WHO European Conference on Screening

UN City, Copenhagen, Denmark
11–12 February 2020
ABSTRACT

The WHO Regional Office for Europe held the WHO European Conference on Screening in Copenhagen on 11–12 February 2020 aimed at increasing the effectiveness of screening programmes within the WHO European Region, maximizing benefits and minimizing harm. This Conference constitutes an important step in an initiative by the Regional Office to improve policy decision-making for screening. It was attended by 160 participants from 45 countries, including WHO team members from the global, regional and country levels, technical experts, WHO collaborating centres, colleagues from the European Commission and other United Nations agencies and observers from nongovernmental organizations. Eight cross-cutting issues emerged during the meeting, with associated challenges and areas for development or further support from WHO.
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## Abbreviations

<table>
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<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>BMI</td>
<td>body mass index</td>
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<tr>
<td>CIN3+</td>
<td>cervical intraepithelial neoplasia grade 3 or worse</td>
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<tr>
<td>CT</td>
<td>computed tomography</td>
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<td>EU</td>
<td>European Union</td>
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<td>HPV</td>
<td>human papillomavirus</td>
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<td>IARC</td>
<td>International Agency for Research on Cancer</td>
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<tr>
<td>ICD-10</td>
<td>International Classification of Diseases, 10th edition</td>
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<tr>
<td>UNFPA</td>
<td>United Nations Population Fund</td>
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<tr>
<td>USSR</td>
<td>Union of Soviet Socialist Republics</td>
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<td>WONCA</td>
<td>World Organization of Family Doctors</td>
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Introduction

There appears to be a growing trend in the WHO European Region towards more screening for noncommunicable diseases and health checks throughout the life-course, but policy-makers, health professionals and the public often seem unaware of the potential harm of screening, its cost and burden on the health system and the need for strong quality assurance. This conference aims to increase the effectiveness of screening programmes within the European Region, maximizing benefits and minimizing harm.

The WHO Regional Office for Europe has therefore undertaken an initiative to explore these issues further with a focus on noncommunicable diseases and other conditions throughout the life-course. A WHO European Technical Consultation on Screening, held on 26–27 February 2019, clarified the evidence available for various screening practices (including harm and benefits), the current screening practices taking place in countries and areas in the European Region, and the important divergence between evidence and practice. The 2019 consultation resulted in several publications and guidance and identified some cross-cutting issues and possible solutions.

The purpose of this conference was to generate knowledge and provide tools to improve screening practices and policy- and decision-making related to screening. It highlighted cross-cutting issues (such as the political, social, commercial and technological drivers of screening, the legal, ethical and resource implications of screening, health literacy and the role of civil society) and potential solutions for improving decision-making and successful screening. The outcomes of the conference were a set of key messages supporting smart screening strategies and practices.

Opening and welcome

Bente Mikkelsen opened the WHO European Conference on Screening on behalf of the WHO Regional Office for Europe. She was pleased at the large number of Member States, non-state actors, as well as colleagues from the European Commission, other United Nations agencies, WHO collaborating centres and other technical experts who attended the Conference. She emphasized the importance of developing evidence-based screening programmes that are embedded in health systems to deliver optimal health outcomes.

Hans Henri P. Kluge, WHO Regional Director for Europe, provided opening comments. He started by welcoming participants and colleagues and expressing his gratitude for such an eminent audience attending to discuss such a significant topic and one that has the potential to improve health outcomes and advance universal health coverage.

Evidence-based, well-organized screening programmes have the potential benefits of reducing disability, the severity of conditions and mortality. However, this requires scaling up and adequate quality. The challenge is that “doing more” does not always mean “doing better” and that some screening and health checks raise ethical and legal dilemmas.
The Regional Director told the participants that a report, *Screening programmes: a short guide. Increase effectiveness, maximize benefits and minimize harm*,¹ had been produced to frame the discussion to maximize benefits and reduce harm. He concluded that the Conference presents a great opportunity to reflect, share and learn with colleagues and he wished everyone well in taking this very important topic forward in the European Region.

**Introduction to the Conference programme and expected outcomes**

Jill Farrington, WHO Regional Office for Europe, introduced the programme. She reflected on the technical consultation from the previous year and how it had helped to scope what we do and do not know. Sixteen countries participated and shared their successes and challenges, and this had shaped a programme of work over the past year.

Two publications had been produced following the last year’s consultation with Member States. The first one, *Screening: when is it appropriate and how can we get it right?*,² was directed at high-level policy-makers and the second one, *Screening programmes: a short guide. Increase effectiveness, maximize benefits and minimize harm*,¹ was meant for a wider audience. Other tools are being planned in the coming year.

The programme for this Conference included topics that cut across the implementation of all screening programmes such as health literacy, drivers and ethical and legal dilemmas. There was also an opportunity to examine three programmes in more detail that WHO considered to be evidence-based and could benefit from scaling up. The last meeting clearly showed that colleagues appreciated finding out about the variation in practice across the European Region and listening and learning from one another.

**Supporting effective screening for noncommunicable diseases and through the life-course**

The session started with a review of WHO products and publications that had been produced since the last technical consultation in 2019.

**Screening: when is it appropriate and how can we get it right?**

The European Observatory on Health Systems and Policies produced the policy brief, *Screening: when is it appropriate and how can we get it right?*,² for which the intended audience was high-level policy-makers. The presentation started by reviewing why such a publication was needed and the statement, “Just because something can be done does not mean it should be.” The publication reviewed the definition of screening and the Wilson & Jungner criteria³ and

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discussed why these are important. It considered the challenge of applying these in the light of new technologies. The publication then shifted focus to ensuring a systematic approach to making decisions about whether to screen for any specific condition. The policy brief reviewed elements of the screening pathway and showed that these could be used to think about some of the practical challenges in setting up and designing a screening programme. The publication emphasized monitoring and evaluation and that this cannot be carried out without adequate resources. The presentation closed by highlighting that successful screening requires public engagement and support.

**Screening programmes: a short guide – increase effectiveness, maximize benefits and minimize harm**

The Regional Office for Europe produced this guide. This publication was intended to be an accessible guide to the theory and practice of screening. It could not cover all the details or nuances of every aspect of screening, but it was hoped that it would provide policy-makers with a good understanding of its core principles. An overview of the chapters of the guide was given, including: what is and is not screening; the importance of a pathway; potential outcomes from screening; balancing benefits and harm; decision-making; designing an effective programme; and operational aspects such as quality assurance, participation and monitoring and evaluation. The key aim of the guide was to support policy-makers in developing, designing and implementing effective screening programmes to maximize benefits and minimize harm.

**WHO report on cancer: setting priorities, investing wisely and providing care for all**

WHO headquarters produced the *WHO report on cancer: setting priorities, investing wisely and providing care for all*, which provides country profiles for 190 countries, including details of a country’s capacity and workforce. It also provides information on how cancer screening programmes are organized. The WHO representative noted that some countries are not following evidence-based practices in screening and many have low participation rates. He stressed two programmes recommended as “best buys” that should be given priority are: early diagnosis of cancer and cervical cancer screening. He provided examples of the numerous technical publications and handbooks produced by WHO and the International Agency for Research on Cancer (IARC) on these topics and more generic guidance documents on cancer control.

**Use of computed tomography in asymptomatic individuals for individual health assessments: guidance on regulation and governance**

This WHO guidance is expected to be published soon and was considered a priority because of the increasing use of computed tomography (CT) among people without symptoms. There are issues that transcend radiation safety, such as overdiagnosis, indeterminate findings and ethical dilemmas. The guidance identified several needs, such as: evaluation; further work on the process for justifying testing asymptomatic individuals and the appropriateness of the procedure undertaken; the need for protocols for reducing the dose; improving the image quality and quality assurance of equipment and procedures; and other important factors. It was felt that the practice of using CT for individual health assessment requires greater scrutiny in terms of safety and quality, including a well-defined framework for regulation and good governance involving health authorities and radiation protection bodies.

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Health Evidence Network synthesis report on systematic population-level screening programmes for reducing cardiovascular disease burden

The final presentation in this session described the process of producing Health Evidence Network reports. Since 2003, 80 reports have been published and are available through Medline.

At the technical consultation in 2019, a background paper had been prepared on screening for reducing the burden of cardiovascular disease. As a result of the interest in this work, a decision was made to start a synthesis report on systematic population-level screening programmes for reducing the burden of cardiovascular disease. This will review the evidence on the effectiveness of screening versus no screening for individual or combined cardiovascular disease risk factors, atrial fibrillation and abdominal aortic aneurysm screening among healthy children and adults.

A parallel meeting was planned during the Conference, so that interested participants could contribute to scoping and developing the report.

Discussion

A participant asked for clarification on whether the two publications on screening had been tested on policy-makers. A representative of the WHO Regional Office for Europe confirmed that the draft documents had been circulated to several Member State officials and that the final publications had incorporated their comments.

A country participant commented on the difficulty in evaluating screening programmes and asked for examples of evaluations to be shared. The representative from the European Observatory on Health Systems and Policies indicated the need to spend adequate resources on evaluation and that this would be money well spent given the overall investment in screening programmes. However, he emphasized that each country needs to evaluate their own programmes and cannot use results from other countries, and this is an enormous gap in the research.

A representative of WHO headquarters commented that, based on recent analysis derived from the WHO biannual survey, the figure for investment in monitoring and evaluation is about 10–20% of the total screening programme budget.

Successes and challenges in screening

The chair introduced the session and explained that the purpose was for Member States to share their experiences about what is working well and the areas that remain a challenge.

Lithuania

A participant from Lithuania started by describing the screening programmes offered in Lithuania. This includes newborn screening for four metabolic conditions: congenital hypothyroidism, phenylketonuria, galactosaemia and congenital adrenal hyperplasia. Between 1975 and 2018, about 200 newborns have been identified with these conditions. Lithuania also offers screening for early eye disease and newborn hearing tests. In 2016, it introduced screening for congenital heart defects.

For adults, a screening programme has been offered for risk assessment for cardiovascular disease and diabetes since 2015. Primary care informs people that they have the opportunity to
participate and, if they are at risk, they are offered a range of activities such as lectures on healthy lifestyles, a physical activity plan, healthy eating and stress management. Key health indicators are body mass index (BMI), waist circumference and blood pressure. Of the 1000 people in the programme, 68% said that their lifestyle improved as a result of the programme.

Other screening programmes for adults include:

- cervical cancer screening (since 2004) for women 25–60 years old every three years (Pap smear);
- breast cancer screening (2005) for women 50–69 years old every two years (mammography);
- colorectal cancer screening (2009) for people 50–74 years old every two years (immunochemical faecal occult blood test); and
- a programme for the early detection of prostate cancer (using prostate-specific antigen).

Each programme has a steering committee (representatives from professional groups, nongovernmental organizations, the Ministry of Health and the National Health Insurance Fund).

The participant thought that participation rates could be improved since they are still low in many programmes (40–45%). Introducing coordination centres has improved the delivery of screening programmes.

**Georgia**

The official from Georgia described the background for noncommunicable disease control in Georgia and then described the screening programmes that are available.

Antenatal and neonatal screening includes:

- antenatal surveillance: this entails eight antenatal visits of pregnant women and screening for various infections and genetic disorders; and
- newborn screening for congenital hypothyroidism, phenylketonuria, hyperphenylalaninaemia and cystic fibrosis as well as newborn hearing screening.

For adults, the cancer screening programme in Georgia was initiated in accordance with the recommendation of the Council of the European Union (EU) in 2003 that called for all EU countries to adopt organized screening programmes for breast cancer, cervical cancer and colorectal cancer.\(^5\)

Screening for cancer within the Municipality of Tbilisi was launched in 2008 with the assistance of the National Reproductive Health Council and with financial and technical support from the United Nations Population Fund (UNFPA) Georgia. The National Cancer Screening Centre was established and played a major role in implementing and developing the programme. From 2011, the government decided to expand the screening programme nationwide.

- Breast cancer screening using mammography is offered to women 40–70 years old every two years. Although WHO guidelines recommend that screening should be started at 50 years, in Georgia about 20% of the women with breast cancer are 40–50 years old, and screening is therefore offered to this younger age group.

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• Colorectal cancer screening is offered to men and women 50–70 years old every two years using an immunochemical faecal occult blood test followed by colonoscopy for those who test positive.

• Cervical cancer screening is offered to women 25–60 years old with a three-year recall interval. The participant explained that the main activities in Georgia focus on cervical cancer screening through a pilot project on implementing organized screening (started in 2014) intended to improve quality assurance and increase the efficacy of the cervical cancer screening programme. It was developed in collaboration with UNFPA Georgia. The main emphasis is to build the capacity of the existing health services to enable them to deliver cancer screening programmes. There is a focus on primary health care personnel in rural areas.

• Prostate cancer management programme: men older than 50 years who meet certain criteria can have prostate-specific antigen levels measured.

Screening data are regularly collected and analysed. Cancer registry data is being further improved with the creation of a new unified electronic system for cancer data collection, which will also cover a screening component.

The participant felt that the newborn hearing screening programme was working well since the children can be easily identified and there was good collaboration among health professionals.

The challenges included the following.

• The coverage and participation rate are not high for cancer screening programmes.

• Primary care doctors are not sufficiently engaged.

• Leadership and coordination of quality assurance is lacking across the country. Quality control for cytology is organized by each laboratory and is not consistent across the country.

• A limited number of mammography machines are available to the screening programme. There are not enough radiologists who are trained to read mammograms, especially in the regions.

Once screened positive with cancer, patients are referred to oncologists where they can obtain treatment under the universal health coverage programme. Lack of state funding for parts of the diagnostic aspects of the screening pathway may deter individuals who screen positive from obtaining further necessary investigations, and local authorities have therefore been asked to cover cancer diagnosis for their residents.

**Portugal**

The Portuguese official said that Portugal is giving priority to primary and secondary prevention and has implemented several programmes.

• Prenatal screening is available for aneuploidy screening for chromosomes 13, 18 and 21 and screening for pre-eclampsia for all pregnant women.

