

**SLOVENE NATIONAL CANCER CONTROL PROGRAMME  
2010-2015**

**February 2010**

## INTRODUCTION

The National Cancer Control Programme (NCCP) is a programme of activities, tasks and measures, which are necessary for efficient action in the field of cancer control in Slovenia. New actions have been added to those already being carried out in order to ensure future control over this disease. The NCCP supplements the Resolution on National Plan of Healthcare 2008-2013 "Satisfied Users and Performers of Medical Services" as an independent programme.

The key reason for the production of the NCCP is the fact that cancer is becoming the most important issue for public health - in Slovenia as well as globally.

Cancer is a disease that can develop in all tissues and organs in the human organism and affects both sexes approximately equally. It can appear in people of all ages, but 80% of cancer cases occur after the age of 54. Due to the ageing population, the number of cancer patients is expected to increase. Cancer is thus becoming an important health, social and economic problem facing modern society. According to data from the Slovene Cancer Registry, it is projected that of those born in 2005, approximately 1 in 2 men and 1 in 3 women will develop cancer by the age of 75.

Approximately 11,000 Slovenes develop cancer each year, of this, approximately 5,500 men and 5,200 women. Over 5,000 Slovenes die of cancer each year, of this, approximately 2,800 men and 2,300 women. 50% of men and 65% of women survive five years after being diagnosed.

In the last 10 years (from 1996 to 2005), the incidence of cancer in Slovenia has increased by 40% in men and 35% in women, mortality has increased by 11% in men and 14% in women. Over half of the increased cancer incidence can be attributed to the ageing population. With the further increase in the ageing population, we can expect that the number of new cancer cases will increase, as will the burden on healthcare services.

Epidemiologists forecast that cancer would soon become the leading cause of death and would surpass cardiovascular disease in this respect; this has already been proven true in certain countries, making cancer the main health problem facing humanity. The gradual reduction of mortality from cardiovascular disease can be attributed to the increasing success of prevention, diagnosis and therapy in the field of cardiovascular disease. The most common cancers in Slovenia (skin, colorectal, lung, as well as breast and prostate) are connected to unhealthy lifestyles, smoking, unhealthy diet, excessive alcohol consumption and overexposure to the sun. These risk factors must be reduced by actions in the field of primary prevention, as at least one third of cancer cases are preventable. Prevention is proven to be the most efficient and thus the most powerful weapon in reducing the cancer burden in any individual country. All existing knowledge and methods must be utilised and implemented in the policies of all government agencies in cooperation with involved stakeholders.

The most important method for reduction of mortality from breast, colorectal and cervical cancers (and reduction of incidence for the last two) is the provision of high quality screening programmes, such as ZORA, DORA and SVIT, which are being implemented in Slovenia.

In Slovenia, all cancer patients have the right of equal access to quality treatment, which is provided in the framework of compulsory health insurance. Survival of Slovene cancer patients is increasing, but in the case of the most common cancers, is still beneath the EU average. This can be improved by educating the population but primarily, by better organising healthcare services.

Due to the increasing number of patients and implementation of new methods of diagnostics and treatment, the steady increase of expenditure for cancer control can be expected. For this reason, it is necessary to adapt current healthcare methods to the demands made in the field of cancer control by contemporary methods of prevention, diagnosis, healthcare and comprehensive rehabilitation, palliative care and research. At the same time, it is necessary to ensure the systematic monitoring of the effectiveness of the actions and activities being undertaken.

## **BASIC PREMISES OF THE NCCP**

The Ministry of Health appointed an expert working group that prepared the premises for the development of the NCCP. The working group consisted of top experts in the field of cancer control, who also possess a large working knowledge of the healthcare system. The Ministry of Health then summarised the premises and proposed tasks and actions, which are now presented in the NCCP.

The NCCP has the following overall objectives:

- to assess the situation in the field of cancer control in Slovenia up to this point;
- to propose a comprehensive strategy for cancer control in Slovenia until 2015 (target year of the current NCCP),
- to determine priority actions and measurable goals in all fields of cancer control: prevention, early detection and screening, diagnosis, specific and palliative treatment and rehabilitation of cancer patients,
- to propose collecting indicators for fields in which data on current status is lacking, which will ensure monitoring of progress.

The professional orientation of the NCCP is based on the assessment of the World Health Organization (WHO) that cancer incidence can be decreased by 30% through actions in the field of primary prevention. This is why the NCCP is directed at increasing recognition of the important role of primary prevention in cancer healthcare (CHC), as well as increasing the range of prevention activities.

Since the anticipated results of primary prevention are long-term, the target population are inhabitants that will be diagnosed with cancer in the near future. Early detection, accurate specification of stage and individualised early treatment methods are the most important for ultimate success. The majority of the NCCP is thus targeted to the organisation and execution of secondary prevention activities as well as all the other activities in the framework of OHC. The current situation in Slovenia, namely the scattered nature of CHC, does not allow for the comprehensive treatment of the cancer patient, which must besides good diagnostics and treatment also provide the patient with comprehensive rehabilitation, psychosocial support and palliative care. The NCCP also gives large importance to organisations executing activities in the fields of secondary and tertiary prevention, which will ensure a multidisciplinary approach and the comprehensive treatment of the patient (diagnostics, treatment, rehabilitation and palliative care), as well as professional monitoring of the implemented activities. In order to achieve the above objectives, the NCCP seeks to encourage better connections at the primary level, a concentrated CHC system, a network of specialists at the secondary level and the use of modern information systems.

A variety of specific actions are needed in order to achieve the objectives set out by the NCCP, all of which are further specified in individual chapters of this programme. A system for the monitoring and surveillance of NCCP implementation is also outlined at the end of this document.

## **SPECIFIC OBJECTIVES OF THE NCCP**

- **To slow the increase of cancer incidence:** through effective primary prevention, to prevent the increase of age standardised incidence levels – acceptable increases in men are 5% based on the status in 2004/2005, in women 8 % based on the status in 2003/2004.
- **To decrease cancer mortality rates:** alongside slower increase in incidence, earlier detection and quality healthcare, the objective is to achieve a further decrease in age standardised mortality rates in men and women by 10 % based on the status in 2004/2005.
- **To increase survival rates:** to increase the five-year relative survival rate in both sexes; by 10 % in men and by 12 % in women (comparing the period 2001–2005 to the period 2011–2015).

- **To improve the quality of life of cancer patients** with psychosocial and physical rehabilitation and to increase the amount of patients with advanced stage illness that receive **palliative care**.

## **SUMMARY OF TASKS AND MEASURES FOR SPECIFIC FIELDS**

### **1. in the field of primary prevention:**

- a. increase of personal responsibility for health through health promotion and encouragement of healthy lifestyles,
- b. providing conditions for healthy choices and a healthy environment through the restriction and monitoring of chemical, physical and biological carcinogens in work and living environments.

### **2. in the field of secondary prevention:**

- a. establishment of organised national screening programmes for cervical cancer (ZORA), breast cancer (DORA) and colorectal cancer (SVIT) nation-wide, in accordance with quality standards and achievement of adequate response levels,
- b. ensuring greater effectiveness in early detection of cancer at the primary healthcare level.

### **3. in the field of diagnostics and specific oncological treatment:**

- a. concentration of diagnostics and treatment at second level healthcare,
- b. production of clinical guidelines for treatment,
- c. ensuring multidisciplinary treatment of patients,
- d. ensuring equal access to high quality healthcare services.

### **4. in the field of comprehensive rehabilitation of cancer patients:**

- a. establishment of comprehensive psychosocial rehabilitation with the help of interdisciplinary teams at all levels of the healthcare system.

### **5. in the field of palliative care for cancer patients:**

- a. definition of services within palliative care,
- b. establishment of a palliative care network for cancer patients in accordance with the national programme for palliative care.

### **6. in the field of education:**

- a. supplementation of educational programmes in oncology for all groups of professionals,
- b. monitoring of continued education,
- c. active inclusion of non-governmental organisations in informing the public about cancer.

### **7. in the field of research activities:**

- a. ensuring better connections between research groups,
- b. encouraging greater involvement in international projects,
- c. encouraging academic research,
- d. providing stable financing for research,
- e. ensuring greater access of patients to participation in clinical trials.

### **8. in the field of informatics:**

- a. standardisation of health documentation, from clinical history to all test results,
- b. ensuring a gradual transition to electronic management of all health documentation at all levels of CHC,
- c. inclusion of the Slovene Cancer Registry in IT.

### **9. in the field of financial efficiency:**

- a. monitoring expenditure through the efficient use of IT support.

### **10. in the field of cooperation with civil society:**

- a. inclusion of civil society in decision-making processes and shaping of health policy,
- b. inclusion of civil society in informing the public and patients about their rights and responsibilities.

### **11. in the field of coordination and monitoring of NCCP implementation:**

- a. .appointing the Council for Monitoring NCCP Implementation.

## MEASURES ACCORDING TO FIELD

### *1 PRIMARY PREVENTION*

Primary prevention is surely among the most important approaches to effective cancer control. Through controlling all key risk factors, such as smoking, harmful alcohol consumption, unhealthy diet, lack of physical activity and obesity, harmful sun exposure and exposure to carcinogens in work and living environments, 40 % of all cancers could be prevented.

Primary prevention works in a very broad manner, as the majority of risk factors for cancer are common to all chronic diseases. It is important to realise that primary prevention spans various policies, health promotion activities and prevention programmes, which are targeted at controlling recognised individual risk factors connected to lifestyle and living and work environments.

- ***Health Promotion***

There is a clear need in this field for an **increase in personnel in the field of public health**, which would ensure adequate professional support for decision-making in health and other agencies and thus ensure the concept of health in all policies and reduction of inequalities in healthcare.

#### **Tasks and Measures:**

1. Ensuring the implementation of the concept "health in all policies",
2. Reducing health inequalities and differences in exposure to risk factors across various regions and different population groups,
3. Strengthening the field of public health in terms of knowledge and personnel and ensuring better cooperation between public health professionals, civil society and policy makers,
4. Increasing public knowledge on the connection between cancer and associated risk factors,
5. Producing a comprehensive model for health promotion and education of children and youth in all phases of development,
6. Providing a uniform system for monitoring the efficiency of all measures in the field of health promotion and primary prevention, to be based on indicators comparable to those used in other countries.

- ***Healthy Lifestyle***

A healthy lifestyle can be an important factor in decreasing cancer incidence. In this field, Slovenia has had several successes, but there is still room for improvement.

In 1996, Slovenia passed the Restriction of the Use of Tobacco Products Act, which had a key role in reducing the number of smokers. In 2007, Slovenia supplemented this law and joined the rank of countries with a complete ban on smoking in all indoor public spaces and in the workplace. Additional measures must still be taken to decrease the number of smokers.

Consistent implementation of the Resolution on the National Nutritional Policy Programme 2005-2010 (passed in 2005) and the Republic of Slovenia Government Strategy in the Field of Physical Activity for Strengthening Health 2007-2012 will contribute to the reduction of the cancer burden.

Amongst European countries, Slovenia stands out in regards to the harmful effects of excessive alcohol consumption (liver cirrhosis, alcohol related accidents, etc.). Cancer

(primarily cancer of the mouth, oesophagus and liver) is just one of the harmful effects of excessive alcohol consumption. Apart from the implementation of the Act Restricting the Use of Alcohol (Uradni list RS, no. 15/03), a comprehensive policy must be put into place in order to reduce harmful alcohol consumption and its consequences.

