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National Pilot ICT Model for Cancer Registration Integrating Multiple Data Sources

Pilot study in the Czech Republic: State of play

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Institute of Health Information and Statistics
of the Czech Republic

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National Pilot ICT Model for Cancer Registration Integrating Multiple Data Sources

I. MAIN PRINCIPLES ADOPTED

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A New „Comprehensive – Multiple Source“ Model of Cancer Registration? What does it mean?

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…. In past

All items in cancer registry are reported in special SW (formulas) as „additional“ duty of providers operation

Extensive data collection, mainly outcomes of laboratory examinations, details on hospital stays, etc. are not included. The registration is „only“ epidemiologic.

Linkage of data coming from various sources (providers) is limited due to insufficient legal mandate.

Organization of observational studies is complicated, associated with administrative burden.

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A New „Comprehensive – Multiple Source“ Model of Cancer Registration? What does it mean?

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…. newly implemented model and its ambitions

The system should cover already running data collection processes, their sources and data outcomes (diagnostic units, primary care providers, hospitals, etc.)

Linkage of data coming from various sources must be supported by law with clear mandate and duties for all providers

„Additional“ data collection by hands of health professionals must be minimized and utilized for special studies or purposes

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The National Health Information System: guiding principle of reform

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The Czech strategy is to develop a system utilizing already generated / collected administrative data and health care records

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II. WHAT HAS ALREADY BEEN DONE?

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Multiple-source data integration: what has already been done

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TOPIC I. Legislation

- ✓ Completely new amendments of two laws has been prepared and are currently being negotiated (law on eHealth) or approved (law on health services)

TOPIC II. Data protection policy, GDPR implementation

- ✓ Legal base for linkages of multiple data sources was prepared and legally approved
- ✓ The interconnection is based on eGovernment services (agenda-specific identifier - pseudonym)

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Multiple-source data integration: what has already been done

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TOPIC III. Reference (national) data background

- ✓ Basic components supporting nationwide collection on cancer care data has already been established and are being analysed:
  - ✓ National registry of health care providers
  - ✓ National registry of health care professionals
  - ✓ National registry of reimbursed health services
  - ✓ National registry of hospitalisations

TOPIC IV. Optimization of cancer registration

- ✓ In view of rising accessibility of national reference data, the reporting by providers on cancer cases is optimized (in data model, focus and extent)

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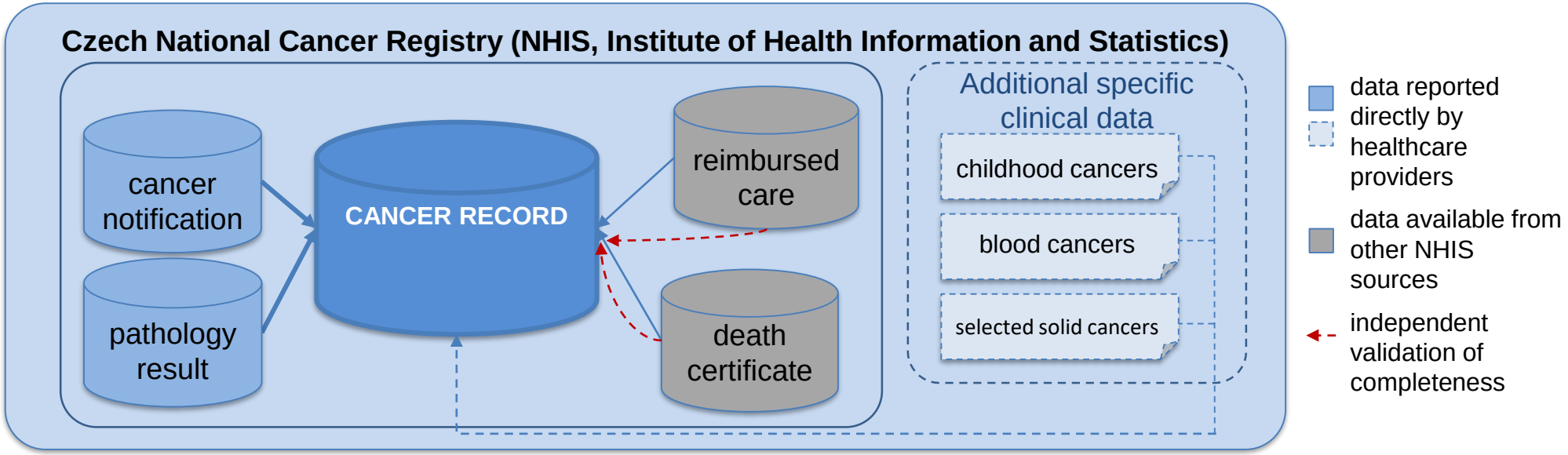
Innovated CNCR data flow



Basic CNCR record:

- CNCR notification (reduced dataset -> reduced reporting burden)
- pathology report (new parametric reporting, including cervical neoplasia)
- cancer care reimbursed by health insurance company
- death certificate

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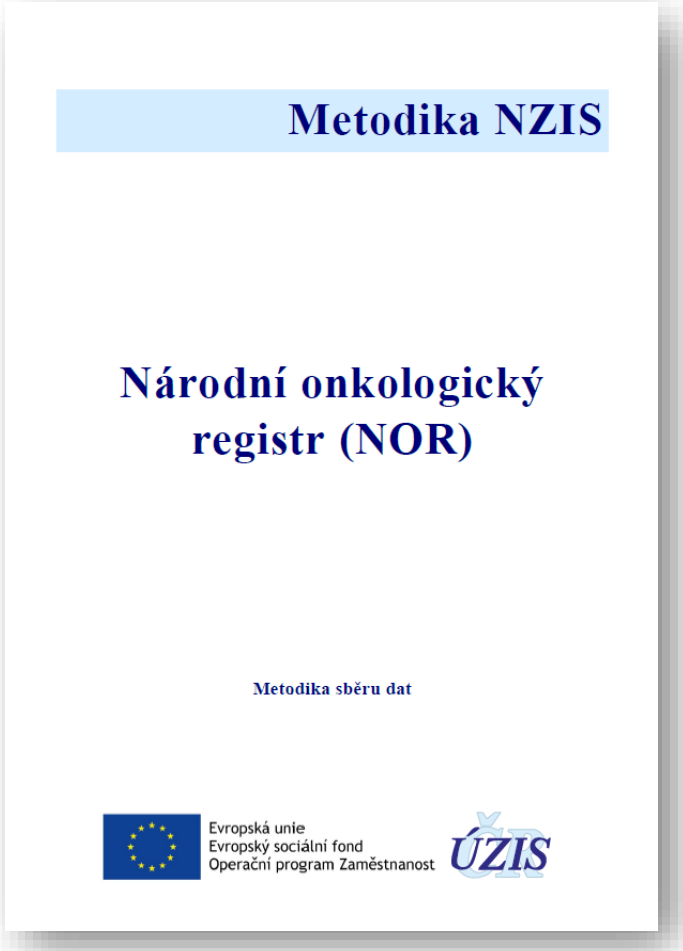
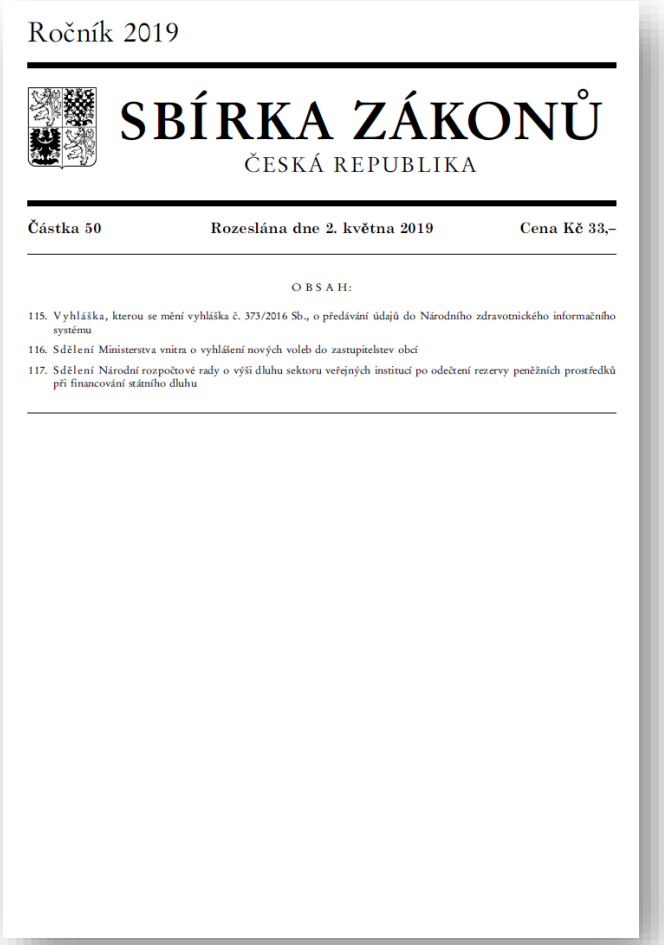
Innovated methodological and legal basis



