

Europe

Compiled by Vesna Zadnik, Slovenian Cancer Registry

November 2023

HIGHLIGHTS

There are currently more than 150 population-based cancer registries operating in European region covering the population of more than 700 million. Some of the countries have the complete population coverage through cancer registries, but in the other there are many regional registries. For the European Union countries, only about 65% of cancers are currently counted in registries. A priority for the European cancer registries community is to develop a common mechanism for estimating the national cancer burden for countries with partial cancer registration to enable direct and more accurate comparisons between countries. And further, to assist the countries with non or underdeveloped cancer registration establishing population-based cancer registries.



Figure: Population-based registries in Europe, 2017.

European population-based cancer registries are collaborating within European Network of Cancer Registries (ENCR) since 1990. For several years now the ENCR activities are supported by the European Commission's Joint Research Centre (JRC).

In 2022 the JRC and the ENCR organised a new data call to the European cancer registries, in order to update the cancer data available in the European Cancer Information System (ECIS). Through a coordinated data call, a common protocol to submit data for both the ECIS and C15 projects has been launched. Collaboration Agreement between the JRC and the ENCR registries is a pre-requisite for the

exchange of cancer registry individual records (personal data). The agreement has so far been signed by 87 registries. For an overview of the ENCR-JRC activities 2021-2023, please see 'EC Joint Research Centre | European Network of Cancer Registries (encr.eu)'. The 2023 ENCR Scientific Meeting has been co-organised as a joint event with the IACR annual meeting. The meeting took place in the Escuela Andaluza de Salud Publica (EASP) in Granada, Spain (14th -16th of November) and was preceded by workshops on treatment, recurrences, survival metrics and IT tools and novel AI approaches for cancer registration.

The cancer registries from the Latin language countries are further cooperating within GRELL (Group for Epidemiology and Cancer Registry in Latin Language Countries), national cancer registries from the Nordic countries are connected within ANCR (Association of the Nordic Cancer Registries) and the United Kingdom and Republic of Ireland cancer registries are allied in (UKIACR) United Kingdom and Ireland Association of Cancer Registries. Several countries (France, Spain, Italy, Germany, etc) with regional cancer registries established their countrywide cancer registries associations.

In this report, we are giving a separate annual overview of activities in GRELL, a country specific report is giving further on, grouped by the four European geographical regions: Northern, Eastern, Southern and Western Europe. There are only 4 countries left (Belorussia, Greece, Moldova, Kosovo) with the European region that are not in contact with the European IACR representative and probably not covered by any population-based cancer registration.

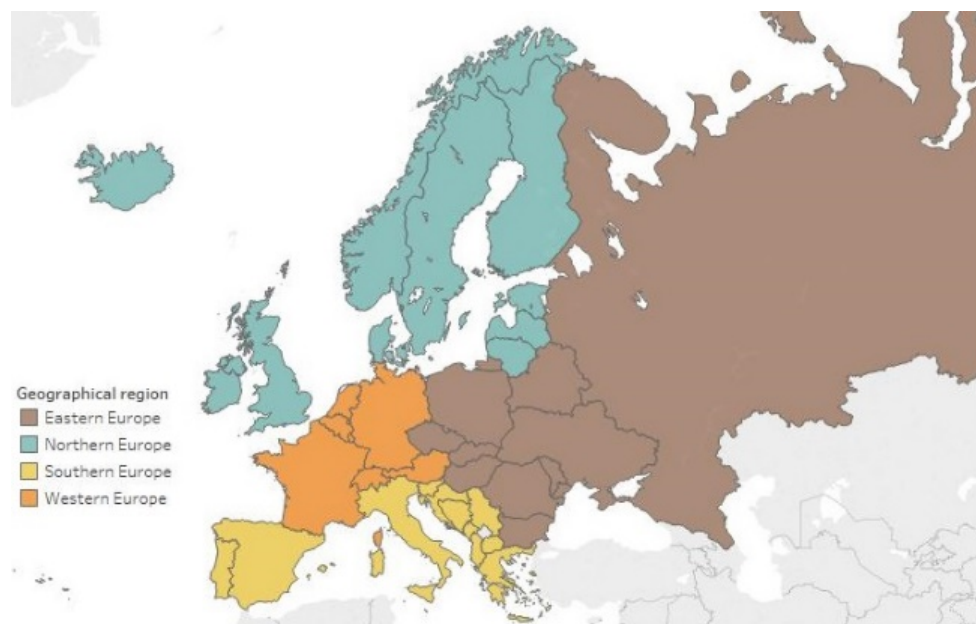


Figure: European geographical regions

GRELL: Group for Epidemiology and Cancer Registry in Latin Language Countries

The Group for Cancer Epidemiology and Registration in Latin Language Countries (Grell) has a long history as a 'self selected group of researchers', which started in the mid-70th. In 2017, it has been newly set up. As determined by the new Statutes, every three years the current members vote representatives from member states. Therefore, Grell is now a scientific association led by a steering committee including elected representatives from 7 member states. Grell has been renewed also with a new logo and with new and continuously updated web site (<https://www.grell-network.org>) where is possible to find all the relevant information about the association and its activities, which include training, grants and awards.

For practical reasons the activity of Grell is mainly done in Europe but the association includes also countries from Central and South America and in other overseas areas. Technology is being applied (streaming) to bridge the geographical gap. Good collaborations are ongoing with national registries of Grell countries and with associations of registries of countries with regional registries (Francim, Airtum, Redecan, Nicer).

The last meeting has been organized in Le Mont Saint Michel in France in May 2023. The first day workshops were dedicated to (1) the Venous cancer and (2) the side effects of the cancer therapies. 66 different works have been presented and various were dedicated to the use of Intelligence Artificial in epidemiology and cancer registries activities. The next one will be hosted in Lausanne, Switzerland on May, 16-18th, 2024.

Many collaborations are ongoing within the Grell Group and together with other International consortia which were represented in the meeting (JRC, Concord, Rarecare, Eurocare, etc.). Grell is fully engaged in all the initiatives aimed at harmonizing and improving cancer registry activity, notably with the ENCR.

*Information for the 2020 report kindly provided by prof. Pascale Grosclaude, director of Tarn Cancer Registry and updated by prof. Marc Maynadié, director of Cote d'Or Hemopathy Registry
mailto: pascale.grosclaude@inserm.fr and mailto: marc.maynadié@chu-dijon.fr*

CANCER REGISTRIES IN NORTHERN EUROPE

ANCR: Association of the Nordic Cancer Registries

DENMARK (Faroe Islands and Greenland), ICELAND, FINLAND, NORWAY, SWEDEN

- The Association of the Nordic Cancer Registries (www.ancr.nu) is the cooperative organ for the national cancer registries of **Denmark**, including the **Faroe Islands and Greenland, Finland, Iceland, Norway** and **Sweden**. The Nordic cancer registries represent some of the oldest population-based registries in the world, all have been in operation more than 60 years. Together the Nordic cancer registries cover a population of 27 million. Collaboration between these registries has long traditions and is a base for development and knowledge-sharing.
- The ANCR Board gathers bi-annually to discuss issues related to cancer registration and quality assurance. Ongoing joint research relate to survival studies, stage-specific incidence, effects of the COVID-19 pandemic, cancer in immigrant populations and socioeconomic determinants.
- The Nordic cancer registries collaborate with IARC on the **NORDCAN** database monitoring cancer incidence, mortality, prevalence and survival. Statistics through 2021 on more than 50 cancer entities are available at <https://nordcan.iarc.fr/en>. The NORDCAN secretariat has been located in Oslo, Norway since 2019. Each country provides aggregate data directly to the database in IARC. User-designated reports on cancer incidence, mortality and survival can be generated in high-quality formats and is a very important tool for researchers and policymakers in the Nordic countries.
- **The biennial Nordic Summer School in Cancer Epidemiology** that integrates education in epidemiologic research methods and cancer surveillance with individual project work has been initiated to introduce a new generation of scientists to the ANCR and to stimulate research in cancer epidemiology. The next course is planned for Aug 2024 in Copenhagen. The Summer School, as well as various joint Nordic projects executed by the ANCR, are financed by the Nordic Cancer Union (NCU).
- The **General Data Protection Regulation** (GDPR) has created considerable barriers to data sharing with institutions outside of the European Economic Area (EEA). The Nordic countries have a major focus on federated analysis and synthetic data to circumvent these challenges, as well as on finding legal solutions within the GDPR framework.
- **Immigrant populations** are increasing in the Nordic countries and several studies address cancer incidence and outcome in these populations.
- There are efforts to strengthen collaborations between the Nordic cancer registries and the **clinical registries** e.g. related to efficient processes for data access, extraction and transfer, harmonize quality variables between diagnoses and countries.
- **Screening programs** are closely connected to the cancer registries in Finland, Iceland and Norway, which allows for monitoring of effects from the screening programs.

*Information kindly provided by dr. Giske Ursin, director of Cancer Registry of Norway
mailto:Giske.Ursin@kreftregisteret.no*

UKIACR: The UK and Ireland Association of Cancer Registries.

The United Kingdom and Ireland Association of Cancer Registries (UKIACR) strive to improve quality assurance of data through the development of Performance Indicators that are carried out annually and enable comparisons of timeliness, quality and data completeness for England, Scotland, Wales, Northern Ireland and the Republic of Ireland. The information is collated and an annual report produced, consisting of a series of datasets, with accompanying explanatory commentary from each of the Registries. The annual performance indicators of data completeness are available on the website www.ukiacr.org/. For IACR European report 2023 we are presenting separate annual overview of activities by each of Registries.

England

- In January 2023 as part of NHS Digital, the National Disease Registration Service (NDRS) merged with Health Education England and NHS England, to become the new NHS England. We are part of the Data & Analysis Function of the Transformation Directorate in the new NHS England.
- We have launched a new website, bringing together all online information about NDRS and its products and services into one single point of access for all users
- In April 2023 we published our strategic plan for 23/24 with 5 key priorities aimed at driving up the timeliness of data, improving linkage and accessibility, greater use of automation and innovative methods while ensuring we are responding to user needs.
- We have made significant progress on registration and are now processing cases from May 2022.
- We have successfully developed a simple and easy to use portal for capturing validated, consistent, structured data on a national scale. The creation of the portal and its continued evolution allows NDRS the most efficient method of receiving large volumes of qualitative data and prospectively offers huge flexibility and scope for future working.

*Information kindly provided by Sophie Newbound, Head of Strategic Engagement at the National Disease Registration Service
mailto: sophie.newbound1@nhs.net*

Wales

- Cancer registration - The Welsh Cancer Intelligence and Surveillance Unit (WCISU) of Public Health Wales has completed the 2020 final cancer registrations. The registration of 2021 cases continues. The final 2020 dataset will be shared in a linkable format with the National Health Service Wales Data Warehouse for wider health service analysis, and with Swansea University's [Secure Anonymised Information Linkage](#) (SAIL) databank for research purposes. The 2020 dataset's quality has been assessed and will be compared to other registries that are members of the UK and Ireland Association of Cancer Registries (UKIACR) in a peer-review process according to agreed quality indicators.
- Data development - Longstanding work with the cancer registry in England and the All Wales Medical Genetics Service to include cancer molecular and genetic data as a new source for cancer registration continues. Receipt of the national all-Wales radiotherapy dataset (RTDS) is now fully functional, and work continues on a national Systemic Anti-cancer Therapy (SACT) dataset to be included in the registry. The new National Cancer Data Standards development was led by WCISU and have now been incorporated into a new clinical oncology system being implemented across the country's hospitals and clinics. This will be our registry's main raw data source for 2023 cases and beyond. WCISU's director is a member of the ENCR Staging Tool Working Group and the ENCR Tumour Recurrence Working Group.

