Information support of programmes of early disease detection in the Czech Republic

Ondřej Májek
1. Establishment of an academic information support system for cancer screening programmes
2. Population-based cancer screening programmes
3. Action plan (national strategy Health 2020) and plans for the National Coordination Centre
1. Academic information system for cancer screening programmes
Organized cancer screening programmes

- Cancer screening programmes are **essential component** of national cancer control programmes
- Screening for cancer of breast, colorectum and uterine cervix is **effective** in decreasing mortality of the diseases
- To guarantee their effectiveness, safety and cost-effectiveness, it is highly recommended to implement the prevention as **organized programmes comprising**:
  - an explicit **policy**, with specified age categories, method and interval of screening
  - defined target population
  - a management **team** responsible for the implementation
  - a health care team for decisions and care
  - a **quality assurance structure** (performance monitoring including collection of all relevant data)
  - a method for **identifying cancer occurrence** in the target population

IARC handbooks of cancer prevention; Albreht et al.: European Guide for National Quality Control Programmes
Cancer screening programmes according to the Council of the EU

Recommendation of the Council of the EU (2003)
... to establish screening programmes for three preventable cancer diagnoses

.... Including efficient background information

Breast cancer
(C50)

Colorectal cancer
(C18 – C21)

Cervical cancer
(C53)
Breast Cancer Screening Programme
- since 2002
- women aged over 45 years
- mammography every 2 years

Colorectal Cancer Screening Programme
- since 2000
- men and women aged over 50 years
  - 50-54 years – faecal occult blood test every year
  - over 55 years – faecal occult blood test every 2 years OR primary screening colonoscopy every 10 years

Cervical Cancer Screening Programme
- since 2008
- all adult women
- annual Pap smear
Data sources for monitoring of cancer screening programmes

MONITORING OF CANCER BURDEN
- Epidemiology of cancer in target population
- Long-term impact indicators

Source of data: CZECH NATIONAL CANCER REGISTRY
Institute of Health Information and Statistics

MONITORING OF SCREENING PROCESS USING CLINICAL DATA
- Early performance indicators at screening centres
- Detection of cancer and precancerous lesions in screening

Source of data: SCREENING CENTRES, NATIONAL CANCER REGISTRIES

MONITORING OF SCREENING PROCESS USING ADMINISTRATIVE DATA
- Population-based early performance indicators
- Monitoring of programmes accessibility by target population

Source of data: HEALTH INSURANCE COMPANIES

Information Support Provider
INSTITUTE OF BIOSTATISTICS AND ANALYSES,
MASARYK UNIVERSITY, BRNO
Breast cancer screening
- 68 mammography centres

Colorectal cancer screening
- 188 colonoscopy centres

Cervical cancer screening
- 36 cytology laboratories
Data collection and analysis from mammography centres

The illustrative example of data collection in screening centres in the Czech Republic

Data management / invitation process

Examinations / results

Data analysis

Data audit (i.e. collection and statistical processing of data) is provided by the Institute of Biostatistics and Analyses of the Masaryk University.
### Time trends in basic characteristics of the breast cancer screening

