidity and mortality	Having a clear policy for drugs, there will be	The essential list will be regularly

marketing of introducing new less effective drugs, based on government funds for health sector	are available during the entire year. After compiling a policy of cost-effective drugs, try to ensure the availability of selected drugs.	(through the National Cancer Registry)	considerable savings.	updated in order to include new curative drugs.
Standardized therapy	Adaptation of the treatment protocols (diagnosis and therapy) for most of the common cancers. Publication of main manuals for clinical oncology and pathological stages of tumors in Albanian language.	Translation into Albanian language and dissemination of guidelines. National Cancer Institute.	Translation, adaptation and printing.	Since 2010 and ongoing update.
Improvement of care	Quality improvement. Periodic monitoring and evaluation.	Compiling of indicators and systems for measuring impact of improved cancer care.	To be evaluated	From 2010 and onwards
Patients who show up following early detection campaigns	Establishing clear referral methods (call center) and focal points for referring general practitioners and potential triage.	Identification of competent centers across the country where patients should be referred and dissemination of the list to general practitioners.	To be evaluated	From 2010 and onwards

4.7. Palliative Care

4.7.1. General Considerations

Palliative care, which includes pain control and care for terminal cases, should be given high priority because the vast majority of cancer patients are incurable. This type of care should be included in all cancer activities and levels of cancer control, from the moment of diagnosis until provision of home care. Finally, through the institutionalization of palliative care in the cancer control program, it must spread and become part of the National Health Plan, which covers all persons in need, such as elderlies on the verge of death, HIV/AIDS patients and persons with cardiovascular diseases.

Attention should be focused on the following components:

- Education, which embeds the training of trainers, training of physicians regarding patient care and the inclusion of palliative care and Pain Relief in undergraduate curricula for family physicians, nurses and clinical pharmacologists.
- Policies/regulations related to drugs, which serve to meet the increasing quota of *International Narcotics Control Board (INCB)*, for fast and slow release generic Morphine which should be available in the health care system and simultaneously find ways to enable the facilitation of providing prescriptions in order that all family physicians to be able to prescribe such drugs.
- Palliative care should be integrated in all levels of the health care system, including home care.

It is estimated that cancer mortality in our country is about 3000 deaths among 4000-4500 new cases detected each year. This means that over 75-80% of cases are presented in a very advanced stage of the disease where chances of eventual recovery are scarce. Public hospitals lack the necessary structures related to palliative care and 95% of patients choose to die at home. Consequently, the urgent improvement of the palliative care situation must be addressed and emphasized as a major problem for the public health care structures.

In conclusion, priority should be given to improving the quality of life for terminal cancer patients, relief of pain and other symptoms, and psychological, social and spiritual problems associated with the disease and its treatment.

4.7.2. Importance of Palliative Care

Palliative care can be considered currently as one of the oldest forms of medical care. For centuries, until the discovery of antibiotics, medicine aimed to alleviate the suffering and ease pain with empirical methods. Starting from the twentieth century, medicine has been dominated by the pharmacological and technological success, focusing only on strictly curative and medical procedures. The price of such achievements was, unfortunately, the reality of still incurable diseases by neglecting complex needs of incurable patients on the verge of death. As a response to this reality, the 1960s marked the birth of "Palliative Care" and the gradual and official recognition of it worldwide as a new medical discipline.

Palliative care emphasizes the psycho-emotional, spiritual and social aspects of human beings, which are just as important as physical aspects, thus offering a comprehensive treatment model.

According to the World Health Organization, *"Palliative Care represents an active and total care to patients, whose disease no longer responds to curative treatment"*.

Control of pain, other symptoms and psychological, social and spiritual problems, are of paramount importance. The goal of palliative care is to achieve better quality of life for the patients and their family members.

Initially, palliative care aimed (not occasionally) to support cancer patients in advanced and terminal stages of their disease, since cancer is one of the main causes of death worldwide. Palliative care has changed the perception of the disease making medical professionals accept their responsibilities for transforming the last part of a patient's life into a time of comfort and dignity.

Due to the late and slow start and evolution without symptoms, cancer most often is detected only in advanced stages. In developing countries, most cases are diagnosed at later stages of the disease (III and IV), when chances of cure and survival are limited and therefore palliative care and pain control are the only realistic treatment options.

Later, palliative care became accessible to other types of chronic pathologies with uncontrolled symptoms in their terminal stages, such as organ insufficiencies, some neurological conditions, AIDS, etc. Pediatrics is a particular challenge for palliative care, not only for the wide range of diseases, but also the special methods of treatment and communication employed. Beneficiaries are the children or adolescents whose disease is diagnosed during childhood, such as: cancer, congenital diseases, neuromuscular progressive dystrophy, organ insufficiencies, cystic fibrosis, spina bifida, AIDS and other life threatening conditions with limited prognosis.

As the disease progresses towards death, attention should be emphasized to reduce patient's suffering. Terminal patients would need similar care, or even stronger than curative efforts, and when curative treatments are no longer appropriate, medical professionals and family members should make all efforts to ease physical, emotional and spiritual suffering of the patient.

Palliative care is a complex, active and intensive care, promoting health quality of terminal patients and their family members. When curative treatments no longer bring improvements, palliative care becomes essential for the patient in order for him/her to die comfortably, with dignity, without pain or other distressing symptoms. Therefore, in advanced stages of the disease, care is focused on controlling pain and symptoms, and supporting family members that are losing their beloved relative.

Palliative care alleviates pain, improves the quality of life and eases death. Pain is one of the most common symptoms. Socio-economic and spiritual existential suffering of the human beings and terminal patients who are dying and their family members can be reduced by palliative care. There is a scientifically valid and simple method (Palliation) that costs little and that can be held in community level so that everything is covered. *Palliative care is a human right.* It would be unethical to not providing palliative care to those who need it, when affordable effective methods are available.

Nothing would improve more quickly and dramatically the life of patients suffering from cancer, chronic diseases, terminally ill children and elderly than making use of a rational public health approach and implementation of the great knowledge available today about pain control and palliative care. Death is a natural part of life and cultural, socio-economic and spiritual traditions as well as societal support will be just as important as medical tradition to quality of life and death.

What is needed is the political will to act, educate and train health professionals as well as necessary drugs, affordable and easily available. The system of cultural, spiritual and socio-economic support should be promoted in order to avoid low quality death by institutionalizing and not over-treating the patient.

4.7.3. Palliative Care in Albania

Palliative care and control for soothing cancer pain are amongst the still unresolved issues in Albania, a situation similar to that of public health systems in other Eastern European countries.

Patients' access to palliative care services and quality of life in advanced and terminal stages of incurable diseases is less than convenient. Despite international experience in modern and cost-effective methods of treatment, health authorities pay little attention to this category of patients. WHO recommends that governments and health authorities promote new methods of pain control and palliative care principles in public health systems, to ensure a better quality of life for the terminal cancer patients.

Palliative care in Albania is relatively new. The first palliative care service for terminal cancer patients was established in 1993 by *Ryder Albania* Association. The Albanian Association of Palliative Care was established in 2002 as a consortium to develop palliative care in the country. Currently there are a limited number of associations and only one public service of palliative care that provide services to terminal cancer patients across the country. But these services cannot meet the high demand for palliative care. They can only cover 34% of needs which means that 66% of patients do not benefit from palliative care services. Meanwhile, there is no pain control unit in the public hospitals, or inpatient units for terminal cancer patients. It should be emphasized that palliative care in our country is not yet a distinct specialty or sub-specialty in the medical field.

Generally, palliative care services are sporadic and do receive financial support from the authorities and public health system. Also, it should be mentioned that palliative care is not integrated into the public health care system.

The objective of our country is to establish palliative care for all those in need, starting with cancer patients. *In general, basic measures of WHO regarding education and training policies, drugs' availability and palliative care institutionalization should be undertaken in Albania.*

In Albania there are about 17.800 deaths annually. It is estimated that about 60% of deaths in Albania (over 10.000 deaths) would need palliative care and pain soothing services by provision of an opioid analgesic such as morphine. With at least two family members taking care of their terminally ill relative, there would be at least 30.000 individuals annually who would have their quality of life much improved if palliative care support is offered. Most people, about 95%, die at home and this is preferable by both patients and their family members. It can be concluded that, the way of death is still not institutionalized in Albania and should be avoided by strengthening of in-house services, better care in the future, as well as strengthening cultural and medical services. WHO recommends including pain soothing and palliative care services in existing institutions of health care, in PHC services. Self-standing institutions of care such as hospitals could be examples of what it can be done, but would not be sufficient to meet all the needs.

Based on the age structure in Albania it is estimated that there are over 4.000 new cancer cases each year. With the ageing of the young generation and population ageing tendency, it is expected that cancer incidence will increase significantly in the future. A high number, over 2/3 of patients, are diagnosed in an advanced and incurable stage of the disease. Therefore, for the majority of those suffering from cancer, pain soothing and palliative care is the more realist and appropriate therapy to be provided. Based on existing asylum data it is calculated that there

should be around 500 people, mainly cancer patients, who receive some form of palliative care. Those most in need of palliative care services are amongst elderlies on the verge of death. On the other hand, the prevalence rate of HIV/AIDS and its related deaths is not yet well known.

4.7.4. Current Resources for Palliative Care

- ***Structures:*** the main structures involved in palliative care in our country are as follows:
    - *Oncology Service in TUHC*, which currently includes a psychologist and a social worker. But terminal patients are not frequently hospitalized in public hospitals, as they prefer to day at home.
    - *Albanian Oncology Association,* is a Not-for-Profit Organization (NPO) active in:

- Public and professional education (organization of national and international scientific activities), and publication of educative materials intended for the general public (books, leaflets, posters, etc.);
- Prevention and early detection (nationwide activities against tobacco), and activities for early detection of breast cancers, skin and gynecological cancers.

- *Ryder Albania*, a NPO, subsidiary of a British charitable foundation, established in 1993, consisting of a multi-disciplinary team of physicians, nurses, social workers and psychologists covering the area of Tirana and Durres, and assisting about 400 patient per year. This NPO has made use of a hospital ("*hospice*") with 10 beds serving as a center of pain control, psychological and physical support for patient and family members, and also as a training center for medical personnel of primary health care, medical students and social workers. In Tirana, this association has 3 full-time and 2 part-time physicians/oncologists providing palliative care at home. The association provides care in Durres as well, with a multi-disciplinary staff.
- *OSH (Oncologic Service at Home)*, public service with 6 physicians and 6 nurses. It covers the area of Tirana. About 500 patients are assisted each year.
- *The Team of Merry Potter*, a NPO composed of 2 physicians, 5 nurses, 1 social worker and 1 pharmacist. This group covers the area of Korca, and about 180 patients are assisted each year.
- *Center of Palliative Care Elbasan*, a NPO providing palliative and soothing care for cancer patients.
- *Center of Palliative Care Lezha*, a NPO providing palliative and soothing care for cancer patients.
- *Medical Center for Prevention Oncology*, involved particularly in cancer education and early detection activities.
- *League against Tumors,* a very active association in prevention and early detection activities.

As it can be noticed from the wide range of NPOs presented above, in the absence of adequate public structures in our country, many non-governmental organizations have been dealing with professional education and training, prevention and end of life care for terminal patients. In the future, more partnerships should be established with other organizations not involved in the fight against cancer as well as with movements that have common goals and may be potential sources of cancer control activities. They may be organizations devoted to other diseases (such as associations of patients with heart and lung

diseases, HIV/AIDS patients, etc.), groups of health professionals (physicians, public health workers, nurses), and environmental, women, consumer organizations etc.

In conclusion, in Albania the majority of the 12 prefectures does not have or do not provide any palliative care service. In total there are 6 services, 1 public and 5 associations providing palliative care.

- ***Availability of medicaments (Opioids):*** total quota of the *International Narcotics Control Board (INCB)* for opioids is 4 kg., a part of which is used for cancer patients, whereas the major part is used for other activities, such as anesthesia, surgery, intensive care, cardiology, etc. The *Ryder Albania* team in Tirana uses 280 g. of opioids to cover pain relief needs of 200 patients (assisted each year). Among approximately 3000 thousand cancer deaths in Albania, in about 70% of them pain is the main symptom. Based on this information, the INCB quota must indispensably increase in the future. Currently, in pharmacies opioids are reimbursed by the Health Insurance Institute (HII) as Morphine-Sulfate tablets with slow release (10 mg.), Morphine-Sulfate with fast release (10 mg.), and Morphine HCL 10 mg. - 1 ml. (ampule). Non-cost effective Meperidine, Codeine 15 mg., Contramal (Tramadol) and Durogesic (Fentanyl) are present in the pharmaceutical market, but they are still not reimbursable.