- Statistics and analysis – Population-based 2020 incidence statutory official statistics has been published in our new [cancer reporting tool](#). We have also published rapid cancer proxy incidence based on pathology confirmed cases only to assess the impact of the pandemic and lockdowns on cancer diagnosis up to May 2023. Population-based net survival statutory official statistics will be published end November up to diagnosis year 2020. After collaboration with other registries on data and methods, this year we published non-melanoma skin cancer incidence in Wales, 2016-2019 for the first time. We have been working with other UK registries on harmonising the reporting of registry-based survival so our annual outputs can be directly compared.
- Research – WCISU is currently recruiting for a new Head of Population Cancer Research which is a permanent and strategic position. As for many in the European region and beyond, we are collaborating with developments on CONCORD-4; VENUSCARE; EURO CARE-7 and RARECARENET, as well as on-going International Cancer Benchmarking Partnership (ICBP) Covid-19 Recovery Module and anticipating the next Phase 3. Like many registries out there, we have been involved in multiple scientific publications with these programmes. We continue to collaborate with multiple academic partners on research examining our health systems' recovery in terms cancer services and outcomes after the Covid-19 pandemic. We are also actively involved in the national leadership of population-based research within the new Wales Cancer Research Strategy. We have published several papers on this topic already and linked our findings to decision makers in government and the health service.

*Information kindly provided by dr. Dyfed Wyn Huws, director WCISU, Public Health Wales
mailto: dyfed.huws@wales.nhs.uk*

Scotland

- 2021 cancer incidence was completed and published in April 2023. Overall, rates and numbers of cancer diagnoses increased not only compared with lower numbers in 2020 but also compared with the pre-pandemic period. The issue of under-diagnosis in 2020 had largely been resolved by 2021 but in more socio-economically deprived areas, there was evidence of this persisting to some extent for certain cancer types (e.g. breast and bowel cancer). 2022 registrations will be completed by December 2023.
- Cancer incidence projections 2019-40. Projections were developed by Cancer Research UK and predict a rise in incident numbers of 22% by 2040, mainly due to an aging population.
- 30-day mortality after SACT. In July 2023 we added 30-day mortality from Systemic Anti-Cancer Therapy to a near-real-time dashboard of all national SACT prescribing.
- Cancer survival for incident cases up to December 2020 was published in May 2023. The 2020 cohort was smaller, with a higher proportion of more advanced cancers compared with pre-pandemic years. For the cohort diagnosed in 2020 compared with 2018-19, one-year survival estimates were significantly lower for colorectal cancer (by 6 percentage points) and prostate cancer (by 1.8 percentage points). Lower survival estimates for the cohort diagnosed in 2020 reflect both under-diagnosis of early-stage cancers and delayed diagnosis/treatment.
- A Cancer Intelligence Platform continues to be built to integrate the Scottish Cancer Registry with all other national cancer datasets (including deaths, hospitalisations, waiting times, and clinical audits).
- Scottish Cancer Strategy and Plan. A new 10-year strategy and 3-year cancer plan were published by the Scottish Government in June 2023. A specific chapter dedicated to cancer data was included. We have worked closely with the Scottish Government to inform both documents and also to develop the monitoring and evaluation framework that accompanies them. This lists 136 actions from the cancer plan.

Information kindly provided by dr. David S Morrison, director of the Scottish Cancer Registry, Public Health Scotland

Northern Ireland

- Dr Damien Bennett (FFPH, PhD, MB BCh BAO, BAI, HDip(Ed)), has been appointed as new Director (Interim) of NICR, having previously been a Consultant in Public Health Medicine with the Public Health Agency. Prof. Anna Gavin, the founding Director of the N. Ireland Cancer Registry (NICR) retired in July 2022.
- The Registry continues to be responsible for production of Official Statistics on cancer incidence, prevalence and survival and have added route to diagnosis (emergency and where applicable screened) and specific COVID-19 impact reports for each cancer site.
- Official statistics on incidence, survival and prevalence of lung cancer, breast cancer, colorectal cancer, malignant melanoma and upper gastrointestinal cancers diagnosed in Northern Ireland during 1993-2021 will be released on Thursday 26th October 2023.
- Official Statistics on all cancers diagnosed in Northern Ireland during 1993-2020 were published on 9th Feb 2023. This release provides details of the number of cancers diagnosed each year along with incidence rates over time and data for a range of geographic areas and cancer types. Survival trends and prevalence (the number of people alive) is also provided. For completeness data on cancer mortality is provided courtesy of the General Register Office for Northern Ireland.
- We are developing Routes to Diagnosis data to add to our official statistics suite, which will report on the routes to cancer diagnosis in Northern Ireland. This data will provide information and analysis of the diagnostic routes for NI patients across the main cancer sites broken down by a range of factors including gender, age, deprivation, HSC Trust, stage of disease and net survival. Previous Routes to diagnosis work and outputs have been developed between NICR, BSO and QUB (<https://bso.hscni.net/directorates/digital-operations/honest-broker-service/routes-to-cancer-diagnosis-in-northern-ireland-new-research/>)
- Due to the COVID-19 pandemic, which began in 2020, an additional report has been compiled for each cancer type detailing how incidence and survival from cancer has changed between 2018-2019, 2020 and 2021 thereby providing an overview of the impact of the pandemic on cancer patients and cancer services in general. For 2020 cases we have examined the impact of the COVID-19 pandemic on the entire cancer patient pathway, from presentation to diagnosis through to treatment and finally to survival. This revealed the adverse impact of COVID-19 on the entire cancer pathway - with 13% fewer cases, greater emergency admissions, significant stage-shift, lower rates of surgery and radiotherapy, higher proportions receiving no treatment and significant reductions in one-year survival.
- Between April 2020 and December 2022 we also produced monthly updates on the impact of COVID on pathologically diagnosed (PD) cancers; From 2023 these have been produced on a quarterly (3-monthly) basis, with the latest for the period to June 2023 showing good recovery across sites such as breast, prostate, colorectal and melanoma but with deficits remaining for lung cancers. The latest is available on the NICR website. <https://www.qub.ac.uk/research-centres/nicr/Publications/ImpactofCOVID-19onCancerDiagnosis/>
- We have published an important paper which examined the impact of COVID-19 control on lung, breast, and colorectal pathological cancer diagnoses between the Netherlands, Aotearoa/New Zealand and Northern Ireland <https://bmccancer.biomedcentral.com/articles/10.1186/s12885-023-11216-3>)
- We continue to contribute to the International Cancer Benchmarking Partnership.
- Working with researchers we continue to increase use of the premalignant datasets housed within NICR- these include Barrett's Oesophagus, Colorectal polyps, Endometrial Hyperplasia, Monoclonal Gammopathy of Undetermined Significance (MGUS) and Premalignant neoplasms of the cervix. The Barrett's Oesophagus register will be a key component of the first All-Ireland Cancer Network, AllCaN, involving researchers from Queen's University and

led by Professor Helen Coleman, deputy Director of NICR. (<https://www.qub.ac.uk/News/Allnews/featured/first-all-ireland-cancer-network-launched-world-cancer-day.html>)

- We are working with a local cancer charity, Cancer Focus, to develop a research audit of secondary breast cancers.
- We have worked closely with IARC and colleagues to develop a free updated automated cancer staging tool which is available internationally on and offline, to population based cancer registries. Link to tool - <https://canstaging.org/>
- The cancer strategy for Northern Ireland (<https://www.health-ni.gov.uk/sites/default/files/publications/health/doh-cancer-strategy-march-2022.pdf>) includes a recommendation for a review of NICR. To support awareness of the nature and scope of NICR work we have hosted multiple visits from key stakeholder, including representatives from the Department of Health, and senior clinical and health sector staff from the likes of the HSCNI Strategic Planning and Performance Group (SPPG) and the Public Health Agency.
- Work on development of an updated IT system is progressing, which will allow recording of recurrences and molecular information. However, recording of these data would require additional recourses.
- Following the COVID-19 pandemic in 2023 staff have safely returned to the office, but hybrid working between home and office is being supported with most staff using a mixed model.
- We have been working with HRUK (Heart Research UK) on the impact of heart disease, dementia and stroke as comorbidities in cancer patients.
- Audits - NICR has produced detailed clinical audits of service provision funded by specific grants over many years. Recent audits include colorectal cancers diagnosed in 2018, oesophageal-gastric cancers diagnosed in 2018-19 and pancreatic cancers diagnosed in 2019-2020 (). Details of NICR clinical audits are available at: <https://www.qub.ac.uk/research-centres/nicr/research-audits/Audits/>. We have also begun an audit/research project to investigate the impact of the COVID-19 pandemic on breast cancers patients and pathways. (<https://breastcancernow.org/breast-cancer-research/our-research-projects/understanding-impact-covid-19-breast-cancer-services-in-northern-ireland>)
- The NICR continues to be very research active and produce high impact peer reviewed publications with the latest see www.qub.ac.uk/nicr

*Information kindly provided by dr. Damien Bennett, director of the N. Ireland Cancer Registry
mailto: damien.bennett@qub.ac.uk*

Republic of Ireland

- In 2023, we published “Cancer Inequalities in Ireland by deprivation, 2004 – 2018” <https://www.ncri.ie/news/article/new-report-national-cancer-registry-assesses-effect-deprivation-cancer>. This report measured differences in cancer incidence, five-year survival and stage at presentation between populations living in the most and least deprived areas in Ireland for the diagnosis period 2014-2018. Key findings included that there was a 7% higher age-standardised incidence for males and a 5% higher incidence for females living in most deprived areas compared to those living in the least deprived areas in 2014-2018. In addition, there was lower five-year cancer survival rates in patients from the most deprived areas compared to those in the least deprived areas. Those in the most deprived areas had a 28% higher mortality risk due to cancer within five years of cancer diagnosis compared to those in the least deprived areas, having adjusted for age, gender, and cancer type.
- In August 2023, we released a report entitled “Childhood , adolescent and young adult cancer(AYA)” which was the first report of its kind to include cancers in those aged from 0 – 24 years of age diagnosed in the decade 2011 – 2020. The report’s key findings indicated that

there has been an increase in the incidence of childhood and AYA cancer between 1996 and 2020 and ongoing significant reductions in mortality, reflecting advances in early detection, treatment, and care. Both reports received significant media coverage.

- We refreshed our Strategy in 2023 and as part of its implementation, are planning to enhance our research capacity and revitalising our Research and Analysis department within the NCRI. We are also seeking to improve the comprehensiveness of our data capture and become the independent, expert and trusted voice on cancer data in Ireland.
- We have automated our capture of non melanoma skin cancers, which has resulted in at least 12,000 fewer cancer pathology reports that need to be scrutinised by the Cancer Data Registrars.
- The Canstaging+ tool has been integrated into our system and the requisite changes to enable TNM8 capture of those tumour sites that are not included in the tool have been made. Testing is currently ongoing and we plan to go live with the tool in January 2024.
- Cancer registration in the Republic of Ireland by the National Cancer Registry (NCRI) is population-based, covering a population of 5.01 million in 2021. NCRI is funded by the Government's Department of Health, and legislation entitles NCRI to request cancer-related information from any organization, although direct reporting to NCRI is not compulsory.

*Information kindly provided by Prof. Deirdre Murray Director of the National Cancer Registry Ireland
mailto: d.murray@ncri.ie*

Estonia

- The Estonian Cancer Registry (ECR) is a population-based cancer registry covering whole Estonia (population 1.3 million). The ECR operates as a unit of the National Institute for Health Development (NIHD), which is the Data Controller of the ECR. The ECR is funded from the state budget through the Ministry of Social Affairs and employs a staff of five persons. Reporting to the ECR is compulsory by law, legislation also enables regular linkage of the ECR data with the Causes of Death Registry, the Population Registry, and the Cancer Screening Registry.
- The most recent incidence data for Estonia are currently available for 2020; data for 2021 will be available by the end of 2023. Register-based research, including population-based survival analysis, is mainly carried out by the Department of Epidemiology and Biostatistics of NIHD. Key research areas include cancer surveillance, and the determinants of incidence and survival. Registry provided data for ECIS project in accordance with ENCR-JRC Collaboration Agreement, for CI5 Volume XII and for CONCORD-4 study.
- The ECR recently published online the annual report "Cancer in Estonia: incidence 2020, survival 2016–2020 and haematological tumours 2011–2020", available for download in PDF format from the website of NIHD ([link](#)).

