The Czech National Health Care Information System (NH-IS) and its strategy in building population-based reporting

Evropská unie
Evropský sociální fond
Operační program Zaměstnanost

Regional reporting of NH-IS

I. Introducing NH-IS

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Evropský sociální fond
Operační program Zaměstnanost

Regional reporting of NH-IS

The Czech National Health Care Information System

NH-IS can contribute to the optimization of health care system and to the monitoring of population of health.

NH - IS

NH-IS = very complex system

Statistical surveys (clinical reports on care, economy of providers)

Health care registries (real – world observations, based on representative reporting)

Reference information systems (eHealth key components)

International collaboration and reporting (Health Data OECD, Eurostat, EHIS, EHLEIS, …)

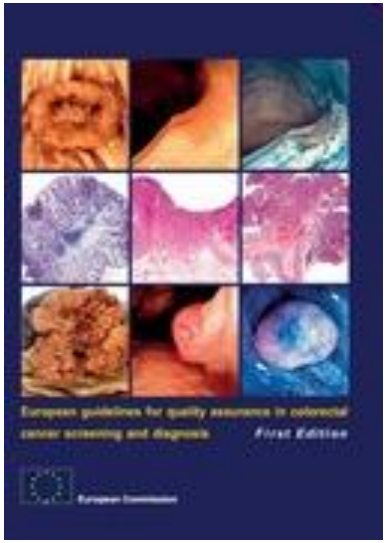
Key mission of the Czech NH-IS I.

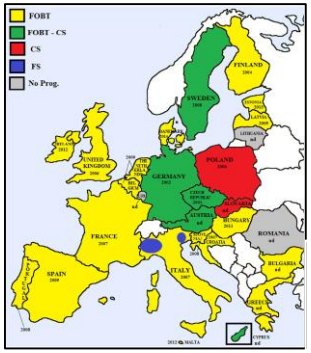
Evidence-based medicine

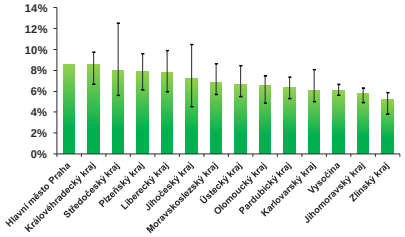
NH-IS

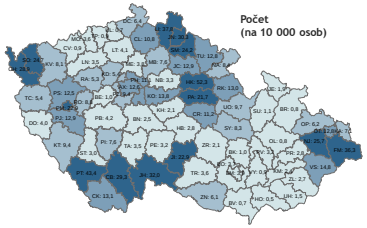
!

Clinically based evidence









Everybody knows what to do!

Does really everybody do it?

Key mission of the Czech NH-IS II.

Basic elements of effective e-health information system – Czech approach:

1. e-identification/certification of health care professionals

   National registry of health care professionals

2. e-identification/certification of health care providers

   National registry of health care providers

3. monitoring of patient's trajectory in the health care system

4. quantification of consumed health care services: classification, extent and cost

   Health care records in centralized data store of reimbursement companies

II. Building NH-IS: main challenges

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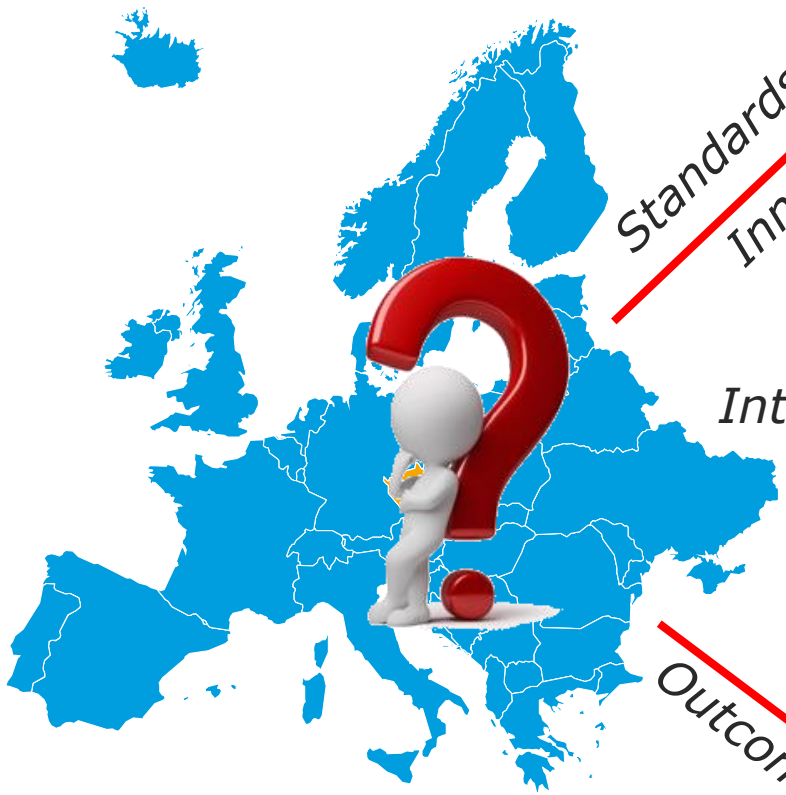
Effective system must answer very complex questions



Standards of care
Innovations

How to facilitate and control implementation of clearly given evidence-based guidelines?
… and how to update them?

Interventions

How to control population –based interventions in a way which supports equity of care?
… and how to interlink consequent steps?

Outcomes

How to control population and its health status (mortality, morbidity, survival, ….)?

Effective system must cover multiple and heterogeneous data sources

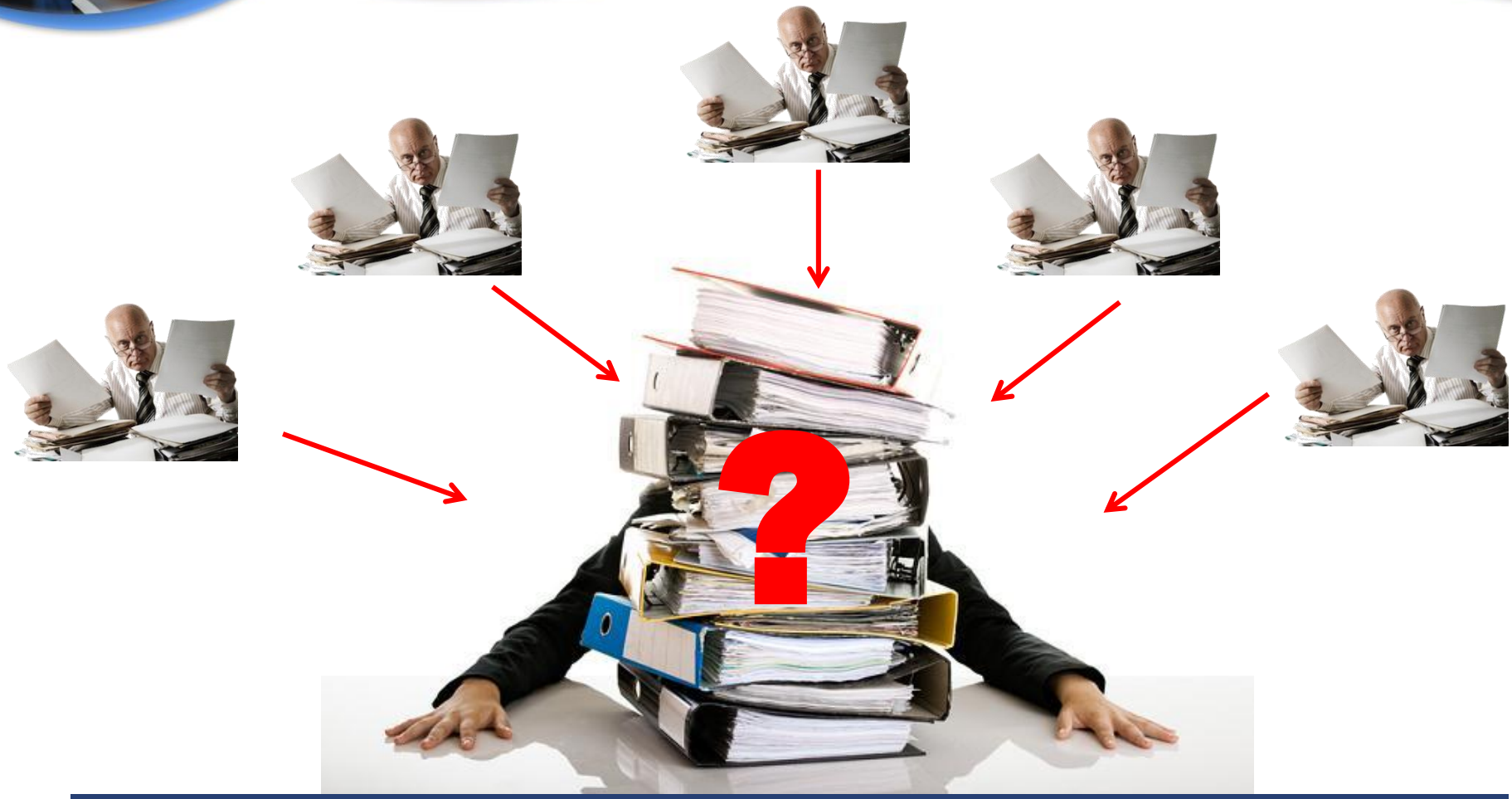
HOW TO MANAGE IT?

DATA INTEGRATION and reporting

SEPARATED KEY INFORMATION SOURCES

NON-STANDARDIZED INFORMATION SYSTEMS

Effective system cannot increase administrative burden of health care professionals



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

III. Three views defining modern NH-IS

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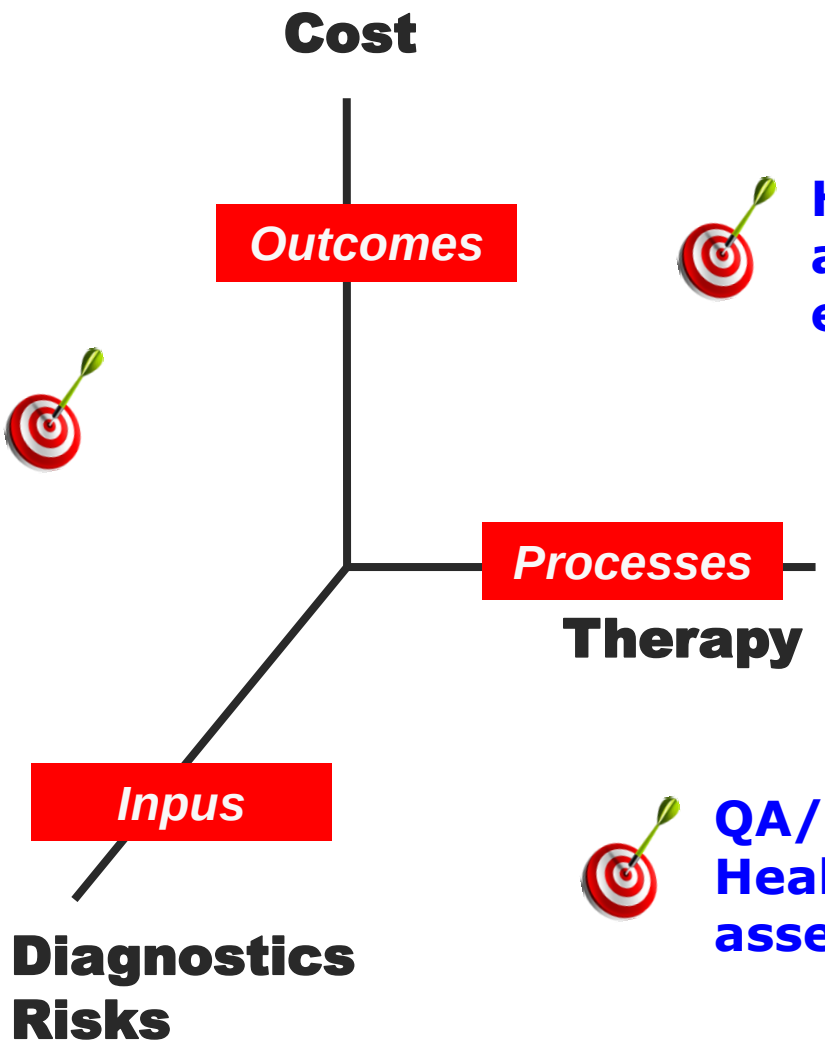
Evropský sociální fond
Operační program Zaměstnanost

