# Guidance on Surveillance for People at Increased Risk of Colorectal Cancer

Personal history of adenomatous polyps

Personal history of inflammatory bowel disease

Personal history of colorectal cancer

2011



Statement of intent

While this guidance represents a statement of best practice based on available evidence and advisory group consensus (at the time of publishing), it is not intended to replace the health

practitioner's judgment in each individual case.

Care decisions should consider the following:

the individual's clinical state, age and comorbidities

personal preferences and preferences of family/whānau

current best practice based on the latest available research evidence.

**Development** 

The New Zealand Guidelines Group has managed the development of this publication for the Ministry of Health. The clinical content has been independently developed through processes

managed by the New Zealand Guidelines Group.

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colorectal cancer 2011. Wellington: New Zealand Guidelines Group; 2011.

Access to the report

This resource has been prepared as a standalone, downloadable guidance document on surveillance for people at increased risk of colorectal cancer due to personal history of

adenomatous polyps, personal history of inflammatory bowel disease and personal history of colorectal cancer. It can be downloaded at www.nzgg.org.nz - search on title.

Other published resources include a primary care practitioner summary resource (Quick Card)

and information for people at increase risk of bowel cancer. These resources are available free

online at www.nzgg.org.nz.

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Surveillance for people at increased risk of Colorectal Cancer

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# About the evidence report

## **Purpose**

The purpose of this report is to provide an evidence-based summary of current New Zealand and overseas evidence to inform best practice in providing colonoscopic surveillance for people who are at increased risk of developing colorectal cancer.

Improving early detection and diagnosis of cancer, and improving access to timely and appropriate treatment are identified as goals of the New Zealand Cancer Control Strategy Action Plan 2005–2010.<sup>1</sup> The use of the best available evidence and development of usable summaries for practitioners based on this evidence support the achievement of these goals by contributing to improvements in national consistency and quality in cancer services. This evidence report was commissioned by the Ministry of Health to meet this identified need.

## Scope of the report

This evidence report covers colonoscopic surveillance for people at increased risk of developing colorectal cancer, specifically, people who have undergone previous colorectal cancer resection, people with inflammatory bowel disease (IBD) and people with adenomatous polyps.

For guidance on the referral of patients presenting with symptoms suggestive of cancer see *Suspected Cancer in Primary Care* 2009<sup>2</sup> and for management of early colorectal cancer see *Management of Early Colorectal Cancer*<sup>3</sup> 2011. Both guidelines are available at the New Zealand Guidelines Group (NZGG) website www.nzgg.org.nz – search on title.

# Target audience

This guidance is intended for primary and secondary care providers who provide care for New Zealanders with adenomatous polyps, IBD or people who have undergone colorectal cancer resection to determine the need for surveillance colonoscopy and the frequency of surveillance.

As consumers are the ultimate beneficiaries of the recommendations, NZGG is committed to involving consumers in the development of all NZGG guidance. Consumers are a part of the Guidance Review Team (GRT), both in reviewing the evidence and contributing to the interpretation of evidence.

# **Treaty of Waitangi**

NZGG acknowledges the importance of the Treaty of Waitangi to New Zealand and considers the Treaty principles of partnership, participation and protection as central to improving Māori health.

NZGG's commitment to improving Māori health outcomes means it works as an organisation to identify and address Māori health issues relevant to each guideline.

In addition, NZGG works to ensure Māori participation is a key part of the guidance development process. It is important to differentiate between involving Māori in the guidance development process (the aim of which is to encourage participation and partnership) and specifically considering Māori health issues pertinent to that topic at all stages of the guidance development process. While Māori participation in guidance development aims to ensure the consideration of Māori health issues by the GRT, this is no guarantee of such an output; the entrenched barriers Māori may encounter when involved in the health care system (in this case guidance development) need to be addressed. NZGG attempts to challenge such barriers by specifically identifying points in the guidance development process where Māori health must be considered and addressed. In addition, it is expected that Māori health is considered at all points in the evidence report in a less explicit manner.

## **Development process**

This guidance was an adoption of sections of the National Institute for Health and Clinical Excellence (NICE) guideline Colonoscopic Surveillance for Prevention of Colorectal Cancer in People with Ulcerative Colitis, Crohn's Disease or Adenomas.<sup>4</sup>

A description of the processes in relation to this evidence report is explained below, with further details outlined in Appendix 1.

This was the first complete adoption (ie, no changes or additions were made to the research review) NZGG had undertaken of an existing guideline. The basic process involved the assessment and summary of the NICE systematic reviews in relation to the research questions of interest, the presentation of these reviews to the GRT for discussion and the ratification of the NICE recommendations. A number of challenges were encountered during this process that are worthy of brief discussion.

In order to maintain the high quality of the existing NICE review, additional research could not be incorporated without significant additional resource being applied. Given this resource was not available, the NICE evidence review had to be accepted as it stood. In reality, colonoscopy surveillance practices can be very dependent upon specific countries populations and health care environments. Specific issues that may have been considered less relevant by the UK Guideline Development Team (and hence excluded from the evidence review or at least downplayed during recommendation development) were more relevant to the NZ environment; the results of which can be gaps in the recommendations.

In addition, there are significant challenges in adopting a guideline in an area of weak evidence (ie, where many of the recommendations are based on international expert opinion). The adoption of an evidence review that has only found weak supportive evidence for a particular practice can make it more challenging for guideline developers to justify adopting specific recommendations to a different setting, where there may be a lack of agreement in the sector.

A multidisciplinary GRT was convened comprising members nominated by NZGG and the Ministry of Health. The task of the GRT is detailed below.

- 1. Consider the evidence that NICE has reviewed in relation to the following question, 'When should colonoscopic surveillance for adults with IBD or adenomatous polyps be initiated and what should be the frequency of surveillance?'
- 2. Consider and discuss the New Zealand epidemiology and risk of developing colorectal cancer given IBD or adenomatous polyps.
- Develop a recommendation/recommendations that are derived from these two bodies of evidence to guide primary care practitioners in the most effective way to carry out surveillance for bowel cancer in those individuals with inflammatory bowel disease or with adenomatous polyps.
- 4. Consider the currency of the existing practitioner summary.

A half-day, face-to-face meeting of the GRT was held, plus additional teleconferences, where evidence was reviewed and recommendations were developed.

Full methodological details are provided in Appendix 1. This appendix also includes details of the GRT members and lists the organisations that provided feedback during the consultation period.

Surveillance refers to monitoring individuals known to have a disease or to be at increased risk of a disease, as opposed to screening, which is the examination of asymptomatic or well individuals in order to classify them as unlikely or likely to have a disease. In this report, recommendations were made about the surveillance of individuals identified to be at increased risk of developing colorectal cancer and therefore the term surveillance rather than screening is appropriate. A greater proportion of this group could potentially benefit from surveillance because the prevalence of the disease is likely to be higher.

# **Summary**

# Changes to current practice

People with inflammatory bowel disease (IBD) should be offered surveillance colonoscopy following 8–10 years of clinical management in order to stratify risk. This differs from existing practice where patients with IBD are risk stratified at the onset of inflammatory bowel symptoms.

# **Summary of clinical practice recommendations**

This is a summary of recommendations developed by the Guidance Revision Team (GRT). Recommendations are grouped under headings that correspond to the individual chapters.

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations (see Appendix 1 for grading details).

Good practice points (identified with a  $\checkmark$ ) are the opinion of the GRT, or developed from feedback from consultation within New Zealand where no evidence is available.

Further details of the grading systems used and other methodology are in Appendix 1.

Recommendations by chapter		
	Source of recommendation	Grade
Chapter 2. Adenomatous polyps		
Patients should be given information about the bowel preparation process and the possible side effects.	NZGG 2011	✓
The following table should be used to classify risk:	NICE	С
Table 2.1. Risk of developing colorectal cancer in people with adenomas		
Low risk:  one or two adenomas smaller than 10 mm.		
<ul> <li>Intermediate risk:</li> <li>three or four adenomas smaller than 10 mm or</li> <li>one or two adenomas if one is 10 mm or larger</li> <li>histological polyps with villous features*</li> <li>polyps with high grade dysplasia*.</li> </ul>		
<ul> <li>High risk:</li> <li>five or more adenomas smaller than 10 mm or</li> <li>three or more adenomas if one is 10 mm or larger.</li> </ul>		
* This was not part of the NICE recommendations but has been agreed by New Zealand experts.		
Consider colonoscopic surveillance for people who have had adenomas removed and are at low risk of developing colorectal cancer.	NICE	С
Offer colonoscopic surveillance to people who have had adenomas removed and are at intermediate or high risk of developing colorectal cancer.	NICE	С
Use the findings at adenoma removal to determine people's risk of developing colorectal cancer.	NICE	С

Recommendations by chapter		
	Source of recommendation	Grade
Chapter 2. Adenomatous polyps continued		
Offer the appropriate colonoscopic surveillance strategy to people with adenomas based on their risk of developing colorectal cancer as determined at initial adenoma removal.	NICE	В
Low risk: consider colonoscopy at 5 years – if the colonoscopy is negative (ie, no adenomas are found) stop surveillance:		
- if low risk, consider the next colonoscopy at 5 years (with follow-up surveillance as for low risk)		
<ul> <li>if intermediate risk, offer the next colonoscopy at 3 years (with follow-up surveillance as for intermediate risk)</li> </ul>		
<ul> <li>if high risk, offer the next colonoscopy at 1 year (with follow-up surveillance as for high risk).</li> </ul>		
Intermediate risk: offer colonoscopy at 3 years – if the colonoscopy is negative, offer the next colonoscopy at 3 years. Stop surveillance if there is a further negative result.		
<ul> <li>If low or intermediate risk, offer the next colonoscopy at 3 years (with follow-up surveillance as for intermediate risk).</li> </ul>		
<ul> <li>if high risk, offer the next colonoscopy at 1 year (with follow-up surveillance as for high risk).</li> </ul>		
High risk: offer colonoscopy at 1 year:		
<ul> <li>if the colonoscopy is negative, or low or intermediate risk, offer the next colonoscopy at 3 years (with follow- up surveillance as for intermediate risk)</li> </ul>		
<ul> <li>if high risk, offer the next colonoscopy at 1 year (with follow-up surveillance as for high risk).</li> </ul>		
Serrated adenomas should be treated as adenomatous	NZGG 2011	✓

polyps until there is clearer evidence regarding their

management.

