

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.



... because life matters

The following countries contributed to the preparation of this White Paper



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It is time to do something!

There are many obstacles to achieving the ultimate vision of a Europe practically free from colorectal cancer deaths. However, EuropaColon believes, that with better understanding, improved awareness, appropriate investment in infrastructure, modification of health systems' objectives and a genuine political will to serve the best interests of the population, **hundreds of thousands of deaths could be prevented.**

Much needs to be done, many things need to be changed; most importantly traditional concepts need to be brought into question:

- Many **governments** are happy to invest considerable sums in promoting and improving road safety yet fail to find the same support for public health strategies.
- **Health system administrators and insurance companies** continue by and large to pursue policies aimed at treating the sick, rather than eradicating disease.
- Certain **healthcare professionals** do not seem to understand the impact of colorectal cancer on the community, or its preventability and treatability. GPs (family doctors) arguably need much more education on this topic, in which they might play a significant and positive role.
- Public **media** in most cases is nervous about commenting on a disease which involves an “unsocial” area of the body, yet is comfortable to publish on “sexy” medical topics such as breast cancer or heart disease.
- Due to lack of awareness and direction, the symptom-free **public** prefer in general not to discuss or refer to cancer, but particularly one which affects a “taboo” body part and function.

There is a real need for all stakeholders to understand more and to co-operate and work together to create a positive impact and save lives.

Resources need allocating to actions listed in this document and also to major information, training and awareness programmes everywhere in Europe.

Change has to happen!

All too often, those who could make a real difference are obliged to choose to take a short term view, often for reasons of political expediency, when what is needed is to make a positive long term commitment to effectively manage colorectal cancer and limit its impact to a minimum.

EuropaColon, on behalf of the citizens of Europe, believes it is time for a new approach, with all stakeholders acting together.

Background

Colorectal cancer (CRC) is the most common cancer; there are about 450,000 people newly diagnosed each year in Europe. Enough is known about CRC to be confident that cases can be prevented and many more can be detected early enough to allow cure if effective prevention and early detection strategies were implemented in all European countries.

This review sets out the current challenges associated with the prevention, early diagnosis, treatment and care of people affected by CRC in Europe. It provides an agenda for action by governments and healthcare providers that, if implemented, will significantly improve the outlook for people at risk of or affected by CRC and will reduce the impact the disease has on society.

EuropaColon is the only European umbrella patient organisation dedicated to CRC and it has played a crucial role in increasing awareness of this potentially fatal disease. EuropaColon and its member organisations have used the experiences and knowledge of patients, their families and carers throughout Europe to prepare this review.

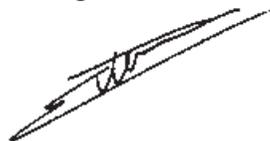
Cancer is rightly recognised as a priority in Europe. Europe demonstrates inequalities in cancer control and care, both within and between EU Member States. According to data from 2008, the estimated colorectal cancer incidence is 3 times higher in the worst performing Member State than in the best.

Because previous EU-level cooperation (Europe Against Cancer Programme 1987 – 2000) provided progress towards a reduction in cancer mortality in Europe the Commission is taking decisive action to support Member States in their efforts to protect the health of European citizens. Concerted action, through the European Partnership for Action Against Cancer, against colorectal cancer – the second most common cause of cancer death in Europe – will make a significant contribution to this programme.

In addition to its efforts on cancer, the European Commission has identified active and healthy ageing as a major societal challenge. It has launched an innovation partnership in this area which aims to enable EU citizens to lead healthy, active and independent lives while ageing, including a focus on prevention and health promotion, and care and cure. The target is to increase the average healthy lifespan by two years by 2020; improving outcomes in CRC has the potential to make a substantial contribution in a significant proportion of the EU population.

Horizon 2020 offers another opportunity to tackle CRC. More research into prevention and early diagnosis, and effective treatment of patients with established and advanced disease has the potential to reduce the CRC burden in Europe.

Implementing the strategies outlined in this review will make a substantive contribution to the Commission's goals in relation to cancer and active and healthy ageing. I hope that the proposed policy changes will be implemented quickly so that people at risk of, or living with, colorectal cancer can gain benefit as early as possible.