Methodology available since 01/2019

Ministry Regulation applicable since 07/2019


Ročník 2019

SBÍRKA ZÁKONŮ
ČESKÁ REPUBLIKA

Částka 50 Rozeslána dne 2. května 2019 Cena Kč 33,–

OBSAH:

115. Vyhláška, kterou se mění vyhláška č. 373/2016 Sb., o předávání údajů do Národního zdravotnického informačního systému
116. Sdělení Ministerstva vnitra o vyhlášení nových voleb do zastupitelstev obcí
117. Sdělení Národní rozpočtové rady o výši dluhu sektoru veřejných institucí po odečtení rezervy peněžních prostředků při financování státního dluhu

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Multiple-source data integration: what has already been done

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TOPIC V. National cancer care reporting

- ✓ The newly developed system has already been used and started to provide reports on cancer care accessibility, equity, performance of providers, quality indicators, ….

TOPIC VI. Support for cancer care management

- ✓ The newly emerging system supports changes in cancer care organization, mainly establishing of regional comprehensive cancer care networks
- ✓ Set of national quality and outcome indicators is being prepared.

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III. REFERENCE DATA BACKGROUND

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National model framework

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Comprehensive approach to cancer registration is proposed to be *embedded in newly re-constructed National Health Information System* of the Czech Republic

This approach has several advantages

Synergy with other complementary information systems

Legal base for health care providers to collect and report data

Obligatory national standards for data model and reporting

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The National Health Information System: structure

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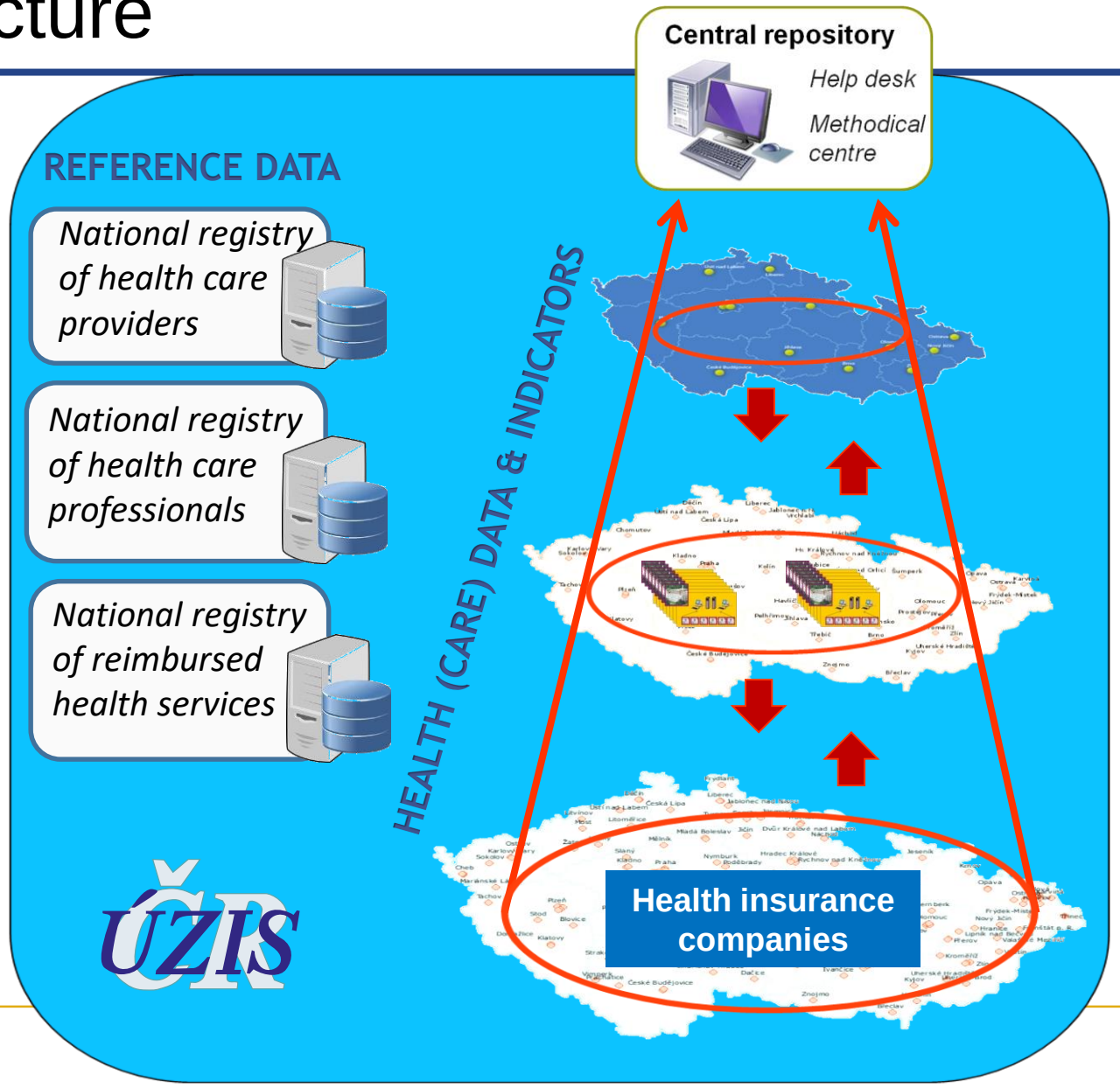

Main advantage of the NHIS is **reference data background** covering representative data on health care **providers**, **professionals** and consumed-reimbursed **services**.

The NHIS thus forms infrastructure supporting cancer registration in all its items.

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The national reference data sources

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National registry of health care providers

✓ Newly established information system covering all relevant providers and interconnecting laboratories, diagnostic units, cancer screening units, health care providers, palliative centers, etc.

National registry of health care professionals

✓ Already implemented information system allowing control over personnel capacities of all health care providers

→ These two components of the system serve as safe entry to the eHealth system and allows safe reporting of data in compliance with GDPR rules.

→ Both registries form representative platform controlling accessibility of care, performance of providers and their capacity for cancer care.

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The national reference data sources

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National registry of reimbursed health services

National registry of hospitalisations

- ✓ Most important components of the whole system. Thanks to implemented reimbursement rules, the Czech health care system is capable to control all consumed health care services – it these new components they are reported via fully representative data model.
- ✓ Each individual hospital stay is recognized as well as each relevant interaction of a patient with any type of health care provider.

Both systems have already been implemented on the basis of innovated law (2018) – even retrospectively, it means that the system can work directly with time series

….currently the interconnection of laboratory examinations and diagnostic units via eGovernment is being prepared.

