



Beat Bowel Cancer

A O T E A R O A



COMMITTED TO REDUCING THE IMPACT OF BOWEL CANCER ON OUR COMMUNITY

Beat Bowel Cancer Aotearoa *2015 Call to Action*

APRIL 2011

Beat Bowel Cancer Aotearoa 2015 Call to Action
to ensure equitable care and improve outcomes at every
stage of the bowel cancer patient's journey.



DEDICATION

*This Call to Action is dedicated to the memory of
Lorraine Stringer
a founding member of Beat Bowel Cancer Aotearoa.*

*Lorraine worked tirelessly to increase awareness
of bowel cancer among her local Waikato and
national communities until her untimely passing.*



Beat Bowel Cancer
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Bowel cancer in New Zealand: our reality and our vision

Bowel cancer is New Zealand's cancer – affecting men and women, young and old.* Each year, almost 3,000 New Zealanders are newly diagnosed – making it our most common cancer affecting both men and women.¹

Bowel cancer is also New Zealand's second most deadly cancer.¹ Currently, New Zealanders diagnosed with bowel cancer have only a 55% chance of surviving more than five years. Beat Bowel Cancer Aotearoa believes that this could increase, conservatively, to a 75% chance with improved screening and treatment, as well as heightened public awareness of symptoms and the importance of early diagnosis.[†] If there are delays in diagnosis or treatment the cancer can spread and chances of survival are reduced.^{2,3}

Therefore, it is of major concern that, by international standards, a smaller proportion of New Zealand bowel cancer patients are diagnosed at an early stage of the disease compared with Australia, the UK, the US and Hong Kong.² **In more than 1 in 5 newly diagnosed New Zealanders, the cancer has already spread to distant organs of the body (metastatic).^{2,4}**

This has led to New Zealand having one of the **highest death rates from bowel cancer in the developed world.**^{4,5} Three times as many people die as a result of colorectal cancer than road traffic accidents.^{1,6}

There are ethnic, socioeconomic and regional inequalities in regard to bowel cancer within New Zealand. **Māori have poorer bowel cancer outcomes** than the general population – particularly Māori women, for whom outcomes are worsening over time.⁷⁻⁹ In addition, people living in deprived areas, or at a distance from a cancer centre, are more likely to die from bowel cancer.¹⁰

Beat Bowel Cancer Aotearoa aims to address this major health issue of national significance with our 2015 Call to Action.

Primarily, we aim to reduce the impact of bowel cancer on our community. It is our belief that, by working together with all levels of government and the community at large, we can deliver a significant reduction in the number of New Zealanders dying from the disease and an improvement in the quality of life for patients and their families. Regional, socioeconomic and ethnic disparities need to be eliminated – where you live and to which ethnic group you belong should not determine the timeframe for care and access to services.

We have, therefore, developed the Beat Bowel Cancer Aotearoa 2015 Call to Action, which sets out 10 Key Calls we ask to see achieved before 2015.

Guided by the over-arching principles of **improved outcomes and equitable care at every stage of the patient and whānau journey**, we call to action the New Zealand community and all levels of the government to work together before 2015 to reduce the impact of bowel cancer for all New Zealanders and to prevent thousands of New Zealanders dying of the disease.

Beat Bowel Cancer Aotearoa

April 2011

www.beatbowelcancer.org.nz

* Throughout this Call to Action 'bowel cancer' refers to colorectal cancer – cancer of the colon and rectum.

† Beat Bowel Cancer Aotearoa acknowledges that some publications report a 90% chance of survival from bowel cancer 'if detected early' – i.e. at Stage I.^{2,3} We accept this. However, we believe a realistic target for bowel cancer survival is 75%. This more cautious estimate does not detract from the very real opportunities to save life-years within New Zealand if we could improve survival from 55% to 75%. While we long for the day when survival for all patients exceeds 90%, there are several reasons for our more cautious estimate of 75%. These include: 1) not all bowel cancers are capable of being detected by the best methods of screening currently available (FOBT or sigmoidoscopy); and 2) no countries have implemented systems for detecting all bowel cancer at the earliest possible Stage I. Indeed, to achieve this, countries would conceivably need to implement programmes such as three-yearly population colonoscopy screening for the entire population from age 20 years onwards – this is not presently feasible.

Our 10 key calls

CALL 1

Rates of bowel cancer in New Zealand are among the highest in the world and our outcomes are among the worst.^{4,5} The Ministry of Health should report regularly on our performance relative to other countries. **Beat Bowel Cancer Aotearoa calls for regular and transparent reporting on bowel cancer outcomes compared to other developed countries.**

CALL 2

1 in 2 New Zealanders do not know the symptoms of bowel cancer.¹¹ **Beat Bowel Cancer Aotearoa calls for education to raise awareness of bowel cancer symptoms and lifestyle modification to help reduce risk of developing cancer.**

CALL 3

Bowel Cancer screening can potentially save 1 in 3 people with bowel cancer from dying of the disease.¹² It is almost certain that New Zealand will not have a National Screening Programme in place for at least 8 years.¹³ During this time another 10,000 New Zealanders will die from bowel cancer.¹ **Beat Bowel Cancer Aotearoa calls for a National Screening Programme to be fully implemented by 2015.**