Professor Eric Van Cutsem
University of Leuven Belgium
EuropaColon Medical Director

EuropaColon

Established in 2004, EuropaColon is the first European umbrella patient organisation dedicated to colorectal cancer. Our mission is to prevent deaths from CRC and to improve the quality of life and support for those affected by the disease. EuropaColon aims to unite patients, carers, healthcare professionals, politicians, the media and the public in the fight against the disease.

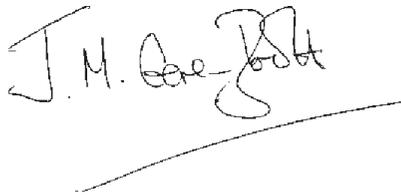
EuropaColon currently has affiliate and associate member patient organisations in 20 European countries; a full list is available at the EuropaColon website: www.europacoln.com

CRC is a societal challenge that is not contained within single nations or regions and, as such, it requires international collaboration. Europe offers an opportunity to achieve such collaboration and EuropaColon is embarking on a programme to support its affiliates and associates in their efforts to introduce formal population screening programmes, effective treatment strategies and psychosocial and supportive care in all European countries. Patient advocates have a crucial role to play in helping promote awareness of CRC and the non-profit sector is a major route towards citizen engagement to help create trust and reinforce mutual civic responsibility in a democratic society.

There are many obstacles to achieving the ultimate vision of a Europe practically free from colorectal cancer deaths. However, EuropaColon believes that with a genuine political will to serve the best interests of the population **many thousands of deaths from CRC can be prevented.**

The recommendations at the close of every section reflect our conclusions to these sections and what we believe is the way forward for the management of colorectal cancer in Europe.

Much needs to be done, but we sincerely believe it is possible and with a concerted effort we can make a real difference to the lives of people at risk of, or affected by, colorectal cancer.



Jola Gore-Booth

Executive summary

- 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.
- CRC is a major healthcare challenge that affects many thousands of people each year. It is the most common form of cancer in Europe. Every year more than 450,000 people in Europe are diagnosed with colorectal cancer and approximately 230,000 will die of the disease.
- 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 factors which contribute to variability in incidence and mortality. 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 less than 10% are still alive after 5 years if diagnosed late.
- 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. The plan/strategy should have 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.

Understanding colorectal cancer

Colorectal cancer (CRC) is a serious health issue in Europe. It is the most commonly diagnosed cancer in Europe and the second most common cause of cancer death. Each year about 450,000 people in Europe are newly diagnosed and around half of these people will die from their disease. (Ferlay et al). Estimates indicate that around 1.2 million European citizens currently are living with a diagnosis of CRC (Globocan).

Evidence from EuropaColon affiliates and associates indicates that the care of people affected by CRC varies considerably across Europe leading to major disparities in outcomes. Moreover, experience gained by EuropaColon indicates that the impact of the disease goes much further, with family, friends and colleagues all adversely affected by a CRC diagnosis.

The incidence of CRC is slightly higher for men, and the risk of the disease increases with age, with the majority of patients aged over 50 years of age at diagnosis. European countries have the highest incidence and mortality related to CRC. From 1998 to 2002, the incidence of CRC in Europe was 38.5 men and 24.6 women per 100,000 inhabitants. The estimated incidence is 3 times higher in the worst performing EU Member State than in the best. (Zavoral et al.)