*Information kindly provided by Margit Mägi, MD Head of Estonian Cancer Registry
mailto: margit.magi@tai.ee*

Latvia

- Latvian population-based cancer registry (LCR) is maintained within the state information system – Register of patients with particular diseases including patients diagnosed with oncological diseases. Since May 2018 cancer registry data has been integrated into the e-health system, managed by the National Health Service.
- In the LCR there is a continuous effort to enhance the completeness, timeliness and quality of data. Due to technical problems in the e-health system (e.g. linkage to other data sources), the completeness of data for the last years is insufficient and health care institutions work on

supplementing this data. In cooperation with the Ministry of Health and health care specialists, discussions have been initiated on improving of the content of the cancer registry data and supplementing it with clinical data.

- In 2022 the development of the Latvian New Cancer registry (1. phase: Population Based Cancer Registry) was started. The new information environment includes API system for data exchange in HL7 FHIR profiles. Update of classifiers ICD-O-3.2 will be available in all environment. Normative regulation for the new data entry standard in Latvia will enter into force since 1st January 2024. CDPC is planning and organizing education activities for the practitioners on using new standards and working with new information system.
- Upon request LCR provides data for international projects, studies, data bases.
- Since March 2022, LCR has involved in project "Improving cancer care coordination and screening in Latvia" (ICCCS, 2022 - 2024). The project is led by International Agency for Research on Cancer (IARC). The objective of this project is to propose a strategic plan and a roadmap aiming to contribute to the reduction of cancer mortality by improving population-based cancer registration and improving coverage and quality of breast, cervical and colorectal cancer screening programmes.

Information kindly provided by Anita Maurina, Head of the Registers Supervision Unit, Centre for Disease Prevention and Control

mailto: anita.maurina@spkc.gov.lv

Lithuania

- Registration of malignant tumors in our country started in 1957. The Department of Epidemiology of the Institute of Oncology was responsible for the collection of cancer incidence data. However, only in 1984 the Lithuanian Cancer Registry was established at this Institute by the Order of the Minister of Health. The population-based Cancer Registry was set up in 1990. Cancer registry have had some legislative issues for few years, but Government of Lithuania approved all regulations covering the registry's activities on August 11 in 2016. From first of January 2017 Cancer Registry has had the legal basis for all information from all hospitals in Lithuania, for information from pathological centres, for periodical linkages with death registry and with Central Population Registry for information about vital status or date of emigration. The registry operates as a department of the National Cancer Institute. Today its staff includes a medical doctor, two programmers and two registry clerks.
- Today, in database Cancer Registry has information about all cancers diagnosed since 1978. Information about mortality is available since 1990. Cancer Registry has full information about cancer incidence, mortality, prevalence and survival in Lithuania.
- The principal sources of information are primary, secondary and tertiary health care institutions in the country. All physicians, all hospitals and other institutions must send a notification to Lithuanian Cancer Registry of all cancer cases that come to their attention. The cancer notifications submitted to the Cancer Registry are immediately stored to the database. Earlier all notifications were in paper form, but now about 50 percent of all notifications are in electronic record forms. All doctors at National cancer institute fill electronic notifications in their computers and registry clerks immediately can see this notification and can store them to system. Cancer Registry collects this data about cancer:
 1. Demographic information about the patient and information for identification: full name, date of birth, personal identification number, place of residence.
 2. Primary tumor information: date of diagnosis, ICD10 code of primary site and topography, stage, pathological TNM, clinical TNM, ICD-O-3 code of morphology, behavior, most valid basis of diagnosis: has cancer histological verification or not, date source and name of the doctor who has diagnosed cancer.

All cancer patients are followed up to their death. The Cancer Registry regularly performs data linkage with the Lithuanian Causes of Death Registry (date of death, the main reason of death as text and as ICD-10 code, other additional fields from death certificate).

- Annual registry reports on cancer incidence and mortality have been published since 1994.
- Lithuanian Cancer Registry is a member of International Association of Cancer Registries and European Network of Cancer registries.
- COVID-19 pandemics impact on the work was not significant. There were no changes in finances or performance. We had all technical possibilities to work from home during quarantine. The whole staff was vaccinated together with medical staff in our hospital among the first in our country. And we had a very early possibility to be back to our office for routine work.

Information kindly provided by Ieva Vincerzevskiene, Head of Lithuanian Cancer Registry National Cancer Institute, Vilnius, Lithuania

mailto: ieva.vincerzevskiene@nvi.lt

CANCER REGISTRIES IN EASTERN EUROPE

Poland

- Data on cancer incidence in Poland is collected for the whole population through a national network of 16 regional cancer registries, which since 2013 have been operating in a single, centralized information system, administered by the Polish National Cancer Registry. The registries are placed mostly within the regional cancer centres, which is beneficial due to the access to patient records and the structure of the cancer treatment system in Poland. The legal basis for the operation of registers in Poland is act on public statistics, the act on the information system in health care and the regulation of the Minister of Health on the Polish National Cancer Registry. New legislation, that meet the needs of clinicians and extend the range of collected data about stage, biomarkers and treatment, has been published in April 2023.
- Cancer notification forms are collected via paper (till the end of 2024) and electronic (using a web application for doctors and their assistants or sent directly from hospital information systems), which are verified before the entry into the database of the Polish National Cancer Registry by employees of regional registries. Registries in Poland work on the basis of ENCR recommendations, using both the ICD-10 (2019) and ICD-O-3.2 classification. Since 2006, the cancer registration system in Poland has been financially supported by the Ministry of Health as part of the Cancer Plan in Poland.
- The National Cancer Registry maintains the website www.onkologia.org.pl, which provides basic knowledge on cancer, cancer prevention, epidemiological data for Poland in the form of reports, or annual bulletins (bulletins in English <http://onkologia.org.pl/publikacje/>). Some of the regional registries also run their websites, on which studies for regions are available. Links to these websites can be found at: <http://onkologia.org.pl/wojewodzkie-biura-rejestracji/>
- The National Cancer Registry in April 2023 has implemented the new software for CR's with two modules: for population based CR and clinical registries (the first is an onco-hematological clinical registry, which collects data on the course of the disease, evaluate the effectiveness of treatment depending on applied treatment scheme). The main aim of the new software is to take the cancer patients medical records directly from HIS and code it in the registry (by cancer registrars) without or with minimum involvement of the medical staff. Machine learning is used to help CR staff with coding and finding information in patient records. Some of the new features of this software would be presented during the ENCR-IACR 2023 Scientific Conference.
- COVID-19 pandemic in Poland has decreased the number of new registered cancer cases in 2020 by c.a. 15%. Data for 2021 would be ready till the end of 2023, but first analyses shows a strong need for an active registration procedures to prepare a reliable dataset.

Information kindly provided by dr. Maciej Trojanowski, head of Greater Poland Cancer Registry
mailto: maciej.trojanowski@wco.pl

Russia

- Registration of oncological diseases in Russia began in 1953. The Order of the Ministry of Health (No. 135, 1999) defines standard special notification forms for transmitting encoded data from all medical institutions to the cancer registers of the subjects of the Russian Federation. Cancer registries are organized in all 85 regions of the Russian Federation. Cancer register of Russia gained 100% population coverage (population more than 146 million in

2022). All patients with malignant neoplasms and cancer in situ are subject to mandatory registration. Registration of malignant neoplasms is carried out in cancer registers in accordance with the IARC rules on the territory of permanent residence of patients.

- Regional cancer registries function as departments of regional oncology centres/dispensaries; their main role is to collect data about cancer cases in the territory, calculate and provide different indicators on cancer morbidity, mortality and prevalence in the region, monitoring of cancer patients. Regional cancer registries use automated information systems. Annually, no later than one month after the end of the previous year, the population cancer registers of all regions provide data on the number of new cancer cases, cancer patients and other indicators to the Ministry of Health in the prescribed form.
- Since 2010, the Federal Cancer Registry is located at the P. Hertsen Moscow Oncology Research Institute-branch of the National Medical Research Radiological Centre of the Ministry of Health of the Russian Federation. The Hertsen Institute is in charge of compiling data for research and monitoring the situation with cancer in the entities of the Russian Federation, developing and providing guidelines on data collection, quality assurance and reporting. Every year, all regional cancer registries transmit summary data on morbidity in the form established by the Ministry of Health, and more than 50 regional cancer registries transmit anonymous patient data in the form of electronic databases. The staff of the Federal Oncological Register analyzes the annual reports of population oncological registers and mortality data of the Main Statistical Office and presents summary data in the form of statistical collections: "Malignant neoplasms in Russia" and "The state of oncological care to the population of Russia". Statistical reports for 2007-2021 are available in Russian on the Internet: http://www.oncology.ru/service/statistics/malignant_tumors/. The Institute spends annual Cancer Registry schools. The purpose of cancer registration schools is to improve the quality of cancer registry data.
- In 2020, during the pandemic of COVID-19 screenings and medical preventive examinations were suspended, which led to decrease cancer incidence. Only 556 036 cancer cases were detected in 2020 (640 391 in 2019). In 2022, the number of registered new cases of cancer increased to 624 835, but the level of 2019 was not reached (2019 – 580 415). In the following years, we expect an increase in the number of new cancer cases.
- 9 regional cancer registries of the Russian Federation (Komi Republic, Karelia, Samara, Vologda Region, Arkhangelsk, Kaliningrad, Murmansk, Orenburg, Pskov) took part in international projects «CI5 XII».

*Information kindly provided dr. Irina Lisichnikova from the P. Hertsen Moscow Oncology Research Institute-branch National Medical Research Radiological Centre of the Ministry of Health
mailto: Irina Lisichnikova irliss@mail.ru , rzto@mail.ru*

Slovakia

- The Slovak National Cancer Registry (NCR) is population based and covers the entire Slovak Republic; in 2022 the population was 5.4 million. NCR Slovakia was established in 1976, and data are available on new cancer cases since 1978.
- Notification of cancer cases and deaths has been mandatory since 1952. Data are collected from cancer notifications and death certificates, as well as autopsy, histology, cytology, and hospital discharge reports. In mid-2015, NCR Slovakia started collecting online electronic notifications and electronic pathology and laboratory reports too. The database is annually reconciled with the database of all hospitalized persons of the Slovak National Health Information Centre. Missing information is requested from providers.
- NCR Slovakia is staffed by two physicians, one epidemiologist, three part-time physicians specializing in oncology or pathology, and 10 registrars.

Information kindly provided in 2023 by Mgr. Valentíková Katarína, MPH and MUDr. Gabriela Valachová from Slovakia Cancer Registry

mailto: nor.sr@nczisk.sk; gabriela.valachova@nczisk.sk

Czech Republic

- Czech National Cancer Registry (CNCR, <http://www.uzis.cz/registry-nzis/nor>) was established in 1976. The registration of cancer cases is mandatory by law. Cases reported by clinicians and pathologists are centrally completed and compared with the nationwide information system of Medical Death Certificates allowing the full registration of cancer cases in the Czech Republic. Time trends and other analyses of many cancer epidemiology indicators based on CNCR data are available online at <http://www.svod.cz>. National reports are available at <https://www.uzis.cz/index.php?pg=vystupy--tematicke-rady&id=752>.
- CNCR participates in international projects as CONCORD, CI5 and EURO CARE. The ongoing innovations in legal and technical background of the CNCR was showcased as a pilot model within the iPAAC joint action, see <https://www.ipaac.eu/en/work-packages/wp7/>
- Since 2019, changes in the coordination and methodology of the data collection are being implemented, including simplified report form focused on diagnostic data and possibility to reporting data both via unified web interface and electronic data interface based on B2B principles. Moreover, integration of data on cancer treatment and follow-up from other data sources of National Health Information System (NHIS) has been implemented.
- The priorities of the registry development include increase of integration of standardized cancer data records (clinical and pathological) into information systems of healthcare providers, increase of effectiveness of the registry validation and data completion for epidemiological analyses using expert opinion and AI processing, improvement of registry's timeliness, and integration of these data into evaluation of cancer screening programmes.

