## National Cancer Registry of the Slovak Republic



MUDr. Kamil Krištof Bratislava, Slovak Republic 3.12.2024



#### Introduction

NCR SR was established in 1976

> National Health Information Center - NHIC (*Národné centrum zdravotníckych informácií - NCZI*) administrates all national health registries

> Legislation

- > Act No. 153/2013 Z. z. The national health information system and amending certain acts
- > Decree of the Ministry of Health of the Slovak Republic no. 74/2014 Coll.
- > Other relevant acts (GDPR etc.)



## Subject of data collection and processing

> Selected epidemiological and clinical data on patients with oncological disease

>C00.0 – C97: Malignant neoplasms

>D00.0 – D09.9: In situ neoplasms

>D37.0 – D48.9: Neoplasms of uncertain behavior, polycythemia vera and myelodysplastic syndromes

>D32.0 – D33.9: Benign neoplasm of meninges, brain and other parts of central nervous system

>D35.0 – D35.9: Benign neoplasm of other and unspecified endocrine glands



#### **Data sources**

- Cancer notifications
- Reports from pathology and hemathology laboratories
- Discharge records (private, public hospitals, oncology departments)
- Outpatient records (private, public hospitals)
- Database of hospitalized patients
- Autopsy services
- Death certificates (Statistical Office of the Slovak Republic)

#### The future/desired data sources:

- Health insurance data
- eHealth
- IS with demographic and administrative data

- Paper form
- Electronic form



#### **Classifications**

- > International Classification of Diseases, 10<sup>th</sup> revision
- International Classification of Diseases for Oncology 3<sup>rd</sup> edition, the 1<sup>st</sup> and 2<sup>nd</sup> revision
- > TNM Classification 7<sup>th</sup> and 8<sup>th</sup> edition
- > Toronto Childhood Cancer Stage Guidelines



#### **Cancer registration in Slovakia - issues**

- till year 2007 the very most of cancer reports were provided by regional oncology commissions (abolished)
- > variety of legislative changes in healthcare system
- Iack of registry personal
- inadequate infrastructure
- insufficient data collection from healthcare providers

decrease of cancer registration (& delay in processing)



#### **Milestones**

- > 2015 launch of electronic data collection
- > 2019 launch of new interactive presentation platform for National cancer registry data
- > 2022 migration of National cancer registry database to new information system
- > 2023 update of interactive platform of National cancer registry data including expanded scope of data
- > 2023 new methodological instructions for healthcare providers, internal for data processing
- > 2023 creation of algorithm to identify expected new cancer cases according to health insurance companies for 2017-2021 and publication of data – in cooperation with the Ministry of Health of the Slovak Republic
- > 2024 launch of a new information system enabling automated processes
  - the Health Record of the Registry (in Slovak: Záznam zdravotného registra 2 ZZR 2), new internal standard procedures for data processing
- > 2024 update of algorithm to identify expected new cancer cases according to health insurance companies
  - > in cooperation with the Ministry of Health of the Slovak Republic
  - > algorithm improvement
  - > 2016-2022
  - > expanded data scope
- > 2024 launch of the project RISEZ (<u>Rozšírenie portfólia služieb a inovácia služieb elektronického zdravotníctva / Expansion of the service portfolio and innovation of electronic healthcare services)</u>
  - > Decrease of administrative burden of healthcare providers by extraction of data from eHealth IS for health registries and statistics



#### new information system



Vikazy Viet

Diffum posiednej zmeny od dd mm mr hh mm ar Diffum posiednej zmeny do dd mm mr hh mm ar

> Aesiac spracovania Všetky IČO (8 znakov) Všetky ra (12-miestny kód) Všetky Názov organizácie Všetky

Trvalé bydísko - obec Všetky Rodné číslo Všetky vyplňa NCZI (Trvalé bydísko - okres) Všetky Dátom roval odvětkov latidra Všetky