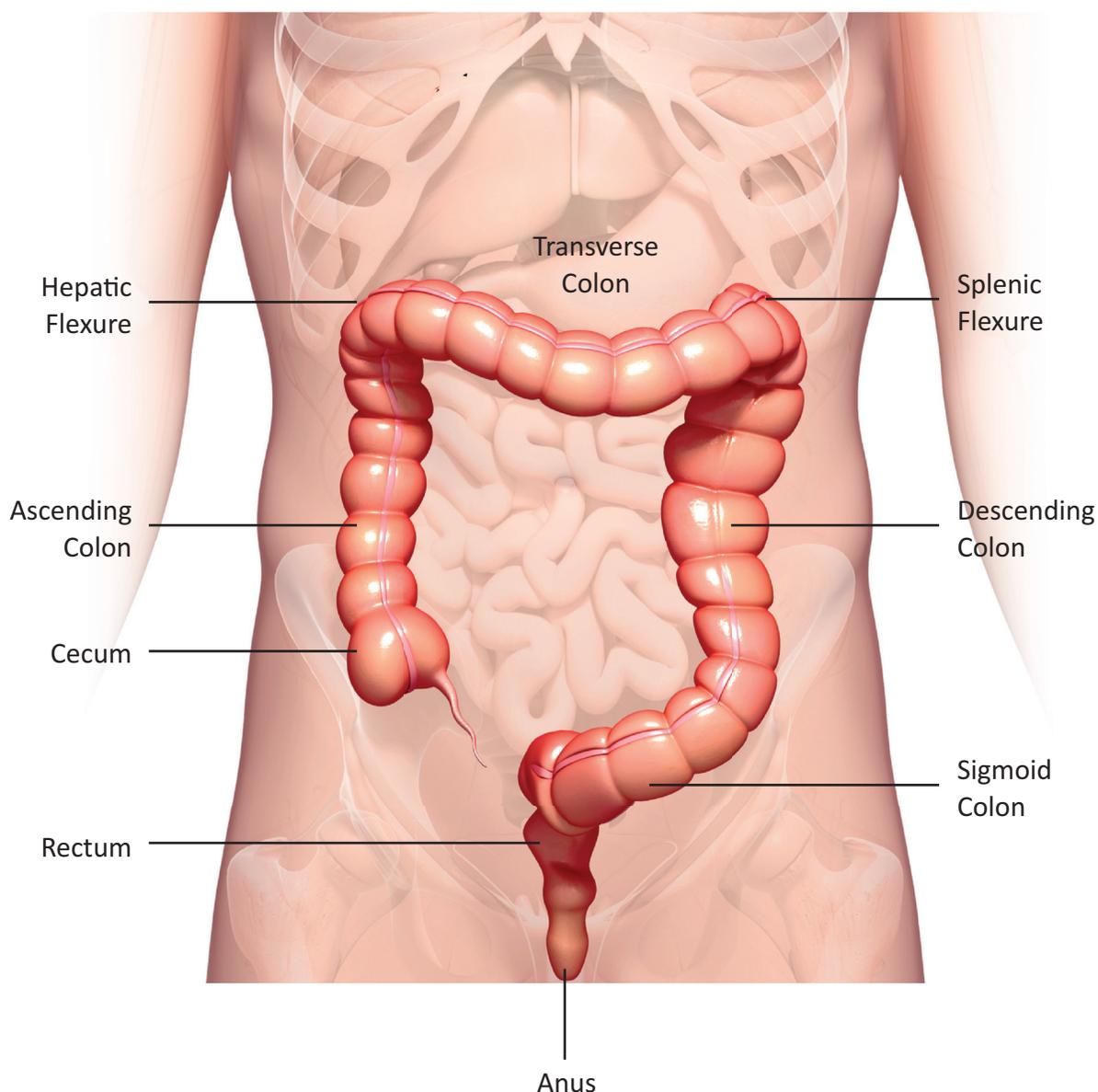
The average incidence of CRC has shown a tendency to increase in recent years with a year-on-year growth of 0.5%. The continuing increase in cancer incidence and prevalence, along with the increasing number of people living with a prior cancer diagnosis makes cancer a significant challenge to European society. The predicted trends for the next decades indicate that the cancer problem will grow to a magnitude which most nations will find difficult to handle. EuropaColon believes that action now can help reduce the personal and societal burden of CRC.

Although some countries have national cancer registries (or regional registries that taken together cover the country), the absence of systematically collated national data for all countries in Europe makes it difficult to provide completely reliable data on incidence and mortality. Complete, timely data is essential if effective services are to be put in place for colorectal cancer patients.

Colorectal cancer affects the digestive tract; the colon (also known as the large intestine) leads to the rectum, which is the last six inches or so of the digestive tract (see illustration). The colon absorbs water and nutrients from food and the remaining waste passes through the rectum and out of the body through the anus as faeces (stools). In early CRC, the disease is confined to the colon and rectum but advanced CRC can lead to the disease affecting other organs, such as the liver and lungs; when colorectal cancer has spread to another site in the body it is known as metastatic colorectal cancer. The stage at which CRC is detected has a major impact on what treatment the patient receives.

