## EUROPEAN COLORECTAL CANCER DAYS

**BRNO 2012 - PREVENTION AND SCREENING** 

"Data driven prevention has the power to save lives."

Prevention – Safety – Effectiveness

Colorectal cancer is the most common newly diagnosed cancer and the second most common cause of cancer deaths in Europe. More than 200,000 Europeans die every year from malignant tumours of the colon and rectum. However, many of these deaths could be avoided. Effective and safe colorectal cancer prevention and early detection are key factors, and these measures do work. Numerous clinical and epidemiological studies continue to bring evidence of the valuable benefit of colorectal cancer screening both for individuals and for the populations and societies. Screening with faecal occult blood test or colonoscopy can help prevent colorectal cancer cases and save lives.

However, evidence-based medicine on its own is not sufficient. Although very important, it covers only one of the several dimensions of a successful screening programme. Strong managerial background and organization, high quality of all associated services and last but not least, compliance by the target population are among the factors which substantially contribute to the desirable decrease in incidence and mortality rates of the screened cancer. Optimal harmony among these factors cannot be achieved without the vital support of national health care authorities, politicians, health care payers and other stakeholders.

Cancer data is undoubtedly the quintessential platform for any functional screening programme. Representative data collection is, therefore, an inevitable component of the screening process that involves mapping of its performance and quality, controlling its safety and effectiveness, and offering "scientifically supported marketing" of the programme. Extensively gathered and appropriately presented data can guide politicians, optimize health care and consequently increase the programme attractiveness for the general public.

This meeting is intended as a networking event which

should help to share up-to-date knowledge and to discuss the application of the hitherto assembled findings in establishing effective systems for colorectal cancer screening and early detection. Regardless of recent advances in many European countries, there are still many rather persistent questions and problems that need to be addressed, such as:

- Are we able to implement new modalities in CRC screening without negatively impacting compliance by the target population?
- Are all other aspects of CRC screening taken into account in developing new strategies (safety, feasibility, cost-effectiveness)?
- What is more important in enhancing screening performance and coverage, medical or managerial factors?
- When looking at the heterogeneity of CRC screening in European countries, what is the gold standard of the population-based programme? – and does the gold standard exist in the first place?
- Can we extrapolate data and experience between countries with different health care management?
- What is the optimum panel for performance and quality indicators in CRC screening?
- Are there verified and positive examples of effective communication with the general public?
- Who is the most powerful "image-maker" of CRC screening? Is it the politicians, health care payers, patients' organizations, physicians ... celebrities?

We hope that such a meeting of the stakeholders supported by representatives of medical societies and patients' organizations can offer a functional platform and a stimulating atmosphere for fruitful exchanges on all of these problems and many other related issues.

The conference was held under the auspices of honorable and with the kind support of



Roman Onderka Mayor of the City of Brno



Leoš Heger Czech Minister of Health



Pavel Poc Member of the European Parliament



John Dalli EU Commissioner for Health and Consumer Policy.

### **Conference executive summary**

### CRC screening & knowledge base

- 1. Colorectal cancer (CRC) is the most common newly diagnosed cancer and the second most common cause of cancer death in Europe. More than 430,000 European citizens are diagnosed and over 210,000 Europeans die each year from malignant tumours of colon and rectum (1).
- 2. Based on the results of numerous randomized controlled trials, mortality from colorectal cancer can be effectively reduced through early cancer detection by the faecal occult blood test (2).
- 3. High-quality screening programme is able to translate the outlined efficacy into a real-life effectiveness, i.e., to prevent cancers (3), to save lives (4) and to save an enormous amount of financial resources (5).

### CRC screening & State of the Art

- 1. In Europe, CRC screening is recognized and recommended as an important healthcare programme (6, 7).
- 2. Many European countries have already implemented CRC screening programmes in recent years (8).
- 3. To maintain a favourable balance between benefits and harms when dealing with large populations, it is necessary to apply comprehensive quality standards and best practice in the implementation of cancer screening programmes. For that purpose, professional European guidelines for quality assurance in CRC screening have been recently published and recommended by the European Commission (9).
- 4. Standard, most common diagnostic methods for CRC screening involve: FOBT followed by colonoscopy in case of positive findings and/or primary screening colonoscopy (9).
- 5. Gold standard of the screening model is well-defined and recommended (9), consisting in a population-based national screening programme. However, where this model is not applicable, opportunistic screening is recommended as a functional alternative and/or a primary step, as a nationwide programme or as an initiative for limited, closed communities.

### **CRC screening & Current Challenges**

- The heterogeneity is still significant between European countries, both in design and in the content of CRC screening
  programmes. More intensive communication, feedback analyses of reached results and a platform to exchange experience between countries should be supported and facilitated.
- 2. Modern CRC screening needs an innovative, up-to-date, comprehensive and effective information policy: a pan-European policy. Methodical effort which will further develop already published guidelines in the field of communication and information policy is highly demanded. The guidelines focused on information policy might help European governments and stakeholders to motivate target groups to participate in cancer prevention, to set up communication priorities and to link all kinds of cancer prevention in a logical model.
- 3. Legislative background of nationwide healthcare programmes such as CRC screening should be more harmonized throughout Europe, namely in two fields: 1) to cover functional and reachable models for addressed invitation of participants to the programme, 2) to allow information services and merge of required data sources within an adequate legislative framework.
- 4. CRC screening promotion should be more visibly enriched by an exact economic dimension. Cost-effectiveness modelling and quantification of economic benefits of the CRC screening should be supported, among others also as a part of European grant policy. Translational research approaches, international collaboration and cross-boundary networking are needed.
- 5. Europe needs a dedicated Centre for Cancer Prevention, unifying the diverse national, professional and scientific activities involved.

