

# 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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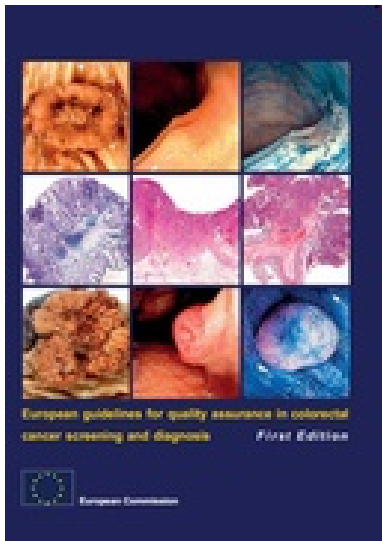


# HOW to optimize and manage CRC screening?

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



<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. Zakej, 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	Colonoscoped	Referred
Rate of complete colonoscopies	Complete colonoscopies	Total colonoscoped
Biopsy rate	Biopsy taken	Colonoscoped
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, otherwise 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	"", "1", "2", "3", "4", "5", "6", "7", "8", "9", "10", "11", "12", "13", "14", "15", "16", "17", "18", "19", "20", "21", "22", "23", "24", "25", "26", "27", "28", "29", "30", "31", "32", "33", "34", "35", "36", "37", "38", "39", "40", "41", "42", "43", "44", "45", "46", "47", "48", "49", "50", "51", "52", "53", "54", "55", "56", "57", "58", "59", "60", "61", "62", "63", "64", "65", "66", "67", "68", "69", "70", "71", "72", "73", "74", "75", "76", "77", "78", "79", "80", "81", "82", "83", "84", "85", "86", "87", "88", "89", "90", "91", "92", "93", "94", "95", "96", "97", "98", "99", "100", "101", "102", "103", "104", "105", "106", "107", "108", "109", "110", "111", "112", "113", "114", "115", "116", "117", "118", "119", "120", "121", "122", "123", "124", "125", "126", "127", "128", "129", "130", "131", "132", "133", "134", "135", "136", "137", "138", "139", "140", "141", "142", "143", "144", "145", "146", "147", "148", "149", "150", "151", "152", "153", "154", 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# Reality in the CRC screening implementation: 27 EU countries = 27 approaches ?

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EDITORIAL

## Colorectal cancer screening in Europe

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TOPIC HIGHLIGHT

WJG 20<sup>th</sup> 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 years or times in LT	Age eligible national population	
	Type	Status			Age (yr)	Persons (× 1000)
Austria	NonPB	Natw	FOBT	1 or 2	> 50	2210
	NonPB	Natw	CS		> 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
	PB	Natw-roll ong		2	50-74	16400
France	NonPB	Natw	FOBT	1 and 2	> 50	24500
	NonPB	Natw	CS	(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					4440
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	1340
	NonPB	Natw-plan	CS	10	> 50	1340
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						-25490
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

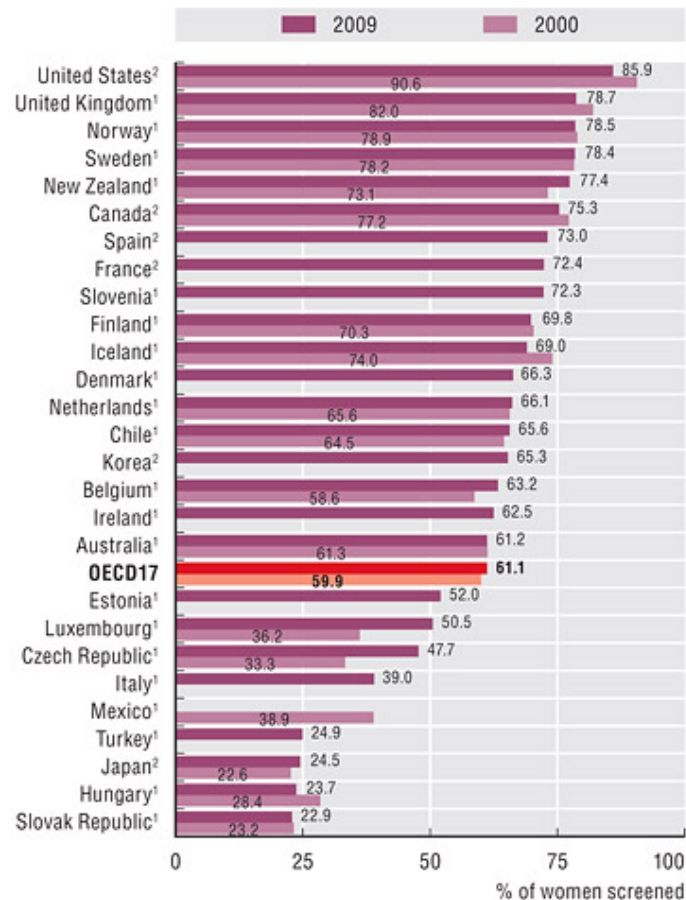


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## OECD Health at a Glance, 2011

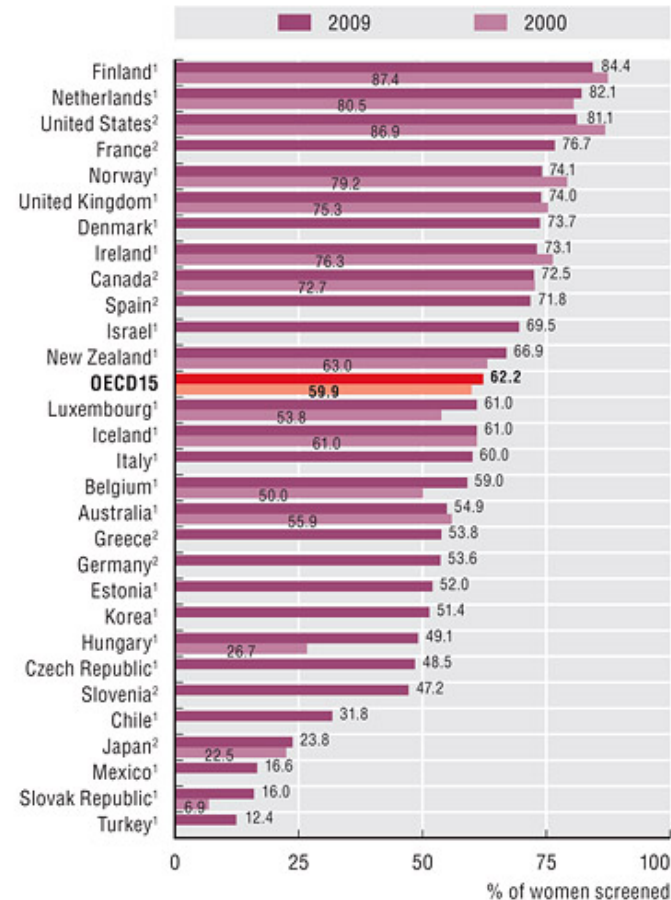
### 5.8.1 Cervical cancer screening, percentage women screened aged 20-69, 2000 to 2009 (or nearest year)



