Best practices in collecting and processing data in CRC screening and after it

The potential of harmonized information policy in effective national implementation of CRC screening

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I.

Best practice requires robust methodical framework

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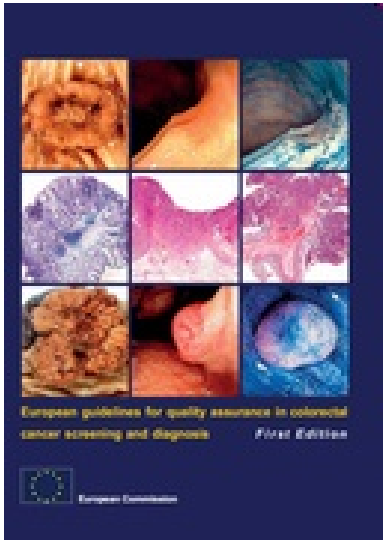
HOW to optimize and manage CRC screening?

European Council Recommendation (2003/878/EC)
The European Parliament Declaration (2010)
European Guidelines (2010)



Population-based CRC screening
- public and democratic
- personalized
- controlled

Comprehensive guidelines must be effectively implemented in real world clinical practice

Addressed invitation

Coverage monitoring

Participation rate

Interval cancers

Follow-up controls

Compliance rate

Detection rate

Population impact

Here, ICT plays very important role !

WHICH DATA **items should be monitored?**

Europe against Cancer: Optimisation of the Use of Registries for Scientific Excellence in research

EUROCOURSE

http://www.eurocourse.org

WP5: "Interface of cancer registries with cancer screening programmes" A. Anttila, A. Ponti, G. Ronco, S. Lönnberg, N. Malila, A. Chil, J. Fracheboud, S. Törnberg, M. Zakelj, L. Karsa

Performance indicators

Indicator	Numerator	Denominator
Extension by screening programme	N target population within the area with the organised screening programme	N of population in corresponding age groups within the whole country
Invitational coverage	N invited during time frame	N eligible in target population
Coverage by examination	N screened or tested during time frame	N eligible in target population
Compliance to invitation (uptake rate)	Screened	Invited
Rate of inadequate tests	Inadequate	Screened
Rate of test positives	Positive test result	Screened
Referral rate to colonoscopy after positive test	Referred	N with a positive test result
Compliance to colonoscopy	Colonoscopied	Referred
Rate of complete colonoscopies	Complete colonoscopies	Total colonoscopied
Biopsy rate	Biopsy taken	Colonoscopied
Lesion detection rate	N with at least one lesion	Screened
Adenoma detection rate	N with at least one adenoma	Screened
Advanced adenoma detection rate	N with at least one advanced adenoma	Screened

Individual-level data

Var#	Variable name	Format	Length	Values	Description
					ID
01	Personal ID	STR	11		Personal identifier
02	Randomisation date	DATE	10		DD/MM/YYYY
03	Randomisation group	STR	2		
04	Date of birth	DATE	10		DD/MM/YYYY

INVITATION

05	Municipality name	STR	50		
06	Birth cohort	INT	4	YYYY	
07	Gender	STR	1	F/M	
08	Screening center	STR	50		Name
09	Screening center code	STR	4		Short name - code
10	Invitation date	DATE	10		DD/MM/YYYY
11	Testnumber	INT	12		
12	Repeated test	INT	1	0/1	0 if first in same round, renewals 1

SCREENING TEST

13	Testnumber	INT	12	unique identifier, link to invitation
14	Date of sample1	DATE	10	DD/MM/YYYY
15	Date of sample2	DATE	10	DD/MM/YYYY
16	Date of sample3	DATE	10	DD/MM/YYYY
17	Date of examination	DATE	10	for endoscopy
18	Date of 1st level examination	DATE	10	DD/MM/YYYY
19	Testresult1A	STR	3	"-", " ", +/-, +, ++
20	Testresult1B	STR	3	"-", " ", +/-, +, ++
21	Testresult2A	STR	3	"-", " ", +/-, +, ++
22	Testresult2B	STR	3	"-", " ", +/-, +, ++
23	Testresult3A	STR	3	"-", " ", +/-, +, ++
24	Testresult3B	STR	3	"-", " ", +/-, +, ++
25	Testresult (FOBT)	STR	3	POS, NEG, REP, or " "
26	Testresult (endoscopy)	STR	6	INADEQ, INCOMP, POS, NEG
27	Testresult comment (endoscopy)	STR	100	Details of positive test
28	Date of answering	DATE	10	DD/MM/YYYY

Reality in the CRC screening implementation: 27 EU countries = 27 approaches ?

2009

WJG

Online Submissions: wjg.wjgnet.com
wjg@wjgnet.com
doi:10.3748/wjg.15.5907

World J Gastroenterol 2009 December 21; 15(47): 5907-5915
World Journal of Gastroenterology ISSN 1007-9327

EDITORIAL

Colorectal cancer screening in Europe

Zavoral M., Suchanek S., Zavada F., Dusek L., et al., WJG 15(47), 2009

2014

WJG

World Journal of Gastroenterology

Online Submissions: http://www.wjgnet.com/esps/
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World J Gastroenterol 2014 April 7; 20(13): 0000-0000
ISSN 1007-9327 (print) ISSN 2219-2840 (online)

TOPIC HIGHLIGHT

WJG 20th Anniversary Special Issues (5): Colorectal cancer

Colorectal cancer screening: 20 years of development and recent progress

Miroslav Zavoral, Stepan Suchanek, Ondrej Majek, Premysl Fric, Petra Minarikova, Marek Minarik, Bohumil Seifert, Ladislav Dusek

Table 6 Colorectal cancer screening programs in 2007

	Program		Test type	Screening interval	Age eligible national population	
	Type	Status		years or times in LT	Age (yr)	Persons (× 1000)
Austria	NonPB	Natw	FOBT	1 or 2	> 50	2210
	NonPB	Natw	CS	10	> 50	2210
Belgium	No Prog					2880
Bulgaria	NonPB	Natw	FOBT	1	> 31	2340
Cyprus	PB	Natw-plan	FOBT	1 in LT	50	10
	PB	Natw-plan	CS	1 in LT	55	10
Czech Republic	NonPB	Natw	FOBT	2	> 50	3010
Denmark	No Prog					1540
Estonia	No Prog					370
Finland	PB	Natw-roll ong	FOBT	2	60-69	570
France	PB	Natw-roll ong	FOBT	2	50-74	16600
Germany	NonPB	Natw	FOBT	1 and 2	> 50	24500
	NonPB	Natw	CS	10 (2 in LT)	55-74	18800
Greece	NonPB	Natw	FOBT	5	> 50	3180
	NonPB	Natw	CS	5	> 50	3180
Hungary	PB	Natw-pilot	FOBT	2	50-70	2630
Ireland	No Prog					940
Italy	PB	Natw-roll ong	FOBT	2	50-69 (70-75)	13800
	PB	Reg-roll ong	FS	1 in LT	58 or 60	80
Latvia	NonPB	Natw	FOBT	1	> 50	630
Lithuania	No Prog					870
Luxembourg	No Prog					120
Malta	No Prog					120
Netherlands	No Prog					4460
Poland	PB	Natw-roll ong	CS	10	50-65	7500
Portugal	PB	Natw-plan	FOBT	2	50-70	2520
Romania	PB	Natw-plan	FOBT	2	50-74	5800
Slovak Republic	NonPB	Natw	FOBT		> 50	1360
	NonPB	Natw-plan	CS	10	> 50	1360
Slovenia	PB	Natw-plan	FOBT	2	50-69	490
Spain	PB	Reg-pilot	FOBT	2	50-69	210
Sweden	PB	Reg-plan	FOBT	2	60-69	220
UK	PB	Natw-roll ong	FOBT	2	(50) 60-69 (74)	7600
Dual prog/test						-25630
Subtotal						106490
Excluded pop.						29500
Total						135990