### References

- Ferlay J, Shin HR, Bray F, et al. GLOBOCAN 2008 v1.2, Cancer Incidence and Mortality Worldwide: IARC CancerBase No. 10 [Internet]. Lyon, France: International Agency for Research on Cancer; 2010. Available from: http://globocan.iarc.fr, accessed on 17/05/2012.
- Hewitson P, Glasziou P, Watson E, et al. Cochrane systematic review of colorectal cancer screening using the fecal occult blood test (hemoccult): an update. Am J Gastroenterol 2008;103:1541–9.
- 3. Brenner H, Hoffmeister M, Brenner G, et al. Expected reduction of colorectal cancer incidence within 8 years after introduction of the German screening colonoscopy programme: estimates based on 1,875,708 screening colonoscopies. Eur J Cancer 2009;45:2027–33.
- Zauber AG, Winawer SJ, O'Brien MJ, et al. Colonoscopic polypectomy and long-term prevention of colorectal-cancer deaths. N Engl J Med 2012;366:687–96.
- 5. Sieg A, Brenner H. Cost-saving analysis of screening colonoscopy in Germany. Z Gastroenterol 2007;45:945–51.
- The Council of the European Union (2003/878/EC). Council Recommendation of 2 December 2003 on cancer screening. Official Journal of the European Union, Vol. 16, p. 34–39. ISSN 1725-2555
- 7. Poc P, Brepoels F, Busoi CC, Leinen J, Peterle A. Written declaration on fighting colorectal cancer in the European Union. The European Parliament, PE449.546v01-00. 20. 12. 2010.
- Karsa L, Anttila A, Ronco G, et al. Cancer Screening in the European Union: Report on the implementation of the Council Recommendation on cancer screening. Luxembourg: European Communities 2008.
- 9. Segnan N, Patnick J, von Karsa L, editors. European guidelines for quality assurance in colorectal cancer screening and diagnosis. Luxembourg: Publications Office of the European Union; 2010.

## **1. Press conference**



Press conference participants
J. Dalli, L. Heger, P. Poc,
R. Kotzian, R. Stockbrügger,
M. Primič-Žakelj, J. Špičák,
Š. Suchánek, J. Vorlíček, L.Dušek





# John Dalli (right), EU Comissioner for Health and Consumer Policy Pavel Poc (left), Member of the European Parliament



Leoš Heger,
 Czech Minister of Health



 Robert Kotzian, Deputy Mayor of the City of Brno



Julius Špičák, President of the Czech Society for Gastroenterology Maja Primič-Žakelj, President of the Association of European Cancer Leagues

Press conference – representatives of expert medical societies: Štěpán Suchánek, *Scientific Secretary of the Czech Society of Gastrointestinal Oncology* 

Reinhold Stockbrügger, United European Gastroenterology, Chair of the Public Affairs Committee

Ladislav Dušek, Director of the Institute of Biostatistics and Analyses, Masaryk University

Jiří Vorlíček, President of the Czech Society for Oncology





 Representatives of the media and patients' organizations

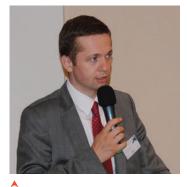


 Interview with John Dalli, EU Comissioner for Health and Consumer Policy

## Press conference - main headlines:

- 1. Colorectal cancer (CRC) is the leading cause of cancer deaths throughout the world.
- 2. Over 90 % of deaths from CRC can be avoided thanks to prevention and screening.
- 3. CRC screening is still relatively weak in performance in many European countries and thus deserves more attention from public health authorities. Only screening which is widely recognized and accepted by the public can reduce mortality and save lives.
- 4. European guidelines for CRC screening were published in 2010 as a professional methodical framework for this healthcare programme. CRC screening was recommended in the EU Council Recommendation (2003/878/EC) and newly in the Declaration of the European Parliament on the Fight Against Colorectal Cancer in the EU (2010).
- 5. CRC screening is a very comprehensive programme. Mutual collaboration of stakeholders, professional medical communities and patients' organizations is highly needed to enhance its performance and quality.
- 6. Policymakers and leading healthcare managers in European countries are challenged to support the promotion of cancer prevention and the motivation of participants, and to strengthen functional screening programmes, namely in the following areas:
  - addressed invitation of citizens to the screening examinations
  - · continuous and effective promotion of all kinds of cancer prevention
  - legislative background for the utilization of information resources supporting screening
  - · optimization of screening networks, both in capacity and in quality measures
  - · adequate reimbursement of standardized screening tests and procedures

## 2. Opening ceremony



### Conference is welcomed by Deputy Mayor of the City of Brno Robert Kotzian

"Political representatives of the City of Brno welcome the conference focused on cancer prevention as a highly valuable event. Support of healthcare programmes and research is obligatorily incorporated in the development strategy of Brno. Regional political leaders can help the prevention by supporting regionally specific projects and activities."