CALL 4

Data show that Māori and people living in deprived areas or at a distance from a cancer centre are more likely to die from bowel cancer than other New Zealanders.⁷⁻¹⁰ **Beat Bowel Cancer Aotearoa calls for equitable access to bowel cancer services throughout New Zealand.**

CALL 5

Many countries have best practice guidelines for managing bowel cancer, including Australia and the UK.^{12,14} **Beat Bowel Cancer Aotearoa calls for comprehensive National Bowel Cancer Management Guidelines and accompanying National Minimum Standards against which all health care providers must be held to account. The public need to know the outcomes.**

CALL 6

Management of bowel cancer requires input from a broad range of specialists, but for patients, this can be complex, confusing and can lead to accumulated delays. In New Zealand, access to these specialists depends on where you live and where you get treatment.¹⁰ **Beat Bowel Cancer Aotearoa calls for all patients diagnosed with bowel cancer to be discussed by bowel cancer experts at a multi-disciplinary meeting, with bowel cancer care coordinators to guide patients through the care pathway and help ensure all patients have timely access at all stages of the journey, regardless of where they live and whether they are treated in the public or private sector.**

CALL 7

In the UK, shorter waiting times for referral for suspected cancer have led to earlier diagnoses for patients.^{15,16} Currently, access to first specialist consultation and waiting times for first specialist consultation vary throughout New Zealand.^{17,18} **Beat Bowel Cancer Aotearoa calls for a maximum 4-week wait between GP referral and first seeing a specialist for evaluation of suspected bowel cancer.**

CALL 8

In New Zealand, only half of all patients have appropriate diagnostic investigations within 2 weeks of seeing a specialist, with some waiting longer than a year.⁴ **Beat Bowel Cancer Aotearoa calls for a maximum 2-week wait for full diagnostic examination after seeing a specialist in patients with high-risk symptoms.**

CALL 9

New Zealanders with advanced bowel cancer have poorer access to effective drug treatments than if they lived in the UK, Australia, Canada or the US.¹⁹⁻²² **Beat Bowel Cancer Aotearoa calls for improved access to drug treatments for advanced bowel cancer. Appropriate bowel cancer drugs must be funded.**

CALL 10

About 1 in 3 patients who have potentially curative surgery for bowel cancer will die as a result of recurrence.¹² **Beat Bowel Cancer Aotearoa calls for systematic and regular follow-up of all patients (public and private) including colonoscopy when appropriate. National standards for follow-up care should be implemented and all health care providers audited against these standards.**

Our reality: 2 stories from 2,800+ stories each year in New Zealand

The patient's journey...

Symptom recognition



Diagnosis



Surgery and treatment



Follow-up

Kerry's story

My name is Kerry. I am 55 years old and the Deputy Principal of a secondary school in the South Island. I am separated but I have one of my 2 daughters and three mokopuna living in the same town.

I work hard and am fully involved in my community. I had put my increasing tiredness down to that. However, after 6 months, I went to my GP's surgery where I saw a locum who told me it was unlikely to be a health concern.

Eighteen months later the tiredness was habitual and overwhelming. I found it an effort to do the things I had previously enjoyed. I finally went back to the doctor's surgery and was seen by a new GP who had recently arrived.

This GP took a family history and discovered that my auntie had died of bowel cancer aged 67. He ordered blood tests which revealed I was anaemic. He then referred me to the local DHB for a colonoscopy. Unfortunately my local DHB could not fit me in for 8 weeks.

My whānau were very alarmed about this delay. They had learnt a bit about bowel cancer and that death rates for Māori women were increasing. We looked into going private. I have a good income but also support a number of my family. A private colonoscopy would have cost me \$2,300 which I could not afford. So I waited.

Three weeks after the colonoscopy I had surgery. The cancer had spread to my lymph nodes and I was given a diagnosis of moderately advanced (stage III) cancer and a 50% chance of surviving the next 5 years.

A 6-month course of chemotherapy followed, which hopefully should increase my chance of cure to 60–70%, according to my doctor.

I am now back at work and spend as much time with my mokopuna as I can.

Although I try to remain positive, my family and I wonder if I would have a better prognosis if blood tests had been ordered and acted on after my first visit to the GP.

I am on the routine list for regular colonoscopy follow-ups. They say these should be every 3–4 years, but I understand the wait is more likely 10 years.

I am currently having symptoms of bowel bleeding so I saw the colorectal nurse recently. She got me put onto the colonoscopy list and I am currently waiting (again) for that.

David's story

My name is David and I am a 31 year-old builder from Auckland.

I am a keen triathlete.

I was visiting my doctor for a throat infection and mentioned that I had noticed blood and mucus in the toilet on a number of occasions. My GP was concerned and ordered a blood test. This showed that I was anaemic and I was referred to my local DHB for a colonoscopy.

I had to wait 6 weeks for the procedure which was very concerning for myself, my partner and my parents. The colonoscopy and biopsy revealed rectal cancer and I was scheduled to have surgery 3 weeks later.

Prior to surgery I was alarmed when the nurse drew a mark on my abdomen where a stoma for an ileostomy bag may have needed to be sited. Even though I was told this procedure was likely to be reversed, I felt that my life was all but over. How could I train with a stoma? Would my partner, although very supportive, still find me attractive?

I had the surgery and did require a stoma. I felt very much alone at that time. I wish I could have spoken to someone about what it meant to have a stoma before waking up with one!

