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

\[ \text{NH-IS} \]

\text{NH-IS} = \text{very complex system}

- Health care registries (real-world observations, based on representative reporting)
- Statistical surveys (clinical reports on care, economy of providers)
- Reference information systems (eHealth key components)
- International collaboration and reporting (Health Data OECD, Eurostat, EHIS, EHLEIS, ...)

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

Everybody knows what to do!

NH-IS

Clinically based evidence

Does really everybody do it?
Basic elements of effective e-health information system – Czech approach:

1. e-identification/certification of health care professionals

2. e-identification/certification 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
II. Building NH-IS: main challenges
Effective system must answer very complex questions

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

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

How to control population and its health status (mortality, morbidity, survival, ....)?
Effective system must cover multiple and heterogeneous data sources

DATA INTEGRATION and reporting

NON-STANDARDIZED INFORMATION SYSTEMS

HOW TO MANAGE IT?

SEPARATED KEY INFORMATION SOURCES

Diagnostics

Clinical monitoring

Health care payers
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
I. Management view
Integration of very complex data

- Optimization of networks; reasonable distribution of care
- QA/QC: Health care quality assessment
- Health technology assessment; cost effectiveness

Diagram:
- Cost
- Outcomes
- Processes
- Therapy
- Inpus
- Diagnostics
- Risks
II. System view

Comprehensive coverage of all segments of care

Prevention screening → Primary care → Diagnostics & therapy → Follow-up Supportive care → Palliative 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

- National registry of health care professionals
- Specialized registries
- Health care records in centralized data store of reimbursement companies
- Targeted surveys

Diagram:
- National registry of health care professionals
  - Targeted surveys
  - Specialized registries
  - Health care records in centralized data store of reimbursement companies
Example of outcomes:
The Czech National Cancer Care Information System

Czech National Cancer Control Program - Information Platform
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**

- 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

<table>
<thead>
<tr>
<th>Equity</th>
<th>Accessibility</th>
<th>Health care quality indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population data</td>
<td>Hospital data</td>
<td>Specialized registries</td>
</tr>
<tr>
<td>Regional monitoring</td>
<td>Case mix monitoring</td>
<td>Analyses of target groups of patients</td>
</tr>
<tr>
<td>Distribution of care</td>
<td>Migration of patients</td>
<td></td>
</tr>
<tr>
<td>Prevention</td>
<td>Compliance with standards</td>
<td>Specific algorithms &amp; protocols, adherence</td>
</tr>
<tr>
<td>Diagnostic and therapeutic standards</td>
<td>Quality control</td>
<td></td>
</tr>
<tr>
<td>Standards</td>
<td>Safety</td>
<td></td>
</tr>
<tr>
<td>Efficacy</td>
<td>Safety</td>
<td>VESPA:  - Adverse events  - Specific problems  - Mortality</td>
</tr>
<tr>
<td>Safety</td>
<td>Safety</td>
<td>VESPA:  - Therapy-related complications</td>
</tr>
<tr>
<td>Efficacy</td>
<td>Efficacy</td>
<td>VESPA:  - Overall survival  - Disease free survival</td>
</tr>
<tr>
<td></td>
<td>Safety</td>
<td>VESPA:  - Therapy-related complications</td>
</tr>
<tr>
<td></td>
<td>Efficacy</td>
<td>VESPA:  - Quality of life  - Cost effectiveness  - Economic analyses</td>
</tr>
</tbody>
</table>
EXAMPLE OF RESULTS - I.
Modern comprehensive data-based reporting

www.svod.cz

Czech National Cancer Control Program - Information Platform
National on-line data-based reporting
Examples of reporting: I. Population level & II. Hospital level

**Model diagnosis: colorectal carcinoma**

### Main trends: incidence & mortality

- **ASR(E) / 100,000 inhabitants**
  - **incidence**
  - **mortality**

<table>
<thead>
<tr>
<th>Year</th>
<th>Incidence</th>
<th>Mortality</th>
</tr>
</thead>
<tbody>
<tr>
<td>1990</td>
<td>120</td>
<td>80</td>
</tr>
<tr>
<td>1992</td>
<td>100</td>
<td>60</td>
</tr>
<tr>
<td>1994</td>
<td>80</td>
<td>40</td>
</tr>
<tr>
<td>1996</td>
<td>60</td>
<td>20</td>
</tr>
<tr>
<td>1998</td>
<td>40</td>
<td>10</td>
</tr>
<tr>
<td>2000</td>
<td>20</td>
<td>0</td>
</tr>
</tbody>
</table>

