

Partners in Care co-design case study

What I wish I'd known when I received my bowel/rectal cancer diagnosis

Context

New Zealand has one of the highest bowel cancer rates in the world, and bowel cancer is the second highest cause of cancer death in New Zealand.¹

The Midland region comprises five district health boards (DHBs): Taranaki, Waikato, Lakes, Bay of Plenty and Tairāwhiti (Figure 1). Waikato DHB serves a population of more than 360,000 people, Lakes DHB serves a population of more than 102,000, Taranaki DHB serves a population of approximately 104,280, Bay of Plenty DHB serves a population of approximately 200,000, and Tairāwhiti DHB serves approximately 45,000 people.

Figure 1: Map of the five Midland region DHBs



In 2017, the incidence of bowel cancer for the region was 39.0 persons per 100,000.²

Table 1 shows the incidence of colorectal cancer for each DHB within the Midland region for the year 2017.

¹ <https://www.health.govt.nz/your-health/conditions-and-treatments/diseases-and-illnesses/bowel-cancer>

² <https://www.health.govt.nz/publication/new-cancer-registrations-2017>

Table 1: Incidence of colorectal cancer in the five Midland region DHBs, 2017

	Male	Female	Total
Waikato	154	132	286
Lakes	38	27	65
Bay of Plenty	91	91	182
Tairāwhiti	15	14	29
Taranaki	39	47	86

Many receive their likely diagnosis following a colonoscopy undertaken to investigate symptoms the person was experiencing. A confirmed diagnosis follows after examination of any biopsies taken at the colonoscopy.

The Midland region DHBs want to ensure that consumers within the region diagnosed with bowel cancer know and understand the steps along the pathway from the point of diagnosis to a treatment plan.

Receiving a diagnosis

Within the Midland region, all consumers who are believed to have a bowel/rectal cancer at endoscopy are told of the findings of the endoscopy by a health professional just prior to discharge following the colonoscopy. These consumers usually have a support person with them.

Currently within the Midland region, only one DHB (Lakes) accompanies this verbal communication with a written handout.

Anecdotally, consumers have told us that when they receive a diagnosis of bowel cancer, what they want to know is 'What happens next?' and 'When will it happen?' However, the word 'cancer' can make any words that follow both insignificant and forgettable.

When sedative medications and opioid pain relievers (used in endoscopy) are added to the mix, it is understandable that consumers and their whānau have difficulty in remembering what health professionals told them about their likely diagnosis.

Aim

The aim was to explore the experience and memories of consumers and their whānau who have undergone the experience of being diagnosed with bowel cancer, then to use this knowledge to help inform and guide others along the bowel cancer diagnosis pathway.

The second part of our aim was to construct information that meets the needs of consumers and whānau and is generalisable to the bowel cancer diagnosis pathway but is institutionally and geographically specific.

Start up

Our original intention was to engage with consumers and staff from each of the five Midland region DHBs.

However, because of a range of challenges, including work constraints, staffing changes, and role changes, we were not able to achieve this.

We needed to reduce the scope of our project and engaged with people from two DHBs: Bay of Plenty and Lakes.

We created an initial plan which aligned to the co-design methodology, which included:

- recruiting two consumers from each of the two DHBs to work with us on the project team
- developing an elevator pitch to help others to understand what we aimed to achieve
- developing a set of questions as a starting point to use after our elevator pitch
- collecting data to help us understand current experiences
- reviewing the data and looking for themes and ideas for improvement
- co-developing an information tool
- evaluating the experiences of people who use the new information tool.

Engage

A cancer journey from diagnosis of bowel/rectal cancer to an identified treatment involves many people, so this project endeavoured to capture perspectives from the following stakeholder groups:

- consumer/patient
- family/whānau/support person of patient/consumer – these are the people who walk with/alongside and may have their own questions and/or know the questions their loved one asked
- staff – including day-stay nurses, endoscopists both surgical and medical, and colorectal nurses.