John Dalli, EU Comissioner for Health and Consumer Policy "It is my firm belief that, together, we can fight colorectal cancer and support Member States in their efforts to set up screening programmes for this type of cancer."



### Pavel Poc, Member of the European Parliament

"If there is the competency, the power, those who have it should also have the responsibility. A written declaration of the European Parliament which I tabled in 2010 reminded the Member States of this principle. And if it is not enough, we have to keep on working. We have to attract public opinion, raise awareness, administer adequate pressure on the Member States and when their administrations wake up, then help them to promote prevention and screening, exchange best practices and experiences. This is our role until healthcare becomes a communitarian issue."



### Reinhold Stockbrügger, United European Gastroenterology, Chair of the Public Affairs

"The United European Gastroenterology (UEG) represents Europe-wide all medical specialists engaged in the prevention, diagnosis, treatment and followup of colorectal cancer. The UEG has decided to maximally support the efforts made by political, administrative and patient initiatives in this respect by providing scientific documentation, initiating necessary new research and involving its pan-European National Societies in the fight against this individual and societal threat."



## Leoš Heger, Czech Minister of Health

"Colorectal cancer is still a crucial health risk in the Czech Republic. Only through mutual cooperation between the administration, medical professionals, patient initiatives and NGOs we will succeed in combating those. Occasions such as this important international conference are an essential part of it, which is why I am very happy to participate in this event."



Štěpán Suchánek, Scientific Secretary of Czech Society of Gastrointestinal Oncology

"The Czech National Colorectal Cancer Screening Programme was launched in year 2000 and it has grown into its current state with 23% target population coverage. In order to improve this main programme quality indicator, the organized personal invitation needs to be implemented. The support of the Czech Ministry of Health would be crucial and very helpful to fulfil this task."



Julius Špičák, President of the Czech Society for Gastroenterology "Oncology constitutes one of the leading issues in gastroenterology together with endoscopy, acidopeptic disorders and inflammatory bowel diseases. The role of gastroenterologists in the diagnostic work-up, screening, treatment of early stages and palliation of neoplasms is irreplaceable."



### Jiří Vorlíček, President of the Czech Society for Oncology

"Support of CRC screening is an important task of the Czech National Cancer Control Programme. Although not involved directly in the screening diagnostics, clinical oncologists work as partners of the screening centres, as they are responsible for therapy and follow-up of CRC patients. Every Comprehensive Cancer Centre should develop some kind of cancer prevention programme."

### Petr Dvořák, vice-rector of the Masaryk University

"There are significant scientific achievements that define a cancer stem cell niche within colorectal tumours and show its central role in colorectal cancer relapse. Clinicians and scientists should work together to prevent or even treat this disease more effectively."



### Videogreetings from Meinhard Classen, Chairman of the Gastroenterology **Foundation Munich**

"Czech colorectal cancer screening can be proud of its rich history and has already reached visible results. Primary methodical base prepared by Prof Frič and his colleagues in 1990s has been expanded and provides an inspiring example. Meetings joining a wide spectrum of professionals engaged in the screening are highly welcome."



Maja Primič-Žakelj, President of Association of European Cancer Leagues

"Non-governmental organisations, such as cancer leagues, are the most important in screening promotion, while governments are responsible for good quality of screening, through monitoring and evaluation of the results. ECL strongly supports the Czech Cancer League in promoting the national colorectal cancer screening!"

### 3. Conference sessions – State of the art I





John Dalli, EU Comissioner for Health and Consumer Policy "For patients, high quality screening and diagnosis of cancer can make the difference between life and death. We could save the lives of many Europeans if we could diagnose the disease at an early stage. This is why the Commission presented the European Guidelines for Colorectal Cancer Screening, which provide a benchmark for best practice. I would encourage the Czech Republic to continue its efforts towards a full implementation of colorectal cancer screening."



## Leoš Heger, Czech Minister of Health

"Colorectal carcinoma in the Czech Republic poses a very serious problem. There is an urgent need to set up the right incentives within the system to change key parameters – e.g., personal responsibility or preventive programmes – so that ultimately, we can see incidence and mortality rates decrease. We are looking forward to cooperating with the Czech Medical Association, patient initiatives and specialists to put these into practice."



## Pavel Poc, Member of the European Parliament

"What would media do with air transport if one jumbo jet crashed every working day? Would they stay calm and quiet as they do when it comes to colorectal cancer? I think not, and considering that this disease develops for years, there is a good reason to try saving some of those people. And for those "economists", for whom money is more important than human life, the cure of an average cancer patient costs about one million CZK. Prevention is close to free and screening is very cheap."

### 4. Conference sessions – State of the art II



Reinhold Stockbrügger, United European Gastroenterology, Chair of the Public Affairs

"There are still huge inequalities between EU nations in prevention and treatment of colorectal cancer:

- On the way to implementation of population-based CRC screening, alternative opportunistic tactics have to be employed.
- Secondary prevention by screening should always be paired by a 'primary prevention', i.e., positive lifestyle changes.
- Europe needs a dedicated Centre for Cancer Prevention, unifying the diverse national, professional and scientific activities involved."