Zoznam výkazov
Zber ZR\_NOR\_ZN-2015 - Hlásenie zhubného nádor

Filtračné položky ZR\_NOR\_ZN-2015

#### old IS (used until November 2022)

- Rozsireny zaznam Priezvisko: Rodne meno: Meno: Pocet diagnoz: O Pocet zaznamov Dg. 9: Dg.10: - Zoznam Reg. cislo Priezvisko		Rodne meno		
pistracne cislo: 15/01-01-000	(7) Da Zak1 Priez Rodne Trval Adres Datum Pohla Poda	meno: e bydlisko: 01 (kraj-o : : tnanie: narodenia: V vie: V	tovi	Strana 2   Strana     (32) Dokumentacia:   (32) Tokumentacia:     MKCH   ICD9:     Laterarita:   ICD10:     T:   N:     T:   N:     Kinicke stadium ochorenia:   Klinicky rozsah madoru:     Klasifik. LYMFOMOV a LEUKEMII:   Topograficka Dg.:     Topograficka Dg.:   -3     Histologicka Dg.:   -3     Ochorenie zistene:   0
Terapia Chirurgicka- Radio- Chemo- Hormonalna- Imuno-	Liecba —	V. vysledok liech		Plan primar. liecby: PgDn o stranu   F10- ULOZ Esc- NAVR
Zdroj: Datum: Pitva: Dg.smrti (9):	omorbidita ————————————————————————————————————	Ostatne Duplexy:0 0 Stav: PgUp o : F10- ULOZ	stranu î	

— TNM klasifikáci	a	
	a	
	Prevodník TNM klasifikácie T (tumor):	
	Prevodník TNM klasifikácie N (nodes):	
	Prevodník TNM klasifikácie M (metastasis):	
	TNM klasifikácia N+- (nodes):	
	TNM klasifikácia stupeň (súhrný):	
	TNM klasifikácia pT (tumor, patohistologicky):	09 - T2 (1978-9999)
1	FNM klasifikácia pN (nodes, patohistologicky):	02 - N0 (1978-9999)
TNM	klasifikácia pM (metastasis, patohistologicky):	2 - M0 (1978-9999)
	Klinické štádium ochorenia:	1 - štádium I. (1978-9999)
1	Klinický rozsah nádoru pred zahájením liečby:	2 - nádor lokalizovaný (1978-9999)
	Toronto guidelines Tier 1 (2014-9999):	
Ц	Toronto guidelines Tier 2 (2014-9999):	
	Klasifikácia lymfómov a leukémií:	
TN	M klasifikácia cT (tumor, klinicky) (2014-9999):	09 - T2 (1978-9999)
TN	M klasifikácia cN (nodes, klinicky) (2014-9999):	02 - N0 (1978-9999)
TNM klas	sifikácia cM (metastasis, klinicky) (2014-9999):	2 - M0 (1978-9999)
	Poznámka v sekcii TNM (2015-9999):	

Topografická diagnóza, ICD-O:	
Topografická diagnóza, ICD-O, 3. edícia:	C199 - Rektosigmoideové spojenie
Morfologická/histologická diagnóza, ICD-O:	
Morfologická/histologická diagnóza, ICD-O 3.edicia:	81403 - Adenocarcinoma, NOS
Poznámka v sekcii ICDO (2015-9999):	
Klinický rozsah malígneho melanómu (Clark):	
Klinický rozsah malígneho melanómu (Breslow) [mm]:	
Grading:	G1 - dobre diferencovaný (1 - stupeň I.) (1978-9999)



## What is the Health Record of the Registry?

> It is workspace enabling gathering all sources located in information system in "one place" according to the predefined rules:

- > Electronic sources:
  - > Electronic notifications
  - > Database of hospitalized patients
  - > Database of deaths
- > Paper sources
- > This workspace enables:
  - > Direct linkage of electronic sources through patient identification number
  - Coding incidence cases from all sources specialized processed performs by NCR doctors according to the international guidelines for NCR
  - > Decrease administrating burden of healthcare providers and NCR staff as well
  - > Faster and simplifying NCR data processing

> This workspace allows linkage with other health registries resulting in much wider data analysis and publication



## **Data quality**

- > Quality Check Software
- > Consistency within variables
- > Consistency between variables
  - > Coherence between dates
  - > Coherence between age/topography/morphology
- > Detection of duplicates
- Other quality check related to our local information system for processing data



#### JRC TECHNICAL REPORT

A common data quality check procedure for European cancer registries

Carmen Martos, Francesco Giusti, Liesbet Van Eycken, Otto Visser On behalf of the JRC Cancer Information Group and the ENCR Steering Committee



May 2024 update





## Improving cancer care coordination and screening in Latvia and Slovakia project (ICCCS)

- > Project took place in 2023
- > Part of the project was dedicated to National cancer registry of Slovak Republic
  - Representative of IARC\* Dr. Mario Šekerija (Epidemiologist, Head of Croatian National Cancer Registry, Croatian Institute of Public Health) visited registry NCR SR
  - > The aim of this mission was to review the process of cancer registration in Slovakia with a view to providing recommendations for improvement.
  - > Recording from closing event on youtube: ICCCS Slovakia Closing Event