Recommendations by chapter		
	Source of recommendation	Grade
Discuss the potential benefits, limitations and risks with people who are considering colonoscopic surveillance including:	NICE	✓
<ul> <li>early detection and prevention of colorectal cancer and</li> <li>quality of life and psychological outcomes.</li> </ul>		
At each surveillance test, discuss the potential benefits, limitations and risks of ongoing surveillance. Base a decision to stop surveillance on potential benefits for the person, their preferences and any comorbidities. Make the decision jointly with the person and if appropriate, their family or carers.	NICE	✓
If there are any findings at surveillance that need treatment or referral, discuss the options with the person and if appropriate, their family or carers.	NICE	✓
People aged 75 years or older should be carefully considered before offering surveillance because the potential risks associated with ongoing colonoscopic surveillance are likely to outweigh the benefits.	NZGG 2011	✓
People with significant comorbidities should be carefully considered before offering surveillance because their fitness for colonoscopy may be impaired and may significantly decrease life expectancy.	NZGG 2011	<b>✓</b>

Recommendations by chapter		
	Source of recommendation	Grade
Chapter 2. Adenomatous polyps continued		
To mitigate risks of renal impairment associated with bowel cleansing prior to colonoscopy, bowel purgatives should be chosen with attention to patient age and comorbidities. Those associated with severe fluid or electrolyte shifts and renal impairment should be avoided in high-risk groups, and judicious use of oral or intravenous electrolyte replacement should be considered.	NZGG 2011	✓
Chapter 3. Inflammatory bowel disease		
Interpreting dysplasia and visualising DALMs/adenomas is more difficult when there is active inflammation. Dysplasia should be confirmed by a second pathologist before commencing treatment.	NZGG 2011	✓
Offer a baseline colonoscopy* and appropriate biopsies to people with IBD who are being considered for colonoscopic surveillance to determine their risk of developing colorectal cancer. This baseline colonoscopy should be 8–10 years following a definitive diagnosis.	NICE	С
* The NICE guideline states colonoscopy with chromoscopy; however, chromoscopy is not currently available in New Zealand and was therefore not considered for this guidance. For this reason the reference to chromoscopy has been removed and will be considered in future updates.		

Recommendations by chapter		
	Source of recommendation	Grade
The following table should be used to classify risk.	NICE	С
Table 3.1. Risk of developing colorectal cancer in people with IBD		
Low risk:		
extensive but quiescent ulcerative colitis or		
extensive but quiescent Crohn's colitis or		
<ul> <li>left-sided ulcerative colitis (but not proctitis alone) or Crohn's colitis or similar extent.</li> </ul>		
Intermediate risk:		
extensive ulcerative or Crohn's colitis with mild active inflammation that has been confirmed histologically or		
<ul> <li>post-inflammatory polyps or</li> </ul>		
<ul> <li>family history of colorectal cancer in a first-degree relative aged 50 years or over.</li> </ul>		
High risk:		
<ul> <li>extensive ulcerative or Crohn's colitis with moderate or severe active inflammation that has been confirmed histologically or</li> </ul>		
<ul> <li>primary sclerosing cholangitis (including after liver transplant) or</li> </ul>		
<ul> <li>colonic stricture in the past 5 years or</li> </ul>		
<ul> <li>any grade of dysplasia in the past 5 years or</li> </ul>		
family history of colorectal cancer in a first-degree relative aged under 50 years.		
Offer colonoscopic surveillance to people with IBD based on their risk of developing colorectal cancer, determined at the last complete colonoscopy.	NICE	С
Low risk: offer colonoscopy at 5 years.		
Intermediate risk: offer colonoscopy at 3 years.		
High risk: offer colonoscopy at 1 year.		
For patients with high or intermediate risk, consider extending the interval of colonoscopy to five years after two consecutive surveillance colonoscopies have shown endoscopically and histologically quiescent disease with no dysplasia – and no other risk factors (such as PSC, stricture or family history exist).	NZGG 2011	<b>✓</b>

Recommendations by chapter	-	
	Source of recommendation	Grade
Chapter 3. Inflammatory bowel disease continued		
Discuss the potential benefits, limitations and risks with people who are considering colonoscopic surveillance including:	NICE	✓
early detection and prevention of colorectal cancer and		
quality of life and psychological outcomes.		
At each surveillance test, discuss the potential benefits, limitations and risks of ongoing surveillance. Base a decision to stop surveillance on potential benefits for the person, their preferences and any comorbidities. Make the decision jointly with the person and if appropriate, their family or carers.	NICE	✓
If there are any findings at surveillance that need treatment or referral, discuss the options with the person and if appropriate, their family or carers.	NICE	✓
People aged 75 years or older should be carefully considered for surveillance because the potential risks associated with ongoing colonoscopic surveillance are likely to outweigh the benefits.	NZGG 2011	✓
People with significant comorbidities should be carefully considered for surveillance because their fitness for colonoscopy may be impaired and may significantly decrease life expectancy.	NZGG 2011	✓
Risk stratification should be based on extent of disease either microscopically or macroscopically defined.	NZGG 2011	✓

Recommendations by chapter		
	Source of recommendation	Grade
Chapter 4. Previous colorectal cancer resection		
All people who have undergone colorectal cancer resection should be followed up intensively.	NZGG 2011	✓
All people who have undergone colorectal cancer resection and develop relevant symptoms should undergo clinical assessment.	NZGG 2011	✓
For people with colon cancer at high risk of recurrence (Stages IIb and III), clinical assessment is recommended at least every six months for the first three years after initial surgery and then annually for a further two years or when symptoms occur.	NZGG 2011	В
For people with colon cancer at lower risk of recurrence (Stages I and IIa) or for people with comorbidities restricting future surgery, clinical assessment is recommended when symptoms occur or by annual review for five years after initial surgery.	NZGG 2011	В
All people with colorectal cancer should have a colonoscopy before surgery or within 12 months following initial surgery.	NZGG 2011	В
For people with colon cancer at lower risk of recurrence (Stages I and IIa), follow-up colonoscopy every three to five years is recommended.	NZGG 2011	В
For people with rectal cancer, digital rectal examination (DRE), proctoscopy or sigmoidoscopy should be undertaken at three months, six months, one year and two years after initial surgery. Thereafter colonoscopy should be undertaken at three- to five-yearly intervals.	NZGG 2011	В
Follow-up should include physical examination and CEA.	NZGG 2011	В
All people with colorectal cancer Stages I to III should have liver imaging between years 1 and 3.	NZGG 2011	В
The use of faecal occult blood testing as part of colorectal cancer follow-up is not recommended.	NZGG 2011	В

# Recommendations by chapter Source of Grade recommendation Chapter 5. Familial risk Category 1. Individuals with a slight increase in risk of colorectal cancer Individuals with a slight increase in risk of colorectal cancer due to family history. • One first-degree relative with colorectal cancer diagnosed over the age of 55 years. NZGG 2004 No specific surveillance recommendations are made for this group at this time given the slight increase in risk, the uncertainty regarding the age at which this additional risk is expressed and the concern regarding the appropriateness of colonoscopy as a surveillance procedure in this group. Prompt investigation of lower bowel symptoms is advised. NZGG 2004 Individuals requesting information should be fully informed NZGG 2004 regarding their absolute risk of developing colorectal cancer and advised of the reasons for this recommendation. Category 2. Individuals with a moderate increase in risk of colorectal cancer Individuals with a moderately increased risk of colorectal cancer have one or more of the following: • one first-degree relative with colorectal cancer diagnosed under the age of 55 years • two first-degree relatives on the same side of the family with colorectal cancer diagnosed at any age. NZGG 2004 Offer colonoscopy every 5 years from the age of 50 years C (or from an age 10 years before the earliest age at which colorectal cancer was diagnosed in the family, whichever comes first). NZGG 2004 Fully inform individuals about their risk of developing colorectal cancer and the reason for this recommendation. NZGG 2004 Individuals should be informed that colonoscopy is generally a safe procedure, but it is an invasive procedure with some rare but recognised risks.

#### Recommendations by chapter

Source of recommendation

Grade

#### Familial risk continued

#### Category 3. Individuals with a potentially high risk of colorectal cancer

Individuals with a potentially high risk of risk of colorectal cancer have one or more of the following:

- a family history of familial adenomatous polyposis (FAP), hereditary non-polyposis colorectal cancer or other familial colorectal cancer syndromes
- one first-degree relative plus two or more first- or second-degree relatives all on the same side of the family with a diagnosis of colorectal cancer at any age
- two first-degree relatives, or one first-degree relative plus one or more second degreerelatives, all on the same side of the family with a diagnosis of colorectal cancer and one such relative:
  - was diagnosed with colorectal cancer under the age of 55 years or
  - developed multiple bowel cancers, or
- developed an extracolonic tumour suggestive of hereditary non-polyposis colorectal cancer (ie, endometrial, ovarian, stomach, small bowel, renal pelvis, pancreas or brain)
- at least one first- or second-degree family member diagnosed with colorectal cancer in association with multiple bowel polyps
- a personal history or one first-degree relative with colorectal cancer diagnosed under the age of 50, particularly where colorectal tumour immunohistochemistry has revealed loss of protein expression for one of the mismatch repair genes (MLH1, MSH2, MSH6 and PMS2)
- a personal history or one first-degree relative with multiple colonic polyps.

Refer to:	NZGG 2011	✓
a cancer genetic service or the New Zealand Familial Gastrointestinal Cancer Registry		
a bowel cancer specialist to plan appropriate surveillance and management.		