  The total INCB imported quota is 4 kg. in recent years. This amount is totally insufficient to meet the needs of all those necessitating pain relief. Slow release morphine such as 10 mg. MST tablet, will cost about 35$ for 60 tablets, meaning more than 0.5$ per tablet. Instant release Morphine is not available. An injectable Morphine ampule 1%/1 ml costs 1 dollar. The cost of drugs is important for a cost-effective policy on essential generic drugs.

Palliative Care Education: includes: (i) two lectures of 1.5 hours in the fifth year of the Faculty of Medicine (General Medicine branch); (ii) two months of lectures and practices included in the main curricula of Oncology post-graduate specialization, and; (iii) some lectures at the Faculty of Nursing.

There are a few physicians formally qualified in palliative care in Albania. However, oncologists have started to provide palliative care, by integrating it with routine cancer care and some hospital physicians have attended course abroad. During recent years several training courses have been organized. Guidelines and manuals have been translated into Albanian language and some educative materials have been prepared. Palliative Care is included in the 3-year course of Oncology. However, there are no specific curricula that include pain relief and palliative care.

4.7.5. Recommendations for Palliative Care

Palliative Care aims to soothe pain and improve quality of life of terminal patients and provide death with dignity. World Health Organization aims to orientate all member states toward rational public health approaches that include palliative care national programs. Council of Europe has advised the Health Ministries on the importance and necessity of palliative care. Pain relief and palliative care represent public health problems not yet addressed in Albania. Two-thirds of cancer patient are incurable and will need palliative care starting from the moment of diagnosis.

Nowadays, there exist many affordable and scientifically valid treatments to control pain and resolve a number of issues that cause suffering not only to cancer patients, but also in terminal patients, elderly and children regardless of their diagnosis, such as e.g. cardiovascular diseases, vascular accidents, traffic accidents and AIDS. It is unethical to not provide palliative care to improve quality of life for people living with advanced stage diseases and their family members.

Some of the main recommendations for palliative care in our country are presented below:

- All persons needing pain relief and palliative care should be provided with these services.
- It would be unethical if palliative care would be provided only to cancer patients.
- Palliative care should be addressed by establishing a Palliative Care National Program (PCNP), included in the Cancer Control National Program (CCNP), as one of the 4 key priorities for a comprehensive cancer program.
- Institutionalization of palliative care should start with cancer, by creating a considerable level of expertise, experience and knowledge to support the inclusion of palliative care in all levels of health care in our country.
- Integration of palliative care at all levels of health care system.
- Facilitating and making possible the availability of immediate and slow release generic Morphine and simultaneously to establish a rational prescriptions policy.
- Training and education about palliative care of physicians, nurses, pharmacists, psychologists and social workers at all levels.
- Inclusion of pain relief and palliative care in undergraduate curricula of Medical and Nursing students, and for clinical pharmacists and social workers.
- Establishment of the sub-specialty of palliative care (Palliative Medicine).
- The system of continuing education of policy makers for drug regulators, medical professionals, social workers, volunteers, patients and their family members (training, seminars, TV programs and publications).

- Institutionalization of palliative care at the National Cancer Center (Oncology Service in TUHC), which serves as a reference center for quality, teaching and training.
- Strengthening community efforts in all prefectures for the institutionalization of palliative care.
- A twinning process with Catalonia should be considered, being a WHO demonstration project since 1989 that has guided continuing care reaching high coverage of many diseases.
- Future clinician leaders of palliative care should have access to training scholarships in most excellent international training centers. From the cultural, geographical and linguistic perspective, Italy is closer to Albania and it also has a center of Palliative Care. Therefore, training in Italy and Italian funding for that should be explored. Some Albanian physicians have been previously trained in Poznan, Poland, and this represents another cost-effective alternative as well.
- A 3-week training course for about 24 physicians in the best international faculties should occur as soon as possible. The course should be coordinated with the availability of immediate and slow release generic Morphine.
- Funding: beginning of funds allocation from government for palliative care at the moment that it will become part of the national health plan. Funds must be allocated to the Center of Reference in the NCC, the new services of palliative care, and home care teams.
- Research and application for international financial donations, agreed according to pre-determined priorities and projects.

5. THE NATIONAL CANCER REGISTRY

5.1. Status of Cancer Registry

5.1.1. Establishment of the Institution and Service

The Cancer Registry, which will archive the information on cancer cases, specific tumors or pre-cancerous diseases in Albania, will be based and operate in the premises of TUHC (Oncologic Institute) with the support of IPH. This information will form the basis for planning, prioritizing and monitoring of cancer control activities and will supply important data for the development of prevention policies and measures.

The role of the Cancer Registry is to gather, compare, analyze and interpret cancer incidence, mortality and survival data. The Cancer Registry has to be in full accordance with other cancer registries elsewhere in the world contributing to unveiling the causes of cancer through field studies.

In addition, attention is paid to cancer prevention activities, early detection and *screening* programs as well as chemotherapy prevention.

5.1.2. Cancer Registry Data

The gathered information is classified into 4 categories: demographic data, tumor identification, treatment, and vital status:

- ***Demographic data*** consist of personal information about the patient such as name, age, sex, ethnic group and birth place. This very information identifies the cancer patient. The lack of identification and control could lead to data duplication and inappropriate analyses.
- The cancer data are retrieved as soon as ***patient diagnosis is settled***. This includes data on primary location and malignity, cell type and spread of the disease.
- Data are collected after the patient has been diagnosed with cancer as well. This information relates to ***cancer treatment*** i.e. surgery, radiotherapy, chemotherapy, hormone-therapy, immunotherapy, etc.
- More data are collected even though the patient completes the treatment, i.e. ***discharged from hospital***. The status of the patient is monitored through patient follow-up surveillance which generates data on survival.

5.2. Reporting

5.2.1. Reporting from Health Centers

- The Ministry of Health in collaboration with IPH will demand the information on cancer cases, other specific tumors and pre-cancerous diseases, as well as additional specific information on reported cases and/or control population to be reported as a necessary means toward recognition, prevention, treatment and control of neoplasms.
- The Cancer Registry is authorized to adopt the legislation in force. It has to describe the information pathways, regulations and specific rules intended for public and private health professionals, and other entities which are required by law to report information on neoplasms.
- The activity regarding the reporting form is carried out by the health service in accordance with the legislation and is coded by the Cancer Registry staff.
    - The Cancer Registry will collaborate even with those health services which do not have the necessary capacities to report cancer cases according to agreed rules.
    - If the Cancer Registry audit group control detects that a health center continues to not report even 30 days after the control, then such center shall be penalized according to law.
- HII and third parties that pay health care for the residents of the country must report cancer cases based on selection criteria according to the specified reporting format.
    - A health center that provides health care but that does not report must be penalized with a fine under the law for every unreported case.
    - All the collected fines will be entitled to the Cancer Registry.
- The information gathered will be electronically available 6 months after the accuracy of information is verified. Aggregated data, by age, sex, and cancer type will be made public 6 months after the verification. The Cancer Registry will not make public any information which is relevant in any way to the identity of a particular person.

5.2.2. Reliability of Reporting

All the data will be used solely by the Cancer Registry and the relevant health agencies and yet no information will be made public about the identity of the particular reported person. Such reports will not be subject to public surveillance.

5.2.3. Cancer Reporting, General Requirements

- Cancer cases, other specified tumors and cases with pre-cancerous diseases must be reported to the Cancer Registry.
- All reporting cases should be sent within 6 months of the date of diagnosis or 3 months after the date of discharge from the health center.
- *Follow*-up reports will be sent for every cancer case, each year in order to confirm the vital status. These *follow-up* reports will be required until the patient's death.

5.2.4. Health Centers that Report

a. Administrative offices of each health center shall report to the Cancer Registry every case with cancer or specific tumors, and pre-cancerous diseases when diagnosed, or when the patient is contacted for the first time or treated for any reason at this health center. For every diagnosed primary cancer an individual reporting form shall be reported.

b. All the reporting forms are filled in by the health center when it diagnoses or treats 100 or more cancer cases per year. The reporting forms are coded by persons working in the Cancer Registry.

c. The information that will be reported shall be:
    - submitted in accordance with unified standards of the Cancer Registry, and;
    - including the information identifying the patient, disease history, cancer treatment, and an annual report to confirm the patient's vital status.

d. Health centers that lack internal capacities to report cases as required by points (b) and (c) will be contracted by the Cancer Registry to enable the case reporting (active data collection).

e. The Cancer Registry will establish a fee for the services provided in health centers as stated in point (d).

f. Health centers that do not comply with the reporting standards will be penalized with a fine for every unreported case with cancer, specific tumors or pre-cancerous diseases.

g. Health centers that do not send to the Cancer Registry via mail the cases with cancer, specific tumors or pre-cancerous diseases will be penalized with a fine.

5.2.5. The Physician, the Dentist and Other Health Professionals who Report

- Any physician, dentist, or health professional who diagnoses or provides treatment for cancer patients must report to the Cancer Registry the initial diagnosis of each case with cancer, specific tumors and pre-cancerous diseases not initially referred to or diagnosed in these health centers. An individual report will also be reported for each case.
- The information that will be reported shall be:
    - submitted to the Cancer Registry specified and unique and,
    - including information identifying the patient, disease and cancer treatment.
- The physician, dentist, or healthcare worker can send the reports to the Cancer Registry.
- The physician, dentist, or healthcare worker who does not report is subject to fine penalty for each unreported case.

5.2.6. Reporting of Clinical Laboratories

- The director of any clinical laboratory shall report to the Cancer Registry.
- The results of tissue samples and/or hematological examinations which are positive for cancer or specific tumors and pre-cancerous diseases that have not been previously reported by the laboratory.
- The information that will be reported shall be:
    - submitted in a specified format to the Cancer Registry and,
    - including all information identifying the patient such as name, address, and/or telephone number of the referring physician.
- The director of the clinical laboratory sends the reports according to the standard formats specified by the Cancer Registry.
- Any laboratory opposing to report will be fine penalized for each unreported case with cancer, specific tumors or pre-cancerous diseases.

5.2.7. Reporting of Health Insurance Centers

- The Centers of Health Insurance (HII) and third parties must report to the Cancer Registry all cases with cancer, specific tumors and pre-cancerous diseases, based on criteria specified by the Cancer Registry.
- If the information is reported, it shall be:
    - submitted in formats specified by the Cancer Registry and,
    - including all information identifying the patient, history of disease, cancer treatment and an annual report to confirm the patient's vital status.
- HII and other parties must submit their reports according to the standards specified by the Cancer Registry.

5.2.8. Additional Information

Additional information is needed to clarify the medical and demographic data under the request of the Cancer Registry. This information will include and shall not be limited to the following: copies of pathology and/or hematology reports, surgery reports, and information on treatment, history and physical sections of medical outcomes.

5.2.9. Information and Available Data

The available data might serve to the following categories:

- Cancer researchers need accurate data and continuous information to study the causes of cancer.
- Medical administrators need the available data to make decisions about purchasing of equipment and building cancer prevention and control programs.
- Health department members need these data for selecting the appropriate sample to fit the study aim.
- Medical students need cancer statistics to support their project ideas.
- In general, anyone can easily find cancer information on the Internet, but often individuals will have to secure a permission to obtain information about cancer.
- Every health center, clinical laboratory, physician, dentist, or other health worker diagnosing or providing treatment for cancer patients as well as centers of health insurance will be allowed by the Cancer Registry to obtain information from medical

records, pathology, and other data related to cancer cases, as necessary to fulfill the functions of the Cancer Registry program.

- Every health center, clinical laboratory, physician, dentist, or other health worker diagnosing or providing treatment for cancer patients as well as centers of health insurance, will have the opportunity to be informed or to provide the necessary information about characteristics of specific patients with cancer and other patients for conducting research studies on cancer etiology, prevention and control in the country.
- The reports compiled according to the guidelines of this sub-chapter shall be used only by the Cancer Registry and other principal health agencies. These reports shall not be subject to public surveillance or copying.

5.3. Action Plan of the National Cancer Registry

Cancer Registry

The Cancer Registry is *"the office or institution responsible for collecting, storing, analyzing and interpreting the data of persons with cancer"*.

The Cancer Registry is used to enable planning and evaluation of programs, to determine the Burden of Cancer, to study trends and to predict the future of cancerous diseases in the country.

Obviously the National Cancer Registry is part of the health information system.

The availability of the National Cancer Registry in Albania (NCRA) is a right of the health system, just as is the use of advanced information and communication technologies.

The main purpose of the NCRA is to recommend the necessary actions to fill the gaps in the health information system and to shave the path for the optimal use of health information associated with malignant pathologies.