\* IARC – International Agency for Research on Cancer



### **Statistics**

#### Home | About us | Statistical Outputs | International cooperation | Provision of information | Contacts

#### 💳 💥 f in

<nczi>

National health information centre



NCZI > Statistical outputs > Topical Statistical Outputs > Oncology

0

PUBLISHING PROGRAM OF STATISTICAL OUTPUTS

HEALTH STATISTICS YEARBOOKS

TOPICAL STATISTICAL OUTPUTS

Archive

#### ONCOLOGY

Outputs from the National Cancer Registry of the Slovak Republic (NCR SR) National Cancer Registry of the Slovak Republic, incidence of cancer, location of disease, mortality

- Incidence of cancer English version
- Interactive presentation of NCR SR outputs
- Selected outputs

#### Nuclear medicine, clinical oncology, radiation oncology

radionuclide examinations, chemotherapy, palliative treatment, anti-tumor and non-tumor therapeutic procedures



## NCR reporting – annual publication

- > Standard aggregated outputs in the table form
- > Graphic visualizations
- > Updated presentation platform from 2023 of NCR data in Power BI

- > Extended data granularity and information, for example:
  - clinical stages according to the age group
  - > data quality indicators, MIR
  - > and others



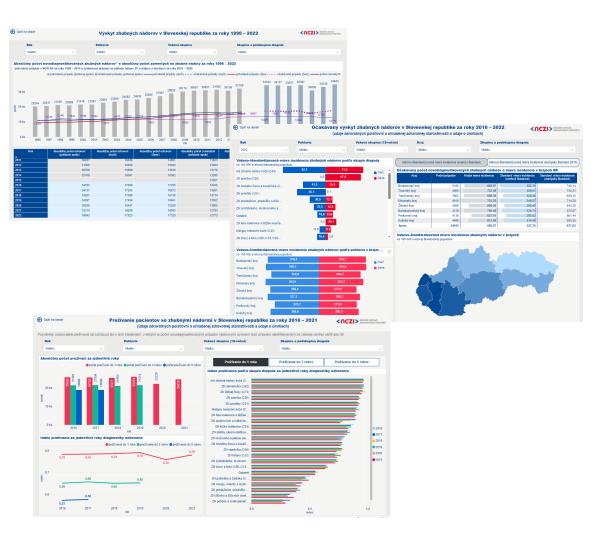


#### Health insurance data as a source

> 2023 – publication of expected number of cases of newly diagnosed malignant tumors for 2017-2021 based on health insurance\* data and database of deaths in interactive Power BI platform

#### > December 2024

- > publication of data according to updated algorithm
- > extended years: 2016 2022
- > extended scope:
  - standardized incidence (World, Europe population)
  - regions
  - > maps
  - survival
  - > focus on screening diagnoses
- > Algorithm was created according to the processes in NCR SR
- > Data quality limitation and data scope limitation





## NCR SR – current state

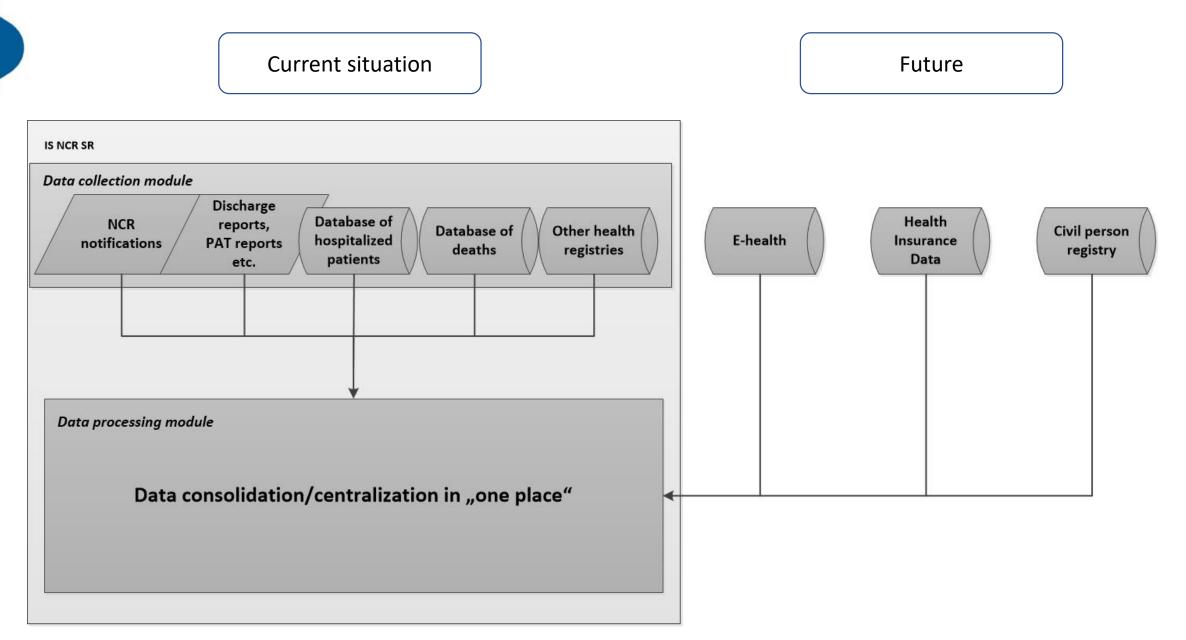
> Processed incidence data of 2015 (finalized, preparation of publication)