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

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

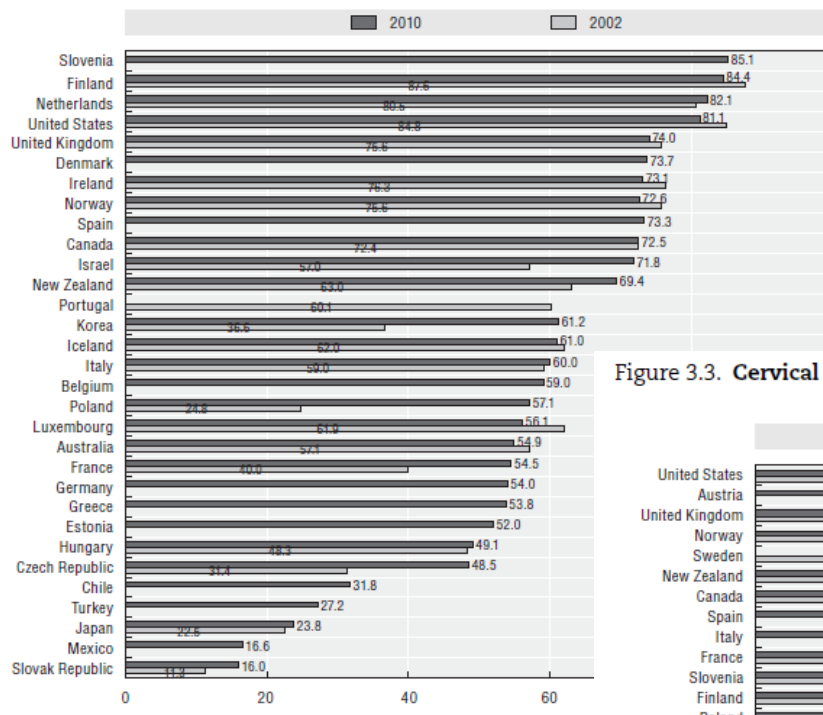
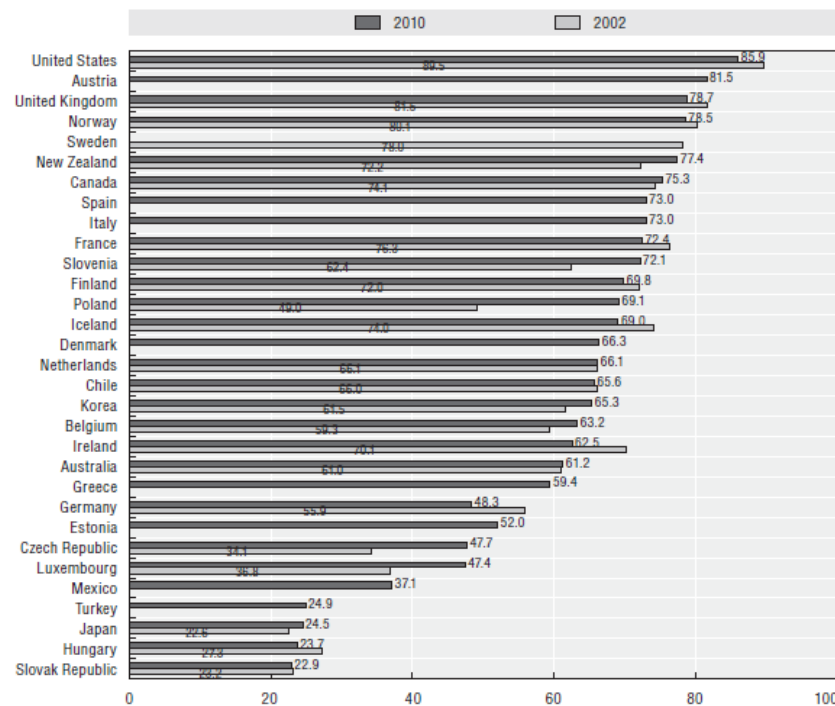


Figure 3.3. Cervical cancer screening, percentage of women screened aged 20-69, 2002 and 2010 (or nearest year available)