When preparing to engage with a consumer to share their lived experience, we developed criteria which included age, gender, ethnicity and the need for the patient to be within 6 months of their diagnosis so that their experience was fresh in their mind. Colorectal nurses from each of the two DHBs involved identified consumers who would meet the criteria and in each case asked the first consumers at their clinic who met the criteria if they would like to be involved.

All consumers who were invited were only too happy to share their experiences. If whānau or support people accompanied the consumers, they were also included in the discussion.

Elevator statement

To engage people within this project, we developed two elevator statements, one for consumers and one for staff. These provided a short narrative to help them understand what we are aiming to achieve.

Bowel cancer patients/support people/whānau

The starting point

We understand that a diagnosis of bowel cancer is very scary. People have told us they are very anxious and that they would like clear information about what happens after the colonoscopy.

We would like to find out what information helped you and your whānau and what would have helped you to have a better understanding of what was going to happen next.

We would appreciate if you could spend 10 to 15 minutes of your time to share your experience and ideas with us so that we can develop information that is helpful for future patients like you.

Everything you say to us/me is confidential and will not in any way affect your ongoing care.

Day-stay staff

(This includes members of the team – eg, nurses, surgeons, gastroenterologists, registrars.)

The starting point

Consumers have told us that after a diagnosis of bowel cancer the most important thing for them is to understand ‘what happens next’, and they do not always feel that they do.

As you have interactions with these consumers, we would appreciate if you could spend 5 to 10 minutes of your time sharing your experiences of providing information to them, and any ideas about what we could do to create the most useful information from your perspective.

All information was collected on an anonymous basis. This was explained to all individuals contacted to assure them their privacy was protected, and to reassure patients/consumers that any information given would not affect their ongoing treatment/surveillance in any way.

Capture

To capture experiences, we designed a set of survey questions for consumers/whānau and a separate set for staff. Participants were given a survey document to complete. Four of the consumers chose to verbalise their answers to the colorectal nurses involved.

We approached consumers from the two DHBs who were within 6 months of diagnosis. Their demographics were:

- 6 male aged 45–79
- 6 female aged 43–80
- 5 NZ European
- 4 Māori
- 1 Samoan
- 2 European/other

Questions designed for consumers (12 in total – 7 Lakes DHB, 5 Bay of Plenty DHB)

Thinking back to when you were told you had bowel cancer...

- Where did you get information from?
- What information helped you?
 - What was good about that information?
 - What was not good about that information?
- How was the information provided (eg, verbally at the consultation when you were told of your diagnosis; in an information sheet/booklet; from friends/whānau who have experience with bowel cancer; from Google)?
- Now that you are further along in your journey can you tell us what information was missing? For example, what do you know now that would have made things better if you had the information earlier?
- How would you like this information (eg, written as a handout, online, video online)?

Staff from the two DHBs whose role was associated with bowel cancer were approached. This included the following staff roles:

- (15) day-stay nurses
- (11) endoscopists both surgical and medical
- (3) colorectal nurses. (Unfortunately, one of the colorectal nurses changed roles, and although she provided initial information, she did not survey her consumers.)

Questions for staff

Thinking back to your interactions with patients who had just been given a diagnosis of bowel cancer...

- After the diagnosis of bowel/rectal cancer, what information or questions did patients/consumers and/or their whānau/support persons ask you?
- What information do you think we need to provide for these people?
- What ideas do you have about how we can provide that information?

Understand

After completing the capture phase, we then set out to review the responses to learn about people's experiences of providing and receiving information about the cancer diagnosis.

Consumer/whānau and staff responses are listed below.

Consumer/whānau responses

Where did you get information from?

- The person who did the procedure
- Colorectal nurse
- Once I told my friends and family, people kept telling me what had happened to their friends
- Written handout (Lakes DHB)
- On the internet

What information helped you? (What was good about that information?)