# 1 Introduction

# Colorectal cancer epidemiology

Colorectal cancer is an important public health problem; there are over one million new cases of colorectal cancer diagnosed world-wide each year and 600,000 deaths.<sup>5</sup> Like most cancers, colorectal cancer is more common among older people (Table 1.1). Males generally report a higher incidence of colon cancer; worldwide the ratio is approximately 1.4:1.<sup>5</sup> Men have considerably higher rates of rectal cancer.<sup>6</sup> Each year between about 2500 and 3000 New Zealanders (2726 in 2005, 2805 in 2006, 2809 in 2007, 2134 in 2008) will be diagnosed with colorectal cancer and between 1100 and 1200 will die as a result of colorectal cancer.<sup>7</sup>

Table 1.1. Age-specific colorectal cancer incidence in New Zealand 2008

			Risk of
Age group (years)	Colorectal cancer registrations	Rate per 100,000	developing CRC during 5-year period (%)
	_	4.0	
0–24	4	1.3	<0.1
25–29	8	2.9	<0.1
30–34	13	4.8	<0.1
35–39	21	6.7	<0.1
40–44	52	16.5	<0.1
45–49	75	23.5	0.12
50–54	130	47.0	0.23
55–59	206	84.3	0.42
60–64	285	134.9	0.67
65–69	372	223.5	1.12
70–74	434	344.3	1.72
75–79	439	419.7	2.10
80–84	420	540.8	2.70
>85	295	464.2	2.32

Source: Cancer: new registrations and deaths 2008. Ministry of Health, 2011

In 2008, colorectal cancer was the second most common cancer registered and the second most common cause of death from cancer in New Zealand accounting for 14% of all cancer registrations and 15% of all deaths from cancer. Both registration and mortality rates fell between 1997 and 2008; male and female registration rates both dropped by 12%, while mortality rates fell by 9% for males and 17% for females.

Colorectal cancer rates have been slowly declining over the last decade and are projected to decline in all age groups except for those aged over 75 years for both sexes; the biggest decline, by approximately one-quarter, is in the 45 to 74 year age group. The age-standardised rate in males is projected to fall from 71 per 100,000 in 2006, to 59 per 100,000 (95% CI 48–70) by 2016, a decrease of 17%. In females the age-standardised rate is projected to fall from 57 per 100,000 in 2006, to 50 per 100,000 (95% CI 41–58) in 2016, a decrease of 12%. While the rates of colorectal cancer have been steadily declining, the actual number of registrations increases as the New Zealand population increases in size and the greater proportion of the population is in older age groups.

By international standards, New Zealand has a low rate of early stage diagnosis of colorectal cancer and the lowest percentage of surgically curable localised disease (28%) when compared with Australia (New South Wales) (34%), United Kingdom (42%), United States (40%) and Hong Kong (35%) data. Twenty percent of disease at diagnosis in New Zealand is metastatic. In 2001, New Zealand also had the highest age-specific incidence of colorectal cancer in the 50 to 70 years age group, when compared with Australia, United States, United Kingdom and Japan.<sup>9</sup>

## **Ethnic disparities**

In 2008, colorectal cancer was the fourth most commonly registered cancer and third most common cause of death from cancer for Māori compared with non- Māori where colorectal cancer was the second most commonly registered cancer and cause of death from cancer. Colorectal cancer is one of the few cancers for which Māori registration and death rates have historically been lower than non-Māori rates. However, Māori are more likely to have distant disease at diagnosis than non-Māori (30.4% compared with 19.4%) and are more likely to have unknown stage at diagnosis than non-Māori (12.7% compared with 9.4%). A study of Māori and non-Māori colorectal cancer survival in New Zealand Peported that Māori experienced significantly poorer cancer survival than non-Māori (HR 1.33; 95% CI 1.03–1.71). Although there have been no significant differences reported in colorectal cancer rates across deprivation quintiles factors found to be detrimental to cancer survival in Māori patients are comorbidity, smoking and markers of inequity in access to health care, which contributed to one-third of the survival disparity.

For non-Māori males, registration rates appear to have trended downwards. However, for Māori males, trends are less clear (Table 1.2). For females, the Māori registration rate decreased by 7% between 1998 and 2008, whereas the non-Māori female rate fell by 12%.

Table 1.2. Colorectal cancer registrations per 100,000 from 1998 to 2008

	Males			Females		
	Total	Māori	Non-Māori	Total	Māori	Non-Māori
1998	56.8	47.6	57.7	45.2	25.5	46.4
1999	58.7	41.8	59.8	45.4	28.5	46.3
2000	54.2	35.6	55.4	46.5	25.3	48.0
2001	56.2	44.1	56.8	45.0	29.2	45.9
2002	55.2	42.8	55.9	42.5	27.9	43.4
2003	55.0	38.9	55.6	44.0	28.9	44.9
2004	53.6	34.9	54.6	44.6	26.6	45.5
2005	50.8	39.4	51.5	44.1	27.6	45.2
2006	55.1	42.5	55.8	40.6	31.8	41.2
2007	51.8	38.9	52.5	40.4	31.0	40.9
2008	49.8	36.6	50.6	39.7	23.6	40.7

**Source**: Cancer: new registrations and deaths 2008. Ministry of Health, 2011.<sup>7</sup>

Mortality rates appear to be decreasing (Table 1.3). Rates for non-Māori males and females show a slight downward trend; between 1998 and 2008 rates decreased by 18% for both sexes. Māori mortality rates for males and females are much more variable. Between 1998 and 2008 male and female rates increased by 62% and 2%, respectively.<sup>7</sup>

Table 1.3. Colorectal cancer mortality rates per 100,000 from 1998 to 2008

		Males			Females	
	Total	Māori	Non-Māori	Total	Māori	Non-Māori
1998	25.8	13.7	26.5	19.2	14.3	19.4
1999	26.0	24.4	26.0	19.3	9.7	19.7
2000	24.6	20.6	25.0	18.8	14.8	18.9
2001	25.5	20.5	25.7	18.4	13.2	18.6
2002	24.2	26.3	24.0	16.8	10.2	17.3
2003	22.2	20.8	22.1	17.0	11.2	17.2
2004	21.8	14.6	22.0	18.0	13.8	17.9
2005	22.6	21.9	22.6	17.7	11.4	18.0
2006	20.5	19.6	20.6	17.4	16.8	17.4
2007	22.6	18.0	22.6	16.8	9.9	17.2
2008	23.5	22.1	23.4	15.8	14.5	15.9

**Source**: Cancer: new registrations and deaths 2008. Ministry of Health, 2011.<sup>7</sup>

Similarly to Māori, rates of registration and mortality for Pacific people with colorectal cancer are lower than the national averages. Age-standardised mortality rates for Pacific men and women under 65 years of age between 1996 and 2000 were less than 50 per 100,000 for both males and females. Age standardised mortality rates for females over 65 years of age were approximately 60 and 70 per 100,000 and for males, approximately 200 per 100,000. All Pacific mortality rates were below National averages. Pacific mortality rates were below National averages.

Registration rates for Pacific people of all ages were below the national average, less than half that of the National average in all age groups. Age-standardised registration rates for Pacific men and women under 65 years were less than 100 per 100,000. Age standardised registration rates for females over 65 years of age were approximately 100 per 100,000 and for males, approximately 200 per 100,000.

# Where does this guidance fit among other New Zealand developed guidelines?

Several guidelines and programmes have already been developed to support health professionals to care for people with colorectal cancer in New Zealand (see Figure 1). The following guidelines, reports or programmes are currently underway, or have been published.

### Service improvements and population screening

Ministry of Health Bowel Cancer Programme

The Ministry of Health established a Bowel Cancer Programme in 2009, to lead work aimed at improving bowel cancer outcomes. The Programme's priorities are to strengthen bowel cancer services across the country so they can effectively meet both the current demand and increased demand in the future, and to conduct a four-year bowel screening pilot that will begin by late 2011 to determine whether a bowel screening programme should be rolled out nationally. Waitemata District Health Board (DHB) has been selected to run this pilot project and will commence screening of people aged 50–74 years who live in the DHB's catchment area. 14

#### People presenting with symptoms of Colorectal cancer

New Zealand Guidelines Group – Suspected Cancer in Primary Care<sup>2</sup>

NZGG was commissioned to develop a primary care guideline for people presenting with symptoms suggestive of cancer, which was published in September 2009. The guideline included a chapter on colorectal cancers and presents recommendations for referral criteria, and assessment and investigation in the primary care setting. The guideline covers the period from a person's first contact with a primary care practitioner with a sign or symptom suggestive of cancer up to their first specialist appointment. This guideline is available on the NZGG website www.nzgg.org.nz – search on title.

#### Supportive care

Guidelines for improving supportive care for adults with cancer in New Zealand<sup>15</sup>

In July 2007 the Ministry of Health established an expert advisory group to oversee the development of supportive care guidance for adults affected by cancer, leaning heavily on the United Kingdom-based NICE manual, *Guidance on Cancer Services: Improving Supportive and Palliative Care for Adults with Cancer.*<sup>16</sup> The aim of the New Zealand guidance document is to improve quality of life for people affected by cancer by improving access to, and the quality of, supportive care in New Zealand. The guidance suggests best-practice service approaches that will help to ensure that adults with cancer, their families and whānau have access to the supportive care they need throughout the various stages of cancer, from diagnosis onwards.

#### **Management of Early Colorectal Cancer**

New Zealand Guidelines Group – Management of Early Colorectal Cancer<sup>3</sup>

NZGG was commissioned to develop a guideline intended primarily for the providers of care for New Zealanders with early colorectal cancer. The guideline covers the period from preoperative assessments, through to treatment and also includes recommendations for follow-up. The guideline specifically addresses the management of people with invasive adenocarcinoma of the colon or rectum. The guideline provides recommendations for secondary and tertiary care providers and assumes the patient has already been referred because of suspicious bowel symptoms, or has undergone some initial testing in primary care. This guideline was published in July 2011 and is available on the NZGG website www.nzgg.org.nz – search on title.

Detection of colorectal cancer Groups at high riskfor Patients presenting with symptoms colorectal cancer Population screening Update or - New Zealand Gridelines Group Struelllance and Management or Groups at licreased risk of colorectal carcer 2004 Ministry of Health bowel cancer screening pilot 2011-2015 New Zealand Onldelites Group Suspected Carcer In Primary Care 2009 Management of early colorectal cancer Diagnostic tests and Management of epithelial Polyps preoperative polyps assessment and staging Acute presentation MOT meeting Metastatic Non-metastatic Supportive care Unresectable Suitable to Information resect Rectal cancer Colon cancer Communication Psychological support Social support Complementary and Alternative therapy Pre-operative therapy Co-ordination of care Missimy of Health Guidance for Improving supportive care for adults with career in New Zealand 2010 Surgery Follow up Adjuvant therapy New Zeatand Gridelines Group Management of Early Colorectal Cancer 2011 Management of advanced Recurrentand colorectal cancer advanced colorectal cancer Palliative treatment

Figure 1. Where does this guideline fit with other New Zealand guidance?