Regional reporting of NH-IS

I. Management view
Integration of very complex data

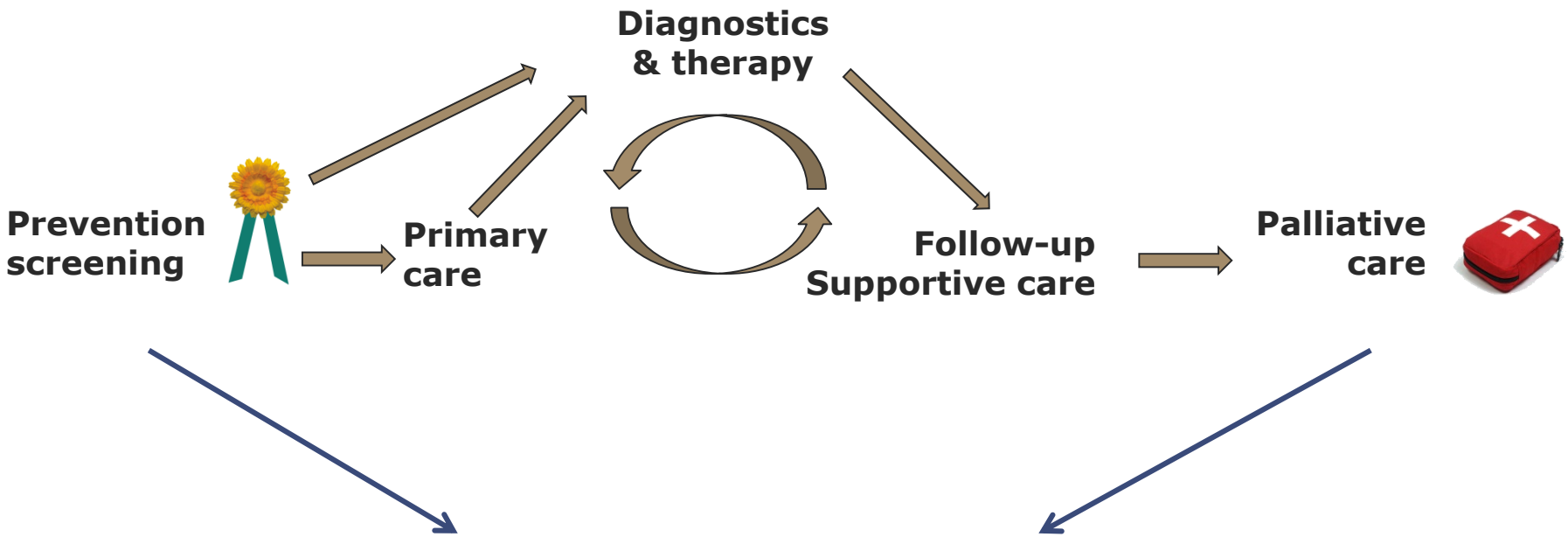


Health technology assessment; cost effectiveness

Optimization of networks; reasonable distribution of care

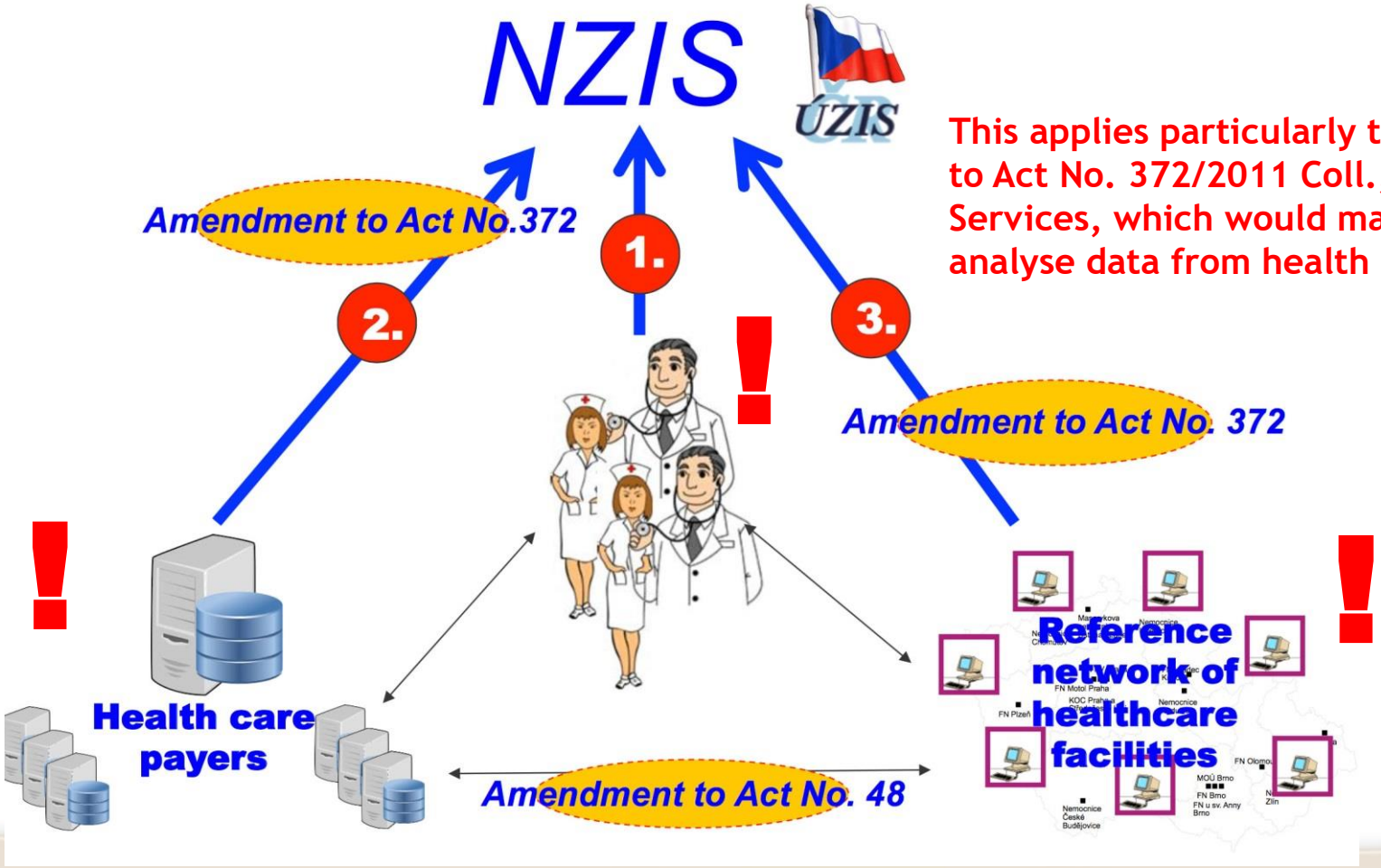
QA/QC: Health care quality assessment

II. System view
Comprehensive coverage of all segments of care



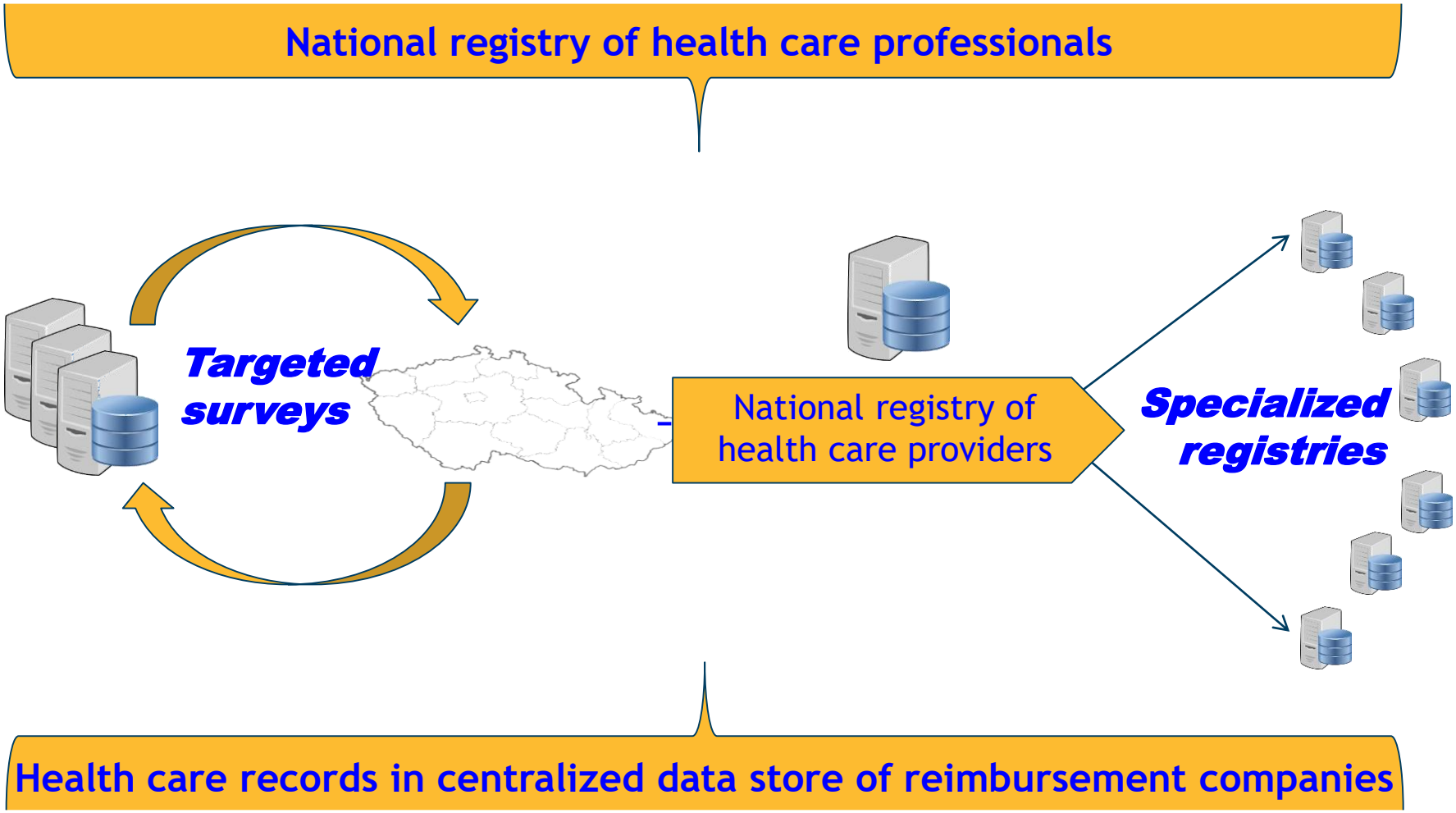
Really comprehensive national health care data collection cannot be based on hundreds of separated registries for individual diagnoses

Ensuring representative data is a significant step to guarantee the system functionality; this also includes the legislation.



This applies particularly to the Amendment to Act No. 372/2011 Coll., on Health Services, which would make it possible to analyse data from health care payers.