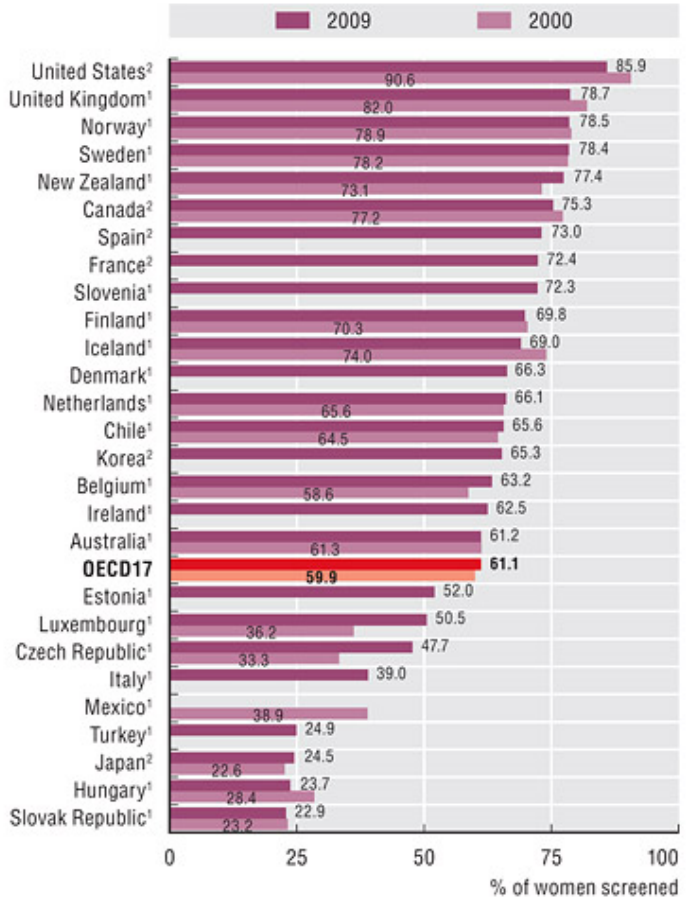
The practical implementation of the CRC screening in Europe is evidently heterogeneous and not well reported, although methodical standards are clearly given.

WHAT TO DO ?

The same reality also in the other programmes

OECD Health at a Glance, 2011

5.8.1 Cervical cancer screening, percentage women screened aged 20-69, 2000 to 2009 (or nearest year)

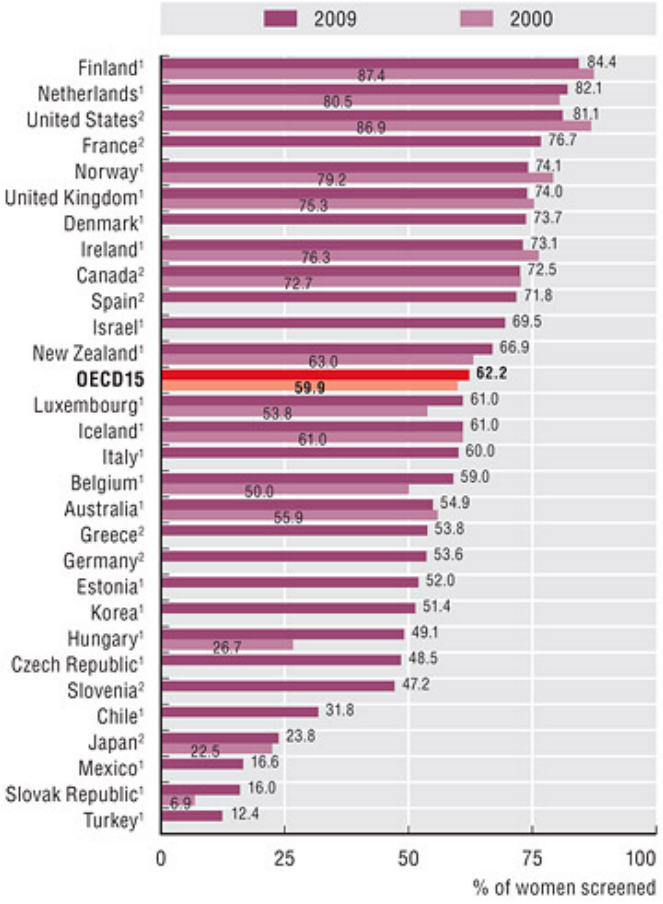


1. Programme. 2. Survey.

Source: OECD Health Data 2011.

StatLink http://dx.doi.org/10.1787/888932525362

5.9.1 Mammography screening, percentage of women aged 50-69 screened, 2000 to 2009 (or nearest year)



1. Programme. 2. Survey.

Source: OECD Health Data 2011.

StatLink http://dx.doi.org/10.1787/888932525419

The same reality also in the other programmes

OECD Health at a Glance, 2013

Figure 3.2. **Mammography screening, percentage of women aged 50-69 screened, 2002 and 2010 (or nearest year available)**

