



# ABOUT THIS BOOKLET



This booklet is for anyone who has been diagnosed with, or would like more information on, bowel cancer. We hope you find it helpful.

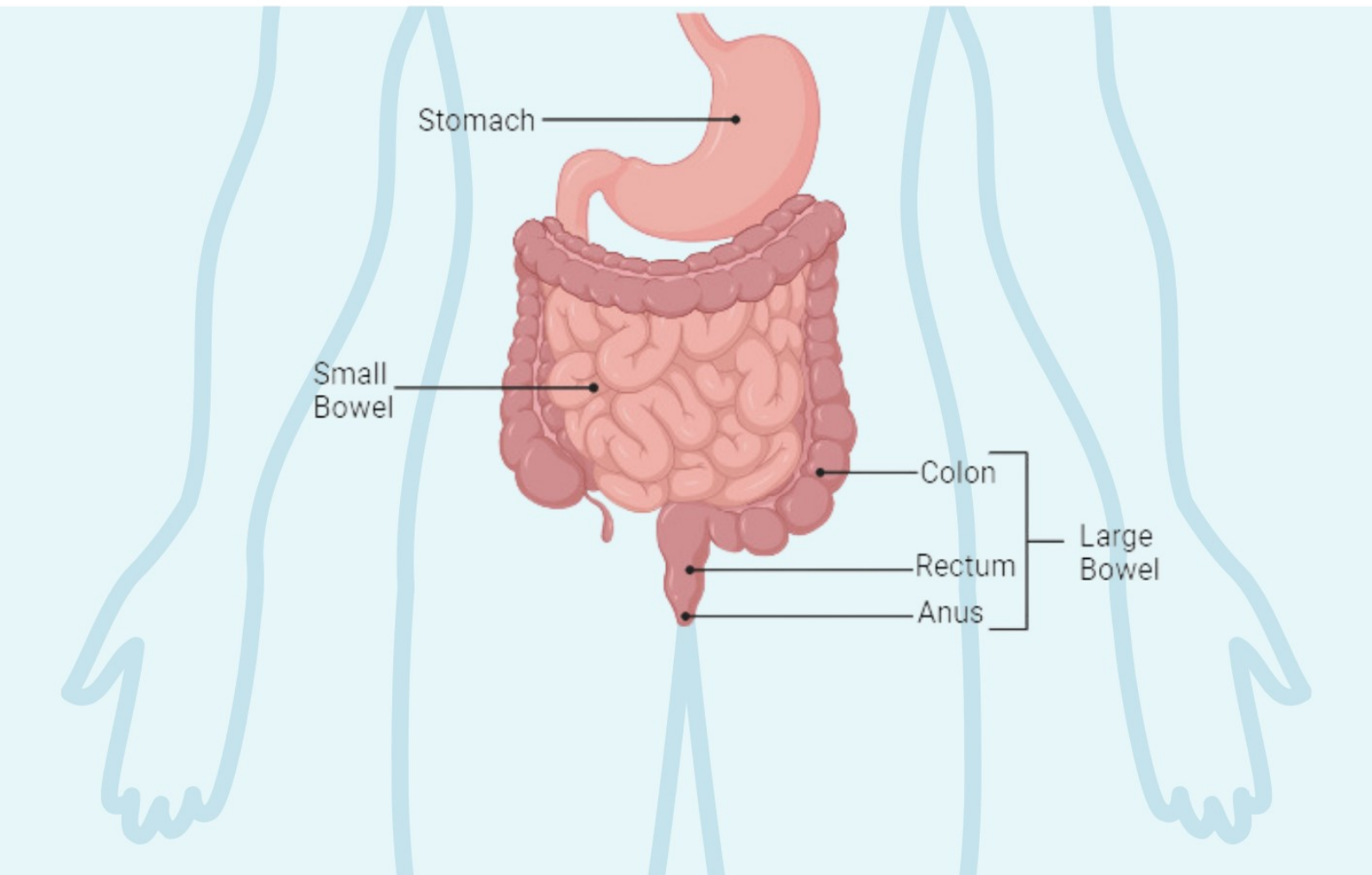
Bowel cancer, also known as colorectal cancer, usually affects older people (over the age of 50). However, in recent years there has been a significant rise in the incidence of bowel cancer in younger people (under the age of 50). It can be hard to find information and support that meets your needs. This booklet aims to raise awareness about the signs, symptoms and risks associated with bowel cancer, and to give patients a better understanding of their diagnosis and treatment options.

We have provided an introduction to the key research areas being studied to better understand this disease and aid in the development of more effective treatments. We also wish to highlight the important contributions that patients make to research.

At the end of each section, we tell you where you can find more information along with contact details for all the organisations mentioned.

Please speak to your healthcare team if you have questions about any information presented in this booklet or in relation to your care.

# WHAT IS THE BOWEL?



When people talk about the bowel, they usually mean the large intestine, which includes the colon and rectum. When you eat, food travels down the oesophagus to the stomach where it is broken down into tiny pieces. When food leaves the stomach, it enters the small bowel (also called the small intestine), where nutrients from food are absorbed. After the small bowel, waste enters the large bowel, which is made up of the colon and the rectum. Here, water and salts are absorbed. Solidified waste (also known as stool, faeces, or poo) is stored in the rectum until you are ready to go to the toilet. Poo passes through the anus as it leaves the body.



# WHAT IS BOWEL CANCER?

Bowel cancer refers to cancer of the large bowel. It is categorised into two major types based on where it is found – colon cancer or rectal cancer– which are collectively known as colorectal cancer (CRC).