Conclusion: NH-IS architecture



Example of outcomes: The Czech National Cancer Care Information System

Czech National Cancer Control Program – Information Platform

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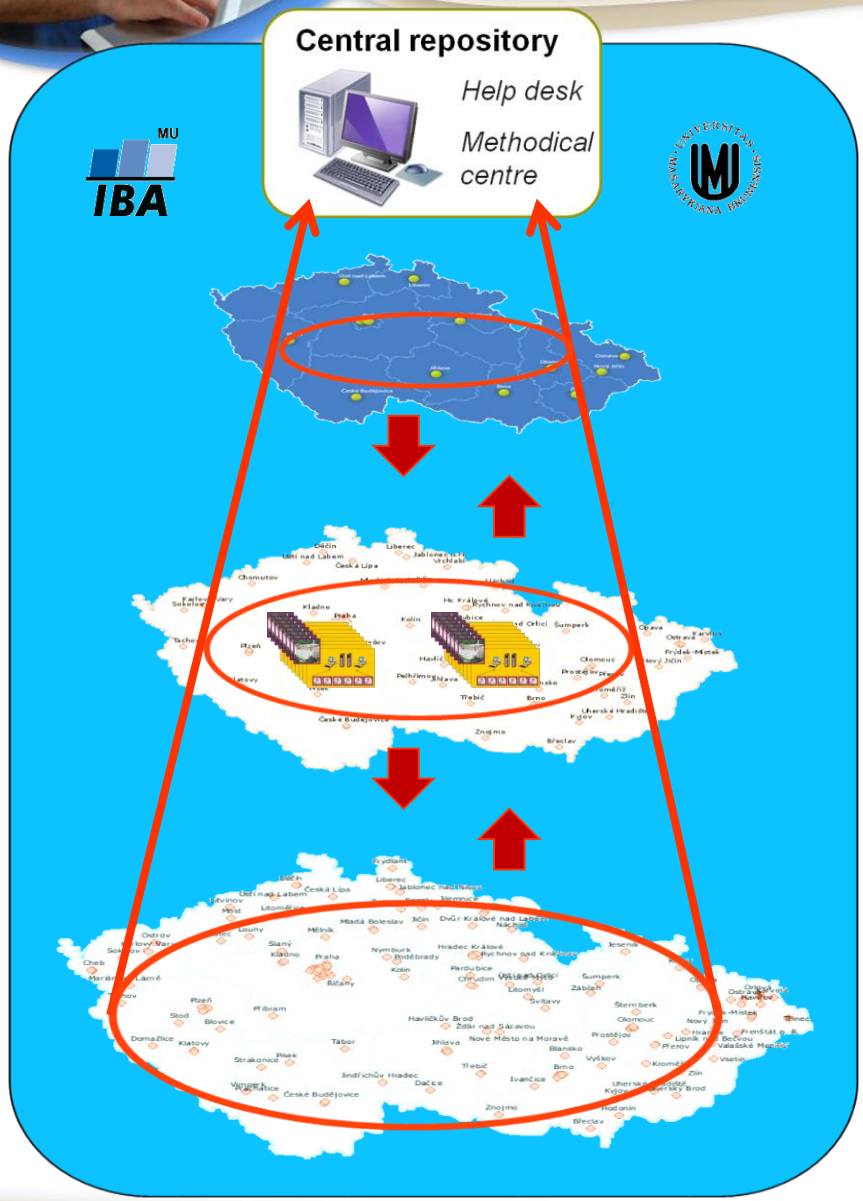
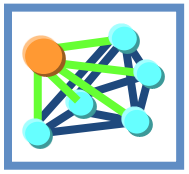
IT infrastructure for monitoring of cancer care



Cancer centres network as a regional managing system



Epidemiology
Population-based registries

Population and treatment burden
National Cancer Registry

Hospitals
Specialized registries

Hospital information systems
Local and national registries

Monitoring of health care
EHR

Primary care (GPs, gynaecologists)
Hospital care
Specialized care and cancer centres

REPORTS

Equity of health care

Structure of health care

Results of health care

Quality of health care

Distribution of health care

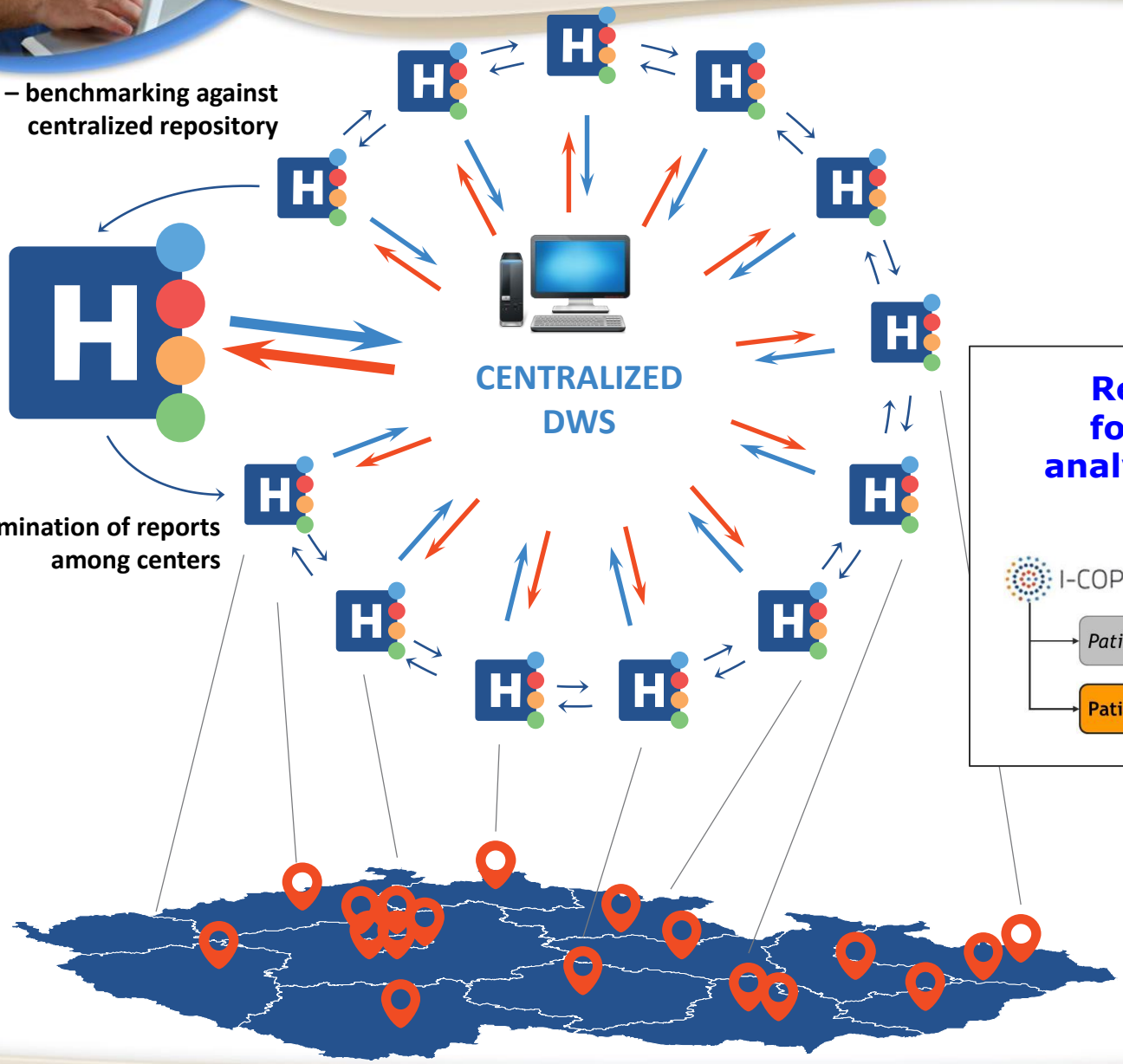
Volume of health care

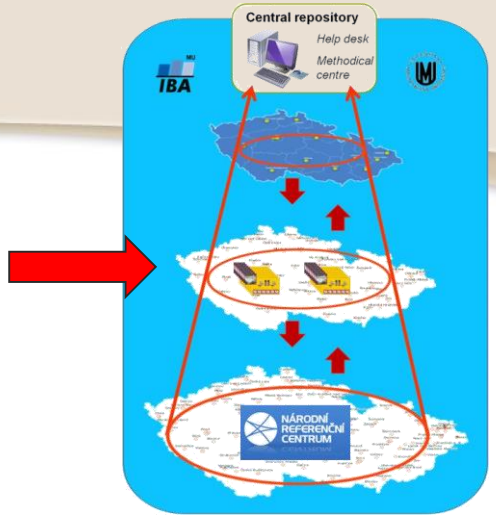
Data validation

Examples of IS functionality: Hospital-based monitoring

Self – benchmarking against centralized repository

Dissemination of reports among centers





Representative base for clinically relevant analyses of consecutively treated patients

I-COP

All patients treated in centers 1/2007- 12/2014 N = 7 788 839 (100 %)

- *Patients without cancer* N = 7 228 262 (92,8 %)
- Patients with cancers N = 560 577 (7,2 %)

Set of indicators: health care quality & population-based health indicators

	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

EXAMPLE OF RESULTS - I.
Modern comprehensive data-based reporting

www.svod.cz

Czech National Cancer Control Program - Information Platform

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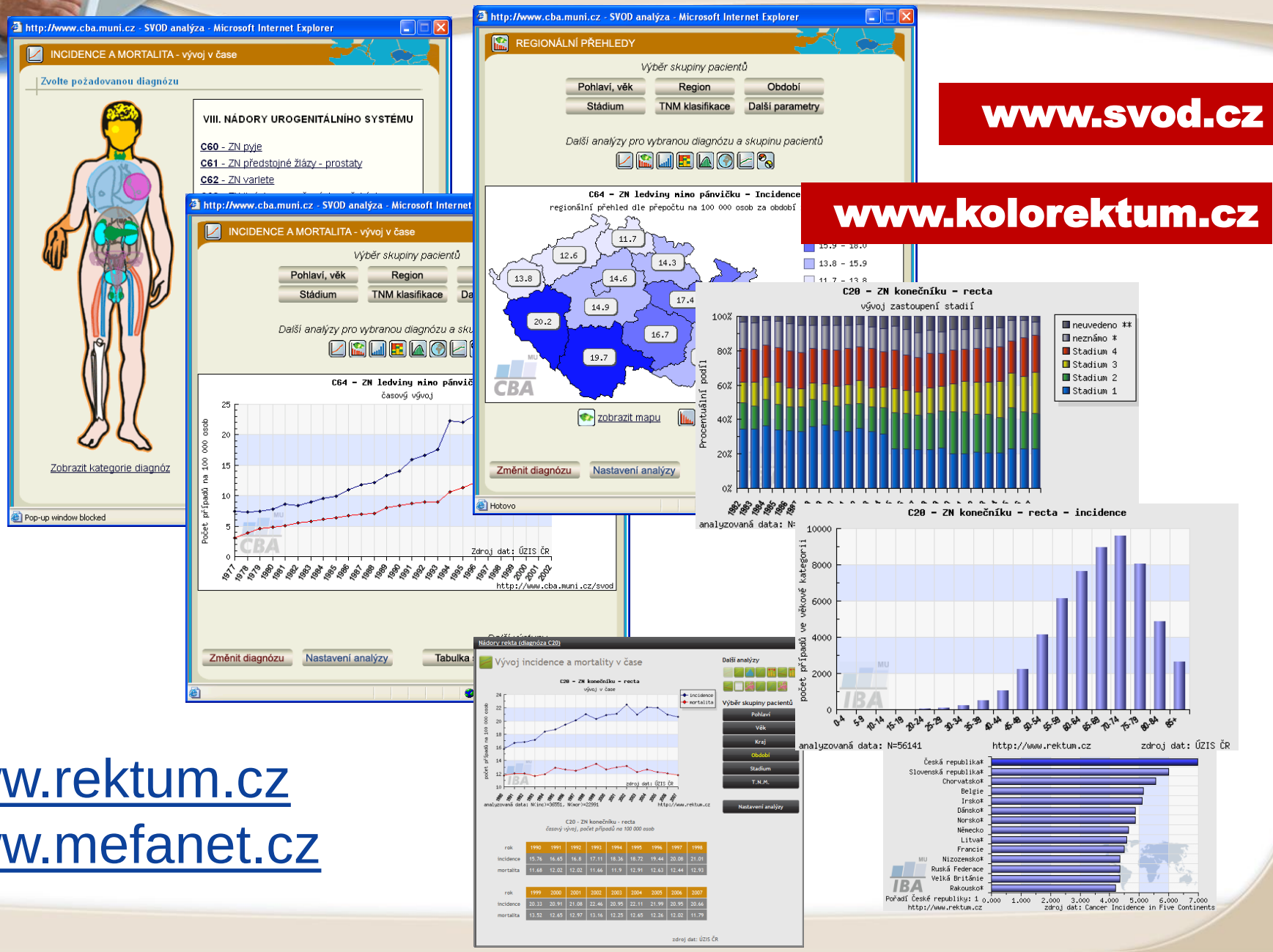
National on-line data-based reporting



