

The logo for the 3rd DiCE CRC Screening Summit. It features a blue circle with the number '3' and a superscript 'rd' inside. To the right of the circle, the words 'DiCE CRC' are written in a bold, blue, sans-serif font. Below this, the words 'SCREENING SUMMIT' are written in a smaller, blue, all-caps, sans-serif font.

3rd DiCE CRC
SCREENING SUMMIT

Future Challenges & Opportunities
for CRC Screening in Europe
Wednesday, November 30, 2022

Summit Report

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The Third Colorectal Cancer Screening Summit

For the third year, Digestive Cancers Europe held an online event to gather all the stakeholders involved in the design, implementation, and participation in colorectal cancer (CRC) screening programmes across Europe. This consolidated initiative represents a moment for sharing experiences, points of view, and knowledge on CRC screening programmes. This year we acknowledge the support of 20 experts from 15 countries to discuss the *Future Challenges and Opportunities of CRC Screening Programmes in Europe*.

Why has DiCE run its third Summit on CRC screening?

Each year, approximately 500.000 citizens in Europe are diagnosed with CRC, and about 250.000 die from the disease. Many of these deaths could be avoided by applying preventive practices and screening. Detection of CRC at stage 1 is associated with 90% five year overall survival. Moreover, the difference in cost between the early and late stages is probably tenfold, between 4.000€ and 40.000¹.

Today, significant disparities across Europe in CRC cancer screening are still registered. Few countries, such as Slovenia and the Netherlands, have an active participation rate of 65%. Alarmingly, only 14% of European citizens of the recommended age group (50–74 years old) have been invited for population-based CRC screening².

Organised screening programmes can be lifesaving, cost-effective, and cost-saving for European citizens and countries. Early screening detection is one of the crucial pillars of [Europe's Beating Cancer Plan](#). In this framework, on 3 February 2021, the Plan announced support for Member States to ensure that 90% of the EU population who qualify for breast, cervical, and colorectal cancer screenings are offered screening by 2025. The Plan also proclaimed revising the 2003 Council recommendation on cancer screening. Almost 20 years have passed since and science has made incredible advances.

Based on the scientific opinion of its Group of Chief Scientific Advisors, the Commission, presented a new cancer screening recommendation proposal on 20 September 2022. Besides adding screening for new cancers to the EU-wide recommendations, the new text also suggests updated breast, cervical, and colorectal cancer guidelines. The EU Member States also recommend “adequate, timely, and complementary diagnostic procedures and treatments for those individuals with a positive screening test.”

In advance of the approval of the new recommendations, this summit will examine what the European institutions and nations have managed to achieve in the last 20 years, what has been the biggest obstacle to the implementation of screening programmes in Europe, and what has been learned so far to improve screening programmes and improve patient care. In addition, we will examine the phenomenon of the increasing incidence of CRC among the young population (under 50) to see how a targeted screening programme could be of benefit.

¹ [White Paper – Colorectal Screening in Europe. Digestive Cancers Europe, 2019.](#)

² [The European Colorectal Cancer Road Map. Digestive cancers Europe, 2020](#)

The 2022 CRC Screening Summit

This year event was opened by DiCE co-founder Prof. Eric Van Cutsem, and the chair of the DiCE Board Ms. Lieve Wierinck. Which were followed up by interventions from Dr. André Ilbawi from the World Health Organization, and MEPs Dr. Sara Cerdas and Dr. Deirdre Clune.

During three engaging panel discussions, experts discussed three major topics for European CRC screening. A roundup of what happened in Europe since the first screening recommendations, and the future of screening programmes opened the discussion. This was followed by a conversation on how we foresee data collection and analysis, examples from countries and the role of patients and the general population, and GDPR. The last group of experts discussed screening for the expanding phenomenon of CRC in the under-50 population.

Finally, DiCE's CEO, Zorana Maravic, provided a perspective on the role of patient organisations and citizen groups in shaping the way forward.

Ms. Tamsin Rose moderated the event.