“Colorectal cancer is the most commonly diagnosed cancer in Europe and the second most common cause of cancer death”

European guidelines for quality assurance in colorectal cancer screening and diagnosis



Simplified view of the colon and rectum

If detected in the early stages, people with CRC can often be cured by surgery. However, if the disease is more advanced at diagnosis the treatment is more prolonged, involving one or more of chemotherapy, radiotherapy or biological therapy (with or without surgery) and the outlook is potentially poorer. There is considerable variation across Europe in the percentage of patients diagnosed with early disease and, similarly, variation in the outcomes for patients.

Despite the December 2003 European Council recommendation that EU Member States implement population-based screening programmes using evidence-based tests for colorectal cancer (Council of the European Union 2003), formal population screening programmes are only available in very few European countries.

The Council Recommendation invites EU Member States to take common action to implement cancer screening programmes with an organised, population-based approach and appropriate quality assurance at all levels. Where screening is available, there is no consistency in the screening method used. In addition, much is of an “opportunistic” nature, rather than organised formal population screening.

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There is also considerable variation in access to treatment, with consequent variation in outcome, for people diagnosed with the disease. Such a situation is unacceptable in Europe where the focus on patients' rights has resulted in the Cross Border Health Bill (Directive 2011/24/EU of the European Parliament and of the Council of 9 March 2011 on the application of patients' rights in cross-border healthcare.)

There is evidence that CRC can be prevented in patients at high risk (those with a family history of the disease), via the use of regular "screening" procedures – a number of different screening methods are available. There is also substantial evidence that a healthy lifestyle, with a diet based on a high fibre intake and limited red meat consumption together with regular exercise can help protect against CRC. Currently the only known link to CRC is obesity.

In the early 20th century, infectious diseases were the main cause of death but as treatments for these illnesses have improved so the cause of ill health and early death has changed to non-communicable diseases (NCDs). NCDs such as heart attacks and strokes, cancers, diabetes and chronic respiratory disease account for over 63% of deaths in the world today; that is, 9 million people aged under 60 die of an NCD each year. In 2011, the World Health Organisation and the United Nations held a summit on NCDs with support from an alliance of four disease-related organisations, including the International Union Against Cancer (UICC). The summit called for action to reduce the burden of these four diseases and published a political declaration reaffirming the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

Such a call reinforces the European Charter of Patients' Rights (<http://www.activecitizenship.net/patients-rights/projects/29-european-charter-of-patients-rights.html>). The charter was developed in 2002 by Cittadinanzattiva, the Italian Citizens' Rights organisation, with funding from the EU and support from a range of organisations in Europe, and sets out 14 Rights including:

- 'Every individual has the right to a proper service in order to prevent illness'
- 'Every individual has the right of access to the health services that his or her health needs require. The health services must guarantee equal access to everyone, without discriminating on the basis of financial resources, place of residence, kind of illness or time of access to services'

Evidence from EuropaColon members is that, even today, these rights are not respected in many parts of Europe.

Disease statistics do not fully portray the emotional impact on family members and friends, associates and work colleagues, or the overall societal and economic impact of CRC.