www.svod.cz

www.kolorektum.cz

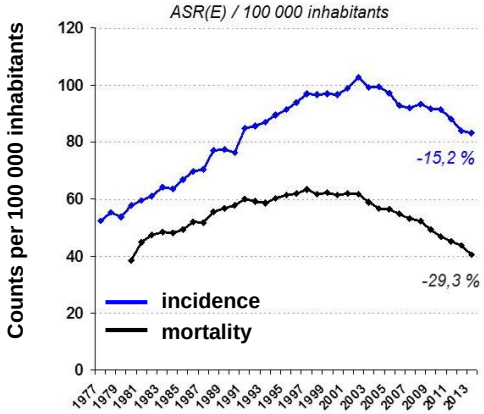
www.rektum.cz

www.mefanet.cz

Examples of reporting: I. Population level & II. Hospital level

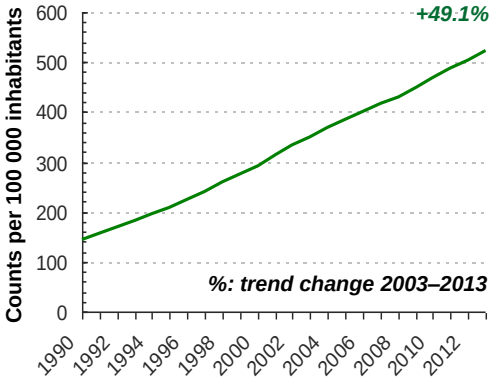
Model diagnosis: colorectal carcinoma

Main trends: incidence & mortality



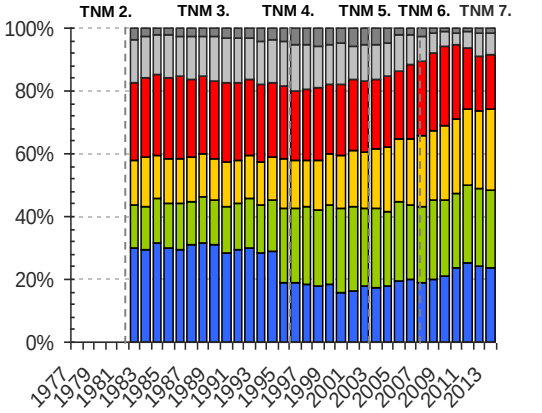
	incidence	mortality
Absolute counts in 2013	8 066	3 716
Counts per 100 000 in 2013	76.7	35.4

Main trends: prevalence



	Prevalence (31/12/2013)
Absolute counts	54 982
Counts per 100 000	523,1

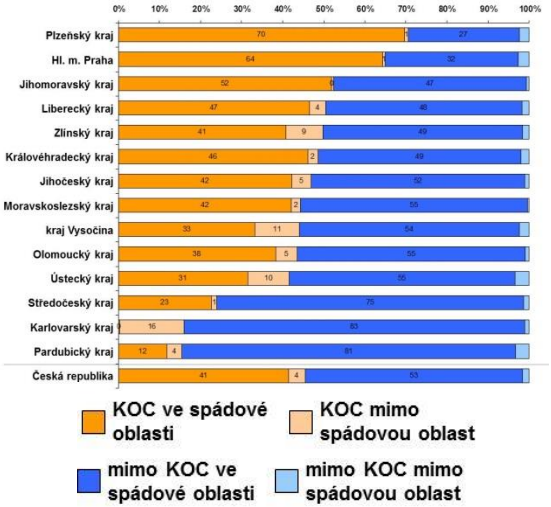
Clinical stages: primary diagnosis



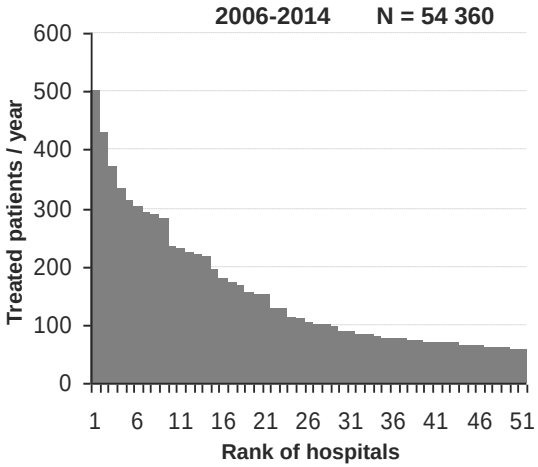
Stage of the disease

1 2 3 4 unknown not recorded

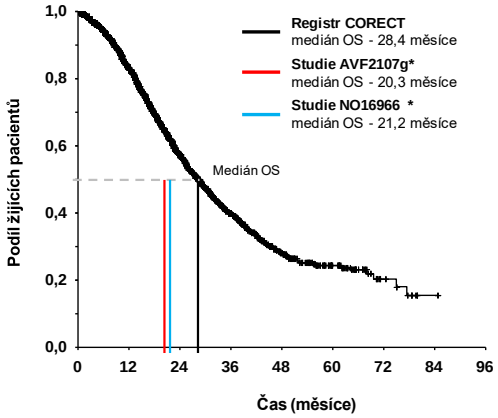
Distribution of care among regions/centers



Volume of cancer care: capacity mapping

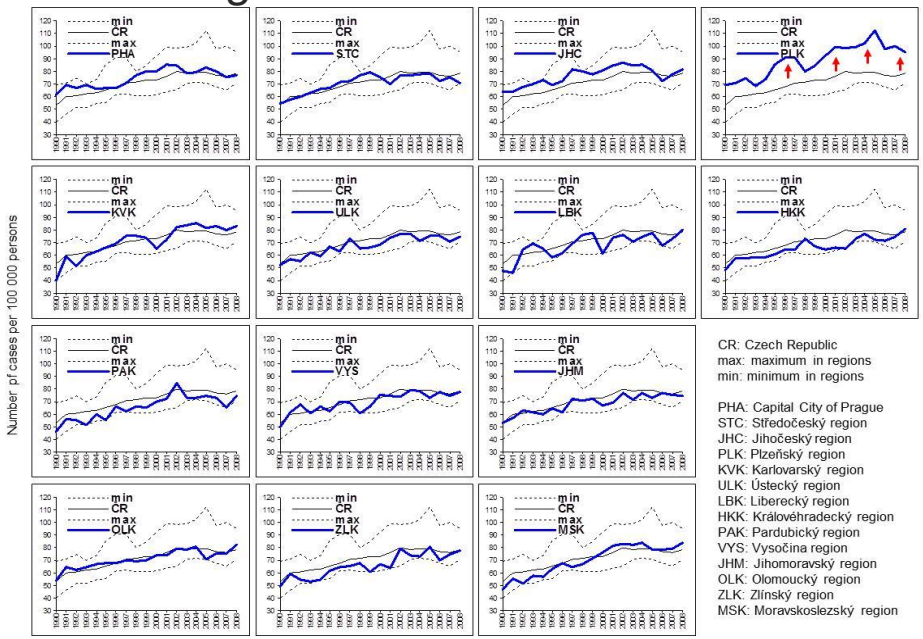


Benchmarking of outcome measures: Survival after given medication vs. EBM trials



Examples of reporting: III. Predictive mapping of cancer burden

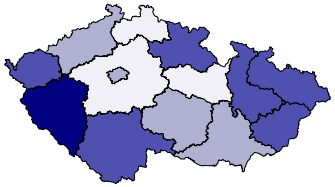
Model diagnosis: colorectal carcinoma



CR: Czech Republic
max: maximum in regions
min: minimum in regions

PHA: Capital City of Prague
STC: Středočeský region
JHC: Jihočeský region
PLK: Plzeňský region
KVK: Karlovarský region
ULK: Ústecký region
LBK: Liberecký region
HKK: Královéhradecký region
PAK: Pardubický region
VYS: Vysočina region
JHM: Jihomoravský region
OLK: Olomoucký region
ZLK: Zlínský region
MSK: Moravskoslezský region

CRC (C18 – C20)	INCIDENCE (95 % CI)	PREVALENCE (95 % CI)
	---------- Prediction: 2016 ----------	
Stage I	**2050** (1903; 2197)	**21 376** (21 136; 21 616)
Stage II	**1951** (1844; 2057)	**19 104** (18 877; 19 331)
Stage III	**2117** (2010; 2226)	**15 114** (14 912; 15 316)
Stage IV	**1631** (1359; 1903)	**7083** (6945; 7221)
TOTAL	**8037** (7298; 8777)	**65 331** (64 911; 65 751)



Pavlík et al. BMC Public Health 2012, 12:117
http://www.biomedcentral.com/1471-2458/12/117

BMC Public Health

RESEARCH ARTICLE Open Access

Estimating the number of colorectal cancer patients treated with anti-tumour therapy in 2015: the analysis of the Czech National Cancer Registry

Tomáš Pavlík[1], Ondřej Májek[1], Jan Mužík[1], Jana Koptíková[1], Lubomír Slavíček[1,2], Jindřich Fínek[1,3], David Feltl[4], Rostislav Vyzula[1,5] and Ladislav Dušek[1*]

Abstract

Background: Colorectal cancer (CRC) represents a serious health care problem in the Czech Republic, introducing a need for a prospective modelling of the incidence and prevalence rates. The prevalence of patients requiring anti-tumour therapy is also of great importance, as it is directly associated with planning of health care resources.

Methods: This work proposes a population-based model for the estimation of stage-specific prevalence of CRC patients who will require active anti-tumour therapy in a given year. Its applicability is documented on records of the Czech National Cancer Registry (CNCR), which is used to estimate the number of patients potentially treated with anti-tumour therapy in the Czech Republic in 2015.

Results: Several scenarios are adopted to cover the plausible development of the incidence and survival rates, and the probability of an anti-tumour therapy initiation. Based on the scenarios, the model predicts an increase in CRC prevalence from 13% to 30% in comparison with the situation in 2008. Moreover, the model predicts that 10,074 to 11,440 CRC patients will be indicated for anti-tumour therapy in the Czech Republic in 2015. Considering all patients with terminal cancer recurrence and all patients primarily diagnosed in stage IV, it is predicted that 3,485 to 4,469 CRC patients will be treated for the metastatic disease in 2015, which accounts for more than one third (34-40%) of all CRC patients treated this year.