# 2 Adenomatous Polyps

This chapter discusses adenomatous polyps, including:

- · the epidemiology of adenomatous polyps
- the NICE summary of evidence and recommendations
- New Zealand developed recommendations.

Adenomatous polyps are visible protrusions that can develop on the mucosal surface of the colon or rectum, and consist of benign neoplastic tissue derived from glandular epithelium and show varying degrees of dysplasia. Most carcinomas are thought to arise from adenomatous polyps. Adenomatous polyps may include tubular adenomas, tubulovillous adenomas and villous adenomas. The aim of colonoscopic surveillance of adenomatous polyps is to detect lesions that would, if left *in situ*, carry a significant risk of eventual carcinomatous change. The frequency of colonoscopic surveillance should be timed to allow detection of high-risk polyps prior to the development of carcinoma and should be targeted at those most at risk of new polyp formation.<sup>17</sup>

The incidence and prevalence of adenomatous polyps in New Zealand is unclear. Internationally there are very few published epidemiological studies describing rates of adenomatous polyps and most of these are autopsy studies where conditions are clearly different from detection methods on colonoscopy. The general trend found in autopsy studies has revealed that populations at high risk for colorectal cancer also have a high prevalence of adenomas compared with populations at low risk for colon cancer. <sup>18 19</sup>

A study undertaken at Middlemore Hospital in South Auckland compared the prevalence of colorectal adenomas in Māori and New Zealand European patients and found that the prevalence in Māori was approximately half that found in New Zealand Europeans. At colonoscopy, polyps were found in 213/643 Europeans (33.1%) but only 35/149 Māori (23.5%); p=0.029. This finding mirrors the reported difference in colorectal cancer incidence and supports this being a real finding. There were no significant differences between Māori and New Zealand Europeans in the proportion of high risk adenomas, the total number of polyps found and the location in right or left colon.<sup>20</sup>

## NICE summary of evidence

NICE investigated the evidence for surveillance in people with adenomatous polyps.

Six relevant articles comparing different surveillance strategies were retrieved; two meta-analyses and four observational studies. The evidence statements are below.

- 1. Low to moderate quality evidence showed that the detection of new adenomas was higher at 1 and 3 years compared with 3 years alone.
- 2. Low to moderate quality evidence showed that the detection of new advanced adenomas tended to be the same at different surveillance frequencies.
- 3. Very low to low quality evidence showed that the detection of colorectal cancer was higher at 4 years compared with 2 years.
- 4. Moderate quality evidence showed adverse events of perforations and polypectomy syndrome during follow-up at 6–48 months.
- 5. Very low quality evidence showed that having at least three tubular adenomas smaller than 10 mm, or tubular adenomas larger than 10 mm, or villous adenomas or high-grade dysplasia at baseline colonoscopy were significant predictors for risk of new neoplasia.
- 6. Very low quality evidence showed that having high-grade dysplasia compared with no neoplasia at baseline colonoscopy was a significant predictor for high-grade dysplasia or colorectal cancer in the future.
- 7. Very low quality evidence that studied the risk associated with small adenomas and distal location showed that the prevalence of advanced histology\* increased with the size of the polyp.
- 8. Very low quality evidence on the risk associated with small adenomas and distal location showed that the prevalence of advanced histology in the distal colon increased with polyp size and was statistically significant in the 6–9 mm and >10 mm groups.
- 9. Low quality evidence showed that being older, being male, an increase in the number and size of previous adenomas, the presence of villous features and proximal location at baseline colonoscopy were significant predictors for advanced metachronous neoplasia (advanced adenomas and invasive cancer).
- 10. Moderate quality evidence showed that increased adenoma size, multiplicity of adenomas, parental history of colorectal cancer and an interactive effect between adenoma size and sex (male) were significant predictors for advanced metachronous adenomas.<sup>†</sup> Men with large adenomas had a significantly higher risk than other people.
- \* Advanced histology was defined as an adenoma with villous or serrated histology, high-grade dysplasia, or an invasive cancer.
- † Advanced metachronous adenomas were defined as larger than 10 mm or with high-grade dysplasia or invasive carcinoma.

- 11. Moderate quality evidence showed that the time taken for advanced metachronous adenomas to develop in 5% of people at low risk<sup>‡</sup> was10.4 years, in 10% it was 12.2 years and in 20% it was 16.2 years.
- 12. Moderate quality evidence showed that the time taken for advanced metachronous adenomas to develop in 5% of people at high risk<sup>§</sup> was 0.5 years, in 10% it was 6.1 years and in 20% it was 15.6 years.
- 13. Moderate quality evidence showed that the risk for recurrent advanced adenomas\*\* increased with increasing number and size of adenomas at baseline colonoscopy.

## **New Zealand recommendation development**

The Guidance Review Team (GRT) discussed the risks of colonoscopy to the patient including bowel preparation, bleeding, perforation, dehydration, comorbidities among others and the need to discuss these risks with the patient prior to entering a surveillance programme. The GRT agreed that although these were significant risks, the absolute risk has decreased with improvement in technological advances and colonoscopic training and audit. A good practice point was developed about the risks of colonoscopy. In addition to the physical risks, the GRT discussed the need to sufficiently prepare the patient for colonoscopy including providing information on the bowel preparation process and the possible side effects.

The GRT discussed risk stratification of patients and agreed that stratification by practitioners may be variable because the measurement of polyps is not standardised and there is likely to be a significant margin of error. Additionally, the GRT discussed their concerns about the definition of the high risk groups being more inclusive than the current criteria and therefore causing increased workload for DHBs. However, the GRT also acknowledged that it was difficult to quantify whether these recommendations would also reduce the number of people currently on a surveillance programme by allowing an end to surveillance protocols after normal findings. However, it was agreed that the high risk group definition proposed by NICE would be retained. The GRT also discussed their concerns about the low risk group and the fact that these patients should not have a colonoscopy any more frequently than five years.

The GRT discussed the impact of age and comorbidity on colonoscopic surveillance. In terms of age, the NZGG guideline *Surveillance and Management of Groups at Increased Risk of Colorectal Cancer*<sup>16</sup> (2004) suggested that an upper age limit of 75 years is usually considered appropriate for colonoscopic surveillance because the remaining life expectancy is likely to be less than the average time required for new adenomas or dysplasia to progress to malignancy. After this age the potential risks associated with ongoing surveillance are likely to outweigh the benefits of such procedures. In terms of comorbidities, the appropriateness of surveillance in individuals with serious comorbidities, which may impair fitness for colonoscopy and/or

<sup>‡</sup> People at low risk were defined as: no parental history of colorectal carcinoma and with only small (<10 mm) tubular adenomas at index colonoscopy.

<sup>§</sup> People at high risk were defined as: those with multiple or large adenomas, tubulovillous or villous adenomas, or a parental history of colorectal carcinoma.

<sup>\*\*</sup>Advanced adenomas were defined as adenomas ≥1 cm, villous histological features, or with cancer.

significantly decrease life expectancy should also be considered. A good practice point was made to this effect.

The GRT discussed undertreatment as an issue for patients with comorbidities, and given that Māori are more highly represented in this particular group of patients, practitioners need to be aware of the further unequalising impact this issue may have on Māori health. Standardised care along the continuum of care in surveillance for bowel cancer was discussed as a potential mechanism for ensuring Māori patients in particular are not disadvantaged by individualised practices. A good practice point was made to highlight the issue of comorbidities.

Consultation feedback indicated concern about high risk patients undergoing surveillance colonoscopy at one year. The GRT acknowledges that this will increase workload. The GRT made this recommendation because of its concerns in missing synchronous polyps when many are present and because the number of polyps is predictive of risk of advanced colorectal neoplasia.

In terms of polyps with villous features, NICE commented:

Villous histology was also a significant predictor for advanced neoplasia, although the confidence intervals were wide (odds ratio 1.28, 95% CI 1.07–1.52) (Martinez et al. 2009). However, the GDG considered that because pathologists' classification of villous histology tends to vary, particularly for small biopsies, including this predictor could lead to wide variation in referral rates for colonoscopy.

The GRT agreed that variation in pathologists reporting of villous histology is problematic; however, they felt that it was an important enough feature to be included in the recommendations. Similarly high grade dysplasia is a risk for metachronous neoplasia, and although this may be related to the size of lesion, following consultation feedback the GRT considered this should also be included in the intermediate risk category.

The GRT wished to highlight the fact that the following recommendations apply following complete resection of the initial polyp(s); the surveillance intervals apply after polyp clearance.

	Source of recomme ndation	Grade
Patients should be given information about the bowel preparation process and the possible side effects.	NZGG 2011	✓
The following table should be used to classify risk:	NICE	С

# Table 2.1. Risk of developing colorectal cancer in people with adenomas

#### Low risk:

one or two adenomas smaller than 10 mm.

#### Intermediate risk:

- three or four adenomas smaller than 10 mm or
- one or two adenomas if one is 10 mm or larger
- histological polyps with villous features\*
- polyps with high grade dysplasia\*.

#### High risk:

- five or more adenomas smaller than 10 mm or
- three or more adenomas if one is 10 mm or larger.
- \* This was not part of the NICE recommendations but has been agreed by New Zealand experts

Consider colonoscopic surveillance for people who have had adenomas removed and are at low risk of developing colorectal cancer.	NICE	С
Offer colonoscopic surveillance to people who have had adenomas removed and are at intermediate or high risk of developing colorectal cancer.	NICE	С
Use the findings at adenoma removal to determine people's risk of developing colorectal cancer.	NICE	С

continued

Source of recomme ndation	Grade
NICE	R

Offer the appropriate colonoscopic surveillance strategy to people with adenomas based on their risk of developing colorectal cancer as determined at initial adenoma removal.

