New Zealanders' experiences and pathways to a diagnosis of bowel cancer: a cross-sectional descriptive study of a younger cohort

Patient-reported time from first experiencing symptoms to diagnosis, from top: less than 6 months, 6 – 12 months, more than 12 months.

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Abstract

Objective: To describe factors actively influencing colorectal cancer diagnosis in New Zealand, assess their significance as facilitators of or barriers to diagnosis, and describe a range of pathways to diagnosis.

Design: Cross-sectional descriptive study.

Setting: Online questionnaire distributed to the via a patient advocacy group in New Zealand.

Participants: 98 patients and 52 support people, reporting a diagnosis made at any time in New Zealand, recruited between November 2017 and February 2018. Of the 98 patients, 72 (73%) were aged under 60 years, making this a younger cohort than the population diagnosed with colorectal cancer in New Zealand.

Main measures: Description of patient pathway, weightings of factors encouraging and discouraging diagnosis and differences in symptom-to-diagnosis interval (SDI) between groups.

Results: Although symptoms were the most significant encourager of healthcare-seeking behaviours, few (17% patients) suspected bowel cancer, favouring less serious explanations. Few (12% patients) were embarrassed about their symptoms. Most (79% patients) first approached a peer about their symptoms, then sought primary care. SDI was 6 months or more in 56% of patients surveyed. This delay was more likely if patients were younger ($P = 0.05$), without a tertiary qualification ($P = 0.03$), reported a poor/neutral experience at their first related appointment with a healthcare professional ($P = 0.02$), or were diagnosed in the public sector ($P = 0.01$).

Conclusions: Knowledge of typical non-specific symptoms prior to diagnosis appears poor. Most patients first approach a non-professional about their symptoms, then seek care from their GP. Diagnostic delay is prevalent, and several groups (like those under 60 years of age, without tertiary education or in public care) are at particular risk. Further research in a larger, more representative sample is essential.

What is already known:

- New Zealand's colorectal cancer incidence and mortality rates are among the highest in the world.
- Little research exists in New Zealand on the time period to diagnosis, or the patient experience of this diagnosis.
- Several factors, like older age, or experiencing abdominal pain, appear to facilitate diagnosis.
- Any delay is multifactorial. Patients tend to normalise symptoms and attempt to generate less serious explanations.

What this study adds:

- Measures symptom interpretation and levels of concern, across different groups.
- Outlines a range of patient pathways to a diagnosis of colorectal cancer.
- Highlights important potential facilitators of and barriers to a diagnosis.
- Indicates factors which appear to influence diagnostic delay, and highlights those needing further research.

Contents

Table of Acronyms

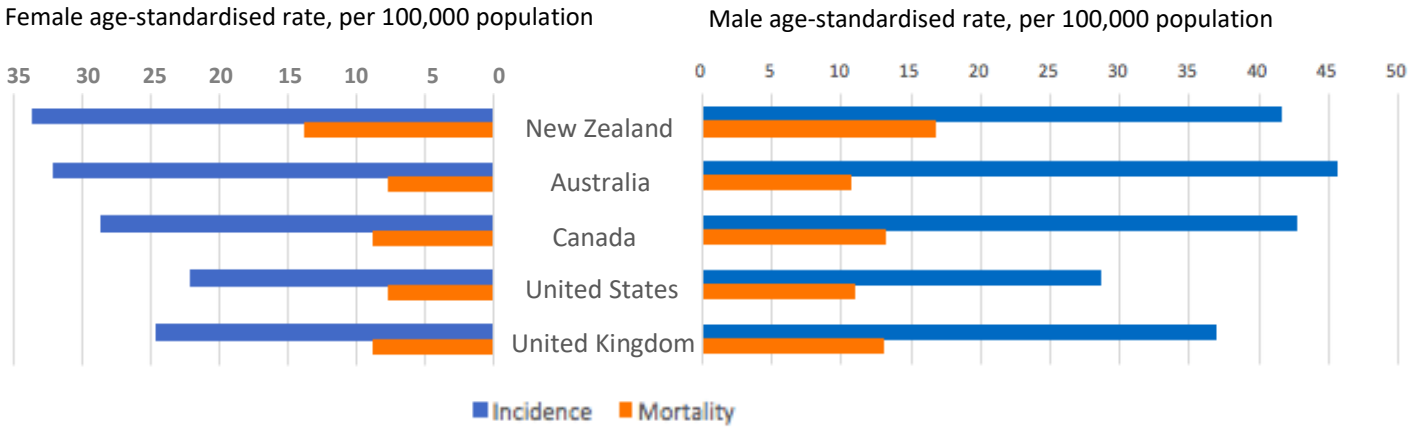
CRC	Colorectal cancer
HCP	Healthcare professional
MoH	Ministry of Health, New Zealand
SDI	Symptom-to-diagnosis interval: length of time between patient first noticing symptoms and reaching a diagnosis of colorectal cancer.
BCNZ	Bowel Cancer New Zealand: patient advocacy group facilitating recruitment.
FSA	First specialist appointment (excluding at an Emergency Department).

