

## 9.K. Workshop: Towards improved cancer screening in Europe

Organised by: EU-TOPIA consortium

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Although more than 40% of cancer deaths can be prevented, cancer remains a key public health concern and a tremendous burden on European societies being one of the two most important causes of death in Europe. There is now compelling evidence that well-designed organised screening for certain cancers is effective in reducing mortality. Yet, even in well-resourced European health systems, there are large gaps between what is possible and what is actually achieved. The majority out of 28 EU member states have implemented organised population-based cancer screening programmes or are in the roll-out phase. Moreover, the basic principles of organised screening are agreed, following the criteria developed by Wilson and Jungner in 1968, and developed further in European Council recommendations on cancer screening in 2003. Yet the way programmes are implemented varies considerably. There are many reasons for this. First, screening programmes are embedded in and depend upon wider social and health systems. These differ, for example, in the availability and accuracy of population registers, concepts of professional autonomy, and the integration or fragmentation of health systems. Second, the epidemiological situation, evidence base, and technology are constantly changing, exemplified by the introduction of human papilloma virus vaccines, which will have profound implications for cervical cancer screening. Finally, there are trade-offs to be made, for example between cost, sensitivity and specificity. It is not, however, clear how these differences impact on the effectiveness and equity of screening programmes.

This workshop will present emerging developments in a EU funded project that, uniquely, is taking a whole systems approach to evaluating screening programmes. These include, first, a new instrument designed to provide a comprehensive description of elements of the screening system and identify barriers to its optimal operation. Second, it will describe the use of an innovative modelling approach to evaluate the impact of different screening systems. Third, examples of population-based organised screening programmes for cervical, breast and colorectal cancer from Slovenia will be presented to give insight into the most important determinants of screening success that programmes have to tackle in different stages of maturity. Also, an innovative concept of the Slovenian cervical cancer screening programme information system will be presented, that changes the traditional role of the screening registry from an isolated registry used for monitoring and evaluation to an integrated system used for the exchange of structured electronic requests and reports among clinicians and laboratories that concurrently enables direct monitoring and evaluation of the programme and is connected directly to the national eHealth system. The presenters are collaborating in a consortium of EU-TOPIA project funded by the European Union's Horizon 2020 Programme.

### Key messages:

- Cancer remains a key public health concern in Europe. There is now compelling evidence that well-designed organised screening for certain cancers is effective in reducing mortality.
- Inequity in progress to reduce cancer burden persists in Europe. Screening programmes vary substantially between countries and in most long-term effectiveness of screening has not yet been assessed.

### Towards improved cancer screening in Europe

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Breast, colorectal and cervical cancer cause 250,000 deaths each year, representing 20% of EU-cancer mortality. Although important progress has been made in both detection and treatment, there is persisting inequity in progress to reduce its burden. Screening programmes vary substantially between countries and in most long-term effectiveness of screening has not yet been assessed. The objective of EU-TOPIA is to systematically evaluate and quantify the harms and benefits of the running programmes for breast, cervical, and colorectal cancer in all European countries, and identify ways to improve health outcomes and equity for citizens. We will first identify significant inequities in screening outcomes by assessing the key set of quality indicators for benefits and harms in each country. Using these indicators, outcomes and cost-effectiveness of existing cancer screening programmes in 2015 will be estimated. For this, state-of-the-art models of the natural history of the cancers will be constructed, using country-specific data with and from country-specific experts. Barriers hindering implementation of optimal screening programs will be assessed, leading to road maps for improved screening. These road maps contain feasible changes, e.g., to extend or reduce the program, to change the screen test used or change key quality indicators, to perform activities that reduce screen-related harm or incorporate new developments in screening, and provide policymakers with evidence for increased, decreased or optimized use of screening. Capacity for self-evaluation of screening will be built using three web-based tools (monitoring, model-quantification and barrier assessment) explained and trained in workshops with country representatives, also from the Associated Countries. The project will lead to reduced inequity, reduced number of cancer deaths and over-diagnosed cases, and increase in life years gained and better cost-effectiveness by 2025. That is why we call it EU-TOPIA.

### A soft systems approach to identifying barriers to cancer screening programmes. Methodology and application in seven European countries

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The benefits of population-based screening for breast, cervical and colorectal cancer are now accepted although, in practice, programmes often face barriers to implementation. In this presentation, we view the overall screening system as having multiple sub-systems, to identify the population at risk, generate knowledge of effectiveness, maximise uptake, operate the programme, and optimise follow-up and assurance of subsequent treatment. Based on this approach we developed a

Barrier to Effective Screening Tool (BEST) for analysing screening programmes from a health systems perspective. After piloting with key informants in seven European countries, it became clear that, while the first element of the instrument, identifying barriers to their optimal operation, can be undertaken as a self-assessment by those operating screening programmes, subsequent analysis using methodologies to understand the human interactions underpinning those barriers is more complex, demanding knowledge in soft systems analysis. Nonetheless, the first stage provided valuable feedback on the barriers affecting screening programmes and stimulated a greater recognition among those operating them of the need to take a whole systems perspective.