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National Registry of Reimbursed Health Services

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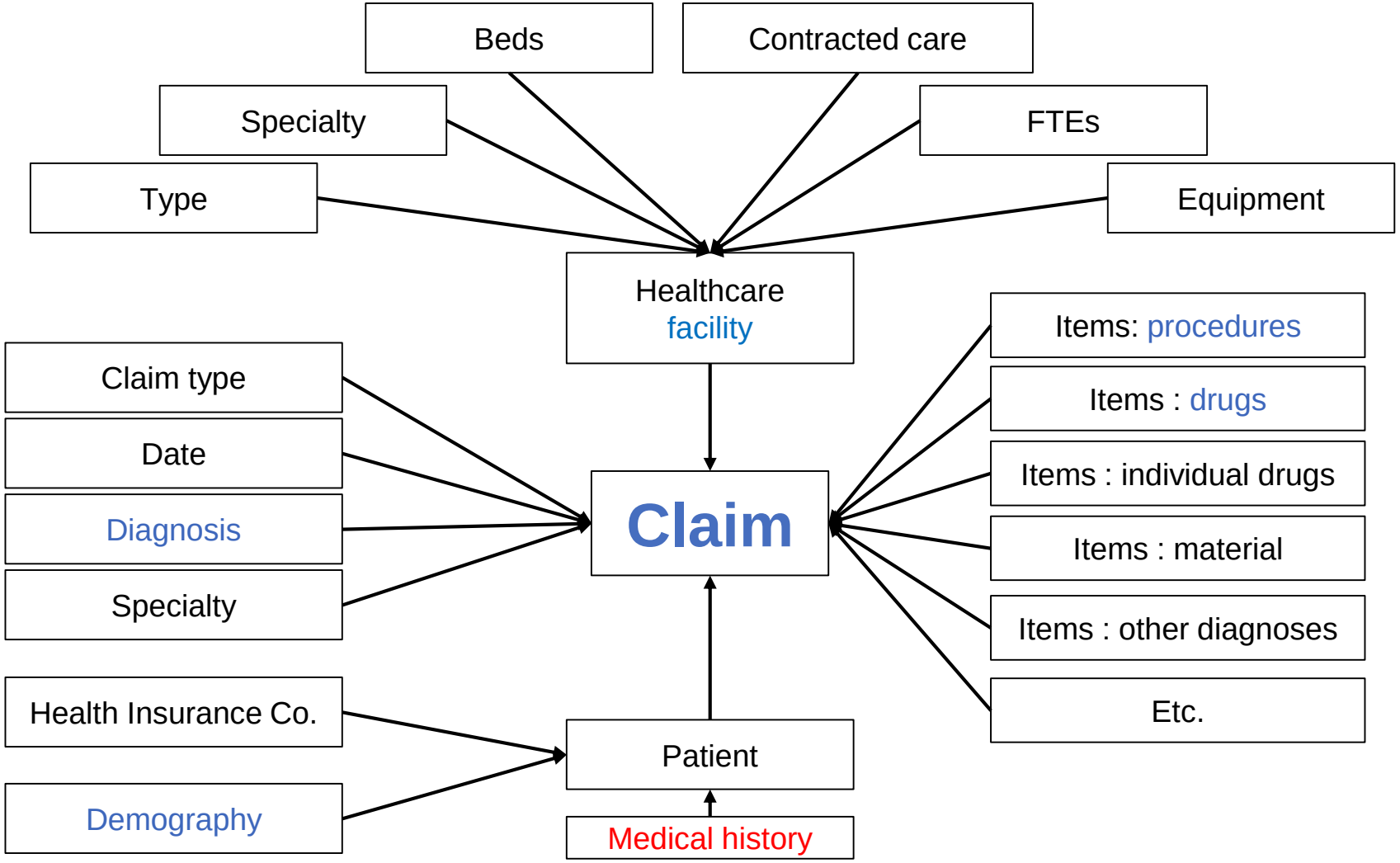
What?

Why?

By whom?

To whom?

Where?



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Cancer registry linkage opportunities

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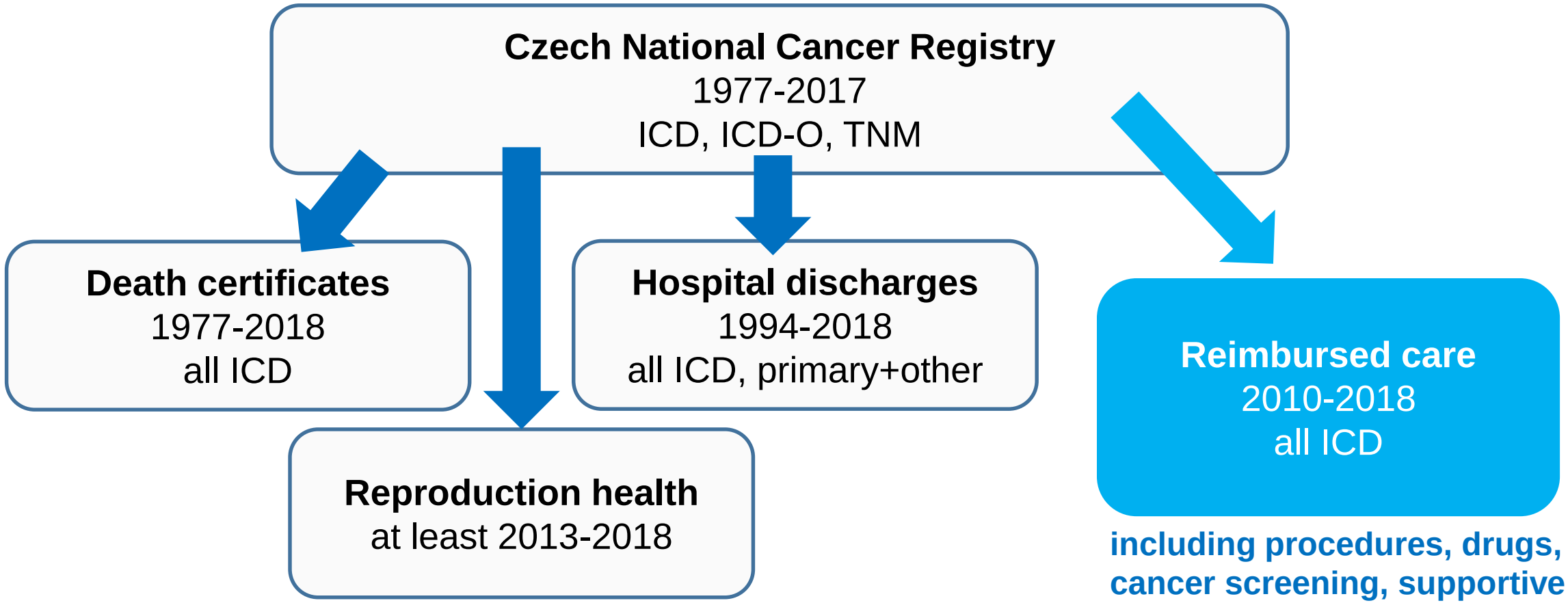

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IV. EXAMPLES OF RESULTS

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Examples of reporting: Infrastructure, providers, personal capacities, …

Reference data

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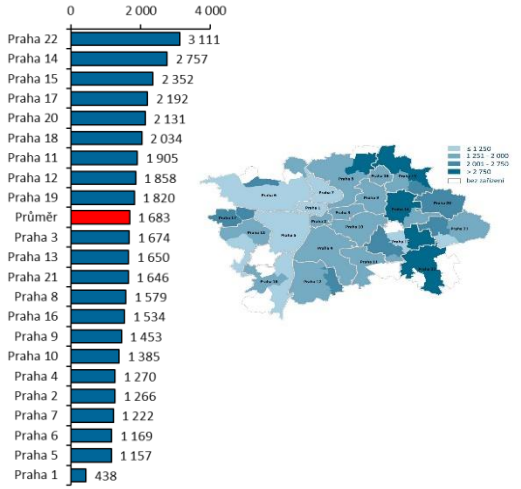
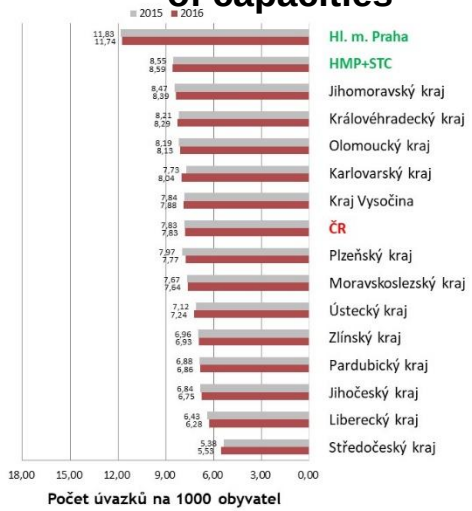
No. of providers Density of network

