Nová evropská konferenční a informační platforma usilující o zlepšení péče o pacienty s kolorektálním karcinomem – www.crcprevention.eu

New European Information and Communication Platform Striving for Improved Care for Colorectal Cancer Patients – www.crcprevention.eu

Dušek L.^{1,2}, Poc P.³, Májek O.^{1,2}, Suchánek Š.⁴, Seifert B.⁵, Gregor J.¹, Zavoral M.⁴

Souhrn

Příspěvek představuje novou informační a komunikační platformu zaměřenou na propagaci prevence kolorektálního karcinomu a na zvýšení kvality péče o pacienty s tímto onemocněním. Vedle cílů platformy jsou zde uvedeny závěry z prvního ročníku mezinárodní konference "Evropské dny kolorektálního karcinomu", která se pravidelně koná v Brně od roku 2012. Veškeré informace jsou zveřejňovány na portálu www.crcprevention.eu.

Klíčová slova

nádory tlustého střeva a konečníku – iniciativa – prevence – screening – konference

Summary

The article introduces a new information and communication platform that focuses on the promotion of colorectal cancer prevention and on the improvement of care for colorectal cancer patients. In addition to the platform's objectives, the article also presents the conclusions of the first year of the "European Colorectal Cancer Days" international conference held annually in Brno since 2012. Further information and news are available at www.crcprevention.eu.

Key words

colorectal cancer – initiative – prevention – screening – conference

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doc. RNDr. Ladislav Dušek, Ph.D.

Institut biostatistiky a analýz LF a PřF MU Kamenice 126/3 625 00 Brno e-mail: dusek@iba.muni.cz

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¹Institut biostatistiky a analýz, LF a PřF MU, Brno

² Ústav zdravotnických informací a statistiky ČR, Praha

³ Kancelář poslance Evropského parlamentu, Brusel

⁴Interní klinika 1. LF UK a ÚVN Praha

⁵Ústav všeobecného lékařství, 1. LF UK v Praze

Na zhoubné nádory tlustého střeva a konečníku je třeba nahlížet jako na celospolečenský problém, jehož řešení nelze očekávat od jednostranných, byť efektivních opatření. Vysoká incidence onemocnění a s ní související mortalita jsou do značné míry objektivním důsledkem demografického vývoje a lze je pozorovat ve většině ekonomicky vyspělých zemí světa. Jelikož je kolorektální karcinom (colorectal cancer - CRC) onemocněním preventabilním, těžiště boje s touto nemocí nutně leží v prevenci. Zdravý životní styl, omezení vlivu rizikových faktorů a v neposlední řadě dobře organizovaný screeningový program jsou základem strategie, která má potenciál nejen snížit mortalitu u tohoto onemocnění, ale i podstatně redukovat jeho incidenci. Nezbytnou součástí takto široce pojatých opatření musí samozřejmě být i propagace prevence a věrohodná, daty podložená motivační kampaň zasahující celou společnost. Informační platforma prezentovaná na portálu www. crcprevention.eu vznikla s cílem vyplnit chybějící prostor pro společná jednání a vzájemnou koordinaci všech odborných, populačních a zájmových skupin, které se mohou v boji proti CRC angažovat. Cílem je sdružit aktivity politických uskupení, vedení zdravotnictví, lékařů nejrůznějších odborností, občanských sdružení a pacientských organizací. Setkání zástupců tak širokého spektra subjektů nebývá běžné, typicky se konference nebo jiné formy jednání zaměřují pouze na určitou oblast problematiky a tím také přímo nebo nepřímo selektují auditorium. Přitom právě mezioborová komunikace a všestranné sdílení informací, byť částečně zjednodušených, může významně napomoci v prosazení hlavních opatření, které prevence, diagnostika i léčba CRC nutně potřebují.

Platforma zahájila svoji činnost v Brně na počátku května 2012 mezinárodní konferencí, jejíž program naplnily přednášky vedoucích představitelů všech výše uvedených skupin. Reprezentativní účast na této konferenci svědčí o faktu, že podobná, široce pojatá setkání a komunikace v evropském prostoru do jisté míry chybí.

První ročník konference podpořil a osobně se jí zúčastnil eurokomisař pro zdravotnictví a spotřebitelskou politiku John Dalli. Setkání pravidelně pořádá Kancelář europoslance Pavla Poce s Asociací evropských lig proti rakovině a ve spolupráci s Institutem biostatistiky a analýz Masarykovy univerzity a dalšími partnery.