- Got everything explained – some of it was too much at one time.
- What I was told was good.
- Was shocked with diagnosis so good to have it written down.
- Liked being told and then having what was going to happen written down as I didn't think I had cancer so after I was told I probably didn't listen very well.
- As my wife and I work in health you would think we would know what might happen, but as soon as that word cancer is mentioned it is hard to hear anything else. It was good to have it written down.
- Didn't read the paper – just rung the colorectal nurse.

(Apart from the above responses, 10 of the 12 respondents also stated that the most helpful information was the contact details of the colorectal nurse and their accessibility and willingness to answer questions/concerns either by phone, text or email in a timely manner.)

What was not good about that information?

- Would be good to have something written down to show to others.
- Would be good to have reliable websites listed.

How would you like this information?

- Written is good.
- Would be good to have it written so I could review it.
- My children might like it online.

Staff responses

What information/questions did they ask you?

- Will I be cured by surgery?
- When can I see a surgeon?
- When will I have my scan?
- What will my scan show?
- How bad is the cancer?
- Do I need to have chemotherapy?
- Who will I see? (surgeon)
- Will an operation cure me?
- When will I get my results?
- What do I do now?
- Is there any treatment?
- How quick will everything happen?

What information do you think we need to provide for patients?

- Plan of what happens next.
- Waiting times for scans and appointments.

What ideas do you have about how we can provide that information?

- Written information.
- Explanation of types of scans/tests.

Improve

Lakes DHB and Bay of Plenty DHB colorectal nurses met with the four consumers on the project teams and reviewed the findings from the data collection process. What was evident was the commonality between the respondents from both DHBs in what information consumers wanted, the questions they asked, and that they liked things written down.

This supported the memories and experience shared by the two consumer reps from Waikato DHB at the first meeting of the co-design project.

They wanted to know:

- What happens next?
- Why does it happen?
- When will it happen?
- When will I know?
- Contact details of a person who could answer their questions.

It was agreed in the first instance to develop a written handout that detailed diagnostics, including approximate timeframes, and explanations that could be used by the health professional who was giving the diagnosis to the patient/consumer.

Patient representatives also felt that reliable websites should be listed. It was felt by the two groups that this was the most cost-effective and equitable way of sharing the information. It was noted that in the future this could also be developed into a web resource.

Existing diagnostic pathways information sheets were reviewed by the two groups. These included lung and gynaecology handouts (both used in Midland region DHBs) and Lakes DHB's 'Where to from here' handout.

We used these examples to develop an initial handout for colorectal cancer (Appendix 1). It was trialled by colorectal nurses in Lakes and Bay of Plenty DHBs. Feedback was also sought from health professionals involved in delivering the diagnosis of colorectal cancer at Waikato, Lakes and Bay of Plenty DHBs, as well as consumers and their whānau.

To do this, we sent the information developed via email to endoscopists (surgeons and gastroenterology consultants) and day-stay nursing staff in Waikato, Bay of Plenty and Lakes DHBs and consumers and their whānau.

We requested feedback from 18 staff members, and 15 responded (83% response rate).

A range of comments and suggestions are listed below.

- It seems very good.
- Fantastic, that looks really good.
- Great idea. I like it for the most part. My only suggestions would be:
 - Lose the blood tests (part of the information sheet) or at least not on the day. I don't organise blood tests on the day of diagnosis, they are usually part of the preoperative work-up.
 - Remove the 'discuss by phone after the multidisciplinary meeting (MDM)'. In some cases this is okay but I much prefer to discuss this kind of thing face to face, preferably with a support person present. Telling someone they have incurable cancer over the phone seems uncivilised. Other than that I love it.
- Will be good to have these to hand out once finalised.
- This is great – so helpful and informative.
- Great work, which I'm sure will be helpful to our patients and families.
- Brilliant – nothing to add.
- I think this is a fabulous initiative and is very much needed. I have given out my first info sheet today. I do wonder if a small blurb against each resource under 'other resources' is warranted so patients know what these services are, may be useful.
- Looks interesting. I presume you have spoken to patients to see what they want to know.
- I like the idea but wonder if it contains too much info. Should it contain a little more about possible surgery?
- Today the doctor has talked about a rectal or bowel cancer. Most patients, family, friends and whānau find this a difficult time. Waiting for results is difficult.
- The following tests are arranged: great diagram.
- For simplicity, the only time frame relevant for the patient is when the plan will be presented to them (i.e. 'up to three weeks?')
- To be added:

- The CT should have ‘usually in Thames’, Blood tests ‘taken today’, MRI ‘in Hamilton’
 - ‘After the tests all the results are gathered and discussed to work out what a best plan might be.’
 - ‘Follow-up appointments or further tests happen after this meeting. They can be in either Hamilton or Thames.’
- Wonderful, love the diagram.
 - Clear information for patients.
 - Good to have it written down.
 - Will ensure consistency within both the hospital and across region.
 - Have tried it and it is easy to use.

In summary, the health professionals generally loved it but wanted to individualise it for their own health care setting.

As this is a regional initiative, the decision was made by the colorectal nurses involved to write a statement on the information sheet such as “times and location of tests and appointments may vary depending upon your DHB. Your clinical nurse specialist will be able to advise you.”

Furthermore, the intent was an information sheet for the diagnostics rather than all treatments, so it was not expanded at this stage. Two of the DHBs have a separate surgery information booklet.

Patient/Consumer and whānau feedback

The intention had been for colorectal nurses within Waikato, Lakes, Tairāwhiti, Taranaki and Bay of Plenty DHBs to a) use the ‘Draft Information Sheet’ with at least five newly diagnosed patients at each location and seek feedback, and b) in Tauranga and Rotorua, to seek feedback in a focus group setting from at least five previously surveyed consumers.

However, COVID-19 meant that our plans needed to change.

It was possible to see the newly diagnosed patients/consumers who were admitted for surgery for their cancer condition. When they had recovered from surgery and just prior to their discharge, 10 consumers (5 from Lakes DHB and 5 from Bay of Plenty DHB) were asked by the colorectal nurses if they would be prepared to evaluate the information sheet. If they agreed, they were given the sheet and asked to write comments. We used the following prompts to help:

- What was good about the information?
- What should we change (think about the words, pictures, information, title)? (We specifically asked about the title as it had been raised by a consumer on the working group as too confrontational).

We requested feedback from 10 consumers and all responded (100% response rate).

What was good about the information?

- I liked the diagram and pictures – don’t change anything.
- It was good it was written down, as I didn’t remember it all when I was told as I was shocked to find I had cancer. (bowel screening patient)
- It was easy to read. It told me what I wanted to know.
- I especially liked the web page links.
- Good to have colorectal nurse details. (×3)

- My investigations were quicker than the time frames given but was good to know what to expect.
- It was good to share with family.
- The document is very helpful. I like the diagram, breakdown of tests and web resources.

What should we change?

- Don't change a thing. (x3)
- The title is appropriate. I liked that the word cancer was used as that is what I had and I had to come to terms with it. (x3)
- Very thorough.
- Can't think of anything else that needs adding to this.

Furthermore, the seven patients from Lakes DHB who had a simplified information sheet and gave feedback earlier in the co-design process were asked to compare the old sheet with the newly developed version and provide feedback. Generally, they saw the new sheet as advancement but reiterated the contact details of the colorectal nurse were the most important as was the accessibility of the colorectal nurse to answer questions/concerns either by phone, text or email.

The five patients from Bay of Plenty DHB who were also involved earlier in the project were also asked to review the information sheet. They too were very positive of the new format, liked that the information was written down, and also voiced the importance of the colorectal nurse details and accessibility.

Next steps

The information sheet was changed with the following statement added as a result of feedback: . Times and location of tests and appointments may vary depending upon your DHB. Your clinical nurse specialist will be able to advise you ' (Appendix 2).