Introduction

Outline

Colorectal cancer (CRC) is a significant contributor to adverse health outcomes in New Zealand, as the second-greatest subset of cancer registrations and deaths.[1] The PIPER study found many patients present acutely; 34% of those with colon cancer first present to the Emergency Department.[2] Potentially linked to this is the overrepresentation of late-stage diagnoses, with 24% of colon cancers metastatic (stage IV), compared with 19% and 17% in Australia and the United Kingdom respectively.[2, 3] All have comparable health systems, yet our later staging at diagnosis predicts poor outcomes, particularly for Māori.[4] New Zealand's CRC mortality rate appears particularly concerning when compared to countries with similar cultures and health systems, as in Figure 1.[5]

Figure 1: Age-Standardised CRC Incidence and Mortality Rates by sex in selected countries, 2012[5]

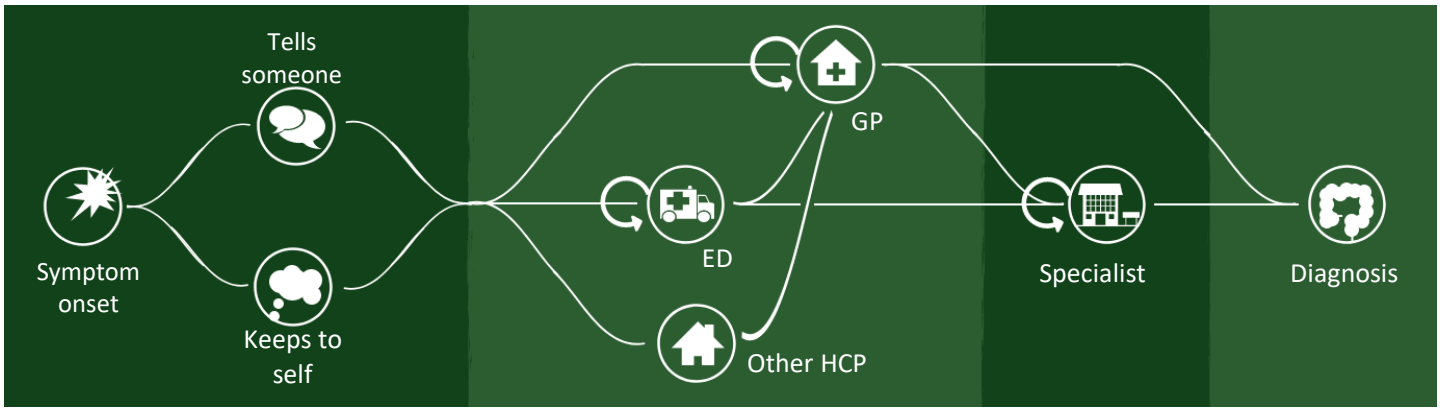


In order to improve these patient outcomes in New Zealand, it is critical to understand the issue, and its potential contributors, from all perspectives.

➢ Pathways to Diagnosis

Symptom-to-diagnosis delay is sometimes implicated in this later staging, but research evidence is conflicting.[6] Later diagnosis appears, if anything, to predict better outcomes.[7] It is unclear whether this is a product of the waiting time paradox, where aggressive disease produces more concerning symptoms, promoting early presentation.[8] Those diagnosed while asymptomatic tend to have better prognoses, supporting this explanation.[9] Perceived delay is more consistently associated with psychological distress, influencing disease outcomes regardless.[10, 11] New Zealand has much to gain from earlier diagnoses.[12] With the introduction of a screening programme targeting ages 60 – 74, our diagnostic process and critical resources are in a state of change.[13, 14] Understanding the present nature of diagnostic facilitators and barriers is critical to measuring the magnitude of this change. Patients progress through healthcare system levels in a linear fashion in theory (as in Figure 2 below), but once these facilitators and barriers are accounted for the system can become more complex.