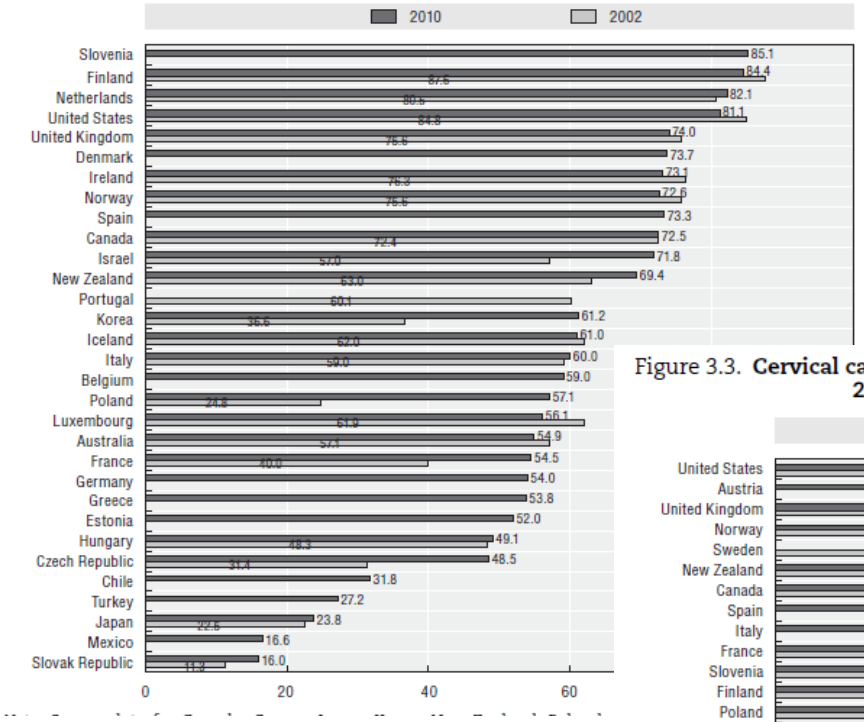
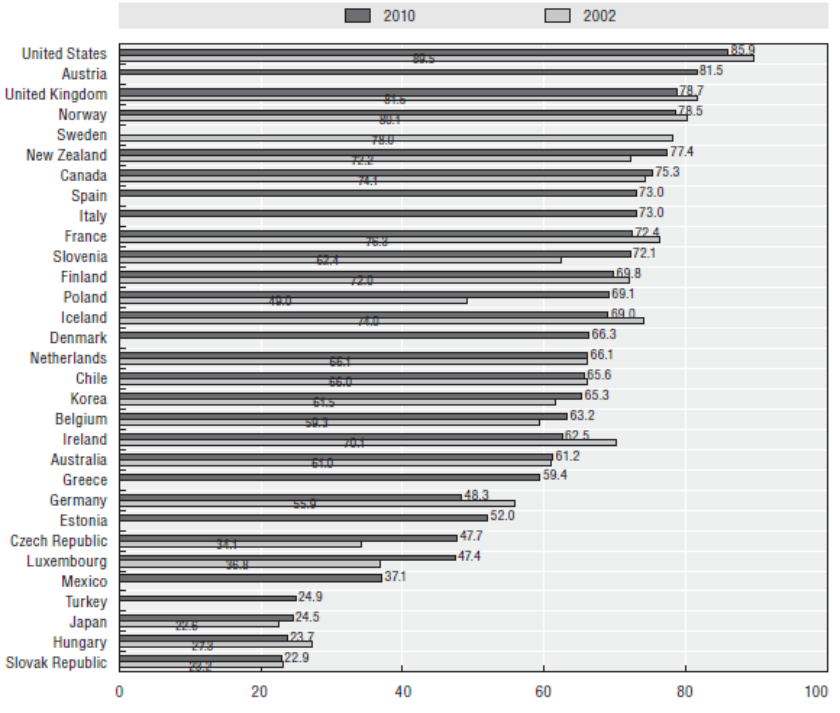
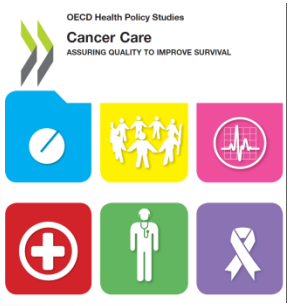


Figure 3.3. **Cervical cancer screening, percentage of women screened aged 20-69, 2002 and 2010 (or nearest year available)**

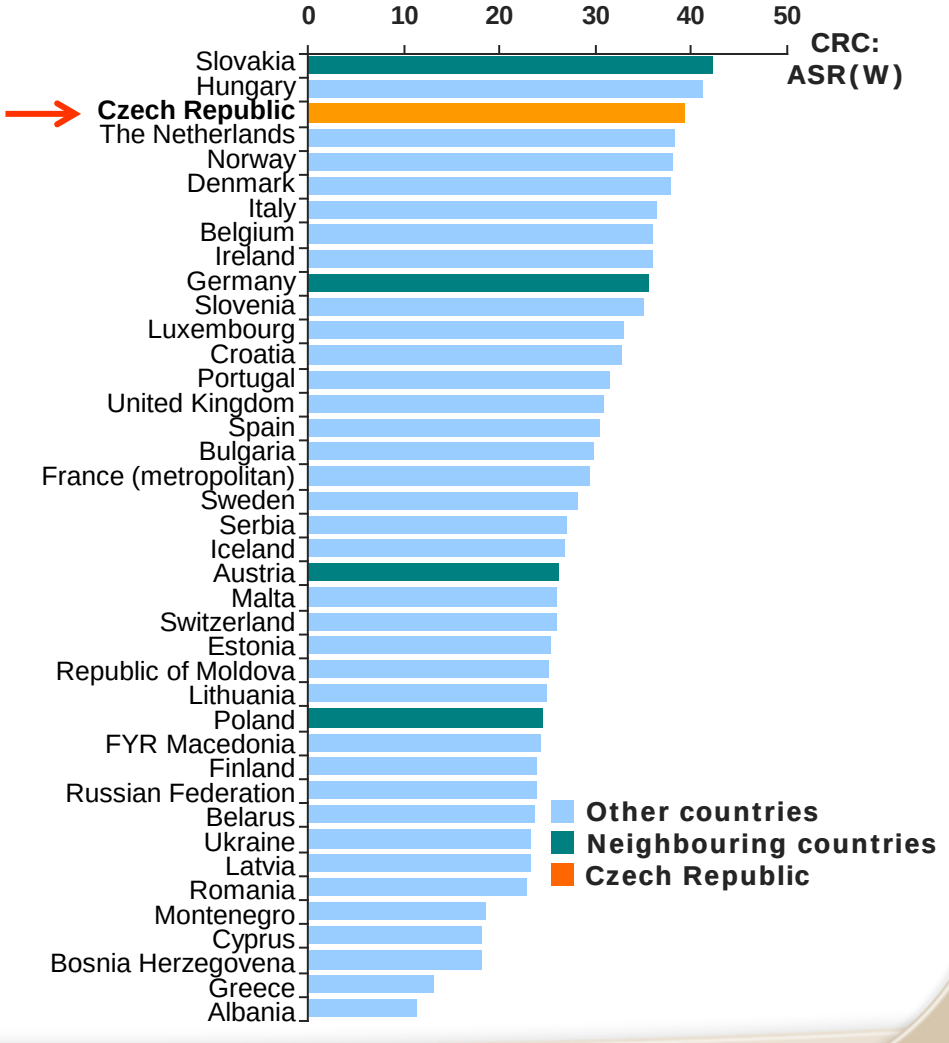




OECD Health Policy Studies, 2013
Cancer Care
ASSURING QUALITY TO IMPROVE SURVIVAL

Can data-based communication help?

Czech experience as practical example



Ferlay J, et al. GLOBOCAN 2008, Cancer Incidence and Mortality Worldwide: IARC CancerBase No. 10 [Internet].

II.