- **Low risk**: consider colonoscopy at 5 years if the colonoscopy is negative (ie, no adenomas are found) stop surveillance:
  - if low risk, consider the next colonoscopy at 5 years (with follow-up surveillance as for low risk)
  - if intermediate risk, offer the next colonoscopy at 3 years (with follow-up surveillance as for intermediate risk)
  - if high risk, offer the next colonoscopy at 1 year (with follow-up surveillance as for high risk).
- Intermediate risk: offer colonoscopy at 3 years if the colonoscopy is negative, offer the next colonoscopy at 3 years. Stop surveillance if there is a further negative result.
  - If low or intermediate risk, offer the next colonoscopy at 3 years (with follow-up surveillance as for intermediate risk).
  - if high risk, offer the next colonoscopy at 1 year (with follow-up surveillance as for high risk).
- High risk: offer colonoscopy at 1 year:
  - if the colonoscopy is negative, or low or intermediate risk, offer the next colonoscopy at 3 years (with follow-up surveillance as for intermediate risk)
  - if high risk, offer the next colonoscopy at 1 year (with followup surveillance as for high risk).

Serrated adenomas should be treated as adenomatous polyps until	NZGG	$\checkmark$
there is clearer evidence regarding their management.	2011	
Discuss the potential benefits, limitations and risks with people who	NICE	✓
are considering colonoscopic surveillance including:		
early detection and prevention of colorectal cancer and		
quality of life and psychological outcomes.		

continued

Source of Grade recomme ndation At each surveillance test, discuss the potential benefits, limitations NICE and risks of ongoing surveillance. Base a decision to stop surveillance on potential benefits for the person, their preferences and any comorbidities. Make the decision jointly with the person and if appropriate, their family or carers. If there are any findings at surveillance that need treatment or **NICE** referral, discuss the options with the person and if appropriate, their family or carers. People aged 75 years or older should be carefully considered **NZGG** 2011 before offering surveillance because the potential risks associated with ongoing colonoscopic surveillance are likely to outweigh the benefits. People with significant comorbidities should be carefully **NZGG** 2011 considered before offering surveillance because their fitness for colonoscopy may be impaired and may significantly decrease life expectancy. To mitigate risks of renal impairment associated with bowel **NZGG** 2011 cleansing prior to colonoscopy, bowel purgatives should be chosen with attention to patient age and comorbidities. Those associated with severe fluid or electrolyte shifts and renal impairment should be avoided in high-risk groups, and judicious use of oral or intravenous electrolyte replacement should be considered. Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations - refer to

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix 1 for grading details.

Good practice points (identified with a  $\checkmark$ ) are the opinion of the Guidance Revision Team, or developed from feedback from consultation within New Zealand where no evidence is available.

# 3 Inflammatory Bowel Disease

This chapter discusses inflammatory bowel disease (IBD), including:

- · the epidemiology of IBD
- · the NICE summary of evidence and recommendations
- New Zealand developed recommendations.

Over the last 50 years there appears to have been an increase in the incidence of IBD in New Zealand. Epidemiological studies show increasing incidence of IBD from between five and six cases per 100,000 in 1962,<sup>21</sup> to 25.2 per 100,000 (16.5 per 100,000 for Crohn's Disease and 7.6 per 100,000 for ulcerative colitis) in Canterbury in 2004.<sup>22</sup> In terms of prevalence, at June 2005 the IBD, Crohn's disease and ulcerative colitis point prevalence estimates were 308.3, 155.2 and 145.0 per 100,000, respectively.<sup>22</sup> In New Zealand, ulcerative colitis is about as common as it is in other developed countries, while internationally, New Zealand has the second highest rate of Crohn's disease. It appears that very few New Zealanders of Polynesian descent have IBD; however, this is based on limited data.<sup>23</sup>

An epidemiological study conducted in Canterbury described the demographic characteristics of people with IBD. There is a peak of diagnosis between 15 and 35 years of age for both Crohn's disease and ulcerative colitis. Females were more likely than males to have Crohn's disease, although the study showed a higher age-specific incidence of Crohn's disease up until the age of 14 in males. There did not appear to be any differences in the incidence of ulcerative colitis between males and females, although males had a higher age-specific prevalence of ulcerative colitis in older age groups than females.<sup>22</sup>

A population-based case-control study carried out in Canterbury assessed the role of childhood and other environmental risk factors for IBD; both Crohn's disease and ulcerative colitis. A family history of IBD, cigarette smoking at diagnosis, high social class at birth and Caucasian ethnicity were significantly associated with IBD; having a childhood vegetable garden and being breast fed were protective against IBD; breast-feeding with a duration-response effect.<sup>24</sup>

A prospective study undertaken in collaboration with the New Zealand Paediatric Surveillance Unit attempted to determine the incidence, presentation and initial management of paediatric IBD New Zealand. Of the 52 cases identified to 2003, 34 (66%) had Crohn's disease, 9 (17%) had ulcerative colitis and 9 (17%) had inflammatory bowel disease type unclassified. The mean age at diagnosis was 11 years with a delay of 8.4 months from clinical presentation to diagnosis. The estimated incidence was 2.9, 1.9 and 0.5 per 100,000 per year, respectively, comparable to North American and United Kingdom figures. Of the children included, 85% were European, while no Māori or Pacific Island children had Crohn's disease or ulcerative colitis. Interestingly, in almost all studies, Crohn's disease is more common

amongst males than females in a paediatric population until 16 to 18 years of age when Crohn's disease becomes significantly more common amongst females.<sup>26</sup>

The GRT agreed to use the NICE definition of colitis: inflammation of part of the large intestine (colon) but excluding inflammation in the rectum only (ie, proctitis). The risk of developing colorectal cancer for people with Crohn's colitis is considered similar to that of Ulcerative Colitis with the same extent of involvement, and for the purposes of this evidence report the term colitis is used to include both.

## **NICE** summary of evidence

NICE investigated the evidence for surveillance in people with IBD. No direct evidence was identified comparing different surveillance programmes, when surveillance should be initiated or surveillance frequency. NICE therefore searched for indirect evidence by formulating a new clinical question: 'Is there any evidence that there are subgroups of adults with IBD who are at higher risk of developing colorectal cancer?' This question assumes that higher risk people would benefit from more intensive surveillance.

Twenty nine relevant articles were retrieved; four meta-analyses and 25 observational studies. The evidence statements are below.

## Frequency of surveillance

- 1. Very low quality evidence (one study) showed that an increased number of surveillance colonoscopies was associated with a lower risk of colorectal cancer mortality (although this was not statistically significant).
- 2. Very low quality evidence (one study) showed a decreased risk for colorectal cancer with an increased number of surveillance colonoscopies.
- Very low quality evidence (two studies) showed an increased risk for advanced neoplasia with an increased number of surveillance colonoscopies (possible detection bias).

#### **Prognostic factors**

- Very low quality evidence (one study) showed that the risk of recurrence or progression of dysplasia was no different for people with Crohn's disease or ulcerative colitis.
- 2. Low quality evidence (four studies) showed that the risk of neoplasia (incidence, recurrence, progression) was no different for men or women.
- 3. Very low quality evidence (one study) showed that the risk of identifying neoplasia was higher in people aged over 45 years, even when adjusted for duration of IBD.
- 4. Low quality evidence (seven studies) showed that the risk of dysplasia or colorectal cancer increased with a lower age at diagnosis.

- 5. Moderate quality evidence (14 studies) showed that the risk of dysplasia or colorectal cancer increased with duration of inflammatory bowel disease.
- 6. Moderate quality evidence (nine studies) showed that people with extensive or total colitis had a higher risk of dysplasia than those without extensive or total colitis; this increased for people with a younger age at diagnosis.
- Moderate quality evidence (nine studies) showed that people with primary sclerosing cholangitis had a higher risk of neoplasia than those without primary sclerosing cholangitis.
- 8. Low quality evidence (four studies) showed that a family history of colorectal cancer was associated with an increased risk of colorectal cancer (which increased if the relative was younger than 50 years).
- 9. Low quality evidence (three studies) showed that increased inflammation was a predictor of neoplasia.
- 10. Very low quality evidence (one study) showed that the risk of recurrence and progression of dysplasia was higher if located distally compared with proximally.
- 11. Moderate quality evidence (one meta-analysis) showed that low-grade dysplasia was associated with progression to high-grade dysplasia and colorectal cancer compared with no dysplasia.
- 12. Very low quality evidence (one study) showed that a normal appearance at colonoscopy was associated with a lower risk of colorectal cancer.
- 13. Very low quality evidence (two studies) showed that post-inflammatory polyps were associated with a higher risk of colorectal cancer.
- 14. Very low quality evidence (one study) showed that colonic stricture was associated with a higher risk of colorectal cancer.

## **New Zealand recommendation development**

The Guidance Review Team (GRT) discussed a definition for the start of disease for IBD and therefore the appropriate period from symptom onset to the initiation of a surveillance programme, which was not addressed by the NICE guideline and for which there is no known evidence. The GRT agreed that the previous NZGG colorectal surveillance guideline was still valid and the recommendation for referral at 8–10 years after diagnosis was retained. This new good practice point was also in line with the NICE guideline which suggested 10 years.

The GRT discussed the management of any grade of dysplasia if found at surveillance; most agreed that patients with dysplasia should be considered for surgery. This relates to the particular pathogenesis of colorectal cancer in IBD. The GRT agreed that

dysplasia should be confirmed by a second pathologist before decisions are made, and a good practice point was developed addressing this issue. It was also noted that the confirmation of dysplasia by a second experienced pathologist was particularly important in smaller towns where a lower number of cases would generally be dealt with by practitioners. The GRT acknowledged that the management of low grade dysplasia is still a controversial area but if a patient with any grade of dysplasia is not considered fit enough to undergo surgery then they should probably not undergo surveillance. Although there is no good evidence to guide the number of biopsies, there have been studies suggesting that the greater the number of biopsies, and the larger the area of colon biopsied, the greater the pick-up of dysplasia at screening. In the absence of advanced techniques to guide biopsy, it seems appropriate to take four biopsies from each bowel segment every 10 cm. The GRT notes, that while dysplasia is diagnosed during colonoscopy, the management of patients with dysplasia is outside the scope of this evidence report.

The GRT discussed the impact of age and comorbidity as for adenomatous polyps. The same good practice point was included for inflammatory bowel disease.