The title was also changed to reflect participant feedback and conversations.

We will use the co-designed information sheet for the next year within the Midland region for all patients diagnosed with bowel or rectal cancer. At the end of the year we will review its usefulness with our consumers and adapt it further as needed.

We will also review the possibility of a video walk-through of the process, similar to the one produced in Wales, if there is funding. This was supported by consumer representatives from Waikato and in consumer feedback.

Working as a co-design team

Ann-Maree: 'The end result justifies the means. However, it was at times a process fraught with difficulty and frustration accompanied by the highs of consumer involvement, participation, and feedback as well as working with likeminded colleagues.'

'Did we achieve our aim? I believe so – however, it did not include all the DHBs as intended.'

Helen: 'The involvement and feedback of consumers and the collaboration with colleagues meant that this project has developed valuable patient information. It would have been good to have more involvement from other DHBs so their consumer input could be included.'

Judy: 'I really enjoyed learning and using the principles of co-design for this project.'

The project team

Name	Role	DHB	Email
Judy Warren	MCN		
Ann-Maree Murphy	Project Lead	Lakes	Ann-maree.murphy@lakesdhb.govt.nz
Helen Collins		Bay of Plenty	helen.collins@bopdhb.govt.nz
Anne Hodges	Consumer	Waikato	
Alan Young	Consumer	Waikato	

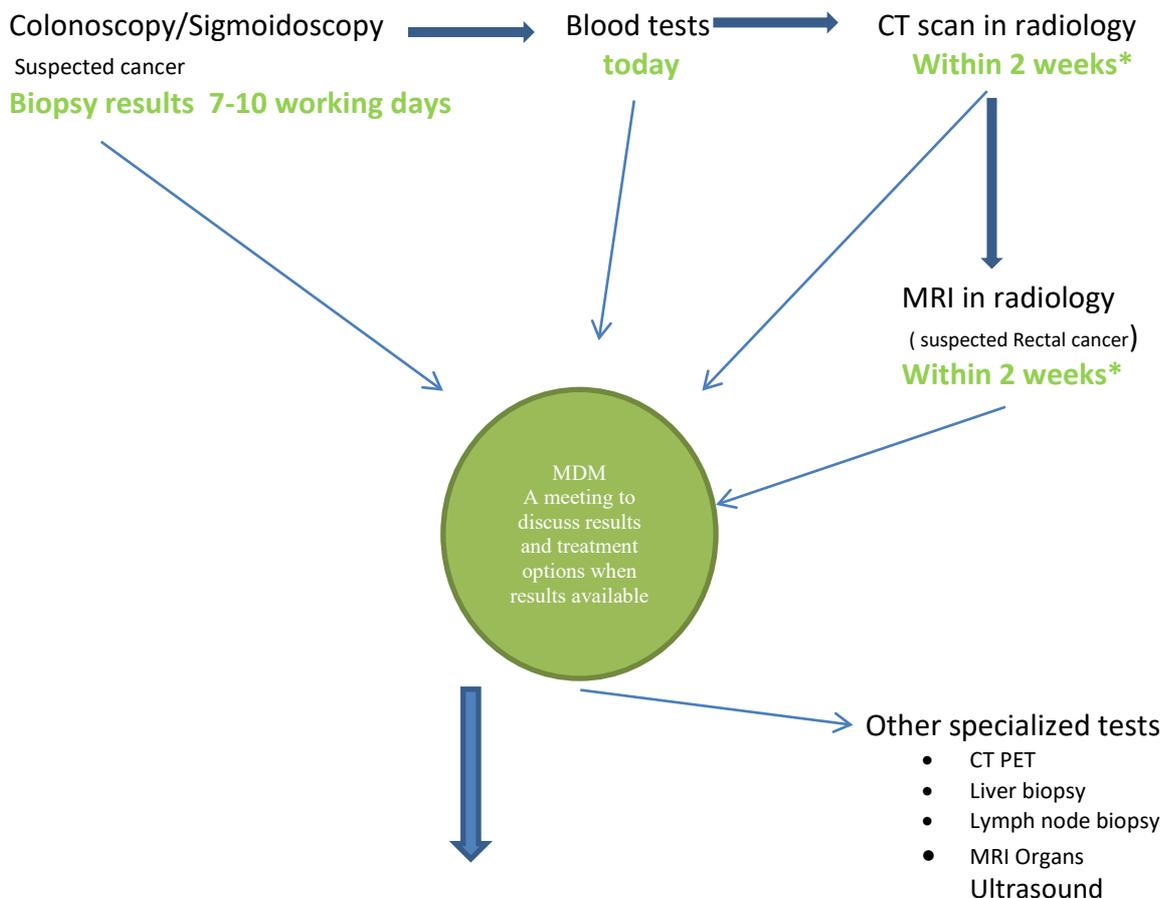
Appendix 1: Diagnostic pathways information sheet