The importance of the availability and development of the health information system has been stated several times and even more under the health reform process.

The NCRA is important to the information needs of not only individuals but interest groups as well. Use of health information is a requisite to provide a safe and quality health care protection to the client/patient, and to develop quality accreditation of the entire health service. Special attention should be paid to stabilizing the infrastructure as a very important element for the future development of the information system.

It should be emphasized that effective use of health information undoubtedly depends on the skills, knowledge, culture and working environment of health services' personnel.

The following table displays some data recently published by INSTAT (CAUSES OF DEATH FOR THE YEAR 2006, www.INSTAT.gov.al).

***Causes of deaths from tumors, 2006**

Tumoral disease	Total	Specific weight	Sex		Residence	
			Male	Female	Urban	Rural
Malignant tumors	2918	100	1807	1111	1196	1722
Benign tumors	81	2,8	48	33	25	56

The latest data published by INSTAT.

The data related to malignant diseases are collected through reports of Ministry of Health, whereas INSTAT, in addition to the information it receives from MoH, collects information from death certificates as well, which constitute a very reliable source of information (as the information is available in individual level) when filled in correctly.

The Ministry of Health collects information on cancerous diseases from the Oncologic Hospital, where the Inter-hospital Cancer Registry operates.

The Actual Cancer Registry is known as Inter-hospital Cancer Registry and covers approximately 80% of cancer morbidity in Albania. This Registry contains information on cancer for all the country and for every district, since 1986. Currently the Cancer Registry is located in the premises of Oncologic Service and it is the only Cancer Registry in Albania.

The data collection in this registry currently is as follows:

- Data on new cancer cases are actively collected by the registry staff at least every month.
- Reporting forms for each cancer patient are filled in according to the requirements proposed by the specialists of epidemiology sector in the premises of IARC, Lion, France.
- Coding of the data is done by the epidemiologist according to ICD-O, since 2003.
- Since 2008 the registry staff operates CANREG 4 software, created and modified by IARC (Lion, France) specifically for Albania thus enabling cancer data entry, processing and analysis.

In this unit actually work 4 persons:

- One epidemiologist (registry leader)
- Two nurses (data recording, operators)
- One operator

and it disposes of a limited physical space and only two computers.

In this situation, there are numerous problems identified, most important ones being:

- Lack of oncology health services across the country, which introduces problems for having accurate and periodic information on cancerous diseases.
- Lack of population stability (demographic movements), that relates directly to the population registration or what so called "loss of cases", which leads directly to essential information gaps
- Identification of individuals deriving by the lack of a unique code for the identification of cancer cases.
- Lack of trained health personnel to accurately collect the required data about these pathologies.
- Lack of cancer cases follow-up, mainly due to the free movement of the population, both across the country and abroad or defects in the documentation materials (patient data not correctly filled in, reporting defects, etc.).
- There is no access for all stakeholders to death certificates (only INSTAT owns this right, and INSTAT provides only aggregated information, which often makes it very difficult or impossible to appropriately analyze the data).
- Very low quality of death certificates filling in (incorrect coding of death).
- Lack of ICD-O translated in Albanian language, which would be of great help to health personnel.

As mentioned earlier, the National Cancer Registry is part of the health information system.

Health Information

An integrated health information system is the array of:

- web-based
- database
- health professionals, managers, researchers, epidemiologists

- data in patient/client level as well as health surveillance data.

Our vision, disclosed in this document, is to ensure that all the stakeholders, public, clients/patients, health workers (non-medical staff, professionals, managers), decision makers, Government, researchers and media, will have access to a reliable information obviously originating from the Cancer Registry which could be used according to their needs.

Principles for the establishment of the NCR:

- ensuring the privacy and confidentiality of health data at the individual level;
- ensuring NCRA as an efficient/useful information system;
- promoting optimal use of health information;
- providing high quality health information.

The objectives of this action plan:

- To support the "establishment" of NCR;
- To create the legal basis for the registry in order for it to be recognized as a self-standing unit which is responsible for maintaining the privacy and confidentiality of health data, when they are used by others;
- To be part of an integrated national health information system, which will include all sources and information systems, thus meeting the needs for health information;
- To establish structures that will ensure the use of all health information by policy makers in planning and implementation process, service providers and to enhance the quality and accountability of health care measures;
- To ensure access to health information for all stakeholders, to the appropriate extent;
- To stabilize health information standards in tumor pathologies, which ensure the quality and enable comparisons of data as well as creating opportunities for sharing of health information not only across health sector;
- To utilize existing technologies for collecting, processing, analyzing and dissemination of information.

The development of this document is strongly motivated by the awareness about continuous needs for information of all interested stakeholders.

We all are aware of the obstacles we face in finding the data, the access we have to use health information, especially when we consider the existing fragmented and non-standardized systems, and the ways in which this information is collected. This, obviously, puts into question their reliability as well.

Improving Health Information

Improving health information and specifically the one coming from NCR, is very important based on its role:

a. To provide information on morbidity and mortality
b. To provide information that will assist in the planning process
    - All health institutions must demonstrate that they use health information in the process of planning of services;
    - The demand for health information must be "an entity" on its own in the planning and implementation of services;
    - Improvement of health information is very valuable in assessing human resources
c. To ensure access to information for interested parties
d. To have an electronic version of the patient data (based on a unique identification);
e. To report on due time
f. To determine the incidence.

The support for the Cancer Registry should follow several steps:

- In the level of government
    - Development of the legal framework, indispensable for recognition of NCR as a self-standing structure.
- Establishment of standards and quality
    - Development of NCR functioning standards
    - Determining the set of indicators
    - Health information received from NCRA will guarantee the quality of information
- Information and communication technologies
    - Information technologies
        - IT
        - Development of suitable software

Implementation

- Implementation and monitoring
    - Necessary administrative and regulatory actions shall be taken to support information from all health institutions (decision of the Council of Ministers (DCM), collaboration agreements, regulations etc.);
    - A system/structure shall be established to evaluate and monitor implementation of the NCRA process;
    - Human resources development to be implemented/supported through training programs shall be required.

Stages of implementation

Given that the collection of information for NCR includes many actors within the health system (public and private hospitals, HII, SII) and outside it (INSTAT, Ministry of Interior Affairs), it is best for a good management of health information system to establish a series of cooperation agreements between these institutions, in order to guarantee the success of the process, which begins with safe sources of information.

Cancer Registry Unit

The unit should be established in the premises of the Oncology Hospital and will be responsible for the development, proper functioning and reporting of data related to malignant pathologies.

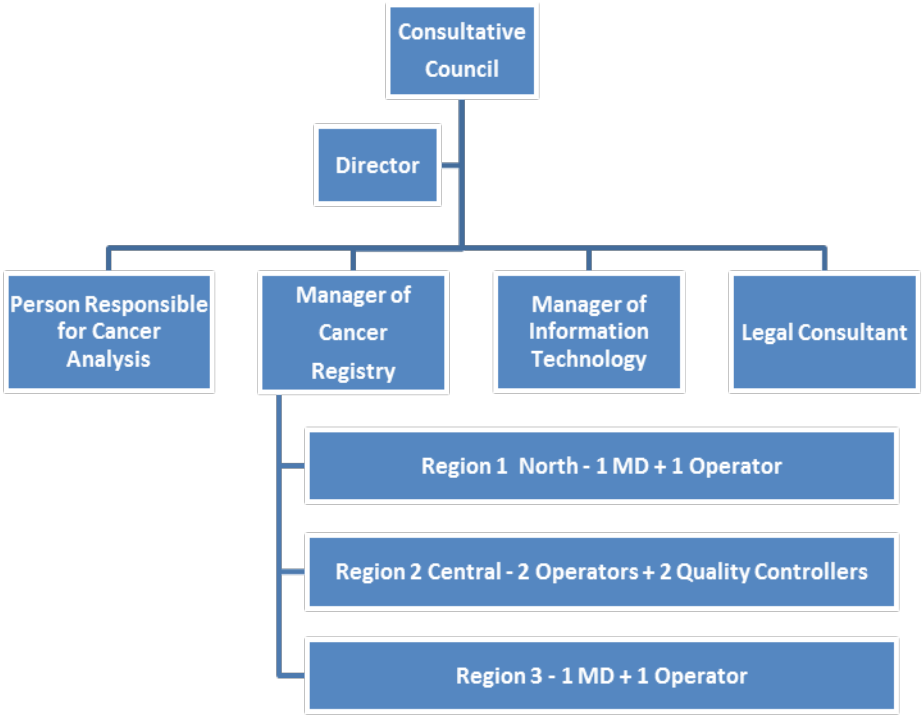
This unit should have its own personnel, in sufficient number and with well-defined tasks, and should have a voice of its own in the budget.

This unit must operate vertically.

The composition of this unit will be as follows:

- Director of the Cancer Registry
- Manager of NCR
- Data Analyst
- Manager of Information Technology
- Legal Consultant
- Operators
- Quality Controller

Organogram of the NCR Unit in Albania:



Consultative Council

The consultative council is an advisory board which members must be representatives of all actors providing information to the National Cancer Registry (NCR) (see Appendix 2).

It is proposed that its members should be representatives of:

- Ministry of Health
- Ministry of Interior
- INSTAT
- HII
- SII
- TUHC (Tirana University Hospital Center)
- Oncology Hospital (head)
- Head of Statistics Service, TUHC
- NCR unit

The consultative council is chaired by the Ministry of Health.

This council should adopt the strategic plan for health information activities, by both the public and private sector.

This council should recognize the role and responsibilities of all stakeholders, including consumers (users) of NCR and facilitate its functioning through potential collaborative mechanisms.

Responsibilities of this council may be:

- Adoption of:
  - the set of data,
  - indicators associated with malignant pathologies,
  - frequency of reporting (e.g. every three, four or six months),
  - performance of the process.

Proposed by the NCR unit, in the premises of oncology hospital

- Coordination of activities to develop the NCR through working with all stakeholders in the public (primary, secondary and tertiary) and private sector to enable the realization of a strategic plan, which, amongst other things, will ensure the cooperation of all stakeholders contribution to NCR;
- Coordinate NCR expenses for health related activities; ensuring that information relating to population and individual health, generated by health service providers, be a priority (in political level), and to sponsor health related projects (for all the population in a wider perspective or for the single individuals);
- Stimulate policies and practices that will provide safe health information and will preserve confidentiality;
- Promote and develop local capacities in health information;
- Promote training methods in medical informatics in public and private sector as well as identify and develop computer techniques for healthcare workers;
- Promote the standard of individual level data (personalized for the client) and of clinical data, associated with all stakeholders;
- Promote international cooperation in areas such as quality and health information related standards.

The consultative council reports to the Minister of Health.

Duties of employees of NCR unit, according to the scheme above, are proposed to be:

- ***Director of the Cancer Registry***

The director of Cancer Registry should have an education as a Public Health specialist and preferably to have at least a master degree in health enterprises' management. Of particular

importance are the scientific vision, leadership skills, knowledge of new information technologies and other technologies, knowledge of information systems and preventive medicine, research methods and ability to collaborate in the internal and particularly the inter-organizational environment. The main duties of the Director of CR are full information and awareness of the CR situation at any time, periodic assessment of the situation, forecasting and planning of strategies, budget and human resources. In addition, the orientation of CR activity in accordance with state policies and organizational policies of the premises where CR is located is a priority. A considerable part of the work of the Director of CR is projected into the future through maintaining ties with similar CR structures in other countries.

- ***Manager of the Cancer Registry***

The manager of CR should be the central technical figure who ensures the daily performance of CR. Educational background should be in the field of public health, systems of classifications and basic knowledge of information technologies. The basis of the work of CR Manager is the provision of timely information, management of information collection and information coding. The CR Manager is the one who makes the connection between the structure of CR and other clinical and administrative structures to ensure the continuity of CR activities. The CR Manager is also the supervisor of all information flow from its sources until the completion and updating of patient reporting forms. In addition, he guides the work for information quality control schemes through making of appropriate interventions whenever problems are verified or new solutions are required.

- ***Person Responsible for Cancer Analysis***

The candidate accepted for the position of the Person Responsible for Cancer Analysis should have finished the Faculty of Medicine, and be specialized in epidemiology, biostatistics, public health or related subjects. He/she must have at least five years of working experience in similar areas and direction. He/she must have experience in quantitative data analysis. Also, being familiar with a vast array of statistical techniques is important as well. The person must have good knowledge of information systems and basics of information technology, along with excellent knowledge of, obviously indispensable, statistical packages. The writing and publishing experience is essential as well.