#### **Tasks and Measures:**

1. New methods must be put into place to ensure future non-smoker generations; smokers must be given support in quitting smoking.
2. Regular monitoring of smoking patterns amongst adults and youth by sex must be continued, as well as ensuring the monitoring of smoking patterns in high-risk groups.
3. Consistent implement of the Restriction of the Use of Tobacco Products Act (Uradni list RS, no. 93707 –official consolidated text) must be ensured and new measures must be taken in line with new information on the efficiency of individual measures.
4. The goals set out in the Resolution on the National Nutritional Policy Programme 2005-2010 and the Republic of Slovenia Government Strategy in the Field of Physical Activity for Strengthening Health 2007-2012 must be realised.
5. A comprehensive policy and implementation plan for the reduction of harmful alcohol use must be passed and implemented.

#### • ***Living and work environments***

In Slovenia, there is a lack of information on the types of carcinogens workers are exposed to and the number of exposed workers. Likewise, there is not enough data on the concentration of chemical substances in work and living environments. With the exception of “asbestos studies”, there are no studies in Slovenia exploring the connection between cancer and exposure to carcinogenic substances in work and living environments. This is why very few cancers in Slovenia are in practice linked to exposure to chemical substances, although many of these chemicals are known to cause cancer.

#### **Tasks and Measures:**

1. Monitoring of carcinogens present in living environments must be carried out and measures must be implemented to reduce their presence.
2. A higher level of awareness must be reached in workers, employers, doctors, professionals and labour inspection officials about the effects of exposure to carcinogens and what can be done to prevent such exposure.
3. Every organisation must make consistent records regarding their use of carcinogens, their concentration and the disposal of carcinogen waste products,
4. Adequate technical and other measures must be ensured in order to prevent exposure to carcinogens in work and living environments.
5. Records must be kept of all locations (places of employment and other locations, illegal waste dumps and official disposal sites) that have been polluted with carcinogens and plans should be made for their redevelopment, beginning with planned and professionally led cleaning activities.
6. Workers who have already been exposed to carcinogens must be adequately protected and educated, so that their actions will not harm themselves and others.
7. Asbestos polluted locations should be clean uncontaminated by 2013 so that an actual reduction in the incidence of mesothelioma could be achieved by 2020.

#### • ***Non-ionising radiation***

Because the development of skin cancer (including melanoma) is linked to overexposure to ultraviolet radiation of both natural and artificial sources, activities must be geared to

reducing exposure to the lowest possible levels and ensuring the timely detection of all suspicious changes to the skin. As regards other forms of non-ionising radiation (primarily low-frequency electromagnetic waves), caution should be exercised, although there is currently not enough information on its carcinogenic properties.

**Tasks and Measures:**

1. Support and coordination must be given to preventive programmes aimed at various target groups with the aim of reducing exposure to ultraviolet radiation and early detection of suspicious skin changes.
2. Heightening surveillance of tanning beds is required as well as increasing public awareness of the harmful effects of non-ionising radiation. It is also necessary to follow the latest scientific research on the effects of non-ionising radiation on health and objectively inform the public.

• ***Ionising radiation***

The monitoring of ionising radiation in the workplace is governed by various international and national regulations. The population is most at risk due to natural sources (radon) and the non-critical use of diagnostic and therapeutic tools.

**Tasks and Measures:**

1. The level of exposure of patients in diagnostic and other treatments must be reduced.
2. Doses of radiation received during diagnostic procedures should be recorded in the clinical record or noted electronically on the patient's health card.
3. Consistent implementation of the Ionising Radiation Protection and Nuclear Safety Act (Uradni list RS, no. 102/04 –official consolidated text and 70/08) must be ensured, along with other regulations monitoring this field.
4. The level of exposure of the population in buildings that house and carry out educational or cultural programmes (or any buildings where individuals gather for prolonged periods of time) should be reduced, in line with the above regulations.

• ***Infections linked to cancer***

Some infectious diseases, for which vaccines exist, are linked to the development of cancer. In Slovenia, vaccinations against the Hepatitis B virus and some types of the Human Papilloma Virus (HPV) are included in the national immunisation programme.

**Tasks and Measures:**

1. Execution of preventive measures for personal protection against HPV infection,
2. Monitoring of vaccination of target groups against HPV infection.

## ***2 SECONDARY PREVENTION***

Treatment of the majority of cancers is more successful if diagnosed at an early stage. Secondary prevention thus encompasses the early recognition of symptoms by the individual and the timely diagnosis of changes by the doctor. On one hand, we would like to inform the

public of early symptoms and signs of cancer through health education and on the other, train doctors to properly diagnose these symptoms as soon as possible. Through organised screening programmes, that is with the help of simple tests, we uncover pre-invasive or early invasive forms of cancer in people without clinical problems; these early forms of cancer do not yet cause clinical problems. The main element of organised screening programmes is the active invitation of individual population groups to tests, in addition to the monitoring of programme indicators.

On the basis of current scientific evidence, it is recommended that organised population-based screening programmes are implemented for cervical cancer (pap smear examination) in individuals aged 20 – 30, breast cancer (mammography) in individuals aged 50 - 69 and colorectal cancer (faecal occult blood test) in individuals aged 50 - 74. These programmes can only be effective if they include at least 70% of the target population.

In Slovenia, the ZORA screening programme (population-based screening for cervical cancer) has been underway since 2003. The DORA screening programme (population-based screening for breast cancer) began in 2008. The headquarters for both programmes is the Institute of Oncology Ljubljana, which monitors and assesses the success of the programmes from data in the screening registries. The headquarters of the SVIT screening programme (population-based screening for colorectal cancer), which began in 2009, is at the National Institute of Public Health of the Republic of Slovenia.

- ***Cervical Cancer Screening (ZORA programme)***

The national ZORA screening programme began in 2003. The programme is implemented by reproductive health teams – gynaecologists in outpatient clinics, while the coordination, central information system and monitoring of the programme is executed by the Institute of Oncology Ljubljana. The success of the programme is attested by the fact that in the period from 2004 to 2006, almost 70% of women in the age group from 20-64 had their pap smears examined in a three year period. In 2006, there were 161 new cases of invasive cervical cancer reported in the cancer registry, which is 23% less than in 2003 (206 new cases), in 2008, there were 130 new cases reported, which is 38% less than in 2003.

Activities in the following years must be aimed at the fulfilment of two objectives, namely that 80% of women in the ages from 20 to 64 have a pap smear examined in a three year period and that incidence of cervical cancer will fall by 50% based on 2002 values (at most 100 new cases).

#### **Tasks and Measures:**

1. It is necessary to implement a network of laboratories for cytopathology and pathology, which will meet the quality standards of the screening programme.
2. Results of pathology reports must be standardised and a computer database must be implemented, all laboratories must be connected through a central information system.
3. Gynaecologists must be given direct access to the central database of laboratory results.

- ***Breast Cancer Screening (DORA programme)***

An organised screening programme for breast cancer began in 2008 in the Ljubljana region. It will gradually spread to encompass the entire country. It is planned as a centralised system with two stationary diagnostic screening units (Ljubljana, Maribor) and mobile units, which will be equipped with digital mammography sets. Women aged 50 - 69 will be included in the programme; those with abnormalities in their screening mammography, which will be reviewed by two additionally trained radiologists, will be invited for further tests and if necessary, treatment at one of two centres, the Institute of Oncology Ljubljana or the University Medical Centre Maribor. Activities in this programme also aim at the fulfilment of two objectives: inclusion of 80% of women aged 50 - 69 in the organised screening



programme and reduction of mortality from breast cancer in the population participating in the programme by 30%.

### **Tasks and Measures:**

1. To implement the proposed organisational structure and ensure the implementation of the organised screening programme across the entire country.

- ***Colorectal Cancer Screening (SVIT programme)***

The national screening and early detection programme for colorectal cancer, SVIT, is aimed at women and men aged 50 - 69. Individuals from the target population will be included in the programme every two years. The screening procedure is carried out through an immunochemical test for faecal occult blood, which enables detection of individuals which may possibly have developed colorectal cancer. Individuals that test positive in the faecal occult blood test will be invited to a colonoscopy.

As in all organised screening programmes, besides the adequate participation of the target population in the programme, which must be over 50% (optimally 70%), the precondition for success is the quality of all segments of the screening programme. Activities will be aimed at achieving a 50% response rate of those women and men aged 50-69, who must carry out their first faecal occult blood test, as well as reducing the incidence of colorectal cancer in the screening population by 25% and reducing mortality from colorectal cancer in the screening population by around 33%.

### **Tasks and Measures:**

1. Implementation of organised screening across the country and soliciting responses from those invited to participate in the programme.

- ***Early detection of cancer (not in the framework of national screening programmes)***

Opportunistic screening of completely asymptomatic individuals not part of the determined target groups and organised programmes is not recommended. It is of course necessary, regardless of age, to find a cause for any changes that could be an early form of cancer - this is early detection. All such cases are about discovering the early symptoms that may indicate the possibility of cancer. The success of such detection is practically equally dependent on the education of the individual and population as well as the cancer education of the doctor in the primary healthcare system.

An educated doctor will more easily explain the importance of self-examination to his patient, as well as better detect the early symptoms of cancer. An informed patient will not hide the early symptoms. Both must be well informed on modern methods and successful diagnostic methods and treatment of cancer. Most important in this process is good communication between both, which must be based on modern medical findings. The role of the family doctor or general practitioner in early detection of cancer is important due to the fact that they are aware (or should be aware) of the individual's family history of cancer, social background, social status, psychosocial state (excessive stress), habit forming behaviours (alcohol, smoking), dietary habits, exposure to carcinogens during work and other risk factors. All the above information must be noted in the documentation, so that upon the appearance of suspicious symptoms, they can be connected to one another.

The above measures should help achieve a rise in the number of patients with localised illness by 10% in the following years, due to successful early detection (not in the framework of screening programmes).

Early detection of cancer at the primary level spans all the most common forms of cancer which are not included in organised screening programmes. These are: colorectal and breast cancer (for those individuals not included in screening programmes), skin cancer, lung cancer, cancers of the ENT area and urological cancers. Select gynaecologists are responsible for gynaecological cancers. Doctors at the primary level must be well acquainted with warning signs of illness and referral to diagnostic centres. Since early diagnosis tasks cannot be separated from other activities at the primary level, they are listed together with the OHC tasks at the primary level in the next chapter.

#### **Tasks and Measures:**

1. Implementation of planned training for general practitioners and other primary level doctors on early detection of cancer,
2. Informing the public about the early symptoms of cancer.

### ***3 DIAGNOSTICS AND SPECIFIC ONCOLOGICAL TREATMENT***

The diagnostics and treatment process of cancer is usually complex and demands the cooperation of a number of medical and healthcare services. Apart from cell-tissue specialists, imaging diagnostics and several surgery subspecialisations, treatment can also involve gynaecologists, haematologists, pulmonologists, dermatologists, neurologists, paediatricians, psychiatrists, ophthalmologists and others. Modern treatment of cancer cannot occur without radiotherapy specialists completely trained for oncology (radiation therapy) and oncology internists (systemic treatment). Such an approach is **multidisciplinary** in nature. If fields and activities such as psycho-oncology, pharmacy, nutritional science, rehabilitation and nursing, which can add to the quality and success of treatment, are also included, then we may speak of a **multiprofessional** approach.

*The tertiary level of treatment for cancer patients* in Slovenia consists of connections between several specialist activities of the Institute of Oncology Ljubljana (IOL), University Medical Centre Ljubljana (UKC LJ), University Medical Centre Maribor (UKC MB) and the University Clinic of Pulmonary and Allergic Diseases Golnik (KOPA) and also includes the Pathomorphological Institute of the Medical Faculty of Ljubljana (MFLJ). The connections between the above institutions provide the most modern diagnostics, multidisciplinary treatment, modern methods of combined treatment, professional healthcare services, various counselling options and hospital palliative care. These activities, which together act as a comprehensive cancer centre, are executed only in the greater Ljubljana region. The other applicable term in this section is a regional oncology centre, which according to the WHO definition, must at least include independent radiotherapy and medical oncology departments. However, it is not rational to duplicate activities at a tertiary level in Slovenia.