A Diagnosis of Bowel/Rectal Cancer

When you are told you have (or are suspected to have) bowel/rectal cancer it is a very anxious time for you and your family/whanau. You may be offered a number of tests and appointments at the hospital that will help your specialist make an accurate diagnosis, to understand the problem and determine the right treatment for you. Below is a pathway of tests/appointments. **You may not need all of these tests.**

No action will be taken without your agreement and full understanding each step of the way. Your family /whanau / support person can attend all of these appointments with you.

Pathway of tests/appointments



When will my results be discussed with me?

Your test results will be discussed with you and your family/whanau/support person at an outpatient appointment with your specialist, you will have this appointment once all of your results are available. Your GP will also get copies of all your test results.

Contact details of Clinical Nurse specialist-

*Times may vary depending upon your DHB. Your clinical Nurse specialist will be able to advise you

Appendix 2: Patient information sheet

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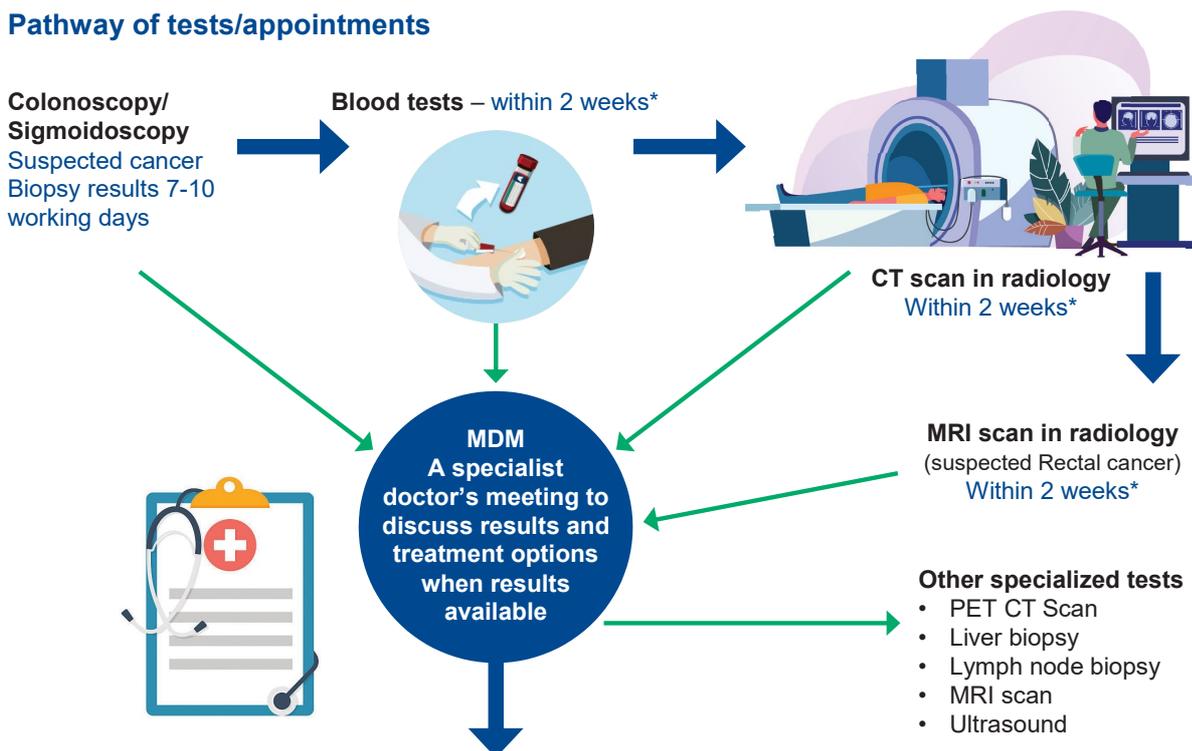
A suspected diagnosis of Bowel or Rectal Cancer