Best practice in data collection requires comprehensive information system

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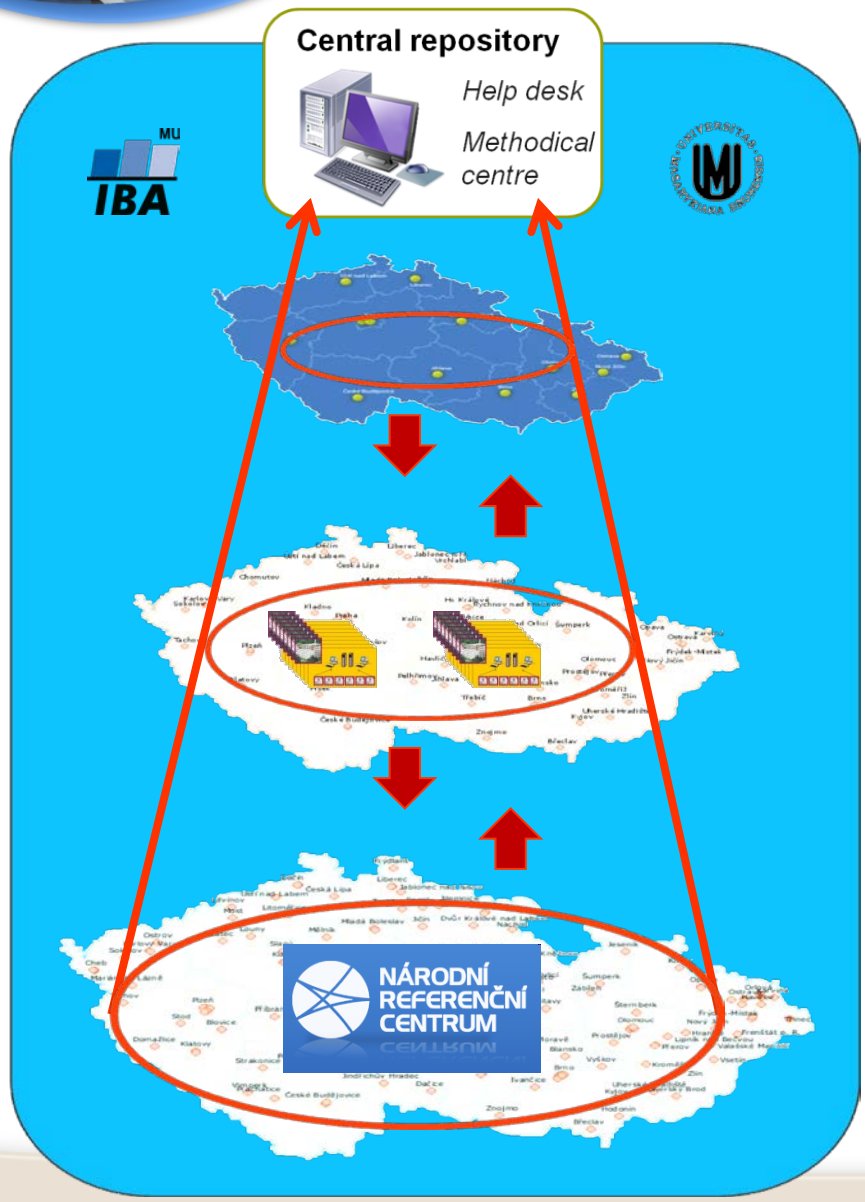
Comprehensive system must cover multiple and heterogeneous data sources

SCREENING PROGRAMME(S)

