

EXECUTIVE SUMMARY

A striking and commonly unknown fact is that colorectal cancer is the second deadliest cancer - approximately 170,000 people dying every year- in the European Union (EU). This fact is even more striking as this type of cancer is both preventable and curable if detected early enough. Unfortunately, most of the patients are detected at stage III and IV. If the European Unionwas able to diagnose more patients in stage I from the current 13% to a 50%, 130,000 more lives could be saved per year and more than 3 billion€ in healthcare budget savings could be generated every year, and possibly the same amount in social and work-related value.

Despite this important opportunity, there are many barriers to early screening at the level of the patient (e.g. psychosocial factors), the health care providers (e.g. low screening recommendation) and the health care systems (e.g. inadequate screening systems). In order to significantly improve 5-year survival rates and reduce the economic burden of colorectal cancer on healthcare systems, screening programmes must be more effective.

We strongly believe the time to act is now and we call policy makers at EU and National level to take key actions, such as: improve national colorectal cancer programmes (from screening to treatment) and their implementation; undertake consistent and regular monitoring at EU level of adherence and effectiveness of screening programmes; organise and support colorectal cancer awareness-raising campaigns and education; and promote multi-stakeholder colorectal cancer initiatives.

01. / Epidemiology



Colorectal cancer is the second deadliest cancer in the European Union (EU)ⁱ, with approximately 170,000 people dying every year, out of a diagnosed population of 370,000. The incidence of CRC is likely to rise significantly in the next decade, mainly due to the ageing of the population and factors such as tobacco use, alcohol use, unhealthy diets, physical inactivity, and obesityⁱⁱ. On the positive side, the age-standardised mortality is decreasing because of better management of the diseaseⁱⁱⁱ and the application of better medical practices and innovative diagnostic, pharmaceutical solutions and surgical treatment options. Today, there are 950,000 colorectal cancer survivors in the European Union^{iv}.

MORTALITY AND INCIDENCE IN THE EUROPEAN UNION						
	Incidence	Mortality	Current number of survivors			
Colon	242,987	117,357				
Rectum	125,260	52,924				
TOTAL	368,247	170,281	950,000			

Colorectal cancer is easier to treat when detected at early stages. When diagnosed at stage I, the overall 5-year survival rate is around 90%, whereas it is only around 10% in the metastatic stage IV. Today, unfortunately, only around 13% of patients are diagnosed at stage IV. Recent studies in the UKvi (table below), Belgiumvii, Switzerlandviii and Italyix, demonstrate figures within the same range, with around 15 to 16% in stage I and 20 to 25% in stage IV.

% of patients diagnosed per stage	Stage I	Stage II	Stage III	Stage IV
	13%	31%	32%	24%

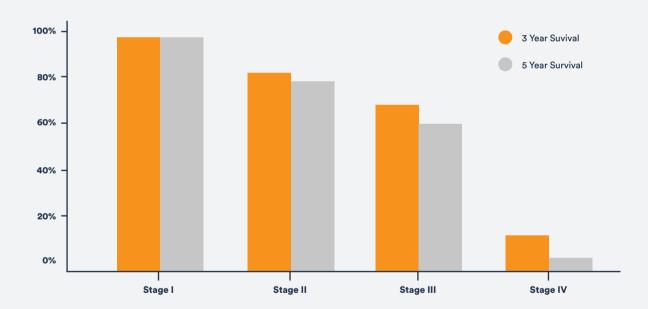
Despite its high incidence, the understanding of symptoms by patients and the diagnosis by GPs of colorectal cancer is not easy. The median time between reporting the first symptoms to a GP and the actual diagnosis is 128 days, with a range from 57 to 257 days. It is obvious that both general practitioners and emergency services of hospitals misdiagnose one of the most common cancers. The majority of patients are diagnosed once symptoms become noticeable and hence at a late stage - and are either referred to hospitals by their GP or present themselves at emergency services. By simply identifying the risk profile of the patient, physicians should take no chances: patients who are older than 50, with a family history of cancer, (former) smokers, with a low level of physical activity or a relatively high body mass index, should qualify for a colonoscopy.



In 2009, the total medical and non-medical cost of colorectal cancer was estimated at 13.1 billion€xii. Today, the cost will likely have increased to over 15 billion€, taking the increase in incidence, costs and inflation rates into consideration. This highly avoidable and treatable disease places a significant burden on healthcare systems, especially because costs increase with more progressive stagesxiii. Despite the significant cost of the treatment, it is hard to find health economic data on costs. Estimates vary widely, ranging from 3,000€xiv for a stage I treatment, to up to 170,000€ for a late stage treatmentxv. On average, one might say that the difference in cost between early stage and late stage is probably tenfold, between 4,000€ and 40,000€.