Opening Messages

In his welcoming message, **Professor Eric van Cutsem**, Professor of GI oncology at the University of Leuven, and co-founder of DiCE, expressed the importance of organising the CRC Screening Summit as a gastroenterologist and medical oncologist. "When you see a lot of patients with different gastrointestinal cancers"- said Prof van Cutsem - "you realise how important it is to go for an early diagnosis, and CRC is the model with which we can better work on early diagnosis." He reflected on the tremendous efforts, of the last 20 years, in implementing and promoting CRC screening across Europe and its extreme relevance for patients, healthcare professionals, and countries. Then he explained his personal experience being part of the team that started the screening programme in Flanders in 2013. He said that according to the data, only 2-3% of CRCs detected through screening are diagnosed at stage four. In comparison, over 20% of CRCs detected outside the screening programme are at stage four, meaning that screening programme can detect CRC at an earlier stage. With this pragmatic example, he wanted to give an overview of what can be achieved with screening. Screening is also important from a patient's point of view. Thanks to screening and advances in medicine, in many countries the five years survivor rate is around 65-70% for CRC. We are now facing the phenomenon of CRC in the young population, a population not targeted by screening programmes. He called for continued work to improve screening programmes and reinforced his commitment to the great work done by the DiCE team and their mission of raising awareness of the importance of screening.

Ms. Rose then invited **Ms. Lieve Wierinck** to share her insights on the importance of CRC screening. She said that with the CRC summit series happening every year, we aim to dive into the details, discuss practical solutions, and present the latest science and developments. She shared her interest in the new European cancer screening recommendations, although in many countries we still need to work for full implementation of the old ones. She recalled that in 1998 (EU-15), CRCs were estimated to cause 14% of all cancers. In 2020 CRC in EU-27 accounted for 12.7% of all new cancer diagnosed and 12.4% of all deaths due to cancer,

remaining the second most frequently occurring cancer (after breast cancer) and the second cause of cancer death (after lung cancer). She welcomed the new European Commission cancer screening recommendations, which aims for 90% of the EU population who qualify for CRC screening to be offered screening by 2025. Representing DiCE, she supported the Commission's proposal of using faecal immunochemical testing (FIT) for CRC screening instead of faecal occult blood screening as the preferred triage test for referring individuals aged 50-74 for a follow-up colonoscopy. **Ms. Wierinck** reinforced DiCE's commitment to working with European, national, and local stakeholders to make it happen.

The Summit continued with a message from **Dr. Sara Cerdas**, Member of the European Parliament (S&D, Portugal), Vice-Chair of MEP Digestive Health Group, and Member of ENVI and COVI Committees. MEP Cerdas shared her hope for the European Beating Cancer Plan to deliver on its promises to European citizens recognizing the divide between EU recommendations and guidelines, and the reality many patients face. She highlighted the importance of ensuring that Cancer recommendations implementation is followed-up by appropriate resources, especially in less affluent countries, where we can see a West-East divide in mortality from CRC. She concluded that inequalities in screening could create disparities in cancer mortality, and this is unacceptable within European borders.



"To reduce the burden of CRC my colleagues and I, in the European Parliament will continue working to ensure that the European project delivers on its economic and social promises".

MEP Sara Cerdas

Also, **Ms. Deirdre Clune**, Member of the European Parliament (EPP, Ireland), Member of IMCO and COVI Committees, and Substitute in ENVI Committee shared her message through a video. Ms. Clune reminded the audience that CRC accounts for the second most diagnosed cancer in the EU, with this figure predicted to rise in the coming years. Thus, ensuring a wide spread of CRC screening practice in the EU is essential. As a member of the special committee of the Beating Cancer Plan, Ms. Clune said that she sees first-hand how important it is to support researchers, doctors, nurses, and social workers in providing real assistance to patients fighting cancer and those who have recovered from it. Ms. Clune said that at the EU level the work on cancer treatment is an expression of solidarity and a responsibility for the well-being of fellow Europeans and she offered her full cooperation in supporting CRC patients. She continued mentioning the new EU recommendations that will reinforce the need for screening programmes for CRC, breast, and lung cancers that account for 55% of cancers diagnosed in the EU annually. She emphasized how feedback from patient groups has highlighted the need for educating healthcare professionals



"Patients should receive continuum support through their journey with clear, understandable information on the available treatment options and support services."