> Data from 2016 – validation process

> Data sources from 2017-2024, quality control:

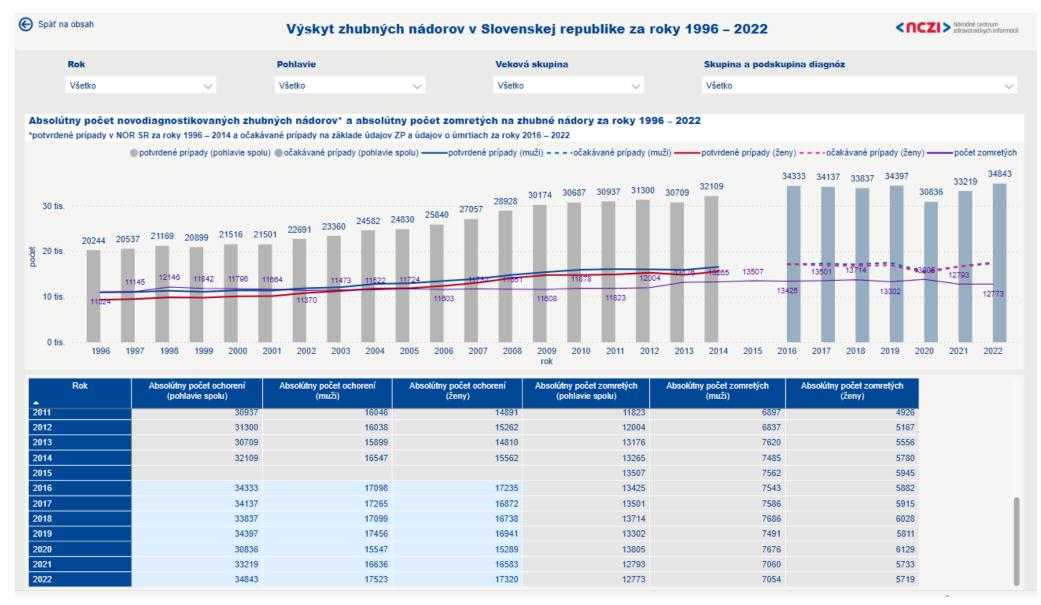
> Review of pathology reports, meetings with experts, preparation of methodology for data collection





## **CZI** National health information center

## Latest outputs - incidence, mortality





## **Latest outputs - incidence**

					arostlivosti a údaj	,		
Rok	Pohlavie		Veková skupina (15-ro	čná) Kraj		Skupina a podskupina diagnóz		
2022	Všetko	$\sim$	Všetko	✓ Všetko		✓ Všetko		~
<b>'ekovo-štandardizovan</b> á a 100 000 svetovej štandardne	á miera incidencie zhubnýci ej populácie	h nádorov podľa sl	kupín diagnóz	Vekovo-štandardizova	aná miera incidencie (sv	etový štandard) Vekovo	o-štandardizovaná miera incide	encie (európsky štandard 201
né zhubné nádory kože (C44)	82,2	71,9	👝 muž 🚖	Očakávaný počet n	ovodiagnostikova	ných zhubných nádor	ov a miera incidencie v	krajoch SR
N prsníka (C50)	0,9	67,5	• žena	Kraj	Počet prípadov	Hrubá miera incidencie	Štandard. miera incidencie (svetový štandard)	Štandard. miera incidencie (európsky štandard)
N hrubého čreva a konečníka (	(C 43,5	25,5		Bratislavský kraj	5165	693,07	352,76	746,1
N prostaty (C61)	55,1	0,1		Trnavský kraj	4006	722,49	359,01	734,3
	30,5	12,7		Trenčiansky kraj	3902	699,39	320,28	659,1
I priedušnice, priedušky a pľú	IC			Nitriansky kraj Žilinský kraj	4915 4090	753,25	349,57 308.42	714,2
l lymfatického, krvotvorného a	a 22,5	18,3		Banskobystrický kraj	4090	700.49	328.74	643,3 672.0
statné	16,0	13,6		Prešovský kraj	4130	537.31	293.52	601.4
		20,1		Košický kraj	4496	612,09	314,60	655,5
I tela maternice a bližšie neur	ice			Spolu	34843	660,07	327,79	677,6
alígny melanóm kože (C43)	11,6	9,3						
N hlavy a krku (C00–C14, C30	) 16,4	3,9	*	Vekovo-štandardizo na 100 000 svetovej štano		encie zhubných nádor	ov v krajoch	
	miera incidencie zhubných	nádorov podľa poh	Ilavia v krajoc 😑 🔐					
a 100 000 svetovej štandardne ratislavský kraj	376,3	343,1	o muž			La la		
mavský kraj	389,7	345,0	• žena				and the section of	
enčiansky kraj	350,8	304,2				1.5	The second second	Sec. 1
itriansky kraj	393,0	324,2			more			
linský kraj	358,4	273,9				<u> </u>		