Nosným tématem konference je prevence CRC a zejm. organizovaný screening tohoto onemocnění. Náplň programu dobře charakterizuje jeho podtitul "Prevence podložená daty má potenciál zachraňovat životy" a rovněž následující text převzatý z konferenčních materiálů:

- Kolorektální karcinom (CRC) se řadí mezi nejčastěji nově diagnostikované nádory a je druhou nejčastější příčinou úmrtí na nádorová onemocnění v Evropě. Na zhoubné nádory tlustého střeva a konečníku každoročně umírá více než 200 000 Evropanů. Mnoha úmrtím by se však dalo předejít, neboť je k dispozici účinná a bezpečná prevence a časná detekce CRC. Stále narůstající počet klinických a epidemiologických studií přináší další a další důkazy o prospěšnosti kolorektálního screeningu jak pro jednotlivce, tak pro celou společnost. Screening pomocí testu okultního krvácení do stolice (TOKS) nebo kolonoskopie může zabránit rozvoji onemocnění a v konečném důsledku zachraňovat
- Medicína založená na důkazech však sama o sobě nestačí. Přestože je velice významná, nepokrývá všechny dimenze úspěšného screeningového programu. Mezi další faktory, které významně přispívají k žádoucímu snížení incidence a mortality sledovaného onemocnění, patří i silné řízení a organizace, vysoká kvalita všech souvisejících zdravotních služeb a v neposlední řadě i ochota cílové populace se programu zúčastnit. Vzájemné harmonie těchto faktorů však nelze dosáhnout bez podpory zdravotnických autorit, politiků, zdravotních pojišťoven a dalších zainteresovaných orgánů.
- V pozadí každého fungujícího screeningového programu jsou nevyhnutelně data. Reprezentativní sběr dat je nezbytnou součástí screeningového procesu, neboť umožňuje monitoro-

- vat jeho výkonnost a kvalitu, kontrolovat bezpečnost a účinnost, ale také poskytovat "vědecky podložený marketing" daného screeningového programu. Pečlivě sbíraná a patřičně prezentovaná data mohou být vodítkem pro politiky, mohou přispívat k optimalizaci poskytované zdravotní péče a zvyšovat atraktivitu programu pro laickou veřejnost.
- Cílem platformy je vybudovat vzájemnou síť kontaktů, která by měla napomoci ve sdílení současných poznatků i v diskuzi, jak tyto poznatky využít pro vybudování účinného systému pro screening a časnou detekci CRC. Ačkoliv v mnoha evropských zemích již bylo dosaženo jistého pokroku, stále přetrvává řada nezodpovězených otázek a nevyřešených problémů, jako jsou např.:
- Jsme schopni implementovat nové modality CRC screeningu, aniž by to mělo negativní dopad na účast cílové populace?
- Jsou při vývoji nových strategií brány v úvahu i všechny ostatní aspekty CRC screeningu, tzn. bezpečnost, proveditelnost a nákladová efektivita?
- Který faktor je významnější při zvyšování výkonnosti a pokrytí screeningu – medicínské nebo organizační faktory?
- Přihlédneme-li k heterogenitě CRC screeningu v evropských zemích, co je zlatým standardem populačního programu? A existuje vůbec takový standard?
- Lze extrapolovat data a zkušenosti ze zemí s odlišným systémem řízení zdravotní péče?
- Jaká je optimální sada indikátorů výkonnosti a kvality v CRC screeningu?
- Existují ověřené a povzbudivé příklady efektivní komunikace s laickou veřejností?
- Kdo funguje jako nejúčinnější "image-maker" CRC screeningu – politici, plátci zdravotní péče, pacientské organizace, lékaři … celebrity?

Po třech úspěšných ročnících konference bude platforma www.crcprevention.eu zcela jistě organizovat další ročníky takto široce pojatého setkání, vždy

s nosným tématem týkajícím se prevence a léčby CRC. Další ambicí je propojovat aktivity různých skupin a přispívat k propagaci prevence a screeningu ná-

dorů tlustého střeva a konečníku i v období mezi konferencemi. Tomu odpovídají i zobecněné závěry dosavadních konferencí, které zde přikládáme v anglickém jazyce (příloha 1) i dosažený výsledek v podobě zahájeného adresného zvaní občanů ČR do screeningu (příloha 2).