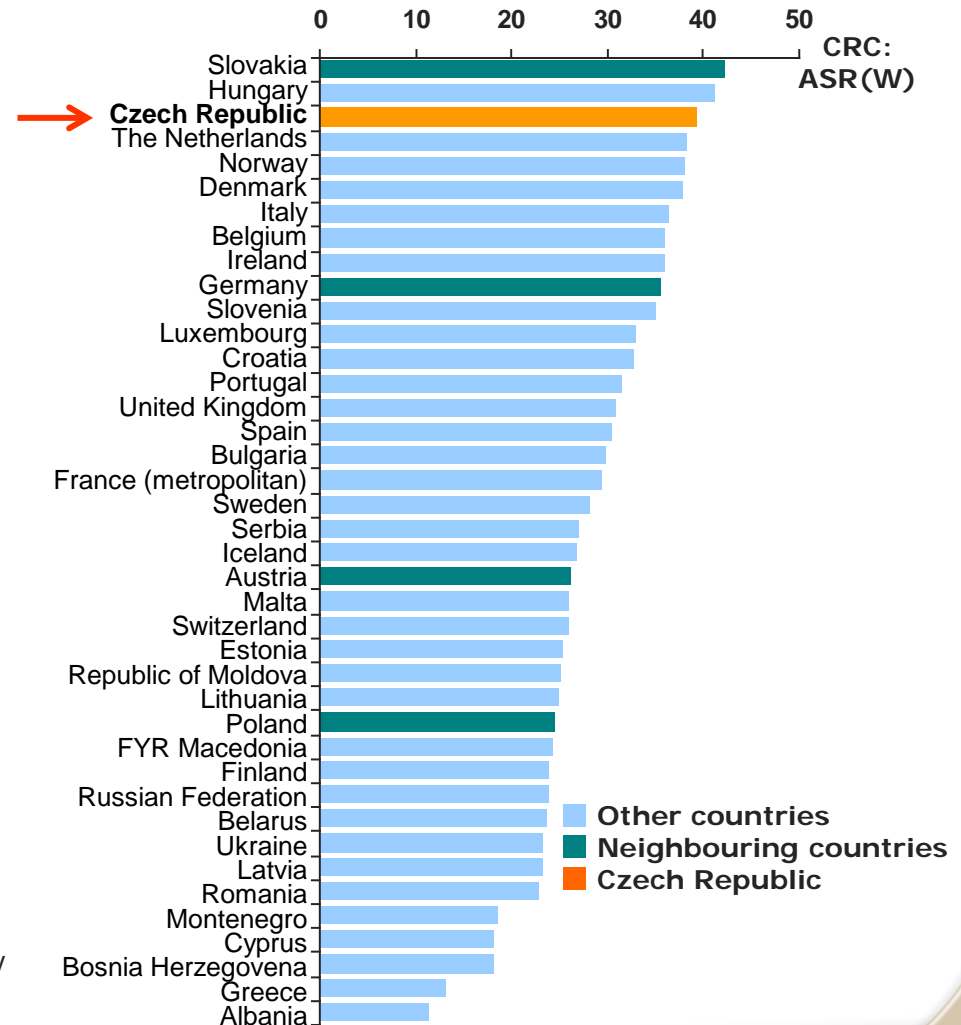
OECD Health at a Glance, 2013



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)**



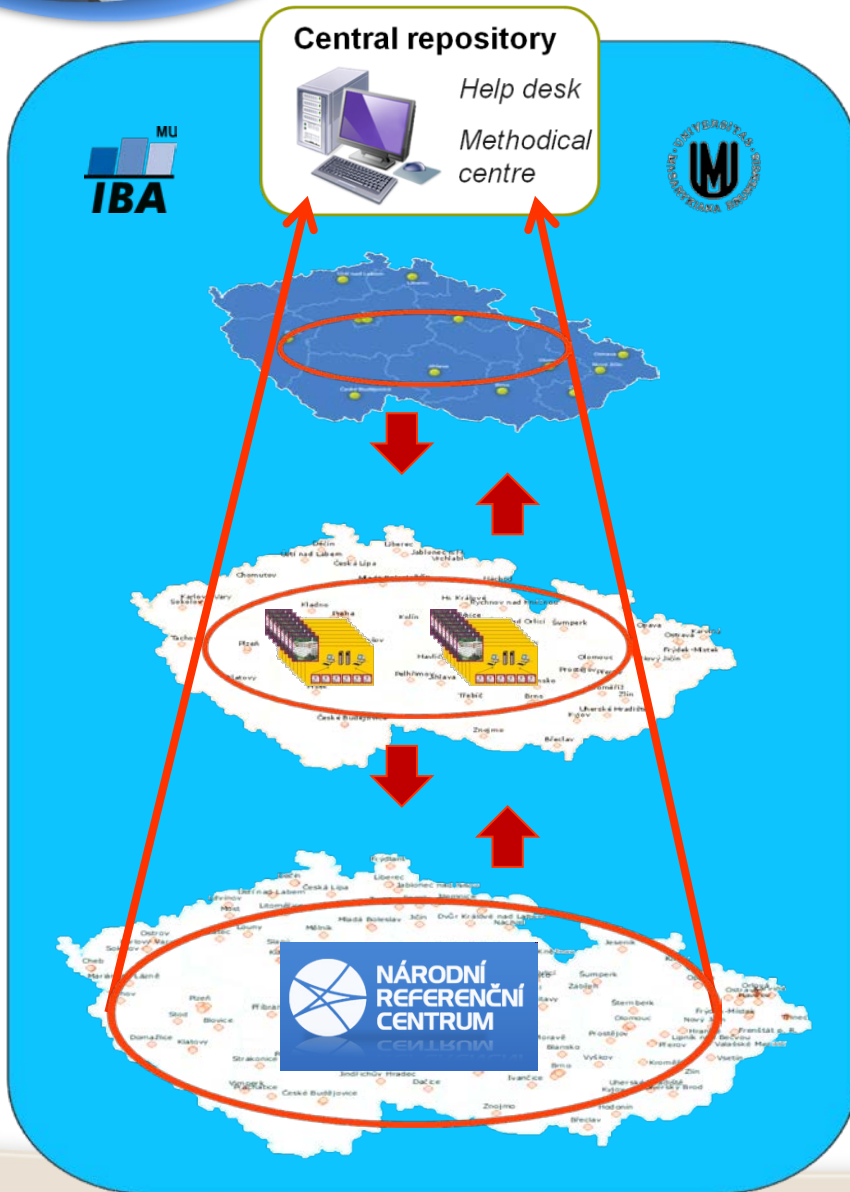
**SEPARATED KEY  
INFORMATION SOURCES**

A collage of various data tables and charts. Three prominent blue boxes with white text are overlaid on the data: 'Diagnostics' at the top, 'Clinical monitoring' in the middle, and 'Health care payers' at the bottom. The data tables contain numerical values and some text labels.