- ***Manager of Information Technology***

The Manager of Information Technology of CR should have a degree in computer sciences and have at least three years of previous work experience with health information systems. He/she assists and improves the methodology of collecting clinical data, pathological anatomy, genetics, molecular and data from other laboratories. He/she maintains and provides support for *web based* reporting and data encryption technologies. Knowledge of SQL server, HTML, CSS, JavaScript, & SML/XHTML req. is required. Experience in MySQL & SAS is preferable. Basic

knowledge of programing languages C, C++, C # (sharp), ASP.Net, Visual Basic, or Perl is required. Knowledge of HL7 standards is preferable.

- ***Legal Consultant***

The Legal Consultant must have a degree in the field of jurisprudence and at least three years of working experience in information management. Excellent knowledge of health legislation and that part of legislation that relates to personal data is a requirement. The task of Legal Consultant is the guidance on legal matters related to Cancer Registry and the problems patients with these pathologies are facing. The array of legal issues concerning the Cancer Registry consists of planning, evaluation, research, analysis, problem solving and reporting cases of ethical and legal nature. The field of activity includes solving of systemic and individual problems of the patients and the structure of Cancer Registry.

- ***Quality Controller***

Control and improvement of information quality is amongst the key points of CR existence. Therefore persons covering such positions should have an education in medical sciences (good knowledge of anatomy and physiology), classification systems and health information systems in general. As a result, being at least a nurse with five years of working experience in this field is the minimal requirement. The main task of the Data Quality Controller is validation of all previously used codes to ensure the completeness, accuracy and consistency of coded information. He/she detects and notifies about the problems with coding and other problems related to information quality.

- ***Operators***

The person working in this area should be a nurse. The Collectors of the Data for Cancer Registry are responsible for collecting and reviewing of cancer patient data, as well as diagnostic procedures and treatments of these patients. They collect data on malignant tumors, benign tumors and suspected tumor cases according to standards established by the Cancer Registry. Very good skills in computer writing and data entering programs are essential. Also they must be able to use the active programs which the Registry operates. In addition, very good skills in coding procedures are required and being organized and committed to work as well.

Functions of the NCR unit *are:*

- determining the set of data;
- setting out the definition of data;
- improving the indicators related to malignant pathologies;
- determining the types of reporting, and the frequency of reporting (e.g., every three months, four months or six months), and

- monitoring the performance of the process.

Duties of the NCR unit are:

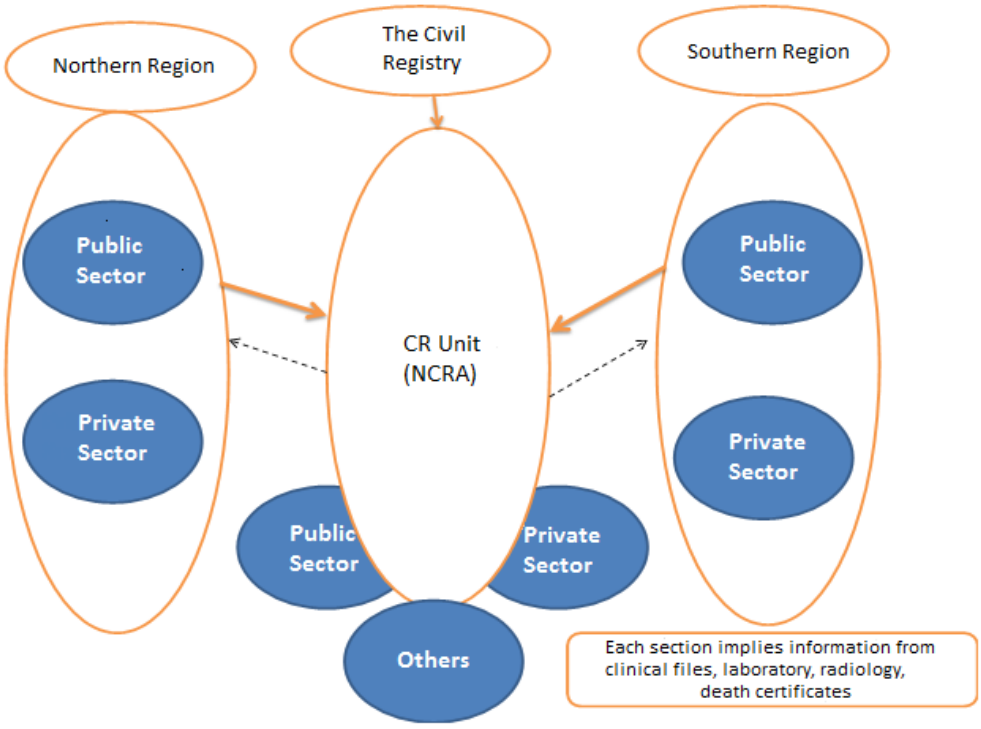
- periodically report on the situation of Cancer (timelines to be set);
- to develop software in line with EU recommendation;
- maintain the website of NCRA;
- give support on problems that may arise regarding hardware maintenance through purchasing of appropriate equipment;
- plan the budget;
- inform the chair person and through him the MoH for the development of reports and indicators;
- report the results to the chair person and MoH.

The unit deals with the preparation of the guidelines, collecting information from the base to the center which is the only source from which this kind of health information is delivered.

This center provides the final check of health information, data cleaning and it shares the information in due time and quality among stakeholders; it produces reports and bulletins (which can be biannual or annual).

In the premises of this unit a central Server shall be established, which will collect the available information related to malignant pathologies. This center will guarantee the up-dating of the data and the access to database for all interested parties that have signed an agreement.

Health information in this unit will include all the information that comes from the public and from the private sector.



The manner of reporting (not the process through which information is secured or compiled, as private entities have their own independence), should be standardized, in a specified format (rules that are defined precisely by the central office). Reporting should be mandatory, accurate, and in due time, aspects which should be defined beforehand (not only for the private and/or public insurance system but for the whole IS). As it can be noticed from the scheme, all sectors submit information to the NCRA unit, while this unit is obliged to give feed-back to these sectors (arrows with broken lines).

NCR unit as a Training Center

The unit of NCR is also responsible for organizing of training which should be designed according to the needs and the level of each target group.

Depending on these needs, there will be defined:

- types of training according to interest groups (operators, IT specialists, data users, trainers, etc.);
- training materials (glossary on terminology of malignant pathologies, for data producers, data users, guidelines for producers and users of data, manual for use of software, etc.);

- content of materials (list of indicators, instructions on how to fill a certain reporting form, etc.).

Sources of Data for the Cancer Registry

Organization of health care system helps us to understand how the information flows, which are the responsible structures, how the information should be collected and which mechanisms should be engaged to collect accurate and timely information.

The Albanian Government is committed to develop an integrated system of health services, emphasizing the importance of primary health care, the central role of the family physician and community nurse as well as continuous training of staff working in hospitals. In this mosaic, it is indispensable to collect accurate information related to malignant pathologies, keeping in mind the various ***sources of data for the Cancer Registry***.

Sources of health information are all entities that can produce information relevant to our focus, including:

- Data from clinical charters (public and private);
- Data from pathological anatomy (public and private);
- Morbidity (Ministry of Health);
- Death certificates (Civil Registry, Ministry of Interior Affairs);
- Pharmacies, SII, HII, Primary Care.

Expected ***advantages*** of NCR implementation are:

- Accurate data on morbidity and mortality related to malignant pathologies;
- Enhanced safety
- Improved services
- Competitive advantages
- Reduction of errors
- Enhanced accuracy
- Enhanced quality
- Improved communication
- Enhanced efficacy
- Higher productivity
- Enhanced efficiency of administration
- Application of new techniques
- Reduction of costs
- Information for all
- Improved financial decisions
- Improved operational control
- Improved management in general

A Successful Information System

- meets and anticipates the demands,
- is cost-effective,
- is safe and simple,
- obeys the law,
- engages an understandable language,
- is a long-term solution,
- could be damaged but not destroyed by risk factors.

These are amongst the criteria to be discussed after the presentation of the current situation and should be considered since the start point of building of the Cancer Registry.

Obviously, the establishment of the NCR unit cannot be accomplished in a single day. First it is necessary to develop a document for the functioning of the Cancer Registry, as well as the legal basis that would recognize this unit as a separate entity, with its own functions, rights and obligations. Then, there must be prepared the appropriate trained staff that will raise and bring this unit to life, which will start to produce its outcomes since in piloting phase (in the Oncology hospital) and during implementation.

Role of Cancer Registries in Budgeting Processes

The role of cancer registration in budgeting processes varies according to organization type and size, the size of the registry, its purpose and the responsibilities assigned to CR. The level of CR responsibility in the budgeting processes ranges from the complete preparation and total control to budget monitoring and justification of potential changes. In some cases, some CRs are responsible to send requests to a larger department part of which they might be. There is a direct dependence link between time devoted to budget planning and reporting structure of registry when the registry is not autonomous, the development of the budget can be limited only to provision of inputs for registry needs; whereas in autonomous registries, more time is required for planning and budget preparation. Regardless of the level of responsibility, each Cancer Registry has a role to play. Understanding of the budgeting process provides Cancer Registries with valuable mechanisms for future professional performances. The objectives of the budget are variable, as seen from the following table.

Participation in budgeting processes allows the staff of Cancer Registry, in synchrony with cancer committee, to set long-term objectives for the department of cancer program and stay in line with institutional objectives, taking the fiscal responsibilities for the department performance, and to coordinate activities with other departments.

Budget Objectives

- *A basic plan* in which all expenditures for all purposes and inputs from all sources can be predicted and presented.
- *A statement related to the objectives* of cancer registration programs, expressed in quantitative terms.
- *An estimation of future needs* in an organized way, covering some or all of the cancer program activities for a specific period of time.
- *Predefined standards* against which the actual activity is compared.
- *Motivation* of all individuals by creating a cost conscious environment.

Budget Components Applicable to the Cancer Registry Functions

Three types of budget components applicable to the CR functions are expenditures, capital and inputs. Budget expenditures include allocation of funds for personnel, supplies, office equipment, mail, and other maintenance. Budget capital is used to purchase most valuable equipment (usually 500 Euros or more, with two or more years of longevity). The inputs in budget predict payment flow-in from patients, service contracts with other entities, donations and fund raising activities.

The cost components may be fixed, variable, or semi-variable, direct or indirect. All of these components are present in the Cancer Registry's budget and can be found in the table below.

Budget Terms

- *Fixed:* costs usually associated with the period of time and tend to remain constant when the volume of activities changes. An example might be the amortization of equipment.
- *Variable:* costs that vary according to the volume of activities. Examples might be the number of staff and supplies.
- *Semi-variable or mixed:* costs comprising of fixed and variable components. Semi-variable costs vary according to the activity but are proportional to changes of operational work. Examples are payment of full-time staff, paid regardless of the number of cancer cases, compared to part-time or temporary staff, which work and get paid only when the work volume is large or the CR is behind with schedule.
- *Direct:* costs that are generated and charged directly to CR budget. Examples are expenditures for personnel and amortization of equipment used specifically for the department.

- *Indirect:* costs of general nature and from which several departments or services benefit. Examples might be electricity, building maintenance, maintenance of accounts and Human Resources services.

The statements presented above indicate the theoretical planning by voices of Cancer Registry budget, whereas budget planning will practically be realized in accordance with choices made in relation to organization and implementation timeframes.

ACTION PLAN

	Objectives	Activities	Stakeholders	Time	Budget
1	Evaluation	1. Inventory of legal documentation associated with CA 2. HR working for CA 3. Infrastructure	OKISH Oncology (MoH) Private	ongoing	OKISH
2	Draft document of functioning of the Cancer Registry	1. Purpose of CR 2. HR 3. Funding 4. Infrastructure	OKISH MoH	2 months	OKISH
3	Creating a legal basis for CR	1. Law 2. DCM 3. Regulation 4. Guidelines	MoH OKISH INSTAT	…	OKISH
4	Preparing and staff	1. Translation of ICD-9-CM 2. Translation of ICDO - 3 3. Training of personnel	MoH OKISH INSTAT MoH OKISH INSTAT	12 months 6 months	OKISH
5	Piloting	Oncology Hospital	OKISH MoH	6 months	
6	Implementation	Albania	…	2 years	

In the *Budget* section, OKISH assumes all modalities of budget planning.

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7. APPENDIX 1

National Standards for Palliative Care

Acknowledgements

This document is the first attempt to develop clear standards for palliative care services in Albania. The project of compiling the national standards for palliative care aims to improve the medical care for a category of considerably vulnerable and inadequately assisted patients.

Standards may be considered as a set of criteria to be implemented by any potential service of palliative care and can also be used by health authorities and financiers to evaluate existing services and palliative care needs in Albania. The team that has contributed to the compilation and publication of these standards has not attempted to define them as an aspiration level, but rather as an essence of basic requirements to ensure the quality of palliative care services for patient in advanced and terminal stages of their disease.