MEP Deirdre Clune

on early signs and symptoms. "Increased education and cooperation with healthcare professionals are vital" - Ms. Clune stated- "communication between them and patients is crucial for effective care support. Unfortunately, many patients still nowadays are not receiving complete information". She concluded that Member States must be encouraged to

implement concrete measures to strengthen the prevention and treatment of CRC at the EU level. Investing and expanding screening saves lives.

Dr. André Ilbawi, Technical Lead, Cancer Control, Department of Noncommunicable Diseases, World Health Organisation delivered the last institutional message. Dr. Ilbawi started his speech by saying that cancer is a personal disease as it affects nearly every country and every family. He stated that by 2040 the burden of cancer globally would double, and the fastest rise of CRC cases will be in settings with the least prepared to manage this disease burden. He defined the current situation as frustrating because we have the essential tools to prevent, screen, and treat CRC, still there is a disconnect between what works and how it is implemented. Nearly all screening agencies in Europe and the Americas recommend CRC screening in a setting with strong health systems. Only 40% of EU citizens between 50 and 74 years participate in CRC screening programmes. For Dr. Ilbawi the implementation challenges are, first a lack of enabling public services and public health programmes to maximise access to care and participation in screening services; second profound inequalities within and between countries. These are related to stigma and social, economic, and political determinants of health. Dr. Ilbawi stressed that we have the strategic advantages and the one-in-a-generation opportunity to improve CRC detection and survival in Europe with the roadmap of the Beating Cancer Plan, the political and financial investment of the EU Cancer Mission, the technical capabilities, and most importantly, the strong civil society voice. He concluded his intervention by focusing on the central role of communities. Dr. Ilbawi highlighted the need to innovate with a focus on equity. New cancer detection and treatment technologies are necessary but insufficient; without community-led innovation that improves inequalities, technology will remain unused by the population in need. The focus should be on social and organizational innovation and fighting stigma to empower people affected by CRC.



“If we focus our agenda on people affected by CRC, we will succeed.”

Dr. André Ilbawi

Panel 1 Update of Screening Recommendations: Key Learnings from the Past Toward the Improvement of CRC Screening Programmes

Panellists

Iris Lansdorp-Vogelaar	Professor at the Department of Public Health of Erasmus Medical Centre, Rotterdam, Netherlands, and representing EU-TOPIA, Netherlands
Ciaran Nicholl	Head of Unit, Health in Society, Joint Research Centre, European Commission, Belgium
Tytti Sarkeala	Director of Screening, Ph.D. Finnish Cancer Registry, Finland
Christian von Wagner	Senior Lecturer in Behavioural Research in Early Diagnosis of Cancer, Health Behaviour Research Centre, Department of Epidemiology & Public Health, UCL, UK

The first topic of the Summit focused on **updating screening recommendations; the key learnings from the past towards improving CRC screening programmes.**

Professor **Iris Lansdorp-Vogelaar** from the Erasmus Medical Centre in Rotterdam (Netherlands) opened the first panel with a roundup of CRC screening recommendations since 2003. That was when the Council recommendations already included CRC as one of the three cancers to screen for. Four years later the first report on CRC screening in Europe was published. Still, no country had implemented a population-based CRC screening programme, and only four countries aimed to achieve such a programme. Eight countries had no planning or piloting of CRC screening, while seven countries offered to screen for CRC but not within a population-based programme, meaning there was no active outreach to the population at a certain point in time. Not having population-based programmes represents a big barrier to achieving equity in screening programmes. At this point, it was clear that guidance for implementing CRC screening programmes was highly needed. To provide guidance on the effective and efficient implementation of EU council recommendations on CRC screening, in 2010, the European Guidelines for quality assurance in CRC screening was launched, leading to better results for CRC screening in Europe. In 2016 there was a new status update on CRC screening in Europe. More countries were active in implementing CRC screening, and more countries were organizing population-based screening programmes. Still, key data on the quality assurance structure of the screening programmes were not collected, meaning that we don't know how well the programmes are performing. Without this information, it is challenging to design strategies for improving them. For Professor Lansdorp-Vogelaar, there are five key aspects of CRC screening programmes across Europe that need country representatives' attention:

1. Lack of governance structure for screening: invitations are sent, but no one is responsible for the follow-up.
2. Fragmented and outdated data infrastructure hamper monitoring and evaluation of the programme.
3. Cancer registries lag and suffer from incomplete data.
4. GDPR interpretation differs from country to country, endangering possibilities for population based-invitations.
5. Lack of funding to implement required governance and IT infrastructure.

She concluded underlining that we need to shift the focus from population-based to organized to ensure that also other aspects of organized screening programmes are better covered in future rounds of status reports.

What is an “organized” screening programme?

Organized screening programmes are designed and managed by national or regional health services to ensure that everyone has an equal opportunity to participate in screening and to ensure that if a screening test result is abnormal, the patient receives the correct further testing, support, and treatment. Screening is most effective if it is available to all people in the eligible population and if they choose to participate.

Organised screening programmes are recommended in the European Union because they employ a team of people responsible for ensuring quality of services. That includes checking that guidelines are followed and that the results of the screening programme are regularly reported and evaluated.

They are based on five pillars:

- Explicit policy for age range, test type, and interval
- Defined target population
- Management team for implementation
- Quality assurance structure
- Method for identifying cancer occurrence and death in the population

Following the presentation from Professor Lansdorp-Vogelaar, Ms. Rose invited the three-panel participants to provide the audience with their perspectives on how we can improve CRC screening programmes in the future.

Dr. Ciaran Nicholl provided an overview of the pillars of the [Knowledge Centre on Cancer](#) of the European Commission. The mission is to foster alignment and coordination of topics related to cancer. Among the pillars is the European Cancer Information System. It is based on information from one hundred fifty cancers and is used for projecting and monitoring the burden of cancers. In the future, this registry will include the monitoring of population-based screening programmes. He said "we started to work on the new European guidelines and quality assurance scheme for CRC screening. The aim is to improve the quality of CRC prevention, screening, and care and reduce inequalities in European cancer services". Dr. Nicholl clarified that these are evidence-based guidelines and that the recommendations on prevention, screening, and diagnosis are independent of private, commercial, and national interests. The quality assurance scheme converts the recommendations to policy indicators, which are tailored for Member States for them to implement the guidelines. Also, the guidelines are constantly updated based on the most recent literature evidence. The target is the European Union, but also beyond it. The working group is now in a preparation phase, and by 2025 the guidelines will be delivered. There is currently an open call for experts to collaborate in the working group on their [website](#).

Dr. Tytti Sarkeala presented the FIT population-based programmes initiated in Finland by means of a pilot phase between 2019 and 2021 in nine municipalities. Based on the results and a cost-effectiveness analysis conducted with Erasmus University, Finland launched a national screening Act at the beginning of 2022, followed by the start of a national screening programme for men and women (56-64 years). During the initial months of the national programme, they have been working on protocols, IT infrastructure and creating a network of laboratories for certifying FIT test analysis. Currently, they are producing a national quality manual with the support of an expert group. They are working to keep up with the pilot study

participation rate (80%) and feasibility performance of the screening chain from invitation to treatment to ensure colonoscopies are not delayed.

Dr. Christian von Wagner, shared that the variation we see across the countries in screening programmes uptake is much related to the organization of the screening programmes itself, how routinely people are invited, and the test they use. He suggested that we should make sure people are never left behind. To ensure participation, we need to repeat invitations. This is not just monitoring not responsive within the screening programmes but also the importance of returning to people and never giving up because people can decide to join the programme after various tentative invitations. Groups with specific needs should be included, and people with mental, cognitive, and physical disabilities should be monitored within the programme in a tailored way to ensure their participation and provide additional help. Regarding the implementation of screening programmes, he highlighted that we need to keep monitoring the content to ensure it is up to date with the latest research results on behavioural change models, for example. The use of technology can have an important impact but also integrate stakeholders, expanding this category also to community pharmacists and social workers.