### ¥

### Julius Špičák, President of Czech Society of Gastroenterology

"The costs of cancer care are constantly increasing due to demographic reasons and high costs of new treatment modalities, particularly biologics. The financial analyses are locally different but universally agree on the beneficial contribution of screening programmes. These are generally affordable but they have to be adapted with respect to individual local conditions."





Lawrence von Karsa, International Agency for Research on Cancer "Cancer screening programmes are continuously expanding in the EU. At the same time, techniques are continuously evolving. Priority should now be given to:

- quality documentation, monitoring and evaluation of the experience in the Member States to provide evidence to continuously update the European standards,
- facilitation of effective implementation of the Guidelines in the Member States. The opportunity of the experience and the special capacity in the Czech Republic in organizing, documenting, monitoring and evaluating cancer screening programmes should be used for this purpose."

## Luc Colemont, United Europe against Colon Cancer

"There is still an important lack of knowledge about the possibilities of early recognition of CRC. Not only at the level of the general population, but also at the level of the GPs and the specialists. More attention (and money) should be given to information and education about CRC. If you don't know the enemy, you cannot win the war!"





Dominika Novak-Mlakar, National Institute of Public Health, Slovenia "Slovenian CRC screening practice combines the centralization of the invitation/remainder practice and the central reading of the iFOBT. Assistance of family doctor consists in the preparation of patients for a colonoscopy. The following arrangements are needed for the successful implementation of the programme:

• health professionals and political support,

long-term source of funding."

### ×

### Štěpán Suchánek, Scientific Secretary of Czech Society of Gastrointestinal Oncology

"The Czech National Colorectal Cancer Screening Programme is effective. Since 2006, 82,771 colonoscopies have been performed performed and 26,479 patients with adenomas and 3,463 with cancers have been diagnosed. The basic early performance indicators have been implemented and accomplished. But there are still important challenges: increase of target population coverage and assessment of longterm impact indicators."



## **5. Session of the United European Gastroenterology**

Impact of colorectal cancer prevention and screening: European perspective





#### ▲

### Hermann Brenner, German Cancer Research Centre

"Colorectal cancer (CRC) is both one of the most common cancers and one of the most avoidable cancers: There is now pervasive evidence for the effectiveness of various screening methods, including faecal occult blood tests, sigmoidoscopy and colonoscopy in reducing CRC incidence and mortality. Offers of organized screening with high levels of quality assurance and participation have the potential to lead to substantial reductions in CRC incidence and mortality in the years to come."



### Reinhold Stockbrügger, United European Gastroenterology, Chair of the Public Affairs

"Opportunistic CRC screening works well nationwide (USA, Germany, Poland) and in limited communities such as villages, counties and other areas, but also companies, insuranceguided initiatives and health care institutions. These possibilities can and should immediately be organized if population-based action is slow and/or impossible. Every day lost is a loss of happiness, life ... and money!"



### Bohumil Seifert, Czech Society of General Practice

"Primary care physicians (PCP) stay at the forefront of colorectal cancer early diagnostic and screening. The principal method of identification of colorectal cancer remains to be symptomatic presentation at GPs who are source of referral to secondary care. The involvement of PCP in CRC screening in EU countries varies according to chosen strategy and is direct (performing FOBT), indirect or supportive. The key issues for PCP are adherence of target population, address invitation, choice of primary test and accessibility of endoscopic services."

## 6. Session of the Czech Society for Gastrointestinal Oncology

Data-driven optimization of colorectal cancer screening: Czech experience





### Štěpán Suchánek, Scientific Secretary of Czech Society of Gastrointestinal Oncology

"Although the Czech National CRC programme has improved in recent years, there are still some crucial points of development: organized personal invitation (upgrade to population screening), individual data monitoring, switch from guaiac to immunochemical FOBT and adequate screening procedure reimbursement reflecting this new screening specialty."



## Bohumil Seifert, Scientific Secretary of Czech Society of General Practice

"The critical review of Czech CRC Screening Programme in 2009 showed suboptimal outcomes. Therefore new measures were adopted. After two years, collected data have shown a substantially increasing trend in screening attendance. Introduction of immunochemical tests, annual testing in the age interval 50-55 yrs and involvement of gynaecologists were considered to be effective, while introduction of primary screening colonoscopy did not affect the uptake. Regional variations indicate a space for improvement."



### Ladislav Dušek, Director of the Institute of Biostatistics and Analyses, Masaryk University

"IT infrastructure and comprehensive data support are obligatory components of any functional screening programme. Three principal dimensions should be projected in the information support of the screening: population and epidemiological registries, monitoring of diagnostic processes and long-term follow-up. IT specialists are challenged to develop comprehensive systems with adequate interoperability. Data collection should be legitimized by legislation to allow personalized follow-up of clients who have participated in the screening."



### ۸

Ondřej Májek, Institute of Biostatistics and Analyses, Masaryk University

"Monitoring of performance indicators helps to maintain continuous quality improvement and therefore achieving favourable effectiveness of colorectal cancer screening programme. Using diverse sources of national data in the Czech Republic, we can assess most of the internationally recommended indicators. Routine monitoring shows increasing programme quality, mathematical models can be used to demonstrate important effect of the programme in preventing colorectal cancers."