Information kindly provided dr. Ondrej Majek, from the Institute of Health Information and Statistics of the Czech Republic
mailto: ondrej.majek@uzis.cz

Hungary

- The Hungarian National Cancer Registry (HNCR: <https://onkol.hu/hungarian-cancer-registry/?lang=en>) is a population-based registry, its declared by governmental decrement as of 1999, which ordered the Registry to the National Institute of Oncology. Among the "Catch-up Program" of World Bank Group financial background of the Hungarian Cancer Registry was created, and operation was started according to the international guidelines in 2000.
- Hospitals directly report professional data of the cancer patients to our center, which verifies data quality and reports back for correction and control to the hospitals. Since 2001 the Hungarian Cancer Registry shares annual reports, which aggregate distinct cancerous cases according to sex, age group and regional categorization (<https://stat.nrr.hu>). Based on individual agreements we support scientific research work and serve information about our cases in the database – in compliance with the personal data management policies.
- Next to data provision, the HNCR performs own research projects to analyze trends in cancer incidence and survival. The main task of the HNCR is to provide feedback about the efficacy of primary and secondary prevention as well as oncological treatment modalities in Hungary.
- In the past few years, the HNCR cooperated with International Association for Research on Cancer (IARC), which resulted numerous scientific publications. In addition, HNCR participates in EU projects, such as Cancer inequalities Registry and 4.UNCAN.eu.
- Since the HNCR receives additional mortality data from the Hungarian Statistical Office and financial data from the National Health Fund, establishment of a comprehensive database may open new horizon in the assessment of cancer. On the other hand, the effect of COVID-

19 pandemic on registration process, and for expected future cancer incidence and mortality is under intense examinations.

*Information kindly provided by dr. Kenessey István, head of Hungarian National Cancer Registry
mailto: kenessey.istvan@oncol.hu*

HUNGARIAN CHILDHOOD ONCOLOGIC REGISTRY

- After two decades' close collaboration with National Cancer Registry of Hungary in 2018 a new law was passed redefining disease registries including Hungarian Childhood Oncologic Registry (founded: 1971), which ordered access to death certificates as well. A new name was introduced the National Childhood Oncologic Registry. It is a national, population-based cancer registry with complete coverage for children up till 14 years and partial coverage for ages 15-18 yrs. Centres caring for children with cancer notify each newly diagnosed patient to the registry and send annual updates on follow-up thereafter. We collect a wide range of data on different childhood cancer diagnoses, prognostic factors, document treatments, early and late toxicity to support clinicians continuously improving cure rates while minimizing side effects.
- The Hungarian Pediatric Oncology Network was granted permanent financial support of the Ministry of Human Capacities to run the Childhood Cancer Registry in 2012.
- Years of the Covid pandemic have negatively affected cancer registration in Hungary, but in 2023 we could catch up registration practices and performed the yearly matches with the National Cancer Registry. New informatical developments are under way to link biobank data and outcomes of molecular genetic testing of childhood cancers at different stages of the disease with the data routinely collected by our registry.
- Organizing very successful Pancare 2022 fall conference attracting over 150 professionals from Europe we experienced significant changes in interest of topics survivorship and long term consequences. A special subgroup was founded within our network, new professionals and resources were made available for data collection and research as well. Phd students started life quality monitoring and studying long term consequences of radiotherapy with the background of the registry.
- Pancare twinning activity was launched with Slovenia to experience how long term follow up and data collection is managed on a national scale. Five doctors including one survivor were able to visit Ljubljana in May 2023 thanks to Lorna Zadavec-Zalatel and Ana Mihor.
- Our registry has been actively involved in two projects: the statistical analysis of the Benchista project - comparison of six diagnostic groups of childhood cancer, Toronto stage at diagnosis and disease outcome. A new EU-funded international project named Equol has been initiated with the aim to widely adapt passport like documents and applications for survivors in countries where they have not been introduced in daily practise in partnership with the Erintettek patient and parent association.

*Information kindly provided by dr. Zsuzsanna Jakab, Head of Hungarian Childhood Cancer Registry
mailto: dr.jakab.zsuzsa@gmail.com*

Romania

- In Romania, country with 20 million inhabitants, cancer reporting and registration have become compulsory in 1980. The cancer registration legislation was updated in 2008, taking into consideration the ENCR Guidelines and recommendations. Eight Regional Cancer Registries were founded, covering the whole country. They should transmit the requested data, needed for a national cancer report, to the National Centre of Statistics and Informatics for Public Health (CNSISP). However, Regional Cancer Registries were operational only in 3 out

of eight regions, two of them (Cluj and Timisoara) being ENCR and IACR members. The active registries were financially supported by the Ministry of Health, until April 2022.

- The main sources of data are cancer notification paper forms gathered from treatment and diagnostic centres. In 2016, Cluj Regional CR started a process of changing the registration procedure shifting to the online reporting, through the development of an online tool (<http://nwcanportal.iocn.ro/oncreg/>). The portal is used only in the North-Western Region of Romania and only by few cancer reporting sources. In the last years, Cluj Regional CR sent data to Venuscancer study, IACR and ENCR data call and now, is preparing data for CONCORD 4 study.
- This year, in the framework of the new National Cancer Plan, began the organization, of the National Cancer Registry, based on 8 regional coordinating centers located in two Oncological Institutes (Cluj_Napoca and Bucharest) and 6 Public Health Regional Centers, parts of the National Institute of Public Health, with the diminution of the role, rights and attributions of the former regional registries.
- Since 2009, following the aims of the Romanian Society of Pediatric OncoHematology, Cluj Regional CR offered professional support for the development of the Romanian National Childhood Cancer Registry (RNCCR), accepted as ENCR member in 2018. In the last years, the basic data set was expanded with further diagnostic and treatment information, the registry becoming a more quality clinical registry, population-based, which can monitor the quality of cancer care, by the inclusion of additional variables to traditional reporting of cancer burden indicators (<http://oncped.iocn.ro>). Toronto staging guidelines were adopted and included in the reporting procedures in March 2019. The Neuroblastoma and Wilms Tumours data were sent for inclusion in the in the JARC pilot study, regarding the application of Toronto System by the Cancer Registries. RNCCR is part of BENCHISTA Project. In 2022, the RNCCR benefits from a JRC-ENCR official review. This autumn, for the first time, RNCCR prepared the childhood cancer data base to be included in the CONCORD 4 study.
- One of our main priority is to develop the CR in order to facilitate the linkage with the newly implemented Screening registries, for breast and cervical cancer.
- Other priorities, for the next three years, are to develop three High quality cancer registries, for breast, lung and ovary cancers.

*Information kindly provided by dr. Daniela Coza, Head of Cluj Regional Cancer Registry
mailto: dana.coza@iocn.ro*

Bulgaria

- Cancer registration has been compulsory in Bulgaria since 1952. The system consisted of 13 regional units (regional cancer registries) covering the whole country and the central Bulgarian National Cancer Registry (BNCR). In the 2011 and further years there were changes in the legal framework which drastically influence the cancer registration system, which continues to this day. The state funding of the regional cancer registers activities was stopped. For five years now, neither the Bulgarian National Cancer Registry (BNCR) nor the 13 regional cancer registries have been receiving funding for our activities from the Ministry of Health. During the period of the coronavirus infection all efforts and resources was directed towards controlling the pandemic. All this further influenced the collapse of cancer registration in the country. Containment of the pandemic has not led to an improvement in cancer registration, and the new cancer cases continue to fall. There is still no decision by the Ministry of Health to support and update the activity of the Bulgarian National Cancer Registry.
- Namely, the BNCR continues to register new cancer cases following all the internationally agreed rules and recommendations, however the underreporting of new cases is apparent. New cancer cases decrease almost twice, but not because we have improved cancer care for patients, but because we have a significant drop in registration. Because of unreal number of

new cancer cases, BNCR stopped publishing the annual edition of the "Cancer Incidence in Bulgaria" and is not in a position to send a full and accurate up-to-date database for the needs of international studies after 2013. Also, we cannot take into account the impact of the COVID-19 epidemic on prevention. Due to a lack of funding, we cannot update the specialized information cancer system with which the BNCR and regional cancer registers work. From the beginning of 2022, the National health information system is being upgraded. We are confident that the activities of the BNCR will be part of this system.

- Our estimates on cancer burden are: Bulgaria has the lowest age-standardised cancer incidence in Europe. Cancer mortality is just below the EU average, but Bulgaria is the only country that has reported rising mortality trends for both men and women during the past 10 years. Survival is one of the lowest in Europe and in the world. This is most likely a result of important levels of underdiagnosis, detection of the new cancer cases at a late stage of the disease and last but not least underregistration of cancer. The Bulgarian data should be interpreted with care, considering the indicators and in the light of availability of and access to preventive, diagnostic and screening services for the Bulgarian population.
- As of 2022 Bulgaria is one of the few European countries without an officially approved national cancer plan. However, the National Recovery and Resilience Plan for Bulgaria planned specific reforms in the health care sector, including investment in cancer prevention.
- The new initiatives concerning the future development and activities of the Bulgarian National Cancer Registry are the approved National Plan for Combating Cancer in the Republic of Bulgaria 2027¹ (stated by Order №3/2023 of the Ministry Council on 04.01.2023) and The National Map of the Long-term Need for Health Services² (stated by Order №1073/2022 of the Ministry Council on 29.12.2022). On 01.02.2023 the European Commission published EU Country Cancer Profile: Bulgaria 2023 which identifies strengths, challenges, and specific areas of action on cancer prevention and care in Bulgaria as part of the European Cancer Inequalities Registry, a flagship initiative of Europe's Beating Cancer Plan.
- At the beginning of 2023 experts who are developing the National Health Information System (NHIS) according to the Order of Ministry of Health received full access to the specialized cancer software and the national cancer database with 1018544 records. They are going to integrate the BNCR to the NHIS until 01.01.2024.
- From 29.06. to 03.07.2023 during the GYNOCARE meeting in Sofia there was presentation named "Cancer registration in Bulgaria". The topics in the presentation concerning the development of the BNCR from 1952 until now and the main problems and challenges related to its routine activity.
- If you have any questions don't hesitate to contact us.

*Information kindly provided by prof. Zdravka Valerianova, head of Bulgarian National Cancer Registry
mailto: zvalerianova@sbaloncology.bg*

Moldova

- IARC/WHO EURO advanced cancer registration course in Russian language took place in Chisinau in January 2019. The round table on cancer registration in Moldova with the stakeholders was also held on the occasion. PBCR data available since the year 2016, data quality has not been evaluated. Contact: Oleg Arnaut (arnautoleg1@gmail.com).