**NON-STANDARDIZED  
INFORMATION SYSTEMS**



# Solution? Respect the health care system

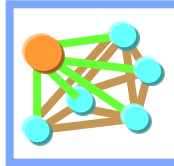


## Central repository



Help desk  
Methodical centre

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*

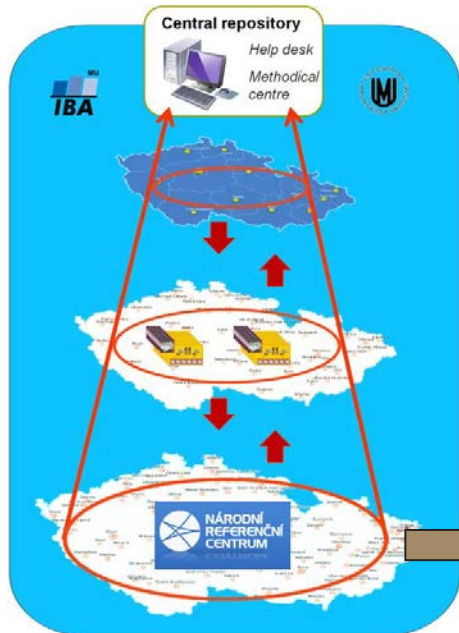
**REPORTS**

*Follow-up*

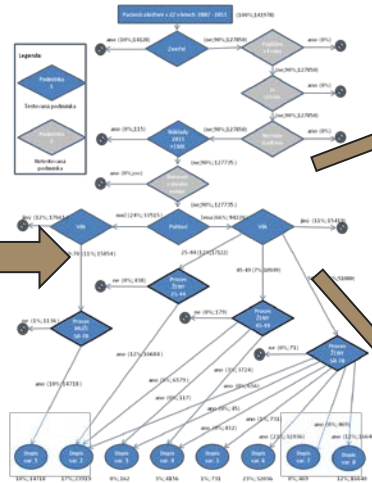
*Compliance*

# Examples of IS functionality:

## I. Management of population-based screening

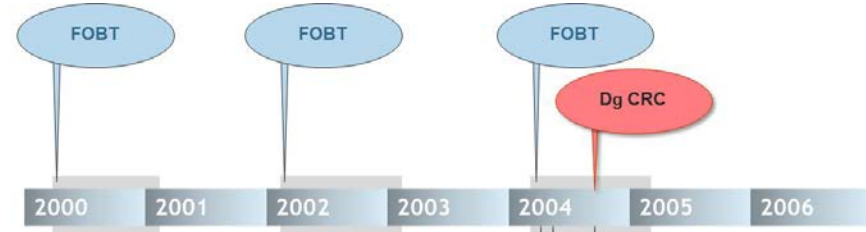
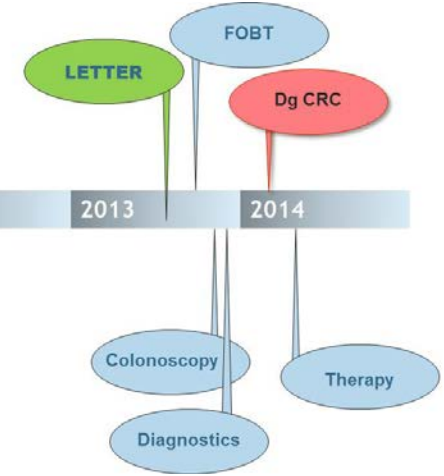


**Selection of people to be invited**

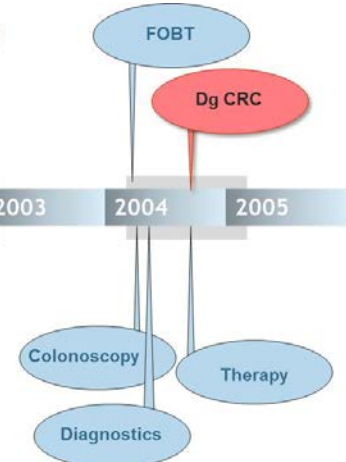


**Backward monitoring**

*Prospective mode*



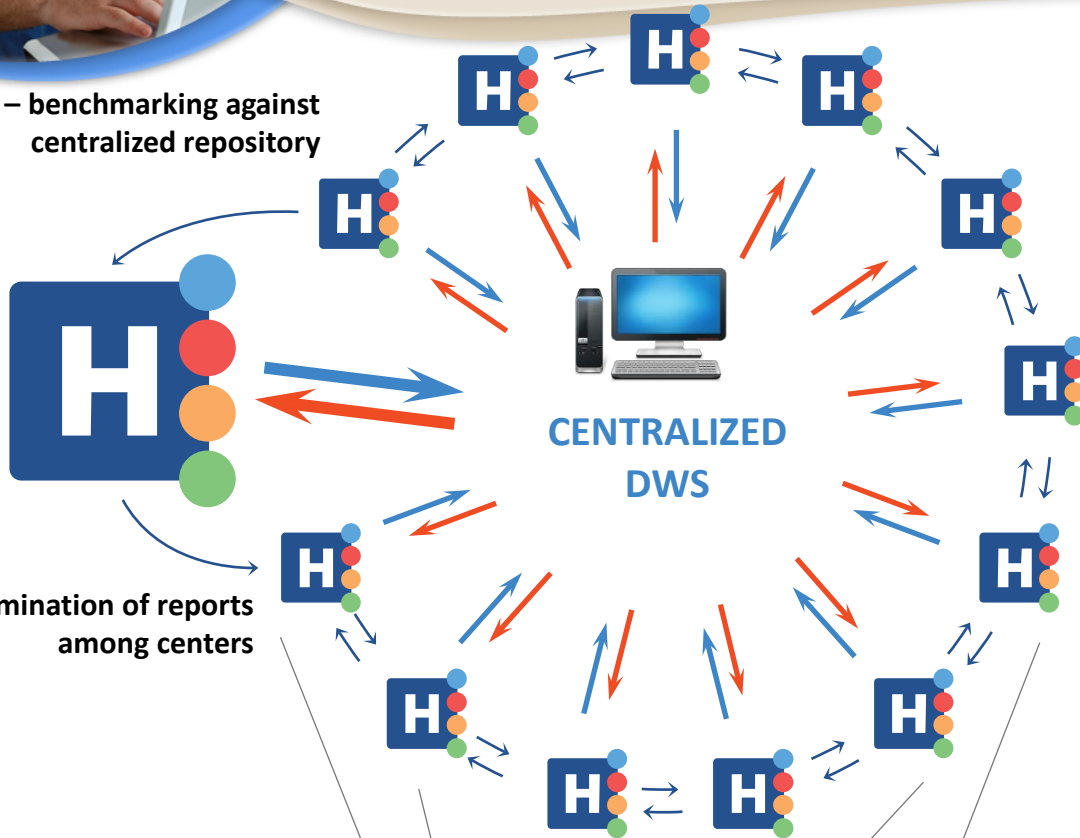
*Retrospective mode*



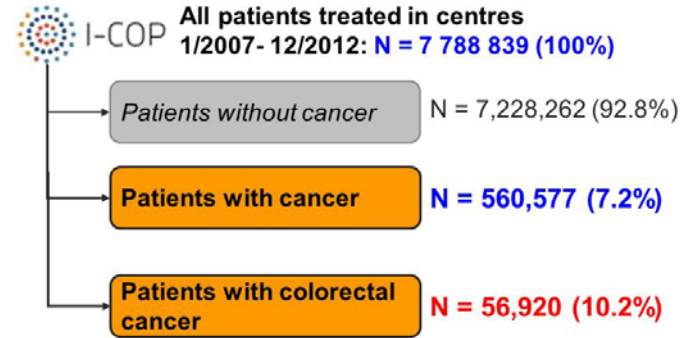
# Examples of IS functionality: II. Clinical (hospital-based) monitoring