Standards for palliative care are the product of a collaboration between all current contributors in palliative care such as the Albanian Association of Palliative Care, Ryder Albania Association, Mary Potter Association, Oncologic Service at Home, Albanian Caritas, Pediatric Oncologic Service at the University Center "Mother Teresa", Accreditation Agency, supported by the Ministry of Health and WHO and funded by the Open Society Foundation for Albania. The extraordinary contribution of Stephen Connor, an international expert in Palliative Care, was crucial for the finalization of this document. We are grateful to funders and to the consultant from USA.

The working group was formed by specialists from hospitals and oncologic service, representatives of non-governmental and public organizations which provide palliative care at home, as well as representatives from the Ministry of Health, Accreditation Agency and OSFA.

Therefore, with such broad participation for developing the standards, the present document expresses the experience of members of the Albanian Association of Palliative Care (AAPC). The Association comprises over 80 members, amongst physicians, nurses and other specialists sharing common interests in improving the quality of care for patients with incurable diseases through interdisciplinary teams (physicians, nurses, social workers, psychologists, therapists, clergy, etc.).

Expertise and information provided by international experts, along with contributions of Albanian specialists, has resulted in adaptation of international experience to the Albanian conditions (social and economic) as well as specific rules of national health system.

The team of experts working on standards:

Dr. Kristo Huta	AAPC
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Dr. Donjeta Bali	TUHC Pediatric Service
Dr. Gerla Koleci	Mary Potter Center
Elona Mehmetaj	Caritas Albania

ACCESS IN PALLIATIVE CARE

Principle 1: Palliative care should be given to all patients who need it.

- **Standard 1.1.** Palliative service provides information to the general public about the availability of palliative care in the community.
- **Standard 1.2.** Beneficiaries of palliative care are patients in advanced stage of the disease.
- **Standard 1.3.** Palliative care services have no restrictions regarding sex, age, nationality, religion, ethnic group, sexual orientation and disability.
- **Standard 1.4.** Patient and his family (identified as important by the patient) are units of care.
- **Standard 1.5.** Patients should be admitted to palliative care when curative therapy prescribed by the physician is not effective anymore and/or patient or family members have decided to give up curative treatment.
- **Standard 1.6.** Any palliative program must have policies and procedures regarding the admission criteria, e.g.: written informed consent of the patient (and/or his or her legal representative) relating to palliative care.

  Patients are referred from: Family Physician, Specialist (in this case approval from family physician is required), and Family members (must consult with family physician).

PURPOSE OF PALLIATIVE CARE

Principle 2: The purpose of palliative care is to provide complex care oriented towards the needs of the patient and family, through a multi-disciplinary team.

- **Standard 2.1.** Palliative care is provided for as long as it is needed. It is based on an initial assessment and periodic reassessments, or whenever this is necessary.
- **Standard 2.2.** Palliative care is provided by a multi-disciplinary team.

EXPANSION OF PALLIATIVE CARE

Principle 3: Expansion of palliative care services addresses a range of physical, psychological/emotional, spiritual and social needs of patients and their families before and after death.

- **Standard 3.1.** In order to attain the best quality of services, palliative care includes medical, nursing, social, counseling/spiritual, volunteer, and death support services.

- **Standard 3.1.1.** Medical services are provided by a qualified physician who is responsible for the coordination of such care.
    - **Standard 3.1.1.1.** Medical services include admission, initial assessment, medical assessment, treatment plan, reassessment and ongoing follow-up, surveillance, communication and education of patients and familiars, as well as research surveys.
- **Standard 3.1.2**. Nursing services are provided by nurses qualified in palliative care who should cooperate to create and implement the plan of care.
    - **Standard 3.1.2.1.** Nursing activities include: patient assessment and implementation of treatment plan, continuous evaluation and adaptation of the plan of care, communication with the patient/familiars/carers and the team, supervision of volunteer assistants, education of patients/familiars/carers, care for the patient and family at the time of death.
- **Standard 3.1.3.** Social services are provided by qualified social workers that address social and psychological concerns of the patients, familiars and other important members, both before and after patient's death.
    - **Standard 3.1.3.1.** Social services include: psychosocial assessment, care planning, inter-disciplinary meetings, counseling, referrals to services, education, protection of patient/family, assisting in the burial procedure, support for familiars after the loss of their relative, participation in selection and training of volunteers, supervision and research surveys.
- **Standard 3.1.4.** Counseling and spiritual/pastoral services are important to help patients and their families to cope with the effects of serious illness, death and pain.
    - **Standard 3.1.4.1.** Spiritual/pastoral care must be provided by a clergyman, or someone qualified with equivalent education and experience and may include: meditation, counseling, prayer, or sacred practices or rituals, active listening and supportive presence, participation in funerals, in memoriam services.
- **Standard 3.1.5.** Counseling is provided at a basic level by each member of the multi-disciplinary team. For complex psychological needs, access should be provided by competent professionals of the field.
    - **Standard 3.1.5.1.** Counseling services may include: individual, familiar or group supportive counseling, intervening during crisis phase, counseling before and after the loss of relatives.
- **Standard 3.1.6.** Voluntary services are an integral part of palliative care.

        - **Standard 3.1.6.1.** Volunteers offer services without any material benefit.
        - **Standard 3.1.6.2.** Selection of volunteers is based on the following qualities: ability to work as part of a team, listening and communication skills, compassion, empathy for people with the disease, awareness for personal limitation, confidentiality, respect for patient's personal beliefs, moral integrity, and having no criminal history.
        - **Standard 3.1.6.3.** Volunteers with personal experience of losing their beloved ones should not be involved in direct contacts with patients or their families for 1-2 years.
        - **Standard 3.1.6.4.** Volunteers working in palliative care services need to have basic training and must be supervised by the volunteer coordinator.
        - **Standard 3.1.6.5.** Volunteer activity is based on a written contract containing the schedule and type of service.
        - **Standard 3.1.6.6.** Volunteer activities include: working directly with patient and families (e.g. society, shopping, recreation, transportation, home maintenance, and support for the loss of relatives), administrative work (e.g. office duties, generating funds, help in organizing special events, building and equipment maintenance).
    - **Standard 3.1.7.** Support for the loss of relatives is an essential part of palliative care services and it is provided to help the patients and families to cope with multiple losses that occur during illness and after patient's death.
        - **Standard 3.1.7.1.** Services for the loss of relatives are provided by: social worker or counselor, staff members and trained volunteers.
        - **Standard 3.1.7.2.** Services for the loss of relatives may include: support before and after death, individual and family counseling, phone calls, visits, in memoriam services and funerals, spiritual and pastoral counseling, support groups, or referrals to communication resources.
    - **Standard 3.1.8.** Any palliative care service must ensure case management for all patients.
        - **Standard 3.1.8.1.** The case manager varies according to patient needs and resources of the program (nurse, social worker, physician).
        - **Standard 3.1.8.2.** Case management activities include: communication and coordination with members of the multi-disciplinary team and with patients or family, ensuring that the patient or family needs are met.
- **Standard 3.2.** Palliative care services provide support for the staff and volunteers in their ongoing work with death and bitterness.

MULTI-DISCIPLINARY TEAM

Principle 4: Hospice and palliative care are operated by a multi-disciplinary team.

- **Standard 4.1.** The structure of a multi-disciplinary team includes: physicians, nurses, social workers and additional staff with appropriate clinical experience and training, according to the counseling needs of patients, psychologist, physiotherapist, priest/clergyman and volunteers.
- **Standard 4.2.** To avoid "burnout" of staff in home care services, management should consider these staff/patient ratios: 1 physician and 3 nurses/10-15 patients, 1 social worker/25-30 patients.
- **Standard 4.3.** Staff should have appropriate qualifications in palliative care.
    - **Standard 4.3.1.** Physician: needs to meet the following criteria: licensed, practicing medicine at least 3 years, completion of a training not less than 12 weeks in palliative medicine.
    - **Standard 4.3.2.** Nurse: needs to meet the following criteria: licensed, 2 years of general nursing experience, completion of training in palliative care including 4 weeks of theory, 4 weeks of practice, 12 additional weeks being supervised by a nurse or palliative care physician.
    - **Standard 4.3.3.** Social worker: university degree in social work, 1 year of experience in social work with individuals/groups, 1 week course in palliative care for social workers, 3 months supervision by an experienced licensed social worker/psychologist.
    - **Standard 4.3.4.** Chaplain: pastoral formal education, training in counseling, 1 week course on the basics of palliative care, 3 months supervision by a medical professional.
    - **Standard 4.3.5.** Volunteer: 1 week training on the basics of palliative care after recruitment, including: *hospice* philosophy, communication skills, multi-disciplinary team, the concerns of dying persons, the role of volunteers, supervision and case manager.
    - **Standard 4.3.6.** All other disciplines involved in palliative care should have appropriate education background and training on the basics of palliative care and appropriate supervision.
- **Standard 4.4.** Teams of palliative care should provide services that are within their competencies/training.
- **Standard 4.5.** Continuous education for each staff member is necessary.

PLAN OF CARE

Principle 5: Multi-disciplinary team together with the patient and family members develops and maintains an individualized plan of care.

- **Standard 5.1.** Patient and family accept the services submitted according to a care plan.
- **Standard 5.2.** Patient and family participate as needed in developing the plan.
- **Standard 5.3.** The care plan of any multi-disciplinary team includes: list of problems/opportunities, the rules of treatment, equipment, medication, teams' activities based on initial and ongoing assessments.
- **Standard 5.4.** The initial plan of care is developed within 2 days of acceptance by at least two disciplines.
- **Standard 5.5.** The care plan of multi-disciplinary team is developed in the first meeting of the team after acceptance and is reviewed as needed at least every week during the meeting of multi-disciplinary team.
- **Standard 5.6.** Meetings of the multi-disciplinary team are held at least once a week.

NUTRITION

Principle 6: Nutrition adapts to patient needs, in order to maintain the quality of life.

- **Standard 6.1.** Palliative care services develop and recommend nutrition guidelines tailored to individual needs and cultural customs.
- **Standard 6.2.** Patient and family will be provided education about the nutritional needs specific to the disease stage.

CONTINUITY OF CARE

Principle 7: To maintain the continuity of care, there should be ensured good communication between staff, family and other programs, when there is a change in the clinical status of the patients.

- **Standard 7.1.** When care provided is *hospice*, there are written policies and procedures regarding patient transfers and moving out.
- **Standard 7.2.** When care provided at the patient's place of residence is no longer possible, transfer procedures ensure a well-coordinated transition, which depends on the level of care required.

- **Standard 7.3.** *Hospice*, in relation to after death procedures orients family members according to current legislation.

SAFETY AND INFECCTION CONTROL

Principle 8: To identify and reduce the risk of infection to staff, patients and family members, *hospice* develops and implements a program to control the infection.

- **Standard 8.1.** Staff knows and implements universal safety measures.
- **Standard 8.2.** Palliative care services require safe disposal of hazardous waste.

MEDICATION, EQUIPMENT AND CONSUMER TOOLS

Principle 9: Hospice offers equipment, medicaments and supplies that serve the terminal condition.

- **Standard 9.1.** To the extent that they are available, *hospice* service provides medicaments, equipment and supplies (see minimum requirements for equipment).
- **Standard 9.2.** Supply, storage and description of medicaments follow legal provisions and regulations in power.
- **Standard 9.3.** Drugs essential to a palliative care service are those drugs that are considered in the availability lists of other countries advised by WHO.
- **Standard 9.4.** According to sources in place, any drug entering to this availability list represents an additional treatment option.
- **Standard 9.5.** Basic medical supplies in palliative care are:
    - Materials for injections and punctures;
    - Tracheal cannula;
    - Urinary catheters;
    - Microsurgery equipment;
    - Materials for biological products;
    - Stoma bags, urine bags, etc.;
    - Automatic mechanical devices and consumable materials for the administration of drugs under the skin.

GOVERNANCE AND MANAGEMENT

Principle 10: Any *hospice* service must have an organized governing body that assumes full and final responsibility for the organization.

- **Standard 10.1.** Governing body is responsible for: fiscal management, budget approval, funds raising, organizational policy, appointment of executive directors and for all required legal certificates.
- **Standard 10.2.** Directors are responsible for hiring the appropriate staff to ensure care and realization of programs and maintaining of a proper staff/patient ratio.
    - **Standard 10.2.1.** All positions must have a job description, by regulation, including qualifications.
    - **Standard 10.2.2.** All staff members should receive the appropriate initial and ongoing training.
- **Standard 10.3.** Heads of departments develop operational policies which are approved by leading authorities on an annual basis.
- **Standard 10.4.** *Hospice* operates under all laws and regulations of the Albanian jurisdiction.