Questions and Answers

Question: Is quality assurance the priority we should be focusing on?

Dr. Tytti Sarkeala: *It is indeed the key for all organizations and programmes. You have to know the target population to invite them and to follow up with invitations. IT systems need to be set up and ready, and you need national guidelines. Finally, you must get the data to be able to monitor your programme and improve it over time. Knowing what is happening from the beginning to the end is key, and you have a clear frame for indicators.*

Question: How can we ensure the homeless are not left behind by screening programmes?

Dr. Christian von Wagner: *We must face several problems to ensure homelessness is not a barrier. In the UK, for example, if you are not registered with your GP, you do not exist for the screening programme. Some specific works are done to try to include the homeless and other groups like, for example, people in prison.*

Question: What is the view of the European Commission on the fragmented interpretation of GDPR across Europe?

Dr. Ciaran Nicholl: *The privacy issue is constantly a challenge, as is the GDPR performance. We should look at GDPR interpretation in a very holistic target way. Different interpretations mean different layers, and a lack of communication across borders. In the scenario of the European network of cancers, we see a wide range of interpretations. Our role will be to highlight this issue to the Commission to find a solution in the coming years. Initiatives are already taken to work on the harmonization of GDPR interpretations.*

Panel 2: New Strategies for Data Collection and Analysis in CRC Screening Programmes

Panellists

Carlo Senore	Piedmont Region Cancer Prevention Centre, University hospital Città della Salute e della Scienza, Italy
Mircea Mănuș	National Institute of Public Health, Head of NCD prevention unit, Cancer prevention, and cancer screening coordinator, Romania
Rema Gvamichava	Professor & Head of Oncology Department, Tbilisi State Medical University (TSMU), Georgia
Andre Carvalho	Senior Scientist, Early Detection Prevention & Infections, AIRC, France
Marianna Vitaloni	Medical & Scientific Project Manager, Digestive Cancers Europe, Belgium

The second panel of the Summit highlighted **new strategies for data collection and analysis CRC screening programmes**.

In the first panel, we heard of challenges where the data needs to flow as it should, meaning if you do not have the necessary data, you miss those falling through the gaps.

Ms. Rose invited **Prof. Carlo Senore** to share insights on tools and programmes that collect and analyse CRC screening data. Prof. Senore started his presentation with an introduction to systematic monitoring as a tool to achieve the expected reduction of disease-specific mortality in the target population. Quality assurance is key, he suggested, and this includes performing regular audits of programme activities to ensure the appropriate feedback and identifying retraining needs is accessible to the screening staff. Making appropriate and valid comparisons across cancer screening programmes is essential for policy and decision-makers to evaluate and improve the processes. Self-assessment tools are also important, as they allow for results to be compared with existing guideline standards and benchmarks. As examples of existing programmes, Prof. Senore discussed the EU-Topia and CANSCREEN5. Next, he addressed some of the EU recommendations which call for nationwide standardised data collection of all phases during the screening process, linking screening data with cancer and mortality registries, and supporting the use of data from screening programmes as a resource of cancer research and technological advancement. The CanScreen, ECIS, portal was highlighted to empower screening programmes to evaluate their performance continuously by using the portal's existing data to improve the quality of cancer screening programmes.