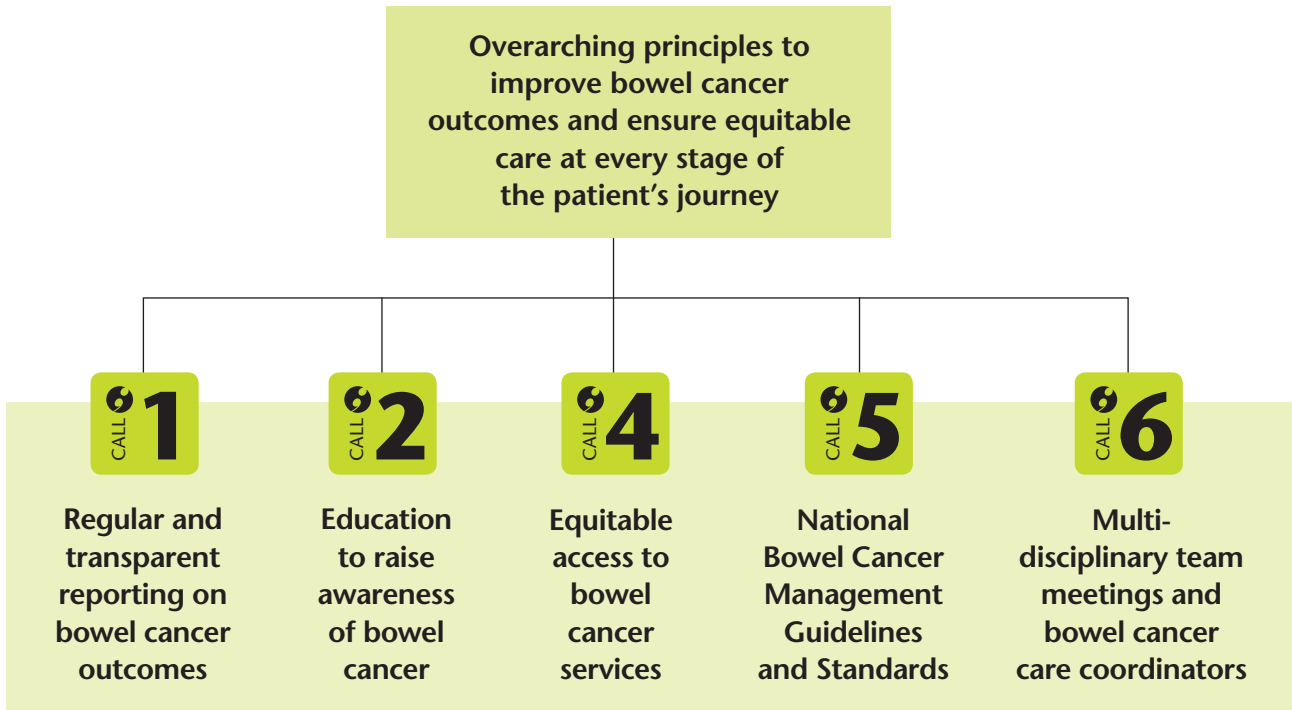
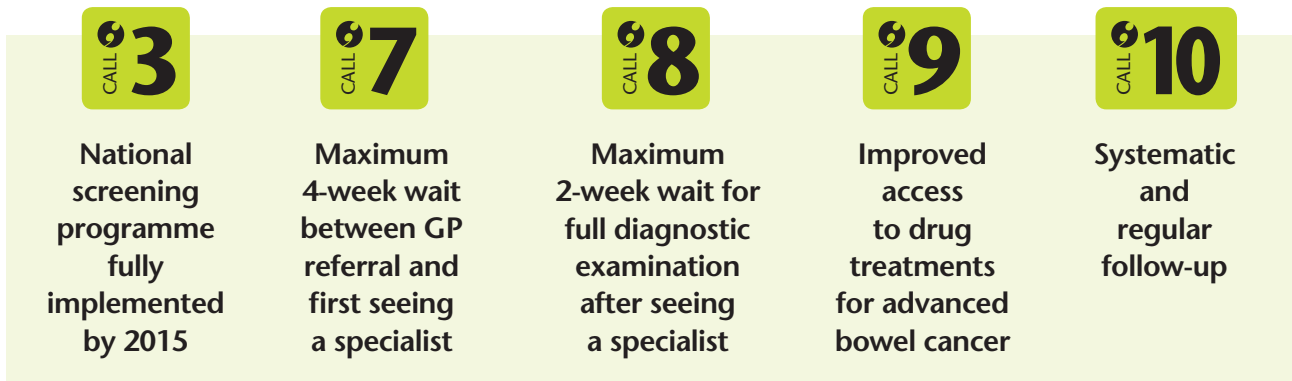
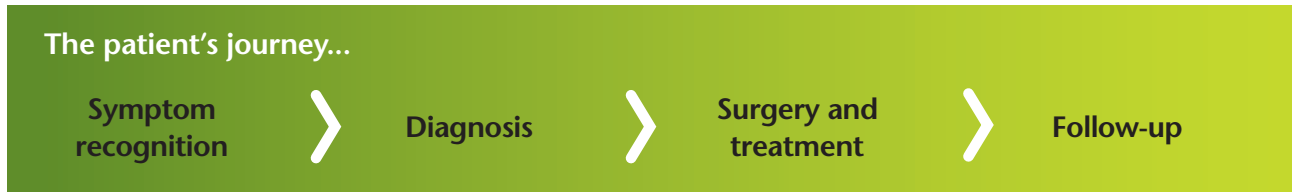
I was told that my cancer was localised. I was given the option of chemotherapy but decided against this. In retrospect, I would have liked more information at that stage and feel I did not have enough time to discuss all options with medical advisors.