*The secondary level of treatment for cancer patients* in Slovenia is executed in 15 general and specialised hospitals. Currently, a general organisational and professional criterion for these hospitals does not exist. A multidisciplinary approach prior to the patient's first treatment is made possible in some hospitals with the help of an organised consultation service in conjunction with IOL or other tertiary institutions. Primary level treatment is not recorded in the Slovene Cancer Registry, as patients from this level are generally referred to treatment at the secondary or tertiary levels. There is data however which shows that 880 cancer cases (8% of all treated cases in Slovenia) were diagnosed in 2004 outside the framework of secondary and tertiary level institutions, of these 402 (46%) of patients were referred to IOL. In Slovenia, diagnostics and treatment of circa 60% of cancer patients is executed in four medical institutions at the tertiary level (three of these are in the greater Ljubljana area and one in Maribor). In recent years, the need for the best possible expert treatment of patients has brought about a concentration of diagnostics and treatment for thyroid and testicular cancer, soft-tissue sarcomas, melanoma, malignant lymphoma and rare tumours. Since then and despite some remaining unresolved issues, we have matched or even exceeded the

European average as measured in international studies of cancer patient survival in Europe (for example, EURO CARE IV). In a broader sense, we can also add lung cancer patients as having concentrated treatment, although the need for improvement in organising imaging diagnostics and non-surgical treatment methods ensures that lung cancer patients are still not being offered equal access to treatment. Treatment of patients with common forms of cancer, such as breast and colorectal cancer, is too scattered and occurs in numerous hospitals. Due to unequal conditions for implementing diagnostics and treatment, this can only be said to be valid for urological and gynaecological cancers as well as non-melanoma skin cancer.

### **Tasks and Measures:**

1. Within the framework of options available in Slovene public health, all citizens that have been diagnosed with cancer must be allowed access to treatment of equal quality at all healthcare levels.
2. All cancer patients in Slovenia must be given a better chance of survival, as well as the possibility for a higher quality of life.
3. Objectives will only be achieved through expert monitoring on the basis of uniform health documentation, which will also allow for a quality comparison of various healthcare levels.
4. Patients must be given access to data comparing the treatment quality of various medical institutions.

## **3.2 Cancer diagnostics by fields**

The process of diagnostics and treatment of cancer patients includes several specialists, which join to form **multidisciplinary teams**. The success of the team is based on:

- the training of the specialists and cooperation between them,
- their equipment and human resources.

### **3.2.1 Cell-tissue and molecular diagnostics**

This is the only type of diagnostics that enables a diagnosis of malignancy and accurate determination of the type of cancer; the examination of the surgical sample allows for a more accurate determination of cancer stage and determines several prognostic factors, which all affect the selection and order of treatment methods. In Slovenia, histopathological and cytopathological diagnostics are carried out in various departments of medical institutions (IOL, UKC MB, Celje, Izola, Nova Gorica, Novo Mesto, Slovenj Gradec, Murska Sobota and the Gynaecological Clinic at UKC LJ), and at the Diagnostic Centre Bled and at the Pathology Institute at MFLJ, which is not a health institution. An actual concentration of diagnostics has only come about for types of cancers where treatment is carried out in specifically defined institutions (lymphomas, hematologic malignancies, paediatric cancer, germ cell cancer, cancer of soft tissues and bones and thyroid cancer). For some forms of cancer (lung cancer, cancer of the central nervous system and ENT), cell-tissue diagnostics are more or less concentrated, for other cancers, diagnostics are scattered as they follow the implementation of surgical activities. This is why the quality of results also varies. Diagnostics directly affects the decision to select an expensive new drug, which is why the scattering of specialists and necessary equipment across numerous departments needlessly increases treatment costs. If the secondary level cannot ensure the necessary direct cooperation between cyto- and histopathologists, diagnostic imaging specialists and specialists in surgical fields, then the development of oncology activities is not worthwhile. The execution of expensive tests, which require specialised equipment and high levels of required expertise, is best concentrated at the tertiary level.

### **Tasks and Measures:**

1. The most modern equipment and diagnostics with dedicated personnel must be concentrated in three tertiary institutions in Slovenia (MFLJ, IOL and UKC MB) at most. It is

necessary to evaluate consultant activities; pathology departments in tertiary institutions must have the possibility of archiving frozen tissue samples.

2. Cancer oriented diagnostics at the secondary level should operate in the framework of multidisciplinary teams and on the basis of organ systems for which the hospital will also carry out diagnostic imaging and operative treatment, in the framework of CHC authorisation. In this regard, the exception is the execution of aspirational and exfoliative cytological diagnostics.

### **3.2.2 Diagnostic Imaging**

The role of diagnostic imaging in the framework of OHC is primarily to determine loco-regional and systemic spread of the disease and consequently the operability and to monitor the efficacy of treatment. The epidemiology of cancer in Slovenia dictates also the need for an oncological orientation in the field of diagnostic imaging. This refers to radiological imaging (x-ray, ultrasound, CT, MRI), nuclear medicine imaging (scintigraphy, PET) and combined imaging (PET-CT). Purchase of equipment in this field must be premised on expert and economic bases. At the primary level it is necessary to carry out a basic x-ray and ultrasound diagnostic scan to ensure the patient's preparedness for surgery. Imaging diagnostics, which determines the stage and operability of cancer and is often connected to interventions (biopsies, injection of catheters) can at the second level only be carried out by trained specialists. Directed, complex and expensive tests within specific organ systems can be found at the tertiary level, which are directly connected to therapeutic fields (for example, PET-CT scans in the assessment of therapeutic effects and planning of radiotherapy, therapeutic procedures connected to nuclear medicine, diagnostics of unseen changes and sentinel lymph nodes, rare tumour oriented diagnostics, MRI in connection with brachyradiotherapy, execution of stereotactic radiotherapy and radiofrequency ablation).

#### **Tasks and Measures:**

1. A more detailed definition of the range of diagnostic imaging at the primary level of CHC is necessary, which must be also be included in updated guidelines.

2. Oncology oriented diagnostics at the secondary level should operate in the framework of multidisciplinary teams and on the basis of organ systems for which the hospital will also carry out diagnostic imaging and surgical treatment, in the framework of CHC authorisation. The activity must follow guidelines of a multidisciplinary nature. Clinical pathways must be put in place for the most common forms of cancer.

3. It is necessary to prepare and finance a post-specialist educational programme of oncology in the fields of ultrasound, CT and MRI scans for radiologists, who will be carrying out oncological activity at the secondary level in future. Hospitals carrying out activities in the framework of CHC must be equipped with digital technology and adequate information systems. The quality of the test execution must be uniform at all institutions, as should the recording of the test results in electronic format.

4. It is necessary to provide a unified overview of waiting periods for CT and MRI scans for all operators in the framework of the public health system (including concession operators) and thus ensure cancer patients timely access to diagnostics.

5. The purchase and implementation of equipment for CT and MRI diagnostics must follow professionally sound principles. The Expanded Professional Collegium for Radiology must, on the basis of current needs, provide a five year needs assessment for CT and MRI diagnostics in oncology. Apart from designating in advance the number of machines and the place of installation, adequately trained professionals must also be provided. The same is valid for further installation of PET-CT diagnostics.

### **3.2.3 Endoscopic diagnostics**

This method of diagnostics, which simultaneously enables the removal of tissue for diagnosis and an assessment of local operability, is mainly overlooked in planning needs of

CHC. It is carried out by surgeons (abdominal, thoracic, urological and ENT orientations) and internists (gastroenterologists and pulmonologists), gynaecologists and radiotherapists.

#### **Tasks and Measures:**

1. In treatment guidelines for specific cancer types, it is necessary to determine which specialists and which institutions should carry out endoscopic diagnostics of cancer.

### **3.3 Treatment of cancer patients by field**

#### **3.3.1 Initial treatment of cancer patients**

The most important element for the successful treatment of cancer is the initial treatment. The first treatment must be planned by a **multidisciplinary team**, which must record their conclusions in the form of standardised documentation. All team reports must be collected in a common national database – the Slovene Cancer Registry.

#### **Tasks and Measures:**

1. The first treatment of all cancer patients must be in accordance with accepted guidelines and must be planned by multidisciplinary teams.

2. Documentation from multidisciplinary treatment must be standardised and provided to the Slovene Cancer Registry.

#### **3.3.2 Surgical activities**

The role of the modern cancer surgeon is as an equal member of a multidisciplinary team; together with professionals from complementary fields (diagnostics, radiotherapists, medical oncologists), they cooperate in all aspects of treatment of the cancer patient – prevention, diagnostics, treatment, monitoring and palliative care. Surgical treatment of cancer in Slovenia is currently organised in diverse ways. For some years, certain types of cancer have been operated on in a concentrated manner only in the larger centres (both University Clinical Centres, Institute of Oncology Ljubljana). Usually these are relatively rare tumours (annual incidence of around 100 new cases in Slovenia) with a specific localisation. The results of treatment of these demanding types of cancer are already comparable to those across Europe. Surgeons from surgery departments across Slovenia operate on other types of more common cancers (annual incidence over 1,000 new cases) – these are mainly breast cancer, colorectal cancer, prostate cancer and skin cancer. Unfortunately, Slovenia does not currently have treatment guidelines and clinical pathways for the majority of cancers; where guidelines do exist, we do not have surveillance over their implementation. Due to differences in surgical knowledge and experience as well as differences in other activities (diagnostics, pre and post-operative treatment and healthcare), results of treatment across different hospitals (regions) in Slovenia vary greatly. Unfortunately, the consequence is an approximately 15% lower five-year survival rate of Slovene patients with these types of cancers (EUROCORE-IV study). Because this lower survival rate affects more patients with cancer types for which treatment is not concentrated, this worse treatment affects the overall success rate of cancer treatment in Slovenia, which does not match the levels found in developed Europe.

Along with special knowledge of surgical procedures, surgical oncology must also encompass knowledge of various diagnostic, clinical, supporting and reconstructive and rehabilitative medical procedures, which ensure the patient survival under the best possible conditions.

#### **Tasks and Measures:**

1. All cancer patients in Slovenia must be allowed professional and quality surgical treatment and have equal access to surgical treatment of comparable quality.

2. The tertiary level of cancer surgical activity must prepare, in association with other fields, the guidelines currently lacking for treatment of some of the common forms of cancer (skin carcinoma, colorectal carcinoma, prostate carcinoma and breast carcinoma).
3. The tertiary level is responsible for preparing basic instructions for the production of clinical pathways for surgical treatment of the most common forms of cancer.
4. On the basis of gathered data, it is necessary to reduce the overall number of hospitals at the secondary level carrying out cancer surgery in future.
5. On the basis of such a future organisation of cancer surgery, it will be possible to link the forming network of multidisciplinary consultations and medical oncology activities, as well as execute and organise the comprehensive rehabilitation and palliative care of patients.
6. Tertiary institutions should carry out the treatment of rare cancers (alongside some secondary activities), as well as the most complex surgical procedures and training of oncologists, who will specialise in carrying out oncology activities.

### **3.3.3 Radiotherapy**

The Institute of Oncology Ljubljana (IOL) is currently the only health institution in Slovenia that includes a department of radiotherapy in its organisational structure, along with the corresponding equipment and systems for the preparation, planning, execution and quality control of irradiation with ionising radiation. Irradiation is used to treat 50% or more of all cancer patients. It is an efficient method of cancer treatment, for both curative purposes (with the aim to cure) and palliative purposes (with the aim to improve symptoms). This area encompasses the fields of teleradiotherapy (TRT) and brachyradiotherapy (BRT), which both require special equipment, which must be installed in dedicated areas that meet the safety criteria of legislation governing ionising radiation. The initial investment of building dedicated spaces and purchasing dedicated equipment is large, but the spaces can serve their purpose for decades and individual irradiation machines have a lifespan of around 12 years. The operation of the radiotherapy department demands not only a team of healthcare staff (radiotherapy specialists, radiology engineers and nurses), but also a team of radiophysicists and electroengineers, who work together to plan treatment and ensure the technical quality of equipment. Specific issues in the field of radiotherapy (RT) in Slovenia include:

- realistic economic calculation of costs for carrying out radiotherapy treatment,
- mid-term plan for renovation and expansion of radiotherapy in Slovenia,
- timely acquisition of human resources;
- ensuring a multidisciplinary approach in the framework of CHC in Slovenia.