• Neonatal screening is provided for congenital cardiac abnormalities, congenital cataracts, newborn hearing and retinoblastomas. If these are found, the baby is referred to a specialist.

• Neonatal screening is also provided for 26 diseases. Analysis is carried out at a national laboratory.
• Childhood screening is carried out for a variety of conditions every two years.
• Diabetic retinopathy screening is provided for adults with diabetes.
• A breast cancer screening programme started in 1999. Women 50–69 years old are screened every two years. The current geographical coverage is 83%. The geographical coverage of the country is expected to be 100% in 2020.
• A cervical cancer screening programme started in 2008. Women 30–60 years old are offered screening. The current geographical coverage is 98% and the participation rate is 88%.
• A colorectal cancer screening programme started in 2013. Adults 50–74 years old are offered screening. The geographical coverage is 74% and the participation rate is 30%.

The official described the organization of the programmes. Screening programmes for cervical, breast and colorectal cancer are regional programmes with central oversight.

The main problems facing the programmes are:
• inadequate response by secondary care to screening referrals because of lack of capacity;
• inconsistency in how regional programmes are implemented;
• inability to assess how programmes perform in real time;
• poor participation in colorectal cancer screening; and
• geographically challenging inequalities.

Strategies to address these issues include:
• creating differential reimbursement packages to positively discriminate hospital-based activities related to screening in colorectal screening;
• developing national standard operating procedures to improve consistency in field implementation;
• developing software to integrate real-time data; and
• improving participation through health literacy initiatives.

Activities that are working well include:
• good geographical coverage to improve participation; and
• the breast cancer screening programme is working better than other programmes.

**Serbia**

The Serbian official explained that the National Institute of Public Health in Serbia is responsible for cancer screening programmes.

In 2012, organized screening programmes were introduced and supported by the EU:
• cervical cancer screening: women 25–64 years old are offered screening every three years (Pap smears);
• breast cancer screening: women 50–64 years old are offered mammography screening every two years; and
• colorectal cancer screening: people 50–74 years old are offered screening using an immunochemical faecal occult blood test.
All programmes use EU standards. The Ministry of Health has supported the programmes to enlarge and increase geographical coverage. The programmes have been legally adopted with increasing targets for programmes such as participation rate.

There have been some interesting findings using different methods of invitation. They have found that telephone invitations are more effective than postal invitations.

The official went on to describe some of the developments that have occurred recently, such as developing a central platform for mammography that enables all diagnostic images to be sent to a central place for reading and interpretation. This has led to improvement in the quality of the reading as well as reduced delays in issuing results.

Other areas doing well are capacity-building among personnel who provide screening, with guidance documents developed for all grades of personnel.

**Discussion**

The chair of the session then invited colleagues from the floor to share their experiences in implementing screening programmes and asked them to identify their successes and challenges.

A participant from Norway described how the cancer registry, which carries out the invitations and monitoring of the cancer screening programmes, results in very high-quality data that is fed back to the services. This also enables careful monitoring and evaluation of newly implemented programmes or changes to programmes. The challenge that Norway faces is poor participation by low-income groups, especially for cervical cancer screening.

A participant from Iceland said that attendance is low for all cancer screening programmes, such as less than 60% for the breast screening programme. One reason is that screening is not free of user charges in Iceland and the charge for screening deters some people from participating. Also, the age for breast screening starts at 40 years, which does not meet EU recommendations.

Panel members responded to comments from the floor and especially picked up on issues of payment for screening. Participants from Portugal and Serbia stated that screening in their countries is free of charge, but the participant from Georgia noted that, although the screening is free of charge, and diagnosis and treatment is free of charge for those with low incomes, other groups given a positive screening result would have to pay for diagnostic investigations, and this could deter some people with a positive result from seeking further investigations. Local authorities have therefore been asked to cover the additional cost of cancer diagnosis for their residents.

A participant from Lithuania explained that all screening programmes that were approved by the Ministry of Health were required to comply with quality assurance and audit requirements. The recent eHealth system also strengthened the quality of the programmes.

Colleagues from the floor raised several other points.

- Cancer screening programmes will not necessarily reduce total mortality, only disease-specific mortality.
- If primary health care is included in screening programmes, how should the opportunity costs of their involvement be taken into account in the overall costs and effects of a screening programme?
Given the discussion about informed consent, is it appropriate to measure the success of screening by uptake or should it be measured in terms of success in providing information?

A participant from Croatia commented that their participation rate for immunochemical faecal occult blood test in the colorectal cancer screening programme had been 25%. After the involvement of home nurses in primary care, it had risen to 50%. Also, Croatia is planning to introduce low-dose CT scans for lung cancer among heavy smokers 50–74 years old and for those who have quit within the past 15 years.

A colleague from Austria said that they were currently evaluating the Austrian Breast Cancer screening programme in which ultrasound is used for women with increased breast density after mammography as part of the screening process and not part of the assessment as in other organized screening programmes.

A participant from Germany remarked that their newborn hearing screening programme is successful. However, one challenge is a struggle with members of the deaf community, some of whom did not want cases of deafness identified in children since they did not view deafness as a disability to be prevented.

The chair summarized the main issues that had emerged from the session.

- Understanding the costs of screening is important: the impact of out-of-pocket costs to the population, which can deter participation, and the costs to the health system of implementing a screening programme.
- There is a need to carefully manage the transition from one system of implementing screening programmes to another, for example, moving from Pap smears to human papillomavirus (HPV) testing.
- Involving patients in designing and implementing an effective screening programme is important.
- The role of professionals in screening programmes and how incentives for professionals can alter their behaviour need to be understood.
- Screening programmes can lead to bottlenecks and waiting lists in diagnostic and treatment services, and these need to be managed.

**Applying good screening principles in practice: systems for deciding whether to start or stop a screening programme**

The chair introduced the session and explained that the purpose was to explore how different countries tackle introducing or stopping screening programmes.

The chair then asked three countries to present their experiences.

**Country experience: United Kingdom**

The official from the United Kingdom provided an overview of the system for making decisions. The United Kingdom National Screening Committee is a scientific advisory committee providing evidence-based recommendations on all aspects of screening programmes to the four United Kingdom departments of health through the chief medical officers. This includes starting and stopping a programme; making big changes to a programme; piloting a programme; and keeping a programme going. The recommendations are made to the Government, but are not legally binding (although they are generally accepted).
Screening programmes are only recommended when the offer to screen provides more good than harm at reasonable cost. The United Kingdom National Screening Committee reviews more than 100 topics on a regular basis (about every three years). The reviews are based on the latest research evidence and international criteria and are informed by multidisciplinary groups, including professionals and patients. The reviews are carried out in accordance with the internationally recognized criteria of the United Kingdom National Screening Committee. These cover the condition being screened for; the screening test; the treatment for the condition; and the screening programme itself.

The official described how reviewing so many conditions is a significant task. The United Kingdom National Screening Committee website lists more than 100 conditions, and the United Kingdom uses 20 criteria (many with subsections) to reach a decision. To date, there is a recommendation to screen for more than 30 conditions. The United Kingdom National Screening Committee also receives requests to change existing programmes (for example, changing tests and age ranges).

The decision on whether to recommend screening for a condition needs to be based on contemporary evidence and to be credible. For the United Kingdom National Screening Committee to be effective, it needs to exercise judgement, consider acceptability, ethics and feasibility and recognize that decisions about screening are often highly political and that communicating recommendations clearly and comprehensively to the public and professionals can be a significant challenge.

The presentation then moved on to discuss the process of reviewing the evidence. Stakeholder input or proposals or the three-year cycle can trigger reviews. The United Kingdom National Screening Committee evidence summaries are developed using rapid review methods. They evaluate the “volume and direction” of the literature on a single question or set of questions on a given screening topic. The purpose of the evidence summaries is to gauge whether there have been significant developments in the evidence based on key questions identified in previous reviews on the same topic and to establish whether a current recommendation can be reaffirmed or whether a topic is likely to benefit from further assessment by developing different types of evidence products, such as systematic reviews, cost–effectiveness studies, disease modelling exercises or primary research.

The use of rapid review methods enables the United Kingdom National Screening Committee to publish up-to-date and robust reviews on a broad range of topics and filter out those with a poorer evidence base and to identify gaps in the evidence that might provide the basis for research or more detailed evidence reviews. This helps to ensure that the Screening Committee’s recommendations reflect the most up-to-date evidence on a wide range of topics.

Lastly, the speaker described the process to make major modifications to a programme, which follows the same principles as the process for introducing or stopping a programme.

**Country experience: Sweden**

The official from Sweden outlined the governance for deciding and implementing screening programmes in Sweden. The decision-making process is led by the National Board of Health and Welfare, a government agency that evaluates and recommends national screening programmes. Sweden’s 21 health-care regions are responsible for implementation. In theory, the regions do not have to follow the recommendations of the National Board of Health and Welfare, but they do in practice.
The decision-making process started in 2014. The screening programmes that have been recommended through this process are cervical cancer, breast cancer, colorectal cancer, abdominal aortic aneurysm and newborn screening for 25 conditions. Programmes that have not been recommended included prostate cancer screening and atrial fibrillation.

The model used in Sweden to evaluate or recommend a screening programme has three key components: (1) the groups that oversee the process, (2) the criteria used to make the decision, and (3) a defined process that describes how the decision is made.

The speaker then considered these in more detail. Three subgroups are involved in the decision-making: (1) an expert group advising on the scientific evidence; (2) cross-functional groups that also have scientific experts, but also clinicians involved in the diagnostic and treatment pathway for the condition of interest and patient representatives; and (3) the national screening committee that oversees the whole process and is responsible for making the final recommendation to the National Board of Health and Welfare. This is a permanent group that includes politicians from six regions, which is important as the politicians represent the regions that will have to implement the programmes, so in a sense they also represent the public’s interests.

The criteria are based on WHO criteria. The final criterion, whether the overall benefits will outweigh the harm, is often the hardest to assess. Where there are ethical issues, the national screening committee consults with ethics experts.

Lastly, the participant described the workflow process. First, the expert group provides the evidence to consider the first 10 scientific criteria. These are then considered by the cross-functional group and lastly by the national screening committee. If the committee finds that the first 10 criteria are met, then the subgroups move on to consider the next five organizational criteria. Finally, the national screening committee makes one recommendation to the National Board of Health and Welfare on whether to support the screening programme based on all 15 criteria.

The speaker concluded with a reflection on how to ensure that decision-making remains relevant. They felt that this requires follow-up evaluation of existing programmes, close dialogue with the regions, experts and patient organizations, and the ability to consider applications for new programmes.

**Country experience: Kazakhstan**

The official from Kazakhstan described the history of screening in the country. In 2013, in addition to screening for cervical, breast and colorectal cancer, Kazakhstan also offered screening for:

- oesophageal and stomach cancer: people 50–60 years old every two years using endoscopy;
- prostate cancer screening: men 50–66 years old every four years with prostate-specific antigen tests; and
- liver cancer: adults with liver cirrhosis 2–4 times per year using alpha-fetoprotein and ultrasound tests.

An evaluation of the screening programmes found that the results were not in accordance with findings for cancer screening programmes in Organisation for Economic Co-operation and
Development (OECD) countries. In November 2016, a joint imPACT Review\(^6\) by the International Atomic Energy Agency (IAEA), WHO and IARC made recommendations to stop screening for oesophageal, liver and prostate cancer and instead move to an early diagnosis programme and observation of people with chronic diseases (high-risk group). The review also recommended strengthening the cervical, breast and colorectal cancer screening programmes.

As a result, by 2018 the screening programmes in Kazakhstan were:

- cervical cancer screening: women 30–70 years old offered a Pap smear every four years;
- breast cancer screening: women 40–70 years old offered mammography every two years;
- colorectal cancer screening: adults 50–70 years offered an immunochemical faecal occult blood test every two years.

The participant went on to describe the experience of stopping the oesophageal, liver and prostate cancer screening programmes. The process started with analysing the screening results, reviewing the existing equipment and revising the existing guidelines. This was followed by an open discussion regarding stopping screening for oesophageal-stomach, prostate and liver cancer. It involved professionals, medical and public health institutions and regional health-care departments. After a decision was made to change the programme in 2018, there was a media campaign, which included TV appearances and interviews with the Minister of Health and senior policy-makers, newspaper articles and the use of social media. Lastly, there was a focus on training and teleconferences with the heads of regional health-care departments, health-care professionals, nongovernmental organizations and opinion leaders.

The presenter summarized the impact of these changes. Oesophageal, stomach and hepatocellular cancer have moved to early detection programmes. Ending the non-evidence-based programmes allowed the release of resources and increased investment in cervical, breast and colorectal cancer programmes within the same budget envelope. Changes made as a result of the increased investment included extending the screening age to 30–70 years old for cervical cancer screening and increasing coverage to 80%. This has led to an increase in the detection of pre-cancerous lesions in the cervical cancer programme. The age range was also increased to 40–70 years old for the breast cancer screening programme which, along with digitization of the programme, led to improved service quality. Increased investment in more endoscopists and sedation for the colorectal cancer screening programme has led to improved coverage. Prostate-specific antigen testing is now offered via general practitioners to men 50 years and older in polyclinics. Lastly, primary and secondary health-care specialists welcomed this decision, since they perceived the burden of all six programmes as excessive.

**Discussion**

The chair thanked the presenters and asked participants to share their country experience in four areas.

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1. **How does a country decide which screening programmes to implement? Are there different approaches for cancer and non-cancer screening programmes?**

The following country participants responded:

- Cyprus stated it was a health ministry decision with input from the scientific community and relevant stakeholders, including civil society.
- Germany does not have a steering committee or decision-making body. They reference other countries (such as the United Kingdom).
- Slovenia has a committee for monitoring and reimbursement. However, they do not have an agency to decide on new programmes. The health ministry will establish a screening committee with an intention to organize the process slightly differently (such as applications from non-state actors with health ministry review).