### Main trends: prevalence

- **%: trend change 2003–2013**

<table>
<thead>
<tr>
<th>Year</th>
<th>Prevalence</th>
</tr>
</thead>
<tbody>
<tr>
<td>2003</td>
<td>30%</td>
</tr>
<tr>
<td>2013</td>
<td>60%</td>
</tr>
</tbody>
</table>

### Clinical stages: primary diagnosis

- **Stage of the disease**
- **Incidence**
- **Mortality**

### Distribution of care among regions/centers

- **Rank of hospitals**
- **Treated patients/year**

<table>
<thead>
<tr>
<th>Region</th>
<th>Rank</th>
<th>Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>KOC ve spádové oblasti</td>
<td>1</td>
<td>54,360</td>
</tr>
<tr>
<td>KOC mimo spádovou oblast</td>
<td>2</td>
<td>37,160</td>
</tr>
<tr>
<td>mimo KOC ve spádové oblast</td>
<td>3</td>
<td>21,000</td>
</tr>
<tr>
<td>mimo KOC mimo spádovou oblast</td>
<td>4</td>
<td>12,000</td>
</tr>
</tbody>
</table>

### Volume of cancer care: capacity mapping

- **2006-2014 N = 54,360**

- **Regist CORECT** median OS - 28.4 měsíce
- **Studie AVF2107g** median OS - 20.3 měsíce
- **Studie NO16966** median OS - 21.2 měsíce

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

- **Medián OS**

<table>
<thead>
<tr>
<th>Year</th>
<th>OS (měsíce)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006</td>
<td>28.4</td>
</tr>
<tr>
<td>2008</td>
<td>20.3</td>
</tr>
<tr>
<td>2010</td>
<td>21.2</td>
</tr>
</tbody>
</table>
### Examples of reporting: III. Predictive mapping of cancer burden

**Model diagnosis: colorectal carcinoma**

---

**CRC** (C18 – C20)  
<table>
<thead>
<tr>
<th></th>
<th><strong>INCIDENCE</strong> (95% CI)</th>
<th><strong>PREVALENCE</strong> (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Stage I</strong></td>
<td>2050 (1903; 2197)</td>
<td>21 376 (21 136; 21 616)</td>
</tr>
<tr>
<td><strong>Stage II</strong></td>
<td>1951 (1844; 2057)</td>
<td>19 104 (18 877; 19 331)</td>
</tr>
<tr>
<td><strong>Stage III</strong></td>
<td>2117 (2010; 2226)</td>
<td>15 114 (14 912; 15 316)</td>
</tr>
<tr>
<td><strong>Stage IV</strong></td>
<td>1631 (1359; 1903)</td>
<td>7083 (6945; 7221)</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>8037 (7298; 8777)</td>
<td>65 331 (64 911; 65 751)</td>
</tr>
</tbody>
</table>
Predictive mapping of cancer burden – model concept

Population-based predictive models

Adjusted for clinical stage

Primarily treated patients

Stage-specific estimate of prevalence of treated patients

Surviving cancer patients with relapse/progression of primary disease

Expert inputs and corrections

Scenario 1 (%)

Scenario (%)

Scenario (%)

Scenario (%)

Cost calculation

Cost calculation

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

Tomas Pavlik, Eva Janauskova, Jiri Mayer, Karel Indrak, Marie Jarosova, Hana Klamova, Daniela Zadková, Jaroslava Voglová, Edgar Faber, Michal Karas, Katerina Machova Poláková, Zdenek Racil, Eva Derneckova, Ludmila Demirovova, Elena Tothova, Jan Chudej, Karel Krul, Eduard Cunnil, Tomas Kozak, Jan Muzik, and Ladislav Dusek.
Example of clinical outcome assessment