In Germany, the cost of treatment in private hospitals is around 75,000€ on average^{xvi}, without follow-up costs. The cost is probably higher than in public hospitals, so the assumption that the treatment of stage IV colorectal cancer is around 40,000 to 60,000€ is acceptable.

Survival rate by stage of the disease



03. / Screening in Europe



State of play: screening rates, models and costs

In a Council Recommendation of December 2003, the Council of Health Ministers recommended that all Member States implement population-wide screening for colorectal cancer, for all citizens between 50 and 74 years old, using the faecal occult blood test or other newer tests if they have demonstrated evidence of being effective^{xviii}. Despite these recommendations, only three member states have actually implemented the programmes as intended fifteen years ago and only 14% of European citizens participate in colorectal cancer screening programmes.



Even if the information is hard to get by country, in practice, only Slovenia, Ireland and France have formal population-based screening programmes that address all citizens between 50-74 years old. In 13 other Member States, screening programmes are organised regionally, resulting in sometimes major differences within one country, or with different age groups. Seven Member States have just started formal population-based screening programmes, and five Member States have no screening programmes at all.

CRC Screening Status in Europe

- Correct (population based & 50–74 years)
- Partial (regional or >50 or >60)
- Started
- No Screening

Participation rates

A European Council report sets a 65% participation rate as desirable for the defined target population.

Despite this, today only 14% of EU citizens between 50 and 74 year old (have the opportunity to) participate in colorectal cancer formal population-based screening programmes. Having a programme is not sufficient, it also has to meet quality criteria in terms of awareness creation, repeat messages, and sensitivity to tone and style that will enhance citizen participation. The fact that the objectives of the European Council are realistic can be demonstrated by breast cancer screening programmes for which participation rates between 60% (age 50-74y) and 68.9% (age 45-49y) are achieved.

Some countries, such as the Netherlands, have a very high participation rate of 70%, even if the country only addresses citizens older than 55 years old. The results have been significant, with 48% of patients now diagnosed at Stage I, as compared to 15% without screening*viii. Another good example is the Basque country in Spain, where a very high participation rate of 75% is achieved, and 92% of all patients with a positive test also adhere to colonoscopy. Slovenia reaches 62% within the full target group across the country, also resulting in 48% of the patients now being diagnosed at Stage I^{xix}.

Having a full population-based screening programme requires an ongoing political prioritisation and a sustained effort to keep a high awareness among citizens of the need to participate. If not, participation rates will drop, as is demonstrated by France, where a good programme dropped to a participation rate of approx. 33% of the target population^{xx}.

Today, the Fecal Immunological Test (FIT test), which has a 95% sensitivity to correctly diagnose colorectal cancer, is the recommended screening test and, according to a recent study^{xxi}, it has also demonstrated higher participation rates.

Early diagnosis saves lives

The main argument for colorectal cancer screening is saving the lives of citizens. As colorectal cancer is a slow-developing form of cancer, screening programmes have a good chance of early diagnosis^{xxii}. Considering the very high incidence and mortality, colorectal cancer screening should become a priority for every Member State. It will help meet the UN Sustainable Development Goals of reducing premature mortality from non-communicable diseases with 33% by 2030 in one sweep.

Considering the successful results of the Netherlands, the benefits are immediately obvious. Shifting the distribution of patients diagnosed in stage I from the current 15% to a higher percentage of 50%, would raise the number of citizens with an expected overall survival rate of 90% from 55,500 to 185,000 in the EU, reducing the overall healthcare costs by billions of euros. Unfortunately, few studies have been conducted to evaluate this health economic benefit.

In Germany, the colonoscopy screening programme prevented more than 180,000 cases of cancer between 2003 and 2012***. More outcomes studies are needed urgently.

Apart from an expected increase in overall survival, early detection also allows for minimally invasive surgery, which results in a faster recovery of the patient, and is cheaper for the healthcare system as a consequence.

The importance of treatment capacity and compliance

In order to avoid bottle-necks or long waiting times for colonoscopy and treatment, the setting up of a robust infrastructure is a basic requirement, that should be an integral part of any population-based screening programme, ensuring the presence of the right imaging and surgery technology. Citizens with pre-cancerous adenomas and treated patients also require systematic monitoring and follow-up.