Figure 2: A summary of pathways to a diagnosis of CRC



The Model of Pathways to Treatment is applied in Figure 3 (*next page)*, and provides an analytic framework, dividing the process into relevant, chronological intervals: symptom appraisal, healthcare-seeking and diagnosis.[15] Particular debate exists regarding the relevance of the appraisal interval. The appraisal and help-seeking intervals are often grouped for ease of data collection. Debate also revolves around the data source - the HCP involved is often approached, rather than the patient. Limited evidence is available for assessing the quality of this measure. It has been suggested that, for the time scale relevant to CRC, the HCP tends to overestimate the appraisal interval when compared to the patient.[16] This means that appraisal interval measurements are often not comparable across studies. All intervals likely contribute to diagnostic delay, but holistic evidence is limited.

Figure 3: Application of the Model of Pathways to Treatment[15]

<table>
<tr><td>Universal influencers:</td><td colspan="3">Intervals:
While chronological in theory, patients move through intervals freely, entering and exiting at any stage.</td></tr>
<tr><td rowspan="4">The patient:
Background, external factors including demographics and established frequency of HCP contact. Psychological, internal factors like priorities, health concerns, attentiveness and response tendencies.[17]

The healthcare professional and system:
Patient access to an appropriate healthcare provider, including cost factors.
Streamlined diagnostic pathways, particularly via colonoscopy, where criteria need to be met for a patient to proceed.[18]

The disease:
Underlying pathology, indicated at a basic level by site and stage.
Primary determinant of symptoms.</td><td>Appraisal:
The time period between symptom recognition, and perception of a health issue. The perceived health issue does not need to be CRC.</td><td rowspan="2">Practical appraisal interval for data collection</td><td rowspan="3">Symptom-to-diagnosis interval (SDI)</td></tr>
<tr><td>Help-seeking:
The time period between perception of a health issue, and action taken in response. Conventionally, this action is measured by the first appointment with an HCP.</td></tr>
<tr><td colspan="2">Diagnosis:
The time period between the first healthcare-seeking behaviour, and diagnosis with CRC.</td></tr>
<tr><td colspan="3">Pre-treatment:
The time period between diagnosis and the start of treatment. Previously investigated in the Auckland region, and less relevant to the immediate aims of this exploratory study.[19]</td></tr>
</table>

➢ Gaps in Understanding

In New Zealand, existing research begins at the point of referral.[19] The events leading to this referral have not yet been explored. Current research identifies the most significant time period as that to first assessment by a specialist, but we suggest this time period needs to be broken down further. Australian studies have qualitatively investigated the corresponding diagnostic and pre-treatment intervals, from the perspective of the healthcare professional (HCP).[20, 21] Evidence linking symptoms and diagnostic delay is limited. Rectal bleeding and a change in bowel habit have been linked with a shorter time to diagnosis, evidence also exists relating rectal bleeding to a longer time to diagnosis.[22, 23] Older age, experiencing multiple symptoms and disclosing these to others, have been more conclusively associated with shorter time to diagnosis.[22, 24, 25]

While this broadens knowledge on diagnostic facilitators, the patient perspective is important, and largely absent when considering diagnosis as a whole. Investigation into this patient experience is most comprehensive at the appraisal interval, as the primary component of delay.[26, 27] This delay, like healthcare utilisation in general, appears multifactorial.[28] Attempts to normalise symptoms and reluctance to seek care appear to be diagnostic barriers.[29] Intermittency of symptoms, in particular, has been linked via the patient response to a longer time to diagnosis.[30] Many use the equivalent "cyclical" measure, derived from the Revised Illness Perception Questionnaire.[31] Other links between these patient perspectives and diagnostic outcomes have not yet been investigated - none to our knowledge in New Zealand.

The broad CRC diagnostic process is well-documented, but research is fragmented. Important studies in New Zealand quantify key efficacy measures, but the holistic experience of the patient and whānau has been poorly understood.