Six months later my stoma was removed and my bowel re-joined without complication.

I am now back training for a short course triathlon in October.

Looking back, I am aware how lucky I have been to be diagnosed at an early stage when my cancer was curable – all due to the fact that I thought to mention the symptoms when consulting my GP over another condition.

Our vision





CALL 1

Regular and transparent reporting on bowel cancer outcomes

- New Zealand has one of the highest death rates from bowel cancer in the developed world.^{4,5} It is now killing more than 3 times the national road toll.^{1,6}
- Cancer Control New Zealand conducted a 2009 Cancer Care Survey of patient experience and is advising health professionals and managers to use the results to improve general cancer services.²³ A dedicated bowel cancer survey is required to improve patient experience of diagnosis, treatment and follow-up services for this common and deadly form of cancer.
- Record keeping and maintenance of patient registries on clinical outcomes in bowel cancer is critical for healthcare professionals to evaluate their practice against professional standards.
- Waiting times from initial detection to confirmatory diagnosis to receipt of treatment for bowel cancer should be recorded on a national register and published and compared against target performance standards.
- Audits on national outcomes data should be used to assess the impact of new guidelines and the introduction of new therapies.
- A national audit of bowel cancer services, including access to colonoscopy and treatment, is required to identify areas of low availability and to rectify deficiency.



Rates of bowel cancer in New Zealand are among the highest in the world and our outcomes are among the worst.^{4,5} The Ministry of Health should report regularly on our performance relative to other countries.

Beat Bowel Cancer Aotearoa calls for regular and transparent reporting on bowel cancer outcomes compared to other developed countries.

CALL 2

Education to raise awareness of bowel cancer

Public awareness of bowel cancer prevention and symptom recognition

- 1 in 2 New Zealanders do not know what the symptoms of bowel cancer are.¹¹
- Only 1 in 5 New Zealanders between the ages of 20 and 29 know the signs of bowel cancer. Pacific peoples are also less likely to be aware of bowel cancer symptoms to look out for.¹¹
- The general public need to understand what symptoms to look out for and what to do if they notice anything unusual. It is recommended that people be watchful for:¹²
 - **Change of bowel habit:** Recent persistent change of bowel habit, e.g. looser more diarrhoea-like motions, constipation, or a mixture of diarrhoea and constipation. Change of bowel habit is especially important if there is also bleeding.
 - **Rectal bleeding.**
 - **Tiredness, pale complexion, unexplained weight loss.**
 - **A lump or mass in the tummy.**
 - **Persistent abdominal pain.**

- Those with a family history of bowel cancer should be aware that they are at increased risk and be encouraged to be extra vigilant of symptoms.^{12,24}
- The general public need to be aware that simple changes to diet and lifestyle can reduce the risk of bowel cancer.²⁵
- High intakes of red or processed meat and fat have been associated with an increased risk of bowel cancer and stomach cancer; whereas, eating lots of vegetables, fruit, fish and foods high in fibre have been associated with reduced risk of bowel cancer.¹²
- There is strong evidence that physical exercise can protect against bowel cancer.¹²
- Alcohol intake and tobacco smoking have been associated with an increased risk of bowel cancer.^{12,26}

It was through training for a duathlon that I realised I didn't feel as well as I should. This combined with blood and mucus in my bowel motions, a major change in bowel habit and overwhelming tiredness prompted me to see my GP. I am an excellent example of someone who sought medical advice promptly, therefore the cancer had not spread and surgery was all that was required.

In the words of my specialist, "I have had the best possible outcome". I have gone on to live a normal, active life, for which I am very grateful.

RACHEL

Clear, comprehensive patient information

- Currently available written consumer cancer information resources in New Zealand lack cross-cultural relevance and sensitivity.²⁷
- Well-informed patients feel more in control and achieve a better psychological adjustment over time.¹²

Accurate recognition of bowel cancer in primary care

- Overseas data show that people with bowel cancer have more negative experiences in the primary care setting than those with other cancer types, reflecting the difficulty that GPs have in separating bowel cancer symptoms from those of other conditions, with resulting longer waits for referral and diagnosis.²⁸
- GPs and other healthcare professionals need to receive continuing medical education to ensure that they accurately recognise bowel cancer symptoms and are able to distinguish them from other conditions, in order to avoid misdiagnosis.
- All New Zealanders should be aware that they have the right to obtain a second opinion at any time.
- Due to increased risk for those with a family history of bowel cancer, primary care physicians should enquire about the family history of all their patients. Those at increased risk should be referred for regular bowel cancer screening.¹²



1 in 2 New Zealanders do not know the symptoms of bowel cancer.¹¹

Beat Bowel Cancer Aotearoa calls for education to raise awareness of bowel cancer symptoms and lifestyle modification to help reduce risk of developing cancer.