PŘÍLOHA 1

Colorectal Cancer Screening in Europe in the Era of the Guidelines Issued in 2010 – Current Progress Opens New Methodical and Managerial Challenges

A Report of European Colorectal Cancer Days (ECDD) as a Networking Event Supporting CRC Prevention

Introduction

Colorectal cancer (CRC) 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. In many cases, however, these deaths are avoidable. Numerous clinical and epidemiological studies continue to bring evidence of the benefit of CRC screening both for individuals and for the populations and society. CRC screening is thus one of the most desirable forms of organized cancer prevention which should be supported by modern health care systems.

The methodical aspects and scientifically driven promotion of the CRC screening were the main topics of the European Colorectal Cancer Days (ECCD) conference, held on 4-5 May 2012 in Brno, Czech Republic. The conclusions of this event challenged the organizers to continue this networking activity. Consequently, the second and the third years of the ECCD conference, focused on CRC prevention, its progresses, problems and potentials, were organized in 2013-2014 in the same place. The primary emphasis of these events involves sharing of experiences and networking among European countries in respect of standardization of colorectal cancer screening. This document is a brief summary of the outcomes of the previous meetings, which predetermined the main topics of the upcoming one in 2015. Further information can be found on the portal www.crcprevention.eu.

Outcomes and proposals of the European Colorectal Cancer Days platform

Both the previous and the future ECCD meetings are intended as a networking event, the aim of which is to share up-to-date knowledge and to discuss the application of the hitherto collected findings as regards the establishment of effective systems for screening and early detection of CRC. Regardless of the recent advances in many European countries, there are still numerous rather persistent questions and problems that need to be addressed. One of the subtitles of the Brno meetings, "Data driven prevention has the power to save lives", aimed to focus attention on the achieved outcomes of the preventive programmes which cannot be evaluated without a methodically strong information background. In the era of colorectal prevention known as "The Era of CRC Prevention Guidelines" which were issued in 2010 [1], the methodical standards are known and recommended as well as the principal endpoints of the effective

colorectal screening programme. It has been widely documented that only population-based CRC screening really has the potential to prevent colorectal cancer and save lives.

However, the heterogeneity in design and in the content of the national prevention strategies is still significant in the European region [2]. More intensive communication, feedback analyses of the results achieved, and platforms for the exchange of experiences should be supported and facilitated in Europe. More than ever before, we need to implement functional information systems monitoring performance and quality of the CRC screening programmes in real-world clinical practice and allowing unlimited communication and sharing of the experience gained in individual countries. The principal questions facing health care scientists, payers and the other stakeholders are:

- 1. Is CRC screening as widely practised as it should be according to the conclusions of evidence-based medicine?
- 2. Is it sufficiently reimbursed in the heterogeneous European health care systems?
- 3. Do practising clinicians follow the methodical guidelines and the rules corresponding to the population-based design of the screening?

The following key points summarize the most important outcomes of the ECCD 2012–2014 meetings and emphasize some problems challenging future development in this field:

CRC screening & knowledge base

- 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 the colon and rectum [3].
- 2. Based on the results of numerous randomized controlled trials, mortality from CRC can be effectively reduced through early cancer detection by the faecal occult blood test [4].
- 3. A high-quality screening programme is able to translate the outlined efficacy into real-life effectiveness, i.e. to prevent cancers [5], to save lives [6] and to save an enormous amount of financial resources [7].

CRC screening & State of the Art

- In Europe, CRC screening is recognized and recommended as an important healthcare programme [8,9].
- 2. Many European countries have already implemented CRC screening programmes in recent years [10].
- 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 recently been published and recommended by the European Commission [1].
- 4. Efficacious and feasible CRC screening methods are known – FOBT (guaiac or immunochemical) followed by colonoscopy in the case of positive findings and/or endoscopy (sigmoidoscopy or screening colonoscopy) [1].
- 5. The gold standard of the screening model is well-defined and recommended [1,11] a population-based screening programme. However, where this model was not possible at the very

beginning of the programme, opportunistic screening started as a primary step, often as a nation-wide organized programme or as an initiative for limited, closed communities [2].