Self – benchmarking against centralized repository



**Representative base  
for clinically relevant  
analyses of consecutively  
treated patients**



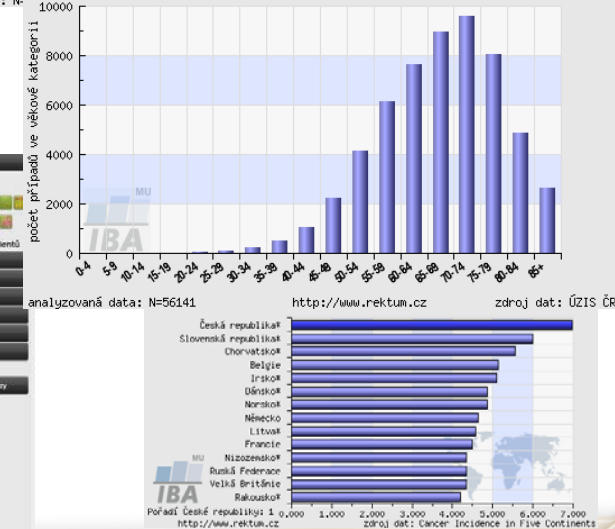
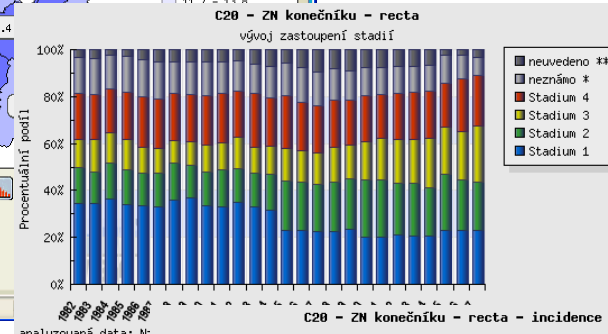
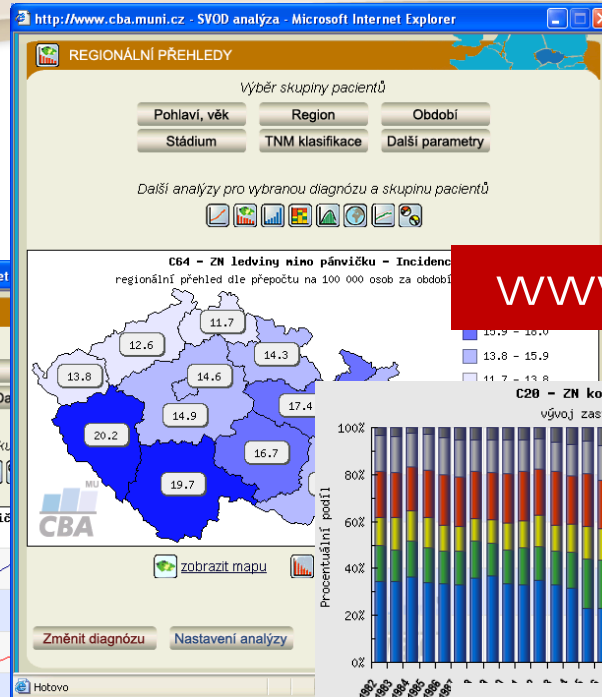
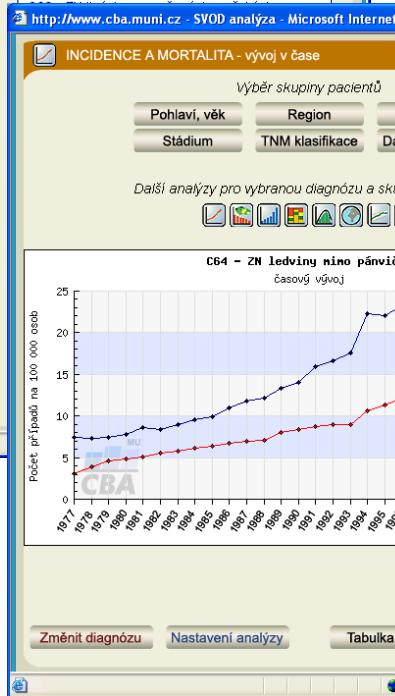
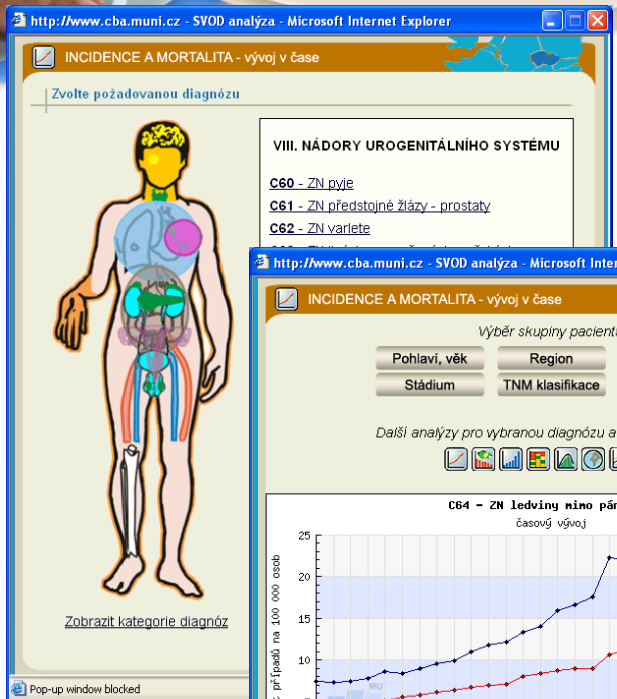
Dissemination of reports among centers



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

[www.svod.cz](http://www.svod.cz)

[www.kolorektum.cz](http://www.kolorektum.cz)