Conclusions: A new model for the estimation of the number of CRC patients requiring active anti-tumour therapy is proposed in this paper. The model respects the clinical stage as the primary stratification factor and utilizes solely the population-based cancer registry data. Thus, no specific hospital data records are needed in the proposed approach. Regarding the short-term prediction of the CRC burden in the Czech Republic, the model confirms a continuous increase in the burden that must be accounted for in the future planning of health care in the Czech Republic.

Background

The Czech population, with an annually diagnosed 78.7 colorectal cancer (CRC) patients per 100,000 inhabitants (2008), presently occupies an undesirable 3rd position in international statistics of age-standardised CRC incidence rates [1]. Moreover, the number of newly diagnosed cases is supposed to be high in the future as well, namely due to population ageing. This health care problem is further worsened by the fact that a large proportion of colorectal carcinomas are primarily diagnosed in a metastatic stage (25% in 2008) [2].

Thus, there is a strong need for a prospective modelling of CRC incidence and prevalence rates, as these measures are necessary for monitoring of the overall cancer load and its dynamics [3]. The prospective estimates should also enable us to quantify the resources necessary for the health care system [4], provided that we are able to adjust the rates for patients untreated for

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Predictive mapping of cancer burden – model concept

Population-based predictive models ⟷ **Expert inputs and corrections**

Adjusted for clinical stage

Stage-specific estimate of prevalence of treated patients

Primarily treated patients

Relapse/ progression

Surviving cancer patients <u>with relapse/progression of primary disease</u>

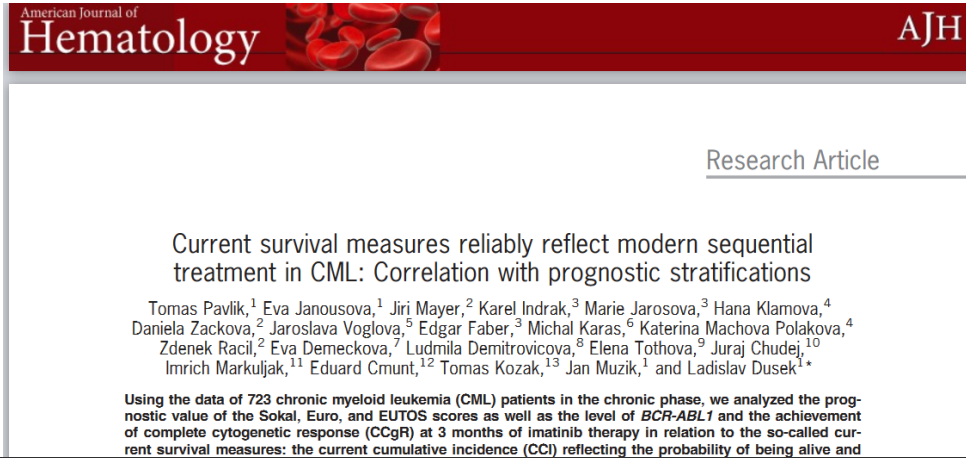
Scenario 1 (%)

Scenario (%)

Scenario (%)

Scenario (%)

Cost calculation


American Journal of Hematology AJH

Research Article

Current survival measures reliably reflect modern sequential treatment in CML: Correlation with prognostic stratifications

Tomas Pavlik,[1] Eva Janousova,[1] Jiri Mayer,[2] Karel Indrak,[3] Marie Jarosova,[3] Hana Klamova,[4] Daniela Zackova,[2] Jaroslava Voglova,[5] Edgar Faber,[3] Michal Karas,[6] Katerina Machova Polakova,[4] Zdenek Racil,[2] Eva Demeckova,[7] Ludmila Demitrovicova,[8] Elena Tothova,[9] Juraj Chudej,[10] Imrich Markuljak,[11] Eduard Cmunt,[12] Tomas Kozak,[13] Jan Muzik,[1] and Ladislav Dusek[1]*

Using the data of 723 chronic myeloid leukemia (CML) patients in the chronic phase, we analyzed the prognostic value of the Sokal, Euro, and EUTOS scores as well as the level of *BCR-ABL1* and the achievement of complete cytogenetic response (CCgR) at 3 months of imatinib therapy in relation to the so-called current survival measures: the current cumulative incidence (CCI) reflecting the probability of being alive and

Example of clinical outcome assessment

Model diagnosis: colorectal carcinoma

Contents lists available at ScienceDirect

Cancer Epidemiology

The International Journal of Cancer Epidemiology, Detection, and Prevention

journal homepage: www.canceredpidemiology.net

Trends in stage-specific population-based survival of cancer patients in the Czech Republic in the period 2000–2008

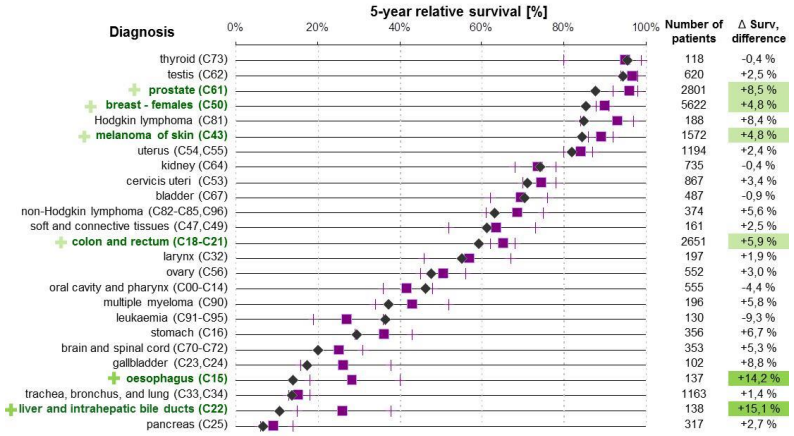
Tomáš Pavlík[a], Ondřej Májek[a], Tomáš Büchler[b], Rostislav Vyzula[c], Jiří Petera[d], Miroslav Ryska[e], Aleš Ryška[f], David Cibula[g], Marko Babjuk[h], Jitka Abrahámová[b], Jiří Vorlíček[c], Jan Mužík[a], Ladislav Dušek[a,*]

Population-based monitoring

CRC: 5-yr relative survival

	Cohort 1990–1994	Cohort 1995–1999	Period 2005–2009	Period 2010–2014
Stage 1	64,9 %	76,2 %	87,6 %	91,8 %
Stage 2	48,4 %	62,9 %	73,7 %	79,4 %
Stage 3	40,0 %	41,8 %	54,5 %	62,2 %
Stage 4	12,0 %	10,7 %	13,9 %	16,2 %
Total	47,9 %	51,7 %	59,4 %	65,4 %

Hospital-based benchmarking



EXAMPLE OF RESULTS - II.
Data-driven cancer screening
- population-based design -

Czech National Cancer Control Program – Information Platform

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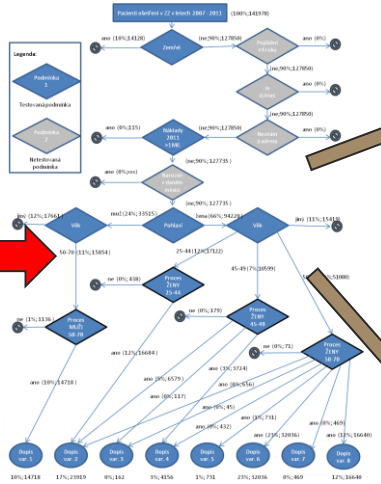
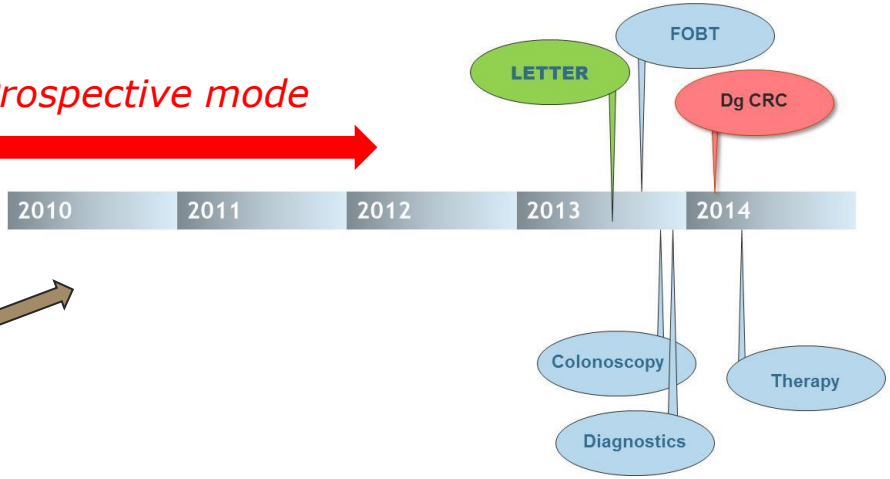
Examples of IS functionality: Management of population-based screening

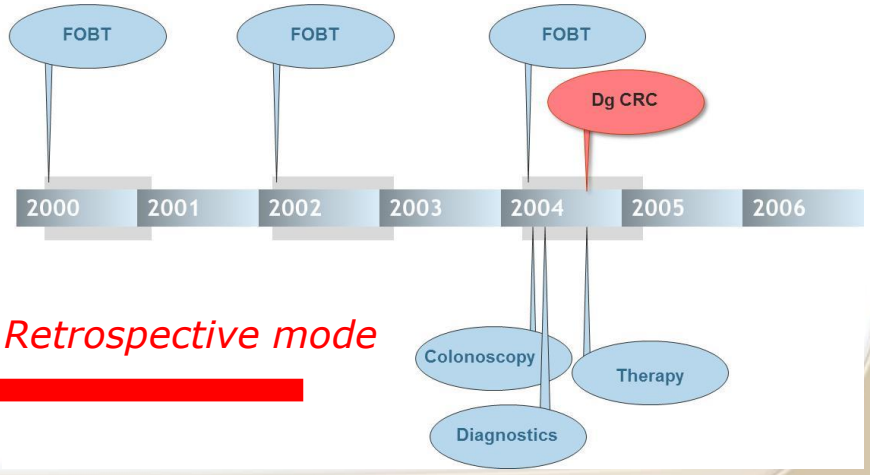
Selection of people to be addressed



Backward monitoring

Prospective mode





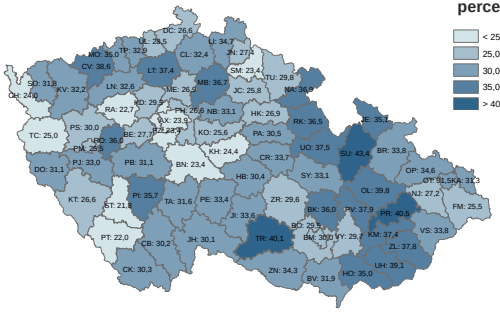
Retrospective mode

Czech PB screening: system of „birthday" invitation driven by health care payers.