## Global Statistics



**2nd** most common cancer type worldwide



**3rd** most common cause of cancer-related death in both males and females



**1 in 10** bowel cancer patients are diagnosed under the age of 50

## Ireland Statistics



**~2500** people each year are diagnosed with bowel cancer



**~90%** of people are diagnosed with bowel cancer over the age of 50



**60%** of patients are diagnosed with late stage bowel cancer

Usually, the cells in our body divide and grow in a controlled manner, with old and damaged cells being removed from circulation. Cancer is a condition where abnormal cells in a part of our bodies grow and multiply uncontrollably. This may cause a growth to form called a tumour.

Most bowel cancers develop from a small clump of cells called a polyp, a small wart-like growth in the bowel. While polyps are usually benign growths, they may accumulate genetic changes over time, enabling them to grow uncontrollably, invade normal tissue, and later spread to nearby lymph nodes (glands) and other organs.

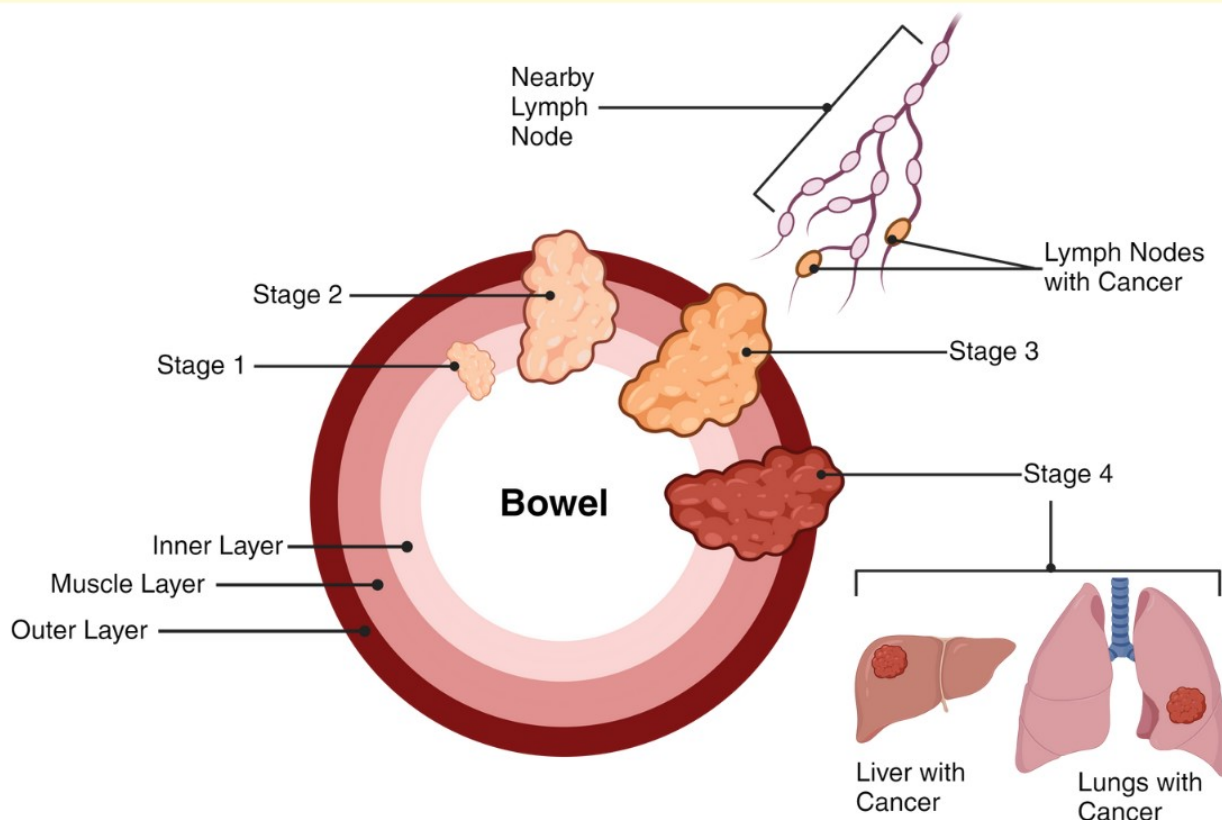
Although bowel cancer is more common in older people, it can affect anyone at any age. Bowel cancer is treatable and curable if diagnosed at an early stage. The 5-year survival rate is 97% for stage I, 90% for stage II, 73% for stage III and only 14% for stage IV (see page 4). Early diagnosis saves lives.



# PROGRESSION OF BOWEL CANCER

Cancer progression describes how your cancer changes and develops over time. Bowel cancer progression can vary from person to person. There are four main stages of bowel cancer (I–IV). Doctors will determine the stage of your cancer after your diagnosis. This guides the treatment that will be recommended to you and can help you understand your choices and expectations.

- **Stage I:** The tumour hasn't spread outside the bowel.
- **Stage II:** The tumour has grown through the bowel wall, and is involving or invading the nearby tissues.
- **Stage III:** The tumour has spread to nearby lymph nodes (glands).
- **Stage IV:** The cancer has spread to other organs in the body, such as the lungs or liver. This is known as 'metastatic cancer'.



# SIGNS AND SYMPTOMS

The most common symptoms of bowel cancer include:



Blood in your stool



Feeling tired or breathless



Unexplained weight loss



The feeling of trapped wind or fullness in your abdomen



Changes in normal bowel movement that lasts longer than 6 weeks (diarrhoea or constipation for no obvious reason)



Persistent pain, aches, or cramps in the abdomen or rectum



A lump in your abdomen or rectum



If you notice any of these symptoms or have any other concerns, contact your GP. Let them know of any family history of bowel cancer or other bowel diseases.