While these resources are vital in moving forward with improving CRC screening programmes, Prof. Senore went on to address some limitations of the current approaches. Including that

data is usually presented for a single year of activity and comparing outcomes across programmes using different protocols is unreliable. A recommend longitudinal approach seems preferable when comparing programmes, which should include a risk-tailored protocol in the future. Moving forward, Prof. Senore presented the proposal, launched by the ICSN CRC interest group, of establishing an international multidisciplinary consortium, to implement a commonly accessible database. An application for funding has been submitted in the context of the European Cost actions by a consortium including DiCE along with 19 European countries, Canada and IARC. The aim of the project is to favour the harmonisation of data across different programmes, to address ethical and legal aspects and to maintain a sustainable collaborative network to ensure optimal knowledge exchange to keep CRC screening up to date. His concluding remarks emphasized the importance of continuous monitoring and reporting to adequately assess the impact of screening programmes on population health. Keeping in mind that measures of quality and equity depend on the collection, computation, and dissemination of accurate and comparable data to measure performance and outcome indicators throughout the screening pathway. Data collection must include the patient throughout the screening process and include data progressing from aggregated to individual-level data, including clinical data points, because ultimately, sharing data may contribute to protecting their health.

Ms. Rose then turned to the four panellists, each from a different European country, to comment on programmes in their region.

Prof. Mircea Mănuș, provided the Romanian perspective as a leader in training programmes for health professionals involved in the CRC pilot-projects and of the quality assurance and quality control system. Through the challenges brought on by the COVID-19 pandemic, Romania has worked hard to develop and implement a CRC screening pilot project with EU funding. As part of their screening programme, 200.000 FIT are scheduled to be conducted before November 2023, along with the development of a national screening register that closely follows all quality control indicators as outlined by Prof. Senore. He explained that he Romanian screening register is designed to work at national level and include step by step all the target population, even if the screening programs are designed to be implemented regionally. The National Institute of Public Health will be able to collect and evaluate all the data at national level and also to measure the quality indicators for all the steps. He also touched upon the challenges brought on by GDPR and how they plan to overcome them through training courses.

Next, **Prof. Rema Gvamichava** gave an update on the national electronic cancer data collection system utilised in Georgia and some of the challenges they are facing. The cancer screening programme in Georgia was established in 2008 and included CRC screening for ages 50-70 in the male and female populations. Prof. Gvamichava addressed a major challenge of improving their low screening coverage of the target group, openly asking for representatives from Georgia's neighbouring countries for ways to resolve the issue. Georgia also has had a national cancer screening registry, since 2015; however, the databases in use are not well connected. Georgia is eager to optimise screening by improving its existing tools and resources.

Dr. Andre Carvalho covered the challenges and achievements of the CANSCREEN5 programme. This programme was created to harmonize data collection; however, this is

proving to be a challenge because of the way many countries present their data. Currently, CANSCREEN5 has data from 84 countries, and they are working on sorting through the actual numbers rather than collecting only the key performance indicators (KPI). Dr. Carvalho addressed the challenges countries face on the national and EU levels in terms of GDPR. Other challenges include that data is shared across different cohorts (time, population, etc.) and inadequate linkage between data from different IT solutions gives a poor overview of the screening programmes.

Tackling these challenges, a work in progress will grant access to better data to better evaluate CRC screening programmes.

Dr. Marianna Vitaloni followed up with the patient perspective. She highlighted patient insights from the 2022 DiCE MasterClass, European Health Data Space Workshop. Patients understand that sharing data is a valuable tool for cancer research and better treatment options. By having a comprehensive view of individual patient data in a single registry, allows for patients to understand their journey better, and supports their healthcare team in designing the best care strategy for them. Individual patient data can be used to evaluate the quality of services provided and prevent further suffering of patients in the future. Dr. Vitaloni also touched upon the responsibility that patient organisations have in informing, educating, and empowering the target population of screening programmes, through awareness, of the importance of medical data collection and sharing. She highlighted that linking screening data to other medical or personal data, can give insight into individual and population risk- or protective-factors. She concluded that data should be used for the collective good to improve and accelerate health systems.

Questions and Answers

Question: How would you see the use of a bio-locker or passport to have all their data in one place?

Dr. Andre Carvalho individuals must be made aware of which kinds of data and information they should be sharing. Apart from the GDPR issues, the linkage of all the data remains different across all EU countries, which makes it hard to share and utilize.

Question: How data is controlled in the Romanian pilot phase so that it can progress to a national screening programme?