ENHANCING PERFORMANCE

Principle 11: Hospice determines a systematic plan to maintain and enhance performance.

- **Standard 11.1.** *Hospice* establishes a process to evaluate and enhance quality of care, or actions. The process includes forming of a group of staff to identify, monitor, evaluate and implement improvements.
- **Standard 11.2.** Enhancement of quality can be evaluated using tools such as patient/family members' satisfaction, staff satisfaction, pain management, etc.
- **Standard 11.3.** *Hospice* uses a process for documenting, monitoring, and responding to complaints, errors and other incidents in due time. All laws and regulations regarding the reporting of incidents are operational.

RECORD OF SERVICES

Principle 12: *Hospice* service uses confidential, complete, timely and accurate recording of services provided to each patient and family member.

- **Standard 12.1.** *Hospice* service has established policies that address the content, maintenance, safety and access to hospice clinical data.
- **Standard 12.2.** The documentation for each patient should minimally include: medical history, biographical data, initial assessment e.g. medical, nursing, social and spiritual

assessment, data of care provided by all disciplines from acceptance until the loss of relative, information on drugs, other agencies involved in care, additional notes as required by law and regulations.

- **Standard 12.3.** Clinical records contain a detailed summary for each discharged patient.

ORGANIZATION FOR SERVICES OF PALLIATIVE CARE

Principle 13: Hospice and other services of palliative care are provided in a range of organizations to adequately meet the needs of patients.

- **Standard 13.1.** *Hospice* and palliative care services may be provided as: community-based home care, hospital care, or day care.
- **Standard 13.2.** Provision of services should be based on available resources e.g. financial, human, physical and informational resources.
- **Standard 13.3.** Home care services are preferred, but inpatient services are desirable for the management of severe symptoms.
- **Standard.13.3.1.** If in the same area a team of home care and an inpatient unit operate in the same time, then the cooperation is realized through:
    - A written agreement for a common policy should be established between home care and the inpatient unit;
    - There should be coordination of home care and staff of inpatient unit;
    - Medical records should be compatible;
    - Assessment should be made by the team of *hospice* palliative care prior to admission to inpatient unit, with the presence of the home palliative care physician and nurse.
- **Standard 13.3.2.** If in an area only the home care team is available, then:
    - The patient should live/reside within the same area of this home care team activity;
    - Providers of primary care should be available;
    - Home care team should have a policy to conduct risk assessment for the safety of patients, family members and staff;
    - Home care team has policies and procedures to ensure the continuity of care.
- **Standard 13.3.3.** If in an area only the inpatient unit is available (*hospice* inpatient unit, hospital team, department of palliative care), then:

- Assessment should be carried out by the *hospice* palliative care team before admission to the inpatient unit;
- Patient and family members need to agree on admission and discharge policies;
- Policies and procedures should be developed and compiled to cover issues such as: 24 hours drug administration, nursing care, provision of everyday nutritional needs, life safety and building requirements (similar to the style of the house), disaster readiness, safety and cleanliness, provision for family members.

ETHICAL ISSUES

Principle 14: The purpose of palliative care is to provide support in the best interest of patients without causing any harm to them.

- **Standard 14.1.** *Hospice*/palliative care services have in place a procedure to allow the patient express his/her own wishes regarding the withdrawal from treatments, such as artificial hydration, artificial nutrition, life support, reanimation, etc.
  - **Standard 14.1.1.** Patients should be given accurate information about the stage of disease, prognosis, available treatments and their effectiveness against adverse effects.
  - **Standard 14.1.2.** Patients have the right to make informed decisions about the types of treatment, including alternative treatment options, interruption of treatment and refusing treatment.
  - **Standard 14.1.3.** Patients have the right to receive adequate treatment, to soothe suffering and aiming to better quality of life.
- **Standard 14.2.** *Hospice* and palliative care do nothing to extend, or shorten the process of death.
  - **Standard 14.2.1.** Palliative care provides, through symptom management and pain control, an improved quality of life for the person who is at the end stage of his/her life.
- **Standard 14.3.** The patient should have access to less invasive and most appropriate treatment options and types.
- **Standard 14.4.** If the patient is not able to decide (unconscious) and his/her will remains unknown, the family has the right to take decisions about treatment and care.
- **Standard 14.5.** The medical team has a responsibility to always offer the best care and act in the best interest of the patient.
- **Standard 14.6.** The medical team has the right to refuse to administer, or to participate in treatments which are against good medical judgment, or their personal principles.

FINANCIAL AND HUMAN RESOURCES

Principle 15: The care of terminal patients involves important financial and human resources, to ensure access, quality and continuity of medical care.

- **Standard 15.1.** Terminal patients should not be discriminated in terms of resources allocation.
- **Standard 15.2.** Hospice and palliative care need resources to provide treatment, medical equipment and consumable goods, qualified and trained staff to address the needs identified in the plan of care.

EDUCATION AND TRAINING

Principle 16: Education is an integral part of palliative care and should be provided at the appropriate level for professionals, volunteers, patients, family members, carers and the general public.

- **Standard 16.1.** Palliative care providers and *hospice* services need training on specific topics that relate to their disciplines.
- **Standard 16.2.** Palliative care training should follow the approved curriculum and include topics on: *hospice* philosophy, ethics, communication, pain and symptom management, loss and death, psychology, social and spiritual support, roles and functions of the multi-disciplinary team, etc.
- **Standard 16.3.** Basic counseling skills are integrated within the training and working practice of all health care professionals involved in palliative care services.
- **Standard 16.4.** Palliative care providers are involved in continuous education, training and supervision.
- **Standard 16.5.** Palliative care services provide education materials and resources for patients, family members, carers and the general public.
- **Standard 16.6.** Palliative care services should promote palliative care education and cooperate with medical universities and other professional schools.

PERSONNEL AND SUPPORT OF CARE PROVIDER

Principle 17: Palliative care for the patient and family members can be difficult for care providers (medical staff, volunteers, family members).

- **Standard 17.1.** Attention should be given to the status of patients, reasonable work load (by type of service and localization) and staff working hours.

- **Standard 17.2.** Palliative care service provides support to its staff.
- **Standard 17.3.** The staff is educated and trained to recognize difficult situations, personal limitations, and use effective coping strategies to access support
- **Standard 17.4.** Staff support derives from a wide variety of sources and can be physical, emotional, spiritual and social: formal/informal, internal/external, and supervisory. E.g. supportive groups, individual and group counseling, supervision.
- **Standard 17.5.** Palliative care team is evaluated periodically regarding personal vulnerability by the supervisor or higher staff.
- **Standard 17.6.** Staff members who experience personal losses should receive special attention.

PEDIATRIC PALLIATIVE CARE

Principle 18: Caring for children in palliative care services represents unique and challenging problems.

- **Standard 18.1.** Pediatric palliative care services are appropriate for children and young adults, whose disease are diagnosed in childhood:
    - Diseases for which curative treatment is possible, but can fail (cancer, organ failure, etc.);
    - Diseases with limited expectations, where intensive treatment can improve the quality of life (cystic fibrosis, neuromuscular progressive dystrophy, etc.);
    - Progressive diseases where palliative care is possible from the beginning (mucopolysacharidosis, invalidating neuropathy);
    - Diseases that cause weakness and increased sensitivity of complications, often associated with neurological deficits (congenital encephalopathy, spina bifida).
- **Standard 18.2.** Staff (including volunteers) requires appropriate training on pediatrics and child development.
- **Standard 18.3.** In order to provide good quality and continuity of care, there should exist good communication between staff, family members, hospitals, child diseases specialists, family physicians and others involved in care.
- **Standard 18.4.** Increasing of psychological support is important to help family members deal with the deep concern due to prolonged disease process, or the bitter end.
- **Standard 18.5.** Children should be encouraged to live the life as normal as possible, including education, recreational therapies, psychological, rehabilitation and physical therapies.

- **Standard 18.6.** *Respite care*, including e high level of nursing care, is an important element that must be provided.
- **Standard 18.7.** Even though operating within limited resources, appropriate care during mourning should be provided for the family and other persons affected by the death of a child as long as necessary.
- **Standard 18.8.** Staff/patient ratio should be: 1 physician/1 nurse/8-10 patients, which depends on the frequency of visits and the width of area covered.

8. APPENDIX 2

Implementation of Strategic Plan for Palliative Care in Albania (action plan)

Priority Area: Policy

Goal 1: Eliminate legal, regulatory and policy barriers to Palliative Care

Objective 1: Recommendations for identification and implementation of legislative, regulatory and policy changes

Activity	Realized by	Timeline	Beneficiary Groups	Results expected and measured by	Potential Source	Total Cost
1.Development of standards of palliative care, based on European ones	1.NPO OSH MoH Accreditation Agency Oncology Hospital International experts	**First 6 months of 2011**	Patients Health service Health staff Family members	Provision of the quality of palliative care service for terminal patients	**Donors**	**922.800**
2.Follow-up of the process for adoption of developed standards	2.NPO OSH MoH Accreditation agency Oncology Hospital International experts	**First 6 months of 2011**	Patients Health service Health staff Family members	Provision of the quality of palliative care service for terminal patients	**Donors**	**40.000**
3.Analysis of legal and regulatory framework for the inclusion of palliative care in health system	3. NPO OSH MoH Accreditation Agency Oncology Hospital International experts	**2011**	Patients Health service Health staff Family members	Identification of needs to build a precise intervention strategy	**Donors**	**450.000**
4. Preparation of a legal and regulatory framework related to the mode palliative care is provided.	4.MoH Groups of Interest	**2013**	Patients Health service Health staff Family members	Institutionalization of palliative care		

5.Analysis of evaluation of social policies and services network for terminal patients and their families.	5.Working group 4 – 5 persons, with representatives of NPOs and relevant Institutions	**2011**	Patients Health service Health staff Family members	Identification of needs to build a precise intervention strategy	**Donors**	**80.000**
6.Organization of two round tables to present results of analysis and discuss intervention strategies to improve the legal framework and social policies for terminal patients and their families.	6. Working group 4 – 5 persons, with representatives of NPOs and relevant Institutions	**2011**	Patients Health service Health staff Family members	Identification of needs to build a precise intervention strategy	**Donors**	**132.000**
7.Drafting the strategy of intervention to improve the legal framework and social policies for terminal patients.	7.Working group *(which will assess and develop the intervention strategy)*	**2011**	Patients Health service Health staff Family members	Development of legal framework for palliative care	**Donors / Ministry of Labor**	**40.000**
8.Organization of lobbying and advocacy activities for the acceptance and approval of final drafts of laws and social policies.	8.Working group	**2011-2012**	Patients Health service Health staff Family members	Development of legal framework for palliative care	**Donors**	**123.000**
9.Acceptance and monitoring the implementation of legal framework and social policies for terminal patients from central and local government according to respective dependencies.	9.Working group 5 persons, representatives of NPOs and institutions involved in the process	**2012-2014**	Patients Health service Health staff Family members	Development of legal framework for palliative care	**Donors**	**110.000**
10.Reassessment of the strategy and action plan and developing the strategy for coming years.	10.MoH HII MLSAEO Accreditation Agency NPOs Donors	**2015**	Patients Health service Health staff Family members	Full implementation of the strategy process and action plan	**MoH**	**164.000**

	Total Cost	**y.2011**	**y.2012**	**y.2013**	**y.2014**	**y.2015**
Goal 1	2.061.800	1.664.800	153.000	40.000	40.000	164.000

Priority Area: Availability of medicaments

Goal: All Palliative Care essential medicaments should be available and accessible.

Objective 1: To increase the number of registered and available medicaments in Albania, so that all drugs on the list of medicaments in Palliative Care be accessible.

Activity	Realized by	Timeline	Beneficiary Groups	Results expected and measured by	Potential Source	Total Cost
1.Assessment of availability of reimbursable drugs for terminal patients and calculation of cost of new drugs proposed to be included in the reimbursement list	1.Working group (representatives of NPOs,OSH, HII, Oncology Hospital, MoH, etc.)	**Every year**	Terminal patients Health team Family members	Number and amount of medicaments that terminal patients benefit from the current list	**MoH/ HII**	**246.000**
2. Sensibilization and awareness campaigns (visual and written media, seminars, round tables, workshops) with all actors involved in the process (physicians, nurses, decision makers, etc.) about the importance of the availability of drugs and morphine like drugs for terminal patients.	2. Working group (representatives of NPOs,OSH, HII, Oncology Hospital, MoH, etc.)	**2012-2013**	Terminal patients Health team Family members	Acceptance and positive attitude towards the importance of the availability of medicaments	**MoH/ HII/ Donors**	**3.848.000**
3.Implementation of procedures to complete the list of HII reimbursable drugs, according to established standards, for terminal patient, gradually (*the cost of new drugs to be calculated by relevant institutions*).	3.Working group with 4-5 representatives of respective public institutions and NPOs.	**2012-2015**	Terminal patients Health team Family members	Reaching and applying European standards (based on the WHO list) for the treatment of terminal patients	**MoH**	**224.800.000**
4.Increasing of import quota for morphine like drugs, based on European standards.	4. Working group (representatives of NPOs,OSH, HII, Oncology Hospital, MoH, etc.)	**2011-2012**	Terminal patients Health team Family members	Availability of morphine like drugs based on real needs of terminal patients	**MoH/ HII**	**1.000.000.000**

Objective 2: To increase the number of competent physicians authorized to prescribe opioids.