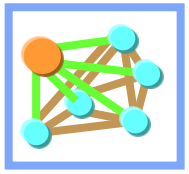
SEPARATED KEY INFORMATION SOURCES

NON-STANDARDIZED INFORMATION SYSTEMS

Solution? Respect the health care system



14 regional coordination offices



Epidemiology
Cancer care

189 health care facilities

Colonoscopy
Diagnostics

160 colonoscopy centers

Primary care
FOBT

4 400 GPs
1 200 gynaecologists

Equity

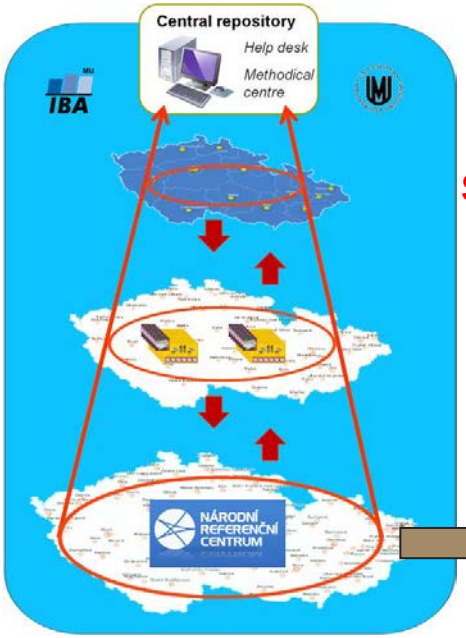
QA / QC

REPORTS

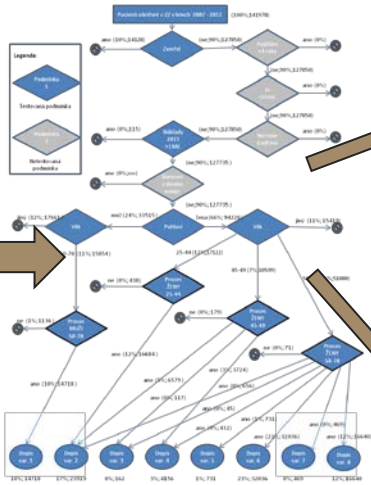
Follow-up

Compliance

Examples of IS functionality:
I. Management of population-based screening

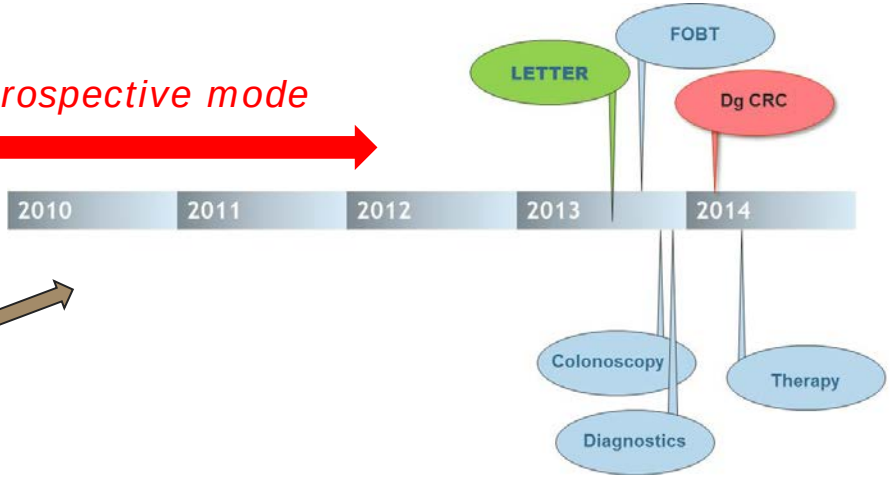


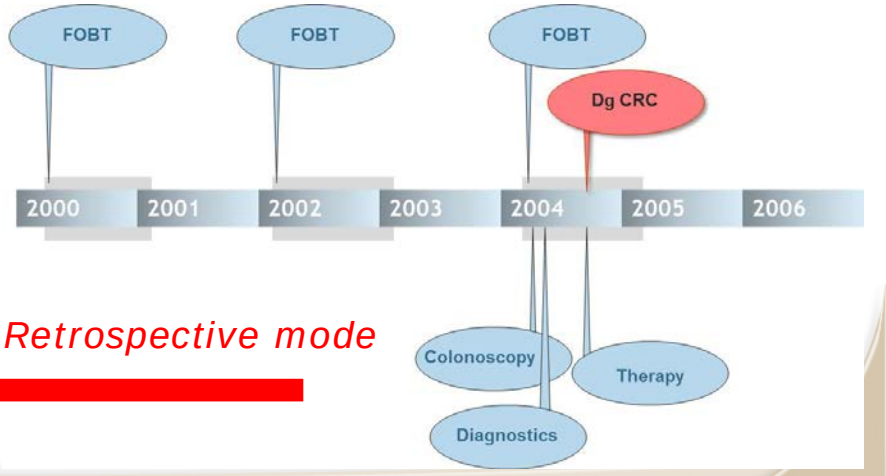
Selection of people to be invited



Backward monitoring

Prospective mode

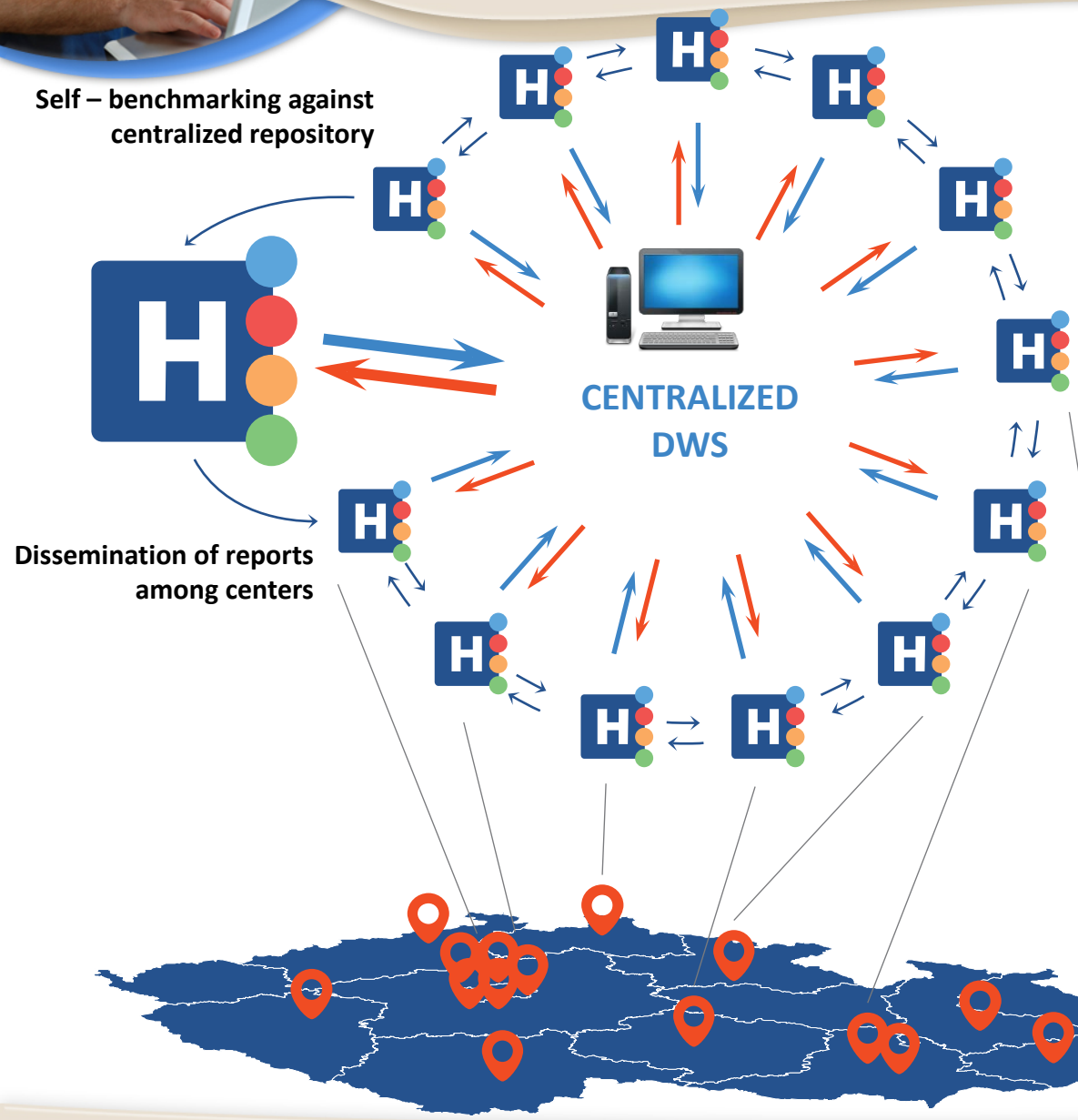




Retrospective mode

Examples of IS functionality: II. Clinical (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 centres 1/2007- 12/2012: N = 7 788 839 (100%)

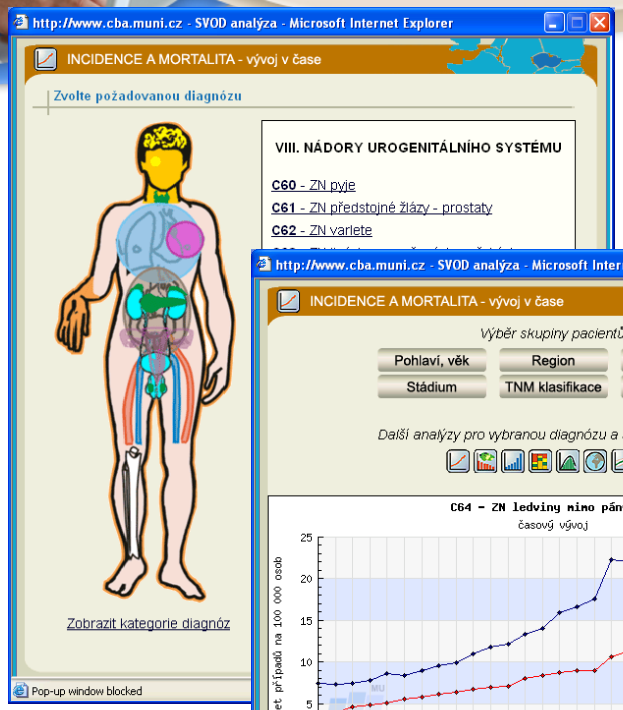
- *Patients without cancer* — N = 7,228,262 (92.8%)
- **Patients with cancer** — **N = 560,577 (7.2%)**
- **Patients with colorectal cancer** — **N = 56,920 (10.2%)**

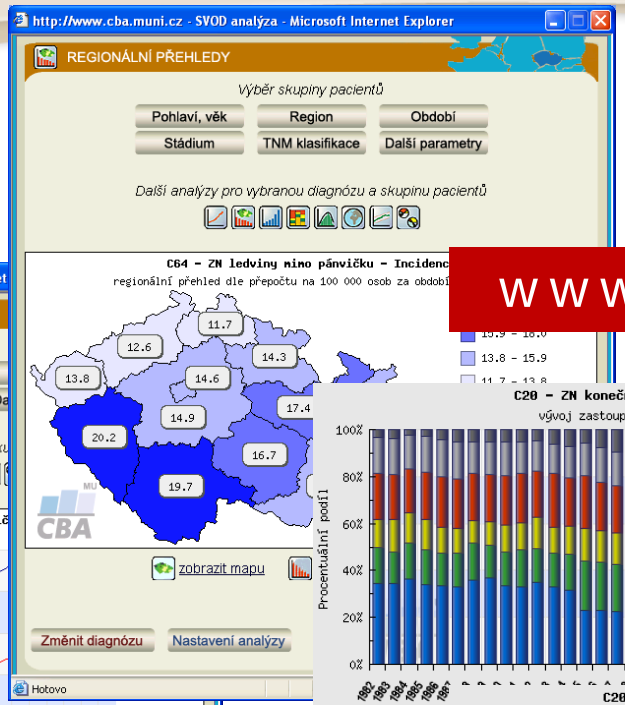
INVESTICE DO ROZVOJE VZDĚLÁVÁNÍ

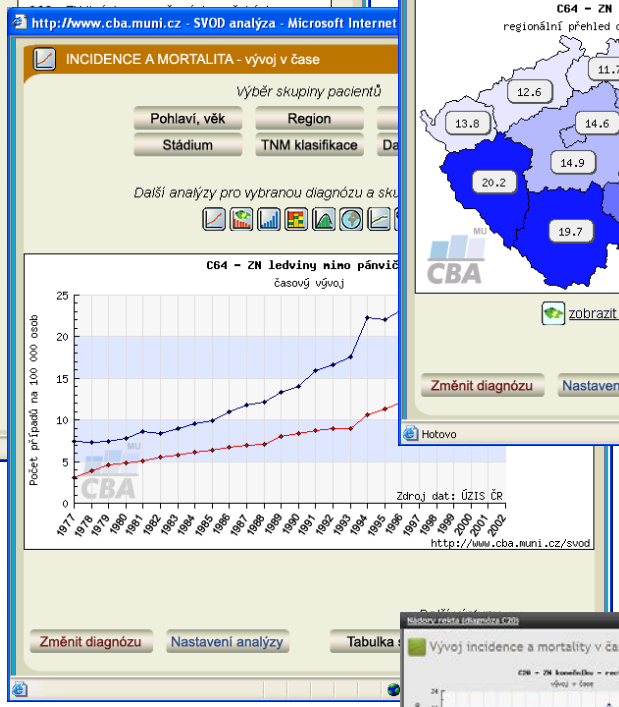
Examples of IS functionality:
III. National on-line data-based reporting