Example of reports on the Czech PB colorectal cancer screening program

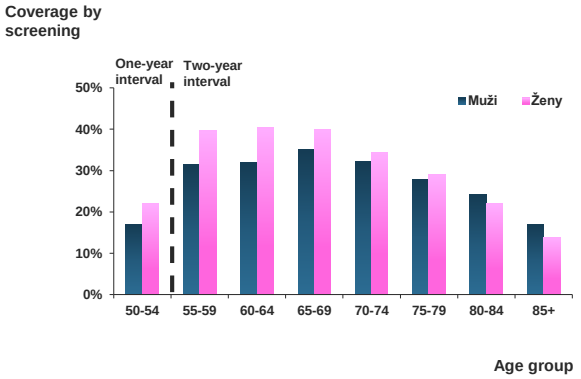
CRC screening: FOBT regional coverage

Men and women aged over 50



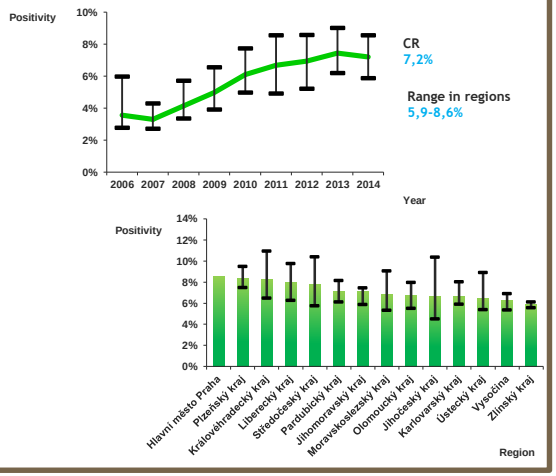
21,8% ⟷ 30,8% ⟷ 43,4%

CRC screening: age-specific coverage



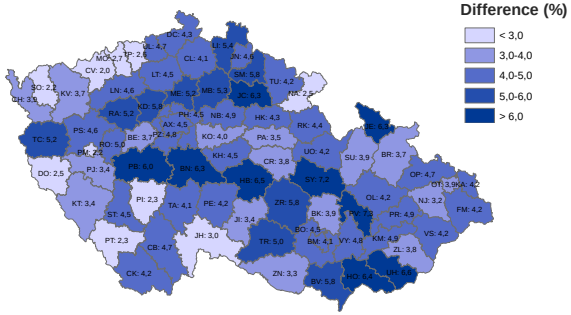
FOBT positivity: time trend and regional profile

Men and women aged over 50



Coverage in time trend: 2013 vs. 2014

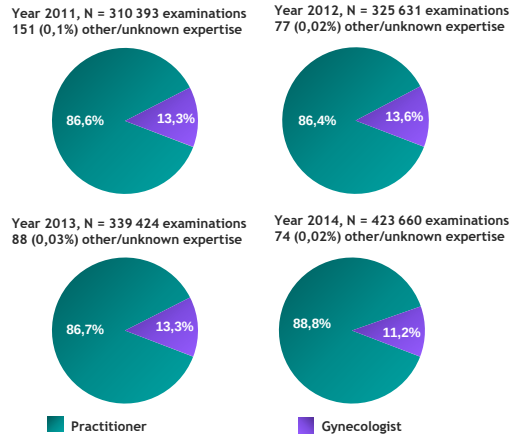
Men and women aged over 50



+2,0% ⟷ +4,4% ⟷ +7,3%

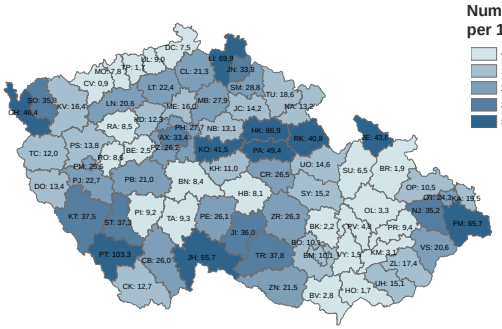
Share of primary care specialists

Women aged over 50



Primary screening Colonoscopy – regional coverage

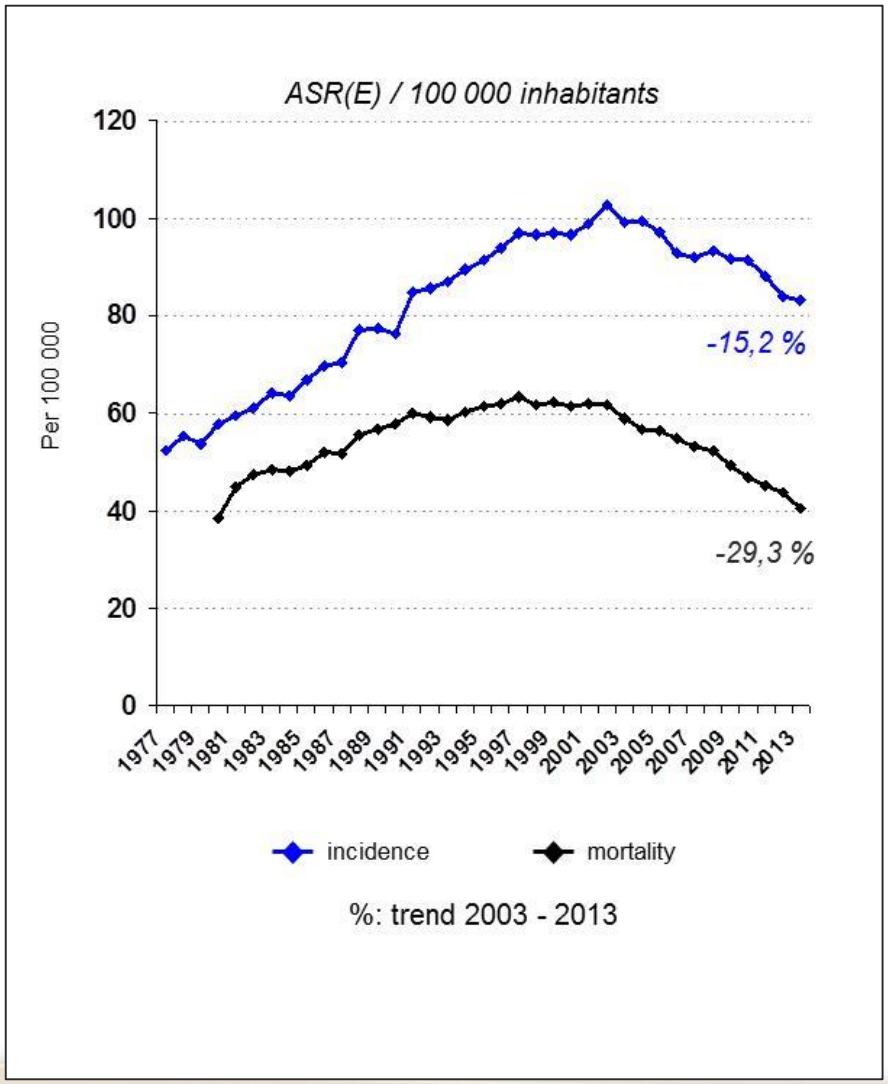
Men and women aged over 50



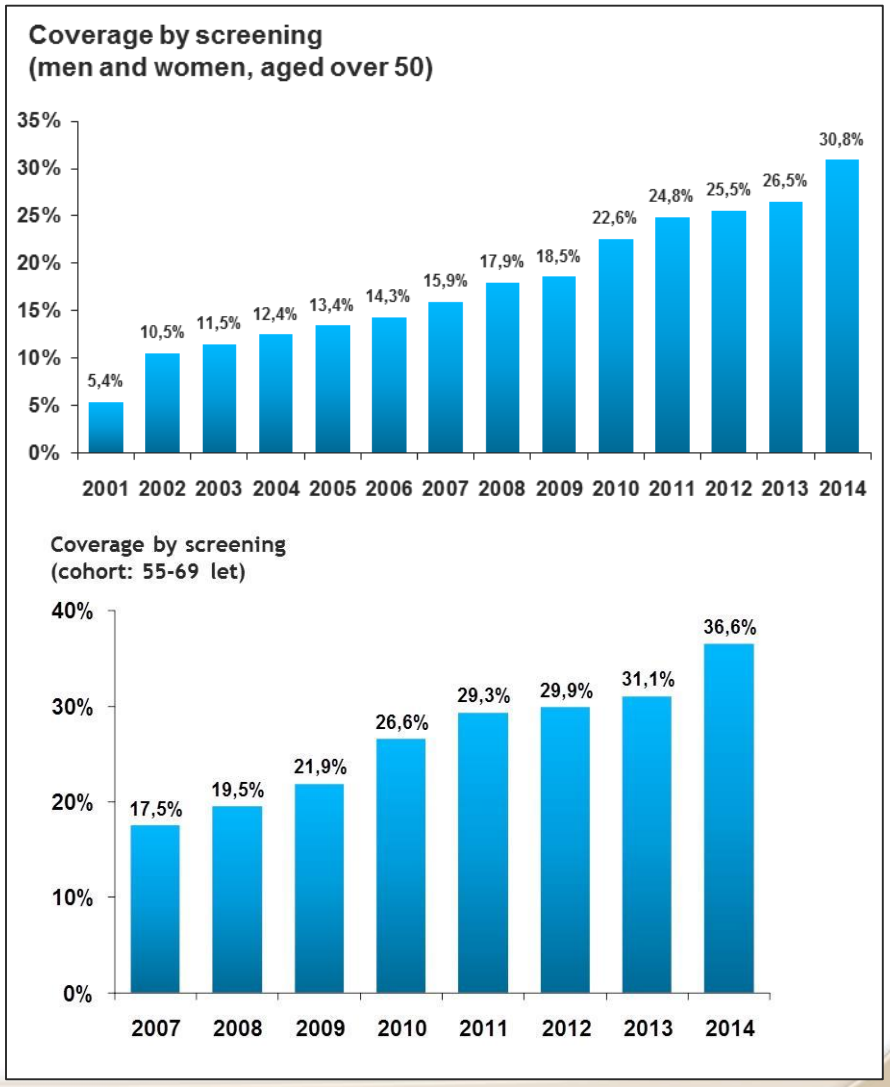
0,9 ⟷ 23,2 ⟷ 103,3

PB CRC screening: improvement 2010 -> ……

Colorectal cancer epidemiology



Colorectal cancer screening



EXAMPLE OF RESULTS - III.
Data-driven changes in cancer care management

www.onconet.cz

Czech National Cancer Control Program - Information Platform

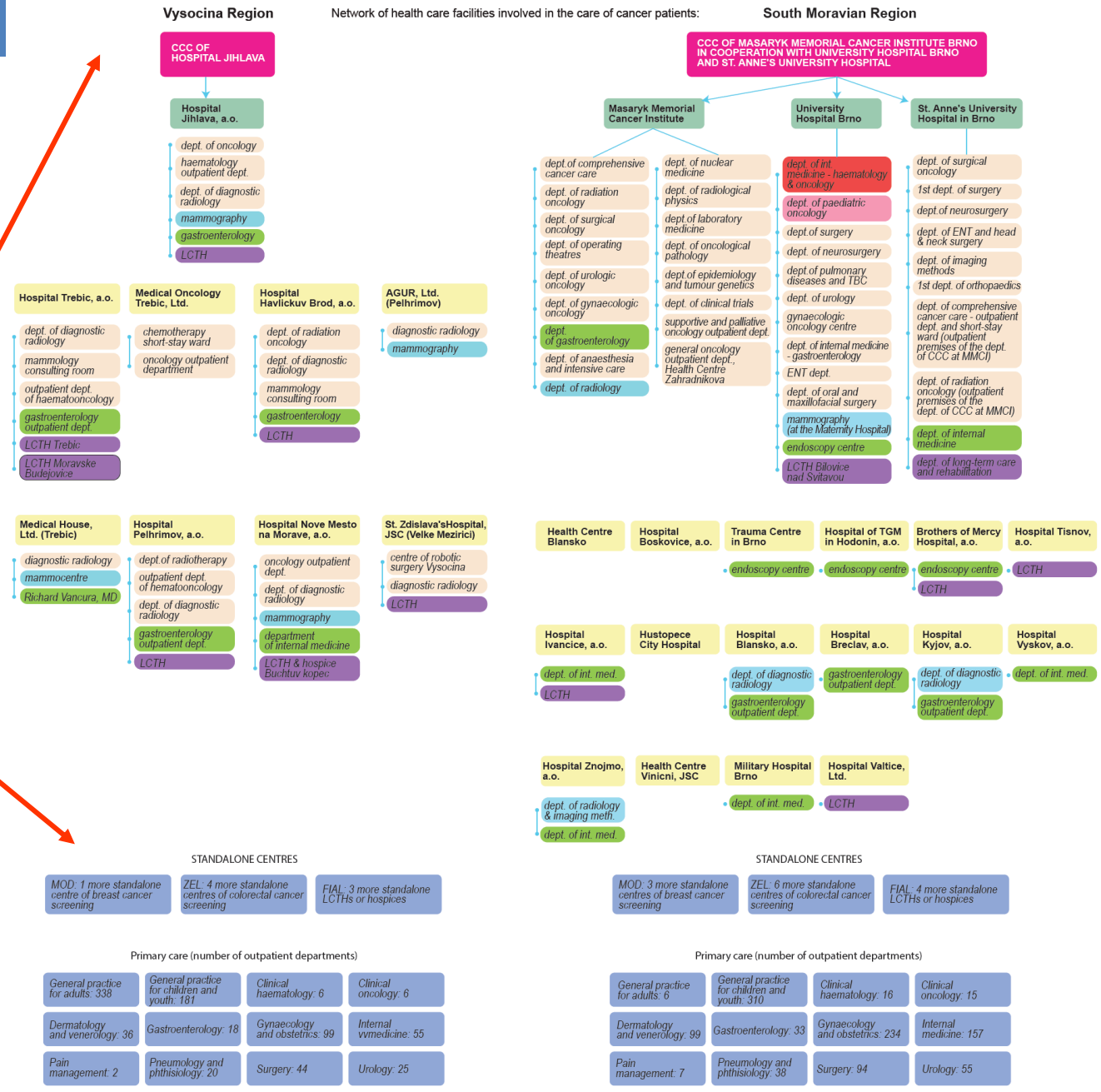
Diagrams of cancer care available for each region