Consultation feedback highlighted concerns about the relapsing and remitting nature of IBD and the high probability that disease may be missed in intermediate and high risk individuals if additional colonoscopies were not offered. The GRT recommended two consecutive surveillance colonoscopies to show endoscopically and histologically quiescent (inactive) disease with no dysplasia – and no other risk factors (such as PSC, stricture or family history exist) before high or intermediate risk patients could be moved to the low risk group.

Consultation feedback also highlighted the need to define the extent of IBD. The NICE guideline did not discuss this issue. The GRT agreed that the greatest extent of IBD, defined either macroscopically or microscopically was appropriate.

Source of recommendation NZGG 2011 Grade

Interpreting dysplasia and visualising DALMs/adenomas is more difficult when there is active inflammation. Dysplasia should be confirmed by a second pathologist before commencing treatment.

NICE

^

Offer a baseline colonoscopy\* and appropriate biopsies to people with IBD who are being considered for colonoscopic surveillance to determine their risk of developing colorectal cancer. This baseline colonoscopy should be 8 to 10 years following a definitive diagnosis.

\* The NICE guideline states colonoscopy with chromoscopy; however, chromoscopy is not currently available in New Zealand and was therefore not considered for this guidance. For this reason the reference to chromoscopy has been removed and will be considered in future updates.

The following table should be used to classify risk.

NICE

C

# Table 3.1. Risk of developing colorectal cancer in people with IBD

#### Low risk:

- · extensive but quiescent ulcerative colitis or
- · extensive but quiescent Crohn's colitis or
- left-sided ulcerative colitis (but not proctitis alone) or Crohn's colitis or similar extent.

#### Intermediate risk:

- extensive ulcerative or Crohn's colitis with mild active inflammation that has been confirmed histologically or
- post-inflammatory polyps or
- family history of colorectal cancer in a first-degree relative aged 50 years or over.

#### High risk:

- extensive ulcerative or Crohn's colitis with moderate or severe active inflammation that has been confirmed histologically or
- primary sclerosing cholangitis (including after liver transplant) or
- colonic stricture in the past 5 years or
- any grade of dysplasia in the past 5 years or
- family history of colorectal cancer in a first-degree relative aged under 50 years.

Offer colonoscopic surveillance to people with IBD based on their risk of developing colorectal cancer, determined at the last complete colonoscopy. NICE

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- Low risk: offer colonoscopy at 5 years.
- Intermediate risk: offer colonoscopy at 3 years.
- High risk: offer colonoscopy at 1 year.

For patients with high or intermediate risk, consider extending	NZGG 2011	✓
the interval of colonoscopy to five years after two consecutive surveillance colonoscopies have shown endoscopically and histologically quiescent disease with no dysplasia - and no other risk factors (such as PSC, stricture or family history		
exist).		
Discuss the potential benefits, limitations and risks with people who are considering colonoscopic surveillance including:	NICE	✓
early detection and prevention of colorectal cancer and		
quality of life and psychological outcomes.		
At each surveillance test, discuss the potential benefits,	NICE	✓
limitations and risks of ongoing surveillance. Base a decision to stop surveillance on potential benefits for the person, their		
preferences and any comorbidities. Make the decision jointly		
with the person and if appropriate, their family or carers.		
If there are any findings at surveillance that need treatment or referral, discuss the options with the person and if appropriate,	NICE	<b>√</b>
their family or carers.		
People aged 75 years or older should be carefully considered	NZGG 2011	✓
for surveillance because the potential risks associated with ongoing colonoscopic surveillance are likely to outweigh the		
benefits.		
People with significant comorbidities should be carefully	NZGG 2011	✓
considered for surveillance because their fitness for colonoscopy may be impaired and may significantly decrease		
life expectancy.		
Risk stratification should be based on extent of disease either	NZGG 2011	✓
microscopically or macroscopically defined.		
Grades indicate the strength of the supporting evidence, rather than the importance of the 1 for grading details.  Good practice points are the opinion of the Guidance Revision Team, or developed from the control of the 1 for grading details.		
Zealand where no evidence is available.		

# Horizon scanning

The GRT are aware of recent and upcoming studies in the use of chromoscopy, narrow band imaging and microendoscopy. These topics will be kept under review for future updates.

# 4 Previous colorectal cancer resection

This chapter addresses surveillance for people with previous colorectal cancer resection who have undergone curative resection for colon or rectal cancer.

This information and guidance on components of follow-up are reproduced from Chapter 11 Follow-up after curative resection in the guideline *Management of Early Colorectal Cancer*<sup>3</sup> 2011, which is available at www.nzgg.org.nz – search on title.

#### Components of follow-up

Clinical question: What components of follow-up are important?

#### **Body of evidence**

#### Guidelines

Eight clinical practice guidelines were identified and made recommendations about follow-up for people with colon and rectal cancer.<sup>27-34</sup>

Most guidelines commented on the uncertainty about the effectiveness of different aspects and forms of follow-up. The relative importance of early assessment of symptoms versus screening tests in the diagnosis of resectable recurrence is unknown. Most guidelines also acknowledged the uncertainty of the timing of scheduled follow-up visits.

A broad summary of the recommendations for follow-up include:

- both colon and rectal cancer patients who did not undergo complete colonoscopy before surgery should be offered colonoscopy within six months of discharge
- intensive follow-up is likely to be more beneficial than less intensive follow-up
- clinical assessment yearly for suggestive symptoms of relapse
- high-risk patients should have a colonoscopy every six months to one year for the first three years, then yearly for at least five years
- low-risk patients should have a colonoscopy every three to five years
- clinical assessment for colon cancer patients include CEA, chest, abdominal and pelvic CT scans, colonoscopy and liver ultrasound
- clinical assessment for rectal cancer patients include CEA, chest, abdominal and pelvic CT scans, colonoscopy and proctoscopy or sigmoidoscopy.

#### Systematic reviews

Five systematic reviews were identified. All compared intensive with less intense (conventional) follow-up strategies. A Cochrane systematic review<sup>35</sup> comparing

different follow-up strategies in a meta-analysis was considered to be of good quality and another systematic review<sup>36</sup> was also considered to be of good quality.

One meta-analysis<sup>37</sup> was considered to be of average quality. A systematic review<sup>31</sup> comprising six RCTs was considered to be of good quality. The review which formed the basis of the recommendations of the American Society of Clinical Oncology was considered to be of average quality.<sup>38</sup>

#### **Primary studies**

Three primary studies were identified. An RCT of more frequent *versus* conventional colonoscopy<sup>39</sup> and a comparison of more intense surveillance with standard postoperative surveillance with additional imaging<sup>40</sup> were both considered good quality. A RCT, which added FDT PET to a standard follow-up protocol was considered average quality.<sup>41</sup>

#### **Summary of findings**

#### Intense versus conventional follow-up

Five of the systematic reviews/meta-analyses suggested a benefit in five-year overall survival of intensive follow-up when compared with conventional or less intense follow-up. 31 35-38 This was reported as an absolute risk difference of 7%. 38

Intensive follow-up was associated with significantly earlier detection of recurrences (p <0.001), an increased detection rate for isolated local recurrences (RR 1.61; 95% CI 1.12–2.32; p=0.01) $^{36}$  and asymptomatic recurrences more frequently (p<0.00001) and 5.9 months earlier than less intense interventions (p <0.0001).

One good-quality systematic review found no evidence for an effect on the outcome of recurrences between different strategies although there was a significant effect on time to recurrence in favour of intensive follow-up (mean difference -6.8; 95% CI -11.06–-2.44; p=0.002) and for curative surgery attempted at the time of recurrence in favour of a more intense strategy (OR 2.41; 95% CI 1.63–3.54; p<0.00001). The review also reported an overall mortality benefit for more tests *versus* fewer tests (OR 0.64, 95% CI 0.49–0.85, p=0.002). Curative re-operation rates were more likely to occur in the intensive follow-up groups (24.3% *vs* 9.9%; p=0.0001) compared with less intense strategies.

Two trials reported no differences in overall survival.<sup>39 40</sup> However, a more intensive strategy increased the proportion of resectable tumours and improved the prognosis of Stage II colon cancers and rectal tumours.<sup>40</sup>

One systematic review<sup>37</sup> concluded that the observed reductions were in fact associated with the application of an investigation rather than more frequent performance of the investigations and cancer-related mortality was unaffected by the intensity of follow-up. Another systematic review suggested that factors other than salvage may contribute to survival, such as psychological well-being and/or improved treatment of coincidental disease.<sup>36</sup>

#### Investigations

#### Endoscopic surveillance

Trials using colonoscopy demonstrated a significant impact on overall survival (p=0.04);<sup>37</sup> however, there was no effect of more *versus* less colonoscopy. In contrast, another study found no evidence for a benefit in overall survival with a more intense strategy.<sup>39</sup> Colonoscopy-detected tumour recurrence accounted for the highest resectability rate<sup>40</sup> and detection of asymptomatic recurrences.<sup>37 39</sup>

One RCT<sup>39</sup> recommended a conventional strategy of annual colonoscopy in postoperative years 1 and 2 and then three- to five-yearly, and a systematic review<sup>31</sup> recommended that all patients with resected cancer (Stage I, II, III) should undergo colonoscopy at follow-up if this had not been performed postoperatively. If high-risk polyps (villous/tubular >1cm) were present these should be excised and annual colonoscopy performed until no longer found; otherwise colonoscopy every three to five years was recommended.