### **Slovenian national colorectal cancer screening – Programme SVIT**

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Slovenia belongs to the countries with the highest colorectal cancer incidence and mortality. In line with the recommendations of the European Council and with the European Guidelines for Quality Assurance in Colorectal Cancer Screening and Diagnosis, Slovenia set up a National screening programme for colorectal cancer – Program Svit in 2009. In first three screening rounds the target population included men and women aged 50 to 69 years. Since 2015, the upper age limit of target population is set to 74 years. Responsible institution is National Institute of Public Health. Faecal occult blood test is used as a screening method. Program Svit is designed as a user friendly programme with a special emphasis on communication. Re-invitations and reminders are sent. Special attention is given to disabled people. There are around 600.000 people, who are invited according to a pre-defined scheme in the period of two years. A test kit is sent by mail to invitees who completed and returned a signed statement of participation to the central unit of the screening programme and have no exclusion criteria. All faecal samples are analysed in one central laboratory. The results of the screening test are sent by mail to the tested person and general practitioner. Participants with a positive screening test are referred to colonoscopy. The positive effects of the programme were seen already after the implementation of the first screening round. In Program Svit 67-70% of cancers were detected in stage I and II, so additional oncological treatment for these patients was not required. According to the Cancer registry for Slovenia colorectal cancer incidence is decreasing since 2011. Well organised colorectal cancer screening proved to be effective in lowering detected cancer stages and cancer incidence. Program Svit is collaborating in a consortium of EU-TOPIA project funded by the European Union's Horizon 2020 Programme with purpose to improve the planned activities and outcomes.

### **Ten years of Slovenian national breast cancer screening – Programme DORA**

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Breast cancer screening programme in Slovenia (DORA) is organized, national and population based. The Slovenian screening target group numbers 280,000 women. The initiation of organized screening implementation started in 2008 and has been gradually expanding for 10 ten years. Rollout was completed in April 2018, therefore extension by organized breast cancer screening programme is now days 100%. Programme is centralized with one managing,

implementation, training and auditing unit. It is supported with coherent information technology systems with linkage to crucial registries on a daily basis. Screening policy is in place, the invitational scheme is set and screening monitoring and database is prescribed by a law. Comprehensive quality assurance system is in place for technical quality, quality of radiographers and radiologists. In the programme we have developed unique Slovenian classification for quality control of mammographic images and specially designed web application for daily data monitoring of the technical indicators required by the European guidelines for each mammograph involved in the screening. Performance indicators of the programme are regularly monitored, since all the screening data is available in the screening registry. The programme follows the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis since the very beginning and meets its recommendations for performance indicators. Average participation rate exceeds 70%, as proposed in the European guidelines. From 2008 to 2017 the average participation rate was 73%, the recall rate for further assessment was 4.8% in the initial screening round and 1.8% in the subsequent. Breast cancer detection rate per 1,000 screened in the initial and in the subsequent screening rounds was 7.7 and 5.2, respectively. In 10 years the programme DORA has invited more than 230,000 women, performed more than 320,000 screening mammographies and diagnosed more than 2,000 women with breast cancer.

### **Fifteen years of Slovenian cervical cancer screening programme ZORA. A change in a registry concept**

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Organised, population based cervical cancer screening programme ZORA was implemented in Slovenia in 2003 with Pap test and a 3-year screening interval in age group 20-64 years. The 3-year coverage of the target population with screening test is just above 70 % and 5-year coverage just above 80%. After 2003 the incidence of cervical cancer has almost halved and has reached historically the lowest rate in 2012, with crude incidence rate 11.0 and age-standardised incidence rate (WS) 6.8/ 100,000 women. Copies of all Pap test, HPV test and histology reports are registered at the Central screening registry ZORA, reporting is obligatory by the law. ZORA registry has an online connection with the Central population registry and the Registry for spatial units; it also bilaterally exchanges data with Cancer registry. Screening is entering the era where innovative technology solutions and new evidence from research are accumulating rapidly. This may change the traditional role of screening registries from being used as additional systems within the screening programmes for monitoring and evaluation of the programme, to the central communication and decision supporting tool between the professionals involved in screening, diagnostic, follow-up and treatment of women. The concept of such screening information system was developed at ZORA. It will become integrated with the national open eHealth platform that offers seed services that support communication between healthcare system networks and promise more effective resource allocation. Open platforms suggest a structured component-based service architecture that encourages participation and enable the platform ecosystems concept which is inter-organizational networks. In the context of platforms, ecosystems represent the platform and all the applications specific to the platform. New ZORA information system will be presented and demonstrated at the workshop.