If you are experiencing any of these symptoms, it is important to note that it may not be cancer. These signs/symptoms can be associated with a number of other conditions. However, if it turns out to be cancer, early detection significantly increases the chances of successful treatment and recovery.



# RISK FACTORS FOR BOWEL CANCER

Risk factors are things that increase your chances of developing a disease. These factors include aspects of your lifestyle and environment which you can influence (modifiable), as well as factors beyond your control (non-modifiable), such as age and family history. It is important to understand that having one or more risk factors does not mean you will definitely develop bowel cancer. Many individuals diagnosed with bowel cancer have no known risk factors for the disease. This is why researchers need to continue investigating the risk factors associated with bowel cancer.

## MODIFIABLE RISK FACTORS



**Smoking:** Tobacco contains chemicals that increase your risk of developing cancer. Tobacco products include cigarettes, chewing tobacco, pipes and cigars.



**Diet:** You can reduce your risk of bowel cancer by taking some simple steps to improve your diet. You can do this by limiting your intake of both processed food and red meat, and eating plenty of fibre from wholegrains, pulses, vegetables and fruits.



**Body weight:** Higher body weight can affect your hormone levels and your immune system, increasing your risk of bowel cancer. Eating a balanced diet, being physically active, getting enough sleep and taking care of your mental health can help to maintain a healthy body weight.



**Excess Alcohol:** When alcohol is broken down in your body it can damage your body's cells. You can reduce your risk of developing bowel cancer by drinking less alcohol.



**Lack of physical activity:** Physical activity can reduce your risk of bowel cancer by promoting healthy hormone and insulin levels, reducing inflammation, and helping maintain a healthy body weight.



## NON-MODIFIABLE RISK FACTORS

- **Age:** Bowel cancer is most common in people over the age of 50.
- **Inflammatory Bowel Disease:** People with chronic Ulcerative Colitis or Crohn's disease have a higher risk of developing bowel cancer.
- **Previous History of Cancer:** If you have had bowel cancer before, you have a higher risk of disease recurrence.
- **Family History:** If a member of your immediate family has had bowel cancer previously or was diagnosed with bowel cancer at a young age (under 50).
- **Hereditary Syndromes:** Some people are at very high risk of bowel cancer due to the genes they carry. Around 5% of all bowel cancers are due to these inheritable genes. If a number of your family members have bowel cancer, particularly at a young age, your family may carry one of these genetic disorders. These cancer 'syndromes' include:
  - Lynch syndrome (hereditary non-polyposis colon cancer or HNPCC)
  - Familial adenomatous polyposis (FAP)
  - MUTYH-associated polyposis (MAP)
  - Oligopolyposis
  - Juvenile polyposis syndrome
  - Cowden syndrome
  - Peutz-Jeghers syndrome

## LYNCH SYNDROME

The risk of developing cancer, including bowel cancer, is higher in people with Lynch Syndrome because some genes that help protect us from cancer are no longer working properly. Genes involved in Lynch Syndrome include MLH1, MSH2, MSH6, PMS2 and EpCam. The lifetime risk of bowel cancer is 20–80% for Lynch Syndrome.

If you have Lynch syndrome, your family members may be invited to go for genetic testing. Genetic testing involves giving a small blood or saliva sample so your DNA can be checked for mutations. If any of your primary family members have Lynch syndrome you will be offered a colonoscopy every 1–2 years from the age of 25 years old.

“My older sister was diagnosed with bowel cancer at age 35. Subsequently, after a number of further cancers, she was genetically tested and a diagnosis of Lynch Syndrome was given. I reluctantly engaged in colonoscopy surveillance in 2006 and following my third colonoscopy, I was diagnosed with bowel cancer. After my diagnosis, I was genetically tested to confirm the Lynch Syndrome MSH2 mutation.” – **Pat Fahey, Lynch Syndrome Ireland**

# BOWEL CANCER SCREENING



## What Is Screening?

Screening tests allow for the early detection of bowel cancer before symptoms emerge, enabling treatment at the most manageable stage. This process also identifies individuals who may require further assessment. The ultimate goal of effective screening is to reduce both the occurrence of bowel cancer and the number of deaths it causes, safeguarding public health through proactive measures.

## Why Should I Participate In Bowel Cancer Screening?

Screening can help prevent bowel cancer by identifying potentially harmful polyps before they become cancerous. Most people don't develop symptoms until the disease is advanced and at that point, it can be difficult to treat the cancer. An early diagnosis could save your life.

## How Do I Get Screened?

Currently in Ireland, people aged 59–69 can register for BowelScreen. It is a free programme. After registering, you are sent a home kit which you use to collect some stool (poo), and send it to the lab to look for trace amounts of blood (that cannot be seen by eye). A positive test alone does not mean you have bowel cancer, but you will be recommended to have additional testing (usually a colonoscopy) if the amount of blood in your stool sample is above the screen limit. It is recommended that you do the test every two years until you turn 69. The National Screening Service is planning to extend BowelScreen services to people aged 55–74 over time as outlined by the National Cancer strategy (2017–2026).

If you do need a colonoscopy, the doctors will remove any polyps they find, which can prevent them from turning into cancers. Even if they don't find cancer, screening can reduce your risk of bowel cancer by detecting and removing these growths.