Colon and rectal cancer patients should have a pre- or peri-operative documentation of cancer and polyp free colon.<sup>38</sup> Colonoscopy was recommended after three years and then if normal five-yearly after that. Different recommendations are made for those with high risk genetic syndromes as per American Gastroenterological Association. For patients with rectal cancer, flexible sigmoidoscopy of the rectum was recommended every six months for five years.<sup>38</sup>

#### Serum CEA levels

Trials using serum CEA demonstrated a significant impact on overall survival (p=0.0002).<sup>31 37</sup> More frequent monitoring of CEA after curative surgery was the only test associated with a significant improvement in overall mortality (p=0.03). This resulted in a significantly higher detection of asymptomatic recurrence (p=0.007) and curative re-operation rate (p=0.0006).<sup>37</sup> CEA increased the detection of asymptomatic recurrence (p<0.0001).<sup>37</sup>

A guideline recommended that in patients at high risk of recurrence (Stage Ilb/III), who are willing to undergo investigations and treatment if required, there should be clinical testing every six months for three years and then annually for five years. At these visits the individual may undergo CEA testing, chest X-ray and liver ultrasound.<sup>31</sup> Another systematic review recommended postoperative serum CEA should be performed every three months in patients with Stage II or III disease for at least three years after diagnosis, if the patient is a candidate for surgery or systemic therapy.<sup>38</sup>

Analysis limited to two RCTs found no significant effect of CEA *versus* no CEA testing.<sup>35</sup>

#### **Imaging**

Trials, which included liver imaging reporting an overall survival benefit (RR 0.74; 95% CI 0.63–0.97; p=0.0004),<sup>31</sup> recommended that patients at high risk of recurrence (Stage IIb/III), who are willing to undergo investigations and treatment if required, should be clinically tested every six months for three years and then annually for five years, and that at these visits the individual may undergo CEA testing, chest X-ray and liver ultrasound.<sup>31</sup>

Mortality was reduced by 25% in patients undergoing liver imaging compared with non-imaging strategies. The benefit was thought to be derived from the usefulness of liver resections for metastatic cancer of limited extent.<sup>38</sup> In contrast, imaging of the liver and CT of the abdomen and pelvis were not associated with any improvement in mortality.<sup>37</sup> Neither was there evidence of a benefit for chest X-ray as a follow-up modality.<sup>37 38</sup>

Chest X-ray (p <0.00001), liver ultrasound (p=0.009) and CT scan (p=0.007) increased the detection of asymptomatic recurrence.<sup>37</sup> However, increased frequency of testing had no additional benefit.<sup>37</sup>

The American Society of Clinical Oncology (ASCO) recommended that for those colon and rectal cancer patients at higher risk of recurrence, and where curative intent was an option, CT imaging of the chest and abdomen should be undertaken annually for three years. A pelvic CT should be considered for rectal cancer surveillance, especially for those who had not received radiotherapy. There is an acknowledgment of the additional financial burden with more frequent imaging.<sup>38</sup>

Faecal occult blood (FOB) testing

Periodic testing of FOB was not recommended by one systematic review.<sup>38</sup>

#### PET

An RCT<sup>41</sup> examined the addition of FDT PET to routine follow-up procedures. This resulted in a higher number of curative surgical interventions being performed in the PET group than in the conventional group. However, the authors noted that as technology progresses, there is a need to evaluate the cost-effectiveness and also the role of PET CT.<sup>41</sup>

#### Scheduling of clinical visits

One systematic review<sup>38</sup> acknowledged the lack of efficacy testing for follow-up schedules. As a result of this review the American Association of Clinical Oncology recommended a clinical visit every three to six months for the first three years after treatment with decreased frequency thereafter for two years for colon cancer patients. After five years, follow-up is left to physician discretion.<sup>38</sup>

#### **Recommendation development**

The Guidance Review Team (GRT) noted that the definitions of 'intense' and 'conventional' strategies are highly variable between the studies. <sup>31 37</sup> Many of the studies described within the systematic reviews pre-date adjuvant chemotherapy as a treatment, and surgical interventions and imaging techniques have changed over time. <sup>35 37</sup> One guideline <sup>31</sup> noted that it was unclear which test or combination tests are optimal and there is a lack of formal testing of optimal scheduling.

The GRT agreed that there is evidence to suggest improved survival in patients undergoing more intense follow-up strategies and that the regular use of colonoscopy, liver imaging and CEA is supported by the literature. The use of chest X-ray and FOB testing is not supported by the literature.

The GRT also discussed side effects of follow-up investigations and noted that it is known that some side effects of cancer treatment may not become apparent until years have elapsed. A potential benefit of long-term follow-up is the opportunity to detect unanticipated side effects of new cancer treatments. Unanticipated events are inherently difficult to study and they are unlikely to be addressed by future research, so the GRT has made no recommendation on this issue.

#### Recommendations

	Source of recomme ndation	Grade
All people who have undergone colorectal cancer resection should be followed up intensively.	NZGG 2011	<b>✓</b>
All people who have undergone colorectal cancer resection and develop relevant symptoms should undergo clinical assessment.	NZGG 2011	✓
For people with colon cancer at high risk of recurrence (Stages IIb and III) clinical assessment is recommended at least every six months for the first three years after initial surgery and then annually for a further two years or when symptoms occur.	NZGG 2011	В
For people with colon cancer at lower risk of recurrence (Stages I and IIa) or for people with comorbidities restricting future surgery, clinical assessment is recommended when symptoms occur or by annual review for five years after initial surgery.	NZGG 2011	В
All people with colorectal cancer should have a colonoscopy before surgery or within 12 months following initial surgery.	NZGG 2011	В
For people with colon cancer at lower risk of recurrence (Stages I and IIa), follow-up colonoscopy every three to five years is recommended.	NZGG 2011	В
For people with rectal cancer, digital rectal examination (DRE), proctoscopy or sigmoidoscopy should be undertaken at three months, six months, one year and two years after initial surgery. Thereafter colonoscopy should be undertaken at three- to five-yearly intervals.	NZGG 2011	В
Follow-up should include physical examination and CEA.	NZGG 2011	В
All people with colorectal cancer Stages I to III should have liver imaging between years 1 and 3.	NZGG 2011	В
The use of faecal occult blood testing as part of colorectal cancer follow-up is not recommended.	NZGG 2011	В

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix 1 for grading details.

## 5 Familial risk

The NZGG guideline Surveillance and Management of Groups at Increased Risk of Colorectal Cancer<sup>16</sup> 2004 addressed familial risk and stratified patients into three groups; slightly increased risk, moderately increased risk and potentially high risk of colorectal cancer. The Guidance Revision Team (GRT) re-assessed these risk categories. Minor changes were made to the 2004 guideline; most notable is the inclusion of referral to the New Zealand familial gastrointestinal cancer registry. Contact details for the New Zealand Familial Gastrointestinal Cancer Registry and Genetic Services are included in Appendix 2.

## Category 1. Individuals with a slight increase in risk of colorectal cancer

#### Recommendations

Individuals with a slight increase in risk of colorectal cancer due to family history.

 One first-degree relative with colorectal cancer diagnosed over the age of 55 years

	Source of recommendation	Grade
No specific surveillance recommendations are made for this group at this time given the slight increase in risk, the uncertainty regarding the age at which this additional risk is expressed and the concern regarding the appropriateness of colonoscopy as a surveillance procedure in this group.	NZGG 2004	<b>✓</b>
Prompt investigation of lower bowel symptoms is advised.	NZGG 2004	<b>✓</b>
Individuals requesting information should be fully informed regarding their absolute risk of developing colorectal cancer and advised of the reasons for this recommendation.	NZGG 2004	<b>✓</b>

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix 1 for grading details.

## Category 2. Individuals with a moderate increase in risk of colorectal cancer

#### Recommendations

Individuals with a moderately increased risk of colorectal cancer have one or more of the following:

- one first-degree relative with colorectal cancer diagnosed under the age of 55 years
- two first-degree relatives on the same side of the family with colorectal cancer diagnosed at any age.

	Source of recommendation	Grade
Offer colonoscopy every 5 years from the age of 50 years (or from an age 10 years before the earliest age at which colorectal cancer was diagnosed in the family, whichever comes first).	NZGG 2004	С
Fully inform individuals about their risk of developing colorectal cancer and the reason for this recommendation.	NZGG 2004	✓
Individuals should be informed that colonoscopy is generally a safe procedure, but it is an invasive procedure with some rare but recognised risks.	NZGG 2004	<b>√</b>

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix 1 for grading details.

## Category 3. Individuals with a potentially high risk of colorectal cancer

#### Recommendations

Individuals with a potentially high risk of colorectal cancer have one or more of the following:

- a family history of familial adenomatous polyposis (FAP), hereditary non-polyposis colorectal cancer or other familial colorectal cancer syndromes
- one first-degree relative plus two or more first- or second-degree relatives all on the same side of the family with a diagnosis of colorectal cancer at any age
- two first-degree relatives, or one first-degree relative plus one or more second degree relatives, all on the same side of the family with a diagnosis of colorectal cancer and one such relative:
  - was diagnosed with colorectal cancer under the age of 55 years or
  - developed multiple bowel cancers, or
  - developed an extracolonic tumour suggestive of hereditary non-polyposis colorectal cancer (ie, endometrial, ovarian, stomach, small bowel, renal pelvis, pancreas or brain)
- at least one first- or second-degree family member diagnosed with colorectal cancer in association with multiple bowel polyps
- a personal history or one first-degree relative with colorectal cancer diagnosed under the age
  of 50, particularly where colorectal tumour immunohistochemistry has revealed loss of
  protein expression for one of the mismatch repair genes (MLH1,MSH2,MSH6 and PMS2)
- a personal history or one first-degree relative with multiple colonic polyps.

	Source of Recommendation	Grade
Refer to:	NZGG 2004	✓
<ul> <li>a cancer genetic service or the New Zealand Familial Gastrointestinal Cancer Registry</li> </ul>		
<ul> <li>a bowel cancer specialist to plan appropriate surveillance and management.</li> </ul>		

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix 1 for grading details.

### Appendix 1

### **Evidence report development**

This appendix describes the guidance development process for this evidence report undertaken by NZGG and includes:

- the guidance revision team (GRT)
- · the scope of the evidence report
- · clinical questions
- · guidance development methods.