### Rudolf Hrčka, University Hospital Bratislava

"The main objective of CRC screening is a significant and sustained reduction of mortality and incidence of the disease at the risk population. The major problem worldwide is the lack of acceptance of the screening by the targeted population. This can be overcome only by a fundamental change in our approach to the screening. Until there is no institute of a so called 'wise-man violence' in this field, there will be no major increase in the participation of the targeted population. Simply, until there will be no legal obligation set for the targeted population to participate in the execution of the standardized faecal occult blood test subject to effective sanctions, the epidemiological parameters will not decline and the society will continue to lose human lives and huge financial resources unnecessarily. In Slovakia, such a 'wise-man violence' was already employed in the area of stomatology. Those who are not willing to undergo an annual checkup are obliged to pay for their dental treatment in full cost."



### ▲

Přemysl Frič, Czech Society of Gastrointestinal Oncology, founder of the Czech CRC screening

"National programme of colorectal cancer screening is a multifaceted and orchestrated project. It has many players but only one conductor. Every player has his notes and should play as prescribed in the notes and under the leadership of the conductor. The role of the conductor belongs to the Ministry of Health and cannot be transferred to any other institution, e.g., to health insurance companies. The prerequisite is, however, that the preventive programmes will be considered by the Ministry of Health the cornerstone of the state health politics. The health insurance companies are frontmen but not conductors of public screening programmes."



## 7. Session of the League Against Cancer Prague & ECL

Colorectal cancer prevention and screening viewed by patients and health care payers



Michaela Fridrichová, Chair of the League Against Cancer Prague "Prevention is always significantly less complicated and cheaper than the therapy of malignant tumours. Our leading effort must be to protect people from cancer."



Pavel Sobotka, Director of the Frentech Aerospace, CRC patient "Each year, cancer takes a huge toll in EU countries. Cancer is a societywide and pan-European problem, and a major economic problem, too. It is essential for EU countries to join their financial and human resources in some body working like a cancer agency which will be primarily focused on basic research with the aim to eliminate cancer. For the time being, we are fighting cancer with prevention. Prevention must be actively promoted! Treatment of cancer is painful, very expensive and its success is doubtful in many cases. A proactive fight against cancer must become one of the primary aims of the EU. At present, cancer is mostly dealt with too late - after a diagnosis. Cancer presents a big challenge for the EU."



### Pavla Freij, Director of Onkomaják, and Jiří Pešina, Roche

"Colon Tour (StřevoTour) project = the awareness campaign, with Roche as a main partner, is focused on improving public awareness and understanding of colon and rectal cancer and its prevention. The public has an opportunity to visit a giant inflatable gut and get information on symptoms, prevention, screening methods and treatment. More than 25,000 people went through the giant gut model, obtaining information on colorectal cancer symptoms, prevention and treatment in 2010 and 2011. The countrywide campaign was covered by 248 media outputs. Onkomaják was awarded the winner's trophy in the Non-Governmental Organisations category at the European Excellence Awards in 2010. From May 2012, the Colon Tour has been continuing in other towns and cities."



### Marie Ředinová, Chair of the Czech ILCO

"I stick to the motto 'most importantly, do not be afraid': do not be afraid to solve problems, do not be afraid to talk about unpopular issues. I have been living with a permanent ostomy for 10 years as a result of bowel cancer. At the very beginning, I managed to cope with the new situation thanks to volunteers from an association of ostomates, and I have worked as a volunteer for the Czech ILCO since 2006. I have been encouraging new patients and working in the Information and Support Centre for Ostomates and Bowel Disease Patients. I became the fourth President of the Czech ILCO in 2010. Under the Czech ILCO leadership, all ILCO associations have participated in the project called 'Get to know colorectal cancer' and have pledged to promote cancer prevention. I have been actively participating in the project 'You and us together' that provides information on colorectal cancer prevention to the public and on treatment possibilities to CRC patients. Patient organizations play an indispensable role in the health care provided to CRC patients."

Post-conference workshop

## GPs and other medical specialists in the 1<sup>st</sup> line support of colorectal cancer screening

### Interactive workshop focused on challenges and potential barriers in colorectal cancer screening at the primary care level.









### Chairs: B. Seifert, B. Skála

### **Contributions:**

- B. Seifert, B. Skála: GPs are not alone but still are the main power in the 1<sup>st</sup> line of CRC prevention
- M. Pískovská: Colorectal cancer screening case reports
- N. Král: Role of GPs in CRC screening in data-based survey via Europe
- A. Skřivánek: Role of gynaecologists in the primary care system
- P. Kocna: Immunochemical faecal occult blood tests (iFOBT) for colorectal cancer screening
- V. Válek: Virtual colonoscopy a screening opportunity for specifically indicated clients?

