

70 years

of the Slovenian  
Cancer Registry



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# Director's Address

Owing to the Slovenian Cancer Registry, which has been operating within the Institute of Oncology Ljubljana for 70 years, Slovenia has a very long tradition of monitoring cancer burden and the quality of cancer care. The Slovenian Cancer Registry is recognized as one of the oldest and of the best quality population-based cancer registries worldwide. Its beginnings lie in the visionary ideas of the late professor Ravnihar, who was aware that the effectiveness and efficiency of the efforts of health services and health policy to manage cancer can be evaluated only with appropriate data on the burden of disease. This was many years prior to when recommendations for establishing cancer registries were endorsed by the World Health Organization.



We are proud that the Slovenian Cancer Registry has operated continuously during all this period, and what is more we have also co-created the development of such services worldwide. With perseverance and courage data was collected and published regularly at home and around the world. The high reputation among the professional and lay public and trust in the collected data and reports of the Slovenian Cancer Registry underpins our commitment to maintain quality and strive for further development. Moving forward, the core mission of the Slovenian Cancer Registry remains the same - to provide all users with up-to-date and accurate information on the cancer burden in Slovenia and globally and to provide an overview of the quality of Slovenian oncology healthcare. All of us who work within the Slovenian Cancer Registry wish and believe that through our professional work and research we will continue to make an important contribution to cancer control.

prof. Vesna Zadnik, MD, PhD  
director of the Slovenian Cancer Registry

# Mission, Role, and Vision

## High-quality data is the foundation of cancer control

The Slovenian Cancer Registry was established in 1950 at the Institute of Oncology Ljubljana and has maintained its basic mission of being the national registry for the collection, processing and presentation of high-quality data on all new cancer cases and the survival of cancer patients in the country for seven decades.

In line with the development of society and the needs of the healthcare system, the Cancer Registry today also focuses in depth on the ongoing monitoring of the quality of treatment of cancer patients.



## **One of the most complete healthcare databases in the country**

Today, the Slovenian Cancer Registry is a reputable professional institution of national importance, and with its 70 years of work, it is also recognized as one of the oldest and best population-based cancer registries in Europe and the world. With high quality data on cancer burden in the country, it is one of the most complete healthcare databases in Slovenia and a starting point for the preparation of national cancer control programmes, which contribute to the prevention and early detection of cancer as well as improved treatment, survival, and quality of life for all cancer patients.

## **Trust as the key to successful cooperation**

The Slovenian Cancer Registry aims to compile and make available complete, accurate, and timely data to a wide range of users: decision-makers in the healthcare system, clinicians, researchers, the media and the general public, advocacy groups and other local, national, and international organizations. At the same time, its aim is to raise awareness of the importance and necessity of cancer data and to maintain the trust of all users.

## **Future in knowledge and integration**

The Cancer Registry will continue to strive to make an important contribution to the fight against cancer in Slovenia and beyond. It will accomplish this with a highly trained team working hand in hand.

# History of the Slovenian Cancer Registry

## Establishment of the Slovenian Cancer Registry

The Slovenian Cancer Registry was established in 1950 at the Institute of Oncology Ljubljana and has maintained its basic mission of being a nation-wide registry for the collection, processing and presentation of high-quality data on all new cancer cases and the survival of cancer patients in Slovenia for seven decades. Since its establishment, it has been financed from public funds and has always operated under the auspices of the Institute of Oncology Ljubljana.

The Slovenian Cancer Registry has had a legal basis to operate since its establishment. Reporting on cancer cases and the health status of cancer patients has been compulsory for all health care institutions from the very beginning.

## The first publication of data on cancer in Slovenia

In 1951, an article by Prof Dr Božena Ravnihar and I. Gruden, titled The Statistical Review and Brief Analysis of Reported Cancers in the Area of the People's Republic of Slovenia for 1950, was published in the Slovenian medical journal Zdravstveni vestnik.

**1950**

Slovenian Cancer Registry is established

Founder and director is Prof Dr Božena Ravnihar

**1951**

First maps of cancer burden



## Did you know?

The Slovenian Cancer Registry was the fourth national registry with mandatory reporting of cancer cases in the world (after the state of New York in the USA, the province of Saskatchewan in Canada, and New Zealand).