When you are told you are suspected to have bowel or rectal cancer it is a very anxious time for you and your family/whānau. A number of tests and appointments will be arranged at the hospital that will help your specialist make a diagnosis and plan the right treatment for you.

No tests will be done without your understanding and agreement .

Below is a pathway of tests/appointments. You may not need all of these tests. Your family / whānau / support person can attend all of these appointments with you.

Pathway of tests/appointments



When will my results be discussed with me?

Your test results will be discussed with you and your family/whānau/ support person at an outpatient appointment with your specialist.

You will have this appointment once all of your results are available.

Your GP will also get copies of all your test results.

***Times and location of tests and appointments may vary depending on your DHB. Your Clinical Nurse Specialist will be able to advise you.**

Contact details of
Clinical Nurse Specialist –

Information explaining these tests and MDM meeting is over the page.

Biopsies

The biopsies will generally confirm the diagnosis of cancer.

Blood Tests

A number of blood tests are done to help doctors evaluate how well organs—such as the kidneys, liver, and heart are working, to see how well nourished you are, and a CEA (carcinoembryonic antigen). The CEA is a tumour marker which can be elevated in cancers of the bowel and rectum.

CT Scan (Computerised Tomography Scan)

This scan gives a three dimensional view of your chest, abdomen and pelvis. It gives information about the cancer and also whether it has spread to other parts of the body such as liver and lungs. This is called “staging” and is important for choosing the right treatment.

MRI Scan (Magnetic Resonance Imaging)

If your cancer is low in your bowel (rectum) you will also (as well as the CT) need another x-ray - a MRI scan which uses magnetic and radio waves to provide better pictures of the cancer.

Multi Disciplinary Meeting (MDM)

When all the results of the tests are available your case will be discussed at a meeting held every week on a Wednesday. Present at this meeting are a number of specialists including a radiologist who looks at your xrays, oncologists (chemotherapy and radiation doctors) and surgeons. All the relevant information is reviewed, discussed and an agreed treatment plan is made that is specific to you, your cancer and circumstances.

YOU are not required to attend this meeting as a number of other patients and confidential information is discussed.

A report on the meeting is sent to your GP. The outcome (treatment plan) is discussed with you and your family at a clinic appointment with your specialist. Sometimes this meeting requests further tests/investigations.

Other resources/people available to help you at this time

Psychologist, Social Worker, Cultural Support, Cancer society liaison nurse – ask your nurse specialist to refer you to these support services.

Websites

Midland cancer Network www.midlandcancernetwork.org.nz

NZ Cancer society www.cancersociety.org.nz

Beating Bowel cancer www.beatingbowelcancer.org

Beat Bowel cancer NZ www.beatbowelcancer.org.nz

Bowel cancer NZ www.bowelcancernz.org.nz

Cancer research (UK) www.cancerresearchuk.org

Cancer research NZ www.malaghan.org.nz