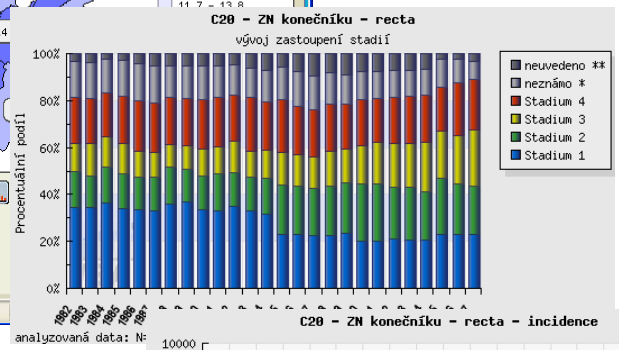
www.svod.cz

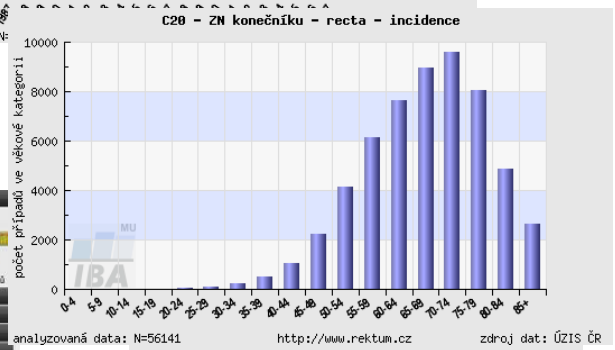
www.kolorektum.cz

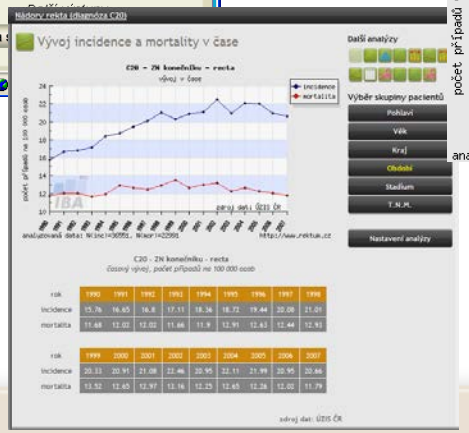


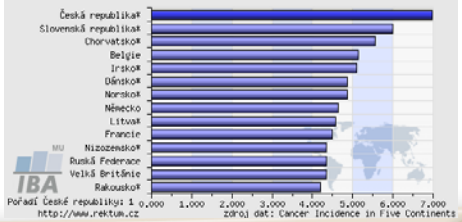












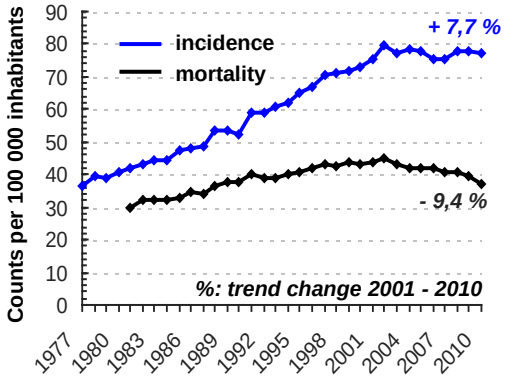
www.rektum.cz

www.mefanet.cz

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

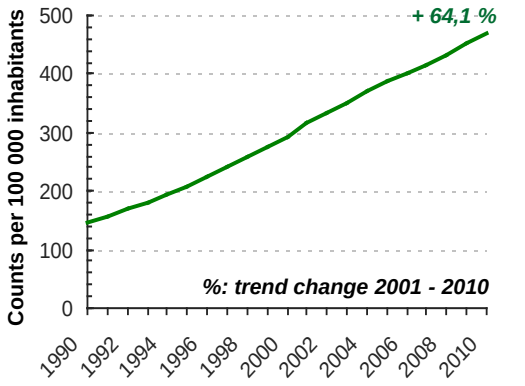
Model diagnosis: colorectal carcinoma

Main trends: incidence & mortality



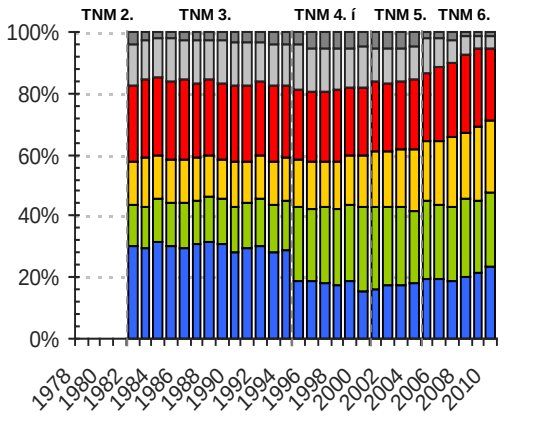
	Incidence	Mortality
Absolute counts in 2010	8 136	3 810
Counts per 100 000 in 2010	77,2	36,2

Main trends: prevalence



	Prevalence (31.12.2010)
Absolute counts	49 470
Counts per 100 000	469,7

Clinical stages: primary diagnosis



Survival of patients in time trends

Colorectal carcinoma (C18-C20)	5yr relative survival (95% IC)	
	2000-2004	2005-2009
All patients	44.7 (43.4-45.9)	50.1 (48.9-51.3)
stage 1	66.8 (64.3-69.1)	73.3 (71.1-75.4)
stage 2	54.0 (51.9-56.0)	61.2 (59.2-63.1)
stage 3	38.2 (35.6-40.9)	46.8 (44.4-49.1)
stage 4	9.9 (8.2-11.7)	12.6 (10.8-14.4)

*** Period analysis**

Stochastic predictions of incidence and prevalence

Colorectal carcinoma (C18-C20)	Predictions for 2014	
	Incidence	Prevalence
Stage I	**2 091** (1918; 2267)	**19 245** (18 27; 19 563)
Stage II	**1 934** (1796; 2070)	**17 186** (16895; 17477)
Stage III	**2 261** (2106; 2415)	**12 955** (12697; 13213)
Stage IV	**2 130** (1956; 2305)	**7 602** (7 404; 7 800)
Stage unknown – objective reasons	**256** (165; 349)	**2 413** (2 300; 2 526)
Stage unknown – not recorded	**71** (46; 98)	
TOTAL	**8 743** (7987; 9504)	**59 401** (58223; 60579)

