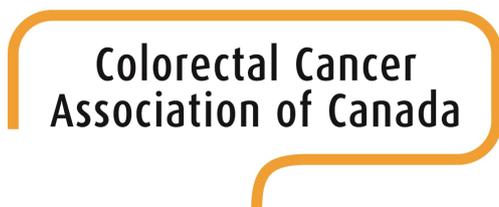




**Get Personal**  
UNLOCK YOUR TREATMENT OPTIONS

## Get Personal

Unlocking treatment options for metastatic colorectal cancer



## Get Personal: A global force for change

Get Personal is a global campaign determined to make real change happen by increasing **survival rates**, improving **quality of life** and reducing variation in **access to best treatment and care** for people living with metastatic colorectal cancer around the world.

Bowel Cancer Australia, Bowel Cancer UK, Colon Cancer Alliance (US), Colorectal Cancer Association of Canada, and Fondation A.R.C.A.D. (France), five leading colorectal cancer non-profits in their respective countries, have come together to form a united partnership to unlock treatment options for people with metastatic colorectal cancer.

By working together the global Get Personal campaign hopes to ensure every patient with metastatic colorectal cancer is given the best treatment and care no matter where ever they live in the world.

## Metastatic colorectal cancer: a global problem

Globally, colorectal (bowel) cancer is the second most common cancer in women and the third most common in men [1]. Each year there are 1.4 million new cases and 694,000 deaths - accounting for 8.5% of all cancer deaths [1,2]. Many of these deaths are caused because the disease is detected too late when the cancer has spread to other parts of the body, such as the liver or lungs. This is known as metastatic colorectal cancer.

Approximately 20% of people across Europe and the US are diagnosed when the cancer has spread and even more go on to develop metastatic colorectal cancer after having been diagnosed at an earlier stage [3,4].

There are many reasons why people are diagnosed with metastatic colorectal cancer, which are common across the five partner countries. These relate to people being unaware of the symptoms of the disease or being unaware of their potential seriousness, leading to delays in seeing a doctor about any symptoms they may be experiencing, delays in their doctor referring them for diagnostic tests, being misdiagnosed with another condition or told their symptoms are nothing to worry about. But regardless of the reason, for these patients, being told they have metastatic colorectal cancer is a devastating and distressing time for them and their family.

*"I was on a walking holiday with my wife in the Pyrenees in 2007 when I became aware that something was wrong, I just didn't know how wrong. When I returned home my GP referred me to a specialist who immediately saw a huge tumour in my colon – we didn't even have to test for cancer. It was a shock. I had a wife and had four children – I had a lot to lose. Worse still, a scan revealed that the cancer had spread through to my liver and had spread too far to operate."* – **Nicholas, UK**

## What are the issues?

As well as coming to terms with a life changing diagnosis of metastatic colorectal cancer, patients also have to contend with additional challenges and issues relating to poor survival rates and gaining access to and navigating a complicated treatment and care pathway. These are issues that transcend borders and that the Get Personal campaign is committed to addressing.

**Survival rates.** People diagnosed with metastatic colorectal cancer have poor survival rates, no matter where they live in the world. In the US, UK, France and Australia only around one in ten people survive. By comparison, people diagnosed at the earliest stage, have a 9 in 10 chance of surviving [4,5]. Colorectal cancer is more easily treated and even cured when diagnosed early but with timely access to effective treatment and high quality care even people with metastatic disease can see their survival chances and their quality of life dramatically improve.

*"In 2012 on February 7th I was diagnosed with bowel cancer. At the age of 24 being told you have cancer is something you do not expect to hear. From the faces of my doctor I could tell it was pretty serious and was referred to have a CT scan and to a surgeon. I was told that my cancer had spread to my liver putting me in the stage 4 category of bowel cancer and I was told I had 5% chance of survival and would need immediate surgery on my bowel followed by chemotherapy to shrink the tumours on my liver."* – **Hollie, Australia**



**Access to treatment.** Access to the full range of treatment options, including surgery, chemotherapy, radiotherapy and precision medicines, is essential to prolonging and enhancing quality of life and giving patients hope that they may be able to spend more time with their loved ones. But for too many patients access to treatment is dependent on where they live, whether they have insurance or if their public health system has approved the treatment rather than what clinicians believe could benefit them the most.

In the US access to treatment largely depends on individual health insurance coverage, with people on low income having the most difficulty getting the treatment they need. The public healthcare system in the UK has meant that although treatment is available for free on the NHS, access to it is dependent on whether the treatment is approved for use. In Canada, where the healthcare system is decentralised to a province level, access to drugs depends on where in the country you live. This has led to variation in access to treatment. However the treatment a patient has access to should not depend on where they live or the ability to pay but whether the treatment will work for them.