The cost-effectiveness of screening

The 'business case' for colorectal cancer screening is an easy one, on the condition that the screening programme is of high quality. Since it is much cheaper to treat patients in early stages, and if - thanks to better screening - 50% of patients would be diagnosed in stage I, instead of the current 15%, more than 3 billion€ in savings could be generated in the healthcare budget every year, and possibly the same amount in social and work-related value. A German study mentions savings of up to 623€ per screened citizen^{xxiv}. The screening itself can be done relatively cheaply. The investment is around 2€ per screened citizen^{xxv}.

This means that public intervention is possible with a low-level investment, which in turn leads to better survival rates, better quality of life for patients, and reduced long-term health-related costs.

04. / Call For Action: Policy Recommendations



It is also clear that the cost-effectiveness increases with high participation rates. Setting up a whole formal population-based screening programme with limited participation will inevitably be very costly. This implies that the quality of the programme will depend on the collaboration between all stakeholders, the smooth transition between positive testing and colonoscopy and the quality of the direct communication to individual citizens.

The barriers for screening

Despite the obvious value of colorectal cancer screening, many barriers exist that must be taken into account when setting up programmes:

- Patient barriers, such as fear, socio-demographic, psychosocial, economic or geographic factors as well as awareness, understanding or lifestyle.
- Health care providers' barriers, including low screening recommendation, poor coordination and communication between patients and providers, or lack of follow-up.
- Health system barriers, including inadequate access, screening costs, test-specific factors or delays, as well as the capacity to move patients from screening to colonoscopy to effective treatment*xxvii.

The political importance to tackle this second cause of cancer deaths in Europe was re-iterated in other reports by the European Commission, the European Parliament and some task forces set up in the context of Europe Against Cancer, and further reinforced by the Commission publication on "European Guidelines for Quality Assurance in Colorectal Cancer Screening and Diagnosis" (2010), by the Cancer Control Joint Action's (CanCon) "European Guide on Quality Improvement in Comprehensive Cancer Control" (2017), and the Commission Publication "Cancer Screening in the European Union (2017).

The European Commission**xviii considers that work in the area of implementation and updating of screening programmes and networking between centres and experts remains a **priority public health objective** at the EU, national and regional level.

Overcoming the existing barriers at the level of patients, clinicians and health systems are critical for success. Society needs a political commitment to improve the uptake of cancer screening by raising awareness and education, and by supporting countries that lack the capacity for proper screening and treatment.

We are actively working to drive a policy debate addressing this societal challenge and recommend EU and Member States to focus on the following policy areas, which should be considered in ongoing action plans as well as in EU and National legislation.

Member States:

- 1. Organise and support colorectal cancer awareness-raising campaigns and education to overcome barriers to screening;
- ✓ 2. **Involve all key stakeholders** to set up or improve colorectal cancer screening programmes targeted at the total population of 50 to 74 years old; to have a concerted action between the regions and the national government to discuss collaboration on funding and savings;
- 3. Review and improve national colorectal cancer programmes (from screening to treatment) and their implementation, including effectiveness of awareness programme; adherence and effectiveness of screening programme. These reviews should be based on an integrated care approach (including standardized patient pathways);
- ✓ 4. Ensure that the necessary capacity is available to diagnose and treat patients.

EU-wide and Member States:

- 5. Undertake consistent and regular monitoring at EU level of adherence and effectiveness of screening programmes, including Key Performance Indicators of the colorectal cancer national programmes;
- ✓ 6. Undertake health economic analyses to track how money can be best invested and how the programmes need to be adjusted to improve outcomes;
- ✓ 7. Organise an annual conference on colorectal cancer screening to exchange best
 practices between Member States, Regions and Healthcare Organizations;
- ✓ 8. Promote multi-stakeholder colorectal cancer initiatives, such as European and National Councils in charge of leading, managing, monitoring and assessing colorectal cancer detection, treatment and outcomes;
- 9. Create education materials for citizens and primary care to increase the possible diagnosis of colorectal cancer.



We Can Save Patients' Lives and Reduce Costs by Putting These Basic Screening Initiatives into Practice.

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- ^{xxi} Carlo Senore et al. "Performance of Colorectal Cancer Screening In the European Union Member States", in Gut, December 2018
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- ^{xxiii} Chen Chen, Michael Hoffmeister & Hermann Brenner (2017) The toll of not screening for colorectal cancer, Expert Review of Gastroenterology & Hepatology, 11:1, 1-3, DOI: 10.1080/17474124.2017.1264269 The same study comes to the following conclusion: "Studies that demonstrated the effectiveness of screening, in fact, reveal an unsettling truth a large proportion of the 700,000 CRC-related deaths every year should not occur. This is the toll of not screening for CRC. Underuse of CRC screening is a public health issue that patients, healthcare providers, scientists, and policy-makers all must work together to overcome".
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