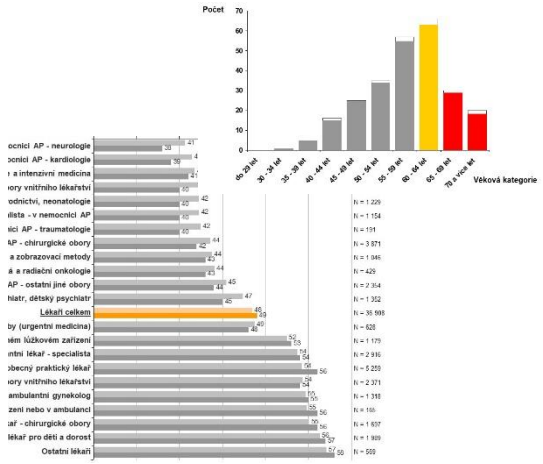


Time-related trends in accessible capacity

Regional distribution of capacities



Age (ageing) of physicians and nursers



- **Lack of personnel capacities, both physicians and nurses; hospital care and selected segments of primary care**
- **Critical situation in number of nurses in acute hospital care**
- **Significant ageing of primary care specialists and GPs – risk of non-equity**
- **Inequal distribution of capacities among regions of the country**

The National Health Information System: network of healthcare providers – web portal

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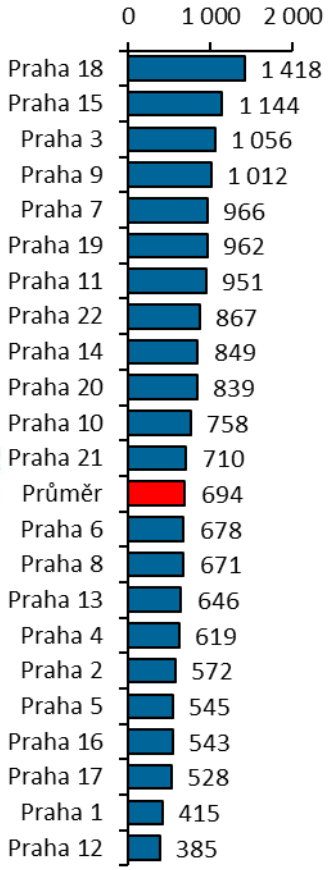
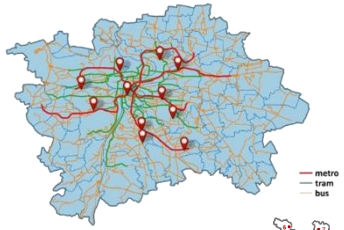
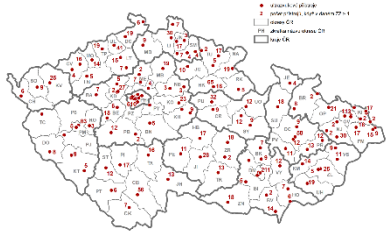
http://nrpzs.uzis.cz

Národní registr poskytovatelů zdravotních služeb (NRPZS) poskytuje kompletní přehled o všech poskytovatelích zdravotní péče v České republice, bez ohledu na jejich zřizovatele. Poskytuje údaje o profilu a rozsahu péče poskytované jednotlivými zdravotnickými zařízeními, obsahuje kontaktní údaje na daná zdravotnická zařízení a další podrobnější informace.

Health care networks and infrastructure

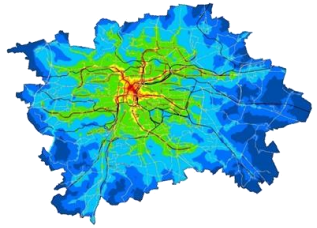


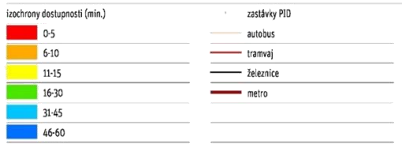




Accessibility of services

Dostupnost do centra Prahy prostředky PID v kombinaci s pěší docházkou ke stanici





Regional models of cancer care, presenting professionals and navigating patients

www.onconet.cz

Regional models of cancer care on-line

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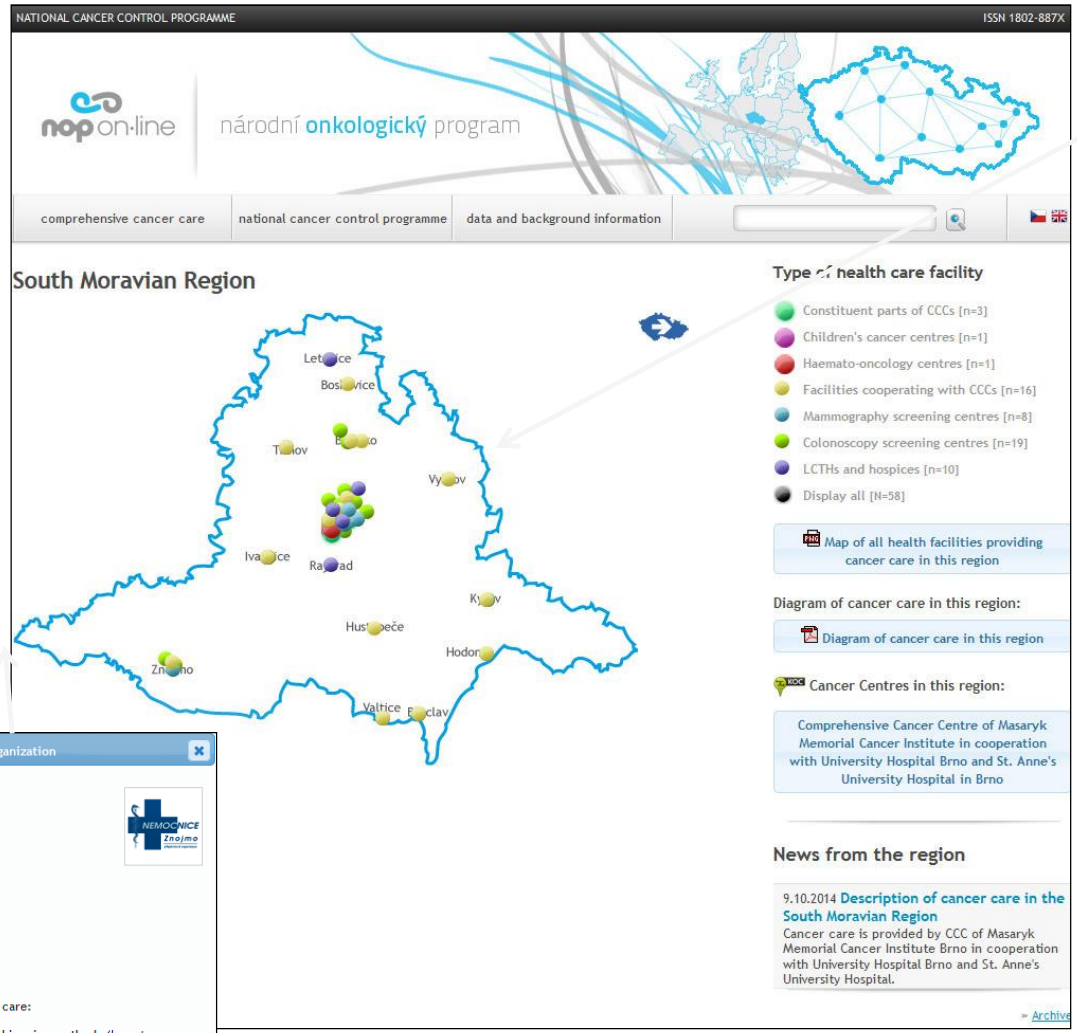