**For more information visit: <https://www2.hse.ie/conditions/bowel-screening/>**



# BOWEL CANCER DIAGNOSIS

## What Should I Do If I Am Experiencing Bowel Cancer Symptoms?

If you are experiencing symptoms, the first step is to consult with your GP who will discuss your symptoms with you. If you have any previous history of cancer or a family history of bowel cancer, make sure to inform your GP. Your GP will likely conduct a few tests, such as a rectal exam, blood test, or stool exam, to better understand your symptoms. If your symptoms persist, or worsen, or if your GP deems it necessary, you will be referred to a specialist or sent for a colonoscopy.

## How Do I Get Diagnosed With Bowel Cancer?

Doctors diagnose bowel cancer through a variety of tests, including computerised tomography (CT) scan, colonoscopy, proctoscopy, and sigmoidoscopy. All of your bowel is examined during a colonoscopy. A sigmoidoscopy is an examination of your bottom and some of your bowel, while a proctoscopy is a procedure to diagnose problems with your rectum and anus.

During a colonoscopy, the doctor will pass a flexible tube with a light and camera through your anus to look at the inside of your bowel. During this test, they can remove any polyps or precancerous lesions they find. They also may take physical samples (i.e. biopsies) of any abnormal areas. The test takes about an hour and most patients go home a few hours later. Before the procedure, your bowel must be completely empty, and you will need to take medication to empty your bowel. You will be offered sedating medication to help keep you relaxed and comfortable during the test.

Any biopsies taken during the procedure will be examined and used to look for cancer cells. Most people get their colonoscopy test results within 2 weeks. If cancer cells are found in the biopsy, you will need further tests to determine the cancer stage. These tests normally include blood tests, a CT scan, and/or a magnetic resonance imaging (MRI) scan.

If you have additional questions regarding colonoscopies please talk to your GP or visit: <https://www2.hse.ie/conditions/bowel-screening/colonoscopy-after-bowel-screening> for more information.



# CURRENT TREATMENTS

Depending on your individual cancer, your treatment may involve one or more of these therapies. Your doctors will guide you through your treatment, including the benefits, risks, and potential side effects of these different treatment types.



**Surgery:** The most common treatment for bowel cancer is surgery. This may be keyhole surgery (laparoscopic surgery) or open surgery. Surgery aims to remove the tumour with some surrounding healthy tissue, including lymph nodes (glands). Depending on the location of the tumour, you may need a stoma brought out through an opening in your abdomen, and poo empties into the bag instead of through your back passage. This is usually temporary and can be reversed after your body has had time to heal. However, if the cancer is close to your anus, it may be permanent.



**Chemotherapy:** This is a form of treatment that involves the use of anti-cancer drugs to destroy cancer cells. Chemotherapy may be given before surgery (neoadjuvant) or after surgery (adjuvant) to help reduce the risk of your cancer returning or progressing.



**Radiation Therapy:** This treatment, which is commonly used to treat tumours localized in the rectum, uses high-energy X-rays to destroy the cancer cells and stop their growth. There are different types of radiotherapy based on the patient's needs. It is normally directed at the tumour but can cause damage to nearby tissues. However, radiation treatment is carefully planned and recent advancements in technology allow patients to receive the greatest benefits with the fewest side effects possible.



**Targeted Therapy and Immunotherapy:** Targeted cancer drugs work by targeting the differences in cancer cells that help them grow and survive. Commonly used targeted therapies are cancer growth inhibitors or monoclonal antibodies. These laboratory-produced molecules are engineered to targeted specific pathways that help prevent the growth of cancer cells. Immunotherapies help the immune system to recognise and destroy cancer cells. Immunotherapy primarily involves checkpoint inhibitors. Checkpoint inhibitor drugs block proteins that stop the immune system from destroying cancer cells. However, it's important to note that not all patients are suitable candidates for these targeted or immunotherapeutic treatments. Researchers are working to develop new therapies that will continue to give patients more treatment options.



# CHALLENGES WITH BOWEL CANCER



## EARLY-ONSET COLORECTAL CANCER

The incidence of bowel cancer in people under the age of 50, also referred to as early onset bowel cancer (EOCRC), is increasing globally. Approximately 10% of all new diagnoses of bowel cancer are early onset. With the age of patients diagnosed with bowel cancer decreasing, bringing attention to the needs of younger patients is critical. Young adults experience psychosocial and fertility issues, and face the risk of premature death. Furthermore, younger patients tend to be diagnosed with more advanced disease due to late diagnosis, making the disease harder to treat. While some cases of EOCRC are due to hereditary cancer syndromes, the underlying mechanisms and risk factors are not fully understood. However, if caught at an early stage, bowel cancer is curable in ~90% of cases.

Often, we hear that younger people have had their symptoms for a long time before reaching a diagnosis. Bowel cancer is no longer just a disease of 'older people'. No one knows your body better than you, so listen to it and if something isn't right make an appointment to speak with your GP straight away. However old you are, you should never be told by your doctor that you are "too young" to have bowel cancer.

## TREATING METASTATIC DISEASE

The stage at which you are diagnosed with bowel cancer can significantly affect your survival. Around 60% of people are initially diagnosed with or end up with stage III or IV bowel cancer. Unfortunately, only 14% of patients with advanced or metastatic disease survive for >5 years. One of the reasons contributing to a late-stage diagnosis is a lack of general awareness of bowel cancer and its symptoms. This delays people taking action when symptoms arise or are mistaken for benign conditions. If you notice anything unusual with your bowel habits, talk to your GP.

While advancements in chemotherapy, targeted therapy and surgery of metastases have improved the prognosis for some patients with metastatic bowel cancer, only certain patients benefit from more targeted treatments. Currently, there are only a few biomarkers available to guide treatment selection. Improved therapies and the identification of novel biomarkers are under investigation by researchers.