2. **Has any country had to decide to start, stop or change a screening programme recently? What were the challenges in decision-making? Any good examples?**

- The United Kingdom reported that it has stopped selected programmes.
- Denmark stated that it is investigating establishing a formal congenital cataracts screening programme to facilitate the timely diagnosis of congenital cataracts. Currently, congenital cataracts in Denmark are diagnosed at a systematic neonatal examination at week 5 after birth, which may be too late to permit timely surgical intervention.
- Iceland stated that the breast cancer screening programme is changing its target population from 40 years to 45 years.

3. **Do countries need support in this area, and for what? How can WHO and the international community help? How can countries help each other?**

Participants made the following suggestions:

- WHO could facilitate a mechanism for regional dialogue.
- WHO could develop an annex to the screening guide on best practices for programmes and target populations.
- WHO could provide technical support to reconcile and support decision-making in countries (such as the challenges from private and public sector screening programmes regarding the cost of services or variations in practice such as annual Pap smear screenings).
- Convene communities of best practice; WHO could support programme formulations, costings and priority-setting.

The chair summarized the key issues emerging from the discussion.

1. **Decision-making to start or stop a screening programme is both scientific and political.**
   a. All presenters highlighted that political entities have a significant voice in the decision-making process.
   b. Scientific interpretation of data can be shared and communicated across countries and subregions, although there are challenges to the generalizability of the data and findings.

2. **A governance structure is needed:**
   a. to decide whether to screen;
   b. to implement pilot projects and develop strategies for scaling up; and
c. to monitor programme performance and implement quality assurance and quality control measures.

3. A screening committee is an important entity for assessing and reviewing proposed interventions and can be done at low cost.

4. Comprehensive review of interventions should include economic analysis as well as the participation of subpopulations, which is more feasible with the advent of new technologies.

Applying good screening principles in practice: pathways, quality assurance, monitoring and evaluation

The chair introduced the session, the focus of which was to review the principles of quality assurance systems and to hear from countries about their experiences in establishing quality assurance systems. There would also be an opportunity for countries to share their challenges and solutions.

Introduction

The session started with presentations covering the principles of quality assurance systems.

Quality assurance in screening programmes

The first presentation started with an explanation of why quality assurance is important in screening programmes. Parameters of the programme are set to maximize benefits and minimize harm; for example, sensitivity, specificity and how frequently screening is carried out. If the screening programme moves away from these parameters, the programme will not deliver the anticipated benefits. Quality assurance systems are in place to ensure that screening programmes are continually delivered within the agreed parameters. If quality assurance systems are not in place, it may result in unreliable screening results, failure to deliver population outcomes and lack of consistency in how local services provide screening.

A screening quality assurance system has three components. The first is an assurance process to check that quality standards are met. Second, quality improvement activities can drive up quality in an organization, such as through training and audits. Third, steps are taken to reduce the probability of error and risk, such as the use of failsafe systems to track patients or the double reading of images.

The process of establishing a quality assurance system was described. It started with defining the parameters based on evidence-based recommendations. These are translated into quality standards, guidance and standard operating procedures, which all services agree to adhere to. Reaching consensus may be difficult and requires good clinical engagement. Once in place, personnel need to be trained to work with these new systems. The quality assurance standards are then measured in each service and, if an area is non-compliant, then quality improvement initiatives are put in place. The quality assurance system needs to apply to the whole screening pathway. Another consideration is deciding which external agency should measure compliance with quality assurance standards. The choice will depend on the health system and the type of regulation in each country; for example, accreditation bodies, government inspectorates or peer-review models.

Lastly, the speaker described internal quality assurance activities undertaken by individual screening services to maintain quality. These include the training of personnel, the quality
control of testing, such as mammography quality control, audits, double reading of images and failsafe mechanisms to track people who screen positive.

**Structuring pathways and assuring quality – keys to the success of screening programmes**

The second presentation was given by a representative from the International Partnership for Action against Cancer who started with a review of cancer screening in the European Region. The speaker illustrated that cervical cancer screening is not implemented in all European countries and, in some countries where it is implemented, the quality is so low that the programmes do not make much difference. The speaker contrasted the trend in reduction in premature mortality from cervical cancer in EU countries with an upward trend in countries of the former Union of Soviet Socialist Republics (USSR).

The speaker stated that there is often too much emphasis on technology and methods and insufficient attention given to: securing the continuity of processes; registering the people screened; following up on any abnormal findings; assuring the quality of all the elements that influence the outcomes; and ensuring equity of access, for example, by modifying the invitation mechanisms.

Slovenia’s experience in establishing a colorectal cancer screening programme was then considered. The programme was started in 2009 and has successfully completed five invitation cycles. At first, there was modest participation, so action was taken to improve participation. This included taking different approaches to sending out invitations and monitoring participation across the country by the smallest administrative area, so that action to increase uptake could be effectively targeted. The test selected was the immunochemical faecal occult blood test because it was shown to be highly sensitive. In addition, there were regular meetings of colonoscopists, who adopted European guidelines and standards and compared data quarterly, and those not meeting the standards were asked to step down. The outcomes of all these actions have been: participation in the immunochemical faecal occult blood test increased from 29% in 2009 to 64% in 2018; and from 2009 to 2016, the incidence of colorectal cancer declined by about 20%.

**Country experience: Belarus**

A participant from Belarus said that management of the breast cancer screening programme has changed significantly and that this has led to a great improvement in results.

In 2009, Belarus, based on its own experience and that of other countries, started a pilot project for breast cancer screening as the first phase before starting to roll out the programme.

The speaker described some of the challenges Belarus faced during the pilot project, including a misunderstanding by both doctors and policy-makers about how the programme worked, and a limited commitment from the population since it required an additional visit to the doctor.

The country then started a new phase by identifying the core requirements for a successful programme. A key component in this new phase was political will and support. The other necessary components for a successful programme included: equipment, personnel, management, guidelines, telemedicine, a cancer registry and public involvement.

Important steps were considered in more detail.

- Breast cancer screening was integrated into the state programme and instructions were issued on how to conduct breast cancer screening. This covered the entire screening cycle.
Designing standards and regulating the pathway: this included establishing the national coordination centre with subordinate coordination centres for regional breast cancer screening programmes to improve the organizational guidance and quality of services.

Increasing both informed consent and participation: since leaflets did not seem to make any difference, they changed the approach to screening personnel calling women and explaining what the screening programme is, why they should participate and its advantages and disadvantages. This has led to an increase in participation.

Introducing telemedicine: this has enabled more rapid second readings of radiographs and the use of training video conferences.

The speaker then described the next steps to be taken to improve the screening programme: creating a single electronic screening database (currently in pilot operation); introducing changes in the curricula of health professionals since they are afraid of missing a case of cancer and refer many cases (about 20%) for assessment and biopsy; continual training of specialist physicians in taking biopsies under ultrasound and X-ray control; and creating a unified quality control system for radiologists, with technical support from specialists from IARC and WHO.

Country experience: Hungary

The speaker outlined the importance of a quality assurance programme as an integrated component of screening programmes and a basic requirement for screening.


Screening is organized through screening coordination departments in each of the 19 counties and one department in the capital. There is also a National Screening Registry, which is responsible for managing the population list and for measuring indicators for monitoring purposes.

The speaker explained that Hungary is not able to measure all 39 indicators for breast cancer screening as recommended by EU guidelines and has chosen to measure a subset of indicators:

- population list or invitation list;
- participation rate (compliance);
- recall list (for repeated samples, diagnostic verification);
- detection rate; and
- accuracy of the screening test (false negative, interval cancer and false positive).

The National Screening Registry carries out monitoring every three months and provides feedback on the relevant indicators.

Opportunistic screening has a long history in Hungary and the “old” practice is deeply rooted in the population. Currently, most of the screening takes place opportunistically outside the organized screening programme, and the screening results and other relevant details are not reported to the National Screening Registry. Some essential data are therefore missing for the quality assurance programme. The participant pointed out that, although significant work had been undertaken to highlight the benefits of organized screening to the public and professionals, changing behaviour has been very difficult.
Nevertheless, there has been significant progress. Between 2002 and 2012, the breast cancer mortality rate among women 45–64 years old declined by 24% and cervical cancer mortality among women 25–64 years old declined by 25%.

The speaker concluded that, even though the political, organizational, human resources and infrastructural conditions of efficient organized screening of the whole eligible population are in place, there is a cultural basis for the underperformance of the system. This is rooted in traditional practices, such as the population preferring conventional opportunistic screening to organized screening. Therefore, there continues to be room for improvement.

**Discussion**

The chair then asked participants to form groups and consider the following questions.

*Identify one or two main challenges in developing and implementing adequate quality assurance for screening in each country.*

*What solutions were found in each country? How can WHO and the international community help? How can countries help each other?*

Participants identified challenges according to several themes.

1. **Data and quality standards**
   a. Providers use no unified standards; and there is therefore no national or regional data to measure performance.
   b. Poor data quality and inconsistent data collection between providers prevents benchmarking between screening providers.
   c. Unable to collect data along the whole screening pathway because of barriers to data sharing, such as the EU General Data Protection Regulation (GDPR).[^7]
   d. Poorly designed information technology systems prevent high-quality data from being collected.

2. **Participation rates and inequalities**
   a. Uptake remains low among the hard-to-reach groups, exacerbating inequalities.
   b. Informed consent is perceived as a barrier to increased participation in some circumstances.

3. **Professional engagement**
   a. Professionals can be reluctant to engage in quality assurance because of anxiety of being exposed as performing poorly.
   b. Tackling poor performance among clinicians is difficult.
   c. Some countries do not have a culture of audit and measuring performance.

4. **Organization, governance and resources**
   a. Screening programmes are often started without considering quality assurance, and it is then difficult to retrofit a quality assurance system to a screening programme.
   b. Quality assurance requires resources, and obtaining these additional resources for a screening programme is often difficult.
   c. Small countries often do not have the capacity to implement a quality assurance programme.
   d. No one wants to take responsibility for leading quality assurance processes at the regional or local level.

e. In some countries, quality assurance requires legislation and official documents to be effective, and these are not available.

Participants identified several solutions and learning that could be considered.

1. Countries should consider embedding quality assurance into screening programmes from the outset, and resources for quality assurance should be part of a costing exercise when considering starting a programme.
2. WHO could facilitate a community of practice to design effective and simple quality assurance systems.
3. WHO could facilitate learning across countries regarding data collection, including legal solutions to some of the challenges some countries face.
4. Small countries could consider working together to address capacity issues.
5. WHO could facilitate further work on developing a core set of indicators to reduce the burden of data collection.

Health literacy and the role of civil society

The chair introduced the session and pointed out that even the best screening programmes across European Region countries struggle to achieve high participation. One factor may be low levels of health literacy.

Health literacy is a special area of interest in the European Region. Health literacy is more than the ability to read; it is the ability to make informed decisions. An assessment has shown that health literacy levels can be low even in high-income countries. In light of this, the Regional Office for Europe is producing an action plan to improve health literacy levels in the Region.

The chair welcomed the speaker, who was from the International Union for Health Promotion and Education Global Working Group on Health Literacy.

Keynote presentation – health literacy: what does it mean for screening?

The speaker started with a definition of health literacy and an explanation of the different components. Health literacy is linked to literacy and entails people’s knowledge, motivation and competencies to access, understand, appraise and apply health information in order to make judgements and take decisions in everyday life concerning health care, disease prevention and health promotion to maintain or improve quality of life throughout the life-course. The different components are:

- **functional**: sufficient skills in reading and writing to be able to function in everyday health situations;
- **interactive**: skills to actively participate in everyday activities, to extract information and derive meaning from different forms of communication and to apply new information to changing circumstances;
- **critical**: skills to critically analyse information and use this to exert greater control over life events and situations;
- **distributed**: the capacity to share health literacy skills within a social group or network; and
• **public**: the degree to which individuals and groups can obtain, process, understand, evaluate and act on information to make public health decisions that benefit the community.

The speaker went on to describe why health literacy was important and to share the findings of a health literacy survey that was conducted in 2012. The survey showed significant variations between European countries, with levels of inadequate general health literacy between 2% and 27%. Overall, about two thirds of the European population studied did not have adequate levels of health literacy. Studies of health literacy have also shown that people with inadequate literacy levels feel less well, that low literacy levels are higher in lower socioeconomic groups and that increasing health literacy may be a way to reduce health inequalities. These factors may explain why people with lower health literacy are less likely to engage in disease prevention, such as screening for disease among asymptomatic people and immunization programmes.

The speaker went on to consider each of the components of health literacy and how these might relate to participating in screening programmes.

The speaker presented the results of two trials that showed how improving health literacy affects participation in screening and that this can have unexpected results. For example, in one trial it resulted in decreased participation, while it increased informed consent.

The speaker summarized her findings.

- Health literacy is common and affects health and illness, including screening and other disease prevention activities.
- Health literacy has a social gradient.
- Applying health literacy principles to screening can include:
  - simplifying how textual and numerical information is communicated;
  - facilitating patient discussions about screening with health-care practitioners;
  - empowering at-risk groups to overcome barriers to screening; and
  - building public health literacy on screening issues of public health importance using techniques such as community Juries.
- The impact of health literacy activities may be unpredictable.

The chair thanked the speaker and asked for the invited response from the colleague from the Max Planck Institute for Human Development in Berlin, Germany.

**The invited response to the keynote speech**

The speaker outlined that she wished to move the focus from the health literacy of the population to the health literacy of health professionals and the methods used to measure or assess health literacy. A key issue is that studies use self-assessment as a measure of health literacy and, for health professionals, this method is unlikely to be accurate. Studies investigating real understanding show that such self-assessment may have little correspondence with real competencies.

The speaker gave examples in which professionals or the population incorrectly estimated the reduction of risk associated with screening programmes and highlighted that, if policy-makers, patients and physicians do not possess the skills to evaluate medical risk information – that is, they lack medical risk literacy – they are unlikely to judge the benefits and harm of screening and as a consequence may become enthusiastic about unproven and potentially harmful tests or dismiss potentially beneficial ones.
The speaker considered why physicians and patients know so little about risks to health. They dismissed assertions that it is because of cognitive deficit, since it has been shown that school students are able to understand risk if it is presented in the format of natural frequencies. The problem appears to be how information is presented to physicians and patients. This includes misleading presentations of risk such as using relative instead of absolute risk, which often leaves people less informed about the health risks than they were before reading the information.