#### **Tasks and Measures:**

1. Prices for healthcare services in RT must be fixed and must be based on realistic economic estimates and in addition to staff costs also include depreciation costs and maintenance costs for irradiation machines.
2. The Oncology Centre in Maribor urgently requires the creation of a radiotherapy department and a plan for personnel needs.
3. It is necessary to complete construction and equipment of the RT department at the IOL (upgrade of the logistics centre and placement of two additional accelerators).
4. The work of multidisciplinary consultation teams must be financially planned as an additional specialist activity.
5. In the future, it is necessary to provide uniform documentation of RT execution in electronic format, which will ensure the uniform collection of data and monitoring in the event of various providers.

### **3.3.4 Systemic Treatment of Cancer**

In contrast to surgical and irradiation treatment, whose anatomic effects are primarily loco-regional, systemic treatment generally affects the patient's entire organism. Systemic treatment of cancer includes cytostatic treatment or chemotherapy, hormonal therapy and targeted therapy (some biological and small-molecule drugs). Specialists prescribing systemic drugs for cancer patients must also have knowledge for treating symptoms of the illness as well as unwanted side effects of the therapy, in addition to palliative care. The need for the ever more specific knowledge of therapists in this field has brought about the development of medical oncology as an independent field, which is an integral part of the multidisciplinary treatment of cancer patients today. When planning systemic treatment, medical oncologists must cooperate with several experts: pathologists, radiologists, surgeons, radiotherapists, pharmacists and nursing professionals. Because this is a new field, they must also participate in training and clinical trials.

A professional and high quality execution of systemic treatment must include a team of specifically trained experts: medical oncologists, who prescribe drugs, nurses and technicians specialised in working in departments/units and clinics for medical oncology and pharmacists, who take care of the drug supply and its management. The demand for systemic treatment of cancer is increasing each year. In the past five years, the number of patients receiving systemic treatment at IOL has increased by 50%. Because the majority of systemic treatment takes place in clinics and/or day hospitals, the capacity of IOL will not be able to maintain the further concentration of systemic treatment of cancer patients.

### **Tasks and Measures:**

1. An Expanded Professional Collegium must be created for the systemic treatment of cancer, which is key to improving systemic cancer treatment in Slovenia.
2. Uniform documentation for carrying out systemic treatment must be created in an electronic format, which will enable the central collection of data and monitoring.
3. A specialist network, which has already been planned, must begin operating as soon as possible in the field of systemic cancer treatment. Until the completion of training of medical oncologists, these activities should be carried out by internists with additional training in select hospitals. Medical oncologists must be educated and employed in accordance with the approved network at the Medical Chamber of Slovenia (36 specialists by 2015). Nurses must be trained and employed simultaneously.
4. Tertiary institutions must establish a centralised preparation of anti-tumour parenteral solutions (implementation of the Slovene quality standards in the field on oncology pharmacy activities).
5. The tertiary level in the field of systemic treatment (introduction of new drugs, pedagogical activity and clinical research) remains the domain of IOL and oncology oriented clinical departments of tertiary institutions.
6. A unit for clinical trials (for execution of Phase 1 and Phase 2 clinical trials) must be established at IOL within the Division for Medical Oncology.

### **3.3.5 Oncology Pharmacotherapy**

The rational and economically efficient use of drugs is the primary goal of every healthcare system. For the purpose of the health system, Outcomes Research is being carried out, namely pharmaco-epidemiological and pharmaco-economic research with implementation of their results in clinical practice (evidence-based clinical practice). All of the above practices are already taking place in Slovenia, but until now, they have not been fully recognised and have not received a systemic placement in the healthcare system. The professional potential that clinical pharmacists and healthcare workers can provide to clinical practice as well as the healthcare system, has not yet been utilised in Slovenia. The use of knowledge in the fields of pharmaco-epidemiology and pharmaco-economics is also unutilised potential, primarily when making systemic decisions in regards to rationalising and optimising treatment strategies and the efficient use of available funds.

### **Tasks and Measures:**

1. A clinical pharmacist in the field of oncology must be included in practice within the multidisciplinary team of experts. The initial implementation should take place as a pilot project from 2010-2012 with evaluation of the realistic possibilities of including a clinical pharmacist in the oncology field.
2. Groups of pharmacists within pharmacies should be established for executing tasks of clinical pharmacy in IOL departments and departments of all tertiary and secondary institutions carrying out systemic cancer treatment.
3. Research is needed on therapeutic outcomes for individual types of cancer.
4. The economic efficiency of cancer treatment protocols, current as well as new, must be determined (field of pharmaco-economics).

### **3.3.6 Nutritional Treatment**

One of the main fields of treatment for cancer patients is nutrition. By providing the patient with adequate and custom tailored nutrition, the patient's metabolism is supported in the time of illness and treatment. The evidence-based conclusions from this field of medicine have shown that the best solution for an efficient nutritional therapy is a multidisciplinary team approach. Undernourishment can be critically reduced by the adequate nutritional support of hospitalised and out-patient patients. Because adequate individual nutritional support and treatment, which ensures the fulfilment of the patient's nutritional needs, importantly affects the treatment outcome, it is the right of every patient to have nutritional treatment provided in the period of hospitalisation.

### **Tasks and Measures:**

1. Nutritional therapy must be accessible to all cancer patients who require it and at all levels of treatment.
2. A specialist for nutrition (clinical dietician) must be included in the multidisciplinary oncological team.
3. Patients must have free access to enteral and artificial feeding at home and to medical aids for nutritional treatment.

### **3.3.7 Genetic Counselling**

In an accurate family history in cancer patients, we discover that 25 – 30% of all cancer patients have a positive family history. In these cases, we may speak of a familial form of cancer. Approximately one third of cancer patients with a positive family history have a so-called hereditary form of cancer. Today we are familiar with over 30 different tumour suppressor genes or proto-oncogenes, which cause various types of hereditary cancer or their syndromes. The common characteristic of all hereditary cancers is a typical family history. In all patients with hereditary forms of cancer, genetic counselling should be undertaken, which should always include the entire family.

In Slovenia we currently have a well organised genetic counselling service and testing for four types of hereditary cancer: hereditary breast and ovarian cancer, hereditary non-polyposis colorectal cancer and familial adenomatous polyposis colorectal cancer, hereditary malignant melanoma and medullary thyroid cancer in the framework of multiple endocrine neoplasia type II (MEN II).

Aside from the group at IOL, genetic testing for hereditary colorectal cancer is also undertaken by the group at the Medical Faculty – Department for Molecular Pathology, which lacks a key element of treatment for these high-risk patients – genetic counselling.

### **Tasks and Measures:**



1. All forms of hereditary cancer must be adequately treated. For this reason, all doctor profiles (primary, secondary and tertiary levels) which come in contact with cancer patients must be able to set a clinical diagnosis of hereditary cancer upon basic criteria in the family history. In all cases where hereditary cancer is suspected or diagnosed, oncological genetic counselling must be undertaken.
2. Genetic counselling and testing should be executed at the IOL; an appropriate payment for counselling services and tests should be ensured.

### **3.3.8 Management of Side Effects of Oncology Treatment**

Over the past decade, aggressive oncology treatment, which encompasses surgery, irradiation and systemic treatment, has proven to be particularly effective in treating some forms of cancer that occur in childhood and adolescents. Due to the greater possibility of later side effects, which are demonstrated by worsening function of individual organs and psychic troubles, which lead to various levels of disability and even to newly developed treatment-related cancers, this problem must be given special attention. A smaller portion of cancer patients are affected by this, but due to the greater possibilities of a cure, this represents an ever greater portion of overall cancer prevalence.

#### **Tasks and Measures:**

1. A Center for Management of Side Effects of Oncology Treatment must be established in the framework of IOL as a tertiary activity.
2. Funds must be provided for the operation of the Center for Management of Side Effects of Oncology Treatment.

### **3.3.9 Psycho-oncological Treatment of Cancer Patients**

The illness of cancer takes a firm hold on the life of the individual and their family and not only in the field of bodily functioning. Dramatic changes occur overall – in the areas of bodily, psychological and social functioning. At least 50% of patients suffer due to symptoms connected with the stressful circumstances of their illness and its treatment, including feelings of anxiety, irritability, demoralisation and depression. Many develop serious psychopathological states, such as depression and post-traumatic stress disorder. Psychological distress can lead to worse cooperation of the patient in treatment, a lower quality of life, a larger perception of pain, a greater suicidal tendency, etc.

Psycho-oncological treatment includes interventions, whose goal is to lessen the effect of cancer on emotional experiences and improve the capability of the patient to meet the demands of the illness, its treatment and the changed lifestyle due to cancer. Studies have shown that psychosocial treatment as part of the standard care for a patient and their family lowers psychological and psychosocial morbidity connected to cancer and improves quality of life during and after treatment. This is why it is necessary to develop a system for early detection of psychological distress, as well as individual and group psychotherapeutic treatments, as well as psycho-pharmacotherapy.

An important professional component of psychosocial support, which all healthcare workers treating cancer patients must respect, is the development of adequate communications skills for patients in stressful life situations.

#### **Tasks and Measures:**

1. Psychosocial treatment must be a standard component of treatment for cancer patients and/or their families at all levels of treatment and rehabilitation.

2. Specific psycho-oncological interventions (psychotherapy, psychopharmacology) must be developed as a standard element of treatment of cancer patients and their families.
3. Cancer patients in need of psycho-oncological professional support should be actively sought.
4. An adequate number of professional staff (such as clinical psychologists, social workers, psychiatrists, etc.) must be on hand for the psychosocial treatment of cancer patients and their families at the tertiary, secondary and primary levels.
5. Psycho-oncological content must be included in the training process of all health workers.

### **3.4 Oncology Nursing**

Oncology nursing is one of the more important elements of the healthcare system. Today's reality is that a large number of patients are treated in oncology centres or units (IOL and individual units within the other tertiary institutions in Slovenia) and in other secondary-level health establishments. However, the inpatient duration of stay is short. Treatment is becoming acute and is carried out in clinics and day hospitals with increasing amounts of oral medication. The latter has caused a shift in oncology nursing from hospitals to home environments, where the ability to provide oncology nursing is limited. These changes demand the development of a flexible workforce in the framework of oncology nursing. The majority of specialised (oncology) nursing is connected with tertiary institutions, but execution of nursing is in many cases carried out at secondary or primary healthcare levels. Nursing must therefore be focused on the needs of the patients and must not be limited by the boundaries of traditional nursing and individual health fields. Multidisciplinary work is vital to successful nursing.

In the light of the above statements, oncology nursing must go beyond the existing boundaries of organisation and individual disciplines. The needs of patients must be central in developing oncology nursing; this must form the practical framework for clinical practice. Both must be accelerated with the help of:

- lifelong education and training, which includes undergraduate education, specialisation in oncology nursing (postgraduate education) and vocational education and training;
- research, which will ensure trustworthy evidence and the development of a research base.

#### **Tasks and Measures:**

1. Oncology nursing must be based on the direct needs of patients, which is why key medical-technical and nursing procedures, performed by nurses, must be standardised at the level of process and aids needed for work.
2. The need for education and training of nurses for oncology nursing at the secondary and primary levels must be a priority of cancer health policy. Educational programmes must be refined; specific measures are listed in the section on education.