PDF download

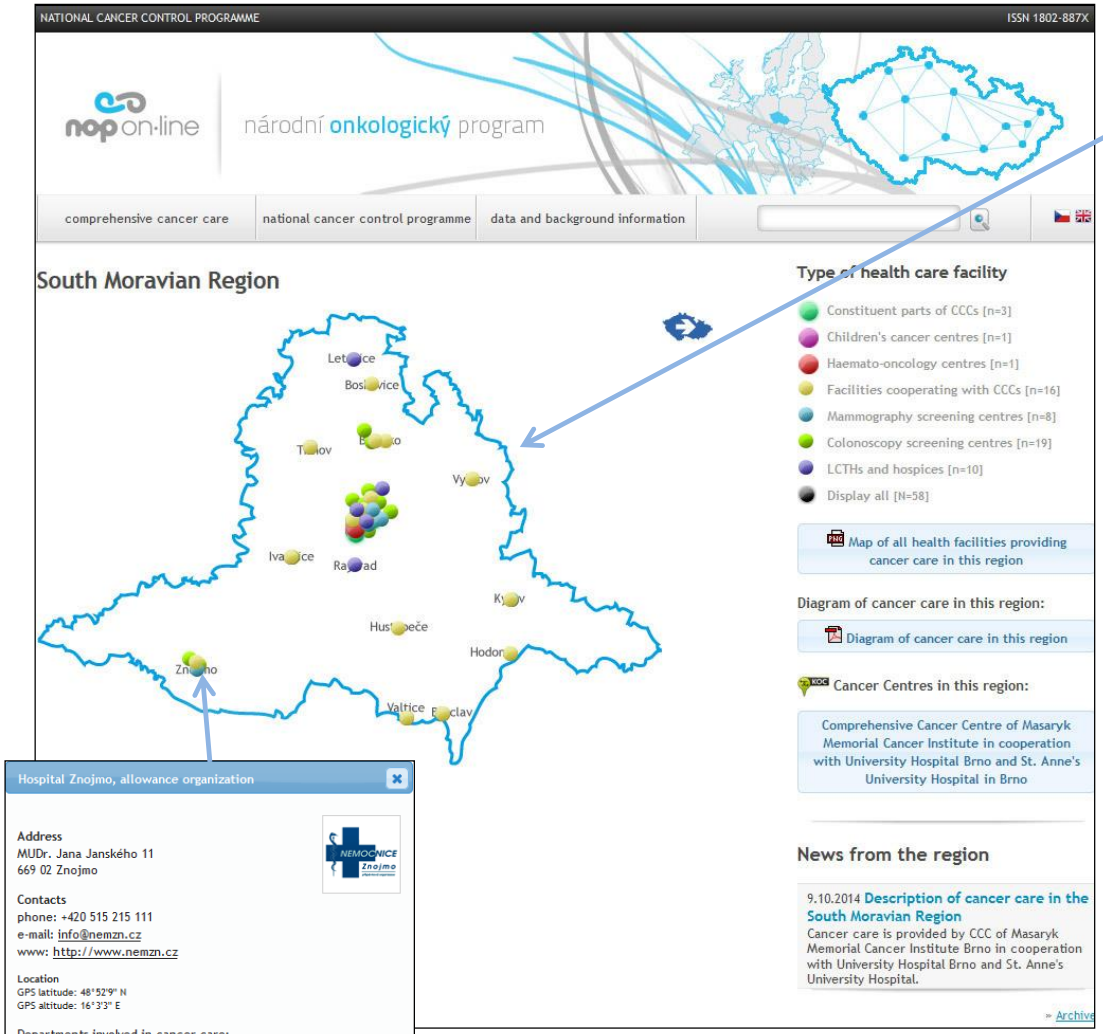
Regional models of cancer care, presenting professionals and navigating patients

Interactive maps

Access points



Regional models of cancer care



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

www.onconet.cz

Cancer Centres On-line

Equipment characteristics

Clinical research

Performance

...and more

Comprehensive Cancer Centre of Masaryk Memorial Cancer Institute in cooperation with University Hospital Brno and St. Anne's University Hospital in Brno

Identification data | Basic characteristics | Contractual relationships with health insurance companies | Hospital and management information systems | Health care quality assessment and documentation | clinical assessment

Basic characteristics

Beds and outpatient departments:
Total number of beds available for cancer patients: 230
Total number of oncology outpatient departments: 26

Medical equipment:

- Spiral computed tomography: ☑ number of instruments: 5
- MRI: ☑ number of instruments: 4
- PET: ☑ number of instruments: 2
- Classical mammography machine ☑ number of instruments: 1
- Digital mammography machine: ☑ number of instruments: 3
- Endoscopic ultraso (EUS): ☑ number of instrume

Other equipment:
-

Comprehensive Cancer Centre of Masaryk Memorial Cancer Institute in cooperation with University Hospital Brno and St. Anne's University Hospital in Brno

Identification data | Basic characteristics | Contractual relationships with health insurance companies | Hospital and management information systems | Health care quality assessment and documentation | clinical assessment

Hospital and management information systems (HIS and MIS)

For the documentation of diagnostic and therapeutic processes in cancer patients, the centre employs a fully electronic Hospital Information System (HIS): ☑
HIS identification: NIS GreyFox tm 9.E
HIS provider: Medicon a.s.

The HIS employed in the centre enables a parametric collection of cancer data, at least in the extent of the report sent to the National Cancer Registry: ☒

Which of the following data are parametrically recorded within the HIS and which of them are easily available for the centre's management:

Data	Údaj parametricky zaznamenáván v NIS	Údaj pohodlně dostupný pro vedení centra
er of diagnosed and/or treated patients	☑	☑
diagnosed and/or treated patients sorted by diagnoses	☑	☑
the time of diagnosis (TNM, clinical stage etc.)	☑	☑
histopathological examination (pTNM, grade etc.)	☑	☑
results of laboratory examination	☒	☑
Results of examination by imaging methods	☒	☑
Records on anticancer pharmacotherapy (regimens, products, doses etc.)	☑	☑
Records on radiation therapy	☑	☑
Records on adverse drug reactions	☑	☑

The centre employs a Management Information System (MIS): ☑
MIS identification: BEE/GreyFox tm 9.E
MIS provider: INSIGHT STRATEGY/ CBA MU, MEDICON
Length of use (in months): 120

oys filmless technologies and telemedicine tools: ☑
PACS ICZ, PACS TatraMed SR
ICZ, TatraMed SR

Comprehensive Cancer Centre of Masaryk Memorial Cancer Institute in cooperation with University Hospital Brno and St. Anne's University Hospital in Brno

Identification data | Basic characteristics | Contractual relationships with health insurance companies | Hospital and management information systems | Health care quality assessment and documentation | clinical assessment

Clinical trials and implementation of new procedures

The centre has a local ethical commision at its disposal: ☑
The centre is willing and has the capacity to take part in new multicentre clinical trials and registries: ☑

Number of clinical trials (being conducted in compliance with the Good Clinical Practice) in which the centre currently participates:
Phase I: Total number: 3
Number of international projects: 3
Phase II: Total number: 23
Number of international projects: 23
Phase III: Total number: 43
Number of international projects: 43
Phase IV: Total number: 0
Number of international projects: 0

The centre is involved in Czech or international clinical registries:
(out of National Cancer Registry, i.e. projects concerned with genetics etc.) ☑

Project title	Identification of project organizers	Diagnosis of registered patients	The centre has been actively participating in the registry since
Registry ČOS	Prof. MUDr. Rostislav Vyzula, CSc.	C18-20, C25, C34, C45, C64, C56, C44	2008

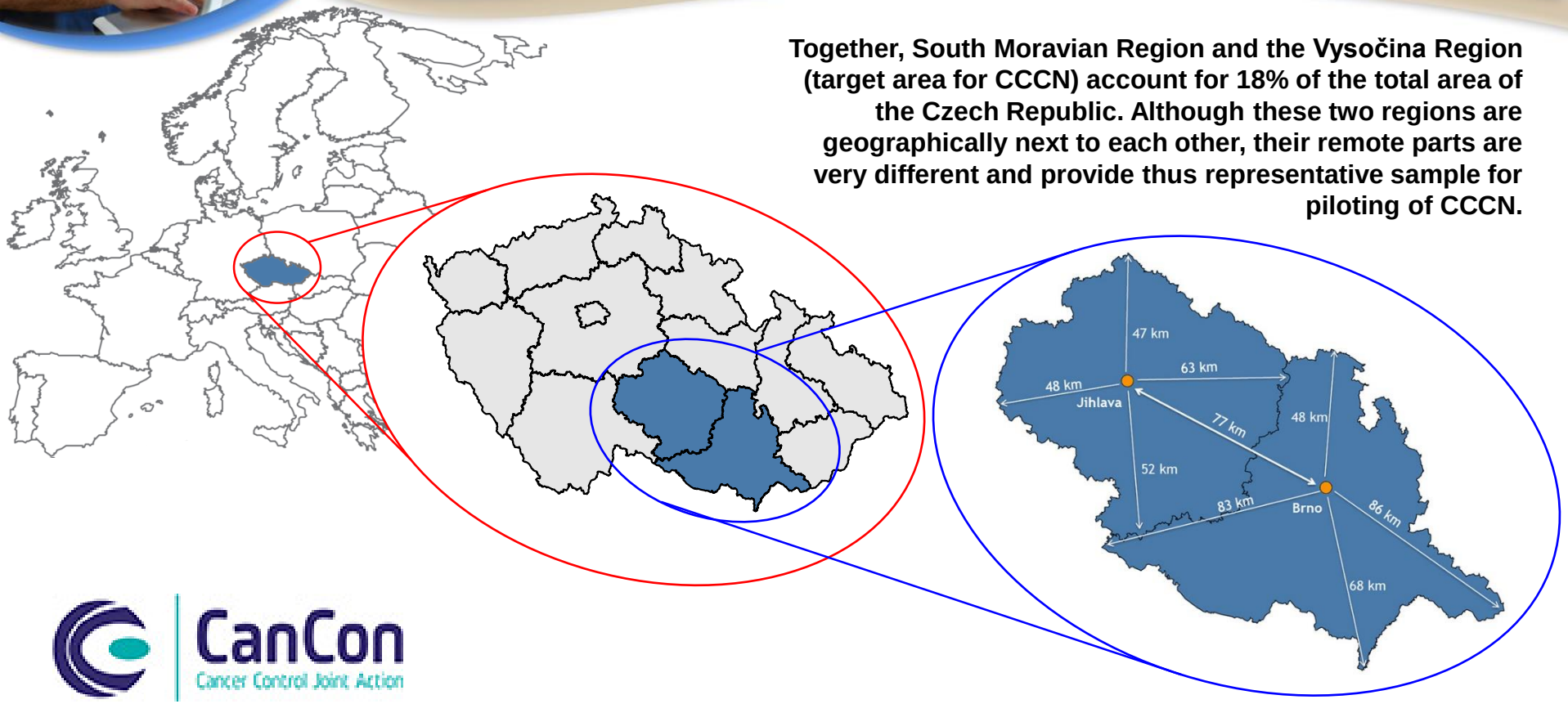
The centre actively participates in prevention programmes:
Primary prevention:
mammary screening, colorectal carcinoma, Stub It Out, counselling service on healthy diet and lifestyle
Secondary prevention:
mammary screening, colorectal carcinoma, melanoma treatment, seniors