This was the first statistical analysis of the cancer burden in Slovenia using data from the Cancer Registry, which showed that in 1950, 1,671 new cases of cancer were reported, of which 708 were in men and 963 in women. Eight hundred cancer deaths were reported. For comparison: in 2017, there were 14,987 new cases of cancer in Slovenia, of which 7,947 were in men and 7,013 in women. In 2017, 6,364 people in Slovenia died of cancer.

When the Cancer Registry was established, the doctor who treated or autopsied the patient was primarily responsible for the accurate and timely reporting of the cancer case. The envisaged penalty for non-reporting was 5,000 dinars or 10 days of correctional work.

## 1957

First publication on the cancer burden in Slovenia

First publication on cancer burden in Slovenia in English language: Cancer in Slovenia 1955

# Zdravstvena problematika

ONKOLOŠKI INSTITUT MED. VIŠOKE SOLE V LJUBLJANI — PREDSTOJNIK PROF. DR. L. ŠAVNIK — PRIJAVNA SLUŽBA ZA RAKA

## STATISTIČEN PREGLED IN KRATKA ANALIZA PRIJAVLJENIH RAKOVNIH BOLENJ IZ PODROČJA LRS ZA LETO 1950

Dr. B. RAVNIHAR — I. GRUDEN

S tem pregledom hočemo prikazati stanje rakovnih obolenj v LRS, kakor se nam kaže po prvem letu delovanja naše prijavnice službe za raka. S sistematično registracijo rakovnih bolnikov na osnovi zbiranja prijav iz vseh bolnic LRS smo pričeli že v septembru

tudi različni starostni strukturi prebivalstva. Ta namreč kaže pri nas značajše prevladovanje mlajših letnikov nasproti starejšim. Na starostno dobo pod 50 let odpade na primer v Sloveniji 54 % prebivalstva v Franciji na okoli 42 %.

*The first report on the burden of cancer in Slovenia for 1950 featured three hand-drawn pictures of the cancer incidence and mortality in the People's Republic of Slovenia.*

*In 1950, the most common cancers were: gastric cancer (17%), skin cancer (14%), cervical cancer (11%), breast cancer (9%), and lung cancer (4%). In 2017, the most common cancers were: skin cancer (20%), prostate cancer (11%), lung cancer (10%), colorectal cancer (10%), and breast cancer (10%).*

## International recognition

In 1957, the first publication on cancer in Slovenia was published in English, titled *Cancer in Slovenia 1955 – A Report on the Incidence of Cancer and the Survival of Cancer Patients in the Period 1950–1955*. With it, the Cancer Registry boldly embarked on the path of international recognition.

The Cancer Registry has been a full member of the International Association of

1957

Publication of cancer reports for the years 1951-1955

1959

Modernization of cancer registration and data processing

Cancer Registries (IACR) since its founding in 1968 and from its establishment in 1990, also a member of the European Association of Cancer Registries (ENCR). In 1992, it began appearing at international meetings as the national cancer registry of the independent Republic of Slovenia.

Since 1966, data from the Cancer Registry has been included in the international comparison of cancer incidence published in the publication Cancer Incidence in Five Continents under the auspices of the International Agency for Research on Cancer (IARC)

ONCOLOGICAL INSTITUTE  
MEDICAL FACULTY, LJUBLJANA, SLOVENIA / YUGOSLAVIA  
THE SLOVENE CANCER REGISTRY

## CANCER IN SLOVENIA 1955

THE 6<sup>th</sup> ANNUAL STATISTICAL REPORT

BOŽENA RAVNIHAR, M.D.  
ANICA VALENTIN  
TONČKA BOŽIČ  
IVICA DOIČ  
DRAGICA PEČIRER

*The directors of the Slovenian Cancer Registry have so far been elected to the executive board of directors at the International Association of Cancer Registries as representatives of Europe three times: in 1975 Prof Dr Božena Ravnihar, in 1996 Prof Dr Vera Pompe Kirn, and in 2018 Prof Dr Vesna Zadnik.*

*The regular annual meeting of the International Association of Cancer Registries was held in Ljubljana in 2007 in collaboration with the Slovenian Cancer Registry under the auspices of the Institute of Oncology Ljubljana.*

**Did you know?**

**1966**

Slovenian cancer data included in the first international report Cancer Incidence in Five Continents



and the International Association of Cancer Registries (IACR). Slovenian data is of sufficiently high quality to have been included in all editions of this international publication. The Slovenian Cancer Registry is one of only 17 cancer registries in the world that have succeeded in doing this, and in 2012 it received a special recognition from the International Association for this achievement.