### **3.5 Alternative and Complementary Medicine**

In the field of CHC, the Slovene National Cancer Control Programme advocates only the execution of activities with an evidence-based and measurable effect. Clinical studies must be carried out only in the framework of highly controlled procedures of official clinical oncology. Some complementary methods (for example, acupuncture, relaxation methods) are already gradually being included in some rehabilitation and palliative programmes, as they serve only to supplement official medicine and not compete with it.

#### **Tasks and Measures:**

1. Verified complementary treatment must be included in the services of compulsory health insurance.

2. The general public must be made aware of the dangers and risks of alternative treatment.

### **3.6 Tasks of Various Healthcare Levels in the Field of Cancer Control**

The primary tasks of CHC in treating cancer patients are interconnected among various service providers and span the following:

#### **3.6.1 Tasks of CHC at the Primary Level**

The rights of cancer patients and the duties of doctors, at the primary level are not well-defined. In some aspects, patients have generous rights (year-long referrals and rights to transport), while the role of the general practitioner during and after treatment is not specifically defined. The blame for the undefined relationship between doctor and patient should not be given to the doctors themselves, as they exert the maximum amount of effort in their work. Various systemic reasons are to blame, which show that the educational and overall healthcare system has neglected the importance of specific treatment of cancer patients at the primary level. Some of the reasons are: education in clinical oncology during specialisation is modest (1 month), education in oncology is not specially required when extending licenses, the role of primary level healthcare is not defined in the accepted guidelines, documentation of individuals which have or may have cancer is not especially undertaken or recorded, communication between the general practitioner and the oncologist occurs mainly through referrals, year-long referrals to oncologists lessen the role of the general practitioner, the method of referral of the patient to rehabilitation from primary level is not professionally defined, the inclusion of the primary level in palliative care is mainly inadequate.

Patients are increasingly more informed and so demand more responsibility from general practitioners and family doctors. For now, complaints (and lawsuits) filed by patients are still primarily aimed at specialists in oncology treatment. In future, patients will increasingly become aware of the role of their family doctors and general practitioners.

#### **Tasks and Measures:**

1. Education and training required for extension of licenses at the primary level must dedicate 20% of its curriculum to the field of oncology.
2. In the framework of unifying medical information systems, a common portal must be set up providing patient documentation from primary level healthcare, on the basis of which time intervals from first symptoms to diagnosis can be tracked.
3. Regular monitoring of early detection at primary level must be undertaken and must be displayed as a reduction of advanced stage cancers upon diagnosis.
4. The reasons behind a large proportion of patients with advanced stage illness upon diagnosis must be investigated.
5. The tasks of the primary level during and after treatment must be included in the guidelines for diagnostics and treatment of various types of cancer, including guidelines for supporting treatment.
6. A costs analysis must be made of the rights of oncology patients to transport to health examinations and treatment, in order to find the most rational solutions.

#### **3.6.2 Tasks of CHC at the Secondary Level**

The execution of oncology activities at the secondary level is currently the decision of the management of the hospital and/or left up to individual therapists. This type of execution of

oncology activities in Slovenia leads to a lack of transparency and causes inequalities in the access of patients to quality services. Conditions must be created in which patients will receive the same high quality services of diagnostics, specific and palliative cancer care in all institutions at the secondary level.

### Guidelines for Development of CHC at the Secondary Level

Only treatment of the most common cancer types is adequate at the secondary level: skin cancer (non-melanoma), colorectal cancer, breast cancer, lung cancer and gynaecological and urological cancers. Thus in the future, it is unlikely that oncology activities will be carried out in more hospitals than the present. On the contrary, good traffic connections and short distances between large cities in Slovenia must be utilised so that high quality treatment will be available in fewer hospitals, which will have an adequate number of professionally trained staff and adequate equipment to carry out oncology activities.

To this purpose, providers of CHC at the secondary level will in future have to fulfil the following requirements:

- the annual number of diagnostic and surgical cases must exceed 150 patients for each of the more common forms of cancer,
- common and uniform health documentation in electronic format must be provided with electronic transmission of data to the Slovene Cancer Registry,
- all specialists taking part in oncology activities will have to obtain a recognised additional form of education in the field of oncology,
- each hospital must organise weekly multidisciplinary consultations with the help of in-house or visiting experts (for example, radiotherapists) for each of the treated forms of cancer, either in the form of face to face meetings or teleconferences,
- the hospital must ensure basic conditions for execution of standard methods of systemic treatment as regards preparation of drugs (pharmacy) and its applications (healthcare) in clinics and hospitals,
- the hospital must provide nutritional treatment and treatment of complications,
- following treatment, the hospital must carry out periodic routine examinations of the patient,
- the hospital must take care of the rehabilitation of the patient after treatment,
- the hospital must offer the patient palliative care in the event of terminal illness.

The above criteria indicate that oncology activities to the extent required will not be able to be carried out in numerous hospitals. In Slovenia, at most 3-4 hospitals should carry out oncology activities in addition to tertiary institutions. In future, it seems prudent to develop oncology activities in Celje and Nova Gorica, as well as Maribor, in the field of urological cancers in Slovenj Gradec as well. Patients will definitely not be deprived due to this reduction, as past unsuccessful treatment of common forms of cancer, attributable to the excessive fragmentation of professionals across the country, shows. The larger number of patients, who must currently travel to IOL in Ljubljana daily or monthly for standard supplementary treatment, would even have their travel times cut by this measure. Common medical documentation will enable the expanded collection of data for the cancer registry and also allow for professional surveillance, which until now has been practically impossible.

### Tasks and Measures:

1. A specific regulation on the execution of oncology activity at the secondary level must determine the conditions and extent of treatment in this field (primarily multidisciplinary treatment and training of the entire team).
2. The secondary level must also carry out regular routine examinations of patients which have been primarily treated at their institution.
3. A system must be put in place for data entry of the number of patients which receive access to multidisciplinary treatment at the secondary level.

4. The registering of treatment in an individual hospital should separate patients in terms of organ system and according to whether they have been solely diagnosed or have also been primarily treated at the hospital (operated on).
5. In the field of diagnostic imaging, a common waiting list for CT and MRI scans should be put into place in Slovenia, which will allow cancer patients timely access to diagnostics.
6. Diagnostic and surgical specialists at the secondary level, who primarily deal with oncology, should be given additional training in tertiary institutions. The length and form of the training should be determined by the Expanded Professional Collegium, the importance of such training which falls under the framework of continuous medical education (CME) must be determined by the Medical Chamber of Slovenia.
7. In organising the specialist network in the field of systemic treatment, it is necessary to provide for equipment, personnel and financing of drugs to the extent anticipated in the mid-term plans. The coordination of this field, which is increasingly important for organisational and professional aspects, can only be provided by the establishment of an Expanded Professional Collegium for Medical Oncology, which must include paediatric oncology and haemato-oncology.
8. It is urgent to unify CHC documentation, which will enable transmission of data to the Cancer Registry electronically. Health institutions must also be electronically connected so that they will be able to hold teleconferences. These connections must adhere to strict regulation in the field of personal data protection.
9. Multiprofessional teams should be established in the field of palliative care in hospitals at the secondary level that will provide comprehensive treatment of cancer patients.

### **3.6.3 Tasks of CHC at Tertiary Level**

Data from the Slovene Cancer Registry shows that around 60% of patients are treated in tertiary institutions. This data show only the proportion of patients treated in tertiary institutions, which does not also mean that they receive service of the highest quality that is exclusive to the tertiary level. The tertiary level carries out too many of the services of the secondary level and the secondary level carries out too many of the services which could be carried out by the primary level. This process can only be salvaged by the tertiary level taking on its role. The secondary level must begin carrying out standard methods of (systemic) treatment as soon as possible and the primary level must be included in organised CHC. Activities falling under the tertiary level in the field of oncology are:

- the Slovene Cancer Registry, which must become the foundational activity of tertiary-level CHC,
- functioning and monitoring of multidisciplinary teams for all cancer types,
- creation and regular updating of national guidelines for diagnosis and treatment of cancer,
- execution of the most complex methods of diagnostics and treatment,
- implementation of new forms of treatment,
- undergraduate and postgraduate education in the field of medicine and nursing,
- execution of basic, translational and clinical research in the field of cancer,
- carrying out publicity activities and organising conferences, seminars,
- cooperation with international associations and institutions,
- cooperation with health policy makers and civil society.

### **Tasks and Measures:**

1. The current role of the Slovene Cancer Registry, which also participates in the execution and monitoring of two screening programmes, must be expanded and a greater role must be provided in terms of its capacity to review oncology activity in Slovenia and consequently provide professional surveillance.
2. Multidisciplinary treatment must be carried out for the majority of patients, in multidisciplinary teams with team consultations; this should also be financially assessed.

3. Guidelines for the most common forms of cancer must be created, regular updating and monitoring of implementation of the guidelines in practice must also be ensured. Expanded Professional Collegiums must have a greater role in this than in the past.
4. Complex diagnostic and therapeutic procedures should be carried out and new activities implemented, pedagogic and research work in the framework of CHC should also be carried out.

#### **4 COMPREHENSIVE REHABILITATION OF CANCER PATIENTS**

The prognosis for the majority of cancers is improving, which is why it is increasingly important to provide all cancer patients the best possible opportunity to function well in the future and a decent life. Increasing amounts of patients survive cancer, but the consequences of their disease and/or treatment poses obstacles in their everyday lives. Rehabilitation measures should be put in place from the beginning of treatment to end of life. The patient's self-respect and overall physical and mental wellbeing must be preserved as long as possible through the aid of rehabilitation. Rehabilitation is (primarily) directed at the improvement of the patient's quality of life and is not (only) aimed at increasing lifespan. According to rough estimates, approximately 50% of cancer patients require rehabilitation; its aim is reducing the adverse effects of illness and side effects of cancer treatment, encouraging the patient to take a more active approach in their treatment, strengthening of the patient's faculties, self-trust, helping patients' families to understand their needs and changing the attitude to cancer in the social environment.

Through appropriate programmes, the goals of comprehensive rehabilitation are to:

- reduce the adverse physical and mental effects of illness and treatment, while teaching new behavioural patterns and equipping patients with adequate tools,
- improve conditions in the wider social environment, which will alleviate social integration for the patient (for example, reducing stereotypes, support programmes for continuation of schooling, employment, etc.),
- improve the quality of life and achieve integration into the social environment: school, family, workplace.

#### Guidelines for Development in the Field of Comprehensive Rehabilitation

When planning, we must take into account the bio-psychosocial approach, which underlines the need for comprehensive rehabilitation at all three levels of healthcare. Rehabilitation must be added to cancer healthcare guidelines.

#### Tasks and Measures:

1. Establishment of a multidisciplinary group of experts from all healthcare levels and from the Health Insurance Institute of Slovenia with the aim to prepare guidelines and programmes for the comprehensive rehabilitation of all cancer patients (physically, psychosocially, and professionally) with specifically defined individual programme elements.
2. Providing conditions for the clinical development of rehabilitation teams for cancer patients in the University Rehabilitation Institute of the Republic of Slovenia.
3. Health workers participating in the diagnostics, treatment and management of cancer patients, as well as members of disability committees of the Pension and Disability Insurance Institute of the Republic of Slovenia and health committees of the Health Insurance Institute of Slovenia (committees on health sanatoriums, sick leave, aids, etc.) must obtain additional education in the field of cancer patient rehabilitation.
4. Electronic records must hold data important for rehabilitation purposes.

5. Additional skills for the rehabilitation of oncology patients must be included in specialisation programmes for physical and rehabilitative medicine and all other programmes that include treatment of cancer patients.
6. Health sanatoriums that candidate for cancer patient rehabilitation programmes (in tenders with specifications) must provide adequately trained staff.
7. A special study should be undertaken to assess the current situation and determine the specific need for measures to provide a better quality of life for cancer patients.
8. 20–30 % of all physical therapy and occupational therapy must be executed at the patient's home. Such treatment must be carried out by all providers within the public health network.