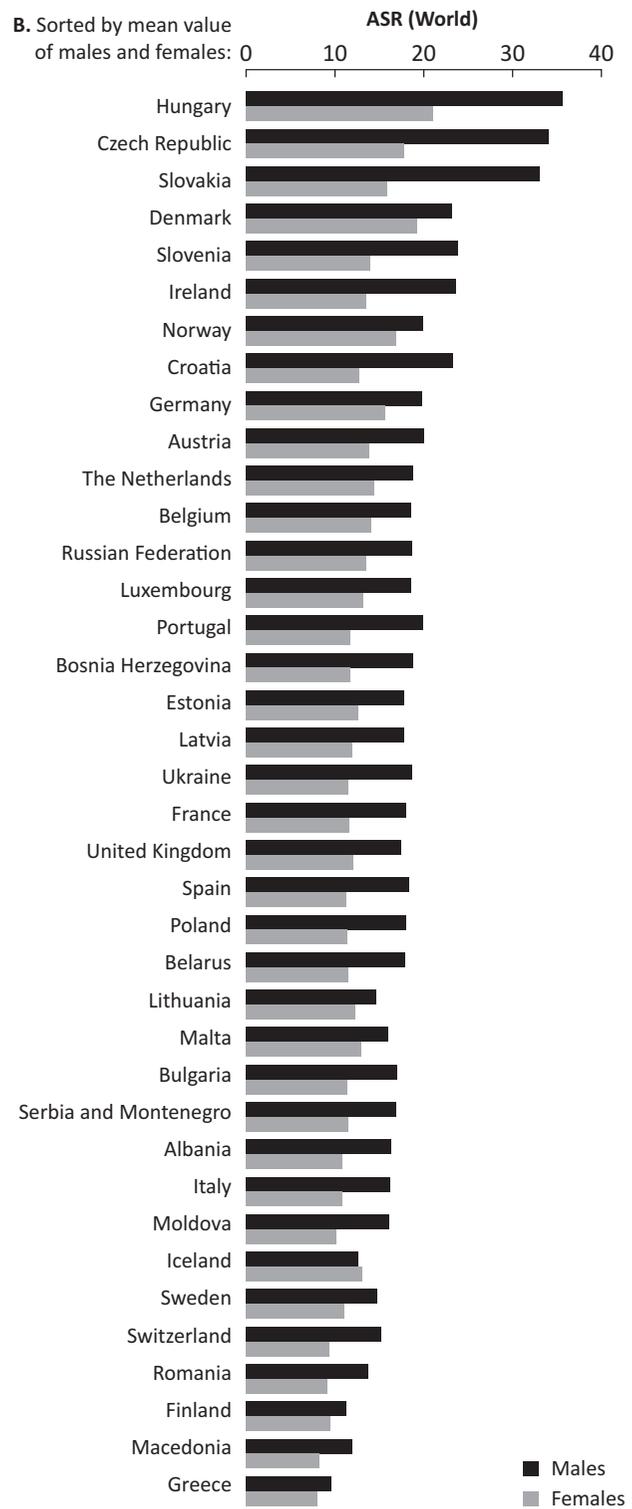
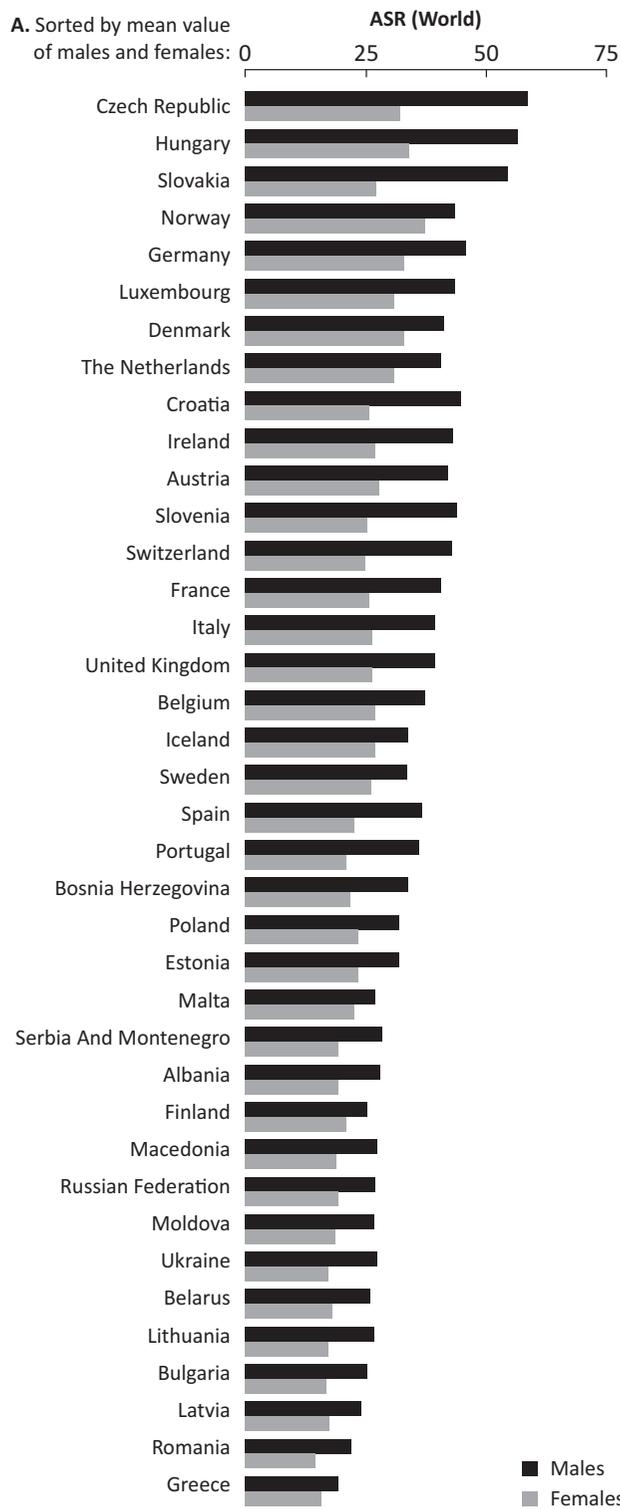