We sought to describe these experiences of the diagnostic pathway and begin to understand their determinants. Specifically, our objectives are to:

1. **Describe the characteristics of participants diagnosed with CRC in our sample.**
2. **Describe their pathways to diagnosis, their points of contact with the healthcare system, and the patient experience at each of these points.**
3. **Understand the experience of specific symptoms and the role of symptoms in the diagnostic pathway.**
4. **Begin to understand factors which may influence the diagnostic pathway and any delays in diagnosis.**

Methods

A cross-sectional questionnaire, hosted by LimeSurvey, was administered via Facebook advocacy groups at no cost. Invitations were placed on two groups facilitated by Bowel Cancer New Zealand (BCNZ): one private for patients and family (n = 404), and one public (n = 4200), in late November 2017 and mid-January 2018. The questionnaire link could also be accessed from the BCNZ website and e-newsletter (subscriber n ≈ 2500), and a regional newspaper.[32] *See appendices for copies of each advertisement.* All potential participants were screened – those eligible were either a patient or "an immediate family member of, or support person for, someone diagnosed with bowel cancer", reporting a New Zealand diagnosis and aged 18 years or older.

The questionnaire included demographics, pre-symptoms, symptoms, help-seeking behaviours and the diagnostic pathway. Questions were structured around the Model of Pathways to Treatment, patient experience factors from the New Zealand Health Survey and established obstacles to early cancer diagnosis.[15, 27, 33-35] Exact questions were directed by previous responses.

Demographic information collected included age, gender, ethnicity, living situation, current employment and highest qualification. Prioritised ethnicity was recorded using Ministry of Health guidelines and Level 1 groupings.[36] 11 were prioritised in total, 10 to Māori. Patient region was grouped into Ministry of Health Cancer Networks for analysis.[37]

Where relevant, respondents were also asked basic healthcare information - how often they saw their regular HCP before diagnosis and how far away from this HCP they lived, how far away they lived from the place at which they were diagnosed, whether they had private healthcare insurance, and whether they were diagnosed in the public or private healthcare sector.

All respondents were asked to recall basic markers of disease: site and staging, at the time of diagnosis. Time of diagnosis was grouped for analysis as 0-5, 6-10 or 11 or more years ago. To identify symptoms, diagnostic facilitators and barriers, all respondents were provided with a multiple-choice checklist of response themes, with a free-format "Other" option. All respondents were asked to quantify the level of concern they associated with each potential symptom, assessed on a scale from one to five, labelled "not at all worrying" to "extremely worrying".

All respondents involved in the healthcare-seeking process were asked to select from a multiple-choice list the diagnostic facilitators and barriers they felt were relevant to the diagnosis they reported. They were then asked to quantify the significance of each factor, regardless of whether they previously selected it, in the decision to seek care, by placing it on a scale from -5 (discourager) to +5 (encourager). The default position was 0 (neutral) on the respondent's screen. If the respondent did not interact with the question, then their response was recorded by the

LimeSurvey software as missing. Where a respondent left only some questions in the block blank, '0' was input in place of these missing values. Respondents leaving the entire question block blank had their responses marked as missing.

Patients were asked to report their symptom-to-diagnosis (SDI) interval in a free-format field. SDI was subsequently classified to the nearest (rounding up when necessary) month, and as under 6 months or at/greater than 6 months for analysis. Data was input based on later responses if the respondent did not specify an SDI. Asymptomatic patients could not report SDI, these respondents were excluded from SDI analyses as is standard practice.[25] Reported SDIs were also cross-referenced against the total time reported in the pathway section of the questionnaire. When there was a discrepancy of >3 months this data was excluded. Patients also reported the length of their practical appraisal interval, the time between developing symptoms and initiating healthcare-seeking, as one of several set time ranges. Appraisal interval was categorised for analysis at both the 1 month and 3 month thresholds. Support people were not asked to report SDI, as accuracy of symptom onset would vary too significantly for meaningful analysis.

All respondents were asked to report as much as they knew about the patient pathway to diagnosis. All were asked a cycling standard set of questions about the type of HCP they saw at that point, their experience with this HCP, and the HCP response. HCP type and response were grouped and respondents were asked to choose from these groups, or to enter an "Other" option in a free-format field. Where a time period was specified, it was rounded to the nearest month for analysis. Exceptions were the time period of "two weeks", which was rounded up to make it distinct from "immediate" steps, or where a range was specified, where an average of the upper and lower bounds was taken.