Prof. Mircea Mănuc the design of the pilot register is structured to encapsulate an individuals data from the screening invitation until the pathologic diagnosis, and the follow-ups from a diagnosis, up until 2 years after. The pilot follows four regions across Romania for now, with quality indicators being provided in the reports, and for the moment, the 80.000 individuals involved are closely monitored.

Question: How do we go from opportunistic to population-based screening? What needs to be done for the population to widely accept such screening programmes?

Prof. Rema Gvamichava the problem must be split, first, the general public needs to be informed and educated. Second, GPs need to be trained on how to explain the importance of screening to their patients, so that they can empower patients with the benefits of screening.

Panel 3: Early-onset CRC Screening: Should CRC Population Screening Begin Before the Age of 50?

Panellists

Elena Stoffel	Associate Professor of Internal Medicine, Director, U-M Cancer Genetics Clinic, University of Michigan, USA
Giulia Martina Cavestro	Gastroenterology & Gastrointestinal Endoscopy Unit, Vita-Salute San Raffaele University, San Raffaele Scientific Institute, Italy
Jose Perea	Principal Investigator at Institute of Biomedical Research of Salamanca, Spain
Andi Cârlan	DiCE Patient Advisory Committee member, Employee Benefits Specialist, CRC Survivor, Romania

The third panel of the 3rd CRC screening Summit focused **on early-onset CRC (eoCRC) screening and whether CRC population screening should begin before the age of 50**. The panel started off by examining the shift in age population, followed by understanding the factors that could be attributed to the shift observed with eoCRC.

Prof. Elena Stoffel who joined the summit from Michigan, USA opened the panel by addressing the pros of early-onset screening under 50. The incidence of CRC is rising among individuals under 50 without a clear established cause; ideally, CRC risk assessment should be performed for every individual before the age of 45, especially for individuals with a family history or red flag symptoms. In the US, multiple medical societies have recommended beginning CRC screenings at the age of 45. US trend data shows that the incidence and mortality have increased by 45% in individuals under the age of 50. Prof. Stoffel highlighted several studies that addressed the benefits of lowering the age of CRC screening along with the increased financial costs associated. In a nutshell, lowering the screening age to 45 could prevent 1 death in 1 000 people screened, and only 28 young adults need to be screened to detect 1 neoplasm; on the downside, screening under 50 years of age would not prevent all cases of eoCRC as most cases are diagnosed much earlier, and lowering the age to expand the screening population would result in significantly increased costs.

Following the presentation from Prof. Stoffel, Ms. Rose invited **Prof. Giulia Martina Cavestro** to share her perspective on the cons of lowering the screening age. Prof. Cavestro started out by defining preventive and early detection screening. With eoCRC both screening types could be useful, and she touched on the FIT test and colonoscopy as the most applied tests today. She also highlighted several US Guidelines that have changed the recommended screening ages to 45, based on estimates of benefits and harms from microsimulation models. It is important to remember that screening leads to large clinical benefits for many individuals. It also exposes some individuals to harm as the screening process involves colonoscopies, follow-ups, and surveillance. Prof. Cavestro highlighted that the increasing incidence rates for adults 40-49 are alarming, suggesting the risk for the younger cohort will carry forward to the 50-54

age group in the coming years. In Europe, she said, we need epidemiological studies to address the morality for early-onset CRC, with updated data across European countries because there seem to be trends in several major European cities.

Prof. Cavestro's talk was followed by **Dr. Jose Perea**, who addressed the factors associated with eoCRC and suggested strategies for screening. Dr. Perea's suggestions include focusing on the population's predisposition and exposure to environmental and lifestyle factors. In terms of predisposition, about 16% of individuals with eoCRC have a germline mutation linked to CRC, with about half having Lynch Syndrome. Additionally, environmental and lifestyle factors including obesity and type 2 diabetes have been linked to eoCRC. Screening-focused risk factors must include hereditary forms, high-risk populations based on CRC family history, and average-risk populations. Research must continue to explore liquid biopsies and the microbiome to identify molecular markers that can define this specific risk population. Furthermore, secondary, and tertiary prevention must be addressed in the population younger than 50 years of age.