Stochastic predictions of therapeutic burden

Colorectal carcinoma (C18-C20)	Newly treated patients in 2014
Stage I	**1 848** (1695; 2004)
Stage II	**1 808** (1679; 1934)
Stage III	**2 120** (1976; 2265)
Stage IV – incidence	**1 431** (1314; 1549)
Disseminated relapses / progressions	**1 854** (1693; 2014)
TOTAL	**9 061** (8 357; 9766)

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

Model diagnosis: colorectal carcinoma

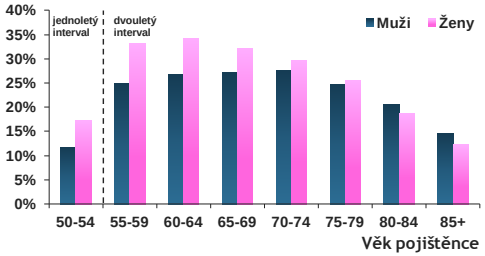
CRC screening: regional coverage

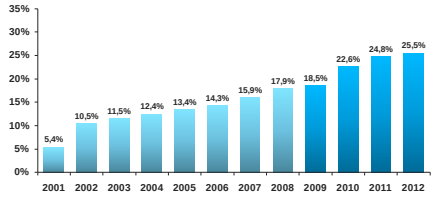
Pokrytí populace v procentech

25,5%

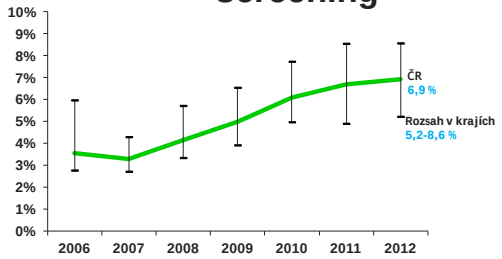
16,0% ⟷ 38,9%

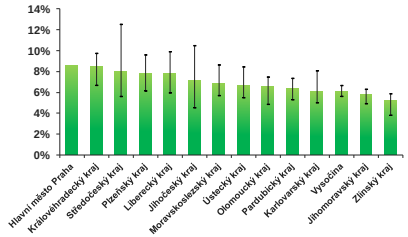
CRC screening: age-specific coverage





QA/QC indicators in CRC screening





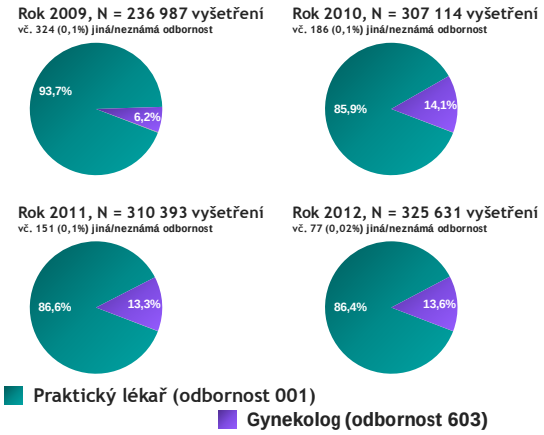
Coverage in time trend: 2009 - 2012

Vývoj pokrytí 2012 vs. 2009 (procentní body)

+6,9%

+1,1% ⟷ +12,2%

Share of primary care specialists



Primary screening colonoscopy

Počet (na 10 000 osob)

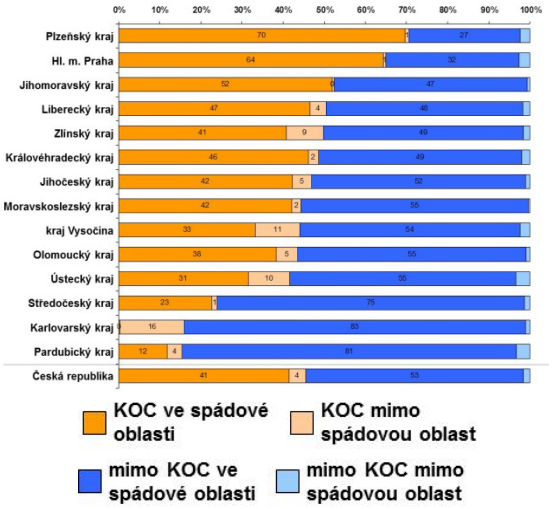
10,9

0,5 ⟷ 52,3

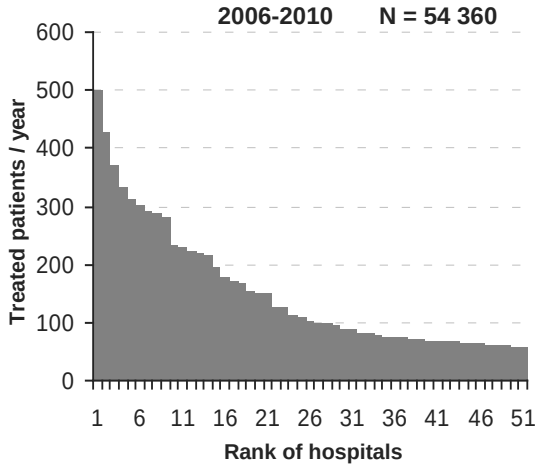
Examples of reporting generated by the Czech National Cancer Control System: II. Clinical centers

Model diagnosis: colorectal carcinoma

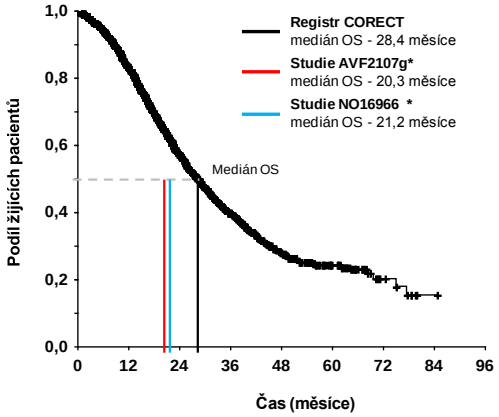
Distribution of care among regions/centers