*Information kindly provided by dr. Ariana Znaor, IARC
mailto: ZnaorA@iarc.fr*

¹ <https://www.strategy.bg/StrategicDocuments/View.aspx?lang=bg-BG&Id=1589>

² <https://www.strategy.bg/StrategicDocuments/View.aspx?lang=bg-BG&Id=1592>

³ https://www.oecd-ilibrary.org/social-issues-migration-health/eu-country-cancer-profile-bulgaria-2023_f6915046-en

Ukraine

- The National Cancer Registry of Ukraine (NCRU, <http://www.ncru.inf.ua/>) was established in 1996 and is currently part of the National Cancer Institute of Ukraine. Cancer notification has been mandatory in Ukraine since 1953, with every medical institution or laboratory (public or private) required by the state cancer registration system to send standard paper notification forms to the regional population based cancer registries (PBCR) for each new cancer case, as well as for prevalent cases receiving treatment. As of 2018 there were 25 regional PBCRs, each operating as a division of the regional oncological centre. In 2022 another two regional PBCRs have lost contacts with the NCRU.
- In 2002 the NCRU gained 100% population coverage, which dropped to 85-90% after Russia's annexation of the Crimea and its support to anti-government breakouts in the East of Ukraine in 2014.
- Another stressing event to the cancer care system of Ukraine in general and cancer registration system in particular happened on February 24th, 2022 with the beginning of the massive and unprovoked Russian full-scale invasion of Ukraine. The NCRU continues collecting data as much as it possible given current situation.
- Nevertheless, publishing of the NCRU's Annual report "Cancer in Ukraine: incidence, mortality, activities of oncological service" was not interrupted available in Ukrainian (hard copy) and English (online)
- The NCRU published latest annual report "Cancer in Ukraine 2021-2022" (http://ncru.inf.ua/publications/BULL_24/index_e.htm).
- Selected publications over the last year:
 - Breast and cervical cancer screening practices in nine countries of Eastern Europe and Central Asia: A population-based survey; <https://doi.org/10.1016/j.jcpc.2023.100436>
 - Progress in reducing premature mortality from cancer and cardiovascular disease in the former Soviet Union, 2000–19; <https://doi.org/10.1093/eurpub/ckac030>
 - Breast cancer risk in Ukrainian women exposed to Chernobyl fallout while pregnant or lactating: standardized incidence ratio analysis, 1998 to 2016; <https://doi.org/10.1007/s10654-022-00913-1>
 - The passive collection of incidence data and active collection of mortality data is in place at the regional level. Main sources of information are 1) notifications and 2) excerpts from the medical records completed for all cancer patients upon discharge from a hospital.
 - As major reform from the centralized towards insurance-based health care system is currently ongoing in Ukraine, the main challenge is to preserve existing cancer registration system and continuum of cancer registry operations.
 - In the international context, the NCRU's data (2013-2017 cancer incidence) was accepted to the IARC's CI5 vol. XII.

*Information kindly provided in 2021 by dr. Anton Ryzhov from National Cancer Registry of Ukraine
mailto: hcr@ukr.net*

Belorussia

No contact / response from Belorussia has been obtained during the preparation of this report. According to available information some efforts to establish/maintain a population-based cancer registration has already been done, however cancer registration in Belorussia face several challenges in their everyday work (including but not limited to):

- outdated legal framework;
- very limited budgets with a lot of uncertainties about funding in the recent future;
- lack of trained staff.

CANCER REGISTRIES IN SOUTHERN EUROPE

Spanish Network of Cancer Registries (Redecan) - 2023

- The Spanish Network of Cancer Registries (Redecan), created at the end of 2010, assembles all population-based cancer registries in Spain. - www.redecn.org.
- Activities of Redecan during the first months of 2023:
 - Annual course for registrars: In June and April the course “Coding of breast and female genital tumors in Cancer Registries” was held. It was held virtually.
 - The estimate of cancer incidence in Spain, 2023 was obtained in January 2023 (available on Redecan website): <https://www.redecn.org/en/projects/3/estimates-of-the-incidence-of-cancer-in-spain-2021>
 - Update of the common database of Redecan: Call of Data for a new edition of the Redecan common database was launched in September.
 - The estimate of cancer incidence in Spain, 2024 will be obtained in January 2024.
 - Publication of “Las cifras del cáncer en España, 2023” (Cancer figures in Spain, 2023) with the Spanish Medical Oncology Society (SEOM). Available in SEOM website): https://seom.org/images/Las_cifras_del_Cancer_en_Espana_2023.pdf
 - Conducting and publication, jointly with the SEOM, of the report titled “Proposal of variables of interest for registration in population-based cancer registries and for high-resolution studies” (in Spanish). <https://redecn.org/storage/documentation/6e9c8bd4-3380-4095-acdf-4ba532eb32cd.pdf>
 - Publication of the article “Incidence and time trends of childhood hematological neoplasms: a 36-year population-based study in the southern European context, 1983-2018” <https://pubmed.ncbi.nlm.nih.gov/37560466/>.
 - Conducting of the study “Tendencias de la incidencia de los cánceres del encéfalo en España entre 1985 y 2015 y su posible relación con el uso de teléfonos móviles (Trends in the incidence of brain cancers in Spain between 1985 and 2015 and their possible relationship with the use of mobile phones). In process of publication.
- The Network is preparing for new analysis on the incidence, survival and prevalence of cancer in Spain.

*Information provided by dr. Jaume Galceran, president of the Spanish Network of Cancer Registries (REDECAN).
mailto: jaume.galceran@salutsantjoan.cat*

Malta

- Notification of cancers has been mandatory by law in Malta since 1957. There were several attempts to establish a nationwide cancer registration in Malta. Since 1991 the Malta National Cancer Registry (MNCR) has been operating: it collects data on cases diagnosed in all (public and private) hospitals, clinics and laboratories on the Maltese Islands. The registry performs data collection through active registration by collecting clinical and administrative data at source. Currently the IT systems are being upgraded to provide better automation of the data collection and more direct linkages with clinical and administrative data sources.
- The Malta National Cancer Registry reports data to ENCR/JRC as well as to IARC databases. Since 1992, incidence and mortality data for Malta have been included in all subsequent

Cancer Incidence in Five Continents publications (latest Vol. XI published in 2017). The registry participated in the last data collection process with data to be included in Vol. XII. From 1993, cancer survival of cancer patients diagnosed in Malta has been analyzed and compared with the survival of cases diagnosed and treated in other European countries and globally in all the successive EUROCARE studies as well as the CONOCORD project. The registry has also continued participating in other projects such as the iPAAC Work Package 7 Workshop - how to integrate cancer registries data with administrative sources, the BENCHISTA project Benchmarking International Survival by Toronto stage and in the COST Action GYNOCARE – European Network for Gynaecological Rare Cancer Research- from Concept to cure. The registry also established collaboration with European Reference Networks related to cancers including EURACAN and PAEDCAN. The registry is currently participating in the work of the European Cancer Inequalities Registry, which is a flagship initiative of Europe's Beating Cancer Plan. It will also be participating in the ORION Joint Action (Monitoring of National Cancer Control Policies)

- The work of the Registry was impacted by the COVID pandemic in view of the fact that there is a finite number of Public Health experts in Malta and the Public Health experts and healthcare workers responsible for the registry had to be deployed to perform COVID duties. Work related to the registries was given a minimum amount of protected time to maintain the basic functions of the registry and to respond to important queries, policy questions, mandatory data collection exercises and fulfil international obligations and participate in important research projects. Despite this, data collection and annual reporting were not impacted by the pandemic. The process of upgrade of the It systems was delayed by the pandemic, however data collection still continued normally using the robust old system while the upgrade of the new system will continue in tandem. A notable improvement was also noted in the period 2019-2021 with the establishment of a system of reporting of Rare Cancers extracted from the Cancer Registry. This Rare Cancer data is then transferred to the Malta National Rare Disease Registry for the registration of these rare cancers.
- The current priorities of the registry are to modernise the current registry by utilising the current IT systems upgrade to provide more timely data collection through automation of the data collection processes and more direct linkages with clinical and administrative data sources. New variables will also be collected including the further definition of tumour types at a molecular level, updates will be made to the staging of tumours at diagnosis such as the uptake of the Toronto Childhood Cancer Stage Guidelines as endorsed by the European Network of Cancer Registries.

*Information kindly provided by dr. Miriam Azzopardi, head of Malta National Cancer Registry
mailto: miriam.j.azzopardi@gov.mt*

Slovenia

- Slovenian Cancer Registry (SCR: www.onko-i.si/eng/crs/) is one of the oldest population-based cancer registries in Europe. Notification of cancer has been compulsory in Slovenia (population: 2 million) since the foundation of SCR in 1950 and is prescribed by law. SCR regularly publishes data on cancer incidence, survival and prevalence. All the cancer burden indicators are available also online: <http://www.slora.si/en/>.
- In the international context, the SCR reports data to ENCR/JRC as well as to IARC databases. SCR participates in several projects, at this moment SCR is involved in the CONCORD, EUROCARE, Benchista, PARC, along many small projects within the Slovenian oncological and public health community.
- In 2023 almost the entire cancer registration procedure is changed from passive to active; instead of gathering notification forms from hospitals, the data are collected directly at the source by trained SCR personal. The hospitals are just providing the SCR with the names of the

patients available for registration, but further the CR staff is accessing the hospitals information systems directly and extracting the data.

- Following the aims of the National Cancer Control Plan SCR has started to expand the basic data set with further diagnostic and treatment variables. In so-called clinical registries, the quality of cancer care could be monitored as well in addition to traditional reporting of cancer burden indicators. As a part of SCR the Slovenian national clinical skin melanoma registry is providing reports from 2017 on; lung cancer clinical registry was established in 2020, breast and colorectal clinical registry started in 2023, but the clinical registry for prostate cancer is on the way. In addition, in the end of 2020 the childhood cancer clinical registry was launched with the aim to assure the appropriate information for follow-up of late consequences of cancer treatment.
- Using cancer registry data we were able to evaluate the impact of COVID on cancer burden and care in Slovenia: up-to-date indicators of COVID-19 impact were available at the Slora/onKOvid dedicated web-portal managed by the SCR. The overall cancer diagnoses burden was lower for about 30%, but there were some cancer types with much larger drop.

*Information kindly provided by prof. Vesna Zadnik, director of Slovenian Cancer Registry
mailto: vzadnik@onko-i.si*

Croatia

- Croatian National Cancer Registry (CNCR: <https://www.hzjz.hr/sluzba-epidemiologija-prevencija-nezaraznih-bolesti/odjel-za-maligne-bolesti/>) started collecting the data on persons who died of cancer in 1959, and the data on incident cases in 1962. Notification of cancer is compulsory in Croatia (population by 2021 census: 3.87 million) since the foundation of CNCR and is prescribed by the yearly plan of statistical activities brought by the Croatian Bureau of Statistics and promulgated by the Croatian Parliament. CNCR regularly publishes data on cancer incidence in Croatia, and the bilingual (Croatian and English) reports are available at: <https://www.hzjz.hr/sluzba-epidemiologija-prevencija-nezaraznih-bolesti/publikacije-odjel-za-maligne-bolesti/>. The report for 2021 will be published during November 2023, preliminary data indicate a drop in overall new cancer diagnoses in comparison to 2019 (albeit, a slightly higher number of diagnoses than in 2020).
- In the international context, the CNCR reports data to ENCR/JRC as well as to IARC databases. CNCR participates in several projects; at this moment CNCR is involved in the CONCORD (submitted data to the 4th wave), EURO CARE, CraNE, JANE, along many smaller projects within the Croatian oncological and academic community.
- Currently, the main source of data are pathological/cytological reports, cancer notification forms gathered from all hospitals and diagnostic centres in Croatia (in electronic form since 2017), along notifications from GP offices and data on underlying causes of death. A new software, produced in recent years has enabled linkage of the registry to the data from hospital discharge database and mortality database, as well as some other databases at the Croatian Institute of Public Health, of which CNCR is an integral part. In 2023, a linkage with data from Croatian Health Insurance Fund was planned and the data has recently been obtained. We are in the process of determining the best way to use this data for the registry's purpose. We have piloted the delivery of the pathological reports in a fully electronic form in a database format from the Clinical Hospital Centre Zagreb, and are currently working with other hospitals to obtain these reports in a standardized manner.
- The first Croatian National Cancer Plan has been adopted in 2020, and the cancer registry is recognized as an important tool for advancement of overall oncological care in Croatia. Future developments should focus on providing more resources that would enable including more data sources, expanding the dataset and performing data quality audits with more focus on policy-making based on high-quality data analysis. Also, a move towards active data registration (with appropriate resources) is envisaged and has been communicated to the

policymakers. Initiatives regarding implementation of National Oncology Network and underlying National Oncology Database have been underway; the importance of linking with the CNCR has been stressed repeatedly to the policymakers.

- The COVID-19 pandemic has placed an additional stress on the already thin resources of the registry, with additional duties in the public health system (the Registry is part of Croatian Institute of Public Health) and temporary displacement of registry staff towards COVID-19 related procedures (swab testing, vaccination, etc.) and displacement due to the renewal of the registry's premises (because of renovations due to 2020 Zagreb earthquake). Even with these circumstances, we have managed to keep having our yearly report published in dedicated time frame (within two years of end of calendar year).