Source of data: National Breast Cancer Screening Registry

<table>
<thead>
<tr>
<th>All age groups</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Number of screened women</strong></td>
<td>435,608</td>
<td>538,323</td>
<td>555,451</td>
<td>602,044</td>
<td>649,362</td>
<td>683,259</td>
</tr>
<tr>
<td><strong>Number of detected cancers</strong></td>
<td>2,030</td>
<td>2,912</td>
<td>3,037</td>
<td>3,315</td>
<td>3,610</td>
<td>3,782</td>
</tr>
<tr>
<td><strong>Detection rate (per 1000 examinations)</strong></td>
<td>4.7</td>
<td>5.4</td>
<td>5.5</td>
<td>5.5</td>
<td>5.6</td>
<td>5.5</td>
</tr>
<tr>
<td><strong>No. of diagnosed women according to the size of primary tumour</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ca in situ</td>
<td>234 (11.5%)</td>
<td>337 (11.6%)</td>
<td>317 (10.4%)</td>
<td>364 (11%)</td>
<td>390 (10.8%)</td>
<td>416 (11%)</td>
</tr>
<tr>
<td>T1</td>
<td>1 280 (63.1%)</td>
<td>1 820 (62.5%)</td>
<td>1 925 (63.4%)</td>
<td>2 105 (63.5%)</td>
<td>2 302 (63.8%)</td>
<td>2 418 (63.9%)</td>
</tr>
<tr>
<td>T2</td>
<td>256 (12.6%)</td>
<td>304 (10.4%)</td>
<td>325 (10.7%)</td>
<td>322 (9.7%)</td>
<td>356 (9.9%)</td>
<td>382 (10.1%)</td>
</tr>
<tr>
<td>T3</td>
<td>11 (0.5%)</td>
<td>13 (0.4%)</td>
<td>21 (0.7%)</td>
<td>12 (0.4%)</td>
<td>22 (0.6%)</td>
<td>26 (0.7%)</td>
</tr>
<tr>
<td>T4</td>
<td>3 (0.1%)</td>
<td>7 (0.2%)</td>
<td>6 (0.2%)</td>
<td>7 (0.2%)</td>
<td>8 (0.2%)</td>
<td>8 (0.2%)</td>
</tr>
<tr>
<td>Tumour modified by treatment</td>
<td>72 (3.5%)</td>
<td>119 (4.1%)</td>
<td>99 (3.3%)</td>
<td>104 (3.1%)</td>
<td>105 (2.9%)</td>
<td>107 (2.8%)</td>
</tr>
<tr>
<td>Unknown size</td>
<td>174 (8.6%)</td>
<td>312 (10.7%)</td>
<td>344 (11.3%)</td>
<td>401 (12.1%)</td>
<td>427 (11.8%)</td>
<td>425 (11.2%)</td>
</tr>
</tbody>
</table>
### Results of cervical screening cytology examinations

#### Source of data: National Cervical Cancer Screening Registry

<table>
<thead>
<tr>
<th>Category</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. No intraepithelial lesion or malignancy</td>
<td>2,120,371</td>
<td>96.33%</td>
</tr>
<tr>
<td>2. ASC-US</td>
<td>35,024</td>
<td>1.59%</td>
</tr>
<tr>
<td>3. ASC-H</td>
<td>5,201</td>
<td>0.24%</td>
</tr>
<tr>
<td>4. LSIL</td>
<td>26,734</td>
<td>1.21%</td>
</tr>
<tr>
<td>5. HSIL – cannot exclude invasion</td>
<td>3,214</td>
<td>0.15%</td>
</tr>
<tr>
<td>6. HSIL – cannot exclude invasion</td>
<td>209</td>
<td>0.01%</td>
</tr>
<tr>
<td>7. Squamous-cell carcinoma</td>
<td>116</td>
<td>0.01%</td>
</tr>
<tr>
<td>8. Glandular atypia</td>
<td>5,260</td>
<td>0.24%</td>
</tr>
<tr>
<td>9. Glandular cells atypia (favour neoplastic)</td>
<td>218</td>
<td>0.01%</td>
</tr>
<tr>
<td>10. Adenocarcinoma in situ</td>
<td>18</td>
<td>0.001%</td>
</tr>
<tr>
<td>11. Invasive adenocarcinoma</td>
<td>45</td>
<td>0.002%</td>
</tr>
<tr>
<td>12. Other malignancy</td>
<td>16</td>
<td>0.001%</td>
</tr>
</tbody>
</table>

Examinations in 2014

\[ n = 2,201,201 \] women incl. 4,775 other/not recorded/unable to diagnose

In under 4% of women the results are abnormal, mostly ASC-US or LSIL
Support by BCA 2012/2013

- Cooperation between WHO and Masaryk University
- APW within the framework of BCA 2012-2013
  - Drafting of Evaluation report on existing early detection programs on cancer
  - Published Data-based report on performance and quality of national cancer screening programs
  - Preparation of proposals and recommendations on evidence based interventions to strengthen running cancer screening programs
  - Organization of national workshop with roundtable expert discussion

Launching of the population-based screening
2. Population-based programme
Aims and methodology of the invitation project

- population-based screening programmes including **personalised invitation of targeted individuals** are widely recommended to ensure high coverage
- in the Czech Republic, screening programmes were in place as **organised non-population-based**; participants were enrolled by GPs or gynaecologists as part of their regular preventive check-up
- the aim of our project was to integrate population-based approach to existing organised non-population-based programme on the basis of **invitation of non-attenders by health insurance companies**, which cover the entire Czech population