Patient experience was a composite measure derived from the New Zealand Health Survey.[33] This splits patient experience into six components, of which respondents were asked two: How good the HCP was at listening to the patient, and how good the HCP was at taking the patient seriously. Both patients and support people were asked to rate the HCP on each, with the options "very good", "good", "neither good nor bad", "poor", or "very poor". Respondents allocating a "very good" or "good" score for both measures were said to have had a good experience with that particular HCP, on that occasion.

Data was housed securely on a department server, exported and checked for inconsistencies and duplicates. Univariate and bivariate analyses were performed with Stata, version 15.1. *P*-values were obtained using a chi-squared test when 20% or fewer cells held frequencies of less than 5, or Fisher's exact test when more than 20% of cells held frequencies of less than 5. Patient-reported and support-reported data were analysed separately, there were significant differences in the characteristics of tumours they reported.

Design and reporting, where possible, followed the Aarhus statement, a set of guidelines on researching early cancer diagnosis.[38]

Ethical approval was obtained via the University of Otago Ethics Committee (Health).

Results

150 respondents satisfactorily completed the questionnaire. 10 had been excluded: 8 reported a relationship with the patient outside our bounds, 2 reported a diagnosis made outside of New Zealand. Of those satisfactorily completing the questionnaire, 98 identified as patients and 52 as support people. Of these support people, most were the patient's child (n=24, 46%) or partner (n=20, 38%). Demographic information was collected from all respondents, as in Table 1.

Table 1: Respondent Demographics

Demographic factor:	Patient n (%)	Support n (%)	*P*
	98 (65)	52 (35)	
Age:			
Patient category at diagnosis:			
≤ 39 y	17 (18)	10 (20)	**0.030**
40 – 49 y	24 (25)	5 (10)	
50 – 59 y	31 (32)	12 (24)	
60 – 69 y	18 (19)	15 (29)	
70 – 79 y	6 (6)	7 (14)	
≥ 80 y	0 (0)	2 (4)	
Patient mean at diagnosis (years)	51	54	
Patient region by Ministry of Health Cancer Network:[37]			
Northern (Northland, Auckland)	23 (23)	14 (27)	0.65
Midland (Waikato, Lakes, Bay of Plenty, Gisborne)	13 (13)	6 (12)	
Central (Taranaki, Manawatu/Wanganui, Hawke's Bay, Wellington)	23 (23)	8 (15)	
Southern (all South Island)	39 (40)	24 (46)	
Respondent gender:			
Female	76 (78)	48 (92)	**0.038**
Male	21 (21)	4 (8)	
Respondent ethnicity:[36]			
NZ European/Pākehā	83 (85)	44 (85)	0.60
Māori	8 (8)	6 (12)	
Other	7 (7)	2 (4)	

Patient and support groups were significantly different in age and gender distribution, so groups were kept separate for the remainder of the analysis. There was no overlap between patients in the patient-reported group and support-reported group.

It should be noted that while support people were mostly female (n=48, 92%), many (n=20, 38%) were reporting the diagnosis of a male partner. Also note a similar proportion of patients and support people reported patients living alone, this was the minority living situation group.