## **5 PALLIATIVE CARE**

Palliative care (PC) is care for patients with an active, progressive and terminal illness. It encompasses nursing, management of pain and other accompanying symptoms, alleviation of mental, social and spiritual problems with the aim to provide the patient with the highest possible quality of life and help the patient's family and loved ones during illness and after death. The PC of cancer patients is not differentiated from the PC of patients with other illnesses and is in line with the National Programme for PC. In Slovenia, PC has been implemented for quite some time, but it is unorganised, unconnected and lacking norms in the fields of education, personnel and other requirements.

The precondition for the normal functioning of PC is the determination of services which are classified as PC and an agreement on which services fall under CHC and which may need to find other funding sources (field of social assistance, civil society foundations and private funds). It is likewise necessary to ensure appropriate education at an undergraduate level for all professionals working in PC and maintain their continued education in the framework of regular postgraduate educational programmes.

### Guidelines for Development in the Field of Palliative Care in Slovenia

Palliative care is carried out at the primary level, secondary level (specialist PC in hospitals), tertiary level (IOL: specialist PC, education, research), in hospices and retirement homes for patients whose social situation does not allow care at home and when symptoms make it impossible to provide care in the home.

Coordination of PC is carried out by regional coordinators and the national coordinator.

Volunteers may take part in all three PC levels. Apart from the appropriate selection of volunteers, they must also be properly trained, monitored and the responsibilities of the institution to the volunteers must be determined.

Certain drugs must be available for an adequate level of PC and must be provided for within compulsory health insurance funds, together with tools for subcutaneous drug administration.

### Tasks and Measures:

1. A network of palliative care (primary, secondary and tertiary levels) must be established for all cancer patients who require it.
2. The PC services, which fall under compulsory health insurance, must be determined.
3. Drugs and aids for PC must be provided and covered by compulsory health insurance; a Committee for Access to PC Drugs must be established.

## **6 EDUCATION OF DOCTORS, HEALTH PROFESSIONALS AND THE PUBLIC**

### **6.1. Undergraduate and Postgraduate Education of Doctors**

### **6.1.1 Undergraduate Education of Doctors**

Epidemiological data shows that cancer is the second most frequent cause of death in Slovenia. At the Medical Faculty in Ljubljana, there is a relatively small Chair of Oncology and Radiotherapy with a minimal amount of staff (consisting of a head and three assistants) and consequently, a small number of programme hours dedicated to the subject (28 hours). It is true that cancer falls within the framework of various subjects, but oncology should be understood as multidisciplinary and not a unilateral approach to the treatment of cancer patients.

It would be prudent to increase the range of the subject programme and transfer the subject to the last year of study or restructure it in the framework of the currently existing programme at the MF. Additionally, it could be possible to implement oncology as optional content within the programme, as well as think about the implementation of a study programme in Palliative Medicine (for example, in the framework of family medicine).

#### **Tasks and Measures:**

1. Study the possibilities for increasing the programme of oncology and radiotherapy in the undergraduate study programme at both medical faculties,
2. The subject of oncology with radiotherapy must be held in the last year of the course of study.

### **6.1.2 Postgraduate Education of Doctors**

In Slovenia, the following specialisation programmes in the field of oncology are currently on offer:

- specialisation in radiotherapy and oncology (since 1950),
- specialisation in medical oncology (since 2000),
- in the framework of other specialisations (primarily internist and surgical fields of study and family medicine), although oncology is unfortunately treated in a small manner or not at all. It is urgently necessary to include education in the field of oncology in programmes for surgical specialisation. Doctors should develop a firm grasp of the idea of a multidisciplinary approach during their education in order to implement it in their working environment as specialists.

#### **Tasks and Measures:**

1. Oncology must be included in specialisation programmes for internist and surgical fields of study and in family medicine.

### **6.2 Undergraduate and Postgraduate Education of Pharmacists**

Pharmacists are educated in the framework of the undergraduate university programme, Pharmacy, and the postgraduate scientific programme, Biomedicine, at the Faculty of Pharmacy of the University of Ljubljana. These academic programmes must include more lectures on the theme of oncological pharmacotherapy. Cooperation in the educational and research levels in the field of oncological clinical pharmacy must be fostered between the Faculty of Pharmacy and the Medical Faculty, Chair of Oncology and Radiotherapy and all tertiary (university) hospitals that carry out diagnostics and cancer treatment. The Faculty of Pharmacy together with the Slovene Chamber of Pharmacy have been carrying out specialist clinical pharmacy programmes for a number of years. A possibility should be found within this programme of including a subspecialisation in the field of oncological clinical pharmacy, as well as a possibility of acquiring specific knowledge in the field of oncological pharmacy.



### **Tasks and Measures:**

1. Current academic programmes must include more content from the field of oncological pharmacotherapy.
2. Cooperation must be fostered in educational and research fields in the area of oncological clinical pharmacy.
3. The possibility of including a subspecialisation in the field of oncological clinical pharmacy should be assessed as well as the possibility of gaining specific knowledge in the field of oncological pharmacy.

### **6.3 Undergraduate and Postgraduate Education in the Field of Nursing**

Health colleges (institutions of higher education) currently include nursing of the cancer patient in the framework of other subjects. Due to the ever greater need for trained nursing staff, oncology nursing and oncology must be added as an independent subject. The implementation of an independent programme will improve the basic knowledge of registered nurses. The subject should be carried out by habilitated college teachers who are in constant contact with cancer patients and the development of the professional field.

With the transition to the Bologna educational system (3 + 2), it is necessary to actively prepare the academic programmes for the Master's and doctoral degrees in oncology nursing. In the framework of postgraduate study, nurses should begin clinical research in oncology healthcare (management of side effects of treatment, primary and secondary prevention of cancer, palliative care, genetic counselling, nutritional support, health education counselling, management of the process of care of the cancer patient, etc.). Such research will bring oncology nursing in Slovenia closer to that of other developed European countries, where nurses with postgraduate degrees hold an important role in providing quality treatment of cancer patients.

### **Tasks and Measures:**

1. Oncology nursing and oncology must be treated as a special subject in the undergraduate education of registered nurses.
2. All training programmes for all levels of health professionals in the field of oncology nursing should be supplemented
3. The continuous education of staff in the field of oncology nursing is required, this should take the form of functional training in cooperation with the Professional Group of Nurses and Health Technicians for oncology (within the Nurses and Midwives Association of Slovenia), oncology centres and postgraduate academic programmes of oncology nursing. With the transition to the Bologna educational system (3 + 2), it is necessary to actively prepare the academic programmes for the Master's and doctoral degrees in oncology nursing.

### **6.4 Undergraduate and Postgraduate Education of Other Health Professionals and Colleagues**

A multidisciplinary and multiprofessional approach to the treatment of cancer demands several other health professionals and colleagues, such as clinical psychologists, social workers, physical therapists, occupational therapists, speech therapists, etc. This field is in general need of many more staff additions – only a few professionals of each individual profile work on cancer treatment at the tertiary level, many more are in contact with cancer patients at the secondary and primary levels. The acquisition of knowledge and skills in individual areas related to oncology is unorganised and mainly dependent on the personal motivation of the individual health professional; organised education and training for individual professional groups in the field of needs and treatment of cancer patients practically does not exist due to the small scale.

### **Tasks and Measures:**

1. Specific content in the field of oncology must be included as part of the educational process at an undergraduate level in numerous academic fields of study for various professional groups, as well as at postgraduate level (such as for example, the specialisation in clinical psychology).

### **6.5 Continuous Education of Health Professionals in the Field of CHC**

In order to ensure development of certain fields and adequate training, continuous education is needed at all levels, which can be implemented in the form of seminars, courses or other types of education. Various programmes are traditionally held in this field, such as the Oncology Weekend, Jurij Reja Seminars and other like initiatives, the IOL a School of Malignant Melanoma and Palliative Care.

### **Tasks and Measures:**

1. Assess the possibility that the Medical Chamber of Slovenia require not only a certain amount of collected points for the extension of licenses, but could also assess which field they were acquired in. In this way, doctors dealing with cancer should collect at least 20% of points through education in the field of oncology.
2. Specialists in diagnostics and surgery at the second level dealing primarily with oncology must undergo additional training in tertiary institutions. The length and form of the training should be determined by individual Expanded Professional Collegiums; the importance of such training which falls under the framework of continuous medical education (CME) must be determined by the Medical Chamber of Slovenia.
3. Continuous education of staff in the field of oncology nursing must take the form of practical training and specialisation, which should be implemented in the framework of postgraduate programmes at health colleges.
4. The continuous education of health professionals and colleagues should also include learning communication skills, strategies for managing stress and relaxation techniques, which would help to strengthen the mental health of the employee and would contribute to a reduction of burnout syndrome.

### **6.6 Informing and Educating the General Public**

The public must be given access to the most up-to-date reputable information on cancer, from information on prevention to early detection, new treatment methods, rehabilitation, psychosocial and palliative care.

As many target groups should be reached as possible while using a variety of communications channels. It is important to provide: thematic websites (for example, IOL and Ministry of Health), which are an important source of information for health professionals, patients and the general population, professional journals, for example the journal 'Onkologija' and accessible educational programmes for the general public, which can also be carried out by non-governmental organisations.

Non-governmental organisations and patient associations have a special role in raising awareness and informing the public. Their activities are especially important in promoting healthy lifestyles and prevention of cancer, promoting screening programmes, supporting patients and cooperating with the media.

### **Tasks and Measures:**

1. To ensure reputable and up-to-date information in relation to cancer,

2. To provide thematic websites,
3. To provide non-governmental organisations support in informing and educating the general public.

## **7 CANCER RESEARCH**

In order to advance in cancer control, research and new knowledge is needed in all levels of cancer control, from prevention, diagnostics, treatment and rehabilitation to palliative care. Due to the ageing population and other risk factors, cancer is becoming one of the most common illnesses of modern society and a large public health problem; research in the field of public health is becoming a priority in oncology. A wealth of new discoveries, particularly in the field of molecular biology, demands a quick transfer of new knowledge to the everyday care of a patient, which is the reason for the increasing importance of translational research. The boundaries between basic and clinical research are collapsing and translational research is more and more prominent, as it is the only type which allows for rapid development and transfer of new methods of prevention, diagnostics and treatment into everyday practice. Patients included in clinical trials have a greater chance of survival than those not included in clinical trials.

The main source of research financing in Slovenia are national budgetary resources; the Slovenian Research Agency (ARRS) finances research projects (basic and applicative), research programmes (of a national interest) and young researchers and provides co-financing for purchase of research equipment. Other sources of funding are bilateral projects, international projects within EU Framework Programmes, clinical trials backed by academic associations, pharmaceutical companies, industrial projects and projects financed by public institutions themselves. There is practically no funding provided by charitable organisations.

The institutions that carry out cancer research in Slovenia are: public health institutions (Institute of Oncology Ljubljana, UKC Ljubljana, UKC Maribor, KOPA Golnik), university institutions (University of Ljubljana – Faculty of Medicine and Faculty for Electrical Engineering) and public research institutions (National Institute of Biology). The connection between basic and clinical research is carried out through applicative ARRS programmes and projects and in the framework of a small number of translational studies. This cooperation is of an inferior quality and the number of translational/clinical studies is too small. Clinical trials take place mainly in the Institute of Oncology Ljubljana, since 1974 also with the cooperation of international academic networks (SIOP, LBCSG, CEEOG, EORTC, CECOG). To a smaller extent, clinical research is also underway at UKC Ljubljana, UKC Maribor and at Golnik Hospital. In recent times, clinical trials sponsored by pharmaceutical companies have been more numerous than academic clinical trials, which are of vital importance for multidisciplinary research. The predominant trials being carried out are those of expanded access to drugs (EAP), which are sponsored by and primarily in the interest of industry. There are too few academic Phase 3 trials, while there are almost no Phase 2 and Phase 1 trials in which Slovene patients could get involved. The number of Slovene patients included in trials is definitely too low. At IOL in 2007, only around 3% of patients referred there participated in trials. Information on clinical and translational cancer research carried out at IOL is publicly accessible through IOL's website, but the list is not complete and is not updated accordingly.