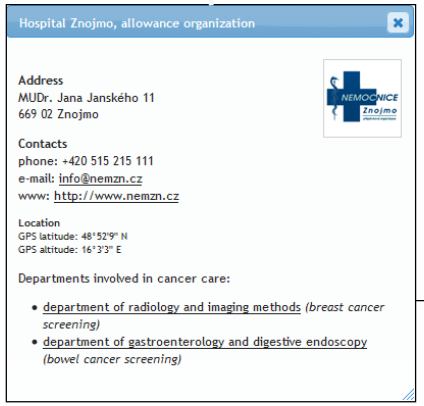

Map of facilities involved in comprehensive cancer care

Types and numbers of facilities

Diagram of cancer care

Link to a regional Cancer Centre

Regional news

Detail of a health care facility

Cancer Centres On-line

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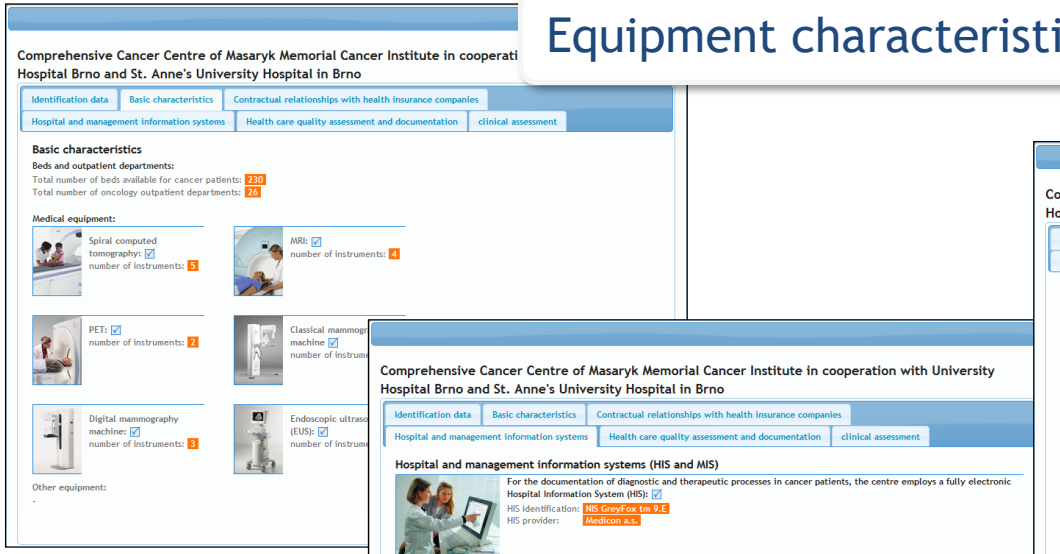
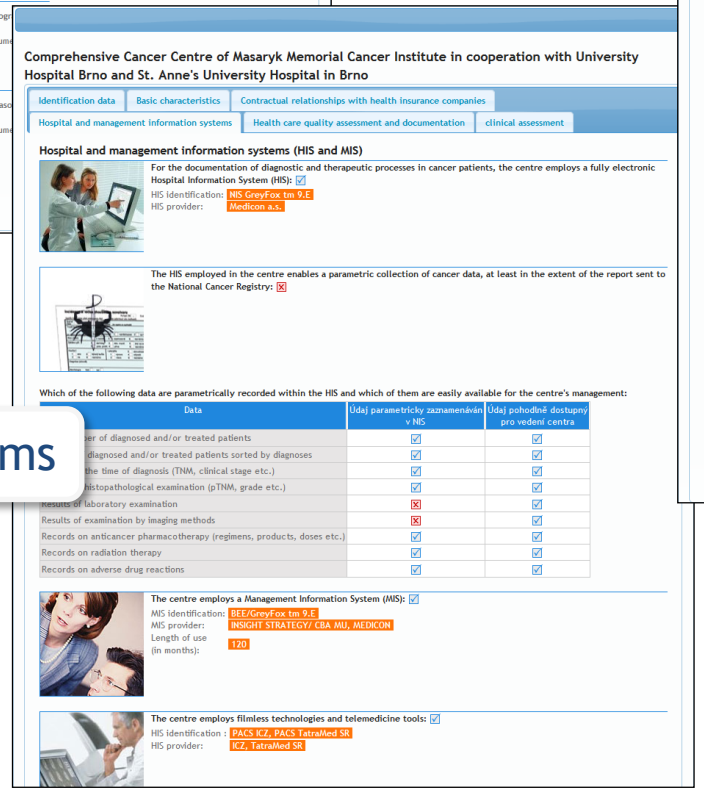
Equipment characteristics

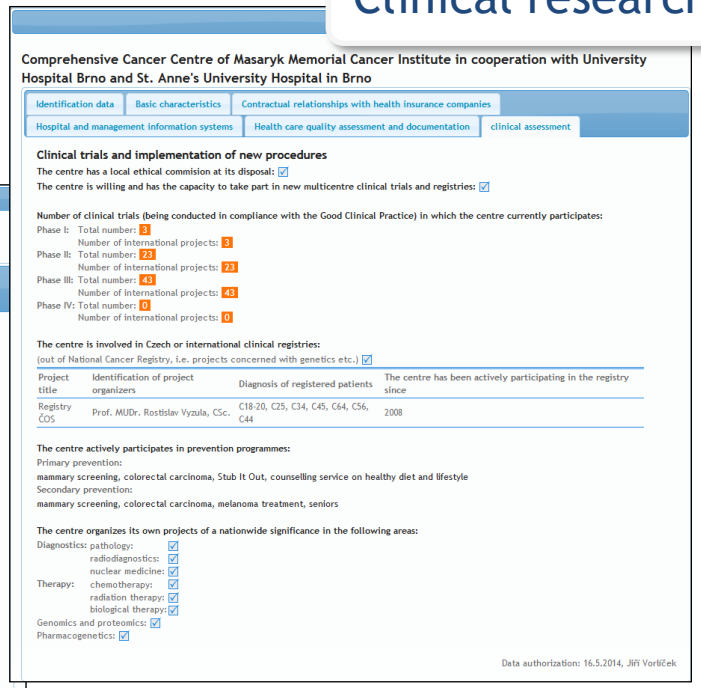
Clinical research

Information systems

...and more







Examples of reporting generated by the Czech National Cancer Control System: I. Epidemiology

Model diagnosis: colorectal cancer

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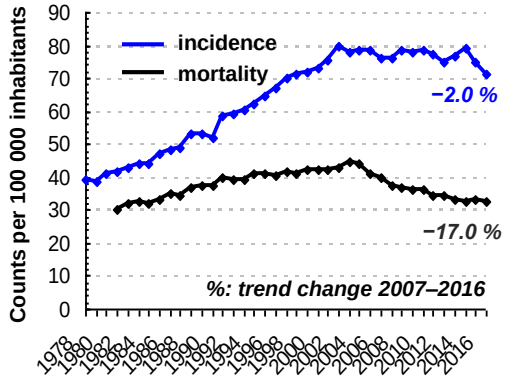
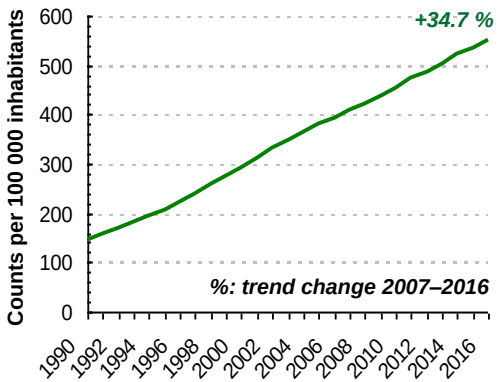
Main trends: incidence & mortality



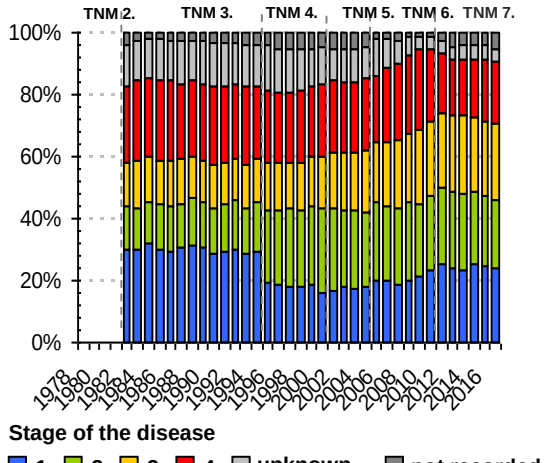
	Incidence	Mortality
Absolute counts in 2016	7,553	3,445
Counts per 100 000 in 2016	71.5	32.6

Main trends: prevalence



	Prevalence (31.12.2016)
Absolute counts	58,234
Counts per 100 000	551.2

Clinical stages: detection at primary diagnosis



Survival of treated patients in time trends

Colorectal carcinoma (C18-C20)	5yr relative survival (95% IC)	
	2005–2009	2010–2015
All patients	57.9 (57.2–58.6)	63.2 (62.5–63.8)
stage 1	86.4 (84.9–87.7)	89.9 (88.8–91.0)
stage 2	72.3 (70.9–73.6)	77.0 (75.8–78.2)
stage 3	52.9 (51.4–54.3)	59.3 (58.1–60.5)
stage 4	12.2 (11.3–13.1)	13.3 (12.4–14.2)