Figure 1: Epidemiology of colorectal cancer in European countries.

A: Incidence in international comparison-European countries;

B: Mortality in international comparison-European countries.

Adapted from: Ferlay J, Bray F, Pisani P, Parkin DM. GLOBOCAN 2002: Cancer

EuropaColon recommendations to improve outcomes:

- **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**

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Prevention and early detection

Although the treatment options for CRC have developed considerably over recent years, prevention of the disease is clearly the preferred option for individuals as well as all of society.

Lifestyle is acknowledged to have an impact on CRC development and data from the UK estimates that around 57% of colorectal cancer cases in men and 52% in women in the UK are linked to lifestyle and environmental factors. (Parkin et al). Lifestyle issues which have been shown to have an impact on CRC incidence include smoking, physical activity, body composition, alcohol intake, and diet. Red meat consumption is associated with an increased risk and a diet high in cereal fibre and whole grains linked to a reduced risk. Taking daily aspirin or hormone therapy can reduce the risk of CRC, but these are associated with other health risks.

Changing behaviour is difficult and educating children while they are at school may provide an opportunity to instil healthy lifestyle habits in the population from an early age.

Genetic factors can affect the potential of developing CRC. Having a family history of CRC or a history of inflammatory bowel disease and age over 50 are risk factors. This is important when considering early detection strategies. Individuals at high risk of CRC should be monitored appropriately to prevent the disease developing.

CRC can be prevented by the detection and removal of pre-cancerous lesions (polyps) in the colon and rectum. There is also a clearly defined early stage of CRC where the disease is locally confined. The management of screen-detected pre-cancerous lesions and early disease is intended to reduce CRC mortality and this is the rationale for screening. The evidence for screening is very strong and nationally implemented population screening programmes based on a call/recall system does significantly reduce disease-related mortality.

A number of modalities for formal population screening are available, and others continue to be developed. Currently the EU recommendation is testing for the presence of blood in faeces (Faecal Occult Blood Test, FOBT). Modalities under study include testing for abnormal DNA in faeces, minimally invasive examination by colonoscopy and methods such as computed tomographic colonography (“virtual colonoscopy”).

In 2008, the EU Report on the Implementation of the Council Recommendation on Cancer Screening noted that some form of CRC screening is running or being established in 19 of 27 EU countries with a target group of approximately 136 million individuals aged 50 to 74 years. However, it is clear from EuropaColon members’ monitoring activities that screening for colorectal cancer is by no means providing comprehensive cover of the target population. EuropaColon supports the EU recommendations for formal population screening in all countries.

A systematic review of cost-effectiveness studies of colorectal cancer screening showed that all studies found that colorectal cancer screening was cost-effective or even cost-saving compared with no screening. However, the review also demonstrated that the studies disagreed as to which screening method was most effective or had the best incremental cost-effectiveness ratio. (Lansdorp-Vogelaar et al)

Since survival from effective treatment for early CRC exceeds 90% (Ries et al), it is feasible that formal population screening can dramatically reduce mortality from CRC and many lives could be saved each year in Europe.