The data of the Slovenian Cancer Registry are also included in many other internationally recognized databases and projects and used in leading international studies on the population burden of cancer.

## Informatization of data and work processes

**Did you know?**

*In the 1970s, the Federal Statistical Office of the Federal People's Republic of Yugoslavia tested its programs using data from the Cancer Registry.*

In the first decade of its existence, the collection and processing of data in the Cancer Registry was manual. In 1959 and 1960, data processing with the IBM punch card system was introduced, which was a major advance for that time. In 1969, the Cancer Registry carried out the first one-off computer processing of data on cancer incidence and mortality for the period 1961–1965, foreshadowing further informatization advancements in the work of the registry. The

**1968**

Establishment of the International Association of Cancer Registries; Slovenian Cancer Registry is a full member since the beginning



*The Cancer Registry was the first regular external user of data from the Central Population Register.*

1970s were marked by the creation of the first cancer registry computer database, which was established in 1975 on a large computer at Iskra Commerce, and the development of software for automated data processing.

In 1988, the Cancer Registry was linked to the Central Population Register through the unique personal identification number (EMŠO) which was added to the cancer registry database in addition to other personal data. This enabled

Cancer Registry begins publishing yearly reports called Cancer in Slovenia, which are bilingual (in Slovene and English)

simplified follow-up of the vital status of cancer patients, and also made it virtually impossible to erroneously enter double registrations of individuals with the same, similar or illegible names, which had been a major problem until then.

In 1992, a modern information system of the Cancer Registry was established on its own server, which enabled faster and less costly analyses and facilitated inclusion of Slovenian data into international studies.

The next major technological upgrade of the Cancer Registry information system took place in 2010. The Cancer Registry established a direct on-line connection with the Central Population Register and the Register of Spatial Units, which enabled daily updating of patients' vital status and precise identification of patients' addresses, which are needed for detailed analyses of spatial distribution of cancer. In 2010, the interactive website SLORA (SLOvenija in RAK, 'Slovenia and Cancer') was established. It enables simple and quick access to current data on the burden of cancer in Slovenia. Easy access to foreign cancer databases also enables the comparison of the cancer burden in Slovenia with other countries in Europe and the world.

In 2018, the Cancer Registry started introducing data collection with so-called active registration: individual hospitals no longer fill in paper cancer notification forms, but only prepare a list of patients eligible for registration, and data on these are then collected and recorded directly from back-office information systems by the trained staff of the Slovenian Cancer Registry.

1969

First one-time computer analysis is performed for incidence and mortality data for period 1961-1965

## Regular annual reports and introduction of new publications

The population-based cancer registry warrants its existence if the collected data are also regularly processed, published and used. From its establishment until 1964, data on cancer were regularly published in various forms (in articles, as part of other publications, etc.). Since 1965, the Cancer Registry has also regularly published data in annual reports entitled Cancer in Slovenia, which are bilingual (Slovenian and English). Since 2004, the reports have also been available online.

**Did you know?**

*Cancer data were the first health data in Slovenia that were available online in an interactive form.*



**1972**

First publication of age-standardized cancer incidence data

**1975**

Prof Dr Vera Pompe Kirn becomes director of the Cancer Registry

## Did you know?

*In fifty years, the five-year survival of Slovenian cancer patients increased by 30% in men and 17% in women. Today, almost 60% of cancer patients are still alive five years after diagnosis.*

As early as the 1950s, the Cancer Registry began to prepare in-depth analyses at the initiative of clinicians, either for a specific area or for a particular type of cancer.