National Screening Programme fully implemented by 2015

- Although bowel cancer can occur at any age, the risk increases 4-fold between the ages of 40 and 50 years.¹²
- Overseas data show that only half (56%) of people over 50 years intend to test themselves for bowel cancer.²⁹
- Population screening would involve regularly testing all New Zealanders past a certain age, in order to identify individuals at risk of bowel cancer.¹²
- Randomised controlled trials show that population screening reduces the number of new cases of bowel cancer by 20% and potentially saves 1 in 3 people with bowel cancer from dying of the disease. It has also been shown to be cost effective for healthcare funding.¹²
- Overseas clinical guidelines recommend that annual or biennial bowel cancer screening of average-risk individuals should commence at age 50 years.^{12,14}
- A bowel cancer screening pilot is due to begin in New Zealand in late 2011 to determine whether a bowel cancer screening programme should be rolled out nationally. Waitemata DHB has been selected to run the 4-year pilot. Only people aged 50 to 74 years who live in the Waitemata DHB area will be eligible to take part.¹³
- This is a positive first step toward tackling this major disease, but it is too little too late.³⁰ Although screening programmes are complex and need to be introduced carefully, the success of bowel cancer screening has already been well established in randomised controlled trials and from experience with programmes that are already established

My sisters have both had bowel cancer and my mother died of it. I see only 2 options for my future, since I have a very high risk of developing bowel cancer. I can develop a 'symptom' in 2 or 3 years and press for an investigation. Or I can let the disease run its course and let it be discovered in 5 years' time. Neither of these is acceptable.

CHRISTY

I did not experience any symptoms except a change in bowel habit, which to me didn't seem to be major. Indeed I had little awareness of bowel cancer – I thought it was an 'old person's' disease.

If it wasn't for the 'free' medical check-up (via a medical insurance loyalty scheme) and a good GP (whom I would rarely otherwise visit), the outcome would have been a lot worse for me as the tumour was quite advanced.

PETER

in the UK, France, Italy, Canada and Finland.³¹ The long and drawn-out proposed pilot in New Zealand (and particularly the 'incident phase') will simply delay effective action to save lives.

- The Ministry of Health has indicated that no decision will be made on implementing a national programme until the pilot and evaluation report are completed in 2016.^{13,32} Should the Minister of Health then decide to implement a national screening programme, the time required to 'roll out' screening throughout New Zealand means that it is almost certain that New Zealanders will have to wait at least another 8 years for a National Screening Programme to be in place throughout the country. In the meantime, 10,000 New Zealanders will die due to the late detection of bowel cancer.¹



Bowel Cancer screening can potentially save 1 in 3 people with bowel cancer from dying of the disease.¹² It is almost certain that New Zealand will not have a National Screening Programme in place for at least 8 years.¹³ During this time another 10,000 New Zealanders will die from bowel cancer.¹

Beat Bowel Cancer Aotearoa calls for a National Screening Programme to be fully implemented by 2015.

CALL 4

Equitable access to bowel cancer services

- Data show that Māori have worse bowel cancer outcomes than that seen in the general population.⁷⁻⁹
- Deprivation and geographical access to health services also impact on survival rates, with people living in deprived areas or at a distance from a cancer centre being at increased risk of mortality.¹⁰
- Regional, socioeconomic and ethnic disparities must be eliminated – where you live and to which ethnic group you belong should not determine the timeframe for care and access to services.



Data show that Māori and people living in deprived areas or at a distance from a cancer centre are more likely to die from bowel cancer than other New Zealanders.⁷⁻¹⁰

Beat Bowel Cancer Aotearoa calls for equitable access to bowel cancer services across New Zealand.

CALL 5

National Bowel Cancer Management Guidelines and Standards

- Many countries have best practice guidelines for managing bowel cancer, including Australia and the UK.^{12,14}
- Currently the only New Zealand guidelines available are for the management of people at high risk of bowel cancer.²⁴ Yet bowel cancer is New Zealand's most common cancer affecting both men and women.¹
- Absence of New Zealand-specific guidelines may contribute to the high rate of late-stage detection of bowel cancer, the delays in receipt of diagnostic colonoscopies and appropriate treatment and high death rates, in comparison to other countries in the developed world.^{4,5}
- New Zealand-specific clinical practice guidelines are required to clarify best practice in prevention, early detection, diagnosis and management of bowel cancer.
- Beat Bowel Cancer Aotearoa calls for the Ministry of Health to implement national standards for all stages of the bowel cancer patient's journey.
- New Zealand healthcare providers need to be measured against these standards on an annual basis, and the public need to be notified of the outcomes.

Many countries have best practice guidelines for managing bowel cancer, including Australia and the UK.^{12,14}

Beat Bowel Cancer Aotearoa calls for comprehensive National Bowel Cancer Management Guidelines and accompanying National Minimum Standards against which all health care providers must be held to account. The public need to know the outcomes.