### Main conclusions:

- 1. Priorities are clear. Every population screening programme has some limitations, but its value and finally reachable effectiveness ultimately depend on its quality and the adherence of clients.
- Screening tests must be reasonably offered to clients in a way which is widely acceptable. The role of GPs and other specialists in primary care is fundamental for the adherence to repeated testing.
- 3. Current CRC screening performance is limited due to the lack of two principal arrangements, which must be managed at the governmental level (payers, ministry): addressed invitation and proper motivators for primary care specialists. Knowledge-based model for addressed invitation should be adopted to invite and recall participants to the screening. CRC screening should be widely practiced and adequately reimbursed by payers.
- 4. Colonoscopy is not the primary dominant test in the Czech screening programme, the coverage is driven by FOBTs; iFOBT should be preferred providing there is standardized methodology and optimized cut-off value of its positivity. The heterogeneity of available immunochemical tests is high, further consideration must be given to how well different iFOBTs work.
- Advanced diagnostic tests such as virtual colonoscopy can be recommended at special occasions for indicated patients, but they cannot replace standardized screening tests.





Post-conference workshop

## Can we utilize real-world data to support colorectal cancer control?

This methodically oriented workshop discussed data sources required to manage CRC control in contrast to their accessibility in routine clinical practice. Innovative solutions in automated merging and mining of heterogeneous multi-professional databases were proposed.









### Chairs: O. Májek, T. Pavlík

### **Contributions:**

- J. Mužík: Hospital-based data in regional and local strategies optimizing CRC control and management: real-world outcomes of the Czech National Cancer Control Programme
- M. Blaha: Automated exploration and mining of real-life hospital cancer care data as a challenge for IT experts a proposal of functional solution
- O. Májek: Can we utilize hospital-based data to improve the performance CRC screening?

Main conclusions:

- 1. Colorectal cancer screening is a comprehensive health care programme, translating efficacy (proved as evidence-based input) to effectiveness (outcome proved using real-world evidence, data from clinical practice).
- Computerization of all required data sources is an elementary methodical component of any functional screening programme. Screening information system should centralize data from three principal sources: epidemiological registry, e-data capture systems monitoring diagnostic processes and longterm follow-up.
- 3. IT tools supporting screening should be implemented as an intrinsic component of comprehensive systems for colorectal cancer management and control. Effective evaluation should cover not only outcomes of the screening itself but also results of cancer diagnostics in a wider sense. Equity in cancer diagnostics and screening should be evaluated as well.
- 4. IT specialists and researchers should be tasked with developing electronic health records in all dimensions of cancer screening, from population registries to clinical level. Insufficient interoperability and lack of comprehensive ontologies still represent important obstacles in screening evaluation.
- 5. Managers and stakeholders should be tasked with improving of legislative background of data analysis in cancer screening. Merging of different data resources, personalized monitoring of clients' trajectories in the screening process should be legitimated in legal systems.
- 6. IT should aim to support holistic approach to screening and cancer prevention in general. Information sources should be widely available to the public in order to support healthy lifestyle and primary prevention as well.



**Conference Exhibition** 

## Czech Civic Association Onkomaják presenting a nationwide educational cancer prevention programme with an inflatable model of bowel



Onkomaják o.s. was founded on April 10, 2009. Its main purpose is to help anybody who is in need to get some information about cancer diseases. The first and still ongoing project is focused on colorectal cancer. It is called "Střevotour" ("Colontour").

### "Střevotour", "Colontour"

Since the end of 2009 OnkoMaják has been travelling with an inflatable model of colon across the Czech Republic. During the first year (2010) OnkoMaják visited all the major cities with special hospitals – Cancer Centres. In 2011 OnkoMaják also included smaller towns and hospitals into its itinerary. In 2012 OnkoMaják started to visit unusual places such as town halls, special events in cooperation with radio stations, TV stations, smaller hospitals, theatres. The tour is focused:

- on colorectal cancer prevention
- on the education of general public and cancer patients about the way how their treatment plan should go, what steps should be made, about their rights to have second opinion from independent doctor, about the importance of a multidisciplinary team when being a cancer patient.

OnkoMaják also communicates with the general public and with cancer patients via the following websites:

- www.onkomajak.cz
- www.rakovinastreva.cz
- http://www.facebook.com/pages/Onkomaj%C3%A1k-os/130494926961043
- www.facebook.com/nebudstrevo











OnkoMaják is proud to have been awarded:

### **European Excellence Awards**

• in the category of nongovernmental organisations for the communication of the project Střevotour 2010 (Colontour 2010)

A prestige award, which is given each year for an outstanding success in the field of public relations and communication.



## Masaryk Memorial Cancer Institute & Institute of Biostatistics and Analyses, Masaryk University

### Pre-conference presentation of the Czech National Cancer Control Programme

Masaryk Memorial Cancer Institute (MMCI, www.mou.cz) is a leading comprehensive cancer centre in the Czech Republic, providing complete diagnostics, treatment, and preventive care in oncology for all patients including international clients. MMCI is the only health care provider in the Czech Republic carrying two quality approvals: by the Joint Commission International and by the independent Czech Republic Joint Accreditation Commission. The institute initiated a comprehensive cancer prevention programme including both screening and complex diagnostic examinations supporting early cancer detection and encouraging healthy lifestyle of the clients.