# LIVING WITH AND BEYOND CANCER

Cancer survivorship refers to the unique life experiences and challenges cancer patients must navigate from the time of diagnosis, during treatment and post-treatment. Survivorship not only encompasses the immediate difficulties posed by cancer treatment but it also includes broader issues like financial hardship, psychological stress, and additional health complications.

In Ireland, there is the National Cancer Control Programme (NCCP) Survivorship Programme, which aims to optimise patients' health and wellbeing by developing and improving cancer survivorship services, assessing and managing cancer treatment side effects, and distributing helpful information, guidance and support for cancer patients and their families.

**For more information about survivorship visit:**

**<https://www.hse.ie/eng/services/list/5/cancer/profinfo/survivorship-programme/nccp%20survive%20prog.html>**

The following resources are not an exhaustive list of all the resources out there to help cancer patients. Consult your oncologist if you have any questions or concerns.





# FINANCIAL SUPPORT

When you are diagnosed with bowel cancer, you may experience financial strain. There are various financial aid funds aimed at helping cancer patients and their families with the financial burden that comes with cancer treatment. Below are a few different cancer funds for patients in Ireland. This list of financial supports for patients diagnosed with cancer is not exhaustive.

**For more information:** <https://www.cancer.ie/cancer-information-and-support/cancer-support/coping-with-cancer/information-for-patients/money-and-finances>

## Marie Keating Foundation Comfort Fund Service

This service provides financial assistance to patients >18 years old with a cancer diagnosis, receiving treatment when the application is submitted, and facing financial difficulties as a result. Applications for financial support must be submitted online by your medical social worker or healthcare professional on your behalf. All criteria must be adhered to.

### You may qualify for this fund if you have...

- Increased medical costs such as consultant fees and prescriptions
- Additional travel and parking expenses for treatment
- Increased household utility bill and/or food costs
- Increased cost due to the need for additional child-minding services

**For more information visit:** <https://mariekeating.ie/cancer-services/comfortfund>

## Irish Cancer Society Children's Fund

This fund provides financial aid for patients under the age of 18 on active cancer treatments and for their families.


**For more information visit:** <https://www.cancer.ie/cancer-information-and-support/cancer-support/getting-organised/financial-support>

## Travel2Care Fund

This fund aims to provide financial aid for patients who must travel over 50km one way to their treatment hospital.

**For more information:** <https://www.cancer.ie/cancer-information-and-support/cancer-support/getting-organised/organising-travel/travel2care>





## FERTILITY AND BOWEL CANCER

Radiation, surgery, and chemotherapy can carry a risk of infertility for both females and males. If you are worried about this, it is important to talk with your doctor **before** starting any treatment. While cancer treatments can affect fertility, there are still many resources for individuals who want to preserve their fertility.

**For more information visit:** <https://www.cancer.ie/cancer-information-and-support/cancer-information/cancer-treatments-and-side-effects/coping-with-side-effects/fertility-and-cancer-treatment>

**Fertility Preservation Before Cancer:** Sperm- and egg-freezing are common practices used to preserve fertility in people with a cancer diagnosis. This is a fairly new practice in Ireland, but there are various clinics to support cancer patients with their fertility journey. Collecting and storing eggs, and sperm banking is currently free for all cancer patients living in Ireland at certain clinics funded by the HSE. Your consultant will refer you to these clinics. Before your appointment, it is important to check this is still the case.

**Egg Freezing:** Mature eggs are collected from the ovaries through a minor surgical procedure and then frozen for future use. If the individual later wishes to try for a pregnancy, their eggs are fertilised using a sperm injection. If this is successful, and an embryo develops, it can then be implanted into the uterus. This is known as in-vitro fertilisation (IVF). Not all patients will be eligible for egg freezing; it will depend on the location of your cancer, your age and medical history.

**Sperm Freezing:** Sperm can also be collected and frozen for future use. When an individual later wishes to use their sperm, it can be thawed and used to fertilise an egg using IVF.

**Fertility Preservation After Cancer:** If fertility preservation is important to you, it is recommended that you talk to your healthcare provider before starting cancer treatment. Certain drugs can have a significant impact on fertility so it is better to pursue fertility preservation before exposure, if at all possible. There may not be time to collect and freeze eggs if you are advised to start treatment as soon as possible. Your health will take priority.

Anti-mullerian hormone (AMH) levels can be used to assess fertility in women who have already gone through cancer treatment. AMH is a hormone released by small follicles in your ovary, which contain your eggs. The level of AMH directly correlates with the number of eggs: the higher the AMH level, the greater the number of eggs available for conception.



# WHAT IS CANCER RESEARCH?

Cancer research is crucial in transforming and saving lives. Its primary goal is to develop safe and effective methods for preventing, detecting, and treating cancer, with the ultimate aim of finding a 'cure'.

Given the high mortality rates associated with advanced stages of bowel cancer, it is essential for both doctors and scientists to conduct ongoing research. This research helps deepen our understanding of the disease's causes and progression, leading to innovative treatments. Without such research, we would lack the critical discoveries needed to enhance patient care and improve survival outcomes.

## WHY IS CANCER RESEARCH IMPORTANT?

The importance of cancer research cannot be overstated. A deeper understanding of cancer allows us to make significant strides in mitigating its devastating impact and the economic burden it places on individuals diagnosed with the disease.