Mr. Andi Cărlan spoke next, sharing his perspective on being diagnosed with eoCRC; at the age of 36 when he was rejected as a blood donor due to his low levels of haemoglobin. The first diagnosis was anaemia. He was recommended several tests including a colonoscopy but chose to delay it because he was embarrassed by it, and no one explained why he should undergo a colonoscopy. Five months later, the pain was too much to manage, and he was diagnosed with stage III CRC, needing emergency surgery, and six months of adjuvant chemotherapy. The hard news was that if he had followed through with the colonoscopy on time, cancer could have been caught at an earlier stage when it could have been curable with surgery only. This was difficult to accept for Andi, which is why he advocates for young people to be aware of their symptoms. Doctors, he suggests, should be more inclusive of the younger population in terms of cancer risk, rather than rushing to treat them for irritable bowel syndrome, anaemia, gastritis, etc. Andi encourages everyone to take the time to speak with their doctor and confirm their health status once a year.

Questions and Answers

Question: *Prof Iris Lansdorp commented that risks should drive the starting age of screening, however the threshold recommended by the BMJ panel is 3% which if applied, most women wouldn't be screened until age 65?*

Prof. Elena Stoffel: *each person's risk for CRC is not the same, suggesting that in addition to age and family history, other risk factors must be explored through blood and stool-based analysis to identify high-risk populations more precisely versus lower-risk*

Question: *Are there any studies examining the benefits of screening for eoCRC compared to promoting risk reduction?*

Dr. Jose Perea: *it is important to educate the general young population on good lifestyle habits, including exercise, nutrition etc. Moving forward this could add great value in prevention. Prevention programmes may be more practical, financially, because many risk factors linked with eoCRC are risk factors for numerous diseases. Prof. Cavestro chimed in agreement; also highlighting that the older population must serve as an example to the younger population in making diet and lifestyle changes.*

Question: Can the overuse of antibiotics from a young age contribute to the risk of eoCRC?

Dr. Jose Perea: *there may be a link to the microbiome, suggesting that studies have shown that the microbiome population with eoCRC is very different from that of healthy individuals of the same age, and even different from late-onset CRC, connecting the increased use of antibiotics in the 70s and 80s to the current adult population.*

Prof. Elena Stoffel: *while the risks are much higher for the younger generations, the reasons behind the risks have yet to be fully identified and validated. The issue with antibiotics could also be linked to a diet high in animal products from animals treated with large amounts of antibiotics. Furthermore, diet and lifestyle have changed tremendously since the 60s which could be linked to the increase incidence observed. younger population in making diet and lifestyle changes.*

Closing Remarks

The Role of Patient Organisations and Citizen Groups in Shaping the Way Forward

Ms. Zorana Maravic thanked all the patients, Member Organisations (MOs), and partners who have been working together throughout the journey of raising awareness about CRC. Despite having a long way forward, patient organisations cherish every single digit number in statistics as a success, knowing that it is a life saved, a family rescued from the aftermath of devastation, and a life lost too soon.

The role of patient organisations is to continue raising awareness and providing support. In this sense, DiCE works closely with European policymakers and has contributed to creating recommendations and guidelines which ensure the patient perspective is included. To raise awareness among national policymakers about screening programmes to be implemented locally, Ms. Maravic announced that next year, DiCE will support MOs and work closely with them to ensure that national health authorities and policymakers understand the importance of implementing CRC screening programmes.

In her opinion, another key task for patient organizations is to empower the general public and facilitate their participation in screening programmes. DiCE aims to achieve this throughout the year, with a spotlight in March for European Colorectal Cancer Awareness Month (ECCAM). In 2023, DiCE will launch its biggest campaign to date, to raise awareness among the general population about the prevention and early diagnosis of CRC.

Ms. Maravic also mentioned the role of healthcare professionals in this journey, explaining that DiCE has great trust in the professionals they collaborate with as part of several consortiums and working groups, such as the European United Gastroenterology, along with other professional entities with whom they have the pleasure of cooperating.

3rd DiCE CRC SCREENING SUMMIT



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