Europacoln recommendations to improve outcomes:

- **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**

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Treatment of people with early disease

CRC detected at an early stage can be treated successfully by relatively straightforward surgical procedures. Since treatment for early disease is potentially curative, it is critical that the quality of that treatment is of an appropriate standard. Surgery is the first line of treatment and can save lives. Surgeons operating on patients with CRC should have attained a minimum standard of qualification and outcomes should be reported to ensure that individual practitioners are achieving at least a national standard in outcomes.

If the cancer has begun to spread the question of whether adjuvant treatment is needed becomes significant. It is essential that the pathological stage of the cancer is accurately determined to allow the correct treatment strategy to be determined for an individual patient.

Staging of colorectal cancer

Stage I	Primary tumour into but not through muscularis propria, and no metastases
Stage II	Primary tumour going into muscularis and the serosa but without metastases or without lymph node metastases
Stage III	Any size of primary tumour with lymph node metastases
Stage IV	Presence of distant metastatic disease

The issue of how to treat patients with early stage CRC has not been clearly demonstrated. There is some evidence that adjuvant chemotherapy is valuable in patients with high-risk stage II colon cancer.

In stage III CRC adjuvant chemotherapy for six months can reduce the chance of relapse and improve survival.

Once a patient has been treated for colorectal cancer, there is always a risk that their disease will return, even after apparently curative surgery. The benefit of detecting recurrent disease by routine surveillance of the patient compared with waiting for the patient to experience symptoms is the subject of ongoing debate.

NICE guidance states: *'What should constitute good clinical practice in terms of follow-up has not been established and there is enormous variation in terms of frequency, duration, clinical setting and interventions employed. It is also not clear to what extent follow-up can be tailored to the risk of recurrence as defined by pathological stage.'*

One aspect which may not have been given adequate consideration is the patient's perspective: what reassurance do they get from regular follow up and how does this impact on their quality of life. Since the treatment is aimed at benefiting the patient (although national economic and social benefits are derived from treating patients effectively), it is important that all aspects of care that impact on a patient should be considered.

Patients and their caregivers should be given clear information about their disease and all the treatment options available to them. It is here that patient organisations can play a major role.

Formal recognition of patient organisations and understanding of their contribution in the prevention and management of disease does not appear to be widespread at health system levels.

EuropaColon recommendations to improve outcomes:

- **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

For many CRC patients, their disease will not be curable if it is detected when it has already spread from the original site. However, the availability of modern medicines means that patients with metastatic disease can have their lives extended by months or even several years with reasonable quality. Different patients will want different things from their treatment, depending on their experience to date, their life situation and their hopes for the future but all deserve the chance to receive effective treatment.

It is not just chemotherapy, radiotherapy and biological therapy that is important at this stage of disease. If the cancer spread is limited to the liver or lung it may be possible to have the metastasis removed by surgery or radiofrequency ablation (RFA). Surgeons performing liver or lung resection or RFA need to have expertise in this area to ensure that the patient has the best possible chance of a successful outcome. Indeed, the management of people living with late stage disease needs to be carried out by clinical specialists and teams who are experienced in treating the disease.

It is clear from EuropaColon members that access to treatment for people with late stage colorectal cancer varies considerably across Europe. One reason for this is the cost of the medicines and how the value they deliver is assessed. From a patient perspective, the issue of value relates to what the treatment will offer in terms of: more time with the family; time to put their affairs in order; time to do the things they always wished to do; or even time to continue working.

Reimbursement decisions concerning treatment for people with advanced CRC should be based not just on the cost of the treatment but on the benefit it brings to the individual and their family.

In order to improve treatments and to ensure that they have every opportunity to gain benefit from treatment, people with advanced CRC should have easy access to clinical trials of new therapeutic options. "Centres of Excellence" throughout Europe, using standard protocols and methodologies and linked into an international clinical and scientific network would help achieve this.

EuropaColon recommendations to improve outcomes:

- **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**
- **Patient experience data should be incorporated into the Health Technology Appraisal process**

When active treatment is no longer possible

For some people there will come a time when active treatment is no longer an option and they will die of their disease. At that time it is essential that patients continue to have the best quality of care and support that is available. Key to keeping patients as well as possible for as long as possible at this stage of the disease is the management of their symptoms. Patients should not, for example, live with pain due to lack of access to effective medication.