*Information kindly provided by dr. Mario Šekerija, head of Croatian National Cancer Registry
mailto: mario.sekerija@hzjz.hr*

Bosnia and Herzegovina

Two regional population-based cancer registries in Bosnia and Herzegovina, namely the Population-based Cancer Registry of the Federation of Bosnia & Herzegovina and the Republika Srpska Cancer Registry, are official members of the International Association of Cancer Registries (IACR). However, the advancement of an integrated and comprehensive cancer registration system in Bosnia and Herzegovina is impeded by legal, organizational, and financial challenges.

Despite stakeholders' expressed interest in improving the existing population-based cancer registries in Bosnia and Herzegovina, and the presence of a regulatory framework within strategic documents, there has been little recent advancement in the Federation of Bosnia and Herzegovina. In the Federation of Bosnia and Herzegovina, only non-comprehensive reports on the registry are published in the Annual Health Statistics Report. GLOBOCAN estimates for the country are based on the population-based cancer registry within Republika Srpska entity, which are collected by the Public Health Institute in Republika Srpska.

Some electronic procedures were introduced in the healthcare system during the COVID-19 pandemic, and ongoing efforts are in place to establish a clinical registry at the University Clinical Center Sarajevo, the largest tertiary care hospital in the country, serving over half of the nation's population and large part of Federation of Bosnia and Herzegovina.

*Information kindly provided by dr. Džan Ahmed Jesenković, from Faculty of Medicine, University of Sarajevo
mailto: dzanahmed.jesenkovic@mf.unsa.ba*

- **Cancer registry Republika Srpska:** The registry for malignant neoplasms in the Republic of Srpska was established in 2001 on the basis of the Rulebook on the form of the registry and its management, the application form and the procedure for reporting malignant neoplasms (Official Gazette of the Republic of Srpska No. 28/01).
- The registry for malignant neoplasms in the Republic of Srpska includes data on: the health institution that reported the malignant tumor, the possible occurrence of multiple primary tumors, personal characteristics of the sick/deceased, the date of diagnosis, the method of diagnosis, the localization of the malignant tumor (primary and secondary anatomical localization), histological tumor type, disease stage, disease outcome.
- Sources of data on sick persons are reports of malignant neoplasms and copies of histological/cytological findings submitted by hospital and outpatient health institutions,

clinics, institutes, institutes, histological-cytological, hematological and other laboratories, as well as data from hospital and outpatient morbidity. The sources of data on deaths from malignant diseases are the death certificates of the Republic Institute of Statistics, which are coded in the Service for Social Medicine, Health Organization and Economics of the Institute for Public Health of the Republic of Srpska.

- Cancer registry Republika Srpska: is included into following international projects: CONCORD, EUROCARE and EURECCA (EU-MELACARE).
- The work on the registry was a little slowed down due to COVID 19. There are many challenges and desires to improve the operation of the registry, but very few opportunities for the same due to weak support.

*Information for kindly provided by prof. Živana Gavrić, head of Cancer Registry of Republika Srpska
mailto: zgavric210@gmail.com*

Montenegro

- The Registry of Malignant Neoplasms of Montenegro (RMN of MNE) was established and started to operate on 1st January 2013 (www.ijzcg.me). It is a national population-based registry that collects data on all new malignant neoplasms registered in the Montenegro population. The host and funding institution of the Registry is the Institute of Public health of Montenegro (IPH of MNE) in Podgorica. Cancer notification in Montenegro is mandatory by law for all healthcare providers in the country (regardless of whether public or private). Data gathering combines two methods, i.e. passive (using a unified malignant neoplasm notification form) and active (searching relevant documentation directly in data sources). The data from the health care system integrated into e-HIS are submitted to the Registry electronically through the information platform specially created to report to population registries in the IPH of MNE in 2012 and 2013.
- The most critical challenge for the Registry is the lack of qualified staff. Unfortunately, there is still just one permanent staff member in the Registry. Therefore, it affects the timelines of annual reporting of cancer incidence in the country: the actual lag is nine years. Hopefully, the Registry will engage additional full-time employees and become more capable of improving the registration process, the data quality and the timeliness of reporting on the cancer burden in Montenegro.
- The Registry reports data on cancer incidence and mortality on an annual basis. The first report on malignant neoplasms in Montenegro for 2013 has been produced, published and disseminated (<https://s3.eu-central-1.amazonaws.com/web.fabrika/ijzcg-media-fabrika/files/1573571155-maligne-neoplazme-u-crnoj-gori-2013.pdf>). The 2014 Annual Report is in the final preparatory phase for data quality check, analysis, and Annual Report finalisation.
- In the international context, the RMN of MNE reports data to ENCR/JRC (done) and IARC databases. In addition, the RMN of MNE participated in the collaborative project of Southern-Eastern-Central-Northern European Cancer Registries coordinated by the NARECHEM-E (CNS tumours among Adolescents and Young Adults 15-39 years old). The Registry also participates in the collaborative study on "Disparities in oesophageal and stomach cancer burden and time trends across South-Eastern Europe".
- Unfortunately, the Registry could not prepare even data for three consecutive years (2013-2015) and participate in Cancer Incidence on five continents edition (2013-2017).
- The Registry updated variables following "A proposal on cancer data quality checks: one common procedure for European cancer registries" (2014). All CORE variables have been incorporated into the Registry application, and their format follows the proposal. We also included ICD-O-3.1 classification for tumour topography and morphology in the Registry application.

- The priorities for the Registry are:
 - Appropriate staffing,
 - Provision of adequate working space,
 - Connection of The Registry of Malignant neoplasms to the National Population Registry of Montenegro,
 - Prepare a procedure manual, including a description of all international standards and guidelines for cancer registration according to the recommendation of the ENCR Standard Structure Review of our Registry (2019),
 - Involvement of primary health care providers in the cancer notification, including pato-histology and cytopathology laboratories,
 - Improvement of the cooperation between our Registry with the National cancer screening programmes.
 - In order to improve the active collection of data from primary sources, the Registry has initiated a connection with databases of relevant health institutions that are included in the health electronic information system. In this way, we would avoid the collection of paper documents and establish a system for the systematic collection of original data as part of the active registration of cases.

*Information kindly provided by dr. Rajko M. Strahinja, head of Registry of Malignant Neoplasms of Montenegro
mailto: rajko.strahinja@ijzcg.me*

North Macedonia

- At the beginning of 2023, several changes were requested in the software solution used for the Cancer Registry. The changes were initiated by the coders from the Public Health Centers, in order to improve the quality of the data, bearing in mind that they are the people who have the role of coders.
- During the second half of the year, data entry continued, but we faced the problem of an insufficient number of reported cases from health facilities. Activities have been undertaken and are aimed at overcoming the problem of reporting by institutions.
- From the Centres for Public Health, where the employees have the role of regional coders, it has been noted that the data coming to the Registry from health institutions is not of good quality. The eHealth Directorate and the Institute of Public Health have made a plan to directly visit the larger facilities that contribute to the Registry, with the coders from the Centres for Public Health. Meetings were held (in October) with the largest clinics in Skopje (UC for Radiotherapy and Oncology, UC for Hematology, Surgical Clinics).
- By the end of November, all institutions are required to complete the registration of cases for 2022, after which coding by the Centers for Public Health and confirmation of the reports by the Institute of Public Health will follow.
- Meetings are also planned with the Association of Pathologists in order to find a way to submit data for the Cancer Registry by private histopathologists in the state, whose data are currently not part of the electronic system.
- We expect that at the beginning of 2024, the activities for entering data for the register for 2022 will be completed, after which the reports and analyses will be prepared.
- We are awaiting the start of the implementation of the action plan from the action document "EU for Improved Health and Social Protection and Gender Equality" in which, as part of the topic "Improved prevention and control of oncological diseases", education activities are included, ie training of health professionals working on cancer registry and data analysis: "Building the capacity of (i) coders working on Cancer registry; (ii) personnel working on data analysis", financed under the Instrument for Pre-accession Assistance (IPA III).

*Information kindly provided by Zhaklina Chagoroska, head of eHealth Directorate Ministry of Health North Macedonia
mailto: zaklina.cagoroska@zdravstvo.gov.mk*

AIRTUM: Italian Association of Cancer Registries

Cancer registration in Italy dates back to the sixties of the 20th century. The National Association of Italian Cancer Registries (Associazione Italiana dei Registri Tumori, AIRTum) was established in 1996 to coordinate the activities of the Italian Cancer Registries. Presently, a relatively large number of population-based Cancer Registries is active (56, including three regional childhood cancer registries and other 4 specialized registries), which ensure 85% coverage of the Italian population (territorial coverage about 72%). A transition phase toward the establishment of a National Cancer Registry based on a network of cancer registries is ongoing, as provided for by law n. 29 of March 22, 2019. **While the National Cancer Registry slowly progress (a decree was promulgated in August 2023 from the Italian Ministry of Health with little involvement of the registries' community)**, the number and population coverage of existing registries are continuously increasing to reach 100% coverage of the Italian population. A large variability exists in the size and administrative area covered by Italian Registries (provincial, local health unit, regional), but there is a tendency toward the establishment of regional networks and regional registries. Cancer notification is not compulsory, but Cancer Registries in Italy are part of the National Health System and access to relevant health archives is provisionally defined on a regional basis. Italian Cancer Registries and AIRTum actively contribute to international projects providing incidence, survival and prevalence data (e.g. the recently concluded European Joint Action Innovative Partnership for Action Against Cancer, Eurocare, and CONCORD studies). In particular, many efforts were devoted to the development of cure models for time to cure and prevalence estimation in collaboration with National Research Institutes. Key research areas include evaluation of cancer screenings, care pathways, socioeconomic influence on cancer risk and oncologic care and spatial analysis based on geocoded data. The existence of many cancer registries contributes to a lively professional and research community in Italy, but some criticisms remains with regard to heterogeneity in clinical detail registered and timeliness; these issues are a consequence of regional variability in the application of data protection rules and resource allocation and the impact of SARS-CoV2 pandemic on cancer registration. The National Recovery and Resilience Plan (NRRP), funded by the EU and recently implemented in Italy, includes interventions to improve digitalisation applied to healthcare data flows and to develop advanced digital functions and tools to allow full interoperability of healthcare, environmental and other data sources. These innovations are expected to improve the capability of PBCRs to support cancer surveillance, research, and health services planning, because of a reduction in the lag-time needed to produce cancer incidence and survival data from primary sources.

In conclusion, cancer registration in Italy has a long-standing tradition, which is maintained from solid multi-professional teams and research groups, and from established national and international collaborations. The main challenges are to establish a clear national framework for cancer registration, to improve digitalisation of healthcare sources, **and to establish a dynamic and evolutionary Italian Registry, taking full advantage of the existing cancer registries network.**

*Information kindly provided by prof. Fabrizio Stracci, the AIRTUM president
mailto: fabrizio.stracci@unipg.it*

Portugal

- The Portuguese National Cancer Registry (RON) is a population-based cancer registry, established in 2018. The cancer registry began its operation in 1988, as part of a program for nationwide cancer registration and it is financed by public health funds. There were initially three regional population-based registries, already covering all national territory, that in 2009 become four regional cancer registries. It is based on compulsory reporting of all new cases. RON comprises approximately 70 health institutions, which serve 10.5 million inhabitants.