The centre organizes its own projects of a nationwide significance in the following areas:
Diagnostics: pathology: ☑
radiodiagnostics: ☑
nuclear medicine: ☑
Therapy: chemotherapy: ☑
radiation therapy: ☑
biological therapy: ☑
Genomics and proteomics: ☑
Pharmacogenetics: ☑

Data authorization: 16.5.2014, Jiří Vorlíček

Target area of CCCN

Together, South Moravian Region and the Vysočina Region (target area for CCCN) account for 18% of the total area of the Czech Republic. Although these two regions are geographically next to each other, their remote parts are very different and provide thus representative sample for piloting of CCCN.



CanCon
Cancer Control Joint Action

	South Moravian Region	Vysočina Region	Both regions
Population (as of 31/12/2015)	1 175 025	509 475	1 684 500
Area (km2)	7 195	6 796	13 991
Population density (per km2)	163	75	120
Number of districts	7	5	12
Number of municipalities	673	704	1 377
Total length of roads and motorways (km, estimation)	4 500	5 000	9 500
Total length of railway network (km, estimation)	800	650	1 450

Pilot CCCN: South Moravian Region and Vysocina Region – cancer care infrastructure

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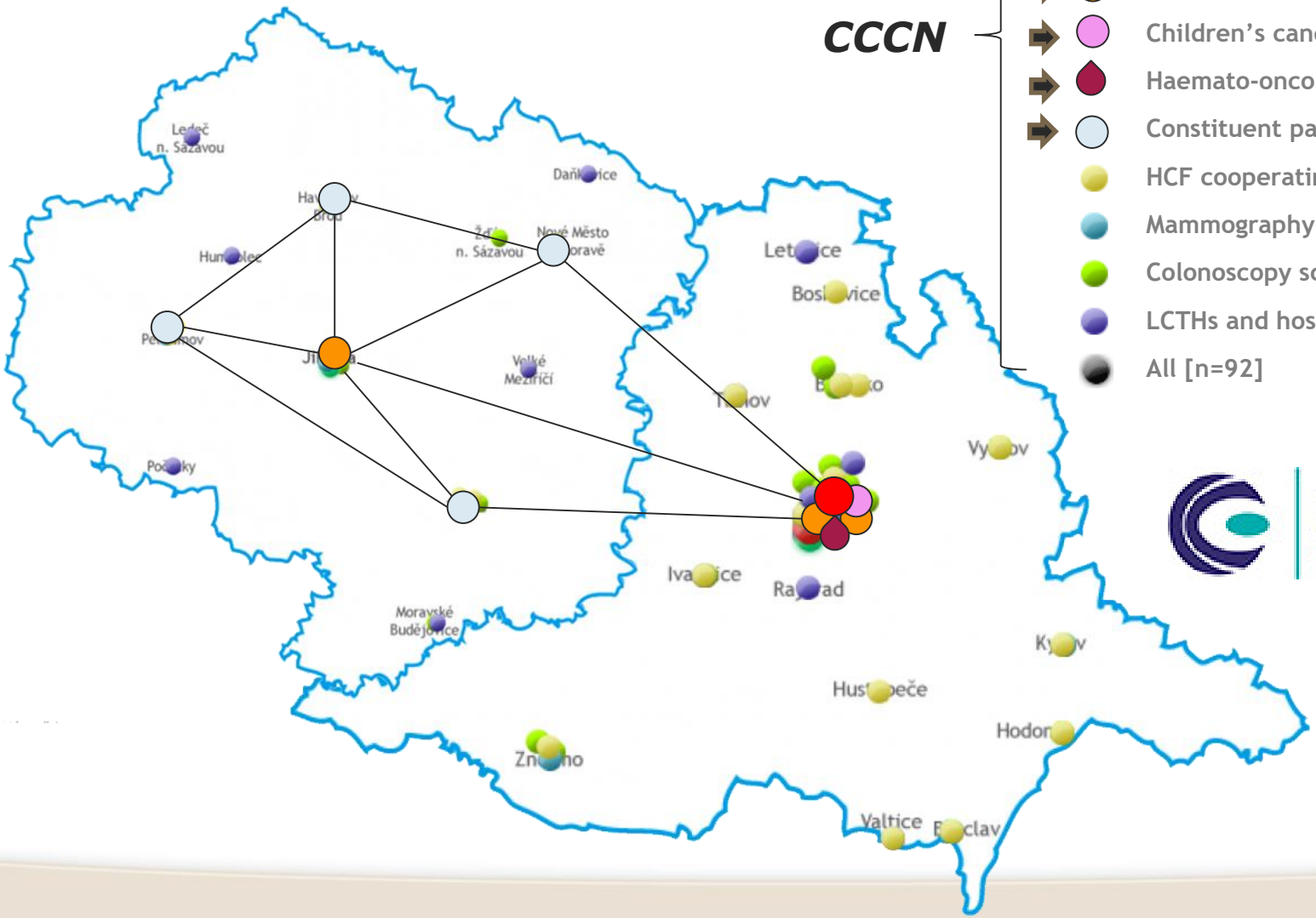


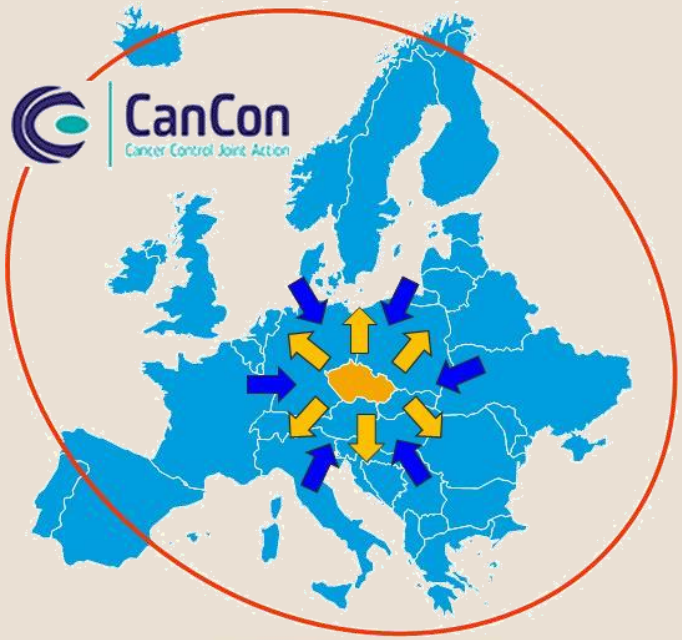
CCCN

Type of health care facility

- Comprehensive Cancer Centre [n=1]
- Cancer Centres [n=3]
- Children's cancer centres [n=1]
- Haemato-oncology centres [n=1]
- Constituent parts of CCCN [n=4]
- HCF cooperating with CCs [n=20]
- Mammography screening centres [n=13]
- Colonoscopy screening centres [n=29]
- LCTHs and hospices [n=20]
- All [n=92]

CanCon
Cancer Control Joint Action

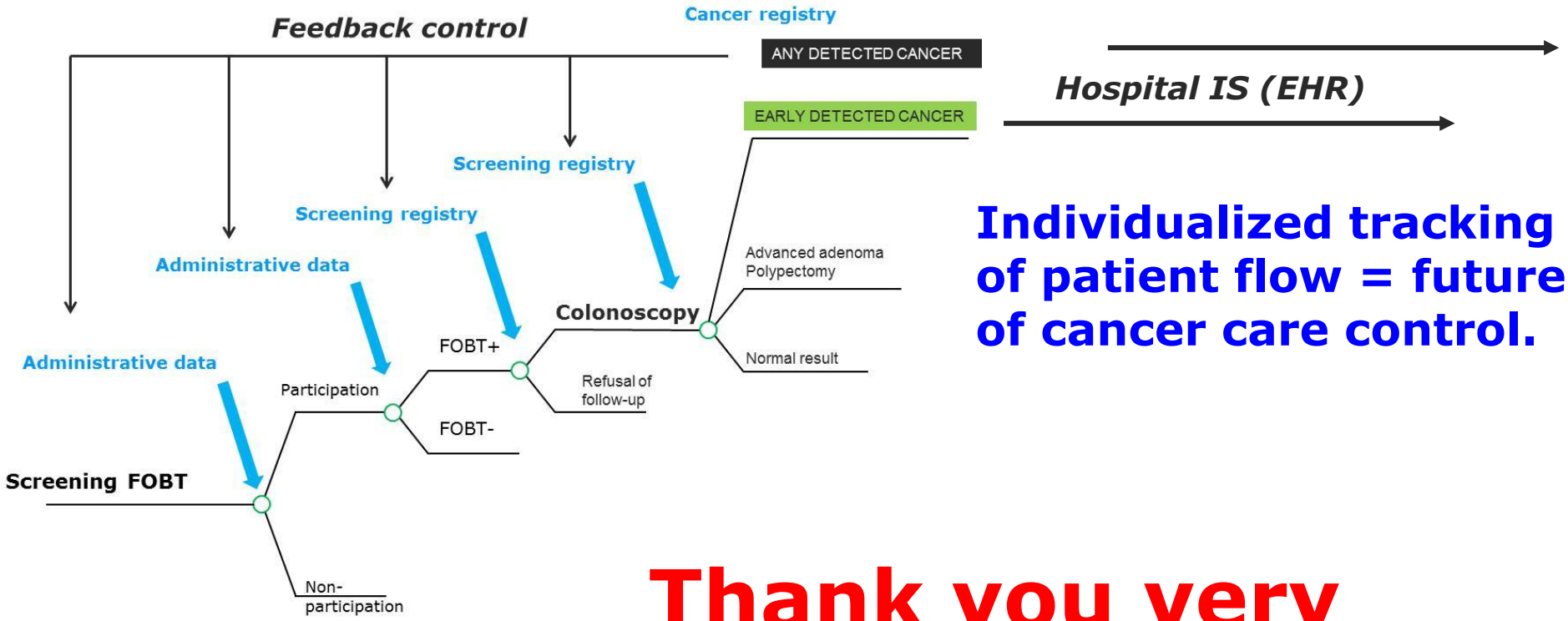
Conclusion and Current Challenges



Evropská unie
Evropský sociální fond
Operační program Zaměstnanost

Regional reporting of NH-IS

Personalized medicine needs personalized data collection and reporting



Individualized tracking of patient flow = future of cancer care control.

Thank you very much for your attention