The speaker argued that, if we wish to have a more health-literate citizenry, we need to increase medical risk literacy among patients, doctors and policy-makers alike. Framing medical information in formats that are most readily understood by laypeople and professionals is a first essential step toward enhancing evidence-based, informed decision-making and recommendations in health care and screening. Fact boxes (for example, visual, tabular tools displaying all risk information of the intervention and control groups side by side in absolute numbers and adjusted to the same denominator) are highly effective in educating laypeople and physicians on the effectiveness of medical interventions in various health settings. In addition, to cultivate an informed population, schools should start teaching the mathematics of uncertainty rather than only the mathematics of certainty. Guidelines about complete and transparent reporting in journals, brochures and the mass media need to be better enforced. The speaker concluded that a critical mass of informed citizens will not resolve all health-care problems but can constitute a major triggering factor for better and more evidence-based health care.

Discussion

The chair asked for contributions from the floor. A comment was made that informed choice and autonomy of decision-making should be considered more important than the participation rate. In addition, a systematic review has shown that physicians overexaggerate benefits and laypeople underestimate harm. This perception gap means that regardless of how good information leaflets are at expressing harm and benefits, they will always be coloured by an individual’s perception. The resource person for the session added that, although health information and health literacy play an important role in participation rates, access to screening remains a very important factor as well.

Different perspectives on initiating a new screening programme: the example of lung cancer

The moderator introduced this session, explaining that the purpose was to explore how decisions are reached about whether to start a new screening programme. Lung cancer screening was being used as a tracer subject, and four panellists had been chosen to present different perspectives. The moderator asked each panellist to consider three questions:

- From your perspective, how did you get involved and reach a decision?
- How did you synthesize the information?
- How did you engage with the implementation process?

Academic perspective

The IARC representative provided an academic perspective. The presentation started with the statement that the need for lung cancer screening reflects the failure of public health policies on primary prevention (mainly tobacco control). Then the findings from the Nederlands-Leuven...
Longkanker Screenings Onderzoek (NELSON) trial\(^8\) were presented. This was a randomized trial of screening for lung cancer using low-dose CT. The data presented showed that, after 10 years, lung cancer mortality per 1000 person-years was significantly higher in the control group (relative risk 0.76, 95% confidence interval 0.62–0.94) and there was a shift in the screening group to diagnosis at an early stage.

The speaker went on to show the complex pathway for screening, the impact of screening on a population using an infographic, and a comparison of strategies of who to screen. This illustrated that the number of screens needed to prevent one lung cancer death varied from 676 screens for an ever-smokers strategy (50–79 years old) to 268 for a pack-years strategy (≥30 pack-years and less than 15 years since quitting) to 181 for a risk-based strategy.

Therefore, although the NELSON trial\(^8\) has shown that screening with low-dose CT is effective, there remains a significant evidence gap about how to implement a screening programme. The gap in evidence included the following.

- **How can high-risk individuals be better selected?**
  - Can biomarkers be used?
  - Are there better models for a risk-based approach, such as occupational or environmental exposure?

- **What target age range should be used?** (How should comorbidities versus increasing life expectancy be balanced?)

- **What are the long-term effects of chest low-dose CT?**
  - Radiation exposure from low-dose CT is 15 times higher than a chest X-ray dose.
  - Each low-dose CT is equivalent to six months of natural background radiation.

The speaker concluded that the next task for the academician will be to identify the population in which it will be acceptable and cost-effective to implement low-dose CT for lung cancer screening.

The moderator summarized responses according to the questions that had been originally posed.

- The decision was reached based on disease burden.
- Information was synthesized based on high-quality data informed by clinical trials.
- Infographics were used to illustrate implementation issues.

**Professional perspective**

The European Society for Medical Oncology provided the first professional perspective, with the main vision being to offer education and to support the integration of care from disease prevention to terminal care. The Society has tended to be most vocal regarding treatment, while recent data from IARC has shifted its focus to disease prevention.

The principle of the right treatment of the right person at the right time can be translated to screening. It is important to get things right at the outset and to engage with the population and to set up dialogue with stakeholders.

Lastly, the speaker stressed the importance of guidelines that are based on published data.

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The second professional perspective was provided by the European Respiratory Society, which comprises respiratory physicians, pathologists, surgeons and radiologists. They are very aware of the significant burden of lung cancer and are firmly behind the findings from the NELSON trial.\textsuperscript{8} They recognize that any screening programme needs to balance benefits and harm.

The speaker considered a number of implementation issues. This included a need to collect and monitor data across Europe, requiring advanced data capture that is standardized across Europe as soon as possible. Second, standard protocols are needed to guide clinical practice. Third, quality assurance systems need to be in place to support newly emerging screening programmes.

The moderator summarized this perspective as follows.

- Decisions are informed by the public health burden, and professions can act as advocates of public health.
- Data are derived from multiple stakeholders.
- Professional networks are very important in disseminating guidelines. The professions also need to engage with policy-makers.

**Policy-maker perspective**

The official from Sweden’s National Board of Health and Welfare described the policy-making process in Sweden. For lung cancer screening, oncologists initiated the request to consider starting a programme.

Any decision regarding starting a screening programme has to consider the benefits and harm. Sweden uses 15 criteria based on Wilson & Jungner\textsuperscript{3} to guide their decision-making. This includes determining that the screening programme is ethically acceptable, that it distributes resources in a fair way and that it meets the organizational criteria. A particular challenge for this programme is to ensure that the programme reaches high-risk groups.

**Discussion**

The moderator noted that this final perspective showed how policy-makers need to reconcile data and ethics to reach a decision. Discussion was then opened to the floor.

- A representative of the European Stroke Organisation shared the experience of patient groups asking for advice regarding screening for atrial fibrillation. The Organisation stressed the importance of evidence and had successfully engaged with patient groups.
- Other comments from the floor included the challenge for policy-makers to know when they have sufficient evidence to decide whether the benefits outweigh the harm and how to create a dialogue with the public about how to balance benefits and harm. One member of the panel thought that it was not possible to gain consensus for this kind of question; another said that using techniques such as citizen juries might provide a way forward.
- Another concern was raised about how to manage conflicts of interest, in particular when emotions colour decision-making. The colleague from Sweden said that involving the public in assessing the criteria and having a consultation period may address these kinds of concerns.
• A colleague questioned whether the findings from the NELSON trial\(^8\) would be replicated in real life since the participants in the trial were motivated individuals and this may not be true in the general population of smokers. A panellist challenged whether this was correct and said that participation in United Kingdom pilots had been 40–50%.

• A participant, who noted that people with less education have a lower participation rate for cervical screening and are also at higher risk, asked how informed consent and increased participation can be achieved for those at higher risk.

• A comment was made that starting a new screening programme might negatively affect other programmes.

• Panellists then debated whether the risks associated with lung cancer screening could be explained adequately so that people can make informed decisions about whether they wish to be screened. One member of the panel pointed out that if absolute numbers and the same denominator were used, then the risks could be explained coherently to laypeople.

The moderator concluded the following.

• Further research is needed before implementing lung cancer screening to target the right populations.

• Increased awareness of people who are disadvantaged and/or left behind is needed.

• A better understanding of the steps for increasing participation in screening is needed.

**Political, social, commercial and technological drivers of screening**

The chair introduced the session. Previous sessions had considered evidence and how to put evidence into practice. This session focused on contextual factors that influence decision-making.

**Keynote presentation: overview of drivers of screening**

The speaker introduced the topic by explaining that external factors that influence decision-making need to be considered and that demand and supply for screening have many drivers. By understanding the influences on demand and supply, strategies can be developed to facilitate the implementation and uptake of appropriate screening programmes and disinvestment in others. The following are needed to achieve this: transparent processes subject to scrutiny and with appropriate opportunities to appeal decisions; use of independent scientific bodies that can assess the case for disinvesting or investing in screening programmes; and clear synthesis of evidence on multiple factors, including effectiveness, cost–effectiveness, inequalities and budgetary impact.

The speaker then considered the role of health professionals and health systems as key drivers of screening demand. Since industry can play a key role in influencing both demand and supply, it was important for a transparent relationship between professionals and the medical and health-care industries. Inappropriate behaviour among health professionals, such as promoting ineffective screening tests, could be addressed through effective communication, contractual arrangements and declarations of any potential conflicts of interest.

The role of the public in decision-making was then considered; this was not straightforward. Advocacy campaigns will legitimately seek to influence public opinion, but there needs to be regulatory measures for full disclosure of conflicts of interest and sources of funding.
It is critical for health systems to engage with the public to appropriately influence demand for screening programmes. A deliberative approach using citizen juries can be used to help with complex decisions. Juries should be a representative (random or stratified) sample of the public, who are briefed by expert witnesses on screening evidence, advantages, disadvantages, treatment options and costs. The citizens become jurors in a transparent manner as part of a democratic process. Since citizen juries are a relatively new practice, how juries and citizen assemblies affect long-term policy and practice needs to be explored.

The speaker concluded that understanding the evidence is insufficient; understanding how it is used in the real world is also important. Several steps can be taken to improve how to place evidence at the heart of the decision-making process, such as: independent evaluation with regular review that is open to scrutiny; public involvement in discussions of sensitive screening topics; disclosing conflicts of interest and transparency mechanisms; implementing contractual and financial incentives to influence professional behaviour; and lastly, investing in action to increase the uptake of appropriate screening.

The chair thanked the speaker and introduced the panel, who provided examples of various types of drivers of screening.

**Commercial and technological drivers: the example of CT scans for individual health assessment**

The speaker described the use of CT scans in opportunistic screening in an asymptomatic population and considered the various drivers for this kind of screening activity.

First, the influence of social and cultural factors as drivers was explored. In some communities, a general perception is that more medicine is always better and the concept of overdiagnosis is counterintuitive and not discussed. In addition, health-care professionals have a low tolerance of uncertainty, which could be exacerbated at times by vested interests and fear of litigation. This can arise as a result of a medical education that focuses on how to reach a precise diagnosis and take action rather than a discussion about when it is better not to intervene.

In some cultures, individuals are encouraged to go for regular check-ups for their health or that of their families and give gifts of a whole-body CT. There are also consumer demands for CT scans from people who feel they risk developing a serious condition.

Technological and commercial drivers were then considered. Manufacturers and vendors push new imaging technology. Screening service providers advertise CT scans in many check-up clinics. Advertising can play on fear by exaggerating benefits and convenience, and failing to mention the associated risks.

The speaker pointed out ethical dilemmas that could arise in the practice of CT for individual health assessment: for example, doctors who own CT equipment and who refer patients for CT investigations may have conflicts of interest. They often do not take steps to ensure that they comply with ethical principles, such as autonomy, equity, justice, beneficence and non-maleficence.

**Medical and legal pressures for antenatal screening**

Obstetrics has a particular problem of defensive medicine leading to excessive testing and overtreatment. This is mainly driven by fear. First, fear of litigation. Medico-legal cases generate
deep fear among doctors, since they can result in a criminal trial in some countries. Prenatal diagnosis of the unborn child is a very difficult area since parents may sue clinicians for missing a diagnosis and courts increasingly uphold these decisions. In some countries, two thirds of obstetricians can expect that they will be sued at least once in their career.

Defensive medicine is also driven by fear of adverse events which still occur, although very rarely. Parents, especially in high-income countries with advanced health systems, expect that they will have a perfect pregnancy and a perfect baby, and when an adverse event does occur, they can experience considerable distress and disappointment. Doctors can feel guilty and lose face with colleagues and suffer blame from the public. In some cases, this can result in physical and verbal abuse.

The speaker concluded that, in these circumstances, it is unsurprising that there is excessive screening, testing and treatment. A solution is needed since the current approach is unsustainable.

Drivers of screening: the examples of direct-to-consumer testing and social pressure

The speaker started by pointing out that screening is a major public health endeavour, but it is also big business and therefore how to govern screening when it takes place outside organized programmes needs to be considered. This means asking how to control the commercial forces that influence screening decision-making. In considering these questions, the presentation focused on the molecular diagnostics industry. There are about 500 companies globally, and 17% of laboratories globally have at least one direct-to-consumer molecular diagnostic product offering. Consumer testing includes: paternity testing, ancestry testing and health-related testing, which is mostly genetic risk assessment for noncommunicable diseases.

There are three main criticisms of consumer genetics companies. The first is whether tests can provide accurate risk scores linked to clinical outcomes. The second is whether the quality of information provided to consumers is adequate for making informed decisions. The third is that companies rarely provide adequate pre- and/or post-test genetic counselling and, if they do, the standard of care does not always meet recognized standards.

The current medical device regulations for in vitro diagnostics are inadequate. Tests are not independently evaluated before they enter the market. However, under a new regulation, all genetic tests and all tests for cancer will be subject to some independent evaluation before they can be marketed. Some European countries have introduced legislation on genetic testing that bans or in some way limits direct-to-consumer services.

The speaker concluded with some actions that can be taken to resist pressure to use direct-to-consumer tests. First, policy-makers should have heightened awareness of the links between industry and advocates for new technologies in professional bodies and patient charities. Second, they should highlight misleading messages that companies use in their marketing and misleading promotional activities used by screening advocates in the public sector.

Child health screening: what is driving it?

The speaker’s main message was that the screening of children and adolescents is too often driven by fear, good intentions and professional interests.
Across the European Region, differences in the number of recommended or mandatory screening tests or healthy child visits are striking, with numbers ranging from two to more than 140 visits during childhood. There is no consensus and little evidence on what these visits should entail.