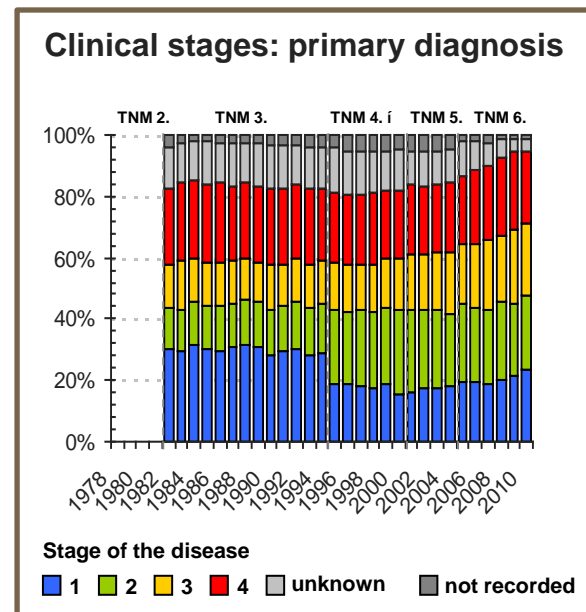
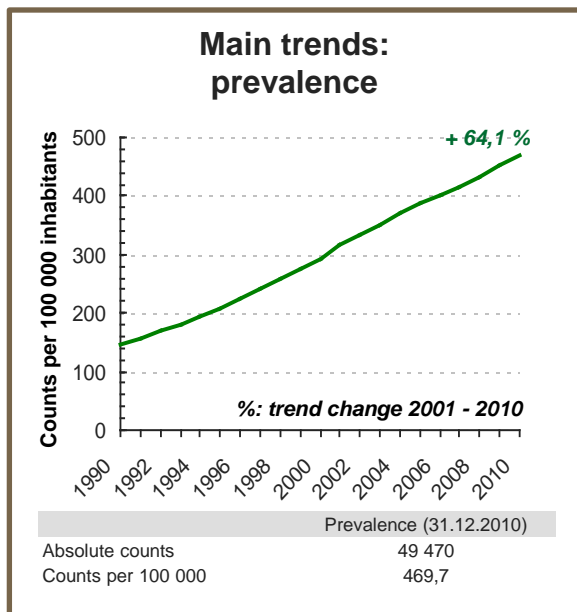
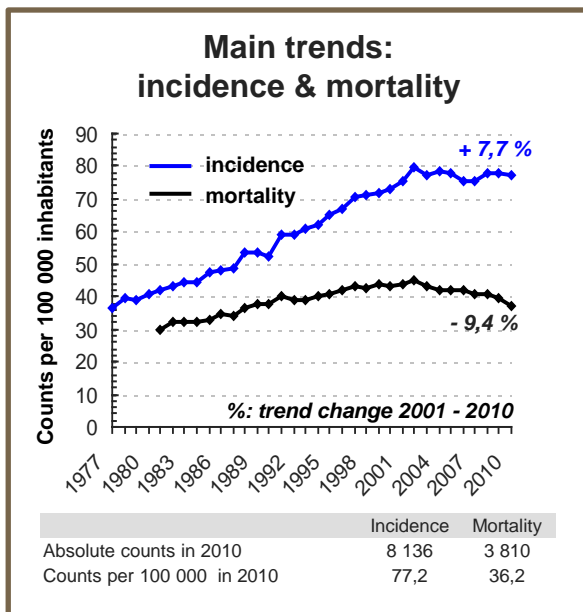
[www.rektum.cz](http://www.rektum.cz)

[www.mefanet.cz](http://www.mefanet.cz)



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

Model diagnosis: colorectal carcinoma



### Survival of patients in time trends

Colorectal carcinoma (C18-C20)	5yr relative survival (95% IC)	
	2000-2004	2005-2009
<b>All patients</b>	44.7 (43.4-45.9)	50.1 (48.9-51.3)
<b>stage 1</b>	66.8 (64.3-69.1)	73.3 (71.1-75.4)
<b>stage 2</b>	54.0 (51.9-56.0)	61.2 (59.2-63.1)
<b>stage 3</b>	38.2 (35.6-40.9)	46.8 (44.4-49.1)
<b>stage 4</b>	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
<b>Stage I</b>	2 091 (1918; 2267)	19 245 (18 27; 19 563)
<b>Stage II</b>	1 934 (1796; 2070)	17 186 (16895; 17477)
<b>Stage III</b>	2 261 (2106; 2415)	12 955 (12697; 13213)
<b>Stage IV</b>	2 130 (1956; 2305)	7 602 (7 404; 7 800)
<b>Stage unknown – objective reasons</b>	256 (165; 349)	2 413 (2 300; 2 526)
<b>Stage unknown – not recorded</b>	71 (46; 98)	
<b>TOTAL</b>	8 743 (7987; 9504)	59 401 (58223; 60579)

### Stochastic predictions of therapeutic burden

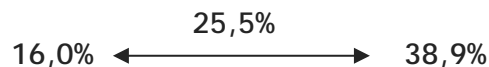
Colorectal carcinoma (C18-C20)	Newly treated patients in 2014
<b>Stage I</b>	1 848 (1695; 2004)
<b>Stage II</b>	1 808 (1679; 1934)
<b>Stage III</b>	2 120 (1976; 2265)
<b>Stage IV – incidence</b>	1 431 (1314; 1549)
<b>Disseminated relapses / progressions</b>	1 854 (1693; 2014)
<b>TOTAL</b>	9 061 (8 357;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

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

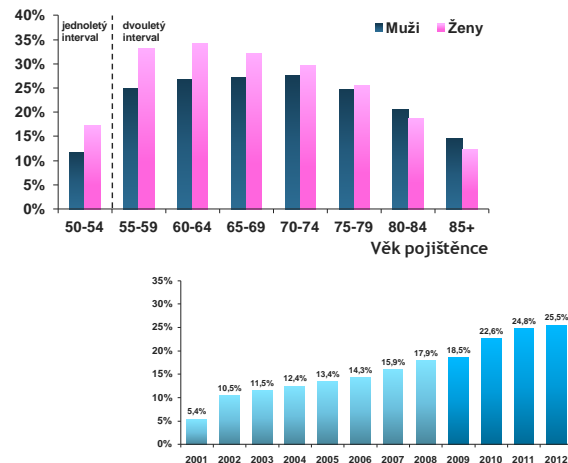
Model diagnosis: colorectal carcinoma

## CRC screening: regional coverage

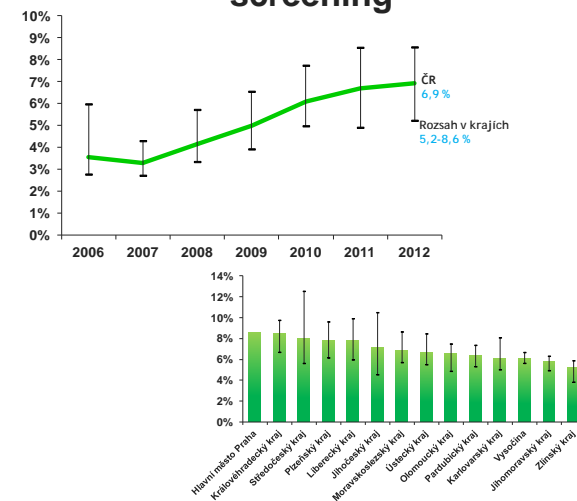
Pokrytí populace v procentech



## CRC screening: age-specific coverage

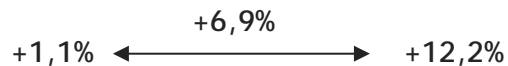


## QA/QC indicators in CRC screening

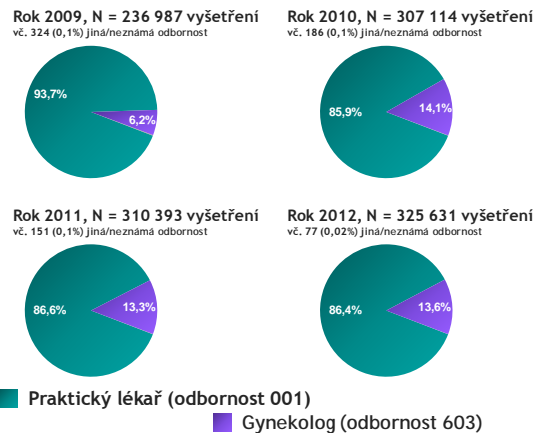


## Coverage in time trend: 2009 - 2012

Vývoj pokrytí 2012 vs. 2009 (procentní body)