275,9

290,3

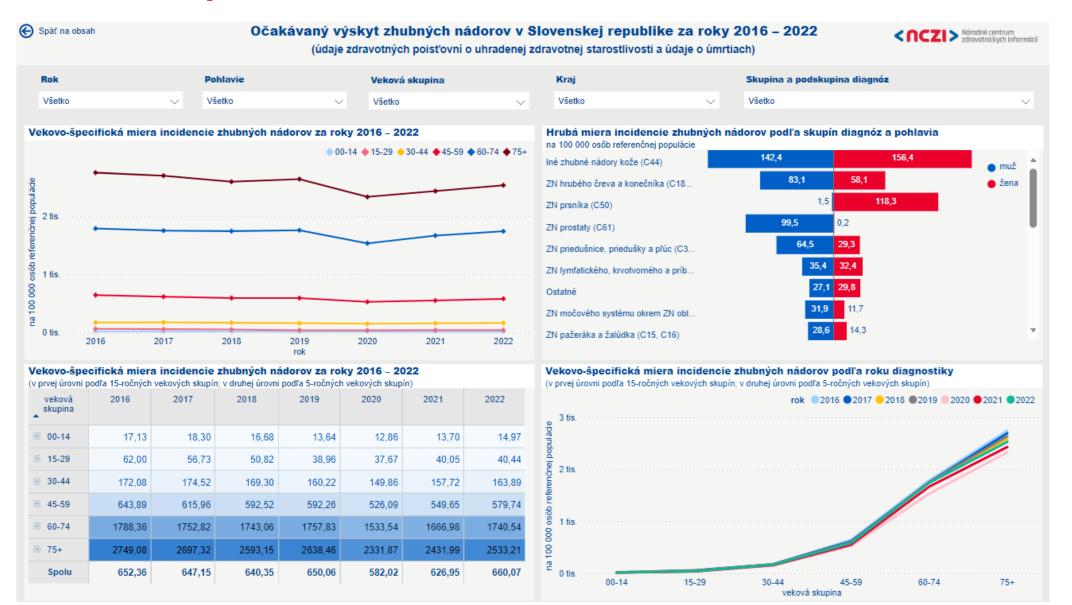
356,0

Prešovský kraj

Košický kraj

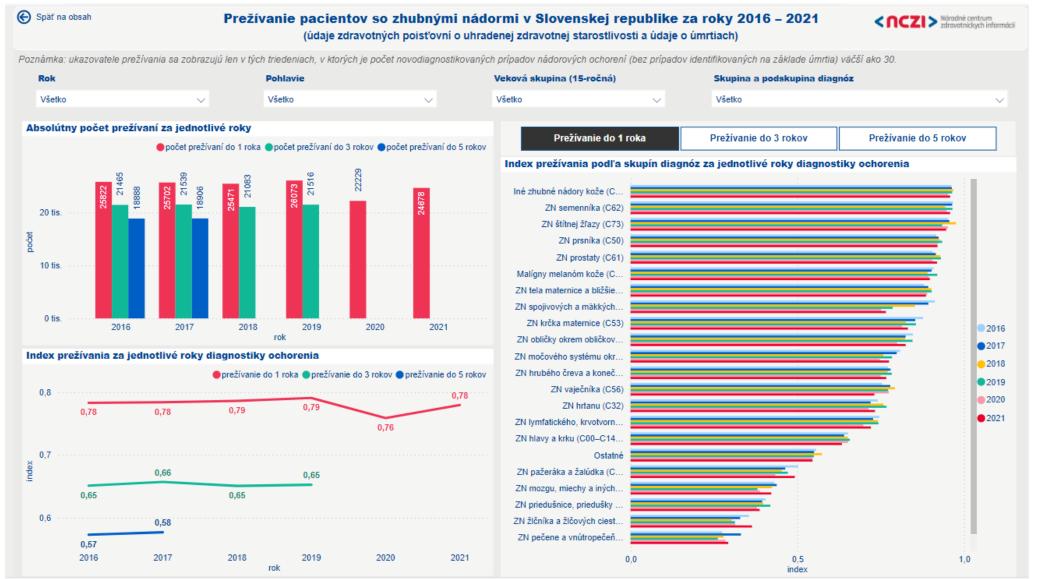


#### **Latest outputs - incidence**



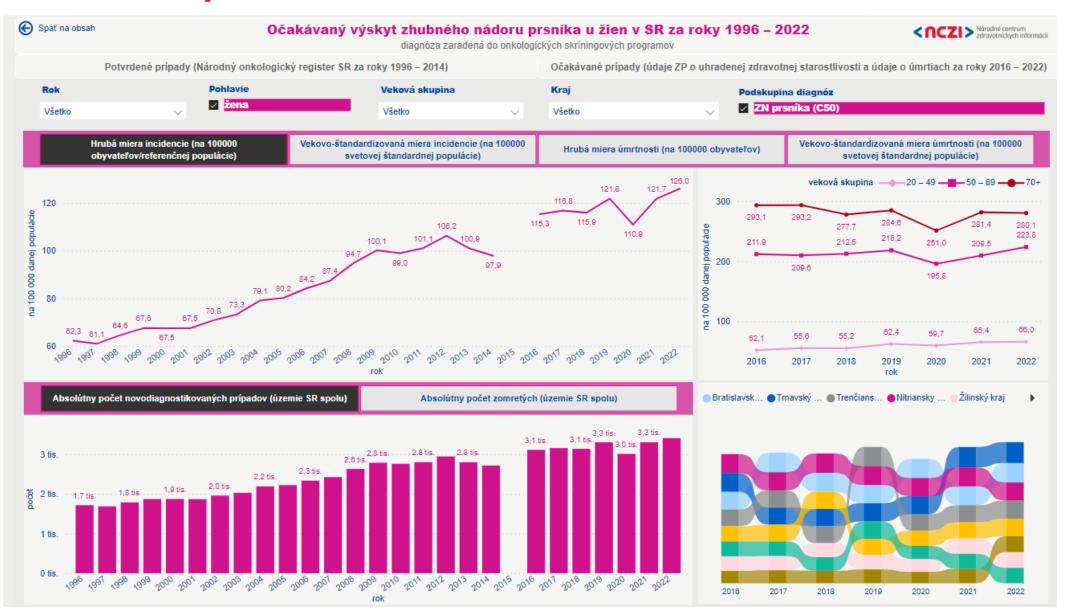


#### **Latest outputs - survival**



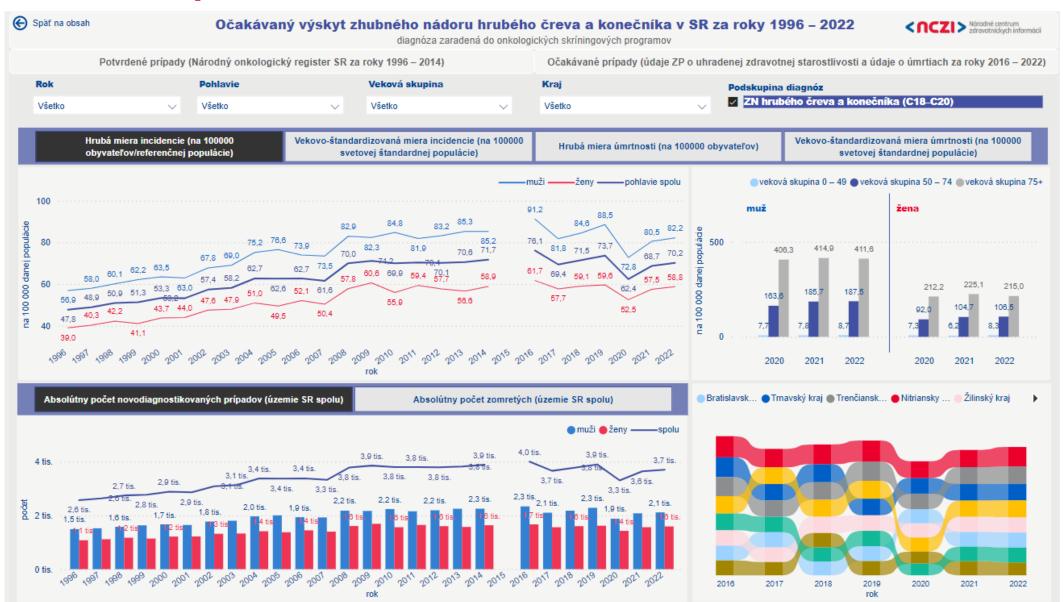