The speaker presented the situation in Belarus and the Russian Federation. According to ministerial orders, each healthy child between 1 and 18 years of age must undergo the following screening tests and specialist consultations:

- blood analyses: 10 times in Belarus and 7 times in the Russian Federation;
- blood glucose: 9 times in Belarus and none in the Russian Federation;
- urine analyses: 10 times in Belarus and 7 times in the Russian Federation;
- electrocardiogram (ECG): 12 times in Belarus and 4 times in the Russian Federation;
- ultrasound of the heart: once in Belarus and twice in the Russian Federation;
- ultrasound of the abdomen and kidneys: once in Belarus and three times in the Russian Federation;
- ultrasound of the thyroid: once in Belarus;
- X-ray of the lungs (digital fluorography): once at 17–18 years in Belarus and older, and X-ray screening starts from 19 years in the Russian Federation;
- paediatric gynaecologist: four visits in Belarus and six visits in the Russian Federation; and
- consultations by subspecialists: more than 20 visits in Belarus and more than 30 visits in the Russian Federation.

One driver of this extensive and non-evidence-based screening in some European countries is the fear of policy-makers and health professionals to be accused of negligence. Stories of sudden death during physical exercise and of rare cancer conditions send shock waves through the media and steer the public discourse.

A second driver is good intentions. Many policy-makers, the general public and specialist physicians think that annual screening tests performed to prevent rare conditions or to detect them early are good practice. However, they often result in overdiagnosis, overtreatment, waiting lists for tests and appointments with specialists, causing anxiety, depression and worrying parents.

The third driver is professional interest. One factor is the fragmentation of specialist paediatric care with the rise in numbers of highly specialized professionals for children. Mandatory screening tests and consultations that are required for children to be allowed to go to kindergarten or school generate significant business for these specialists.

There is also a tendency to medicalize common conditions, especially by highly specialized professionals. Some diseases commonly diagnosed in children in countries of the former USSR are not described anywhere else and are also not included in the International Classification of Diseases (ICD-10).9

Belarus, with the assistance of WHO, reviewed the order on dispensarization to reduce the number of screening tests for children using an evidence-based approach. More evidence is needed at the international level on what healthy childhood visits should include.

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However, evidence alone will not be enough. To address this, health systems must be built on trust and financed in ways that enable care to be provided based on evidence rather than on fear, good intentions or professional interests.

**Scaling up effective and evidence-based screening**

The purpose of the next three sessions was to examine in-depth three programmes that are known to be effective, but that are currently not being delivered at a scale and quality sufficient to significantly improve health outcomes. The sessions for newborn hearing, cervical cancer and diabetic retinopathy screening sought to learn from countries that have successfully implemented these programmes and to hear from other country participants about the challenges they have faced in achieving their effective delivery. The sessions identified potential solutions and actions that WHO can take to support countries in scaling up these programmes.

**Newborn hearing screening**

The chair explained that the purpose of this session was for participants to share their experiences in implementing newborn hearing screening and to understand how such programmes can be scaled up.

**Introduction and situational analysis**

A technical expert from the University Hospital Munster in Germany presented a situational analysis. Globally, in 2015, hearing loss was the fourth most common reason for disability. There has been a steady increase in numbers: currently 466 million people are affected, and by 2050, that number is estimated to reach almost 900 million and 7% of them will be children. Hearing loss remains a global health burden and, in contrast to visual loss, politicians, health professionals and the public do not recognize it as an important issue. It has a low priority and insufficient allocation of resources because it is a hidden disease.

A WHO resolution on the prevention of deafness and hearing loss was launched in 2017 and included calls for hearing screening of newborns and young children. In 2020, WHO produced a manual on planning and monitoring national strategies for improving hearing health care.\(^\text{10}\)

The most effective intervention to reduce hearing loss among infants and children in low-income countries is prevention, while in high-income countries, it is universal newborn hearing screening. The results of recent trials show that universal newborn hearing screening programmes have positive long-term effects on the language, cognitive and academic development of children and adolescents.

The speaker then presented findings from a survey of 158 countries on universal newborn hearing screening, conducted over a 10-year period, that included questions on the types of objective screening tests:

- otoacoustic emissions;
- automated auditory brainstem response alone; or
- two-stage otoacoustic emissions and automated auditory brainstem response screening.

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This showed that 38% of the global population had no or minimal screening coverage, and 33% had full or near universal newborn hearing screening programmes. Otoacoustic emissions is the most widely used screening method (57% of countries), followed by two-stage otoacoustic emissions and automated auditory brainstem response (30%) and automated auditory brainstem response (11%). Loss due to follow-up is high (17%).

The responses of the survey showed that universal newborn hearing screening works better in centrally organized than in regionally organized countries. The survey found that the mean age at which permanent hearing loss was diagnosed among the screened children was 4.6 months and 34.9 months for non-screened children. The mean start of therapy was 6.9 months for screened children and 35.2 months for non-screened children.

The conclusions of the survey were as follows.

• The effectiveness of modern universal newborn hearing screening programmes depends on factors such as government mandates and guidance and central oversight of hearing screenings.
• The target parameters need to be defined.
• Tracking systems are needed, with data transfer from screening devices to screening centres.
• Paediatric audiological services and rehabilitation programmes need to be available.
• The opportunity for case discussions in professional excellence circles with boards of experts are important in driving quality.

Programmes are lacking in low- and middle-income countries, but even in high-income countries there is potential for improvement.

The chair asked what kind of interventions are needed for newborns who are found to have hearing loss. The technical expert gave the following information with approximate figures.

• 5–10% of children need surgery (those with cleft palate, Down syndrome or craniofacial malformation), with the surgery usually carried out at age 0–5 years.
• 60–70% need hearing aids for one or both ears.
• 10% should have watchful waiting, since they have mild hearing loss that might resolve.
• 10% need cochlear implants at 6–12 months of age, and not all centres are able to do this.

Some countries in the former USSR do not have enough technicians who are trained to carry out very specialist hearing aid fitting for children.

**Country experience: Belgium**

The speaker explained that, in Belgium the community governments have responsibility for disease prevention and screening. The three areas are Flemish-, French- and German-speaking, each with their own newborn hearing screening programme. Key differences are the first test (automated auditory brainstem response versus automated otoacoustic emissions), the pathway and the age of the newborns to be screened (2–4 weeks in the Flemish community area in contrast to 2–3 days in the French-speaking community, related to the difference in the first screening test), financing of the screening and registration of the data (full versus partial digital registration). Participation rates are high in the Flemish- and the French-speaking areas, both at
least 90%. Data on the German-speaking community were not available at the time of the Conference.

In conclusion, one of the main issues is that the three communities report data separately because of the differences in the programmes. It is therefore currently not possible to compare data for the three types of programmes or carry out a health economics evaluation for the country as a whole.

**Discussion**

The speaker invited comments from the floor and countries to share their experiences. Iceland stated that their main issues are data gathering and reporting. Most children are screened at five days of age and a very few children are diagnosed with hearing loss, but since they do not get any results at the national level, validating the performance of the screening programme is difficult.

The Netherlands commented that neonatal hearing screening is one of the newborn screening programmes in the Netherlands. It is a centralized programme coordinated by the Netherlands National Institute for Public Health and the Environment and operationalized by youth health-care organizations. The Netherlands commented that this works very well. Currently the Ministry of Health is exploring the possibilities of decentralizing the programme.

Portugal stated that newborn hearing screening is carried out in 40% of hospitals, but it is not organized centrally in contrast to metabolic screening which covers 100% of newborns.

Uzbekistan explained that newborn screening was introduced in 2016 using a Russian auditory system called Neurosoft. In 2017, 58 000 children were screened and 315 children with hearing problems were identified. In addition, cochlear implants were available.

Malta stated that they have problems implementing newborn hearing screening, and it is currently only available for high-risk children. There are organizational, resource and logistical issues in rolling it out to all newborns.

The participant from Belgium was asked to comment on the rationale for the three different tests and pathways operating in Belgium. She explained that this is mainly due to historical, logistic and financial reasons (technical costs). She also explained that Brussels has a mixed system, generally reflecting the different languages that are spoken there.

The chair said that two main issues had emerged in the session. First, since countries vary tremendously in the tests and the pathways they use for newborn hearing, the best approach or system to use is not clear. Second, something should be done to address the large numbers of newborns who are lost due to follow-up issues. The technical expert replied that each system has its advantages and disadvantages; otoacoustic emissions is very cheap and easy to use with excellent sensitivity and specificity, but it misses auditory neuropathy, which is very rare (about 1 in 10 000 children). Automated auditory brainstem response alone is also very good, but it does miss some mild hearing loss. Both otoacoustic emissions and automated auditory brainstem response together give too many false positives. If it is only possible to use otoacoustic emissions alone, this is probably sufficient since babies with auditory neuropathy will usually present in another way and, in any case, cochlear implants are not recommended until children are older.

In relation to the availability of interventions across Europe, most countries can now provide cochlear implants, but in many countries, parents have to pay out of pocket.
The chair noted that WHO should encourage, support and disseminate case studies that document what has worked in addressing these operational issues, supported by indicators to provide evidence of effectiveness.

**Cervical cancer screening**

The chair introduced the session and explained that the purpose of the session was to consider the following.

- What are the main challenges in developing, implementing and/or reforming cervical cancer screening programmes?
- What are potential solutions?
- How can WHO, UNFPA and the international expert community help?

**Introduction and situational analysis**

A situation analysis was provided by a representative of IARC. The incidence and mortality of cervical cancer across the European Region were reviewed. Whereas incidence and mortality have dropped across the European Region as a whole, both incidence and mortality have increased in some countries.

This variation is unlikely to be attributed to differences in cervical infection with oncogenic HPV types and is mainly due to the relative lack of high-quality cervical cancer screening and inadequate high-quality treatment of invasive cervical cancer.

The speaker reviewed the WHO life-course approach to cervical cancer control. Primary prevention includes HPV vaccination for girls 9–14 years old and a range of other activities to prevent HPV transmission in girls and boys. Secondary prevention targets women older than 30 years and recommends a screen and treat strategy. Tertiary prevention is effective treatment and palliative care for all women who are diagnosed with cervical cancer.

In May 2018, the WHO Director-General made a Call to Action to eliminate cervical cancer. This requires a public health approach with a strategy that addresses control, elimination and eradication. The proposed threshold for eliminating cervical cancer by 2030 as a public health problem is an age-adjusted incidence rate <4 per 100,000 women. The targets for 2030 are:

- 90% of girls worldwide fully vaccinated with HPV vaccine by 15 years of age;
- 70% of women worldwide screened with a high-performance test by 35 and 45 years of age; and
- 90% of women worldwide identified with cervical disease (precancer or cancer) receive treatment and care.

To achieve this, testing should move away from complex testing pathways and move towards high-performance tests: HPV testing with or without triage, followed by treatment with cryotherapy or thermal ablation. Triage in the future may involve using molecular markers.

The cost–effectiveness of the 90–70–90 targets by 2030 has been modelled in 78 low- and middle-income countries and has shown that scaling up to the 90–70–90 targets by 2030 will result in elimination of cervical cancer in 95% of countries and will be cost-effective.
Country experience: Romania

Cervical cancer screening was started in Romania in 2012. Screening is offered to women 25–64 years old (5.6 million eligible people) every five years using cytology. The target is to exceed 50% coverage.

The plan is to move to HPV testing, and pilot projects to reform the system have been launched.

The speaker described the main challenges the programme has faced when it was initially launched and some of the possible solutions as it is reformed.

<table>
<thead>
<tr>
<th>Challenges</th>
<th>Solutions</th>
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<tbody>
<tr>
<td>The national programme started without a pilot, so operational issues were not appreciated.</td>
<td>There is now a possibility to reshape the programme by moving to HPV testing.</td>
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<tr>
<td>Low coverage, especially for rural and uninsured women.</td>
<td>This can be addressed with a strategic approach using a sustainable invitation system targeting these groups and increasing access.</td>
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<tr>
<td>Inequity at diagnosis, follow-up and treatment since uninsured women are not covered. Private clinics offer opportunistic testing, and women choose to use private care over the public system, even though it is in a highly centralized health-care system.</td>
<td>Strengthening the public system may address this alongside improved health literacy.</td>
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<tr>
<td>There are problems with trying to increase coverage and using too many laboratories that do not have adequate quality control for the tests.</td>
<td>This could be addressed by moving to HPV testing and introducing quality standards and controls. This might be helped by international expertise.</td>
</tr>
<tr>
<td>Lack of consensus of specialists and civil society over implementation of the programme, alongside frequent and sudden changes of vision at the strategic level, makes planning difficult.</td>
<td>Both need to be addressed through information and communication, using technical and international experts, data and evidence; and advocating relentlessly and fearlessly.</td>
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Country experience: France

A participant from France described the governance system overseeing cervical screening. In 2014, France’s cervical screening programme was opportunistic. The eligible population was 17 million women 25–65 years old. However, coverage of this population was about 60–65%. There were considerable inequalities by age and socioeconomic characteristics. Less than 10% of women were being screened at the recommended interval.

As part of the national cancer plan 2014–2019, a decision was made to move towards an organized programme. The plan was not to eliminate but to complement opportunistic screening.
The target was to achieve 30% mortality reduction in 10 years and reduce inequalities. The population-based programme is:

- free of charge;
- liquid-based cytology every three years for women 25–65 years old;
- a call and recall system for non-participating women;
- follow-up of all women screening positive (invited and non-invited);
- specific actions targeting vulnerable populations to reduce health inequalities; and
- improving quality by monitoring information and taking action to stop inappropriate screening practices (screening intervals and excessive screening).

The speaker noted that bringing about a change has taken a long time.

A health economics study has examined the efficiency of HPV testing every five years, and there are now new guidelines that recommend:

- liquid-based cytology for women from 25 to 30 years old (every three years); and
- HPV DNA testing of women from 30 to 65 years old (every five years) followed by liquid-based cytology triage.

Changing to HPV testing requires further work, including revising the regulatory framework, changing the administration of the programme, reviewing pricing for providers (French health insurance), and improving quality assurance and educational tools for the public and general practitioners.

The speaker concluded that transforming a programme is a major undertaking.