Figure 4: Map of New Zealand showing Patient-Reported Region

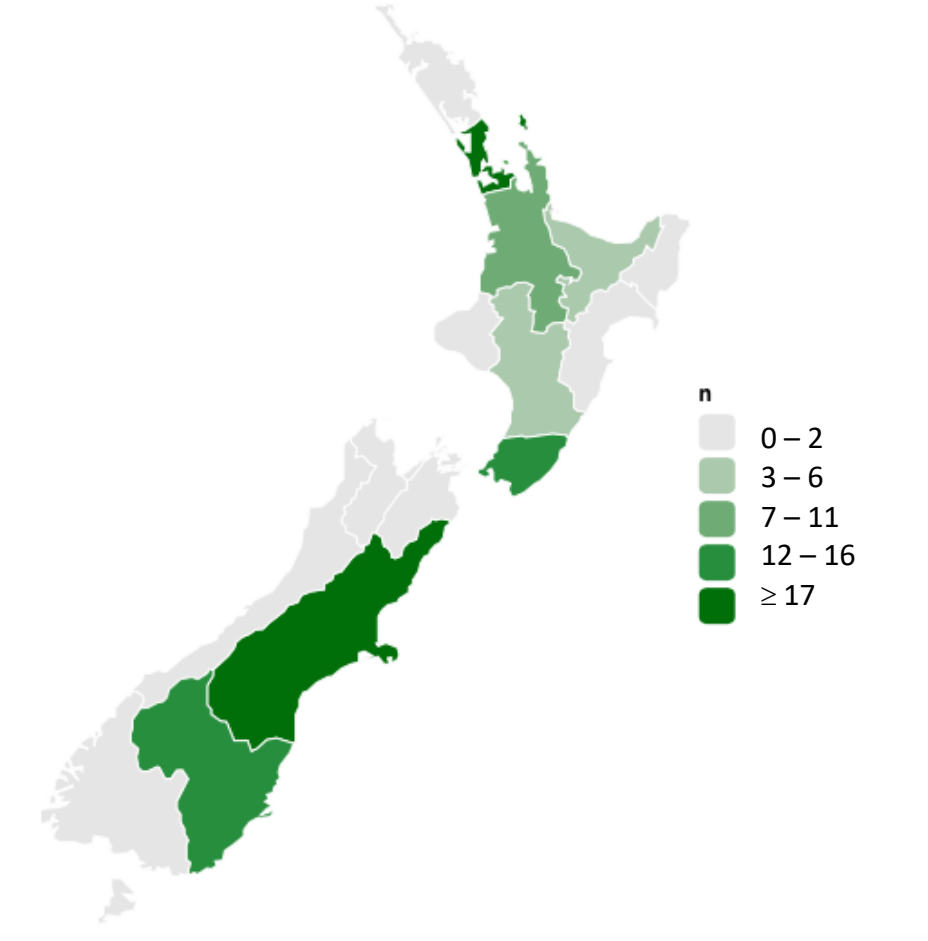


Table 2 presents factors relating to our participants' diagnoses, symptoms and care. Most were diagnosed recently (within the last 5 years) after experiencing symptoms, and first sought care for these symptoms from a GP.

Table 2: Diagnostic Variables, presented by Respondent Category

	Patient n (%)	Support n (%)	P
At diagnosis:			
Time of diagnosis:			
≤ 5 y ago (2013 – 2018)	76 (78)	36 (69)	0.52
6 – 10 y ago (2008 – 2012)	10 (10)	8 (15)	
≥ 11 y ago (2007 or earlier)	12 (12)	8 (15)	
Tumour site:			
Colon	57 (58)	37 (71)	**0.011**
Rectum	37 (38)	8 (15)	("Unsure"
Unsure	4 (4)	7 (13)	removed)
Stage at diagnosis:			
I	17 (17)	4 (8)	**<0.001**
II	26 (27)	9 (17)	("Unsure"
III	45 (46)	9 (17)	removed)
IV	8 (8)	27 (52)	
Unsure	2 (2)	3 (6)	
Patient symptomatic	93 (95)	46 (88)	0.15
Asymptomatic	5 (5)	6 (12)	
Symptoms:			
Change in bowel habit	52 (53)	27 (52)	0.65
Rectal bleeding	55 (56)	20 (38)	
Abdominal pain	39 (40)	18 (35)	
Unexplained weight loss	10 (10)	10 (19)	
Low energy	40 (41)	18 (35)	
Anaemia or iron deficiency	23 (24)	10 (19)	
Palpable mass	6 (6)	3 (6)	
Multiple symptoms possible, symptoms do not add to 100%.			
Appraisal + help-seeking intervals (symptom onset to HCP approach):			
0 – 14 days	26 (30)		
15 – 31 days	15 (17)		
32 – 92 days	17 (20)		
≥ 93 days	29 (33)		
First HCP contact:			
General practitioner	81 (83)	46 (88)	0.39
Emergency Department	10 (10)	5 (10)	
Other	7 (7)	1 (2)	
Number of HCP visits before first specialist appointment (FSA):			
0 – 1	53 (62)	27 (55)	0.69
2 – 3	27 (31)	19 (39)	
≥ 4	6 (7)	3 (6)	
Number of HCP visits before diagnosis:			
1 – 2	46 (53)	25 (51)	0.87
3 – 4	29 (34)	18 (37)	
5 – 6	9 (10)	6 (12)	
≥ 7	2 (2)	0 (0)	
Symptom-to-diagnosis interval (SDI):			
≤ 92 days	23 (25)		
93 – 183 days	18 (19)		
184 – 365 days	25 (27)		
≥ 366 days	27 (29)		

We note the difference in stage distribution between patients and support people. Patients reported largely non-metastatic cases (n=58, 95%), while support people reported significantly more metastatic cases (n=18, 55%). This is to be expected, given the poorer prognosis associated with metastatic disease.