Multi-disciplinary team meetings and bowel cancer care coordinators

- Management of bowel cancer requires input from a broad range of specialists, but access to these specialists depends on where you live and where you get treatment.¹⁰
- In recent years, there has been increasing evidence of the benefits of multidisciplinary care, with good communication between primary care, gastroenterologists, oncologists, other specialist physicians, specialist nurses and psychosocial care teams.¹²
- Multidisciplinary care should be implemented throughout New Zealand as standard practice in bowel cancer management.
- All patients diagnosed with bowel cancer should be discussed by bowel cancer experts at a cancer multi-disciplinary meeting, regardless of where they live and regardless of whether they are treated in the public or private sector.
- Patients should be provided with comprehensive information about the best evidence-based treatments and optimum standard of care, including the latest approved treatments.
- The informed patient and their multidisciplinary healthcare team should decide together on the best treatment plan for the patient as an individual.
- Education is required at every stage of the patient journey so that they are fully informed about the next step in their investigation and management, likely waiting times, and possible alternatives.
- Bowel cancer care coordinators could help to achieve this goal.
- Patients have a right to receive appropriate care at every stage of their bowel cancer journey – including combinations of government-funded and private care.

On Valentine's Day 2007, instead of roses and chocolates I was diagnosed with bowel cancer.

I was 28 years old and had a 6 month old son. The frustrating thing for me was getting some answers about how my fertility might be affected by the chemo and what could be done to prevent this.

A year after my chemo I got pregnant and in May 2009 I delivered a healthy baby boy.

MARY



Management of bowel cancer requires input from a broad range of specialists, but for patients, this can be complex, confusing and can lead to accumulated delays. In New Zealand, access to these specialists depends on where you live and where you get treatment.¹⁰

Beat Bowel Cancer Aotearoa calls for all patients diagnosed with bowel cancer to be discussed by bowel cancer experts at a multi-disciplinary meeting, with bowel cancer care coordinators to guide patients through the care pathway and help ensure all patients have timely access at all stages of the journey, regardless of where they live and whether they are treated in the public or private sector.



Maximum 4-week wait between GP referral and first seeing a specialist

- In the UK, shorter waiting times for people suspected cancer have led to earlier diagnoses for patients.^{15,16}
- Little empirical information is currently available about the waiting time between referral by a GP and first consultation with a specialist in New Zealand.^{17,18}
- Currently, both gaining access to first specialist consultation and waiting times for first specialist consultation vary throughout New Zealand.^{17,18}

I was diagnosed with bowel cancer while living and working in England. My GP was excellent and referred me immediately to the gastroenterology service. England had target waiting times for first consultation for possible cancer patients – so I was seen and given a rigid sigmoidoscopy within two weeks – but that failed to diagnose the tumour on my bowel. Three months later I had a colonoscopy which did. The diagnosis was of Stage III bowel cancer – as the tumour had broken through the wall of my bowel and started to spread through my lymph nodes towards my liver. Now, 7 years on, despite a worrying prognosis, I am lucky to be clear of the cancer.

SARAH

In the UK, shorter waiting times for referral for suspected cancer have led to earlier diagnoses for patients.^{15,16} Currently, access to first specialist consultation and waiting times for first specialist consultation vary throughout New Zealand.^{17,18}

Beat Bowel Cancer Aotearoa calls for a maximum 4-week wait between GP referral and first seeing a specialist for evaluation of suspected bowel cancer.



Maximum 2-week wait for full diagnostic examination after seeing a specialist

- Colonoscopy is widely regarded as the gold standard for confirmatory diagnosis of bowel cancer.¹²
- Overseas clinical guidelines recommend that investigation into bowel cancer should include a digital rectal examination, a rigid sigmoidoscopy and a colonoscopy.¹²
- According to a recent New Zealand study, colonoscopy is used as a diagnostic investigation in just over half of cases.⁴
- UK primary care referral guidelines for adult patients with suspected bowel cancer stipulate that the first diagnostic investigations should be undertaken within 2 weeks of an urgent GP referral.^{15,16}
- In New Zealand, the average time from first specialist assessment to colonoscopy is 10 days, although only half of all patients have colonoscopy within 2 weeks of seeing a specialist. Almost 13% wait more than 10 weeks and some wait longer than a year.⁴

In New Zealand, only half of all patients have appropriate diagnostic investigations within 2 weeks of seeing a specialist, with some waiting longer than a year.⁴

Beat Bowel Cancer Aotearoa calls for a maximum 2-week wait for full diagnostic examination after seeing a specialist in patients with high-risk symptoms.



Improved access to drug treatments for advanced bowel cancer

- New Zealanders with advanced bowel cancer have poorer access to effective drug treatments than people living in the UK, Australia, Canada or the US.¹⁹⁻²²
- Government decisions on funding newly approved, innovative treatments should be made in a timely manner and be consistent with international standards, so that access is equal to that of other developed countries.
- Consideration should be given to the principles of equity, human dignity and disease severity when making funding decisions, rather than solely on financial cost.
- Patients with advanced bowel cancer should have access to treatment options that both prolong their life and give them additional quality of life.

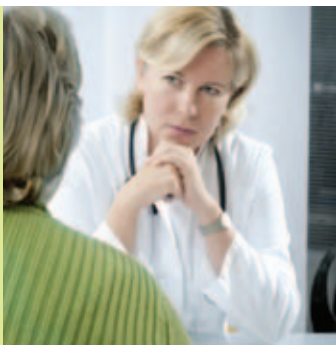
New Zealanders with advanced bowel cancer have poorer access to effective drug treatments than if they lived in the UK, Australia, Canada or the US.¹⁹⁻²²

Beat Bowel Cancer Aotearoa calls for improved access to drug treatments for advanced bowel cancer. Appropriate bowel cancer drugs must be funded.