In 1992, the first atlas of cancer incidence in the then municipalities of Slovenia was published in the publication Maps of Cancer Incidence 1978–1987. Since 2005, the Cancer Registry has periodically prepared more detailed cancer analyses of smaller geographical areas, mostly studying possible increases in risk due to environmental factors.

In 1995, the Cancer Registry published the first publication on the survival of cancer patients for the period 1963–1990, and then regularly prepared reports on the survival of Slovenian cancer patients, which also included international comparisons. Survival data are a complex assessment of the cancer burden in the observed population, as they reflect the performance of all elements of oncology health care—from screening programmes, early detection, diagnosis, and treatment to rehabilitation.

Since 2016, annual reports of the Hospital Cancer Registry of the Institute of Oncology Ljubljana, which has otherwise been operating since the establishment of the Institute of Oncology, have been published regularly. The hospital registry collects data on all new patients who are diagnosed or treated at the Institute of Oncology Ljubljana. The data also serve as an input for the

**1975**

Establishment of the first computerized cancer database

**1984**

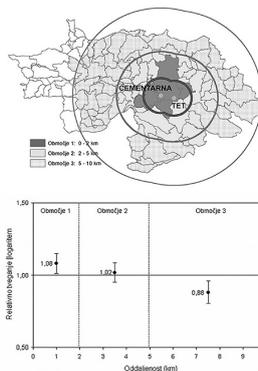
First publication of cancer patients' survival data

national Cancer Registry. Furthermore, the hospital registry data are invaluable for the professional and research work of the Institute and are the starting point for most clinical research.

## The development of new methods for data processing and presentation

Using the data from the Cancer Registry, many new methods of processing and displaying routinely collected data have been developed in Slovenia in the past decades. For instance, as early as 1951, the first cancer maps in Slovenia were drawn – they were among the first cancer maps in the world. In 1972, the first age standardized data were published; this method shows how much of the increase in cancer incidence can be attributed to the ageing of the population. In 1984, the Slovenian Cancer Registry published the first analysis of the observed survival.

Zaščitnost narah bolni v Sloveniji in Evropi



In the 1980s, the Cancer Registry began to intensively involve computer and statistics experts in their research.

1988

First link to the Central Population Registry

1992

Cancer Registry information system moved to an in-house server

In the first publication on the survival of cancer patients in Slovenia in 1995, the Cancer Registry calculated population survival for the first time using the relative survival method, whereby its experts collaborated with foreign experts and were among the first in the world to use this new method of calculating survival. Since 2014, the Cancer Registry has been using the net survival method developed by Prof Dr Maja Pohar-Perme.

*The Pohar-Perme net survival method is an internationally established method of calculating survival, which was developed on data from the Slovenian Cancer Registry and is used today by leading foreign cancer registries. Net survival is the survival that would be observed if the only cause of death was the disease we are studying, i.e. cause-specific survival..*

**Did you know?**

Significant progress in the study of the spatial distribution of cancer in Slovenia was made in 2006 with the introduction of geographic information systems (GIS technology). The Cancer Registry uses the data of the Register of Spatial Units of the Surveying and Mapping Authority of the Republic of Slovenia to perform spatial analyses.

*In 2020, as part of the European Wasaby project, the Slovenian Cancer Registry has been preparing uniform methodological guidelines for drawing maps and performing geographical analyses for all European cancer registries..*

To improve geographical analyses, the Cancer Registry has developed its own method of spatial smoothing that has become established across the world, while in cooperation with French experts, it has developed a Slovenian version of the European Deprivation Index, which it uses to assess the impact of socioeconomic inequalities on cancer.

**1992**

First report on the spatial distribution of cancer incidence

**1995**

First comprehensive report on cancer patients' survival in Slovenia

# Work of the Slovenian Cancer Registry

## Professional activities

The work of the Cancer Registry forms part of the national public health activities to monitor the health of the population and steers strategic development of oncology. It provides indicators on the cancer burden in the country: the number of new cases (incidence), the number of all patients (prevalence), and the survival of cancer patients. With the data, it supports the National Cancer Control Programme in the planning and assessment of primary and secondary prevention, diagnosis, treatment and rehabilitation of oncology patients as well as in the planning of facilities and resources needed to control cancer in the country. Through the Hospital Cancer Registry, it provides the Institute of Oncology Ljubljana with an overview of the number and type of diagnostic procedures and treatments performed.