Volume of primary care: capacity of CCCN

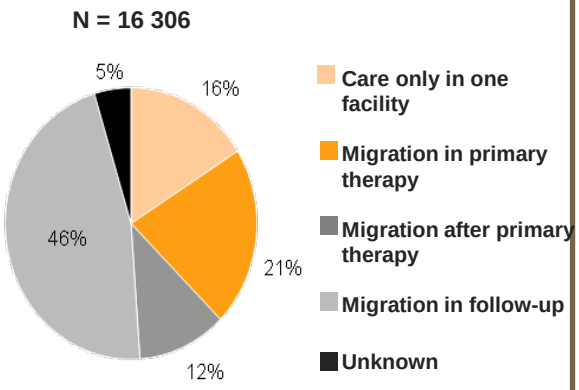


Benchmarking of outcome measures: Survival after given medication vs. EBM trials

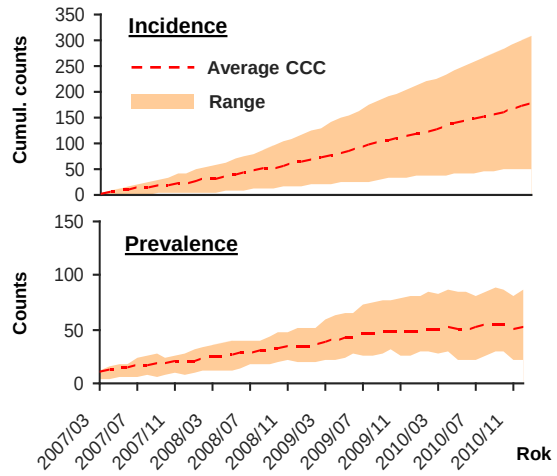


Migration of patients

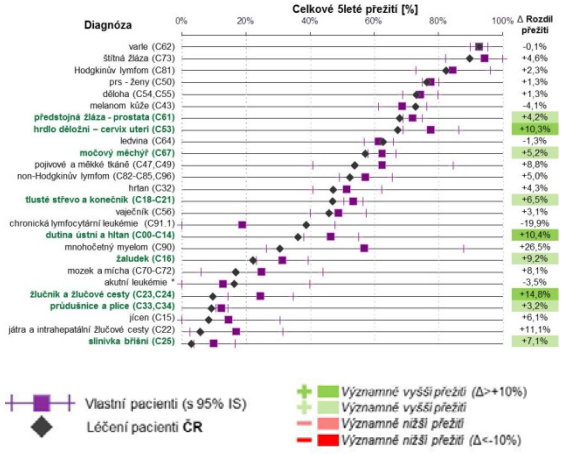
/Example of one CCC/



Incidence and prevalence of treated CRC patients: benchmarking



Benchmarking of outcome measures: 5yr survival – population comparisons



III.
Current challenge for all of us: harmonized implementation of CRC screening in clinical practice

CanCon
Cancer Control Joint Action

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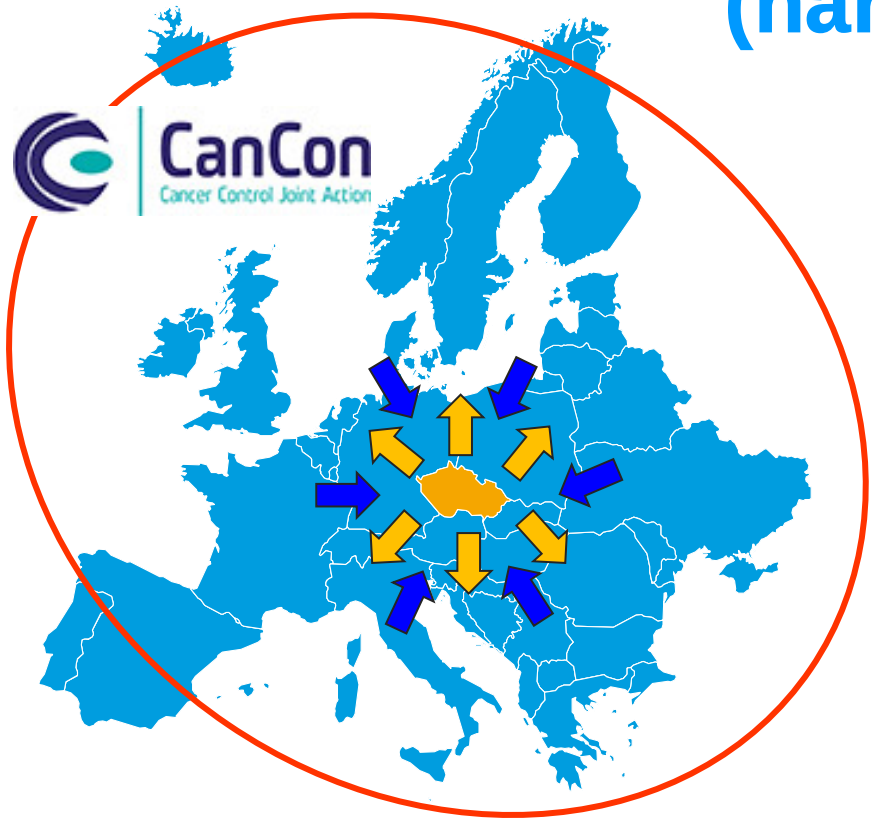
Challenges and questions

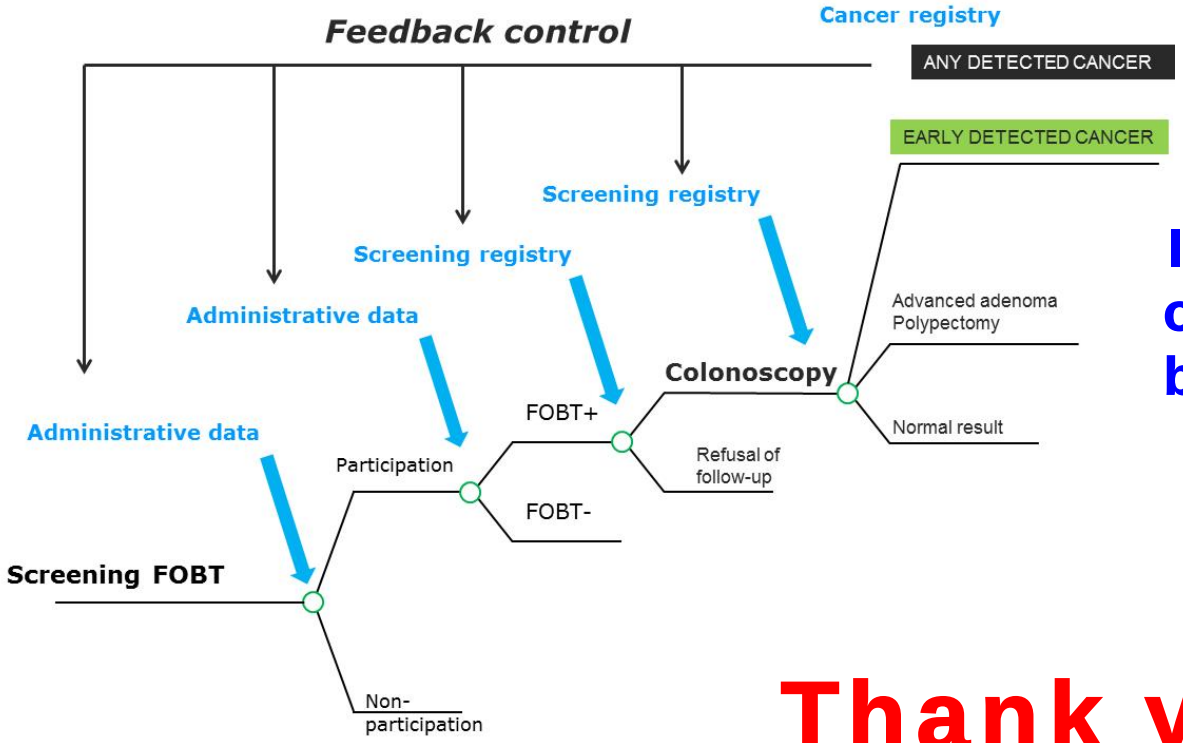
We need to standardize (harmonize):

1. E-data capture systems
2. Integration tools for heterogeneous data
3. Data mining tools
4. **Standard national and European reporting**
5. Employment of population cancer registries
6. IT guidelines for addressed invitation to screening
7. **Communication guidelines**
8. (E) - learning approaches
9. **Legislative support for merging of different data sources**



Excellent example:
European cancer observatory
- http://eco.iarc.fr

Legislative regulation of personal data handling? – What is the acceptable extent?



Individualized tracking of patient flow – will it be possible in EU?

Thank you very much for your attention