CRC screening & current challenges

- 1. The heterogeneity is still significant among European countries, both in design and in the content of the CRC screening programmes. More intensive communication, feedback analyses of the results achieved, and platforms for the exchange of experiences among countries should be supported and facilitated.
- 2. Switching various strategies into fully organized population-based screening represents one of the most important tasks of current CRC prevention. Only an organized programme can provide a way to address most of the problems associated with opportunistic screening strategies, including low coverage of the target populations. Organized screening also represents a template which focuses on the quality of the screening procedures, including long-term follow-up of participants [11].
- 3. Modern CRC screening needs an innovative, up-to-date, comprehensive and effective information policy a pan-European policy. A methodical effort which will further develop and translate already published guidelines in the field of communication and information policy is highly demanded. Guidelines focused on information policy might help the 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 logic model.
- 4. The legislative background of nation-wide 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 merging of required data sources within an adequate legislative framework.

- 5. CRC screening promotion should be more visibly enriched to encompass an exact explanation of its economic dimension. Cost-effectiveness modelling and quantification of the economic benefits of the CRC screening should not be overlooked, also, among other things, as part of the European grant policy. Translational research approaches, international collaboration and cross-boundary networking are needed.
- Europe needs a dedicated Center for Cancer Prevention, unifying the diverse national, professional and scientific activities involved.

Let's upgrade information policy to endorse standardization of CRC cancer prevention in Europe and to attract citizens as active participants

There is no need to invent new CRC screening models or to dramatically modify its content – the European Guidelines are here to help with the design as well as the implementation of an appropriate screening plan [1]. However, responsible national screening coordinators should more intensively communicate their problems, successes and experience with the guidelines and with their implementation. The most recommended way of collaboration would be to share the national usage trend data for applied screening tests.

Different countries have different health care systems. Populations might differ in mentality, culture and inevitably in their attitude to prevention. On the other hand, neighbouring or similar countries have a similar health care environment, similar populations and similar problems with CRC screening. Cross-boundary information platforms should be established 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 kills. But why do they smoke anyway? We should communicate the importance and content of cancer prevention in a really motivating way: in a way the masses will accept.

Cancer typically occurs in elderly people. However, healthy lifestyle and primary prevention should not be perceived by elderly people only. The current promotion of cancer prevention should be innovative and appealing to the young generation. It must be an up-to-date and attractive communication strategy, otherwise it is a "dead-letter message" for perspective age cohorts.

Functional screening must be a well-orchestrated action of many subjects that need to coordinate their activities closely. All the subjects involved should be aware of their role and responsibility in the screening and in cancer prevention. Routinely collected data should prove the dominance of screening benefits over its risks. Data-driven communication should convince politicians and stakeholders about the monetary benefits of CRC screening.

Primary health care provided by general practitioners, gynaecologists and other medical specialists is the most important line in the fight against CRC. All these disciplines should be intentionally involved in the communication and promotion of cancer prevention.

"Data rich – information poor" has become an obligatory phrase or a widely accepted "professional dialect" that is also associated with health care. It might

also apply to CRC screening, but not necessarily. Most problems can be avoided by sharing knowledge, reducing the heterogeneity in input data and effective communication on multiple levels. Progress in CRC prevention increasingly requires standardized and multi-disciplinary exploitation of information resources and their usage on all levels of the "information pyramid" that supports the CRC screening:

- widespread "CRC-related education" strategy, also addressing the young generation:
- powerful 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.

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PŘÍLOHA 2

Czech Project of Personalised Invitation to Cancer Screening Programmes Launched — Report and Conclusions from Experts' Meeting

Report Published on the Basis of the European ECCD Platform, www.crcprevention.eu.

The "Cancer Screening Programmes in the Czech Republic and Importance of Personalised Invitation" workshop, held on 5 December 2013 in the Clarion Congress Hotel Prague, was organised by the Institute of Biostatistics and Analyses at the Masaryk University in cooperation with the WHO Office in the Czech Republic, the Kolorektum.cz Initiative, and the Office of Member of the Eu-

ropean Parliament Dr. Pavel Poc. The workshop was held under the auspices of Martin Holcát, MD, MBA (Czech Minister of Health), Alena Šteflová, Ph.D., MPH (Director of the WHO Office in the Czech



Fig. 1. Dr. Pavel Poc, Member of the European Parliament, and Assoc. Prof. Ladislav Dušek, Ph.D., Director of the Institute of Biostatistics and Analyses at the Masaryk University.