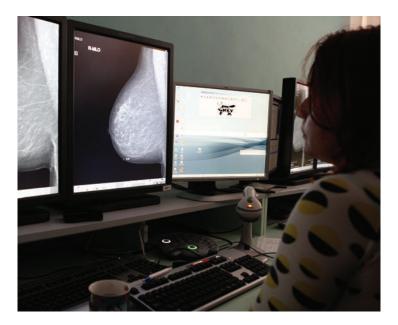


EU commissioner John Dalli accompanied by Member of the European Parliament Pavel Poc and Marek Svoboda, Deputy Director of the Masaryk Memorial Cancer Institute



- 🔺

Jiří Vorlíček, Director of the Masaryk Memorial Cancer Institute, welcomes EU commissioner John Dalli









Visit at the breast cancer screening unit at the MMCI

All three evidence-based cancer screening programmes have been implemented in the Czech Republic, as recommended by the Council of the European Union. An organized screening programme for breast cancer was launched in September 2002. The impact of the screening programme on breast cancer epidemiology has been enormous. A nationwide colorectal cancer screening programme was launched in 2000 with the aim of performing faecal occult blood in a two-year interval. Commencing 2009,



people aged over 55 years can opt for colonoscopy to be performed every 10 years as a screening test. Since 2008, the opportunistic system of cervical cancer prevention has been transformed into a nationwide cervical cancer screening programme. In January 2008, a network of accredited screening cytology centres was established. More information can be found on the official portals of the screening programmes – **Mamo.cz**, **Kolorektum.cz** and **Cervix.cz**.

**Institute of Biostatistics and Analyses** at the Faculty of Medicine and the Faculty of Science of the Masaryk University, Brno, Czech Republic (IBA MU; www. iba.muni.cz) is a research institute oriented to the solution of scientific projects and providing related services, especially in the field of biological and clinical data analysis, organization and management of clinical trials, software development and ICT applications. IBA MU is a provider of information background





for the Czech National Cancer Control Programme, including three cancer prevention programmes – breast, colorectal, and cervical screening. Research activities of IBA MU in the

field of cancer care also include development and analyses of epidemiological and clinical registries and health technology assessment.

A gift for visitors – the book Czech Cancer Care in Numbers 2008–2009



Ladislav Dušek, Director of the Institute of Biostatistics and Analyses, presents main aims of the Czech Cancer Control Programme in prevention

## Municipality of the City of Brno

Pre-conference meeting with Brno representatives



(

Deputy Mayor of the City of Brno Ladislav Macek welcomes the EU Commissioner for Health and Consumer Policy John Dalli, Member of the European Parliament Pavel Poc and the EU Representative of the European Commission in the Czech Republic Jan Michal at the Brno Town Hall.





### <

Deputy Mayor of the City of Brno Ladislav Macek, EU Commissioner for Health and Consumer Policy John Dalli, Czech Minister of Health Leoš Heger, Member of the European Parliament Pavel Poc and the Representative of the European Commission in the Czech Republic Jan Michal before a lunch meeting.

## **Conference summary**

Colorectal cancer is one of the most commonly diagnosed cancers and is the second leading cause of cancer deaths in Europe. More than 200,000 Europeans die each year from malignant tumours of the colon and rectum. These deaths, however, are avoidable in many cases. Numerous clinical and epidemiological studies continue to bring evidence on the benefit of colorectal cancer screening both for individuals and for the populations and societies.

The conference European Colorectal Cancer Days (www.crcprevention.eu), held on 4–5 May 2012 in Brno, Czech Republic, was intended as a networking event, the aim of which was to share up-to-date knowledge and to discuss the application of the hitherto collected findings as regards the establishment of effective systems for colorectal cancer screening and early detection. Regardless of the recent advances in many European countries, there are still many rather persistent questions and problems that need to be addressed. This document attempts to summarize the most important outcomes of the meeting in ten key points.

- Screening with faecal occult blood test or colonoscopy prevents colorectal cancer and saves lives. Very high incidence and prevalence of CRC in Europe keep the mortality from colorectal cancer at the top position among malignant tumours. However, over 90 per cent of these cancers can be prevented due to screening; this fact documents its remarkable societal value.
- CRC screening is recommended and well recognized at the European level. The support stems mainly from the EU Council Recommendation (2003/878/EC), professional methodical guidelines published in 2010 and the Declaration of the European Parliament on the Fight Against Colorectal Cancer in the EU, which was also published in 2010.
- 3. The population-based screening has the potential to significantly reduce the epidemiological burden associated with CRC. It means that the screening process must be able to identify population target cohorts and to support them through addressed invitation. Such scheme can be referred to as the gold standard of the screening design. The current reality, however, is that screening programmes in most European countries still remain in the opportunistic zone, without targeted background reminding the citizens about the screening programme. The opportunistic screening, if equipped with quality assurance and control, might also be effective to a certain degree, at least as the primary step in building appropriate population-based strategy. The opportunistic programmes should be continuously challenged to strengthen their organizational layout in accordance with the population-based model in order to assure the compliance of medical professionals and inhabitants.
- 4. However, an evidence-based design and a declared support of the screening are not sufficient. The practical and everyday implementation of the CRC screening in health care systems still faces major problems in individual countries. Heterogeneity in screening plans, changeable modalities employed, low compliance of the target population and insufficient support of stakeholders should be mentioned as the most important obstacles.
- 5. CRC screening is a complex health care programme which requires a continuous optimization in everyday health care practice. Its implementation in the health care system of any country must incorporate all necessary elements, namely evidence-based design, optimized capacity and succession of employed modalities and tests, quality assurance routines and finally a follow-up monitoring. Long waiting times, overloaded capacity, insufficient standardization of diagnostic tests all of these discredit the screening programme and make further progress impossible.
- 6. CRC screening represents a multi-professional preventive strategy which must be based on robust IT infrastructure. Computerization should become a vital component of a functional CRC screening, namely as the support for inevitable personalized monitoring of invitation, recall and compliance of the target population. Only fully computerized information systems and merged multiple data sources have the potential to follow the individual trajectory of screening participants. In order to be sustainable, the comprehensive information system of the screening process should cover three principal dimensions: a representative population-based epidemiological registry, monitoring of all processes at the screening diagnostic centres, and finally a long-term follow-up. Electronic data capture and subsequent information services must be realized within an adequate legislative framework which is not yet sufficiently harmonized among European countries.
- 7. A formal concept of cost-effectiveness evaluation should be adopted and incorporated as an indispensable component in the screening communication strategy. Financial aspects and reachable monetary benefits should be quantified and more visibly communicated, especially in contrast to the growing cost of cancer therapy.
- 8. Communication and information policy supporting all kinds of cancer prevention should be more standardized and set up to grow in impact. New guidelines focused on information policy were proposed to be published as an activity which might help the governments and stakeholders to motivate target groups to participate in cancer prevention. First-line communication priorities, promotion of healthy lifestyle and primary prevention rules, data-based models of addressed invitation to the screening and highlighting screening motivators both for clients and health care professionals should be emphasized and standardized in some kind of a new communication tutorial.
- 9. Well organized and governmentally supported promotion of CRC screening should be closely linked to spontaneously initiated activities. Internet communication, social networking and up-to-date communication technologies including