#### Latest outputs – breast cancer



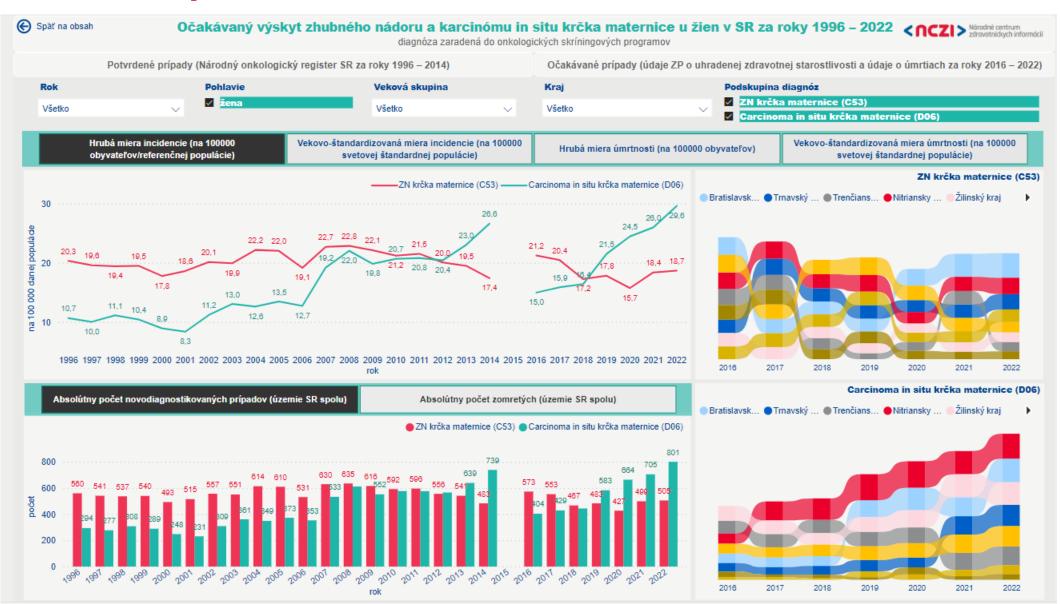


#### Latest outputs – colorectal cancer



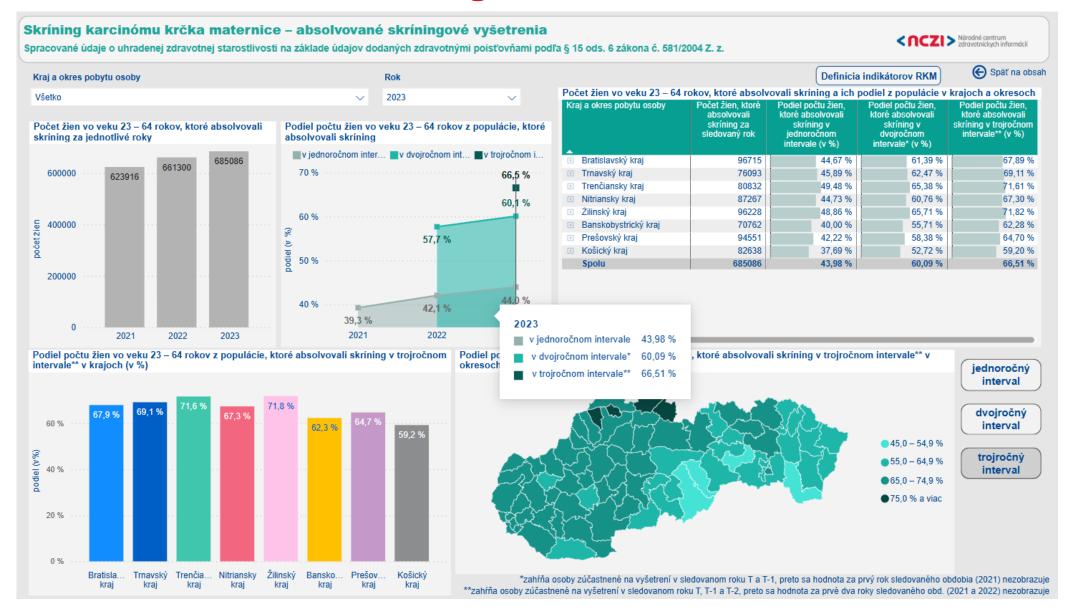


#### Latest outputs – cervical cancer



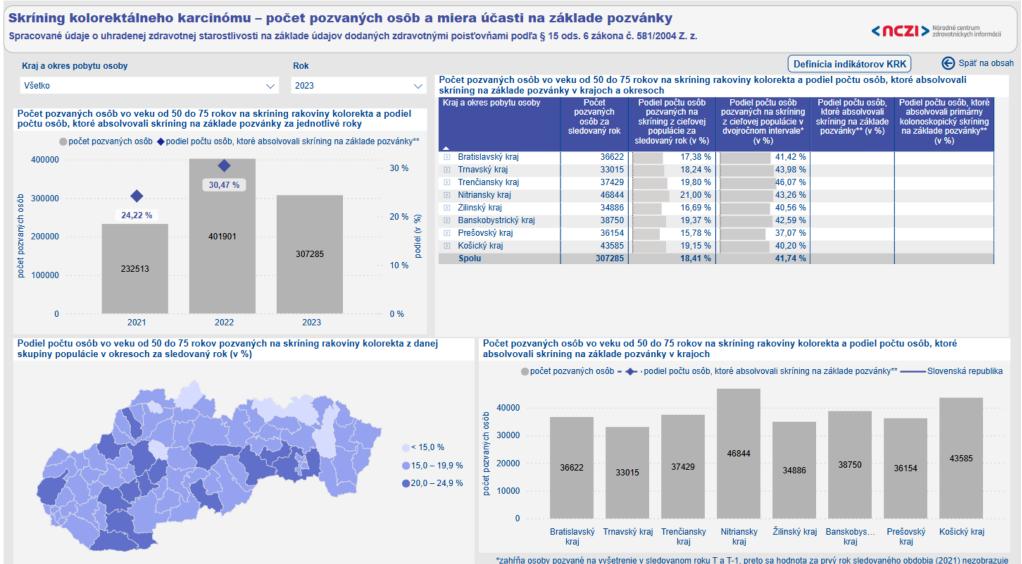


## **Cervical cancer screening**





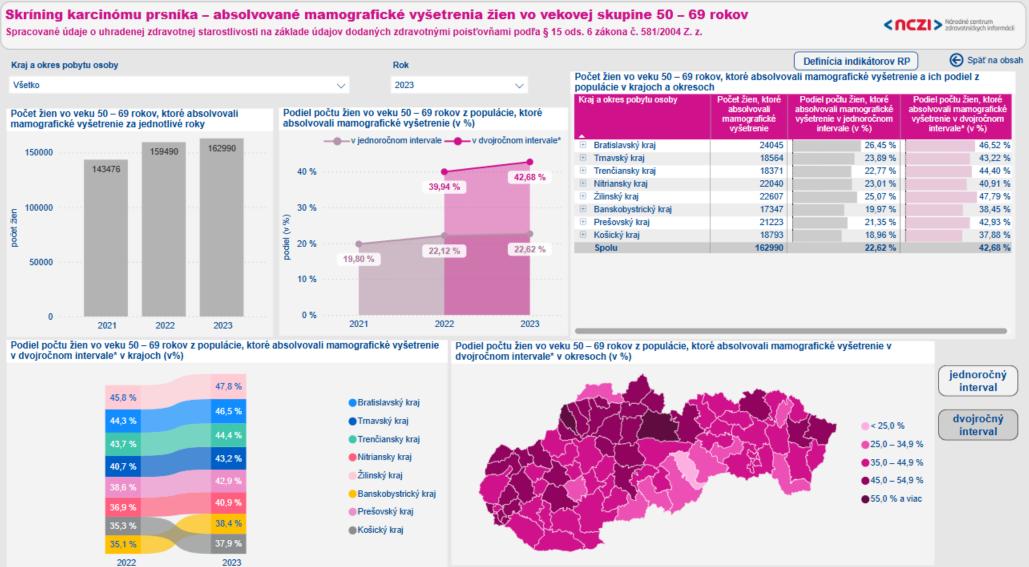
#### **Colorectal cancer screening**



anrna osoby pozvané na vysetrenie v sledovanom roku T a T-1, preto sa nodnota za prvy rok sledovaného obdobia (2021) nezobrázuje \*\*údaj za posledný rok zaslania pozvánky bude vyhodnotený až po ukončení zberu a spracovaní údajov za nasledujúci kalendárny rok



#### **Breast cancer screening**



\*zahŕňa osoby zúčastnené na vyšetrení v sledovanom roku T a T-1, preto sa hodnota za prvý rok sledovaného obdobia (2021) nezobrazuje



## **Contacts:**

#### > NCZI National Health Information Center

- Lazaretská 26 811 09 Bratislava 1 Slovakia
- > Call Center: +421 2 32 35 30 30
- > Web: www.nczisk.sk
- > E-mail: <u>nor.sr@nczisk.sk</u>
  - kamil.kristof@nczisk.sk

# Thank you