- RON allows not only the monitoring of the institutions' activities and the effectiveness of organized screenings, but also epidemiologic surveillance, research, and, in articulation with INFARMED (National Authority for Medicines and Health Products, I.P.), the monitoring of drugs and medical devices effectiveness. Treatment with CAR-T Cells has been actively monitored through RON registered information.
- RON was established to enable the collection and analysis of data regarding all oncologic patients diagnosed and/or treated in Portugal. Since 2000 there is a registry network where data is collected from hospitals and health centres using computers. Later, in 2007, a new network registration system was developed containing data notifications and integration from several different sources such as national health registry database, pathology reports, surgery procedures, hospital patient's admissions, chemotherapy and radiotherapy treatments (<https://ron.min-saude.pt>).
- RON will publish new cancer incidence of 2020, which we expect to be lower than usual, still reflecting the restrictions and lockdown faced during COVID-19.
- The registry of cancer cases continues to contribute to evaluate effectiveness, and the current quality allows it to be used for an increasing number of descriptive and analytical epidemiological studies (either national, institutional, European or international).
- In fact, the last year RON participated in many national and international projects, namely Benchista study and is involved in Venus and Concord-4 studies (with regional data).
- Aiming to disseminate the importance and increase the involvement of health professionals and decision makers in cancer registry, a national meeting is under preparation, planning to occur in May 2024.
- The priorities in the development are briefly three:
 - Continue engaging with Nacional Cancer Registry coordination in the work to ensure the continued update of the cancer registry software and guidelines;
 - Provide up-to-date regional cancer incidence, mortality and survival data;
 - Develop new studies on effectiveness.

*Information kindly provided by dr.Maria José Bento, Coordinator of the National Cancer Registry of Portugal
mailto: mjbento@ipoporto.min-saude.pt*

Serbia

- In the period from 1996 to 2014 the population based, regional Central Serbia Cancer Registry was in operation which covered 18 districts within the Republic of Serbia, which were divided into 115 municipalities. Since, the end of 2014, the Government of the Republic of Serbia adopted new revised The Law on Health Documentation and Records in the Field of Health and the accompanying The Rulebook on Resources for Keeping Records in the Area of Healthcare which further defined the keeping of the Cancer Registry. Serbian Cancer Registry is nowadays a population based national registry. It covers 25 districts, in an area of almost 80.000 km², and with the population of which was 9.02 million at the 2011 census. More than half of the area's residents (56%) live in urban areas. First published report for the whole territory (Republic of Serbia) was for the 2016.
- The report for 2021, Malignant Tumours in Serbia, 2021 is available on the website of the IPH Serbia
<https://www.batut.org.rs/download/publikacije/MaligniTumoriURpubliciSrbiji2021.pdf>
- The registry has been reorganized, resulting in several changes, including decentralization (the main database is located within the Institute of Public Health of Serbia), the initiation of active data collection, new sources of information (oncology institutes and dispensaries, clinics, hospitals, outpatient facilities, pathology laboratories, death certificates, and health insurance records, as well as through targeted searches), additional training of medical personnel, additional informatics support, and the implementation of a feedback system.

- The registry database includes the following data items: personal characteristics, possible occurrence of multiple primary tumours, incidence date, method used for diagnosis, tumour characteristics (primary and secondary anatomical localization, histology type, and stage), and disease outcome. The data are grouped and published according to the territorial organization of the Republic of Serbia. Malignant tumours are coded according to the International Classification of Diseases - Tenth Revision, Volume 1 (codes C00-C96) and according to the International Classification of Diseases for Oncology - Third Edition (codes 8000/3-9941/3), World Health Organization, 2000, Geneva. The Registry does not include tumours "in situ" (codes D00-D09). The source of data concerning the population is 2011 census and population estimates for 2016, 2017, 2018, 2019, 2020 and 2021 from Statistical Office of the Republic of Serbia. The registry uses CanReg4 software and uses IARC and European Network of Cancer Registries (ENCR) methodology for data collection, entry, storage, processing, and analysis.
- Unpublished data of the Republic Statistics Institute were used for the analysis of death due to malignant tumours in Republic of Serbia in 2016, 2017, 2018, 2019, 2020 and 2021.
- The Covid 19 pandemic has changed and slowed oncology health care in Serbia. During 2020 and 2021 the application of restrictive measures regarding the prevention and control of infectious disease covid 19, reduced the total number of diagnostic procedures and admissions to hospitals in Serbia, primarily because of the transformation of certain departments of general hospitals dealing with cancer diagnosis and therapy, in covid 19 centers or hospitals. Only clinical centers and institutes for oncology and radiology continued to operate, but to a lesser extent. During 2021 and especially 2022 with the introduction of immunization as a measure of prevention and control of SARS-CoV-2 virus infection, the health system was slowly but actively returning to normal. Despite the high prevalence of delta strain virus and afterwards omicron strain with its substrains, oncological health care in Serbia was normalizing and began to function more efficiently.
- The process of cancer registration in Serbia has been slowed down primarily because of limited human resources and their reallocation within the health system in the current covid pandemic 19. But during 2022 and 2023 a lot of activities were done for the implementation of the new Project "Development and implementation of the information system of the register of malignant tumours of Serbia" was completed at the end of 2022. Project had 3 Phases: Technical Design, Development, Deployment and Customization and Training. This year, 2023, the development of the information system in the field of oncology started through the improvement of the PUBLIC HEALTH SERVICE information system. Also, this year, a new draft of Law on records in the field of health was adopted, which introduces the REPUBLIC INTEGRATED HEALTH INFORMATION SYSTEM, which ensures the availability of health data to all participants in the health system, in accordance with their rights, roles and responsibilities.
- The Ministry manages RIHIS, with the technical support of the Office for Information Technologies of the Republic of Serbia, in accordance with the law. e-card is being established to exercise the right to health care more quickly and efficiently, the patient's insight into the entire medical documentation and the adequate provision of health services. The deadline for starting the developed RIHIS and e-card is January 1, 2025.

*Information kindly provided by dr. Snežana Živković from the Institute of Public Health of Serbia „Dr Milan Jovanović Batut“
mailto: snezana_zivkovic@batut.org.rs*

Kosovo

No information on cancer registration activities in Kosovo could be obtained during the preparation of this report.

Albania

- The Albanian Cancer Registry (ACR) is set up in Institute of Public Health based on a Decision of the Council of Ministers of the Republic of Albania dated 28.05.2014 by NR 327. The registry is hospital based and the data are collected by both private and public hospitals, including regional hospitals. Forms are based on the IARC models and data are collected by hard copy and electronically when possible. The tertiary hospitals in Tirana, report the hospital data electronically, but in a shortened format. For the time being reporting units report only a basic minimum of variables in the form (incidence date, sex, age, location, etc).
- Institute of Public Health, has been trying to improve ACR by expanding the application of an electronic database already built for this purpose (but not used by most reporting units).
- ACR in Institute of Public Health has organized high level meetings with National Institute of Statistics about exchange of case based coded death certificates (supplying the cause of death). In the interim, deaths are being collected only in an aggregated mode. Increasing access to and use of electronic data sources will be a focus for IPH moving forward. The other key area for ACR improvement is including more data regarding topography and morphology of cancer, means of diagnoses, treatment, and training of registrars at hospitals about cancer abstract and code.
- ACR staff have produced a range of cancer-related reports for government and Ministry of Health, WHO, as well as scientific publications and presentations. The most recent analyzes included cancer incidence rates for pandemic years 2020-2022. There was noticed an unexpected decrease of reported new cases for the year 2020. The rates were returned to their pre pandemic levels in 2022.
- The cancer registry data are presented for the first time in the National NCD Report (2018) and the first National Cancer Report (2021) includes data for the period 2015-2019 (www.ishp.gov.al/wp-content/uploads/2021/06/4Raporti-NCD-final_ed-2019.pdf and www.ishp.gov.al/wp-content/uploads/2023/09/1_Raporti-kancer-2015-2019-draft-final-nov-2021-edited.pdf). A preliminary report which includes data for the year 2022 was also very recently prepared. It is planned to be published in Bulletin of the Institute of Public Health within 2023.
- For the first time this year ACR case based data for the period 2015-2018 have been shared with IARC.
- A special in depth study on skin cancer (including melanoma) is being implemented by Tirana Univerisy Hospital and Institute of Public Health. A similar design is planned to be implemented for breast cancer as well
- During 2022 in Albania ICD10 is being introduced for the first time and problems with death registries as well as cancer diagnoses reporting are expected. Special training sessions about ICD10 are being organized by National Institute of Statistics and Institute of Public Health with local statistical units.
- The priorities about ACR improvement in the next decade are elaborated in a special section in the new National Cancer Control Plan 2022-2030 approved by Minister of Health. (<https://www.iccp-portal.org/plans/national-cancer-control-program-2022-2030>).

*Information kindly provided by dr. Kozeta Filipi from National Cancer Registry and Analysis Service
mailto:kkozeta@hotmail.com*

Cyprus

- The Cyprus Cancer Registry, commonly referred to as CyCR, is a population-based registry that covers the population resident in the Government controlled area of Cyprus. The Registry also includes non-residents who are treated for cancer at facilities operating in the Government

Controlled Areas. The registry operates under the Health Monitoring Unit (HMU), which is a department of the Ministry of Health

- The CyCR uses active and passive case finding from various sources, mainly (a) private and public hospitals, (b) pathology laboratories, (c) haematology departments (d) cytology department and (e) death registry. Today there are available data for a period of 23 years (1998-2020).
- CyCR data are being used mainly for reporting incidence and research. The Registry Data is requested and broadly used by many health professionals for research, reporting and presentations. There is a growing volume for such requests and on many occasions, they are heard or appear in the media.
- In the international context, the CyCR reports data to EUROSTAT, European Network of Cancer Registries, Joint Research Centre and to IARC databases. CyCR participates in several projects, such as CONCORD, EUROCARE, ICCC and has more than 20 publications in scientific journals such as European journal of cancer and Tumori. (<https://pubmed.ncbi.nlm.nih.gov/?term=%28%28Health+Monitoring+Unit%5BAffiliation%5D%29+AND+%28Cyprus%5BAffiliation%5D%29%29+AND+%28Cancer%29&sort=>)
 - Future plans and focuses:
 - Developing and putting into action a new software system to electronically gather and monitor data from various sources.
 - Collect a wider range of data, including more details about diagnosis and treatment.
 - Legislation and special regulations on notifiability of cancer in Cyprus.

*Information kindly provided by Anna Demetriou from Health Monitoring Unit, Ministry of Health, Cyprus
mailto: ADemetriou@moh.gov.cy*

Greece

No contact / response from those countries has been obtained during the preparation of this report. According to available information some efforts to establish/maintain a population-based cancer registration has already been done, however cancer registries in those countries face several challenges in their everyday work (including but not limited to):

- outdated legal framework;
- very limited budgets with a lot of uncertainties about funding in the recent future;
- lack of trained staff.

CANCER REGISTRIES IN WESTERN EUROPE

Germany

- Clinical cancer registration is almost routine in Germany now. The registries recently published an article on the actual state of cancer registration in Germany (Population-Based Clinical Cancer Registration in Germany, <https://www.mdpi.com/2072-6694/15/15/3934>).
- Last year there were different activities to improve interoperability of cancer registry data, data exchange, data linkage and data usage. One working group is concerned with the identification of clinically comparable disease cases, another with the question of how long-term consequences of cancer therapy could be studied with registry data.
- Another focus was on the evaluation of cancer registry data for quality assurance. In the meantime, various quality indicators were extracted from oncology guidelines and operationalized with cancer registry data. This makes it possible to carry out uniform quality evaluations throughout Germany at the level of service providers. Last year, about 100 oncological quality conferences were held in Germany.
- Fortunately, last year there were several calls for funding for research with cancer registries, in particular on the use of artificial intelligence in cancer registration or the analysis of cancer registry data. Most cancer registries are actively involved here.

*Information kindly provided by prof Alexander Katalinic, chair of GEKID
mailto: alexander.katalinic@uksh.de*

Austria

- The Austrian National Cancer Registry (ANCR) is operated by the National Statistical Institution, Statistics Austria and spans the entire country. All statistics prescribed by the Federal Statistics Act are financed by the government. The 1969 Cancer Statistics Act and the 2019 Cancer Statistics Ordinance provide the legal basis for the Austrian National Cancer Registry and oblige hospitals to report every cancer case. According to the Cancer Statistics Ordinance 2019 all cancer notifications are received electronically in a structured format and pseudonyms, as foreseen by the Austrian E-Government Act to fulfil the European General Data Protection Regulation, are used in the database of the Austrian National Cancer Registry.
- ANCR publishes data on cancer incidence and mortality as well as on survival and prevalence. Data are available in print publications and online <https://www.statistik.at/en/statistics/population-and-society/health/cancer>. The changes in the reporting pathway, the cancer registry database, and the reprocessing process due to the 2019 Cancer Statistics Regulation, as well as the different focus in hospitals due to the Covid pandemic, have put a lot of strain on the ANCR in recent years. In the coming years, the focus of the ANCR's work will therefore be on increased quality assurance of the new reporting process, regarding completeness and comprehensiveness.
- In addition, the Federal Statistics Act was amended in 2022 to give the scientific community access to individual data under special terms of use <https://www.statistik.at/en/services/tools/services/amdc-microdata-for-research>.