The staff of the Cancer Registry conduct in-depth epidemiological research on the occurrence of cancer, time trends, spatial distribution, survival of cancer

*Cancer is a growing public health problem in Slovenia and elsewhere in the world. The number of new patients is growing from year to year and currently in Slovenia, about 15 thousand people are diagnosed with cancer every year, somewhat more men than women; almost half of them also die from cancer. In Slovenia, cancer is the leading cause of death in men and the second in women.*

2002

Cancer Registry organizes the first international course on cancer registration

2003

Dr Maja Primic Žakelj becomes director



patients, and monitoring of cancer screening programmes ZORA, DORA, and Svit. At the same time, the Cancer Registry is a starting point for many researchers conducting clinical and epidemiological research by providing data and statistical services as well as guiding them in their research and analysis.

The Cancer Registry publishes data on cancer in Slovenia via regular annual reports, articles and publications, through cooperation with the media, and on the websites of the Institute of Oncology Ljubljana and the SLORA portal.

2004

Yearly cancer burden reports available on-line

2006

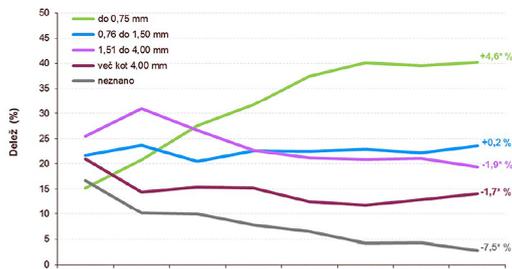
Research into the spatial distribution of cancer and development of new methods

## Clinical registries for evaluating the quality of patient care

Data relating to the diagnosis and treatment of cancer patients are limited in population-based cancer registries. Therefore, countries are introducing clinical registries that collect more detailed data on the type of disease and the method of diagnosis, as well as on treatment procedures and response to treatment. This allows for short-term and long-term monitoring of indicators to evaluate the quality of care of oncology patients.

The 2017–2021 National Cancer Control Programme envisages the establishment of so-called clinical registries within the Cancer Registry for the five most common cancers. In the Slovenian population, the following account for more than half of all cancers: breast, prostate, colorectal, lung cancer, and melanoma.

Slika 3a: Deleží debeline tumorja po Breslowu (mm) pri malignih melanomih kože (C43) s povprečno letno spremembo, Slovenija 1996–2017.



*In 2020, the Cancer Registry will be upgraded with the establishment of the Clinical Registry of Paediatric Cancers, which will make it possible to systematically monitor and more effectively prevent late sequelae of cancer treatment in childhood and adolescence.*

Stepwise establishment of the five clinical registries has been planned. In 2017, the Cancer Registry, in collaboration with clinicians, designed and established a national clinical registry for skin melanoma. In 2019, it continued by designing and establishing a national clinical registry for lung cancer, and in 2020, it will add the remaining three: for breast, colorectal, and prostate cancer.

Clinical registries monitor the entire course of patient care, from diagnosis to treatment, as well as compliance of treatment with current guidelines, the number of annual treatments by individual providers, treatment complications, survival, etc. This data enables the identification and elimination of deviations in the oncology healthcare system as well as verification of compliance with the criteria for the planned networks of oncology centres.

## The Education and Research Reference Centre

The Slovenian Cancer Registry is a teaching base in oncological epidemiology for undergraduate and postgraduate students of medicine and other medical schools, as well as for public health and oncology specialists. It is also a reference and training centre for monitoring the cancer burden and the quality of oncology health care for the South-Eastern and Eastern European regions.

Researchers of the Cancer Registry actively participate in numerous domestic and foreign research projects and are the authors and co-authors of numerous articles, books and reports published in domestic and international forums.