Activity	Realized by	Timeline	Beneficiary Groups	Results expected and measured by	Potential Source	Total Cost
1.Lobbying activities with decision makers, in order for family physicians to be authorized to prescribe opioids.	1. Working group (representatives of NPOs,OSH, HII, Oncology Hospital, MoH, etc.)	**2011-2012**	Terminal patients Health team Family members	Family physicians are authorized to prescribe opioids for terminal patients.	**Donors**	**123.000**
2.Carrying out of 8 workshops and seminars to increase the knowledge level of family doctors on the use of opioids.	2. Working group (representatives of NPOs,OSH, HII, Oncology Hospital, MoH, etc.)	**2011-2012**	Terminal patients Health team Family members	Changing of attitudes towards prescription of opioids. Increasing the level of pain control of terminal patients.	**Donors**	**1.904.000**
3.Preparation of informative materials (1000 informative leaflets, 300 brochures, 1 book) about the use of opioids.	3. Working group (representatives of NPOs,OSH, HII, Oncology Hospital, MoH, etc.)	**2011-2012**	Terminal patients Health team Family members	Changing of attitudes towards prescription of opioids. Increasing the level of pain control of terminal patients.	**Donors**	**355.000**

	Total Cost	y.2011	y.2012	y.2013	y.2014	y.2015
Goal 2	1.231.276.000	1.264.200	259.340.200	258.173.200	256.249.200	256.249.200

Priority Area: Education and training

Goal 3: All health professionals involved in the care of patients with life threatening illnesses that will be treated in Palliative Care.

Objective 1: To train the primary care personnel and the public about palliative care.

Activity	Realized by	Timeline	Beneficiary Groups	Results expected and measured by	Potential Source	Total Cost

1.Development of a standardized training manual for palliative care service.	1.Working group with palliative care specialists from NPOs and OSH.	**2011**	Health personnel Terminal patients Family members	Standardization of training activities.	**Donors**	**1.200.000**
2.Qualification of the trainer of trainers multi-disciplinary group for palliative care, abroad.	2.International experts (Stephen and other experts)	**2011-2012**	Health personnel Terminal patients Family members	Contemporary level of implementation of training sessions.	**MoH/ CEC/ Donors**	**5.320.000**
3.Carrying out of 9-days training sessions, accredited, with primary health care personnel at national level, prioritizing according to incidence level.	3.Group of trainers.	**2011-2012**	Health personnel Terminal patients Family members	Terminal patients will benefit from increased levels of palliative care service.	**CEC/ Donors**	**2.400.000**
4.Publication of palliative care informative materials and literature in Albanian language for the health personnel and patients' family members.	4.Palliative care specialists from NPOs and OSH.	**2012-2013**	Health personnel Terminal patients Family members	Increased professional capacities for palliative care.	**MoH/ Donors**	**355.000**
5.Sensibilizing campaign through written and visual media about the need and importance of palliative care service for family members and the public in general.	5. Palliative care specialists from NPOs and OSH.	**2011-2015**	General public Family members	Sensibilization of the public and family members.	**Donors**	**3.848.000**

Objective 2: To have a medium-term and long-term training program for all professionals who will be working in Palliative Care Service.

Activity	Realized by	Timeline	Beneficiary Groups	Results expected and measured by	Potential Source	Total Cost
1.Analysis of needs assessment at prefecture/district level (*referring to the incidence and standards*) of provision of palliative care services by a specific team.	1.Working group to be created by respective experts.	**2011**	Patients Health system Family members	Terminal patients benefit from the qualified standardized service of palliative care.	**Donors**	**123.000**
2.Organization and carrying out of a round table with principal actors to present the results of needs assessment and to lobby for the establishment of palliative care teams in those prefectures/districts where necessary.	2.MoH NPOs OSH	**Firs 6 months of 2012**	Patients Health system Family members	Preparatory phase (increasing of level of sensibilization and awareness of decision makers) to implement palliative care standards.	**MoH/** **Donors**	**164.000**
3.Preparing of academic experts in the field of palliative care in countries with experience in this area, giving priority to professionals having experience in palliative care.	3.MoH Donors	**2011-2015**	Patients Health system Family members	Provision of academic capacities for the development of palliative care at appropriate levels.	**MoH/CEC/ Donors**	**10.900.000**
4.Lobbying with the MoH, Ministry of Education, High School of Nursing to organize, compile and develop medium-term training programs (3/6/9 months theoretical and practical) for physicians and nurses working in palliative care.	4.MoH NPOs OSH	**2011-2013**	Patients Health system Family members	Implementation of standards for the provision of palliative care service.	**Donors**	**30.000**

Objective 3: To improve the university-level curricula and to create the specialty/sub specialty of palliative care.

Activity	Realized by	Timeline	Beneficiary Groups	Results expected and measured by	Potential Source	Total Cost
1.Assessment of current programs and curricula at the Faculty of Medicine and High School of Nursing.	1.Inter-disciplinary team specialized in palliative care.	**2011**	Physicians and nurses Higher education Patients	Identifying the appropriate need level to improve curricula	**Donors**	**350.000**
2.Carrying out of a workshop with key actors to present the results and importance of improving palliative care curricula.	2.MoH MoE Faculty of Medicine High School of Nursing Oncologic Service OSH NPO	**2012**	Physicians and nurses Higher education Patients	Students will be prepared at the university level for basic palliative care service.	**Donors**	**216.000**
3.Lobbying and advocacy activities with actors and decision makers to improve the curricula for palliative care both in the public and private sector at national level.	3. MoH MoE Faculty of Medicine High School of Nursing Oncologic Service OSH NPO	**2011**	Physicians and nurses Higher education Patients	Students will be prepared at the university level for basic palliative care service.	**MoH MEduc Donors**	**123.000**
4.Reaching an agreement to improve the curriculum.	4. MoH MeE Faculty of Medicine High School of Nursing Oncologic Service OSH NPO	**Within the first year**	Physicians and nurses Higher education Patients	Students will be prepared at the university level for basic palliative care service.	**Ministry of Education**	

5.Establishing a working group to prepare the program and syllabus (lectures) of palliative care, at the university level.	5.Palliative care specialists.	**2012**	Physicians and nurses Higher education Patients	Students will be prepared at the university level for basic palliative care service.	**Ministry of Education**	**1.500.000**
1. 6.Carrying out of a round table with principal stakeholders and decision makers, to discuss the importance of creating a specialty or sub specialty of palliative care.	6.MoH,MoE Faculty of Medicine Oncologic Service Accreditation Agency OSH,NPO	**2013**	Physicians and nurses Higher education Patients	Physicians Patients	**MoH/** **Ministry of Education**	**164.000**
7 7.Persistent lobbying activities at the university level for the specialization creation agreement.	7.NPOs Groups of interest	**2012-2013**	Physicians and nurses Higher education Patients	Physicians Patients	**MoH/** **Ministry of Education**	**123.000**
8. Establishing a working group with representatives from MoH, Faculty of Medicine, High School of Nursing, Accreditation Agency, not-for-profit organizations, to design the specialization program of palliative care.	8.MoH MoE Faculty of Medicine Oncologic Service Accreditation Agency OSH NPO	**2012-2013**	Physicians and nurses Higher education Patients	Physicians Patients	**MoH/** **Ministry of Education / Donors**	**1.500.000**
9.Admission procedures and creating the specialization program of palliative care.	9.Working group of 5 persons, from Faculty of Medicine, Accreditation Agency for Higher Educations, Oncologic Service and two professionals from NPOs with proper expertise in palliative care.	**Within the third / fourth year**	Physicians and nurses Higher education Patients	Physicians Patients	**Ministry of Education**	**80.000**

	Total Cost	y.2011	y.2012	y.2013	y.2014	y.2015
Goal 3	28.396.000	5.306.000	9.702.000	5.150.000	4.165.000	4.073.000

Priority Area: Implementation

Goal 4: To make palliative care available to all Albanian citizens who need it.

Activity	Realized by	Timeline	Beneficiary Groups	Results expected and measured by	Potential Source	Total Cost
1.Implementation of agreed standards by existing teams providing palliative care services.	1.MoH Accreditation Agency	**2012**	Terminal patients Inter-disciplinary team Family members	Ensuring the quality of service	**MoH/** **NCQSA**	
2.Analysis of needs assessment of extension/expansion of palliative care service (home based and inpatient) at the national level.	2.NPO OSH	**2011**	Terminal patients Health system Family members	The opportunity to plan in real terms the intervention strategy	**Donors**	**700.000**
3.Round table with main actors and decision makers to present the results of needs assessment and to discuss and lobbying on alternatives of intervention strategy.	3.Organizations that will carry out the assessment.	**First 6 months of 2012**	Terminal patients Health system Family members	The opportunity to plan in real terms the intervention strategy	**Donors**	**164.000**
4.Persistent lobbying meetings with policy makers to expand the service to other regions of Albania.	4.NPO OSH Other groups of	**2012**	Terminal patients Health system Family members	Creation of opportunities to expand and extend the service at national level	**Donors**	**164.0000**

	interest					
5.Finding of appropriate instruments to expand and support the services provided from existing not-for-profit organizations with public funds.	5.NPO MoH HII MLSA etj	**2011**	Terminal patients Palliative Care Organizations Family members	Continuity of service	**MoH/ HII**	
6.Establishing a unit with 5 beds, for palliative care service in the premises of Oncologic Hospital.	6.MoH Oncologic Hospital Palliative Care Organizations Groups of interest	**2012**	Terminal patients Palliative Care Organizations Family members Health system	Establishment of a national center for palliative care	**MoH**	**16.790.000**
7.Establishing the palliative care service in 4 regional hospitals of the country, based on the outcome of needs assessment.	7.MoH Regional hospital Palliative Care Organizations Groups of interest	**2012-2013**	Terminal patients Palliative Care Organizations Family members Health system	Ensuring and provision to terminal patients of qualified palliative care service	**MoH**	**124.740.000**
8.Establishing the palliative care service in 4 other regional hospitals of the country, based on outcomes of needs assessment.	8. MoH Regional hospital Palliative Care Organizations Groups of interest	**2014-2015**	Terminal patients Palliative Care Organizations Family members Health system	Ensuring and provision to terminal patients of qualified palliative care service	**MoH**	**91.160.000**

9.Providing terminal patients with service at home through multi-disciplinary teams in three regions of the country.	9. MoH Regional hospital Palliative Care Organizations Groups of interest	**2012**	Terminal patients Palliative Care Organizations Family members Health system	Ensuring and provision to terminal patients of qualified palliative care service	**MoH**	**1.181.220.000**
10. Providing terminal patients with service at home through multi-disciplinary teams in four other regions of the country.	10. MoH Regional hospital Palliative Care Organizations Groups of interest	**2014-2015**	Terminal patients Palliative Care Organizations Family members Health system	Ensuring and provision to terminal patients of qualified palliative care service	**MoH**	**2.341.700.000**
11.Establishing a resource center, of research and scientific nature for palliative care, in the premises of Ryder Albania Association, or Oncologic Hospital.	11.MoH, Various local or international donors .	**2014**	Terminal patients Palliative Care Organizations Family members Health system	Development of palliative care at European levels and standards.	**MoH**	**33.000.000**

	Total Cost	y.2011	y.2012	y.2013	y.2014	y.2015
Goal 4	3.800.238.100	700.000	359.295.500	634.267.500	1.197.637.500	1.608.337.500

Summary of action plan costs for the Palliative Care 2011-2015 Strategy in Albania

Costing	Total	2011	2012	2013	2014	2015
Goal 1: Policy	2,061,800	1,664,800	153,000	40,000	40,000	164,000
Goal 2: Availability of medicaments	1,231,276,000	1,264,200	259,340,200	258,173,200	256,249,200	256,249,200
Goal 3: Education and training	28,396,000	5,306,000	9,702,000	5,150,000	4,165,000	4,073,000
Goal 4: Implementation	3,800,238,000	700,000	359,295,500	634,267,500	1,197,637,500	1,608,337,500
Grand Total	5,061,971,800	8,935,000	628,490,700	897,630,700	1,458,091,700	1,868,823,700

Share of the cost of Palliative Care to Health Budget	**2% each year**	
Economic effect (additional funds) that will be needed	**1% of budget each year**	**=2.500.000.000 leke**

9. APPENDIX 3

REPUBLIC OF ALBANIA
MINISTRY OF HEALTH

CABINET

Bulevardi "Bajram Curri" Tirana, ALBANIA, Tel/FAX +355 4 362937 – www.moh.gov.al

Prot. Nr_

Tirana, on....