Research fosters advancements in our knowledge of the biological processes related to cancer development and progression. Breakthroughs in prevention strategies, screening and targeted treatments are often the result of research carried out by scientists in the lab. For continuous progress in cancer research and advancements in cancer care, collaborations between researchers, clinicians, patients and supporting organisations are indispensable.





# THE ROLE OF PATIENTS IN PROGRESSING RESEARCH

Patient participation is crucial for research progression. Much of bowel cancer research is dependent upon samples donated by patients. Patient-derived materials provide a window into the biology of cancer and allow scientists to undertake effective research and create meaningful change for patients in the clinic.

Patient-derived materials can greatly help researchers develop new treatments and create treatment plans specific to each patient. Throughout a patient's bowel cancer journey, patients may have to undergo surgery where a biopsy (small piece of tissue) may be taken. Biopsies taken before and following the completion of treatment can hold important information. By examining these samples at various stages, researchers can observe the changes treatments induce in cancer cells and gain insights into how a patient's cancer responds. Researchers can also use cells derived from patient samples to study the changes that lead to cancer, understand how cancer cells function, identify new biomarkers of disease progression and develop innovative treatments.

As part of your diagnosis and treatment, doctors frequently collect blood samples and biopsies. With your consent, these samples may be stored and used for research purposes, after all necessary diagnostic tests are complete. When your data is used in research, all personal identifiers are removed from the samples to ensure your privacy. You will never be asked to undergo any unnecessary procedures to participate in research.



## BIOBANKING

Biobanks are collections of biological samples (such as blood, DNA or tissue) and healthcare data (such as clinical information) established to support research and improve the understanding of health and disease. Biobanks are an invaluable resource and play a huge role in the development of more precise and personalised medicines. If you want to contribute to ongoing research, talk to your oncologist about any research collaborations they are a part of. They will give you more information about the aim of the project and the role you can play in advancing research.

**For more information visit: <https://biobankireland.com/understanding-biobanks/>**



## CLINICAL TRIALS

One way patients can get involved with research is by participating in clinical trials. Clinical trials are crucial for evaluating the effectiveness of new treatments developed by researchers and clinicians, comparing them to existing therapies to determine if they offer improved outcomes.

Benefits of participating in clinical trials:

- **Access to New Treatments:** Patients can access treatments that are not currently available in the clinic, which may be more tailored to their needs.
- **Understanding Side Effects:** Trials help identify and assess the side effects of new treatments.
- **Exploring Combination Therapies:** Researchers explore various treatment combinations to improve patient outcomes.
- **Optimizing Administration:** Trials aim to enhance the way treatments are administered to minimize side effects.

Clinical trials rely on patient participation. If you are interested, consult your oncologist about any trials for which you might qualify. Before enrolling, a research nurse or doctor will provide detailed information about the trial, including its purpose, requirements, potential benefits, and risks. It's vital to fully understand this information before consenting to participate.

If you have any questions or concerns, discuss them with the research nurse or doctor. Should you decide not to participate, you are not required to explain your decision, and your healthcare team will respect your choice.

**For more information about clinical trials in Ireland visit: <https://www.cancertrials.ie/>**





# CURRENT DIRECTION OF BOWEL CANCER RESEARCH

Currently, researchers working in the area of bowel cancer are trying to accelerate discoveries which will change how we prevent and control cancer, with the aim of improving patient outcomes. Additionally, researchers are trying to determine ways by which we can identify bowel cancer patients that are more likely to have progressive disease or that will have a poor response to certain treatments. The idea is to promote the use of more personalised or tailor-made treatments that will work best for each individual patient.

Understanding the changes in bowel cancer cells, identifying the role the immune system and bacteria play in disease progression, and identifying new biomarkers and diagnostic tests are areas of interest that are currently driving bowel cancer research forward.



**Next Generation Sequencing (NGS):** This is a technology that can be used to read a patient's genetic code, similar to how we read a book. This information can be used by scientists to learn about the changes occurring in cancer cells which allow them to behave abnormally. NGS also has an important role to play in helping us identify new pathways that can be therapeutically-targeted to tailor treatments for individual patients as well as improving diagnostics.



**Circulating Tumour DNA:** A liquid biopsy is a blood test that can be used to detect, analyse and monitor cancer. Scientists can look at the amount of cancer cells present in a patient's blood, which can give them important information regarding the state of a patient's disease and treatment response in real-time. Circulating tumour DNA (ctDNA) is a promising tool for bowel cancer. Currently, researchers are trying to determine how to use ctDNA to detect residual disease after treatment, to monitor treatment response and to help personalise treatments for patients.



**Microbiome:** The 'gut' microbiome describes the communities of bacteria, fungi and viruses that live along the bowel. Researchers have recently shown that the 'gut' microbiome interacts with the body's immune system and is important in protecting the body from 'harmful' bacteria. However, some bacteria can damage our cells along the gut and have been shown to be implicated in bowel cancer progression.

# HOW IS RESEARCH CHANGING BOWEL CANCER TREATMENT?

All bowel cancer research begins in clinical settings or in biomedical laboratories. Both scientists and clinicians work together to understand the changes occurring in our bodies that lead to the development of bowel cancer. New therapies can then be developed by targeting pathways driving cancer progression. Many therapies available to patients in the clinic today have come from lab-based research.

## IMMUNOTHERAPY

Immunotherapies help your immune system to better combat cancer cells. Immune checkpoint inhibitors are a type of immunotherapy which block proteins stopping the immune system from attacking cancer cells. Pembrolizumab and Nivolumab have been approved as a first-line treatment of certain types of metastatic colorectal cancer. Immunotherapies are not offered to all patients – only certain patients will benefit from this form of treatment. Discuss with your oncologist if you have questions about your treatment plan.