Stochastic predictions of incidence and prevalence

Colorectal carcinoma (C18-C20)	Predictions for 2018	
	Incidence	Prevalence
Stage I	**2,156** (2,008; 2,304)	**22,268** (22,023; 22,513)
Stage II	**1,879** (1,760; 1,998)	**19,019** (18,792; 19,246)
Stage III	**2,162** (2,046; 2,277)	**15,265** (15,062; 15,468)
Stage IV	**1,393** (1,186; 1,602)	**6,157** (6,028; 6,286)
Stage unknown	**505** (322; 685)	**3,109** (3,017; 3,201)
TOTAL	**8,095** (7,322; 8,866)	**65,818** (65,396; 66,240)

Stochastic predictions of therapeutic burden

Colorectal carcinoma (C18-C20)	Newly treated patients in 2018
Stage I	**1,927** (1,795; 2,060)
Stage II	**1,761** (1,649; 1,872)
Stage III	**2,007** (1,900; 2,114)
Stage IV – incidence	**937** (798; 1,077)
Disseminated relapses / progressions	**1,583** (1,518; 1,648)
TOTAL	**8,215** (7,660; 8,771)

Examples of reporting generated by the Czech National Cancer Control System: II. Hospital level

Model diagnosis: colorectal carcinoma

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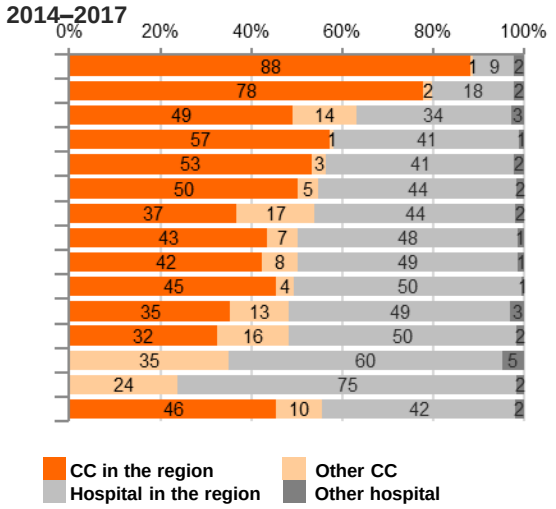
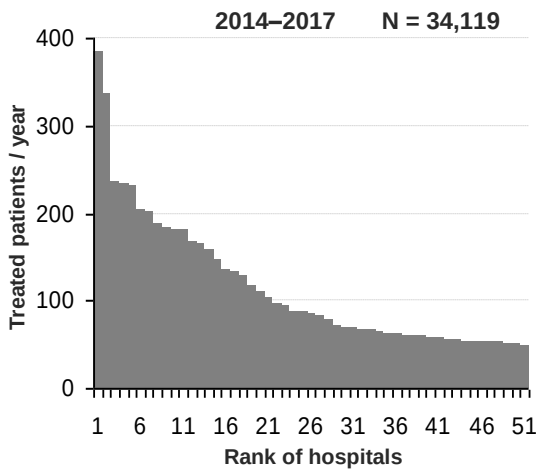
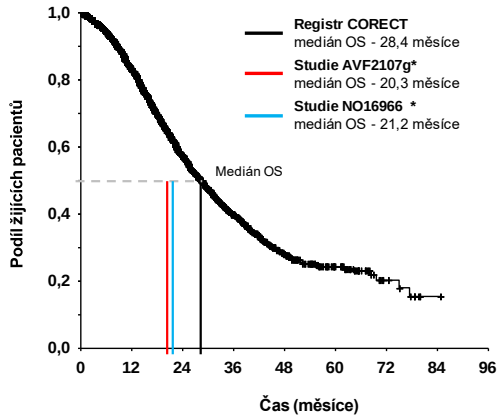
Distribution of care among regions/centers



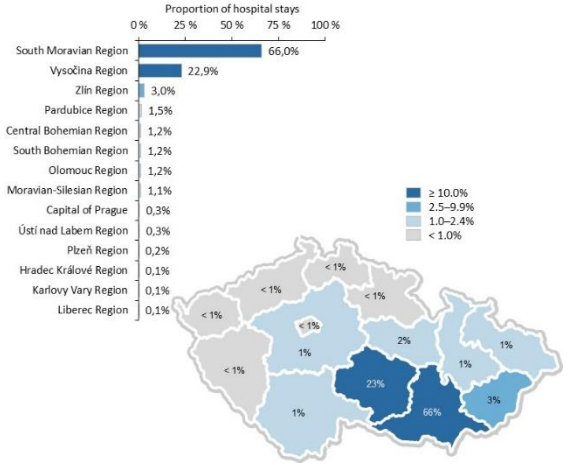
Volume of cancer treatment: capacity of hospitals



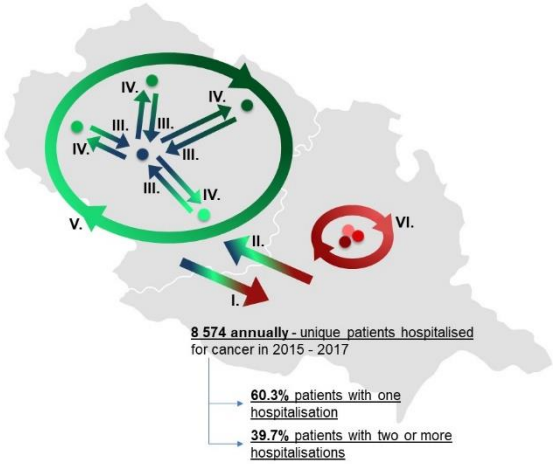
Benchmarking of survival after given medication



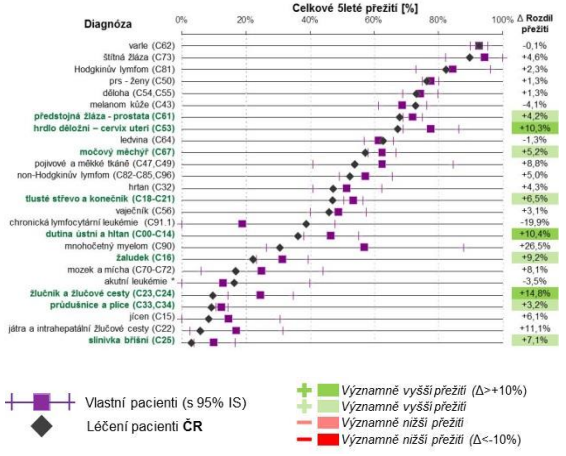
Catchment area of centers and hospitals



Real-world trajectories



Outcome measures: 5yr survival – benchmarking



Examples of reporting generated by the Czech National Cancer Control System: III. Screening

Model diagnosis: colorectal carcinoma

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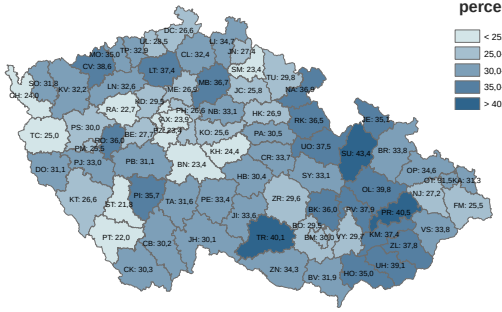
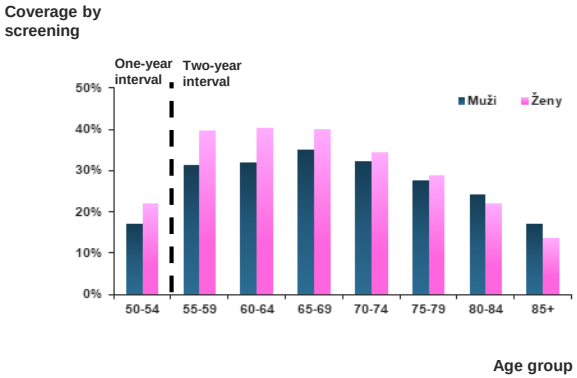
CRC screening: FOBT regional coverage