O R D E R

For the restructuring of the

National Cancer Registry

(Draft)

NR. ., Dt. . .2011

Pursuant to Article ___ of Law No. ___ dated ____"", and the Law No.___ dated "" and in particular the articles (the law on statistics and health law)

1. All public and private health institutions that provide health services for diagnosis and treatment of diseases licensed by the Ministry of Health for this kind of activity must report the individual data for each case of cancer or pre-cancerous condition (Appendix of the diseases) from medical charters, registry data, according to the individual reporting form of the Cancer Registry.

2. The reporting form shall have a unified model, both for public and private health services.

3. There will be operating two types of reporting forms: one for laboratories and one for hospitals. These reporting forms are based on recommendations of the International Agency for Research on Cancer (IARC) (reporting forms are attached as appendixes…).

4. For the codification of neoplasms in the Cancer Registry the ICD-O system must be used (Created in 1976, the latest amended version in 2000).

5. For the electronic storage of data the software CAN-REC 4 must be used (the most updated software by IARC and specific package for Albania).

6. The reporting form of the Cancer Registry will be filled in by the physician who treats the patient and/or laboratory physician, which hold **administrative and legal** responsibility for the information being reported. The physician fills in, signs and seals the reporting form of the Cancer Registry.

7. The person in charge of chronic diseases in the Regional Health Directorates is responsible for collecting the reporting forms of the Cancer Registry. This person is responsible for gathering and sending the reporting forms in the Cancer Registry.

8. Regarding health services in the District of Tirana, reporting forms of the Cancer Registry will be gathered by the RHA and will be delivered in the premises of the Oncologic Hospital at TUHC.

9. The Cancer Registry Office will be physically located in the premises of the Oncologic Institute and will depend upon it. The office is responsible for the completing the abstract, coding of diseases and data entry.

10. The Administrative Unit (Office) of the Cancer Registry should, within one year from the publication of this regulation, submit for approval by the Board of Cancer, the status of functioning. The Board of Cancer approves scientific researches which are attached to the Cancer Registry. This statute must guarantee the preservation of privacy of personal data, to customize access to information and to ensure the periodicity of the publication of information.

11. Human resources and infrastructure for the functioning of the Cancer Registry, are provided from existing sources at the IPH and TUHC.

12. TUHC (Oncologic Institute) and IPH are responsible for producing the annual report of cancer control in Albania. The report contains analysis of data collected from the Cancer Registry and risk factors analysis, use of screening services and the opportunity for access across the country

13. For the implementation of this Order are charged: "Mother Teresa" University Hospital Center, Institute of Public Health and Regional Health Authority, Regional Health Directorates/Public Health Directorates.

14. For monitoring the implementation of this Order are charged the Directory of Hospital Planning, Directory of Public Health, Directory of Health Information and Technology, Directory of Juridical Services and Licensing of Private Activity at the Ministry of Health.

This Order shall take effect immediately.

M I N I S T E R

10. APPENDIX 4

Cancer Registry in Albania – The form of denunciation

Date, complete /__|__/__|__/__|__|__|__/ Case No. in the register|__|__|__|__|__|__|

Identification of the person

Name Family name Father's name

_____ _____ _____

Date of birth /__|__/__|__/__|__|__|__/ Age Sex 1= M 2= F

Place of birth_____|__|__|-|__|__|__|__|

Address_____

Address: Street name _____

District, Commune_____|__|__|-|__|__|__|__|_

Profession_____|__|

Civil status 1= Single 2= Married 3=divorced 4= widowed 9=unknown |__|

Tumor

Hospital Code of hospital Date Clinical chart No.

1_____|__|__|__|__| /__|__/__|__/__|__|__|__/ |__|__|__|__|__|__|__|__|

2_____|__|__|__|__| /__|__/__|__/__|__|__|__/ |__|__|__|__|__|__|__|__|

3_____|__|__|__|__| /__|__/__|__/__|__|__|__/ |__|__|__|__|__|__|__|__|

4_____|__|__|__|__| /__|__/__|__/__|__|__|__/ |__|__|__|__|__|__|__|__|

Laboratory Code of lab Date Registry No.

1_____|__|__|__|__| /__|__/__|__/__|__|__|__/ |__|__|__|__|__|__|__|__|

Topo. ICD-O(3)_____

_____|__|__| |__|

Morfo/beh/grade ICD-O(3)_____

_____

_____|__|__|__|__| / |__|__|

Source of diagnosis (Table 1): 0= (Death certificate) 1 = Clinical status only, **2= Surgery (must be removed).** 3= Radiology (scanner, ultrasound, magnetic resonance, XR) 4= bio-markers/himmuno/ hematology 5=cytology 6=histology of metastasis 7= main histology 8= autopsy 9= unknown |__|

Date of incidence /__|__/__|__/__|__|__|__/ Stage : T|__|N|__|M|__|

SEER Stages summary(table 2): 1= in situ, 2=localized, **3= direct regional nodules (** To be removed) 3= regional lymph nodules, 4=regional & metastasis, 5= distant metastasis,

9 = unknown |__|

Treatment 1 =yes

|__|Surgery |__|Radiotherapy |__|Chemotherapy |__|Immunotherapy|__|Hormone therapy

|__|Other

Follow up

Date of last contact/death /__|__/__|__/__|__|__|__/

Vital status: 1= alive 2= dead |__|

Cause of death _____3 digits ICD9 |__|__|__|

Table 1

Code	Description	Criteria
0	only death certificate	Information in the registry is only from DCO

Non Microscopic

1. **Clinic-**Diagnosis set before death, but without benefiting any of (2-7)
2. **Clinical investigation-** Includes all diagnostic techniques, X rays, endoscopy, NMR, Ultrasound, laparotomy and autopsy, without biopsy

4. Specific tumor markers include biochemical markers and/or immunological markers which are specific for different tumors.

Microscopy

5. Cytology- Examination of cells from primary or secondary sites, including fluid aspiration through endoscopy or needle. Also, it involves microscopic examination of peripheral blood.

6. Histology of metastasis – Histological examination of tissues taken from metastasis, including autopsy.

7. Histology of primary tumor – Histological examination of tissues taken from the primary tumor including all bone biopsy cutting techniques. Also, it includes the autopsy of primary tumor.

9 Unknown

Table 1.a. Specific tumor markers

Human Chorionic Gonadotropin	In choriocarcinoma diagnosis (usually > 100 000 iu in urine)
Prostate Specific Antigen (PSA)	In prostate carcinoma diagnosis (usually > 10 μg/l serum)
Alpha-fetoprotein (AFP)	In hepatocellular carcinoma diagnosis (usually > 200 ng/ml serum
Catecholamine degradation products	(HVA, VMA) In neuroblastoma
High serum immunoglobulin	Myeloma (IgG> 35g/l ose IgA>20g/l) Macroglobulinemia (IgM > 10g/l)
Urinary immunoglobulin	Myeloma (excretion > 1g/24hr)

"Specific" histological codes in absence of microscopic verification

ICD-O M

Code is not allocated for the purposes of specifying the basis of the diagnosis. However, it may be impossible for some specific morphological diagnosis without a histological or cytological examination.

This is the reason why the Register should set some internal control consensus, so that the combination of morphological codes 8001-9989 and the basis of diagnosis code 0-4, or 9 are open to verification. However, such combinations are presented in Table 1 b.

Table 1.b. Combination of specific morphological codes, and non-microscopic basis of diagnosis codes, which are considered as acceptable

Morphology	Most valid	Other criteria	
Code	**Description**	**Basis**	
8800	(Sarcoma NOS)	2	
9590	Lymphoma NOS	1 or 2	
9800	Leukemia NOS	1 or 2	
8720	Melanoma	1 or 2	
9140	Sarcoma Kaposi	1 or 2	HIV positive
8969	Nephroblastoma	2	Age 0-8
9100	Choriocarcinoma	4	F and age 15-49
9500	Neuroblastoma	2 or 4	Age 0-9
9510	Retinoblastoma	2	Age 0-5
9732	Myeloma	4	Age 40+
9761	Macroglobulinemia Waldenstrom	4	Age 50+
8170	Hepatocellular Carcinoma	4	
8150-8154	Tumor of pancreatic cells	4	

9380	Glioma	2	C71.7
9384/1	Subependymal astrocytoma	2	tuberous sclerosis patient
9530-9539	Meningioma	2	C 70
9350	Craniopharyngioma	2	
8270-8281	Pituitary Tumor	4	C 75.1

Clinical Laboratories Reporting Form

<table>
<tr><td>Name Father’s Name
Family Name</td><td colspan="2">Identifying number</td><td><table><tr><td></td><td></td></tr></table>Sex 0 1

Male Female</td></tr>
<tr><td>Sender of the material
(hospital or physician)</td><td></td><td>autopsy
histology
cytology(including fine needle biopsy)</td><td></td><td>Number (in the register)
and date of material</td></tr>
<tr><td colspan="5">Primary location</td></tr>
<tr><td colspan="5">Other locations</td></tr>
<tr><td colspan="5">PAD<table><tr><td>1</td><td>From primary tumor</td></tr><tr><td>2</td><td>From metastasis</td></tr><tr><td>3</td><td>No information available</td></tr></table></td></tr>
<tr><td colspan="4">Pathologists</td><td>Laboratory</td></tr>
</table>

Clinical diagnosis (if known)	
Notes	**Date**

INFORMATION / COMMENTS

1.
PATIENT INFORMATION
1-11 Number of person ddmmyyCcccx
(1/1) < 1, line > dd day of birth
mm month of birth
yy year of birth
C century of birth
+ = 1800
- = 1900
A = 2000
ccc number recorded by (VRK)
x = check digit (VRK rule)
12-61 Name, Family name, first name
(1/2) < 2. Line > (max 50 characters)
62-101 Name E.g. mother's name
(1/3) < 3. Line > (max 40 characters)
102 Sex Code:
(1/4) < 4. line > 0 = male
1 = female
103-120 Commune Code or
(1/5) < 5. line > name of commune
121-160 Complete name of the hospital
(1/6) < 6. Line >
161-200 Name Family name of the physician (max 40 characters)
(1/7) < 7. Line>

2.
SAMPLE INFORMATION
1 Type of sample Kod1: 1 = autopsy
(2/1) < 8. > 2 = histological sample
3 = cellular sample
9 = no information available
2-31 Identification number of the sample according to laboratory system
(2/2) < 9. > laboratory
32-37 Date of analysis ddmmyy
(2/3) < 10.>
38-97 Primary location
(2/4) < 11.>; code can be attached as additional information
98 Object i PAD Code: 1 = primary tumor
(2/5) < 12. line > 2 = metastasis
9 = no information available
99-228 PAD Plain text, does not depend on the code
(2/6) < 13.line >

3.
1-40 Pathologist Family name Name

Additional INFORMATION
41-105 Clinical text, does not depend on the code
diagnosis
(3/2) <15.>
106-170 Other tumors, description
(3/3) < 16. > Other known cancers
171-173 Denunciation (Three digit code is recorded from the Cancer Registry)
(3/4) < 17. >

4.
1-250 Additional information
additional information about sample and/or tumor
(4/1) <18.-25.> if no additional information available

5.
1-250 Supplement, additional information

(5/1) information

11. APPENDIX 5

ACTION PLAN TO ESTABLISH THE NATIONAL CANCER REGISTRY IN ALBANIA (NCRA)

Prepared by:

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- Ferdinand Jorgoni (Hospital Cancer Registry, "Mother Teresa" University Hospital)
- Maldi Dema (Director of Human Resources, INSTAT).

Acknowledgments,

Availability of a Cancer Registry in Albania is a necessity nowadays, especially as the country has left the transition stage behind even in health profile.

Infectious diseases are not anymore in the foreground and chronic conditions account for major causes of death. Amidst the leading causes of death, deaths from cancer rank second.

On this occasion, we would like to thank the Italian Cooperation for Development and the Italian Embassy in the Republic of Albania, for their support in preparing this document.

Tirana, March 2011