**Country experience: Slovenia**

In 2003, Slovenia switched from an opportunistic screening programme to an organized programme. The country has taken a centralized comprehensive approach. It has been a multistep process, requiring quality assurance for each step, including:

- central management;
- legal regulations;
- national guidelines and standard operating procedures;
- a central screening registry collecting comprehensive data from all screening and pathology samples;
- an information technology system;
- data from the entire screening pathway that can be used for quality assurance and monitoring and evaluation;
- switching to liquid-based cytology to be ready for new markers (if there is enough evidence); and
- evaluation of HPV primary testing.
The population-level effects of organized population-based screening in Slovenia can already be observed, with an age-standardized incidence rate of about 7 per 100,000 women and a mortality rate of about 2 per 100,000 women in recent years. In the past, cervical cancer incidence rates were among the highest in Europe, reaching 27 per 100,000 in 1960.

The team has also worked with the EU-TOPIA project, collecting cost–effectiveness data.

**Country experience: Norway**

Norway moved from opportunistic screening to an organized programme in 1995. This led to a 50% reduction in cervical cancer incidence from its peak. A study has estimated that screening has prevented 70% of cervical cancer cases in Norway. The failures were due to:

- 15% of women do not participate in the programme;
- 10% have a false-negative result; and
- 5% attend with a cancer that has already developed.

The biggest issue is attendance. Steps have been taken to increase participation, including social media, revised information, digital reminders and studies to see what increases participation, including self-sampling and mobile technology using an app.

A decision was made to move to HPV testing through randomized implementation of an HPV pilot project involving 25% of the population from 2015 to 2018. Women were pseudo-randomized; 50% of the women had their samples tested first using liquid-based cytology and 50% had their samples tested using HPV as the primary test. Those who were liquid-based cytology positive had their samples retested using an HPV test. The HPV-positive samples were retested with liquid-based cytology. This approach to implementation was expanded nationally.

HPV testing was implemented in this way for two reasons. First, it was safer when combined with continuous monitoring. It enabled those monitoring the programme to compare the results between the HPV primary testing arm and the cytology primary arm and to distinguish whether any changes that occurred could be attributed to changes in the population or how laboratories conducted testing for HPV and, if so, issues with the laboratory processing could be addressed quickly. Second, it was a practical approach since the transition from cytology to HPV was easier both for laboratories and gynaecologists, because it gave them time to switch capacity across different modes of operating. However, the reduction in the number of laboratories has been difficult, and this process is not complete.

The result of the three-year implementation pilot project is that attendance is the same in the two arms. The HPV arm had 6.5% positive and the HPV test detected more high-risk lesions (cervical intraepithelial neoplasia grade 3 or worse (CIN3+)).

The speaker concluded that, for the programme to be effective, quality assurance must apply to all aspects of the programme, including colposcopy.

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11 Towards improved screening for breast, cervical and colorectal cancer in all of Europe (EU-TOPIA) is a five-year project funded by the European Commission’s Horizon 2020 programme (https://eu-topia.org, accessed 8 June 2020).
Discussion

The chair asked for the experience of countries moving from opportunistic to organized screening and the response of practitioners to this change and whether there was resistance because of anxiety that it would reduce their work and income.

Slovenia noted that this did need to be addressed before moving from opportunistic to organized screening, and they had spent a lot of time getting engagement and support from practitioners. The results of the programme have demonstrated that this decision was correct, and the programme leaders hope that when they move to HPV screening, they will get support from both practitioners and the public as they move to a five-year interval. They also noted that the acceptability of the test is part of the Wilson & Jungner criteria, and perhaps as countries consider moving to even longer intervals such as 10 years, they need to consider whether the population and practitioners will find this acceptable.

The United Kingdom explained that England has just moved to HPV primary testing, and there have been considerable transition issues with both laboratories and workforce. They have not yet moved to five-year intervals but are intending to do so.

The discussion then addressed a number of topics.

1. Modelling the impact of the vaccinated cohort and vaccinating boys

Several countries reported that they are considering what to do once the vaccinated cohort has good immunization coverage. Several countries said that they were undertaking modelling, and WHO was requested to put countries at a similar stage in touch with each other to collaborate and share findings.

A representative of WHO provided information regarding some modelling that has been done on HPV immunization for boys. This suggests that if coverage for girls is inadequate, such as 60%, then immunizing boys with the same low coverage will not be adequate to prevent the transmission of HPV in the community. In addition, there is a global shortage of HPV vaccine, and boys being immunized may therefore reduce vaccine availability for girls in some low- and middle-income countries.

2. Self-sampling

Slovenia reported on a pilot project involving 25,000 non-respondents using self-sampling, with an overall 35% increase in uptake. They are planning to introduce this for non-respondents. The Slovenian participant also reported on another problem related to a laboratory in a neighbouring country trying to sell a non-validated self-sample in Slovenia. The Government of Slovenia managed to prevent this, but it remains a concern. Other countries reported concerns about the use of non-validated self-sampling.

3. Validating the HPV test

Several countries expressed their concern about laboratories using non-validated HPV tests. Some countries are planning national tenders to use a single test across the country. There are no international criteria for self-sampling HPV tests, and WHO was requested to pick this up.
4. **Strategy for cervical intraepithelial neoplasia grade 2+(CIN2+)**

Several colleagues discussed that further work was needed on a strategy for managing CIN 2+.

The panellists made final points.

- The cost of HPV tests placed limitations on rolling out programmes for low- and middle-income countries.
- Countries need to deal with both political and industry pressure. For example, there is a risk that commercial interests and the availability of self-sampling HPV tests could result in an increase in opportunistic screening.
- Introduction of biomarkers might be beneficial, but may lead to an overcomplex screening pathway that is difficult to understand for both the practitioner and the individual.
- Slovenia signposted colleagues to the MISCAN website as part of the EU-TOPIA project.  
- International collaboration between countries would be extremely beneficial since so many countries are tackling similar issues.
- Dealing with myths circulating on social media and encouraging health literacy are challenges for all countries.

## Diabetic eye screening

The chair explained that the focus of the session was to explore countries’ experiences of diabetic eye screening and to understand the following.

- What models are in place within countries?
- What are the challenges in implementing diabetic eye screening in an organized and effective way?
- What further support is needed to achieve effective diabetic eye screening?

## Introduction and situational analysis

The global situational analysis of diabetes was presented by a representative of the WHO Regional Office for Europe. In 2014, about 64 million people had diabetes in the European Region. An estimated 35% have some form of diabetic retinopathy, and 11% have vision-threatening disease.


The recommendations include everyone diagnosed with diabetes being advised to receive a retinal examination; repeat screening at two-year intervals or according to the ophthalmologist’s recommendations, and people with type 2 diabetes should be screened when diagnosed. Currently, there are no WHO recommendations on how to run a screening programme.

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(systematic versus opportunistic), the setting (primary or secondary care or other facilities) or using new technologies such as artificial intelligence.

Screening protocols vary according to resource settings. Even the most basic screening method, if well executed, enables the timely identification of lesions. However, screening per se does not prevent vision loss; in the absence of availability of treatment and organized referral, screening is not recommended.

**Situational analysis of screening for diabetic retinopathy in Europe**

The situational analysis of diabetic retinopathy was given by an organizer of the Liverpool Declaration on Screening for Diabetic Retinopathy in Europe. The speaker described the history of diabetic retinopathy screening in Europe, starting with the St Vincent Declaration in 1989 and then followed by the Liverpool Declaration in 2005, which states that:

> European countries should: reduce the risk of visual impairment due to diabetic retinopathy by 2010 through:
> • systematic programmes of screening reaching at least 80% of the population with diabetes;
> • using trained professionals and personnel; and
> • universal access to laser therapy.

Three subsequent conferences have shared the learning and experiences of countries implementing diabetic retinopathy screening programmes. Common challenges faced by countries during implementation have been: lack of resources and sustainability of ad hoc funding streams; working with health insurance and private sector providers; and poor collaboration between ophthalmologists and diabetologists.

Further work is planned to examine: risk-based or stratified screening intervals; models of screening and treatment appropriate to remote and poorly funded settings; and how to mobilize political action on diabetic retinopathy, including involving key international organizations.

Key topics for future research include: the role of optical coherence tomography in screening; how to address non-participation; and the impact of improved diabetes control on macular oedema.

**Systematic screening for diabetic retinopathy – evidence and components**

The Wisconsin Epidemiologic Study of Diabetic Retinopathy gives the most comprehensive data on diabetic retinopathy. The 10-year incidence of any diabetic retinopathy among people with diabetes was 90% for those with type 1 diabetes, 79% for those with insulin-resistant type 2 diabetes and 67% for those with non-insulin-resistant type 2 diabetes. The 10-year incidence of diabetic macular oedema is 20% (type 1), 25% (insulin-resistant type 2) and 14% (non-insulin-resistant type 2).

Laser treatment remains the mainstay of treatment for diabetic retinopathy. It reduces the risk of vision loss by 95%. Intravitreal agents, such as bevacizumab, ranibizumab and aflibercept, are the first-line treatment for maculopathy and have the potential to improve vision (since laser is only 60% effective). Other treatments are steroids and vitrectomy.

Essential features of a systematic screening programme include:

- identifying people with the condition before the vision has been affected and at a stage when treatment is likely to be most effective;
• using an effective test (sensitivity and specificity), such as digital photography;
• timely investigation and treatment of people with retinopathy by an eye specialist (fast-track treatment for advanced disease);
• pathway and protocols appropriate to regional needs;
• good management of the underlying diabetes;
• high population coverage;
• good data, including registries and blindness rates;
• minimizing error (quality assurance);
• adequate health-care funding;
• competency-assured screener and graders – technicians, optometrists and ophthalmologists;
• adequate number of trained ophthalmologists;
• patient and professional education;
• effective communication between screening programmes, primary care physicians, diabetes specialists and ophthalmologists; and
• engagement of all stakeholders.

Country experience: Ireland

Diabetic Retina Screen was started in 2011 and is a government-funded, quality-assured programme that offers free annual diabetic retinopathy screening to people with diabetes. It is a population-based, call-recall programme delivered on an annual basis. Screening is offered to people with diagnosed diabetes aged 12 years and older registered with the programme. The programme aims to reach a growing eligible population of an estimated 200 000 people (based on 5.6% of the population having diabetes).

Quality assurance is a significant component of the programme. The programme has 22 quality assurance standards that follow the screening pathway and processes: call-recall; maximize uptake; maximize the performance of the screening test; minimize harm; treatment; screening interval; and governance and outcomes.

The programme is organized through a national database of people diagnosed with diabetes (about 170 000). Screening is outsourced to two private providers. There are seven treatment clinics (underpinned by clinical practice guidelines). Screening and treatment activity are linked via an integrated information technology platform. The programme management function supervises all activity.

The challenges for the programme are managing non-diabetic eye disease, accessing hard-to-reach clients and private health care in Ireland. Recent successes include providing screening and clinical data to the programme and a new digital surveillance screening pathway.

Country experience: Finland

In Finland, diabetic retinopathy screening is carried out using retinal digital imaging and delivered in accordance with national guidelines published in 1992, 2006 and 2014.
Type 1 diabetics are screened every two years from age 10 years, or more frequently if there are abnormal findings. They are screened in specialist care. People with type 2 diabetes are screened at the time of diagnosis and every three years or more frequently if they have abnormal findings. They are screened through primary care, which is organized by the municipalities. Finland has more than 300 municipalities, and each organizes the care locally. This means that screening can occur in different settings: for example, university hospitals, private hospitals or occupational health facilities. As a result, information is not available on the national situation.

Because of the diverse methods of screening, attempts have been made to improve how it is carried out. In northern Finland, telemedicine and mobile clinics were introduced, and this has resulted in a greater reduction of vision loss from diabetic retinopathy compared with other parts of Finland.

The main challenge for the programme is that screening is not mandatory (not backed by law) and not uniformly conducted in Finland. The quality of digital images and interpretation varies, and there are inadequate resources to manage the referral process and the increasing number of people with diabetes.

**Country experience: Russian Federation**

The speaker explained that in the Russian Federation the approach is not to run separate screening programmes, but to include screening tests that are appropriate for the age, sex and characteristics of each person in the regular check-ups that are conducted for all people. This approach to screening has advantages and disadvantages. A disadvantage is that effective quality assurance cannot be carried out for each test that is part of a combined check-up.

Screening for diabetic retinopathy is included in follow-up checks for all people with diabetes. The protocol or algorithm for care of these people has been developed nationally. People with diabetes attend their primary care facility at least once per year. Care of people with diabetes is covered by compulsory health insurance, and they receive all their medications free of charge and therefore usually attend appointments. Primary care doctors refer people with diabetes to ophthalmologists to check for diabetic retinopathy.

This system poses several challenges. First, people in rural areas can have difficulty accessing care since there are not enough ophthalmologists or endocrinologists.

Second, there are problems in understanding the full extent of diabetic retinopathy. The online registry of people with diabetes is carried out by endocrinologists, but the registry is not complete since general practitioners or primary care doctors do not always enter information into the registry. Based on the registry, about 15% of the people with type 2 diabetes and 18% of the people with type 1 diabetes have diabetic retinopathy. However, epidemiological studies indicate that the rate is likely to be twice as high. The rates of diabetic retinopathy vary from 2% to 46% between regions, which is probably due to the levels of education of the clinicians.

Lastly, whereas national protocols cover the diagnosis of diabetic retinopathy, treatment and management of cases depend on regional health insurance protocols, and this leads to considerable variation between regions.

**Discussion**

The chair asked countries to share their experiences. Several country participants said that there is some screening in their country, but it is unsystematic and lacked adequate funds. In some cases, there are not enough ophthalmologists to either undertake screening or manage referrals of
the people screening positive. In addition, identifying people with diabetes systematically is difficult.

The health system and the financing model influence whether it is possible to run a systematic programme effectively. Several countries reported difficulty in running a programme in largely privately funded health systems.

Diabetic eye screening differs from other screening programmes because the target population already has a condition that is often managed in primary care or a hospital setting. This means that coordinating care across primary care, diabetologists and ophthalmologists is difficult at times.

The issue of inequalities was raised, since vulnerable people with diabetes often have many comorbidities, which makes access to screening difficult and this group is probably the group at highest risk. The participants discussed how to make diabetic retinopathy screening patient-centred rather than eye-centred.