For patients and their families, this inequity of access causes unnecessary stress, worry and anxiety when they are already struggling to come to terms with being diagnosed with a life-shortening disease. Limiting access in this way means that patients may miss out on treatments that could extend their life. The ultimate consequence of this is that many lives are being lost to a disease that is treatable and even curable if there is access to the best treatment options. This needs to change.

*"I researched available treatments, and I asked my oncologist about a new medicine that was being used in Europe and America. I wasn't told about it. This, I was told, would give me my best chance for an operation as the effects of my present chemotherapy were diminishing.*

*Working with Bowel Cancer UK, I applied to the authorities to fund my treatment. Even after an appeal and a solicitor's letter, I was refused.*

*This was frustrating, I was wasting precious time. Cancer doesn't wait for officials! We decided to pay for the medicine. The drug worked dramatically and after only four months I was in hospital and my ascending colon and entire left liver were removed in one operation. I again applied to my authorities to fund four further treatments.*

*I had to prove that I was exceptional in order to have funding. With no hair, weakened by chemotherapy and my operation, I had to fight again, this time for further treatments. I felt that a dozen men in suits were playing God with my life! And they weren't listening to me. I was being ignored. I wanted to be an active participant in my treatment. I was told that I was not exceptional and funding was denied. My cancer did return in the lymph. Another course of chemotherapy seemed to take it away as quickly as it came. I had been in remission for seven years. It cost £4,000 extra to pay for the new medication.” – **Barbara, UK***



*“As a Canadian I am very proud of our healthcare system and have become increasingly dependent on it. There are however significant advances that must be made, particularly in the availability of known treatments that could serve to benefit patients like myself. One of the first things I learned after my diagnosis is you only get one shot at beating this and that shot should be taken as early as possible. I intend to do everything I can to beat this!” – **Bob, Canada***

**Personalised treatment.** Patients should not just have access to treatment and care but access to treatment that is right for them. If outcomes for people with metastatic colorectal cancer are to improve, a one-size fits all approach to managing, treating and caring for people with the disease will not work. Treatment needs to be personalised and tailored to each individual from what drug they receive to what surgery or care and support they are given.

Breakthroughs in research have led to the identification of genetic biomarkers, which means that some treatments are more effective in patients with a specific gene. This has started a shift from everyone receiving the same treatment to people beginning to receive personalised treatment right for them. However despite this crucial breakthrough, compared to many other diseases e.g. HIV, diabetes, chronic myeloid leukaemia, there have not been major, highly effective treatment breakthroughs to cure patients with metastatic colorectal cancer. If we are to achieve major improvements in survival for people with metastatic colorectal cancer, further research and development is needed to develop a personalised approach across the whole care pathway.

*“As I was five years shy of 50, the doctors expected to find ulcers, not colon cancer! I would need radiation therapy, chemotherapy, and surgery to remove the tumour and part of my colon just to give me a chance to live. Without this, my surgeon estimated I would be dead in less than six months.” - **Robin, USA***

## **Delivering long-lasting change**

The Get Personal campaign is determined to address these issues to save and prolong quality of life for everyone diagnosed with metastatic colorectal cancer across the world. The campaign is committed to:

- Eliminating variation between and within countries so that everyone, irrespective of where they live, has access to the best treatment and care.
- Putting metastatic colorectal cancer firmly on the agenda of governments, health care providers and key decision-makers.
- Campaigning for further research to address gaps in knowledge and support the development of new, innovative and effective treatments.
- Raising awareness among patients, clinicians and policy-makers of the full range of tests and treatments to be made available.

Through an international collaborative effort the Get Personal campaign believes these aims can be achieved and it is possible for people to survive metastatic colorectal cancer.

*"After my cancer diagnosis, I rekindled my passion for fine art and started actively painting again, something I had put to the side while being busy with my Creative Direction career. I have recently started showing my art and participate in the Kirkland Art Walk. It is my goal to have an art exhibition benefiting local colon cancer patients through a foundation I have started to work with closely. My artwork Big Blue Hope was also recently selected for the 2017 Expressions of Hope Calendar. Almost two years into my diagnosis, I still work full time and have not stopped doing anything I used to do before diagnosis – to the contrary – I make a conscious effort to enjoy every moment and get the most out of each and every day."* – **Jana, USA**



For more information on the campaign and to find out how to take part visit the Get Personal website [www.getpersonal.global](http://www.getpersonal.global).

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[4] National Cancer Institute. SEER 18 2006-2012, All Races, Both Sexes by SEER Summary Stage 2000. <http://seer.cancer.gov/staffacts/html/colorect.html>

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