## TARGETED THERAPIES

Targeted therapies work by blocking the growth and spread of cancer by interfering with the biology of the cancer cells. Two common targeted therapies for bowel cancer are Cetuximab and Panitumumab, which stop the growth of cancer cells. Another category of targeted therapy is angiogenesis inhibitors, such as Bevacizumab, Aflibercept and Regorafenib. These drugs block the signals that cancer cells use to make blood vessels grow. This makes it difficult for the tumour to get blood, which carries oxygen and nutrients. Targeted therapies are not offered to all patients. Only certain patients will benefit from this form of treatment.

## CANCER VACCINES

Cancer vaccines can be used to boost the body's immune system to fight cancer. Currently, there are no cancer vaccines approved for the treatment of bowel cancer. A new vaccine targeting cancer cells with KRAS mutations has shown promising results in the first phase of a clinical trial. In this phase, 84% of patients had immune cells activated that specifically targeted cancer cells with a KRAS mutation. Currently, there are multiple Lynch Syndrome vaccines in clinical trials. These vaccines aim to prevent or delay the development of cancers associated with Lynch Syndrome, including bowel cancer.



# CURRENT BOWEL CANCER RESEARCH IN IRELAND

## EpiGastro Group at RCSI, University of Medicine & Health Sciences



**Dr Sudipto Das**

### Predicting Bowel Cancer Progression

Dr Sudipto Das' research group focuses on studying how specific chemical modifications to DNA called "DNA methylation" are associated with bowel cancer progression. DNA methylation acts like an 'on/off' switch for a light, controlling the expression of genes. When this system goes wrong, cancer cells are allowed to grow and reproduce at an uncontrollable rate. His group has identified abnormal patterns of DNA methylation that have both diagnostic and prognostic potential. Currently, Dr Das' group is looking to reverse these changes using a 'gene editing' tool to potentially treat metastatic colorectal cancer in the future.

### Exploring the Gut 'Microbiome' as a Therapeutic Target for Bowel cancer

Dr Das' group is seeking to uncover how the community of microorganisms in our bodies, known as the microbiome, influences changes in the way our genes are activated or deactivated in bowel cancer through chemical modification of the DNA such as DNA methylation. The ultimate aim is to discover new targets that could be used to help identify and treat patients with early-onset colorectal cancer (EOCRC).

### New Models to Study Disease Development

Researchers in Dr Das' group are currently developing 3D models to study bowel cancer. Organoids are tiny 3D structures, derived from patient's cells, and grown in a lab to mimic the structure and function of organs in the body. These models are more representative of how cancer cells interact with other cells in the body. Researchers use these organoids to study the characteristics of cancer cells in a controlled environment. They can test different treatments on these organoids to see how the cancer cells respond. This helps scientists understand how individual tumours might react to different drugs or therapies.



## Precision Cancer Medicine Ireland Group at RCSI, University of Medicine & Health Sciences

### Identifying New Markers of Disease and Therapeutic Targets

Professor Annette Byrne's Group at RCSI is concerned with the development of novel precision medicine approaches to treat a number of cancers, including bowel cancer. Her team works to discover novel predictive biomarkers (genomic, transcriptomic, proteomic) and identify new therapeutic targets. To achieve these objectives, medical imaging and Next Generation Sequencing (NGS) approaches are employed. Her team has particular expertise in implementing clinically relevant disease models. Overall, The Precision Cancer Medicine group works on colorectal and brain malignancies to improve patient outcomes.



**Prof. Annette Byrne**

## Centre for Systems Medicine at RCSI, University of Medicine & Health Sciences

### The Role of the Gut 'Microbiome' in Bowel Cancer

Professor Jochen Prehn is the Director of the Centre for Systems Medicine at RCSI. His research focuses on how certain bacteria in our 'gut' increase the risk of developing bowel cancer, and their impact on disease progression. Using new technologies, the group are investigating how local infection of bowel cancers with 'harmful' bacteria influences the surrounding tumour cells to become more aggressive. They have also identified that infection with these bacteria can induce damage to the DNA of tumour cells, making them more resistant to chemotherapy. Professor Prehn's team are aiming to develop new diagnostic tests that can help identify patients at higher risk of disease progression based on their infection with specific bacteria, in addition to developing novel therapeutic strategies to stop the effects of harmful bacteria on bowel cancer progression.



**Prof. Jochen Prehn**

## The Ryan Tumour Immunology Research Group at University of Galway

### New Immunotherapies for Bowel Cancer

The Ryan Tumour Immunology research group at the University of Galway, led by Dr Aideen Ryan, focuses on understanding how the tumour microenvironment influences immune responses in bowel cancer. Based in the Lambe Institute for Translational Research, the Ryan group is made up of an interdisciplinary team including immunologists, cancer researchers, Surgeons and Gastroenterologists. The group's overall objective is to find new therapies that activate the immune response in tumours. The key to finding new immunotherapies is to understand how cells within the tumour communicate with and suppress immune function. Alongside multiple industry and academic collaborators, the Ryan group aims to develop novel strategies and therapy combinations to enhance immune responses in cancer patients.



**Dr. Aideen Ryan & team**



# GET INVOLVED IN BOWEL CANCER ADVOCACY

A patient advocate is someone who uses their voice and experience with bowel cancer to support patients, families, and caregivers and to educate researchers, employers, and policymakers. Advocates work tirelessly to ensure that cancer patient's voices and needs are heard in the research and political communities. To achieve this, advocates organise educational events for the public, plan and participate in fundraisers, advocate for patients to policymakers, and assist scientists throughout the research process. Various organisations such as the Marie Keating Foundation, the Irish Cancer Society, Lynch Syndrome Ireland, and Bowel Cancer Ireland, to name a few, use patient advocates to spread awareness about bowel cancer.