2010

Interactive web portal for cancer burden data in Slovenia ([www.slora.si/en](http://www.slora.si/en)) is launched

Between 2017 and 2019, researchers at the Slovenian Cancer Registry were (co)authors of 60 articles in journals with an assigned impact factor. In 2020, researchers from the Cancer Registry will carry out seven domestic research projects funded by the Slovenian Research Agency, four research projects funded by the European Union, four commercial projects, and five doctoral theses.

*Each year, the Slovenian Cancer Registry prepares additional data for more than 50 researchers and clinicians.*

**Did you know?**



Establishment of a direct on-line connection with the Central Population Register and the Register of Spatial Units

## Commitment to quality

Since the establishment of the Slovenian Cancer Registry, the coding of cancer has been harmonized with international classifications and internal rules of registration. In 2020, the registry received close to 30,000 cancer notifications. Most cancer patients are treated in more than one institution, so the Cancer Registry receives several notification forms for each cancer case. It sends about 3,000 queries for additional data to healthcare providers per year.

To improve the completeness of data on cancer patients, the Cancer Registry is linked to various national databases, including: the Death Registry, the



2010

First National Cancer Control Programme (2010-15) is adopted

2016

First Hospital Cancer Registry of the Institute of Oncology Ljubljana report



Cancer Registry employees are aware of the importance of properly handling personal and health data. From the very beginning of its operation, the Slovenian Cancer Registry has ensured its compliance with legislation on personal data protection.

## Science for all – working with civil society

People are becoming more and more concerned about the possible increased risk of developing cancer due to factors in their living or working environment, as well as other factors. The Cancer Registry is thus approached by individuals or groups, typically associations or civic initiatives, who want answers to specific questions about the cancer burden in their area. The Cancer Registry is aware that civil society is a key partner in developing successful measures to beat cancer, so it takes all such initiatives very seriously and carefully analyses and interprets the results. These initiatives typically require special reports which include data analyses that are not routinely prepared. In such cases, Cancer Registry experts, in collaboration with community stakeholders, determine which cancer groups might be worth exploring in more detail and agree on the form of the research, deadlines, funding and presentation of results.



*From 1950 to 2017, the number of cancer patients per 100,000 people in Slovenia increased by 750% in men and by 600% in women.*

**Did you know?**

**2018**

Prof. Dr. Vesna Zadnik becomes director of the Slovenian Cancer Registry

Stepwise introduction of active cancer registration

*About a third of new cancer cases are due to the effects of various risk factors. Most of these are related to an unhealthy lifestyle.*



2019

An international course on cancer registration held in Ljubljana

Clinical registry of lung cancer is established

# Future of the Slovenian Cancer Registry

The Slovenian Cancer Registry will continue to provide data and estimates of trends in morbidity, mortality and survival of cancer patients with the same dedication it has displayed to date. The work processes, technology used, analytical approaches and interpretation of information will develop in step with the informatization of society, changes in the health care system and in accordance with the needs of users.

The main focus of the work in the future will be on monitoring the quality of treatment and the quality of life of cancer survivors. The Cancer Registry will also serve as a model for the establishment of similar systems aimed at monitoring the quality of treatment for other diseases in Slovenia.

The Cancer Registry will maintain its core mission—it will provide healthcare professionals, political decision-makers, the general public and other users with up-to-date and accurate information on the cancer burden in Slovenia and in the world, and on the quality of Slovenian oncology healthcare. It will continue to promote cancer research and provide data for such research.

The Cancer Registry will maintain its reputation as a leading educational and research institution and its central role in oncological epidemiology in the country as well as in the wider region.

2020

Establishment of clinical registries for breast, prostate and colorectal cancer

Establishment of clinical registry of paediatric cancers

## SLORA.SI

Domov

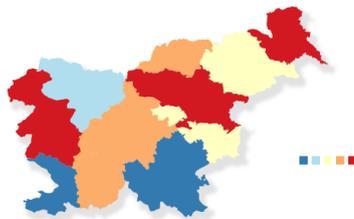
O RAKU

SLOVENSKI  
PODATKI

TUJI PODATKI

POJMOVNIK

POVEZAVE



**Pozdravljeni na spletni strani SLORA! Na njej so vam na voljo epidemiološki podatki o raku v Sloveniji in dostop do podatkovnih zbirk o raku po svetu.**