*Information kindly provided by dr. Monika Hackl, head of Austrian National Cancer Registry
mailto: Monika.Hackl@statistik.gv.at*

The Netherlands

- Since 1989, the Netherlands has a nation-wide cancer registry, initially consisting of eight regional cancer registries (including the former Eindhoven Cancer Registry), hosted by eight Comprehensive Cancer Centres (CCC). In 2008, a national registry was created by combining the regional registries. In 2011 (and in 2014 when the last regional centre joined in) the regional CCCs merged, resulting in one national Netherlands Comprehensive Cancer Organisation (IKNL, www.iknl.nl) hosting the Netherlands Cancer Registry (NCR, <https://www.iknl.nl/nkr-cijfers>).
- Dutch registration clerks directly enter data from the patient files into the national database, either from a working place in the hospital or with remote access. In March 2015, new software for the registry was installed, increasing the flexibility of the item sets and the interchangeability of data. A new (improved) version of this software was released in the beginning of 2019. The registry supports hospitals by registering data for clinical audits, such as for breast cancer, colorectal cancer and head & neck cancer, as well as for clinical trials.
- In 2014, the NCR started with a large revision of all the cancer-specific item sets, generally leading to an increase in the number of items that are registered in the cancer registry (e.g. cytogenetics). In 2018, this revision was completed, however, it will be repeated on a smaller scale in the coming years to keep the item sets up-to-date. For most cancers, follow-up information (recurrence, progression) is included in the item sets. New (cancer specific) manuals were made to include all the new items. Besides, we started a process of specialization, meaning that all registration clerks specialize in one to four different cancer types. This process of specialization was completed in 2023 with the creation of five teams. In each team the registration clerks have the same specialization(s). E-learning's were developed for the training of new registration clerks as well as for experienced staff that changes its specialization.
- Electronic notification from the pathology laboratories started in 2016 and the number of pathology items that is included in the registry automatically is increasing gradually. The majority of skin cancers (including basal cell carcinoma) are registered completely automatically. Since the summer of 2018, pathology-confirmed recurrences are also notified and included in the registry. In 2020, a pilot for the inclusion of supplementary data from the pathology report of 4 pathology laboratories was completed for breast cancer. Since the summer of 2022 the remaining pathology laboratories have started submitting supplementary pathology data for breast cancer, melanoma and colorectal cancer. Other cancer types (head & neck, prostate, cervix) will follow.
- In a European context, the NCR is represented in the steering committee of the ENCR and participated in several projects like EURO CARE, Strong AYA, Blueberry, Darwin EU.
- In 2022, a project was started to abstract automatically cancer registry data real-time from electronic files in hospitals. A pilot for notification of lung cancer cases was completed successfully. The data flow from the first participating hospitals (according to the FHIR standard) to the NCR is expected to start in the fourth quarter of 2023.

*Information kindly provided by dr. Otto Visser, director of Netherlands Cancer Registry
mailto: O.Visser@iknl.nl*

Belgium

- The Belgian Cancer Registry (BCR) is a national, population-based registry (11 million inhabitants) since 2004. The registry relies on two pathways: oncological care programs and pathology laboratories. It has a legal basis to use the national registration number which enables an accurate linkage and follow-up. Detailed information about diagnostic and therapeutic procedures including drugs is obtained through data linkage with administrative

and clinical databases. The Registry regularly publishes data on cancer incidence, survival, trends, prevalence and predictions. A special booklet 'Cancer in children and adolescents in Belgium 2004-2020' was published in July 2023.

- BCR exerted several activities in follow-up of the COVID-19 pandemic. A continued expedited delivery of data by the pathology labs allowed to provide early estimates on new cancer diagnoses for 2022. BCR also continued the collaboration with the authorities to select cancer patients for priority booster vaccination. Finally, the impact of the COVID-19 pandemic on cancer stage at diagnosis (e.g. DOI: 10.3389/fonc.2023.1253968), clinical care trajectories and outcomes was investigated for several cancer types, resulting in a number of scientific publications.
- BCR continued its activities in the evaluation of quality of care (e.g. breast cancer: results published in KCE Report 365, 3/2023). In this context, BCR is also involved in concentration of care initiatives (currently for head and neck cancer) taken by the governmental bodies. In addition, a pilot study was launched in 2023 to implement patient reported outcome and experience measures as an important aspect of care.
- BCR supports the regional screening programs for breast, colorectal and cervical cancer and is involved in their follow-up and evaluation. In 2023, the crucial role of BCR in this regard was confirmed eg in an evaluation of the effect of the Flemish breast cancer screening program on cancer-specific mortality.
- The Belgian Virtual Tumour bank and BBMRI.be are both hosted at the Cancer Registry.
- BCR undertakes several actions to improve the quality and extent of the available data. In 2023, efforts were continued to complete molecular marker information by developing data mining techniques (see e.g. doi: 10.1093/neuonc/noad158 and doi: 10.1159/000529320). In parallel, initiatives were taken towards standardised and structured pathology reports. Also, possibilities were explored to enrich the cancer registration data with socio-economic information and to estimate cancer relapses.
- BCR solidly continues supporting and stimulating epidemiological research integrating BCR data, both at a national and international level.
- All activities at BCR including data collection, data processing, data linkage and usage for research, are carried out in accordance with the GDPR regulation.
- Want to find out more? Check www.kankerregister.org, planned to be renewed in 2024!

*Information kindly provided by dr. Liesbet Van Eycken, director of Belgian Cancer Registry
mailto: elizabeth.vaneycken@kankerregister.org*

FRANCIM: Association of the French Cancer Registries

- 28 registries (10 specialized, 18 general CR: 14 in Europe and 4 in overseas areas); covering 25% of the population. A national registry for children. All certified by the National committee. Regular increase of the population covered
- All CR have signed a contract with Public health authorities to describe their work planning for the next three years.
- Ongoing process of integration of all databases from the 23 French cancer registries in a unique IT server located in the national institute of cancer. We are working on standardization of common mandatory items (ID, sex, age, Morphology code, topography code, stage,...). For specialized registries special spaces will be dedicated by tissue and the same work on standardization is running between us (items and way of coding them).
- Market consultation has been conducted and the choice of the operator will be done soon
- Process of validation of such unique database is also on going. Discussions are open regarding the lead of the database and the place of Francim in the leading process

- The Senate has voted for the creation of a national cancer registry despite our concerns regarding financial and feasibility of such structure. To be effective, the National Assembly have to validate the text but the National Cancer Institute and Fancim are fighting against it.
- We are working collectively on producing specific documents by type of disease on items to collect and on the way to code them in order to ensure a greater homogeneity of data
- Collection of data is becoming somehow difficult because of lack of registrar

*Information kindly provided by prof. Marc Maynadié, director of Cote d'Or Hemopathy Registry
mailto: marc.maynadié@chu-dijon.fr*

Luxembourg

- Luxembourg's National Cancer Registry (Registre National du Cancer, RNC), has developed into a comprehensive cancer registry, recording all new cancer cases diagnosed and/or treated within the country and offering rich insights into clinical characteristics and treatment patterns.
- Established in 2013 to assess incidence, mortality, and survival trends of all new cancer cases diagnosed or treated in Luxembourg, the RNC celebrated on the 5th of October 2023 its **10th anniversary**. A [scientific conference](#) was organized welcoming scientists, clinicians and policymakers from all major healthcare and research institutions, as well as patients and other stakeholders involved in the fight against cancer. It featured several prominent speakers, providing an opportunity to discuss the latest developments in the field of cancer care in Luxembourg, with a particular focus on breast and childhood cancers. A comprehensive [brochure](#) capturing the essence of the event was also produced.
- The [first epidemiological bulletin](#) was published in July 2023 presenting the national incidence data on new case of cancer diagnosed in **children** before the age of 15 years, occurring between January 1, 2014 and December 31 2022, and residing in Luxembourg at the time of diagnosis.
- The RNC embarked on a journey to analyse **breast cancer** data from 2013-2018, aiming to evaluate the quality of care provided to patients, to assess the efficacy of the breast cancer screening program, and to participate in ground-breaking research using its own data. To evaluate the national breast cancer **screening program**, a first-ever linkage has been established between the RNC and the national organised breast cancer screening program data. A comprehensive assessment of the screening program is currently being finalised, including the computation of key indicators recommended at the European level. In addition, this analysis enabled an in-depth evaluation of the impact of the different modes of detection and screening history on breast cancer in the eligible population. Preparations for a national report and scientific publications are actively underway. The RNC hopes that this collaboration will continue in the long term, and could serve as a model for other countries aiming to undertake similar efforts.
- Ground-breaking research is ongoing that's to the [RELIANCE project \(REaL-life cANCER epidemiology\)](#), a pivotal initiative determined to decode cancer epidemiology in Luxembourg through comprehensive population studies. [RELIANCE study](#) aims to answer a spectrum of research questions, utilizing the vast data repository of the RNC and probing potential secondary data linkage. The pilot study, funded by the Ministry of Health under the second national Cancer Plan (PNC2), is set to provide valuable longitudinal statistics on breast cancer, focusing on incidence, mortality, and survival patterns. This is particularly crucial for patients diagnosed at advanced stages, as it affects their **return to work**.
- By establishing connections with other data sources, both nationally and internationally, the RNC enhances its capacity to contribute to the global understanding of cancer. Having joint forces with the European Health Data & Evidence Network (EHDEN), the RNC pursues its

explorations of tools from the Observational Health Data Sciences and Informatics (OHDSI) together with four PBCR from The Netherlands, Norway and Switzerland.

*Information kindly provided by dr. Claudine Backes, scientific director of the Luxembourg National Cancer Registry
mailto: Claudine.Backes@lih.lu*

Switzerland

On January 1st, 2020, a new Swiss Federal Law – the Cancer Registration Act (CRA) with its ordinance (CRO) - came into force. In order to have full and complete data at national level, doctors, hospitals and other private or public health institutions are obliged to report diagnosed cancers to the relevant cancer registry. There are thirteen Swiss regional general and a childhood population-based cancer registry affiliated to IACR and ENCR. The Swiss Federal Department of Home Affairs has prolonged the mandate of the National Institute for Cancer Epidemiology and Registration (NICER; www.nicer.org) to function as the National Agency for Cancer Registration (NACR; nacr@nicer.org) in 2023. The NACR defines standard practices for cancer registration, compiles, quality checks and aggregates data that is collected by the cantonal and regional cancer registries of Switzerland.

- NICER/NACR collaborated with the Swiss Federal Statistical Office to publish the national cancer statistics up to incidence year 2019.
- Requests from academia, industry and media for specific cancer statistics were answered and specific data analyses provided.
- NICER/NACR received, reviewed, and processed 2020 incidence data from the cantonal cancer registries, which for the first time is in accordance with CRA requirements.
- The NICER/NACR published brochures to inform patients about cancer registration, manages the veto statistics, creates concepts for informing the public and answers questions about cancer registration from patients and reporters.
- NICER/NACR answers questions from the cancer registries and the children's cancer registry about cancer registration on a specially developed web-based query portal, preparing support material for registration, and conducting round robin tests and a workshop on treatment data registration.
- The Swiss Cancer Registries have created an independent “Association suisse des registres des tumeurs (ASRT)” to coordinate their policies.

*Information kindly provided by dr. Matthias Lorez, from Swiss National Agency for Cancer Registration
mailto: matthias.lorenz@nkrs.org*