### Guidelines for Development in the Field of Research

Today cancer is among the most important public health issues, which is why public health research is so vital for effective cancer control, particularly among certain population groups. More intense cooperation (networking) amongst institutions and groups would surely bring about higher quality research activities. Convergence of projects in regards to content is very important for work of a high quality and multidisciplinary nature. Many projects already interlink in some way, all that is needed is to find a common denominator. It is necessary to identify interesting fields that we have the capacity to develop to the highest quality and dedicate all efforts in these designated fields.

The amount of international (EU) projects in medicine is extremely small. Only cooperation in international projects and research enables a small country like Slovenia excellence.

In Slovenia we have a unique opportunity to carry out pre-clinical and clinical trials all in one place. This is why the field of oncology can be attractive for such endeavours, as ideas can be transferred into clinical practice in a relatively small amount of time.

Academic and multidisciplinary studies in all fields must be encouraged, from public health studies to those in the fields of diagnostics, treatment, rehabilitation and palliative care of cancer patients. For efficient cancer control in our country, an immediate and greater input in academic and multidisciplinary research and public health research in oncology is needed over the next decades. Cancer is one of the most important public health issues today and only public health research can help solve the issue of how best to curb cancer in various environments.

Financing should be increased to research groups that have proven to be of a high quality, are productive and function well together. These groups have an ever greater value, as they educate young personnel, who will carry out independent research in the future based on these experiences.

The possibilities of granting public health institutions carrying out translational research the same status as public research institutions and universities should be assessed.

Patients should be better informed and have more access to clinical trials and new diagnostic and treatment methods.

### **Tasks and Measures:**

1. Connections in cancer research should be strengthened - between basic and clinical research projects as well as between institutions and research groups.
2. Active cooperation should be sought in international research projects, particularly multinational, academic research and EU Framework Programmes.
3. Translational studies and public health studies should be accelerated.
4. The number of academic translational/clinical studies should be increased, as well as the number of patients participating in clinical trials. Patients and civil society should be better informed about the importance, process and conclusions of research. By 2015, around 15% of patients should participate in clinical trials and a publicly accessible portal with information on cancer research should be produced.
5. Funds for the carrying out of cancer research in Slovenia should be increased, including public funds as well as funds raised by charitable organisations and EU funds.

## **8 CANCER INFORMATION SYSTEMS**

One of the guiding principles of every doctor is the wish to improve the results of treatment. One of the main goals of each healthcare system is the maximum improvement in quality of health alongside the rational and economic use of available materials, spatial and staff capacity. To achieve these goals, the individual as well as the healthcare system requires standardised information. With the help of this information, it is possible to compare the results of our work to the results of the work of other individuals, institutions and healthcare systems and assess the degree of success at a professional and economic level. Success is assessed at three levels. Alongside the professional and economic levels already

mentioned, there is also a third level, which is equally as important: the scientific level, which represents the foundation for development of new treatment methods. Useful and standardised information is not needed just to assess the success of treatment and operation in the designated period, but also to help plan the future.

The status of data collection in Slovenia is currently not ideal. Unfortunately, there are no specific instructions and regulations on the type of information each medical record should include (medical history, pathology results, operative report and so on). Usually medical records are in descriptive or narrative form and are very difficult for further use. Due to the absence of standardised information, it is also impossible to compare treatment quality amongst various hospitals. The indicators which determine treatment quality in oncology are survival, recurrence and quality of life. These are indicators that can be tracked daily with the help of an online application, quality can also be assessed for each individual hospital and the acquired data published online. This data is also useful for the institution funding the service (a higher than average number of complications means substantially higher treatment costs) as well as the patients themselves (on the basis of data, the patient can choose the institution which achieves the best results).

#### Guidelines for Development of IT in Slovene Oncology

The organisation of oncology activities across hospitals in Slovenia should be based on an assessment of quality control, personnel and technological equipment. If it is concluded that the health institution has not achieved the required standards, it will not be able to carry out oncology activity in future. Likewise, institutions achieving high standards could have a higher concentration of cancer patients. The larger revenues of institutions with good treatment results would result in a lesser burden on the health budget, as the costs associated with “lower quality” treatment are extremely high – repeating surgeries (each that follows is more complex, longer and more expensive), long hospitalisation periods, long sick leaves, disability and early retirement.

#### **Tasks and Measures:**

1. Implementation of a common central online electronic register of illness for each patient with a malignant disease irrespective of where the patient is being treated.
2. Standardisation of records for each type of medical record (medical history, status, operative report, course of illness, discharge, pathology results, x-ray results, consultation opinion, etc.)
3. Computerisation of illness records.

### **9. COST EFFECTIVENESS ASSESSMENT**

When assessing the cost effectiveness of oncology activity in Slovenia, the following principles should be taken into account:

1. the costs of cancer treatment should be specifically defined,
2. organisation of CHC in Slovenia should be guided by the rational use of funds,
3. investment in equipment should be directly connected to professionally trained staff,
4. actual control over costs can only be achieved by standardised computerisation in medicine.

Because this is an important social issue, the assessment of cost effectiveness demands the close cooperation of health policymakers, providers of funding for health services, experts and civil society. This area will increase in importance in future due to the increase in the elderly population and the increase in cancer incidence. Strategic documents dealing with healthcare in Slovenia must therefore take into account clearly defined premises and criteria

for assessment of economic efficiency in the field of all chronic diseases (oncological and non-oncological). If this does not occur, the disproportionate use of funds within compulsory health insurance will primarily endanger the increasing population of cancer patients.

### **9.1 Financing Cancer Treatment**

Cancer occurs in over 400 histological variations, of these primarily in 4 illness stages. When assessing the costs of diagnostics and treatment of patients with cancer diagnoses, these differences are very important. Terms such as cure, remission (chronic disease) and palliation are connected with procedures whose costs can vary in a ratio from 1:1,000 and can be inversely correlated with the survival rate. At this moment, Slovenia is not yet able to assess the average cost of treatment, including diagnostics, for individual types and stages of cancer.

#### **Tasks and Measures:**

1. Diagnosis Related Groups (DRG) costs in the field of cancer must include not only basic diagnostic and therapeutic costs but also the execution of all activities which must be included in standard cancer healthcare at the second level: nutritional counselling, comprehensive rehabilitation and primarily, palliative care.

### **9.2 Cost effectiveness of CHC Organisation in Slovenia**

Increasing access of the patient to healthcare at any cost is harmful in oncology. In such a small country, the scattering of cancer healthcare brings about less successful treatment, as shown by the results of international studies (EURO CARE III and IV). Decreased efficiency does not only show itself in lower survival rates, but also indirectly influences needless increase in costs, as a patient that has not been cured is also the most expensive, which is why a concentration of services seems necessary.

#### **Tasks and Measures:**

1. Possibilities for concentrating services at the primary level must be assessed with the aim of efficient early diagnostics and treatment, which lead to less chronic (and less expensive) patients, as well as carrying out periodic examinations for certain patients (lower transportation costs).
2. At the secondary level, merging diagnostics and treatment of the most common forms of cancer in a smaller number of regional hospitals is necessary. With the help of expert surveillance (oncology oriented specialists), a multidisciplinary work method and carrying out procedures prescribed by guidelines, it is possible to achieve a better cure rate (less chronic diseases), lower the costs per patient, increase access to systemic and irradiation treatment (no unnecessary transportation costs) and carry out periodic examinations closer to home (lower transportation costs).
3. The concentration at the tertiary level in terms of merging of equipment and staff to carry out top level clinical oncology, research and educational activities (at least for the period of this cancer control programme) can only be achieved within the comprehensive cancer centre, composed of IOL and tertiary institutions in the greater Ljubljana area.

### **9.3 Financing Equipment, Drugs and Staff Training**

As soon as the professional criteria for carrying out CHC at the secondary level will be followed (implementation of guidelines, ensuring a multidisciplinary approach, minimum number of individual cancer cases treated), it will be easier to plan the equipment needed in those hospitals. Prior to this, it will be necessary to additionally train staff using the equipment. It is anticipated that concentration of secondary level CHC will add to the

improvement in quality of pathohistological and endoscopic tests, surgical procedures and intensive medicine, execution of standard systemic treatment, the central preparation of drugs, nutritional and pharmaceutical counselling and nursing. This is the only method of achieving a reduction in the number of complications during treatment, which generate costs greater than those planned.

The annual financing of costly cancer drugs is a much greater cost than investment in equipment. Development in this field cannot be hindered, so monitoring of the placement of new drugs in the healthcare system and competent prescription of drugs, as well as monitoring use is of vital importance.

#### **9.4 Common Information System as the Basis for Financial Control**

Although some activities planned by the cancer control programme will have to be carried out simultaneously, it is necessary to immediately begin the unification of medical documentation as the basis for a common information system in oncology. Most important is the question of content, which can be aided by the experience of foreign oncologists, also due to the comparability of both health systems. The operating system is already developing in programmes by the Ministry of Health and National Insurance Institute of Slovenia; in the field of oncology it is urgent to connect it with the Cancer Registry, as a large portion of data has already been collected and processed there, at least at a professional level. Because competence and economic efficiency are directly connected in oncology, they should not be separated in the planning of a common information system. The common information system, which will allow a review of competence, professional qualification and waiting periods, will also allow financial monitoring, more specifically:

- tracking of equipment use and staff workload,
- actual costs analysis, based on type and stage of cancer,
- assessment of relationship between costs and treatment effects.

#### **9.5 Criteria for Economic Efficiency of the Slovene National Cancer Control Programme**

Economic efficiency, which would serve as a measure of the quality and length of survival of cancer patients in relation to the invested funds of the entire society, cannot be separated from other health issues. The basis for such assessments of economic efficiency must be governed by dedicated criteria, which will include criteria for measuring the success of overall healthcare in Slovenia. This is why the economic efficiency of preventive, curative and palliative measures in the field of cancer control will only be determined when we have available and comparable data for all epidemiologically important healthcare fields in Slovenia. In this aspect, the Slovene National Cancer Control Programme is setting various measures and criteria to measure success, which will allow for such comparisons in the future.

### **10 ROLE AND TASKS OF CIVIL SOCIETY**

Cancer is an illness which introduces a number of restrictions to the patient and their families; the exchange of experiences can prove helpful to the management of this disease. For this reason, associations in civil society have been established and are increasing in number in Slovenia. These associations have various areas of work: some focus only on cancer, some only on patients, some educate and encourage all members of the general public to decrease their risk of contracting this disease.

Chronologically, the first association of this type to be established in Slovenia was the Association of Slovenian Cancer Societies, which was founded in 1974, the Association of Laryngectomy Patients followed in 1982 and in 1986, the Cancer Patients' Association of Slovenia, several others followed.

Globally as well as in Slovenia, civil society is becoming increasingly more active in health policy issues; its goals are to responsibly participate in decision making processes and help to fight cancer in Slovenia.