Model diagnosis: colorectal carcinoma

Population-based monitoring

CRC: 5-yr relative survival

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 1</td>
<td>64,9 %</td>
<td>76,2 %</td>
<td>87,6 %</td>
<td>91,8 %</td>
</tr>
<tr>
<td>Stage 2</td>
<td>48,4 %</td>
<td>62,9 %</td>
<td>73,7 %</td>
<td>79,4 %</td>
</tr>
<tr>
<td>Stage 3</td>
<td>40,0 %</td>
<td>41,8 %</td>
<td>54,5 %</td>
<td>62,2 %</td>
</tr>
<tr>
<td>Stage 4</td>
<td>12,0 %</td>
<td>10,7 %</td>
<td>13,9 %</td>
<td>16,2 %</td>
</tr>
<tr>
<td>Total</td>
<td>47,9 %</td>
<td>51,7 %</td>
<td>59,4 %</td>
<td>65,4 %</td>
</tr>
</tbody>
</table>
EXAMPLE OF RESULTS - II. Data-driven cancer screening - population-based design -
Examples of IS functionality: Management of population-based screening

Selection of people to be addressed

Prospective mode

2010 2011 2012 2013 2014

Retrospective mode

2000 2001 2002 2003 2004 2005 2006

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

Coverage in percents
- > 50.0
- 50.0-60.0
- 60.0-70.0
- 70.0-80.0
- > 80.0

Coverage by screening
- One-year interval
- Two-year interval

CR: 24,0
SO: 31,8

Age group
50-54
55-59
60-64
65-69
70-74
75-79
80-84
85+

CRC screening: age-specific coverage

Coverage percents
- < 3.0
- 3.0-4.0
- 4.0-5.0
- 5.0-6.0
- > 6.0

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

Difference (%)
- < 2.0
- 2.0-4.0
- 4.0-5.0
- 5.0-6.0
- > 6.0

Share of primary care specialists
Women aged over 50

Year 2011, N = 310 393 examinations
151 (0,1%) other/unknown expertise

Year 2012, N = 325 631 examinations
77 (0,02%) other/unknown expertise

Primary screening Colonoscopy – regional coverage
Men and women aged over 50

Number per 10,000
- < 10.0
- 10.0-20.0
- 20.0-30.0
- 30.0-40.0
- > 40.0
PB CRC screening: improvement 2010 -

Colorectal cancer epidemiology

Colorectal cancer screening

Coverage by screening (men and women, aged over 50)

Coverage by screening (cohort: 55-69 let)
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

Regional models of cancer care, presenting professionals and navigating patients

Interactive maps

Access points

PDF download
Regional models of cancer care
Cancer Centres On-line

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

Equipment characteristics

- **Identification data**
- **Basic characteristics**
- **Hospital and management information systems**
- **Health care specific assessment and documentation**
- **Clinical assessment**

Clinical research

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

- **Hospital and management information systems**
- **Health care specific assessment and documentation**
- **Clinical assessment**

Performance

- **Cancer centres On-line**

- **www.onconet.cz**

- **Comprehensive cancer care**

...and more
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.

<table>
<thead>
<tr>
<th>Population (as of 31/12/2015)</th>
<th>1 175 025</th>
<th>509 475</th>
<th>1 684 500</th>
</tr>
</thead>
<tbody>
<tr>
<td>Area (km²)</td>
<td>7 195</td>
<td>6 796</td>
<td>13 991</td>
</tr>
<tr>
<td>Population density (per km²)</td>
<td>163</td>
<td>75</td>
<td>120</td>
</tr>
<tr>
<td>Number of districts</td>
<td>7</td>
<td>5</td>
<td>12</td>
</tr>
<tr>
<td>Number of municipalities</td>
<td>673</td>
<td>704</td>
<td>1 377</td>
</tr>
<tr>
<td>Total length of roads and motorways (km, estimation)</td>
<td>4 500</td>
<td>5 000</td>
<td>9 500</td>
</tr>
<tr>
<td>Total length of railway network (km, estimation)</td>
<td>800</td>
<td>650</td>
<td>1 450</td>
</tr>
</tbody>
</table>
Pilot CCCN: South Moravian Region and Vysocina Region - cancer care infrastructure

**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]

www.onconet.cz
Conclusion and Current Challenges
Personalized medicine needs personalized data collection and reporting

Thank you very much for your attention

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