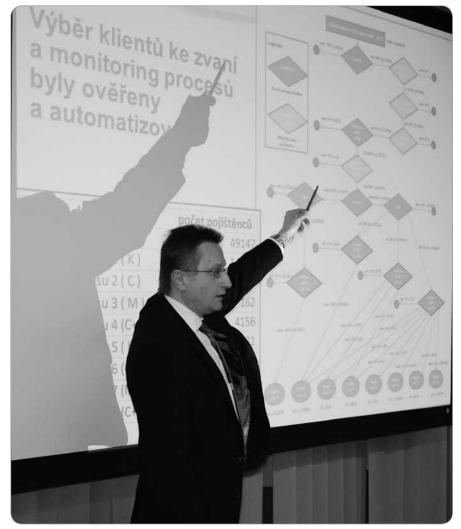


Fig. 2. Assoc. Prof. Ladislav Dušek, Ph.D. introduces the methodology of personalised invitation.

Republic), and Dr. Pavel Poc (Member of the European Parliament).

Guarantors of Czech cancer screening programmes, representatives of the Czech Ministry of Health, health insurance companies and specialities involved in cancer screening, as well as other medical experts (76 participants in total) met in Prague two days after the official announcement by the Czech Ministry of Health that a project of personalised invitation to participate in cancer screening examinations would be launched. A discussion on the shortand long-term impact and effects of this undoubtedly positive step was the main purpose of this meeting.

Personalised invitation has recently been confirmed by health care professionals and experts as the only way to increase the participation of Czech citizens in screening programmes for breast, colorectal, and cervical cancer. The coverage rate of the target population is currently over 50% in breast and cervical cancer screening, and only slightly above 25% in colorectal cancer screening. However, these numbers represent a ceiling that cannot be overcome without a personal invitation to each individual who has not yet attended a screening examination.

A press conference, which preceded the workshop, was attended among others by the Czech Minister of Health, Martin Holcát, MD, MBA, and was intended particularly for journalists and media dealing with health care. The press release distributed within the press conference is attached at the end of this report.

The methodology for personalised invitation to cancer screening programmes in the Czech Republic, developed with the valuable support of the Czech WHO Office and the Czech Ministry of Health, was introduced at the beginning of the workshop by Assoc. Prof. Ladislav Dušek (Institute of Biostatistics and Analyses, Masaryk University, Brno). The latest developments and current status of all three Czech cancer screening programmes were subsequently summarised by their guarantors - Prof. Jan Daneš (General University Hospital in Prague), Prof. Miroslav Zavoral (Military University Hospital Prague) and Vladimír Dvořák, MD (Centre for Outpatient Gynaecology and Primary Care, Brno). Assoc. Prof. Bohumil Seifert (1st Faculty of Medicine, Charles University in Prague) introduced the involvement of general practitioners in cancer screening; and the attitude of health care payers was presented by Hana Šustková, MD (General Health Insurance Company) and Renata Knorová, MD (Czech Industrial Health Insurance Company).

The above speakers' presentations were followed by a discussion, from which the following main points regarding the future of Czech cancer screening emerged:

- Personalised invitation is a step that will turn the existing organised screening programme into a population-based screening programme. All three Czech screening programmes have a comprehensive diagnostic and information background at their disposal, which is well-prepared for the increased attendance anticipated due to the personalised invitation, and is able to assess the project results quickly.
- Invitation of citizens must be accompanied by a high-quality information campaign, which is now under preparation. Top representatives of the specialities involved in cancer screening expressed their wish to contribute to the campaign's form and content, at least during its final stage.
- The long-term effects of personalised invitation and the inevitably higher



Fig. 3. Vladimír Dvořák, MD, Prof. Jan Daneš, MD, Ph.D., Prof. Miroslav Zavoral, MD, Ph.D. (guarantors of three Czech cancer screening programmes) and Martin Holcát, MD, MBA (Czech Minister of Health).

participation in screening programmes are undoubtedly positive, as proven by a number of previously published studies: tumour detection in earlier stages, higher chance of successful treatment, and lower expenses for treatment of advanced cancer. Physicians and health care payers, however, have pointed out that the short-term effect can be quite the opposite. A higher number of people who have neglected prevention and who would come for a screening examination for the first time would probably lead to a higher incidence

- of advanced cancers at the beginning (the so-called "harvesting effect"). Sending out letters and leading a health education campaign will therefore not be the only costs related to the project of personalised invitation; the expected higher number of diagnostic examinations and treatment of newly detected cancers will have to be covered as well.
- The personalised invitation must be a sustainable project in order to achieve the long-term benefits in the form of improved cancer detection and lower mortality rates.