### **Tasks and Measures for Civil Society Organisations:**

1. Helping to raise a healthy and cancer-conscious population and informing the Slovene general public of the issues surrounding cancer, including ways in which to decrease their risk of developing cancer,
2. Encouraging target populations to participate in screening programmes,
3. Supporting patients and their families in the fight against cancer: civil society cannot replace expert psychosocial support, but it can alleviate distress when arriving in hospital (volunteer work), during and after treatment (individual counselling, support groups, hospital visits, talks during and after treatment, etc.) and active inclusion in society,
4. Encouraging patients to participate in clinical trials,
5. Raising the awareness of civil society and politicians of issues for patients and weaknesses in the healthcare system that restrict the access of patients to rapid and quality treatment,
6. Helping the patient in acquiring a second medical opinion, counselling for selection of treatment, overcoming treatment difficulties and helping make the transition back to everyday life,
7. Informing cancer patients about their basic rights, making sure that patients are correctly and timely informed of advances in oncology; civil society should demand from professional and political groups that advances be implemented in treatment,
8. Collecting funds to purchase equipment and satisfy other patient needs, when funds cannot be ensured from the public budget.

## **11 EXECUTING TASKS OF THE NATIONAL CANCER CONTROL PROGRAMME**

The successful coordination, tracking and monitoring of the Slovene National Cancer Control Programme will only be possible with the help of a specially established Council, which will function in the framework of the Ministry of Health. The naming of members to the Council will follow WHO recommendations, its main task will be to review the execution of tasks and measures from the programme and make an annual report to the Ministry of Health, experts and the general public on the programme's implementation.

After the completion of the designated timeframe (2010 – 2015), additional premises and objectives for further periods must be added to the programme. The main premise of the National Cancer Control Programme is that it must be continuously executed.

## **CONCLUSION**

The Slovene National Cancer Control Programme is a comprehensive programme that demands additional measures based on past experience. These additional measures should help to improve the epidemiological situation and activities in the fields of prevention and early detection, diagnostics and treatment, comprehensive rehabilitation and palliative care. It encompasses the period from 2010 – 2015; for future periods, it will be necessary to alter and supplement the programme in accordance with needs. The Slovene NCCP is based on the conclusions of international studies and on WHO recommendations. It is also adjusted to the needs of the Slovene healthcare system, which grants all citizens the right to equal



access and quality of healthcare services in the field of cancer. The Slovene NCCP presents the concerted views of health policymakers, health professionals and civil society in the field of cancer control.

#### Main Points of the Slovene NCCP 2010 - 2015

1. Slovene citizens must be given access to information on risk factors for developing cancer. Awareness of healthy lifestyles must become a topic in the overall system of formal and informal education. Future generations can reduce various forms of cancer primarily through primary prevention, as at least one third of cancers can be prevented.
2. Successful early detection reduces cancer mortality. All citizens should be aware of this fact. Screening programmes will help achieve this in target population groups for three specific cancer types. The main task of early detection therefore remains in the hands of general practitioners and family doctors, who annually detect cancer in only a small number of their patients (<10 %). The Slovene NCCP recommends better training for healthcare providers at the primary level. Cancer mortality can be reduced by 10% with the help of all the recommended measures in the field of secondary prevention.
3. The scattered nature of cancer healthcare (CHC) in Slovenia has brought about a sub-optimal distribution of medical equipment. The Slovene NCCP therefore demands a larger concentration of CHC at all three levels. At the secondary level, criteria for carrying out CHC are listed (multidisciplinary consultation groups, minimal numbers of patients with common individual forms of cancer, carrying out follow-up examinations), which lead to the merging of diagnostics and treatment, a greater level of professional competence and greater control over expenditure. The same measure also serves to reduce the burden on the tertiary level, which cannot adequately carry out its main duty (the execution of complex diagnostic and treatment methods, education and research) due to an overburdening with standard treatment methods.
4. In the field of palliative care, the Slovene NCCP deals only with the problem of cancer patients, although there is a greater problem posed by the treatment of terminally ill patients in general. The implementation of the principles of palliative care is a societal process, which will begin to be solved with a comprehensive programme aimed at all terminally ill patients. Palliative care services for cancer patients must be determined and a network of activity established that will operate in accordance with the comprehensive programme.
5. An overview of the professional competence and economic efficiency of the Slovene NCCP can only be provided by a common information system, which will be established in cooperation with experts, the Ministry of Health and the Health Insurance Institute of Slovenia. This will enable the additional collection of data for the Cancer Registry and give control over quality and economic efficiency of health services. The development projects for construction of the II. phase of IOL and the radiotherapy department in Maribor are also concerned with the content of the Slovene NCCP. Also in this category is the placement of new expensive drugs in the system of compulsory health insurance, as the pharmaceutical industry is constantly launching such drugs on the market. The recommendation of the NCCP is that a special commission is established for this field as has been done in some other European countries, which would be responsible for placing expensive drugs on the list of those recognised in Slovenia by compulsory health insurance.
6. In accordance with recommendations of international organisations, the Slovene NCCP also includes fields such as comprehensive rehabilitation, dealing with the side effects of treatment, nutritional support, genetic counselling and clinical pharmacy, which has not yet been financially recognised as being a part of CHC, although it is an important factor in the final result of treatment and quality of life of cancer patients. The development of the above mentioned activities in Slovenia must be a priority.
7. The successful implementation of the Slovene NCCP is completely dependent on effective monitoring. To this effect, it is necessary to designate members of a Council for

Monitoring NCCP Implementation. The Ministry of Health will decide on the designation of council members and their competence and responsibilities.

<b>TASKS AND ACTIVITIES ARISING FROM THE NCCP WITH INDICATORS for 2010/2011</b>				
<b>Area</b>	<b>Tasks and Activities</b>	<b>Indicators</b>	<b>Priorities in the first year of the programme</b>	<b>Responsible Institution</b>
<b>1. CANCER BURDEN</b>	Collection of data in the Slovene Cancer Registry must be continued and expanded	Incidence, prevalence, survival, mortality – overall and specific to age, sex and other important characteristics of the population	Establishing a national online portal on cancer in Slovenia – SLORA project	Institute of Oncology Ljubljana
<b>2. PRIMARY PREVENTION</b>	Collection and expansion of activities encouraging a healthy lifestyle and reduction of risk factors in the fields of tobacco, nutrition, harmful use of alcohol and sunlight exposure. Monitoring vaccination against HPV.	% of people in the target group (adults, children, adolescents...) without risk factors  Percentage of those vaccinated against HPV	Proposal for indicators and a plan for collecting missing indicators for monitoring NCCP objectives in the field of primary prevention	Ministry of Health, National Institute of Public Health, regional public health institutions, non-governmental associations
<b>3. SECONDARY PREVENTION</b>				
<b>3.1 Organised national screening programmes</b>	Continuation and quality supplementation of the national programme for cervical cancer screening ZORA. Expansion of the national breast cancer screening programme (DORA) in line with the programme's planned time schedule. Execution of the national screening programme for colorectal cancer (SVIT).	% of women (20-64) with pap smear examinations in a three year period  % of women (50-69) having a mammography every two years  % of people (50-74) having taken the test for faecal occult bleeding	Achieving the target response rate of those invited in the programme  Providing information on the programmes on a common portal	Institute of Oncology Ljubljana, National Institute of Public Health
<b>3.2 Early detection of cancer in primary healthcare</b>	To influence the ability of primary level doctors to detect cancer early through being better educated and better informed	Interval between first symptoms and diagnosis  Stage upon	Producing an analysis of current conditions and premises for introducing	Institute of Oncology Ljubljana, National Institute of Public Health

	To study the possibilities of implementing changes in primary level healthcare with the aim of increasing early cancer detection	diagnosis (RRS) % of cases with localised illness % of cases with further metastases	changes and improvements	and Expanded Professional Collegiums, representatives of primary healthcare
<b>4. DIAGNOSTICS AND SPECIFIC TREATMENT OF CANCER PATIENTS BY FIELD AND OBJECTIVES:</b> <b>Within the possibilities afforded by the Slovene healthcare system, all citizens with cancer must be given equal access to expert treatment at individual healthcare levels. All cancer patients in Slovenia must be given a chance at a longer survival period of a higher quality.</b>			Preparation of clinical guidelines for cervical cancer, colorectal cancer, breast cancer, sarcomas and GIST in accordance with the determined priorities. Implementation of clinical registers according to priority.	Institute of Oncology Ljubljana, Expanded Professional Collegiums.
<b>5. PHYSICAL AND PSYCHOSOCIAL REHABILITATION OF CANCER PATIENTS</b>			Preparation of premises for the shaping of multidisciplinary teams in the field of rehabilitation	Institute of Oncology Ljubljana, University Rehabilitation Institute
<b>6. PALLIATIVE CARE FOR CANCER PATIENTS</b>			Prepare foundations for network of palliative care  Form a committee for access to drugs for palliative care	Ministry of Health, Institute of Oncology Ljubljana
<b>7. EDUCATION OF DOCTORS, HEALTH PROFESSIONALS AND THE PUBLIC</b>				
<b>Education</b>	- assess the possibility of expanding the oncology and radiotherapy programme in undergraduate study courses and finding an adequate timeframe - assessing the	- number of hours dedicated to oncology in the undergraduate study programme - amount of nursing specialists and	Situation analysis and proposal for changes	Institute of Oncology Ljubljana, Expanded Professional Collegiums

	<p>possibility of an additional postspecialist educational programme for specialist surgeons, diagnosticians and family doctors</p> <ul style="list-style-type: none"> <li>- assessing the possibility of supplementing educational programmes in the field of nursing</li> </ul>	<p>staff additionally trained in oncology</p>		
<b>8. CANCER RESEARCH</b>				
	<ul style="list-style-type: none"> <li>- providing patients with the possibility of participating in clinical and translational trials in phases 1, 2 and 3</li> <li>- ensuring that patients are well informed about clinical trials</li> <li>- directing public funds meant for cancer research to translational and public health studies (epidemiology, pharmacoepidemiology, pharmacoconomics)</li> <li>- greater connection within the research field (basic-clinical research)</li> <li>- establishing charitable foundations for cancer research</li> </ul>	<ul style="list-style-type: none"> <li>- % of cancer patients included in clinical trials</li> <li>- % of public funds for research aimed at translational and public health research in oncology</li> <li>- amount of funds, their value and percentage of annual financing of cancer research.</li> </ul>	<p>Publication of all research underway in Slovenia on a public portal in the Slovene language</p>	<p>Institute of Oncology Ljubljana</p>
<b>9. INFORMATION SYSTEMS IN ONCOLOGY</b>				
	<ul style="list-style-type: none"> <li>- participating in the implementation of a common central information system for the disease, with electronic records for each patient with a malignant disease irrespective of where they are being treated</li> <li>- standardisation of medical documentation</li> </ul>	<ul style="list-style-type: none"> <li>- number of health institutions using the common central information system for cancer patients</li> </ul>	<p>Participating in the computerisation project, e-Health</p>	<p>Ministry of Health, Institute of Oncology Ljubljana</p>
<b>11 TASKS OF CIVIL SOCIETY</b>				
	<ul style="list-style-type: none"> <li>- informing the public</li> </ul>	<ul style="list-style-type: none"> <li>- the number of</li> </ul>	<p>Participating in</p>	<p>Ministry of</p>

	<p>of prevention and early detection of cancer</p> <ul style="list-style-type: none"> <li>- support for cancer patients and their families</li> <li>- support in palliative care</li> <li>- participating in the decision making process for health policy in the field of cancer</li> </ul>	<p>civil society representatives involved in monitoring the NCCP</p> <ul style="list-style-type: none"> <li>- the number of volunteers involved in OHC programmes</li> </ul>	<p>monitoring the implementation of the NCCP</p>	<p>Health, non-governmental organisations</p>
<b>12 COORDINATION FOR IMPLEMENTING AND MONITORING THE NCCP</b>				
	<ul style="list-style-type: none"> <li>- monitoring of the implementation of the NCCP by the NCCP Council designated by the Minister of Health</li> <li>- reporting on NCCP implementation</li> </ul>	<ul style="list-style-type: none"> <li>- annual reports collecting all programme indicators and assessment of progress with recommendations for improvement</li> </ul>	<p>Preparation of an annual report on NCCP implementation in the first year, with recommendations for priorities for the following year</p>	<p>NCCP Council</p>