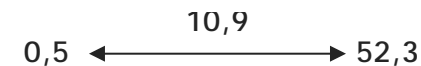


## Share of primary care specialists



## Primary screening colonoscopy

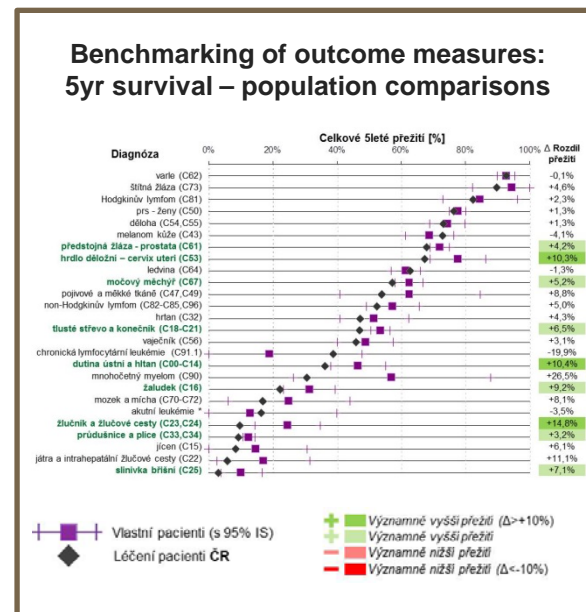
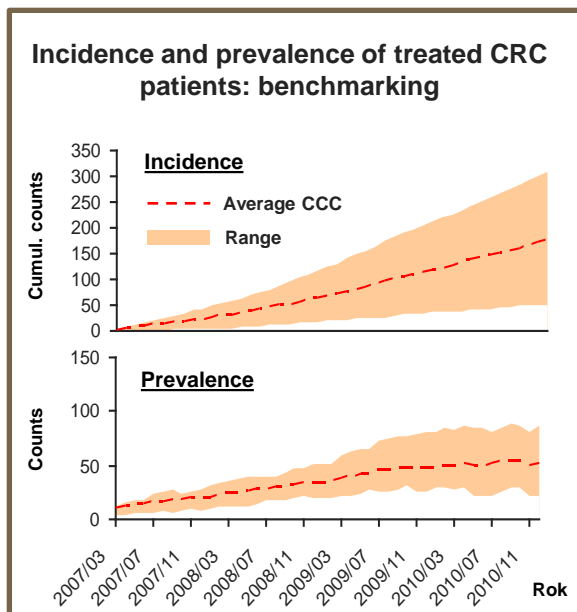
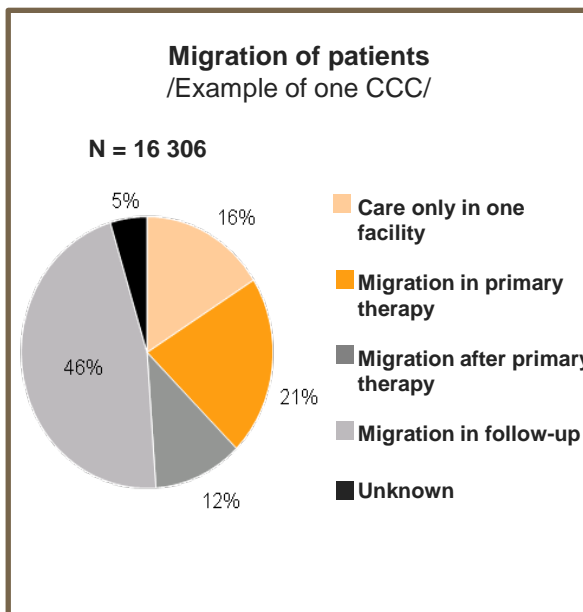
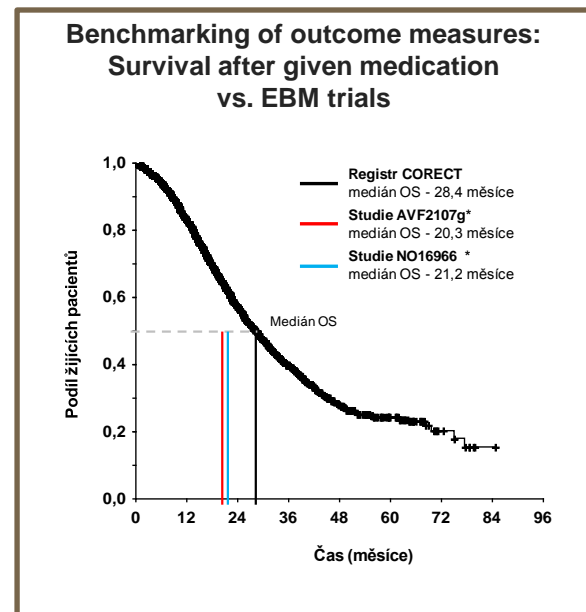
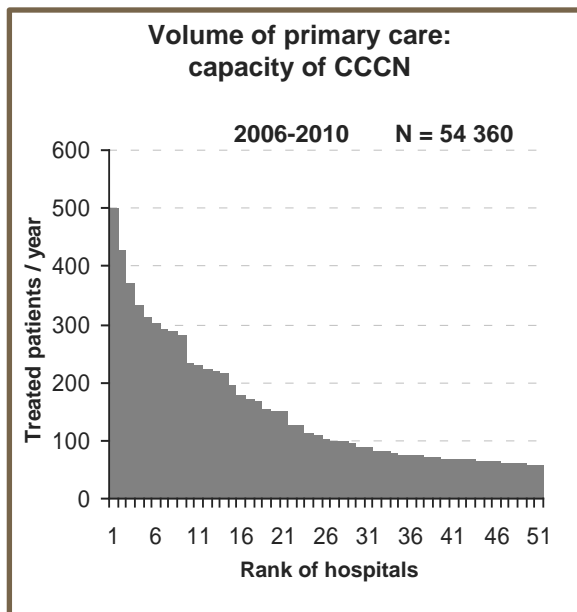
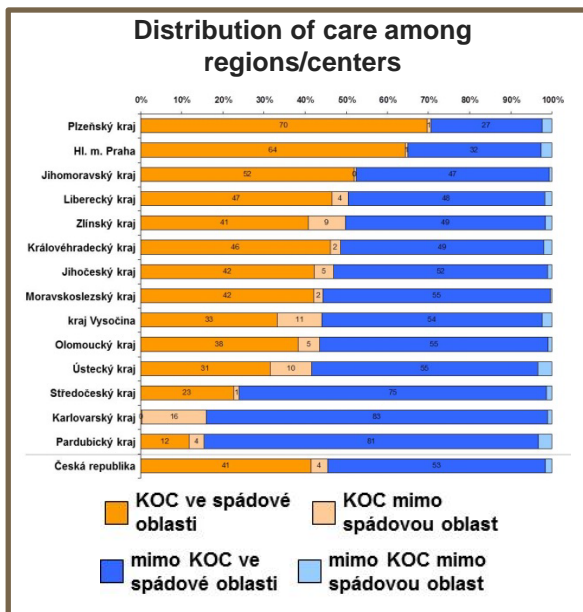
Počet (na 10 000 osob)