Zbiranje podatkov o primerih rakave bolezni ima v Sloveniji dolgoletno tradicijo. Na Onkološkem inštitutu Ljubljana namreč deluje Register raka Republike Slovenije že od leta 1950, s čimer je eden najstarejših populacijskih registrov raka v Evropi. Že več kot 60 let zbira in letno objavlja podatke o incidenci, prevalenci in pridruženju bolnikov z rakom; na portalu SLORA lahko pregledate podatke od leta 1961 dalje. Podatke o umrljivosti za rakom v Sloveniji zbira Inštitut za varovanje zdravja; tu so na voljo od leta 1985.

Če epidemiologije rakavih bolezni in njenega izražja ne poznate dovolj, vam svetujemo, da se najprej poučite o definicijah vseh kazalnikov, preberete spletno o raku in rak v Sloveniji ter se šele nato lotite izdelovanja lastnih analiz.

Prosimo, zavedajte se, da je razlaga rezultatov analiz pogosto strokovno zahtevna, čeprav je izdelava analiz videti preprosta. V Registru raka Republike Slovenije vam ostajamo po svojih močeh na voljo za dodatne razlage in zahtevnejše analize.

### Nasvet za citiranje

Zadnik V, Primic Ž, Škejš M. SLORA: Slovenija in rak. Epidemiologija in register raka. Onkološki inštitut Ljubljana. www.slora.si (DD.MM.YYYY).

### Priporočeni brskalniki

Mozilla 3.5.7. ali več, Internet Explorer 8 ali več, Google Chrom 1 ali več, Opera 10.10 ali več, Safari 4 ali več.

### Kje ste izvedeli za portal SLORA?

- a. na strokovnih srečanjih
- b. obvestil me je kolega ali sodelavec
- c. od znancev ali sorodnikov
- d. našel sem na internetu oz. v klasičnih medijih

# Directors of the Cancer Registry



**1950–1975**

## **PROF DR BOŽENA RAVNIHAR**

Prof Dr Božena Ravnihar – Nataša (1914–2002), physician, oncology professor, politician, central figure in the development of Slovenian oncology in the 20th century.

Until joining the partisans, she worked as a volunteer at the Women's Hospital and Maternity Hospital in Ljubljana; she played a central role in the organization of partisan hospitals in Slovenia. She joined the Institute of Oncology Ljubljana in 1946, and was its director between 1963 and 1982. With domestic and foreign scholarships she acquired

expertise in oncology, radiotherapy, tumor diagnostics, epidemiology, and the organization of the healthcare service. From 1955, she worked as a lecturer at the Faculty of Medicine, and was a member of numerous domestic and foreign professional organizations, societies and associations.

In 1949, she initiated the formation of the Service for the mandatory reporting of cancer in the People's Republic of Slovenia, Yugoslavia, organized and led it herself, and devoted herself to the statistical study of cancer in the country as well as liaising with similar institutions abroad. Between 1975 and 1978, she was the elected Regional Representative for Europe in the International Association of Cancer Registries, and in 1996 she was made an honorary member of that association.



## **1975–2003** **PROF DR VERA POMPE KIRN**

Prof Dr Vera Pompe Kirn (b. 1943), physician, professor of oncological epidemiology and internationally recognized expert in the field of cancer epidemiology. After her specialization in social medicine she furthered her professional development at the International Agency for Research on Cancer, the Scandinavian Cancer Registries, and through several international courses.

From 1969 she worked at the Institute of Oncology Ljubljana, where she was director of the Cancer Registry

between 1975 and 2003. In 1975, she steered the pioneering transition of cancer registration from manual to computer-processed. She participated in international research on cancer epidemiology conducted at two prestigious institutions, the National Cancer Institute in Bethesda, USA, and the International Agency for Research on Cancer in Lyon, France.

In 1996, she was the elected Regional Representative for Europe in the International Association of Cancer Registries, and in 2003 she was made an honorary member of that association. In 2004, she received the Ambassador of Science of the Republic of Slovenia award.