The care at this stage of a person's CRC pathway needs to be directed by experts in symptom control and palliative care. However, although such care is well developed in some parts of Europe there is still major variation in its availability and in attitudes towards the concept of palliative care across Europe.

Patients should be able to die with dignity and without unnecessary suffering whatever their circumstances and wherever they live in Europe

EuropaColon recommendations to improve outcomes:

- **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

There are many components of good quality cancer care. Some relate to medical care such as early diagnosis and access to high quality treatment, but others relate to broader aspects of a patient's life. For example, patients may need advice on financial matters, or help with childcare, practical help to care for themselves or psychosocial support to help them cope with the emotional impact of their illness.

It is very clear that patients want information about their illness, the potential treatments and the side effects they may experience. Such information should be provided as a routine part of care.

Many patients feel they are not given enough information by their physician. This may reflect the way information is provided rather than a lack of information. Some patients may need additional support, such as counselling, and this should be available when needed.

Patient organisations can provide information in a format people can understand – using plain language rather than the technical terms many healthcare professionals use. They can provide someone to talk to who is independent of the patient so that the patient doesn't "burden" family and friends with their problems.

Family and friends often need support to cope with what is happening to their loved one and to equip them to provide support. It is often the caregiver who is with the patient on a daily basis as they live with their illness and who helps patients adhere to treatment and accompanies them to appointments. Information that is geared to caregivers can be a source of reassurance, not least because caregivers may not have ready access to the doctor or nurse to ask questions.

Increasingly it is being recognised that patients are more accepting of a treatment option if they have been involved in the decision about which treatment to have. Patients have many factors in their lives which will impact their treatment choices – including many which are not related to their illness – and these need to be taken into account when decisions are made.

EuropaColon recommendations to improve outcomes:

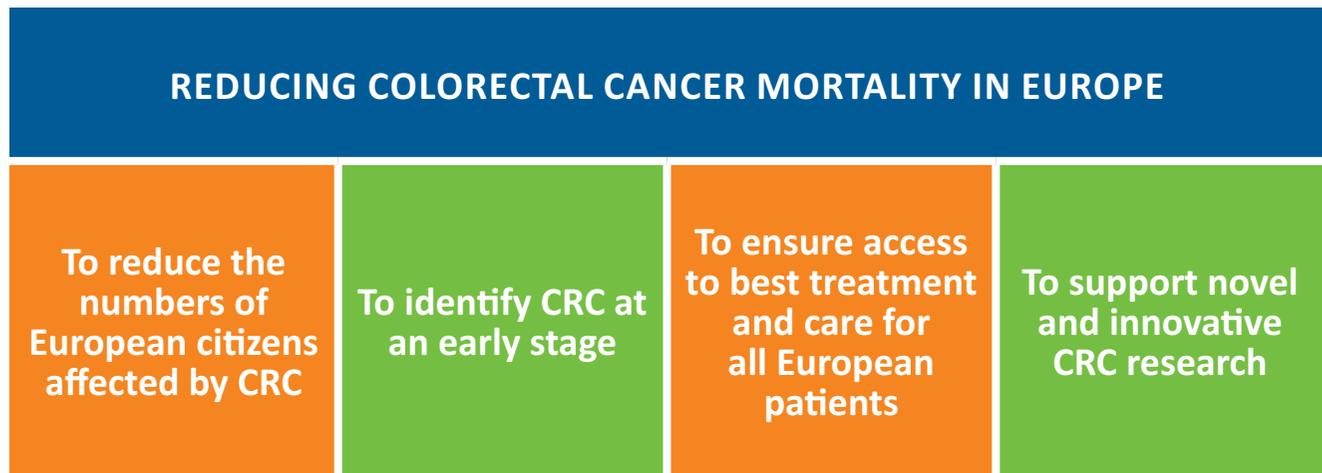
- **Patients, caregivers and patient organisations can provide valuable insights on patient needs and experiences, therefore should be represented in the development of national cancer strategies**
- **A patient support infrastructure reflecting patient needs and based on best practice should be available 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.**



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



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.

EuropaColon acknowledges the contributions from:

Jean Mossman, Keith Spencer, Geoffrey Henning
Design by jhurleydesign.com

Corporate sponsors



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Date of publication November 2012

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