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

Model diagnosis: colorectal carcinoma



# III.

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



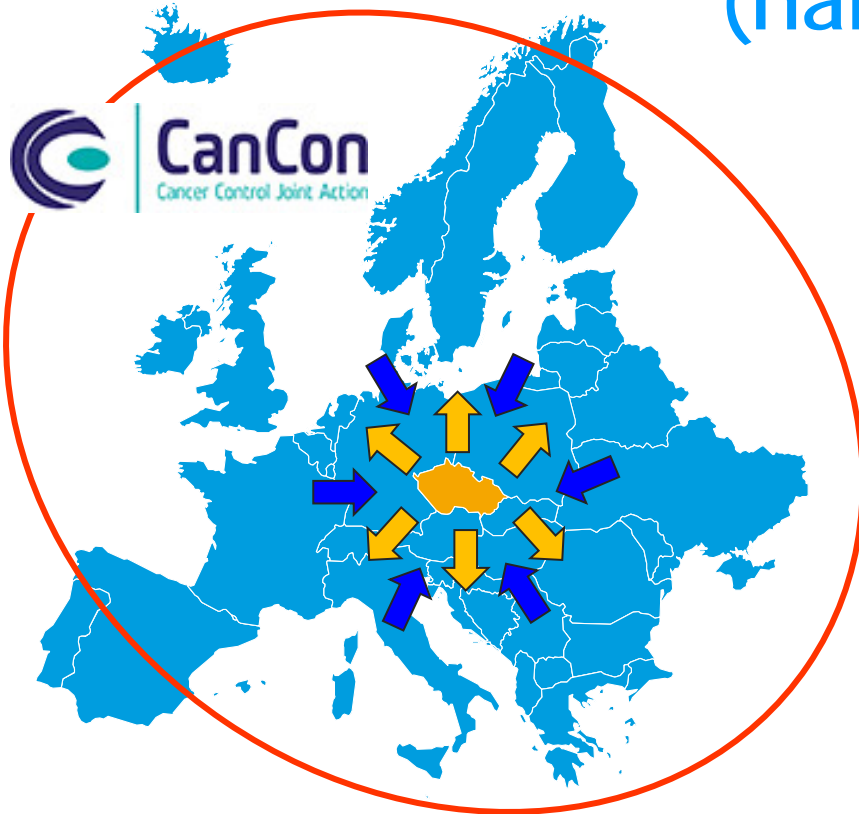
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## We need to standardize (harmonize):

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**

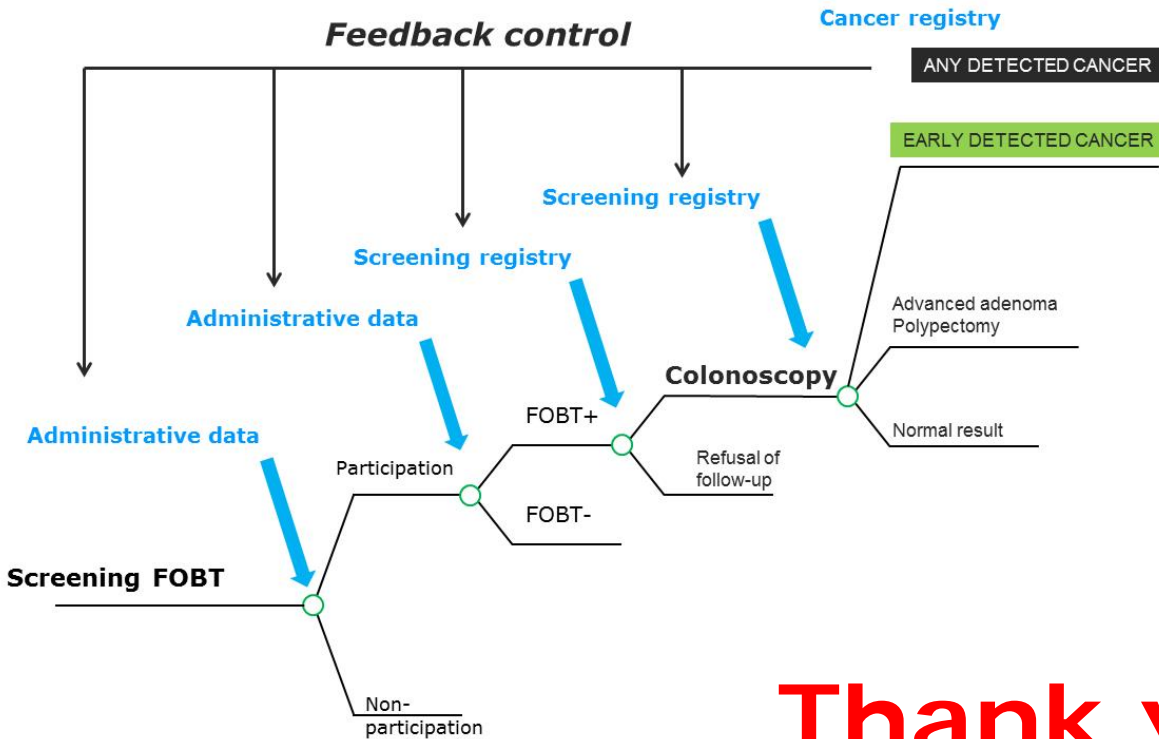


Excellent example:  
European cancer observatory  
- <http://eco.iarc.fr>



# 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**