This Bowel Cancer booklet could not have been created without the guidance and support of bowel cancer patient advocates.

If you are interested in becoming a bowel cancer advocate you can read more about what patient advocacy is or get involved at:

[\*\*https://www.cancer.ie/advocate\*\*](https://www.cancer.ie/advocate)

[\*\*https://mariekeating.ie/contact-us\*\*](https://mariekeating.ie/contact-us)

[\*\*https://ppinetwork.ie/\*\*](https://ppinetwork.ie/)





# TESTIMONIALS

"Bleeding from the bowel is very common, and often can be the only symptom of bowel cancer.

There are many other causes of bleeding – haemorrhoids (piles), a tear in the anus (fissure), or inflammation of the bowel – which are much more common than bowel cancer, but that doesn't mean you should ignore it. If you are having persistent bleeding from the back passage, you need to go to your family doctor, regardless of your age."

**Dr. Ian Stephens, Specialist Registrar Colorectal and General Surgery**

"It is vital that researchers have help in their research through specimen provision and PPI activities. More headway can be made in ensuring that a "cure" or improvement in the current situation is achieved"

**Pat Fahey, Lynch Syndrome Ireland**

"Hearing from patients and learning their stories keeps me motivated as a researcher. It's been inspiring to see how past research has directly impacted these patients' lives, however, there is still work to be done, especially regarding the increasing cases in young adults. I hope that my research can shed light on why this increase is happening and offer potential treatments that can help patients. None of the work researchers do would be possible without the guidance and input of patients."

**Sudili Fernando, PhD Student at RCSI**

"Although a stage IV Colon Cancer diagnosis two and a half years ago devastated me, becoming a patient advocate for Bowel Cancer awareness and new trials has given me a great sense of purpose. In particular, I feel I have found a tribe that gets me and supports me in ways that my loved ones cannot. I call them my soul family as I would have felt a greater sense of loss without them."

**Clodagh, aged 51, Bowel Cancer Ireland & Cancer Trials Ireland**

"My hopes for future research in colorectal cancer include the identification of biomarkers to help diagnose CRC earlier and more knowledge about the earlier incidence of CRC in younger people. I was diagnosed at 49 but I can see that some diagnoses are even at an earlier age, particularly rectal. Why is this happening?"

**Gerard D'Arcy, patient advocate**

"EOCRC tends to be more aggressive and is often diagnosed at advanced stages, making early screening and intervention crucial. The escalating incidence of EOCRC, its aggressive nature, and the evolving screening and detection landscape necessitate increased awareness among individuals, healthcare professionals, and policymakers. This awareness, especially crucial for younger populations, can facilitate early diagnosis and treatment, markedly improving survival rates and the quality of life for those impacted"

**Dr. Paul Nevins Selvadurai, Medical Oncologist**

"I was diagnosed immediately with stage IV rectal cancer. At age 44, with 4 young kids at home, this was terrifying. Ten years ago, I would not have been here 2 years later. Thanks to research in personalised treatment, I live very well and I urge you to support cancer research."

**Niamh, age 46, Dublin, Bowel Cancer Ireland**



# Resources Mentioned and Additional Resources

## **Biobank Ireland Trust- What are Biobanks?**

<https://biobankireland.com/understanding-biobanks/>

## **Centre For Systems Medicine Group Website**

<https://www.systemsmedicineireland.ie/>

## **Current Bowel Cancer Clinical Trials in Ireland**

<https://www.cancertrials.ie/>

## **HSE- BowelScreen Information**

<https://www2.hse.ie/conditions/bowel-screening/>

## **EpiGastro Group Website**

<https://epigastrodrq.com/>

## **HSE- Colonoscopy Information**

<https://www2.hse.ie/conditions/bowel-screening/colonoscopy-after-bowel-screening>

## **HSE- Survivorship Information**

<https://www.hse.ie/eng/services/list/5/cancer/profinfo/survivorship-programme/nccp%20survive%20prog.html>

## **Irish Cancer Society- Advocate for Change**

<https://www.cancer.ie/advocate>

## **Irish Cancer Society- Children's Fund**

<https://www.cancer.ie/cancer-information-and-support/cancer-support/getting-organised/financial-support>

## **Irish Cancer Society- Coping with Medical Expenses**

<https://www.cancer.ie/cancer-information-and-support/cancer-support/coping-with-cancer/information-for-patients/money-and-finances>

## **Irish Cancer Society- Fertility and Bowel Cancer**

<https://www.cancer.ie/cancer-information-and-support/cancer-information/cancer-treatments-and-side-effects/coping-with-side-effects/fertility-and-cancer-treatment>

## **Irish Cancer Society- Travel2Care Fund**

<https://www.cancer.ie/cancer-information-and-support/cancer-support/getting-organised/organising-travel/travel2care>

## **Lay Friendly Descriptions of Bowel Cancer Therapies**

<https://www.macmillan.org.uk/cancer-information-and-support/treatments-and-drugs>

## **Marie Keating Foundation- Comfort Fund Service**

<https://mariekeating.ie/cancer-services/comfortfund/#:~:text=What%20is%20the%20Comfort%20Fund,in%20the%20Republic%20of%20Ireland.>

## **Precision Cancer Medicine Group Website**

<https://www.precisioncancermedicinegroup.com/>

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