The chair concluded with some final points. First, WHO lacks guidance on screening for diabetic retinopathy. Second, diabetic retinopathy screening lacks investment and focus by many countries when compared with cancer screening, although the reason for this is unclear. Lastly, since this is a growing problem, it requires significant further work.

**Legal, ethical and resource implications of screening**

The chair introduced the session and said that it reflects the issues raised in previous sessions and highlights the value of using the ethical framework that is described in the guide: respect for dignity and autonomy; non-maleficence and beneficence; justice and equity; prudence and precaution; and honesty and transparency.

**Keynote presentation: human rights considerations for screening**

The final keynote presentation identified human rights in screening programmes as an issue. The importance of human rights in the WHO Constitution was reviewed. The rights-based framework means not only having equal rights by law, but an ability to exercise these human rights in practice. Human rights can be thought of in terms of freedoms and entitlements. WHO is stepping up its work on human rights and health. There is a range of issues for which violating or promoting human rights can affect health and well-being.

The speaker then addressed the question, “What is a human rights-based approach to public health?”, noting that a rights-based approach has a double aim: to increase respect, dignity and better treatment of the individual and to lead to sustainable and effective public health. It also has a dual focus, which is both on the duty bearers and the rights holders. This requires health systems to be able to the respond to these, which in turn can lead to the concept of “progressive realization”.

The speaker went on to consider what a rights-based approach might look like: inclusive and people-centred, non-discriminatory, informed consent, privacy, confidentiality, participation, transparency, accountability and empowering the health workforce. The speaker suggested that these rights could be considered when revising the Wilson & Jungner criteria.3

WHO needs to undertake further work in reviewing existing guidelines to ensure that they explicitly address human rights, that is, that they are non-discriminatory. Much of the existing
work that has been done on sexual health and the principles developed for infectious diseases should be easily adaptable to noncommunicable diseases.

The speaker then described the AAAQ\textsuperscript{15} human rights framework and gave examples of how it may be relevant for screening programmes:

- **availability**: disaggregation of data; consider rural versus urban, migrants; insured population; health workers’ characteristics;
- **accessibility**: non-discrimination; physical accessibility; economic accessibility; information accessibility;
- **acceptability**: ethically grounded; gender-sensitive; culturally appropriate; confidentiality and informed consent; and
- **quality**: safety (benefits and harm); effective; people-centred.

The speaker then reflected on universal health coverage and which groups in screening are at risk of being left behind. The joint United Nations statement on ending discrimination in health-care settings\textsuperscript{16} was reviewed, and three specific points relevant to screening were pointed out:

- guarantee free and informed consent, privacy and confidentiality;
- prohibit screening procedures that do not benefit the individual or the public; and
- ban involuntary treatment and mandatory third-party authorization and notification requirements.

Gender equality is part of the human rights framework and requires a gender-responsive strategy. This highlights the issue of violence against women and how this might be disclosed in cervical cancer screening. The speaker directed the audience to WHO’s guidance on responding to intimate partner violence and sexual violence against women.\textsuperscript{17} The speaker concluded by considering how gender is also a social determinant of health and cited the European Region’s two health and well-being strategies – one for women\textsuperscript{18} and one for men\textsuperscript{19} – pointing out that they shared the same goal.

The chair asked panellists to comment in their respective areas of expertise.

**Screening for migrants**

This presentation was given by an adviser from the Italian National Institute for Health, Migration and Poverty, the WHO Collaborating Centre on Health and Migration Evidence and Capacity Building. The human rights framework views migrants as a vulnerable population and highlights the importance of making services accessible to them. Factors that need to be considered are the legal status of migrants and logistical issues. As identified by the keynote

\textsuperscript{15} AAAQ: availability, accessibility, acceptability, quality
speaker, having legal status does not necessarily mean that migrants have the ability to exercise these rights, and countries should consider what steps are needed to enable migrants to access screening programmes.

**Incidental findings of screening**

The representative from the Public and Professional Policy Committee of the European Society of Human Genetics gave several examples of screening in which conditions were found that were incidental and not the target condition of the screening. The techniques used to screen newborns for genetic conditions, such as sickle cell disease, can often find not only those with the disease, but also those with carrier status. In such circumstances, physicians often think that if they find information, even though it was not intended but may be relevant, they should report it. This is a real problem if the condition is untreatable and there is no advantage in knowing about it. The question is then whether the physician should tell the person in advance that these incidental findings may occur and ask whether the person wants this information. This gives the individual the opportunity to opt out. This situation becomes increasingly complicated with genetic sequencing, since interpreting findings and giving appropriate advice may not be possible.

If physicians have information, they are legally obliged to share it, but the screened individual may not want the information. Obtaining informed consent prior to screening is therefore extremely important. Incidental findings can also consume resources if they need to be dealt with.

The chair asked how different countries dealt with incidental findings. The official from the United Kingdom described how they had tackled incidental findings from screening for thalassaemia, screening through a process of consultation with haematologists and lay users and agreeing that the screening programme would inform parents and their doctor if any of three conditions were detected as incidental findings, but would not inform them of any other incidental findings. The official acknowledged that such a pragmatic approach works for now, but it may not survive advancements in genetic screening.

**Adult checks in family medicine**

The representative from the World Organization of Family Doctors (WONCA) discussed how screening affects family physicians and the opportunity costs of health screening. There is no evidence to indicate that health checks of asymptomatic people result in improved health outcomes. The resources in primary care are not expanding for new screening tests. For example, the opportunity costs of screening for high blood pressure could be considerable. Implementing the 2003 European guidelines on preventing cardiovascular disease in clinical practice would classify most adults in Norway as being at high risk for fatal cardiovascular disease. Solely following up raised blood pressure would require 99 general practitioners per 100 000 patients, but Norway only has 87 general practitioners per 100 000 to carry out all care. This is therefore unsustainable. In addition, there are ethical issues related to using epidemiological data derived from specialist health-care settings and applying it to an asymptomatic population.

**Occupational health checks**

A colleague from the Institute of Occupational Health in Skopje, North Macedonia, WHO Collaborating Centre for Occupational Health, provided an overview of the ethical issues that can occur in occupational health.
Workers’ health, including occupational health check-ups, is based on a comprehensive legal framework that encompasses international documents, such as International Labour Organization (ILO) conventions, a range of EU directives and specific national legislation and regulations. These state that workers should not pay the cost of occupational health check-ups, and that the employer should be responsible.

Most countries have legislation on health and safety at work that requires occupational health check-ups with one overall goal: continually protecting and promoting workers’ health. There are two types of check-ups:

- occupational health surveillance checks in relation to occupational hazards and health risks at work: prospective and repeated continually; and
- occupational health screening pre-employment checks that assess the suitability for a specific workplace, identify the individual’s risks and the risk that the individual could pose to others from ill health in the workplace.

Several ethical issues can arise as part of occupational health practice. First, occupational health can create inequalities, since many workers are not covered by occupational health legislation, do not have access to occupational health services and can be exposed to occupational health hazards. The WHO principle of universal health coverage and Sustainable Development Goals 1, 3 and 8 support action on this.

Second, the representative from WONCA raised a concern that screening and occupational health check-ups can take the focus away from what individuals consider important about their health and side-track primary care (which often has to deal with the findings from these check-ups) to issues that are not relevant or important for the individual. The health of individuals can be enhanced when systematic occupational health is accounted for.

Lastly, occupational health physicians also have ethical dilemmas, such as confidentiality, workers’ right to know, the autonomy of workers’ decisions and their right to privacy. For example, for a bus driver with poor eyesight, the rights of the individual who is being screened conflict with the rights of people who may be harmed by the individual in carrying out their occupation. These situations require implementing the main ethical principles in medical practice such as beneficence and non-maleficence for the involved actors.

**Cost of screening**

The challenge for policy-makers as they think about the landscape of early detection is that there are many more opportunities for investing in services than there are resources available. So, in the context of cancer screening, the task for policy-makers is to determine a process to set priorities for resource use to achieve the best impact on health outcomes.

WHO carried out an assessment of national cancer control plans and showed that less than 10% of countries that introduced cancer screening programmes had costed them. WHO therefore recommended countries to review this process in the context of their own health system. For example, countries with a weak health system should not screen for breast cancer. Before introducing a new programme, countries should consider whether it is feasible, can be funded and can be provided universally, recognizing the importance of progressive realization: before a new service is introduced, it should be available to everyone.
The speaker then presented findings from the pilot OneHealth tool\textsuperscript{20} developed by IARC and WHO to support decision-making about whether to introduce a breast cancer screening programme. The first question to consider is how much introducing a new programme will cost. The speaker gave an example of a country in which most women present late with breast cancer and contrasted the costs, resource requirements and outcomes for a breast screening programme compared with an early diagnosis programme. An early diagnosis programme may well be able to save a similar number of lives, but at less than one quarter of the cost. This enables policymakers to promote health, equity and universal health coverage.

The chair thanked the speakers and introduced the final presentation, which outlined the EU’s strategic approach to cancer.

**EU initiative on cancer, European Commission**

The speaker outlined the background to the new initiative on cancer, which reflects the priorities of the President of the European Commission. The new cancer plan builds on initiatives that are already in place, such as actions on tobacco control. It is a unique opportunity to develop a health plan that is intersectoral and wide-reaching, working with Commission colleagues on a broad range of issues such as air pollution, employment and taxation.

The plan spans prevention, diagnosis, treatment and survivorship. It was noted that 40% of cancer cases can be prevented, but only 3% of the investment is in prevention.

The initiative, launched on 4 February 2020, started with public consultations. The process involves consultations with Member States, citizens dialogues and targeted stakeholder consultations. There is close linkage with other relevant groups, and the report on the consultation findings is anticipated to be published at the end of 2020.

The speaker encouraged colleagues to contribute to the consultation.

**Conclusions and next steps**

Jill Farrington, as chair, welcomed participants to the last session of the Conference on behalf of the Director of the Division of Noncommunicable Diseases and Promoting Health through the Life-course.

The chair asked the rapporteur to present the report of the Conference.

**Feedback from the rapporteur**

The rapporteur said that the Conference had focused on moving from theory to practice and that several overarching themes had emerged during the discussions. First, there was the challenge of translating evidence into practice, especially when other drivers, such as political or commercial factors, were present. Second, context, including health funding and degree of decentralization, significantly affects how to implement screening programmes. Lastly, in order for policy-makers to be effective in screening, they need to understand both the art and the science of screening and how to achieve a balance between conflicting or competing values and priorities.

The main findings from the Conference would provide additional detail and nuance to the screening guide and policy brief, so the feedback would follow the chapter headings from the guide and would also consider additional information that had been learned from the Conference.

### Table 1. Summary of findings from the Conference

<table>
<thead>
<tr>
<th>Topic</th>
<th>Findings from conference</th>
<th>Where next?</th>
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| **Deciding whether to start or stop a programme** | • Although examples of countries that have a process in place to make decisions is helpful, it is not always possible to replicate to other contexts, such as fewer resources or smaller countries.  
  • Transparent and clear governance structures are crucial for decision-making, such as national screening committees.  
  • Evidence needs to be independent and free from conflicts of interest. One way of achieving this is through commissioned work.  
  • Stopping non-evidence-based screening, such as health checks, remains difficult, especially when dealing with vested interests. Spending time on well-developed communication plans for professionals and the public is key.  
  • Politics plays a significant part in decision-making. | • Several examples of decision-making processes are needed that are context-specific and pragmatic, recognizing resource constraints.  
  **Possible products**  
  • Annex “how to” examples from countries to the screening guide  
  • E-learning resources on decision-making in screening  
  • Master classes |  

| **Deciding whether to start or stop a programme – new technologies** | • The acceleration of new technologies associated with commercial interests is moving forward faster than the health system can respond.  
  • Traditional approaches to evidence review are lengthy.  
  • Governance and regulatory frameworks need to respond to the demands of new technology. |  

| **Operational readiness** | • Inadequate resourcing for monitoring and evaluation and quality assurance is widespread among countries.  
  • Screening affects health system capacity; this needs to be factored into planning and priority-setting for countries.  
  • Countries often do not model and plan adequately before screening programmes are implemented. | • More information on the resources required to run screening programmes and pathways with all core elements, including monitoring and evaluation and quality assurance, would support planning.  
  **Possible products**  
  • Tools to model costs and resources |  

| **Operating screening programmes – quality assurance and monitoring and evaluation** | • Many countries find implementing quality assurance daunting. For example, they find that monitoring all EU standards is not possible. Quality assurance is often an afterthought, without enough resources to make it work.  
  • Poor-quality data limit effective quality assurance and monitoring and evaluation. Barriers to sharing data between agencies to quality assure the whole pathway is a common experience (data protection cited by many countries).  
  • Countries cannot infer the effectiveness of their screening programme by using data from another country. Each country needs to conduct their own evaluation, since context is very important. | • Explore the need for different models of quality assurance and monitoring and evaluation that are appropriate to different contexts and that take a pragmatic approach to quality assurance and monitoring and evaluation.  
  • Explore whether there are solutions to data sharing that can be shared between countries (such as legislative). |
<table>
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| Operating screening programmes – participation | • Low participation remains a problem and compromises the overall effectiveness of screening programmes.  
• Screening programmes can exacerbate inequalities. Low socioeconomic status is associated with reduced uptake.  
• Direct costs of screening to individuals may prevent participation.  
• Recognizing the importance of informed consent as well as increasing participation can create dilemmas for what outcomes should be measured.  
• More work is needed on understanding and addressing barriers to participation – access, service design and low health literacy.  
• Commonly held perceptions (healthy individuals versus patients, more is always better, private is better than the public sector) can affect participation in both evidence-based and non-evidence-based screening programmes. | • Explore the use of behavioural insight and research to support effective interventions.  
• Share examples of service redesign to improve access (including financial barriers).  
• Explore how to build health literacy and public involvement into work on informed consent and participation. |
| Operating screening programmes – working with professionals | • In a desire to increase access, many screening programmes want to engage more with family doctors; however, this is a challenge since it consumes a lot of doctors’ time.  
• Many professionals have low screening and risk literacy, which affects how they communicate risk to their patients.  
• Professional associations’ role in implementing screening programmes can be complex, such as conflicts of interest. It is important to engage with them and focus on using evidence and working with policy and public health colleagues.  
• Doctors’ fear of “making a mistake” in screening leads to defensive medicine and difficulty in maintaining evidence-based thresholds of sensitivity and specificity. In addition, it can lead to anxiety in engaging in quality improvement initiatives, such as audits for quality assurance and evaluation. | • Explore how to create a sustainable role for primary care in screening.  
• Explore how clinicians can be supported to make the right choice for a population. Would a governance and regulatory framework help?  
Possible products  
• Resources for professionals on appropriate techniques to communicate risk, such as absolute numbers in infographics. |
| Operating screening programmes – dealing with activities that operate on the edge of screening | • Incidental findings create significant challenges for those operating screening programmes; these findings are often of conditions for which no interventions are available and thus create ethical dilemmas for clinicians about how to share this information with patients.  
• Commercial testing that is not evidence-based strains health systems and creates ethical dilemmas.  
• Current ethical frameworks do not adequately address these issues. | • Addressing these challenges requires political will. Explore ways to support countries to clearly explain the challenges associated with this kind of testing and how to engage with politicians for their support.  
• Share country experiences of solutions, including regulation and governance frameworks. |
| The art and science of screening | • Evidence is not enough to guide decision-making in screening programmes. Values and ethics need to be incorporated into screening decisions.  
• Countries need strategies to respond to (unwanted) drivers of screening. | Possible products  
• Capacity-building for policy dilemmas  
• Peer support (come to my country and talk to my politicians) |
The chair returned to the purpose of the Conference: to generate knowledge and to provide tools for improving screening practices and decision-making related to screening. The Conference intended to highlight cross-cutting issues and potential solutions. The objective was to develop a set of key messages that would support smart screening strategies and practices.