Systematic and regular follow-up

- Patients need to receive more information as to what to expect following surgery and treatment, including ongoing issues such as increased bowel motions and painful wind, as well as helpful advice and tips (e.g. changes to diet).
- Following curative surgery for bowel cancer, patients have an increased risk of developing bowel cancer again or further growths in the lining of the colon.¹²
- The original tumour can also recur. About 1 in 3 patients who have potentially curative surgery for bowel cancer will die as a result of recurrence.¹²
- Follow-up of all patients (public and private) should be undertaken to improve on these outcomes by detecting recurrence at an earlier and potentially curable stage.¹² Currently, all New Zealanders with bowel cancer do not receive adequate follow-up surveillance.³³ National standards should be implemented for follow-up care; all providers should be audited against these standards on a national basis (see Call to Action 5).
- Patients should receive very clear written information (in their first language) about follow-up care pathways and signs to look out for to detect disease recurrence.



About 1 in 3 patients who have potentially curative surgery for bowel cancer will die as a result of recurrence.¹²

Beat Bowel Cancer Aotearoa calls for systematic and regular follow-up of all patients (public and private), including colonoscopy when appropriate. National standards for follow-up care should be implemented and all health care providers audited against these standards.

About Beat Bowel Cancer Aotearoa

Mission Statement

“We are a nationwide, patient-led organisation committed to reducing the impact of bowel cancer on our community through awareness, education and support.”

Background to Beat Bowel Cancer Aotearoa

The charity began development in 2009 and was officially founded in 2010 by a group of people affected by bowel cancer, with the support of clinicians, committed to improving bowel cancer awareness among the general public and health professionals. The charity aims to provide clear and up-to-date information about the disease, symptoms, what to do if diagnosed and treatments.

We encourage people to communicate frankly about all aspects of this disease, and not to be embarrassed to talk about bottoms and bowels.

Bowel cancer is New Zealand’s cancer. Instead of leading the world in terms of the numbers of people affected by bowel cancer and deaths from bowel cancer, we need to lead the world in terms of finding solutions to this disease and improving outcomes for patients. Every year we wait for a national screening programme many New Zealanders will continue to die unnecessarily from bowel cancer.

For further information about bowel cancer and the charity or how to make a donation, please visit our website www.beatbowelcancer.org.nz, our Facebook site or contact us via our email: info@beatbowelcancer.org.nz or by post: Beat Bowel Cancer Aotearoa, PO Box 6405, Dunedin North, Dunedin 9059, New Zealand.

www.beatbowelcancer.org.nz



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References and further reading

1. Ministry of Health. *Cancer: New Registrations and Deaths 2007*. Wellington: Ministry of Health. June 2010. Available from <http://www.moh.govt.nz/moh.nsf/indexmh/cancer-reg-deaths-2007>.
2. Samson P, O'Grady G, Keating J. An international comparison study of stage of colorectal cancer at diagnosis: how does New Zealand compare? *NZ Med J*. 2009 May 8;122(1294):74-83.
3. Garcia M et al. *Global Cancer Facts & Figures*. Atlanta, GA: American Cancer Society, 2007. Available from http://www2.cancer.org/downloads/STT/Global_Cancer_Facts_and_Figures_2007_rev.pdf [Accessed on 3 February 2011].
4. Cunningham R, Sarfati D, Hill S, Dennett E, O'Donnell A. Colon cancer management in New Zealand: 1996-2003. *NZ Med J*. 2009 May 8;122(1294):51-60.
5. Minister of Health. *The New Zealand Cancer Control Strategy*. 2003, Ministry of Health: Wellington.
6. Ministry of Transport. *Road deaths for the 5 years 2006-2010*. Available from <http://www.transport.govt.nz/research/Road-Toll/> [Accessed 3 February 2011].
7. Frizelle F. *Cancer in New Zealand*. *NZ Med J*. 2009 May 8;122(1294):7-9.
8. Jeffreys M, Stevanovic V, Tobias M, Lewis C, Ellison-Loschmann L, Pearce N, Blakely T. Ethnic inequalities in cancer survival in New Zealand: linkage study. *Am J Public Health*. 2005 May;95(5):834-7.
9. Hill S, Sarfati D, Blakely T, Robson B, Purdie G, Dennett E, Cormack D, Dew K, Ayanian JZ, Kawachi I. Ethnicity and management of colon cancer in New Zealand: do indigenous patients get a worse deal? *Cancer*. 2010 Jul 1;116(13):3205-14.
10. Haynes R, Pearce J, Barnett R. Cancer survival in New Zealand: ethnic, social and geographical inequalities. *Soc Sci Med*. 2008 Sep;67(6):928-37.
11. Phoenix Research. *Community Perceptions Survey – Public opinions about cancer, early detection and screening*. A Research Report for the Cancer Society of New Zealand. June 2009.
12. Australian Cancer Network Colorectal Cancer Guidelines Revision Committee. *Guidelines for the Prevention, Early Detection and Management of Colorectal Cancer*. The Cancer Council Australia and Australian Cancer Network, Sydney 2005.
13. Ministry of Health website. *Cancer control in New Zealand. Bowel Cancer Programme*. Available at <http://www.moh.govt.nz/moh.nsf/indexmh/cancercontrol-strategyandactionplan-bowelcancerscreening> [Accessed 11 Feb 2011].
14. The Association of Coloproctology of Great Britain and Ireland. *Guidelines for the management of colorectal cancer*. 2007. Available at http://www.acpgbi.org.uk/assets/documents/COLO_guides.pdf [Accessed 11 Feb 2011].
15. National Institute for Health and Clinical Excellence. *Referral guidelines for suspected cancer*. June 2005. <http://www.nice.org.uk/nicemedia/pdf/cg027niceguideline.pdf> [Accessed December 2010].
16. National Health Service (NHS). *Primary care referral guidelines for adult patients suspected with colorectal cancer*. January 2008, reviewed January 2010. <http://www.erypct.nhs.uk/upload/HERHIS/East%20Riding%20PCTs/Document%20Store/Policies/Adult%20Colorectal%20Primarycare%20Referral%20Guidelines.pdf> [Accessed December 2010].
17. Southern Cancer Network. *Audit of access to colonoscopy of 33 selected cases in Otago District Health Board*. 2010. Available at <http://www.southerncancernetwork.org.nz/file/fileid/29846> [Accessed 11 Feb 2011].
18. Murray M, Brown J, Hinder V, Merrie A, Hill A, Hulme-Moir M, Sharples K, Findlay M. The colorectal cancer patient's journey: the Auckland region. *NZ Med J*. 2011 March 4. 124(1330).
19. PHARMAC. *Pharmaceutical Management Agency. Pharmaceutical Schedule 2011*. New Zealand Government. Available at <http://pharmac.govt.nz/2011/02/01/Schedule.pdf> [Accessed 11 Feb 2011].