TV are still not saturated in their advertising potential. An innovative, less widespread, but effective communication models should be introduced, such as strongly suggested communication focused on the so-called "closed communities" of people with the same employment, hobby, lifestyle, etc.

- 10. Only the mutual collaboration of stakeholders, professional medical communities and patients' organizations can really eliminate the major barriers to an effective screening process.
- 11. Outcomes of the Brno meeting proved that the European communities engaged in cancer prevention are able to extrapolate data and to share their experience with screening, and that more experienced regions and teams can contribute to the progress of the less experienced ones. This meeting of relevant stakeholders, which was supported by representatives of medical societies and patients' organizations, offered a functional base for experience sharing and a stimulating atmosphere for fruitful discussion of various methodical problems associated with colorectal cancer screening. The multitasking conference joining all the subjects involved in the screening will continue as a new platform generating horizontally managed initiatives which are focused on the support of colorectal cancer screening in all required aspects.

## What should be done?

### Let's upgrade information policy to support CRC cancer prevention

There is no need to invent new models of CRC screening or to dramatically modify its content – European Guidelines are here to help with the design as well as with the implementation of an appropriate screening plan.

• Do responsible national screening coordinators communicate their problems, successes and experience with the guidelines and with their screening programmes? Are they willing to share them?

Different countries have different health care systems. Populations might differ in mentality, culture and inevitably in the attitude to the prevention. On the other hand, neighbouring or similar countries have similar health care environment, similar populations and similar problems with CRC screening.

• Do we use some cross-boundary information platform to help us effectively share solutions, ideas or arrangements?

Everyone today knows the word "cancer". "Cancer prevention" is nearly an overused phrase. People know that smoking is killer. But why do they smoke anyway?

 Do we communicate importance and content of cancer prevention in really a motivating way? In a way acceptable for masses?

Cancer typically occurs in elderly people. However, healthy lifestyle and primary prevention should not be perceived by elderly people only.

• Is the current promotion of cancer prevention appealing for the young generation? Is it an up-to-date and attractive communication, or is it a "dead-letter message"?

Functional screening must be a well orchestrated action of many subjects which need to coordinate their activities closely.

• Are they all aware of their role and responsibility in the screening and in cancer prevention in general? Do we use the collected data to prove the dominance of screening benefits over its risks? Are we trying to convince politicians and stakeholders about the monetary benefits of CRC screening?

Primary health care guaranteed by general practitioners, gynaecologists and other medical specialists is the most important line in the fight against CRC.

• Are they all intentionally involved? Do we search effectively for weak points?

"Data rich – information poor" has become an obligatory phrase or a widely accepted "professional dialect" which is also associated with health care. It might also apply to the colorectal cancer screening programme, but not necessarily. Most problems can be avoided by sharing knowledge, reducing the heterogeneity in input data and by an effective communication on multiple levels. Progress in colorectal cancer prevention increasingly requires standardized and multi-disciplinary exploitation of information resources and their usage in all levels of the "information pyramid" that supports the CRC screening:

- widespread "CRC-education" strategy, addressing also young generation
- · widespread advertising and image-making promotion of screening and prevention
- · addressed invitation and recalling of the target population to the screening
- quality assurance and control, including its international benchmarking
- · cross-boundary communication and networking

Modern CRC screening needs an innovative, up-to-date, comprehensive and effective information policy: a pan-European policy.

























OLOREKTÁLNÍHO KARCINOMU: VENCE A SCREENING



ZASTITOU Is laken our podportou Is renered detackour pode due Is renered detackour pode du