## 2003–2018 DR MAJA PRIMIC ŽAKELJ

Dr Maja Primic Žakelj (b. 1952), physician, specialist in epidemiology and public health, doctor of science in the field of oncological epidemiology and internationally recognized expert in the field of epidemiology of cancer and organized screening programmes.

She joined the Institute of Oncology Ljubljana in 1981, initially at the Department of Cancer Epidemiology, which she also headed from 1996. In 2003, the Department of Cancer

Epidemiology and the Cancer Registry were merged into the single Department of Epidemiology and Cancer Registry, which Dr Primic Žakelj was director of between 2003 and 2018. She established and until her retirement (2018) led the national screening programme for the detection of precancerous and cancerous cervical lesions ZORA; she also participated in the establishment of the national screening programme for breast cancer DORA and the National Cancer Control Programme.

She has been a member of many international expert and research groups, in the period 2002-2015 she served as associate professor at the Medical faculty of the Ljubljana University. She is the author or co-author of numerous articles published at home or abroad, and the editor of over 50 publications. Between 2010 and 2019, she was the president of the Association of Slovenian Cancer Societies, and between 2011 and 2013 she chaired the European Cancer League.



## **2018– PROF DR VESNA ZADNIK**

Prof Dr Vesna Zadnik (b. 1975), physician, professor of public health and internationally recognized expert in the field of cancer epidemiology.

Since 2002, she has been employed at the Institute of Oncology Ljubljana, where she was head of the Department of Epidemiology between 2006 and 2018, and since 2018, she has been director of the Cancer Registry. In 2017 she started establishing clinical registries and initiated the changes in

work processes by introducing active registration. In Slovenia, she has led all research projects that have examined the geographical distribution of cancer in smaller, usually environmentally burdened areas. In cooperation with colleagues from the University of Caen in France, she developed the Slovenian European Deprivation Index and used it to examine socio-economic inequalities in the cancer burden.

She is a member of domestic and international expert and research groups, between 2018 and 2022 she is the regional representative of European cancer registries at the International Association of Cancer Registries, and is the coordinator for cancer burden monitoring in the expert council of the 2017–2021 National Cancer Control Programme.

# Devoted Team of Experts at the Cancer Registry

The quality of the work of the Cancer Registry largely depends on the quality of work of its people. Today, the Slovenian Cancer Registry employs 26 people, including 17 graduate nurses with special expertise in cancer registration, three medical doctors specialised in public health, two administrators, and four associates who perform data analysis. They disseminate the results of their work in close cooperation with the public relations department of the Institute of Oncology. They are part of the research group of the Institute of Oncology and are fully supported in their work by the management of the Institute.

The devoted team of highly qualified Cancer Registry staff strives for excellence daily. Their common goal is to provide relevant and high-quality cancer data. The staff of the Cancer Registry work closely with clinicians and other healthcare professionals, researchers and healthcare policy makers, and provide them with support for the most successful cancer care possible.



Cancer Registry employees are proud that their work is important for society. On the solid foundations of the past and with high goals for the future, they will continue to strive to be a valuable source of information on cancer in Slovenia.

## Cancer Registry Team in 2020

Left side (left to right): Ana Mihor, Vesna Zadnik, Sonja Tomšič, Urška Tomšič, Darja Strle, Boštjan Zavratnik, Tina Žagar, Andrej Kirn, Nika Bric, Katja Kolenc Mokotar, Laura Šenekar Zupanc

Right side: Agata Čampa, Miran Mlakar, Polona Škulj, Katarina Lokar, Branka Pestotnik, Maruška Ferjančič, Martina Omerzo, Brigita Zore, Frančiška Škrlec, Andrej Krašovec, Sabina Prvinšek, Katja Hribar, Vesna Drolec

Not in the photos: Mojca Čolnik and Polona Rus

*In 1970, a total of six employees were employed in the Cancer Registry, and in 1968 there were 3,740 new cases of cancer in Slovenia. For comparison: 30 years later, the Cancer Registry had the same number of employees and there were 8,200 new cases of cancer in Slovenia.*

Did you know?



**Title**

70 years of the Slovenian Cancer Registry: Knowledge, Quality, Applicability

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