The Conference was part of a longer journey towards the goal of achieving effective screening programmes that maximize benefits and reduce harm. The screening guide and policy brief provided the framework for the Conference. This work and the discussions at the Conference highlighted gaps in WHO guidance and clear messages for policy-makers on how to implement screening programmes.

One key message was that books and publications are only part of the solution. Policy-makers need to have practical solutions that recognize the context in which they work. The Conference had opened up several topics for discussion. It identified huge variations in the way screening is implemented across the European Region. Many countries, not just low- and middle-income countries, struggle with how to run programmes effectively. The Conference highlighted the complexities of delivering screening effectively, and many participants expressed their thanks for bringing this topic into focus and enabling countries to share issues and potential solutions.

The chair reviewed the common requests for WHO that have emerged during the Conference:

- to highlight for countries and policy-makers the importance of having adequate resources before embarking on a screening programme;
- to support countries in using the screening guide to implement screening programmes;
- to provide context-specific solutions that work in countries with limited resources; and
- to identify and address the gaps in guidance and standards that countries need to implement effective screening programmes.

Lastly, many participants stressed the importance of ongoing dialogue and networking across the Region, since there is a huge amount to learn and share. They asked for WHO to facilitate different types of meetings and collaboration platforms to support this process.

The chair then asked participants from countries for their reflections on the Conference and what they would like to see developed over the next few years.

Several participants stated that they had found the Conference very useful. Networking, sharing experiences and comparing approaches among countries had been extremely helpful in learning about strategies that work. They also reiterated that the suggestions made by the chair and the rapporteur for further products on how to implement screening programmes would be very helpful.

Other participants confirmed that they would like the Regional Office to organize further meetings and to facilitate international collaboration to work on specific topics. These included:

- modelling for HPV and cervical cancer screening;
- lung cancer screening;
- developing regulatory and governance frameworks to manage the rise of commercial and expanded screening tests, especially for prenatal screening;
- pragmatic approaches to quality assurance; and
- implementing screening in countries with limited resources.
The chair asked participants to provide further information on the kind of products they would like on the Conference evaluation forms.

Finally, the chair thanked everyone who had contributed and who had helped make the Conference a success.

The Conference was closed.
Annex 1. Programme

Tuesday, 11 February 2020

08:00–09:00  Registration at UN CITY

09:00–10:30  Plenary 1: Opening and introduction
Chair and moderator
Bente Mikkelsen, Director, Division of Noncommunicable Diseases and Promoting Health through the Life-course, WHO Regional Office for Europe

Opening comments
Hans Henri P. Kluge, WHO Regional Director for Europe

Introduction to the programme and expected outcomes
Jill Farrington, Coordinator, Noncommunicable Diseases, WHO Regional Office for Europe

Supporting effective screening for noncommunicable diseases and through the life-course
- Screening: when is it appropriate and how can we get it right? Martin McKee, Research Director, European Observatory on Health Systems and Policies
- Screening programmes: a short guide Sue Cohen, WHO consultant

Discussion

Overview of other WHO products being developed

Overview of global cancer products
- André Ilbawi, Technical Officer, Management of Noncommunicable Diseases, WHO

Use of computed tomography (CT) scans in individual health assessments
- María del Rosario Pérez, Scientist, Radiation and Health, WHO

Screening for cardiovascular diseases
- Tarang Sharma, Technical Officer, Knowledge Management, Evidence and Research for Policy-making, WHO Regional Office for Europe
- Oxana Rotar, Head, Department of Epidemiology of Noncommunicable Diseases, Almazov National Medical Research Centre, Russian Federation

Questions

11:00–12:30  Plenary 2: Successes and challenges in screening
Chair and moderator: Martin Weber, Programme Manager, Child and Adolescent Health and Development, WHO Regional Office for Europe
A panel of policy-makers from countries share their experience

- Inga Cechanovičienė, Head, Specialized Health Care Division, Ministry of Health, Lithuania
- Isabel Cristina Fernandes, Associate of the Head of the National Programme for Oncological Diseases, Directorate-General of Health, Portugal
- Verica Jovanovich, Acting Director, Institute of Public Health, Serbia
- Nana Mebonia, Head, Division of Noncommunicable Diseases and Injuries, National Centre for Disease Control and Public Health, Georgia

Discussion

Introduction to the afternoon sessions

12:30–14:00  Lunch break and poster session (13:30–14:00)
14:00–15:30  Parallel session A: Applying good screening principles in practice

1. Systems for deciding whether to start or stop a screening programme. Auditorium 1

Chair and moderator: Jill Farrington, Coordinator, Noncommunicable Diseases, WHO Regional Office for Europe

Resource person: André Ilbawi, Technical Officer, Management of Noncommunicable Diseases, WHO

Introduction

Country experience

- Anne Mackie, Director of Programmes, UK National Screening Committee, United Kingdom
- Mattias Fredricson, Head of Unit, National Board of Health and Welfare, Sweden
- Dilyara Kaidarova, Director General, Kazakh Research Institute of Oncology and Radiation, Kazakhstan

Discussion

2. Pathways, quality assurance, monitoring and evaluation. Auditorium 2–3

Chair and moderator: Marilys Corbex, Senior Technical Officer, Noncommunicable Diseases, WHO Regional Office for Europe

Resource person: Vitaly Smelov, Scientist, Prevention and Implementation Group, International Agency for Research on Cancer

Introduction

- Sue Cohen, WHO consultant
- Tit Albreht, Scientific Coordinator, International Partnership for Action against Cancer (iPAAC)
Country experience

- Irina Novik, Deputy Director, Republican Scientific and Practical Center of Medical Technologies, Informatization, Management and Economics of Public Health, Belarus
- Attila Kovács, Head, Quality Assurance, Monitoring and Control, National Public Health Centre, Hungary

Discussion

15:30–16:00 Break

16:00–17:30 **Plenary 3: Health literacy and the role of civil society**

Chair: Bente Mikkelsen, Director, Division of Noncommunicable Diseases and Promoting Health through the Life-course, WHO Regional Office for Europe

Resource person: Jill Farrington, Coordinator, Noncommunicable Diseases, WHO Regional Office for Europe

Keynote: Health literacy: what does it mean for screening?

Gill Rowlands, Chair, International Union for Health Promotion and Education (IUHPE) Global Working Group on Health Literacy

Response: Odette Wegwarth, Senior Research Scientist, Max Planck Institute for Human Development, Berlin, Germany

Discussion

Panel: Different perspectives on initiating a new screening programme: the example of lung cancer

Moderator: André Ilbawi, Technical Officer, Management of Noncommunicable Diseases, WHO

Academic perspective

- Andre Carvalho, Scientist, Screening Group, International Agency for Research on Cancer

Professional perspectives

- Rosa Giuliani, Director of Public Health Policy, European Society for Medical Oncology
- David Baldwin, Representative, European Respiratory Society

Policy-maker perspective

- Mina Abbasi, Senior Project Manager, National Board of Health and Welfare, Sweden

Discussion

Close of day 1
Wednesday, 12 February 2020

09:00–10:30  **Plenary 4: Political, social, commercial and technological drivers of screening**

Chair and moderator: Tit Albreht, Scientific Coordinator, International Partnership for Action against Cancer (iPAAC)

Resource person: Marilys Corbex, Senior Technical Officer, Noncommunicable Diseases, WHO Regional Office for Europe

Keynote presentation: overview of drivers of screening
David McDaid, Associate Professorial Research Fellow in Health Policy and Health Economics, London School of Economics and Political Science, United Kingdom

Panel
Commercial and technological drivers: the example of CT scans for individual health assessments
- María del Rosario Pérez, Scientist, Radiation and Health, WHO

Medico-legal pressure for antenatal screening
- Nino Berdzuli, Programme Manager, Sexual and Reproductive Health, WHO Regional Office for Europe

Drivers of screening: the examples of direct-to-consumer testing and social pressures
- Stuart Hogarth, Lecturer in Sociology of Science and Technology, University of Cambridge, United Kingdom

Child health screening: what’s driving it?
- Susanne Carai, Child and Adolescent Health and Development, WHO Regional Office for Europe

Discussion

10:30–11:00  **Break**

11:00–12:30  **Parallel session B: Scaling up effective and evidence-based screening**

1.  **Newborn hearing screening. Press room**
Chair and moderator: Martin Weber, Programme Manager, Child and Adolescent Health, WHO Regional Office for Europe

Introduction and situation analysis
Katrin Neumann, University Hospital Münster, Germany

Country experience
- Evelyne Lerut, Head of Team General Prevention, Flanders Agency for Care and Health, Schaerbeek, Belgium

Discussion
2. **Cervical cancer screening. Auditorium 2–3**  
Chair and moderator: Marilys Corbex, Senior Technical Officer, Noncommunicable Diseases and Promoting Health through the Life-course, WHO Regional Office for Europe  
Resource person: Tamar Khomasuridze, Sexual and Reproductive Health Adviser for Eastern Europe and Central Asia, United Nations Population Fund  

Introduction and situation analysis  
Vitaly Smelov, Scientist, Prevention and Implementation Group, International Agency for Research on Cancer  

Country experience  
- Carmen Ungurean, Coordinator, National Cervical Cancer Screening Programme, National Institute of Public Health, Romania  
- Frédéric de Bels, Head, Screening Department, French National Cancer Institute, France  
- Urska Ivanus, Public Health Specialist, Institute of Oncology, Slovenia  
- Giske Ursin, Director, Cancer Registry of Norway, Institute of Population-based Cancer Research, Norway  

Discussion  

3. **Diabetic eye screening. Auditorium 1**  
Chair and moderator: Jill Farrington, Coordinator, Noncommunicable Diseases, WHO Regional Office for Europe  
Resource person: Sue Cohen, WHO consultant  

Introduction and situation analysis  
- Gojka Roglic, Medical Officer, Management of Noncommunicable Diseases, WHO  
- Deborah Broadbent, Joint Organizer, the Liverpool Declaration on Screening for Diabetic Retinopathy in Europe  

Country experience  
- Colette Murphy, Programme Manager, National Diabetic Retinal Screening Programme, Ireland  
- Annika Takala, Senior Medical Officer, Ministry of Social Affairs and Health, Finland  
- Liubov Drozdova, Chief Expert, Medical Prophylaxis, National Research Centre for Preventive Medicine, Russian Federation  

12:30–13:30 *Lunch break*
Plenary 5: Legal, ethical and resource implications of screening

13:30–15:00

Chair and moderator: Juan Tello, Senior Policy Adviser, Noncommunicable Diseases, WHO Regional Office for Europe

Keynote: Human rights considerations for screening
Isabel Yordi Aguirre, Programme Manager, Gender and Human Rights, WHO Regional Office for Europe

Panel

Incidental findings of screening
• Martina Cornel, Co-chair, Public and Professional Policy Committee, European Society of Human Genetics

Screening for migrants
• Gianfranco Costanzo, Health Director, WHO Collaborating Centre on Health and Migration Evidence and Capacity Building, National Institute for Health, Migration and Poverty, Rome, Italy

Occupational health checks
• Jovanka Bislimovska, Head, Department for Education, Research and International Cooperation, WHO Collaborating Centre for Occupational Health, Institute of Occupational Health, Skopje, North Macedonia

Adult health checks in family medicine
• Anna Stavdal, President-elect, World Organization of Family Doctors

Costs of screening
• André Ilbawi, Technical Officer, Management of Noncommunicable Diseases, WHO

Discussion

15:00–15:30 Break

15:30–17:00 Plenary 6: Conclusions and next steps

Chair and moderator: Jill Farrington, Coordinator, Noncommunicable Diseases, WHO Regional Office for Europe

EU Initiative on Cancer
Hana Horka, Policy Officer, European Commission

Feedback from rapporteur
Sue Cohen, WHO consultant

Conclusions and next steps
Jill Farrington, Coordinator, Noncommunicable Diseases, WHO Regional Office for Europe

Discussion

Closing of the Conference
Jill Farrington, Coordinator, Noncommunicable Diseases, WHO Regional Office for Europe
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The World Health Organization (WHO) is a specialized agency of the United Nations created in 1948 with the primary responsibility for international health matters and public health. The WHO Regional Office for Europe is one of six regional offices throughout the world, each with its own programme geared to the particular health conditions of the countries it serves.

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