**MONITORING – INSTITUTE OF HEALTH INFORMATION AND STATISTICS**

- **Inclusion criteria**
  - sex and age
  - previous care
- **Sending the letter**
- **Checking the outcome**
- **Successful Individual included in screening**
- Repeating the process
diverse historical trends of coverage achieved in different screening programmes by spontaneous participation or primary care referral

in 01/2014-06/2015 almost 2.25 million previously non-attending individuals were personally invited to screening programmes

substantial increase in coverage, notably for colorectal cancer screening, small effect in cervical cancer screening
Colorectal cancer screening
Participation rate by sex and age

First invitations between 01/2014-06/2015, 1,697,083 invited in total
Men and women aged 50-70

Total participation rate: **19.5%**
(participation at FOBT or colonoscopy)
One in five invited individuals participated.
Participation rate was slightly higher in women.
the effect of additional personalised invitation was substantial mainly for colorectal cancer screening, where spontaneous participation led to a low coverage by examination, on the other hand, the participation rate in cervical cancer screening was lower

the project showed that integration of non-population-based organised screening and invitation of non-attenders can be a useful approach to increase coverage

this approach may be a possible solution for other countries struggling to achieve a full population-based approach
3. Action plan & future projects
1. **Ensure adequate** governance and decision making about cancer screening programmes
   1) Legislative provision for screening committees

2. **Ensure high** awareness of citizens about risks and benefits of screening examinations
   1) Sustainability of personal invitation system
   2) Preparation of information materials based on scientific evidence
   3) Targeted information campaigns
   4) Methodology for identification of population groups excluded from screening

3. **Ensure high quality and safety** of screening programmes
   1) Methodology for revision of national guidelines
   2) Legislative provision for networks of providers
   3) Legislative provision for external audits
   4) Legislative provision for monitoring of performance indicators
   5) Establishing national competence centre (Institute of Health Information and Statistics)
   6) Legislative provision for data availability
4. **Ensure innovations of screening programmes according to current scientific evidence**
   1) Process for approval of new screening programmes
   2) Establishing methodology for assessment of new technologies
   3) Pilot projects for new screening programmes
   4) Improvement of governance in screening research

5. **Strengthen personal capacity for governance, performance and evaluation of screening programmes**
   1) Support for study programmes concerning screening
   2) Enriching the curricula of health professionals
   3) International collaboration

6. **Strengthen material capacity for performance of screening programmes**
   1) Appropriate motivation of screening providers

7. **Strengthen support of screening programmes through e-Health tools**
   1) Modernisation of data sources
   2) Tools for on-line benchmarking of providers
   3) Establishing the national web portal about screening programmes
   4) Strengthening the use of data standards (DASTA, HL7)
Projects & their activities (2017-2021)

1. National Coordination Centre for Disease Early Detection Programmes
   1) Establishment and operation of a Council for Implementation and Governance of Disease Early Detection Programmes and its working groups
   2) Implementing life cycle of early detection programmes and creation of its methodological framework
   3) Verification of the methodology for planning of a new programme and realization of a pilot project
   4) Communication and Education

2. Data Base for Early Detection Programmes
   1) Expert team for evidence evaluation and early detection programme analysis
   2) Data base for monitoring and evaluation of early detection programmes
   3) Information system for integrated quality assurance
   4) Evaluation of early detection programmes

3. Early detection pilot programmes
Early detection programme life cycle

- establishment of consensus and recommendation for programme planning - Council
- programme planning and pilot project – Working Group and Council
- evaluation of the national programme and "big" innovations - Council
- monitoring of the national programme – Working Group
- Implementation of the national programme – Working Group

Inspired by Lonnberg et al.: Policy recommendations on governance, organisation and evaluation of cancer screening (CANCON guide chapter)
Conclusions
Conclusions

- organized cancer screening programmes recommended by the EU Council recommendations were implemented in 2000s
- these programmes were supported by academic information systems, overseen by the expert societies and committees at the Ministry of Health
- population-based screening programmes were started in cooperation between the Ministry and healthcare payers in 2014
- elements of evidence-informed policy making and top-down sustainable system of monitoring and evaluation will be implemented in following years on the basis of the Action Plan approved in 2015