20. NICE. National Institute for Health and Clinical Excellence. Colorectal cancer guidance. UK National Health Service. Available at [http://www.nice.org.uk/search/guidancesearchresults.jsp?keywords= colorectal%20cancer&searchType=Guidance &healthTopic=2](http://www.nice.org.uk/search/guidancesearchresults.jsp?keywords=colorectal%20cancer&searchType=Guidance&healthTopic=2) [Accessed 11 Feb 2011].
21. PBS. Pharmaceutical Benefits Scheme. Australian Government Department of Health and Aging. Available at <http://www.pbs.gov.au/browse/medicine-listing> [Accessed 11 Feb 2011].
22. Health Canada. Canada Health Act. Available at <http://www.hc-sc.gc.ca/hcs-sss/pharma/acces/index-eng.php> [Accessed 11 Feb 2011].
23. Cancer Control New Zealand. *The Voice of Experience*. July 2010. <http://cancercontrolnz.govt.nz/>.
24. New Zealand Guidelines Group. *Surveillance and Management of Groups at Increased Risk of Colorectal Cancer. Evidence-based Best Practice Guideline Summary*. May 2004. Available from [http://www.nzgg.org.nz/guidelines/0048/Colorectal_Summary_\(Web\).pdf](http://www.nzgg.org.nz/guidelines/0048/Colorectal_Summary_(Web).pdf) [Accessed on 3 February 2011].
25. Pullar J, Chisholm A, Jackson C (In Press). *Healthy Eating after Colorectal Cancer: A dietary guide for optimising health after treatment for colorectal cancer*. Published by Southern Cancer Network, New Zealand.
26. Limsui D, Vierkand RA, Tillmans LS, Wang AH et al. (2010) Cigarette Smoking and Colorectal Cancer Risk by Molecularly Defined Subtypes. *J Natl Cancer Inst*. 2010; 102 (14): 1012-1022. doi: 10.1093/jnci/djq201.
27. O'Brien I, Lambie L, Stacy-Baynes S. Is quality cancer information available for consumers in New Zealand? A national stocktake and review of written consumer cancer information. *NZMJ*. 2009 May 8;122(1294):23-32.
28. National Audit Office (NAO). *Report by the Controller and Auditor General. Tackling cancer: Improving the patient journey*. Department of Health, London 2005.
29. ANOP Research Services. *Australia patient survey. Conducted in partnership with Roche Products*. November 2007.
30. Derrett S. Screening for colorectal cancer: taking New Zealand from 'among the worst' to 'the best'? *NZ Med J*. 2011 March 4, 124(1330).
31. Shaw C, Cunningham R, Sarfati D. *Next steps towards a feasibility study for colorectal cancer screening in New Zealand: Report for the Ministry of Health*. March 2008. [http://www.moh.govt.nz/moh.nsf/pagesmh/7940/\\$File/crc-screening-feasibility-in-nz-mar08.pdf](http://www.moh.govt.nz/moh.nsf/pagesmh/7940/$File/crc-screening-feasibility-in-nz-mar08.pdf).
32. Ministry of Health. *Bowel Cancer Screening Pilot. Request for Proposal*. July 2010.
33. Ahmadi O, Alfadhel M, Allawati H, McKenzie B, Missen S, Song A, Vaastra W, Derrett S, Sharples K, Jackson C. *Clinical audit of follow-up of colorectal cancer patients following curative resection*. New Zealand Society of Gastroenterology Conference. Auckland; November 2010.

Abbreviations

DHB – District Health Board
 UK – United Kingdom
 US – United States of America
 GP – General Practitioner
 Chemo – Chemotherapy

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Beat Bowel Cancer Aotearoa is responsible for the content of the 2015 Call to Action.



COMMITTED TO REDUCING THE IMPACT OF BOWEL CANCER ON OUR COMMUNITY



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