Men and women aged over 50



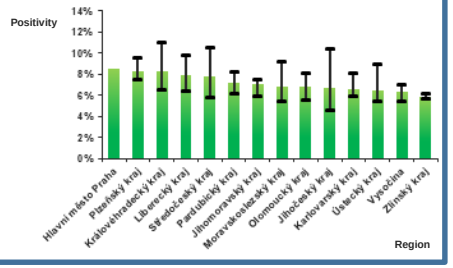
21,8% ⟷ 30,8% ⟷ 43,4%

CRC screening: age-specific coverage



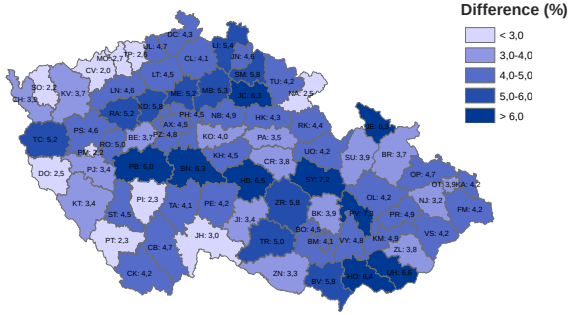
FOBT positivity: time trend and regional profile

Men and women aged over 50



Coverage in time trend: 2013 vs. 2014

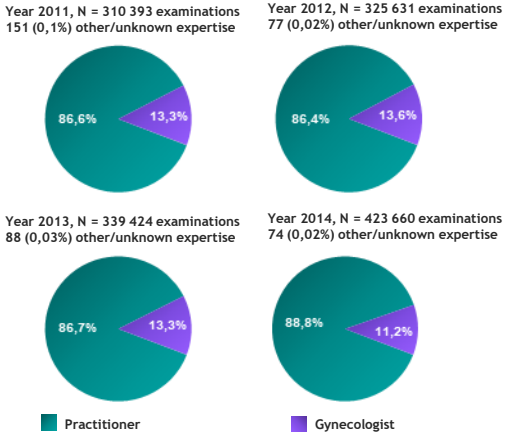
Men and women aged over 50



+2,0% ⟷ +4,4% ⟷ +7,3%

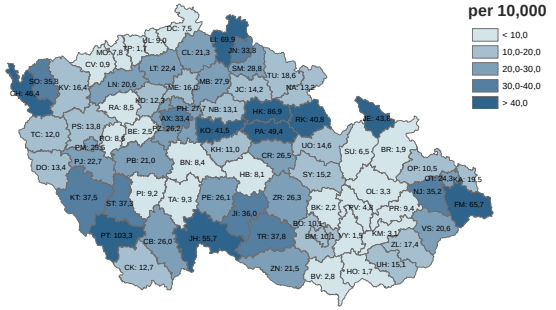
Share of primary care specialists

Women aged over 50



Primary screening Colonoscopy – regional coverage

Men and women aged over 50



0,9 ⟷ 23,2 ⟷ 103,3

Examples of reporting generated by the Czech National Cancer Control System: IV. Palliative care

System controlling data reports over end-of-life care

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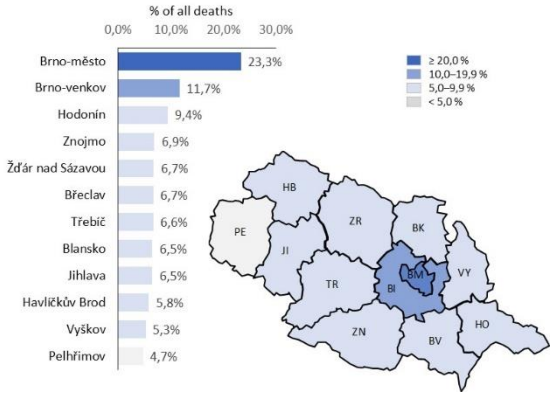
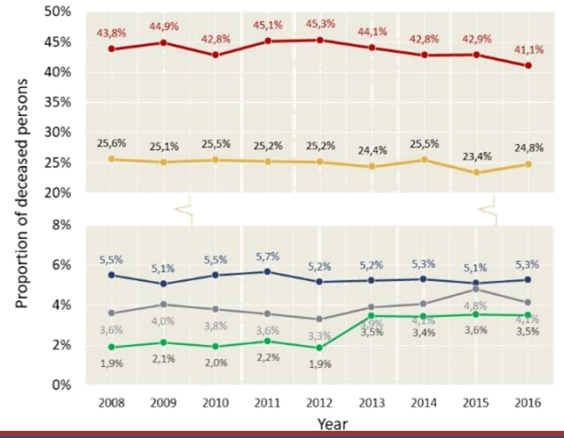
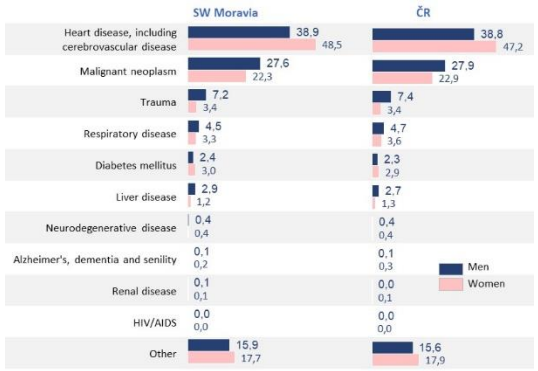
Mortality rates: subregion of death in the CCCN area



Main causes of death in time trends

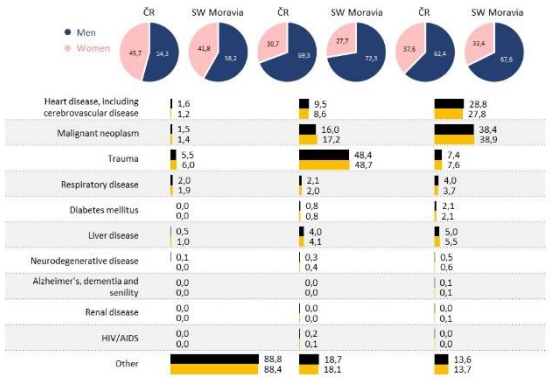


Main causes of death by sex: population benchmarking

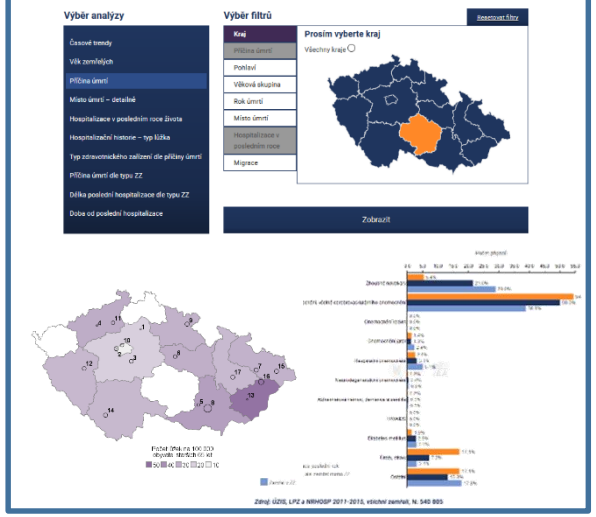


http://www.paliativnidata.cz/

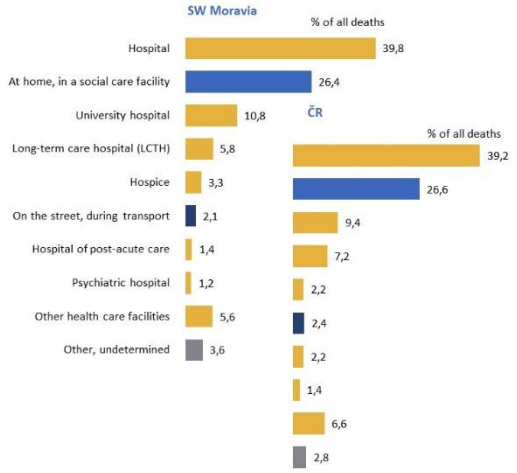
Main causes of death by sex, age and primary cancer diagnosis



Capacity building of end-of-life care and palliative care



Place of end-of-life care: type of health care facility



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National Pilot ICT Model for Cancer Registration Integrating Multiple Data Sources

V. NEXT STEPS

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Future ambition: comprehensive data-based support of cancer care management and organization of care

