

SUMMARY
DOCUMENT



Colorectal Cancer in Europe

A Framework for Improving Outcomes for Patients

EuropaColon, on behalf of the people of Europe, believes it is time for a new approach to colorectal cancer that recognises the size of the health burden it imposes on society. This document sets out a framework of recommended actions that will help improve the outlook for people at risk of, or affected by, colorectal cancer.



EuropaColon

... because life matters

EuropaColon, the only European umbrella patient organisation dedicated to colorectal cancer, undertook a consultation with their Affiliate and Associate partners to evaluate the environment for colorectal cancer patients. These discussions formed the basis of our White Paper, which we believe sets a minimum standard for the delivery of diagnosis, treatment and care for all colorectal cancer patients in Europe.

Colorectal cancer (CRC) is the most common cancer in Europe and the third most common cancer worldwide. Over 450,000 people are newly diagnosed with the disease each year in Europe. It is widely accepted that this is one of the most highly treatable of all the gastrointestinal cancers if diagnosed and treated early. Doing so might help save many of the 230,000 people who die every year in Europe. To achieve this will require a desire to succeed and a concerted effort on behalf of all stakeholders.

We identified wide variations in access to treatment and care. These variations are unacceptable and every Health Ministry should review their Cancer Plan/Strategy and address these variations both between and within Member States.

We believe that our recommendations could make a substantive contribution to the Commission's goals in relation to cancer. We would like to see a commitment on the part of all Member States to engage in cancer prevention, awareness and formal population screening programmes. This should help reduce the numbers of people facing a cancer diagnosis and save associated health costs. Such activity will support the Commission's innovative partnership on healthy ageing, enabling people to lead active and healthy lives while ageing and contribute further to society.

Colorectal cancer is the name given to cancers of the large intestine and rectum. The intestine is the part of the body responsible for absorbing nutrients from food.

To view the White Paper: www.europacoln.com

Executive summary

- CRC is a major healthcare challenge that affects many thousands of people each year. Survival after 5 years from CRC depends on the stage it is diagnosed. Of those diagnosed at early stage, over 90% are still alive after 5 years while only less than 10% are still alive after 5 years if diagnosed late.
- Survival rates vary across European countries due to national variations in healthcare and locally provided treatment strategies; such inequity is unacceptable and strenuous efforts should be made to reduce those factors which contribute to variability in incidence and mortality.
- Further research on primary prevention of colorectal cancer is urgently needed, including research on how

public health and education programmes can reduce the incidence of the disease.

- Each country should have a national cancer registry that collects and publishes data on colorectal cancer incidence and prevalence.
- Each country should have a national cancer plan/strategy that includes a colorectal cancer component. This should include a transparent implementation plan with designated objectives and timescales and progress against the plan/strategy should be audited regularly.
- Formal population screening programmes for colorectal cancer should be in place in all countries in Europe and should be based on published EU recommendations and guidelines.
- First line treatment of CRC is surgery and saves lives. All surgery should be carried out by suitably qualified surgeons
- Best standards of treatment should be available to all patients, irrespective of their geographical location or socio-economic status.
- When active treatment is no longer feasible, patients should have access to appropriate supportive care.
- Information and psychosocial support for patients and their caregivers should be readily available to all who need it.
- All stakeholders should be informed and educated on all aspects of CRC, in order to ensure that thousands of unnecessary deaths are avoided in future years.

Summary of recommendations:

Structure for delivering cancer services:

- Each European country should have a national cancer strategy or plan that includes prevention, treatment and care strategies for colorectal cancer together with awareness and educational programmes
- Each country should have a national cancer registry that annually publishes cancer statistics to enable better management and comparison of cancer internationally
- Annual publication of cancer statistics is essential to effectively monitor and manage CRC
- Cancer registries should record each new diagnosis of CRC with information on the treatments received by individual patients
- Patients, caregivers and patient organisations can provide valuable insights and should be represented in the development of national CRC strategies

Prevention and diagnosis:

- Governments should have strong public health strategies in place to reduce incidence of cancer,
- Public awareness campaigns should highlight the importance of primary and secondary prevention with suggested lifestyle changes individuals can make to reduce their risk of CRC. Evidence shows an obese person is more likely to be diagnosed with CRC
- Public health strategies must include information on risk factors for CRC and suggested lifestyle changes
- More research is needed into accurate, simple and cost-effective methods of early detection of CRC as well as research on prognostic factors for outcomes should be a priority
- Each country should have a call and recall, formal population screening programme for CRC that should meet the published European guidelines for quality assurance in colorectal cancer screening and diagnosis
- Training and accreditation of endoscopists should be standardised across Europe

Treatment of people with early disease:

- National protocols for the management of people with CRC should be in place; where they are not available, international guidelines should be followed
- Fully qualified multi-disciplinary clinical teams should determine the optimal treatment plan for an individual patient
- Patients should be given clear information on all available treatment options and choices available to them
- Surgery remains the first option to curing CRC but quality across Europe remains variable, all surgery should be carried out by suitably qualified surgeons. On going audit and training will improve multidisciplinary management and surgical quality
- Patient organisations should be formally recognised for their role in supporting patients, caregivers and their families

Management of people with late stage disease

- As for people with early disease, fully qualified multi-disciplinary clinical teams should determine the optimal treatment plan for every cancer patient
- Patients should have clear information on all available treatment options and choices available to them

- The introduction of innovative therapies should be based on appropriate pricing models to ensure that price is not a barrier to patient access
- Centres of excellence for managing patients with advanced CRC should be widely available and linked into a European network
- Reimbursement decisions for innovative therapies should include the societal perspective
- Patient experience data should be incorporated into the Health Technology Appraisal process

When active treatment is no longer possible

- All patients with incurable colorectal cancer should have easy access to supportive care and symptom control
- National protocols for symptom management in patients should be followed; where these are not available, international guidelines should be followed
- Care strategies should be based on clinical need rather than treatment cost
- Quality of life should be a key consideration in managing patients when active treatment is no longer available

Support for people affected by colorectal cancer

- Patients, caregivers and patient organisations can provide valuable insights on patient needs and experiences, therefore should be represented in the development of national cancer strategies
- A patient support infrastructure reflecting patient needs and based on best practice should be available in all countries so that information, support and advice are easily available
- Patients should take greater responsibility for their diagnosis. By becoming more empowered they can work alongside their health professional to improve their experience.

Participating Countries



EuropaColon Mission

“EuropaColon is committed to preventing deaths from colorectal cancer and improving the quality of life and support for those affected by the disease”

Europacolon Vision and Goals

REDUCING COLORECTAL CANCER MORTALITY IN EUROPE

To reduce the numbers of European citizens affected by CRC

To identify CRC at an early stage

To ensure access to best treatment and care for all European patients

To support novel and innovative CRC translation search

Working together with all stakeholders

We are working with patients, carers, clinicians, the media, the citizens of Europe, governments and the European Commission to create an effective and powerful colorectal cancer community

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EuropaColon

www.europacolon.com

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