#### A1.1 Contributors

#### **Guidance Revision Team**

#### **Judith Collett (Chair)**

Gastroenterologist, Clinical Advisor NZ Familial Gastrointestinal Cancer Registry; Visiting Gastroenterologist Timaru, Greymouth and Southland Hospitals

#### **Liz Dennett**

Colorectal Surgeon, Colorectal Surgical Society of Australia and New Zealand

#### John McMenamin

General Practitioner, Wanganui

#### Ann Richardson

Epidemiologist, Health Sciences Centre, University of Canterbury

#### **Denise Robbins**

Consumer representative, CancerVOICES New Zealand

#### **Michael Schultz**

Gastroenterologist, New Zealand Society of Gastroenterologists

#### **Nina Scott**

Māori Public Health Physician, National Bowel Cancer Working Group, and the previous Ministry of Health Bowel Cancer Māori Equity Advisory Group

#### **David Theobald**

Endoscopist, Waitemata DHB Clinical Advisor Bowel, Ministry of Health

#### Ministry of Health observers

**Mhairi Porteous** 

Nicola Wilson

**New Zealand Guidelines Group team** 

Jessica Berentson-Shaw Research Manager

Anita Fitzgerald Assistant Research Manager and lead researcher

Margaret Paterson Information Specialist

**Declarations of competing interest** 

#### A1.2 Guidance development process

This guidance was an adoption of sections of the National Institute for Health and Clinical Excellence (NICE) guideline *Colonoscopic Surveillance for Prevention of Colorectal Cancer in People with Ulcerative Colitis, Crohn's Disease for Ademomas.*<sup>3</sup> This was the first complete adoption (ie, no changes or additions were made to the research review) NZGG had undertaken of an existing guideline. The basic process involved the assessment and summary of the NICE systematic reviews in relation to the research questions of interest, the presentation of these reviews to the GRT for discussion and the ratification of the NICE recommendations.

This section provides an overview of the research methodology used during the development of this guidance. It describes how systematic and narrative reviews were undertaken, and the process by which the reviewed evidence was developed into recommendations.

#### Search strategy

As the NICE guideline<sup>2</sup> was in draft at the time of the evidence review, it was not necessary to complete additional systematic reviews of the literature on personal risk for IBD and adenomatous polyps. The NICE systematic reviews and drafted recommendations were used.

The recent NZGG guideline *Management of Early Colorectal Cancer*<sup>3</sup> 2011 investigated follow-up strategies for people who have undergone colorectal cancer resection. Content on components of follow-up from this guideline are reproduced in Chapter 4.

Similarly, the NZGG guideline *Surveillance and Management of Groups at Increased Risk of Colorectal* Cancer<sup>16</sup> 2004 was used as the source document for recommendations on familial risk. Literature searches on this topic were outside scope.

The literature was systematically searched for New Zealand articles that would contribute to an understanding of the epidemiology of colorectal cancer, IBD and

adenomatous polyps. Searches were run in December 2010 and were not limited by date. Additionally, the GRT were invited to contribute published or unpublished studies that were not identified by NZGG on these topics. These were included if appropriate.

Studies investigating cost-effectiveness were not included.

#### Search databases

The systematic review searches were conducted for the clinical questions noted above. The following bibliographic, HTA and Guideline databases were included in the search:

- 1. MEDLINE
- 2. EMBASE
- 3. CINAHL
- 4. Psychlnfo
- 5. Cochrane Library
- National Guideline Clearinghouse (NCG) www.guideline.gov
- 7. Turning Research into Practice (TRiP) www.tripdatabase.com
- 8. Web of Science
- 9. DARE Database
- 10. HTA Database
- 11. CCTR
- 12. Current Controlled Trials
- 13. ClinicalTrials.gov

#### A1.3 Evidence and recommendation grading system

Developing recommendations involves consideration of the whole evidence base for each of the clinical questions. In this case, the evidence comprised work completed by NICE, as well as a previous NZGG guideline. The quality and consistency of the evidence base and the clinical implications of the evidence within a New Zealand context was weighed up by all the GRT members. Each recommendation was assigned a grade to indicate the overall strength of the evidence upon which it was based. NICE did not grade its recommendations; however, because they included GRADE profile tables and a complete summary of the evidence, NZGG researchers assigned a grade based on the evidence underpinning the NICE recommendations. The 2004 NZGG guideline used an outdated grading method (comprising numbers instead of the current lettering system) and NZGG researchers simply updated the grade to reflect the current system.

Using their collective clinical judgment and experience, the GRT discussed the relationship between the benefits and harms of the intervention and the applicability of the evidence within the context of New Zealand's clinical practice environment.

The recommendations were agreed by consensus during the meeting, but in some cases, further research and discussion by teleconference with subgroups of the GRT were required. Recommendations that were drawn up outside the meetings were presented to the full GRT for agreement by consensus. A short summary of the process of recommendation development is presented in the text highlighting particular issues that the GRT took into account while formulating the recommendations.

The NZGG grades of recommendations are as follows:

Recommendations	
	Grade
The recommendation is supported by good evidence (based on a number of studies that are valid, consistent, applicable and clinically relevant)	A
The recommendation is supported by fair evidence (based on studies that are valid, but there are some concerns about the volume, consistency, applicability and clinical relevance	В
of the evidence that may cause some uncertainty but are not likely to be overturned by other evidence)	
The recommendation is supported by international expert opinion	С
The evidence is insufficient, evidence is lacking, of poor quality or opinions conflicting, the balance of benefits and harms cannot be determined	ı
Good practice point – where no evidence is available, best practice recommendations are made based on the experience of the Guidance Revision Team, or feedback from consultation within New Zealand	✓
Grades indicate the strength of the supporting evidence rather than the importance of the evidence.	

#### A1.4 Consultation

A draft of this evidence report was circulated to nineteen individuals and organisations for comment between 18th July and 12th August 2011. Comments were received from the following organisations and individuals.

- Beat Bowel Cancer Aotearoa Inc.
- New Zealand Nurses Organisation
- Crohn's and Colitis New Zealand
- Gastrointestinal Cancer Institute (NZ)
- Midland Cancer Network
- Royal College of Pathologists of Australasia
- Royal New Zealand College of General Practitioners
- New Zealand Society of Gastroenterology
- Gastroenterology Department, Auckland District Health Board
- Members of the National Bowel Cancer Working Group

## **Appendix 2**

## **New Zealand Familial Gastrointestinal Cancer Registry and Genetic Services Contact Details**

#### **New Zealand Familial Gastrointestinal Cancer Registry**

#### **National Office/Auckland**

Building 30 Auckland City Hospital Private Bag 92024 Auckland 1142

Freephone: 0800 554 555 Phone: 09 307 8991

Email: NZFamilialGIRegistry@ADHB.govt.nz

#### Wellington

Gastroenterology Department Level 6, CSB, Wellington Hospital Private Bag 7902 Wellington South 6242

Freephone: 0800 262 780 Phone: 04 918 6766

Email: NZFGCR@ccdhb.org.nz

#### Canterbury

Level 2 Riverside Block Christchurch Public Hospital Private Bag 4710 Christchurch 8140

Freephone: 0800 023 445 Phone: 03 378 6148

Email: FBCR@cdhb.govt.nz

#### **Genetic Services**

#### **Genetic Health Service NZ - Northern Hub**

Auckland City Hospital Freephone 0800 476 12 Email gensec@adhb.govt.nz

#### **Genetic Health Service NZ - Central Hub**

Wellington Hospital Freephone 0508 364 436 Email genetic.services@ccdhb.org.nz

#### **Genetic Health Service NZ - Southern Hub**

Christchurch Hospital Freephone 0508 364 436 Email genetic.services@ccdhb.org.nz

# **Appendix 3 Abbreviations and glossary**

#### A3.1 Abbreviations

AGREE Appraisal of Guidelines for Research and Evaluation

CEA Carcinoembryonic antigen

CI Confidence interval

CT Computerised tomography

CRM Circumferential resection margin – represents the retroperitoneal or peritoneal

adventitial soft-tissue margin closest to the deepest penetration of tumour

DALMs Dysplasia Associated Lesion or Mass

DHB District Health Board
GRT Guidance Review Team
IBD Inflammatory bowel disease

NICE National Institute for Health and Clinical Excellence

NZGG New Zealand Guidelines Group

OR Odds ratio

PSC Primary Sclerosing Cholangitis
RCT Randomised controlled trial

RR Relative risk

#### A3.2 Glossary

Adenomatous polyp	Visible protrusions that can develop on the mucosal surface of the colon or rectum and consist of benign neoplastic tissue derived from glandular epithelium. Such polyps show varying degrees of dysplasia. Most carcinomas are thought to arise from adenomatous polyps
Carcinoma	Most common type of cancer; malignant neoplasm (tumour) derived from epithelial cells, chiefly glandular (adenocarcinoma) or squamous (squamous cell carcinoma)
Colonoscopy	Visual examination of the colon using a colonoscope
Computed tomography	A diagnostic imaging technique that uses X-rays and a computer to produce a detailed picture of a cross-section of the body
Concurrent	Occurring at the same time

Counselling	Encompasses supportive care delivered by a variety of health practitioners. Techniques are diverse and may include supportive listening, the provision of practical information and education, instruction in relaxation therapies, assistance with communication and relationship problems, training in assertiveness and advice on problem-solving
Dysplasia	Abnormal development or growth of tissues, organs, or cells. A precursor to carcinoma
Excision	The act of surgically removing or 'cutting out' tissue from the body
Grading	The degree of malignancy of a tumour, judged by its appearance under a microscope
Heterogeneous	Having a large number of variants
Histology	An examination of the cellular characteristics of a tissue
Incidence	The number of new cases of disease in a defined population within a specified period of time
Metachronous	Multiple primary cancers developing at intervals
Metastases	The spread of cancer away from the primary site (origin) to somewhere else via the bloodstream or the lymphatic system
Morbidity	A diseased condition or state
Mortality	Death
Multidisciplinary team	A team with members from different health care professions (eg, surgery, oncology, pathology, radiology and nursing)
Narrow band imaging	The use of blue and green light at certain wavelengths to examine capillaries, veins and other tissues. It allows these to be seen more easily in and below the mucosa, or lining, of the gastrointestinal tract
Prevalence	The number of persons in a given population with a disease or other health-related event at a specified time
Primary care	Services provided in community settings with which patients usually have first contact (eg, general practice)
Prognosis	A prediction of the likely outcome or course of a disease; the chance of recovery or recurrence
Recurrence	Relapse of the cancer in the same place or elsewhere in the body
Staging	The clinical description of the size and extent of a patient's tumour, by its allocation into internationally agreed categories (see <i>Management of Early Colorectal Cancer</i> , Appendix 2 for details on TNM staging, the most widely-used classification for colorectal carcinomas
Surveillance	The regular collection, monitoring and analysis of information in a given population or subpopulation to detect the presence of disease

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