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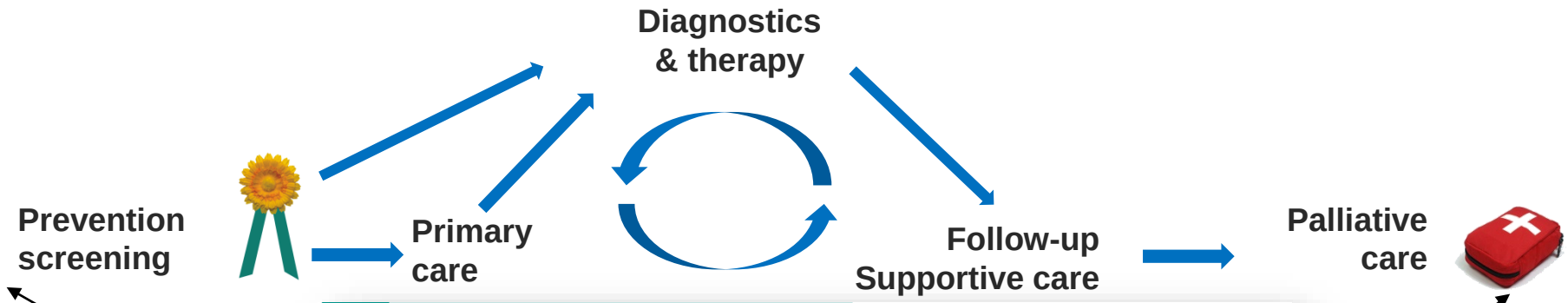

64 Problem Solving in Patient-Centred and Integrated Cancer Care

PERSPECTIVE

13 Integration of Cancer Care between Primary Care and Hospitals

Peter Selby, Geoff Hall, Ladislav Dusek, Fotios Loupakis, Lucio Luzzatto, Tit Albreht, Richard D. Neal, Rob Turner, Sean Duffy

Introduction

Despite encouraging progress, outcomes for cancer patients are still patchy and inequalities are apparent even across Europe.[1–3] Integrated cancer care, bringing together primary care and hospital care and forming closer links between institutions, can improve the quality of care and outcomes for patients.[4] This chapter summarizes approaches to improving integration between

CanCon
Cancer Control Joint Action

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Future ambition: multiple data sources interconnected for reporting over complex indicators of quality

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	Population data	Hospital data	Specialized registries
Equity Accessibility	Regional monitoring Distribution of care Prevention	Case mix monitoring Migration of patients	Analyses of target groups of patients
Standards	Diagnostic and therapeutic standards	Compliance with standards Quality control	Specific algorithms & protocols, adherence
Safety	Adverse events Specific problems Mortality	Therapy-related complications	Toxicity assessment and grading
Efficacy	Overall survival Disease free survival	Therapeutic response Time-to event analyses	Quality of life Cost effectiveness Economic analyses

→ **cancer care data**

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Legal basis for monitoring

Věstník
Ročník 2017
MINISTERSTVA ZDRAVOTNICTVÍ
ČESKÉ REPUBLIKY
Částka 13 Vydáno: 15. PROSINCE 2017 Cena: 605 Kč

OBSAH:

1. Cenový předpis Ministerstva zdravotnictví 1/2018/DZP ze dne 5. prosince 2017 2
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Organisation and evaluation of cancer care
Published 12/2017

Věstník
Ročník 2019
MINISTERSTVA ZDRAVOTNICTVÍ
ČESKÉ REPUBLIKY
Částka 11 Vydáno: 21. listopadu 2019 Cena: 249 Kč

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1. Centra vysoce specializované hematologické péče 2019 2
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Centres for highly specialised cancer care
Published 11/2019

- **multidisciplinary teams**
- **regional cancer groups**
- **performance indicators**

Legal basis for performance indicator (methodology, disclosure) is being established (amendment of Act on Health Services undergoing legislative process)

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Linkage as a basis for evaluation and monitoring: example of cancer screening

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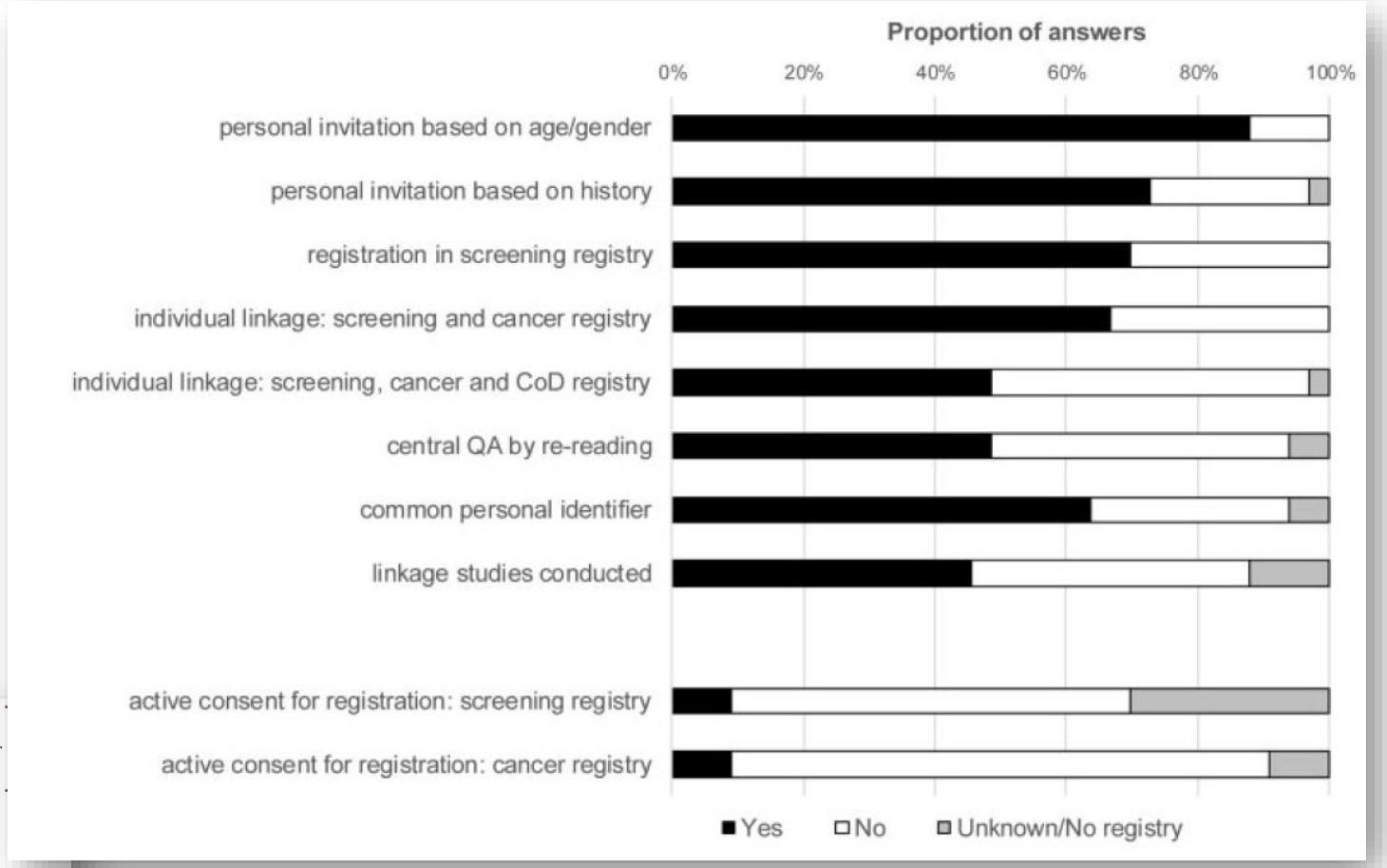
Key elements of legal framework in 33 responding countries



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The legal framework for European cervical cancer screening programmes

Ondřej Májek[1,2], Ahti Anttila[3], Marc Arbyn[4], Evert-Ben van Veen[5], Birgit Engesæter[6], Stefan Lönnberg[3]

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Current steps and future plans

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Legal and technical background

Definite legal basis for monitoring of cancer care, interconnection via eGovernment services within eHealth system must be realized and methodically published

Reporting

Standards of national reporting focused on cancer care management and quality must be prepared

Base for research

Methodical base for realization of various types of studies must be prepared

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Thank you very much for your attention

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