Combinations of patient-reported symptoms were analysed, results are shown in in Table 3.

Table 3: Cross-table showing Patient-Reported Symptom Combinations

	Change in bowel habit	Rectal bleeding	Abdominal pain	Unexplained weight loss	Low energy	Anaemia or iron deficiency	Palpable mass	Total
Change in bowel habit n (% row)		35 (67)	24 (46)	7 (13)	26 (50)	10 (19)	3 (6)	52
Rectal bleeding n (% row)	35 (64)		21 (38)	5 (9)	26 (47)	11 (20)	2 (4)	55
Abdominal pain n (% row)	24 (62)	21 (54)		8 (21)	23 (59)	11 (28)	3 (8)	39
Unexplained weight loss n (% row)	7 (70)	5 (50)	8 (80)		6 (60)	2 (20)	1 (10)	10
Low energy n (% row)	26 (65)	26 (65)	23 (58)	6 (15)		17 (43)	3 (8)	40
Anaemia or iron deficiency n (% row)	10 (43)	11 (48)	11 (48)	2 (9)	17 (74)		5 (22)	23
Palpable mass n (% row)	3 (50)	2 (33)	3 (50)	1 (17)	3 (50)	5 (83)		6
No other symptoms n (% row)	10 (25)	14 (35)	9 (23)	0 (0)	1 (3)	3 (8)	0 (0)	One symptom only: n=26
Total	52	55	39	10	40	23	6	98

Trigger symptoms were also isolated and analysed, results are shown in in Figure 5.

Figure 5: Diagram showing trigger symptom reported by >5% of patients

Area of circle proportional to response, n (%)

Low energy
6 (6%)

Abdominal pain
18 (19%)

Bleeding
27 (28%)

Change in bowel habit
19 (20%)

Anaemia or iron deficiency
9 (9%)

A further 7 (7%) reported that they were symptomatic, but waited for a routine appointment with an HCP, rather than seeking help for this symptom only. Of those waiting for a routine appointment, 4 (57%) each reported a change in bowel habit and low energy, 3 (43%) each reported rectal bleeding, abdominal pain and anaemia. 4 (57%) were reporting more than one symptom.

Patient variables were analysed against categorised SDI, results are shown in Table 4 (*next page)*.

Table 4: Diagnostic Variables, presented by Patient-Reported Symptom-to-Diagnosis Interval (SDI)

Patient characteristics	SDI less than 6 months n (%)*	SDI 6 months or longer n (%)*	OR (95% CI)**	*P* value**
Age:				
< 50 years	13 (32)	28 (49)	1.00	**0.05**
50 – 59 years	11 (27)	20 (35)	0.84 (0.31 – 2.26)	
60 years or older	15 (37)	9 (16)	0.28 (0.10 – 0.80)	
Ethnicity:				
NZ European / Pākehā	36 (88)	47 (82)	1.00	0.23
Māori	1 (2)	7 (12)	5.36 (0.63 – 45.56)	
Other	4 (10)	3 (5)	0.57 (0.12 – 2.73)	
Any tertiary qualification	34 (83)	37 (65)	1.00	**0.03**
No tertiary qualification	6 (15)	20 (35)	3.06 (1.10 – 8.53)	
No family history of CRC	26 (63)	36 (63)	1.00	0.98
Any family history of CRC	15 (37)	21 (37)	1.01 (0.44 – 2.33)	
Tumour site:				
Colon	26 (67)	31 (56)	1.00	0.57
Rectum	13 (33)	24 (44)	0.84 (0.11 – 6.37)	
Unsure	2 (5)	2 (4)		
Stage at diagnosis:				
I or II	20 (49)	23 (42)	1.00	0.50
III or IV	21 (51)	32 (58)	1.33 (0.59 – 2.99)	
Unsure	0 (0)	2 (4)		
Asymptomatic	1 (2)	4 (7)	4.80 (0.48 – 47.68)	0.16
1 symptom	20 (49)	20 (35)	1.00	
>1 symptom	20 (49)	33 (58)	2.07 (0.87 – 4.91)	
No intermittent symptoms	17 (41)	14 (25)	1.00	0.21
Any intermittent symptom	23 (56)	39 (68)	1.70 (0.74 – 3.90)	
Good experience at first HCP appointment	36 (88)	33 (58)	1.00	**0.02**

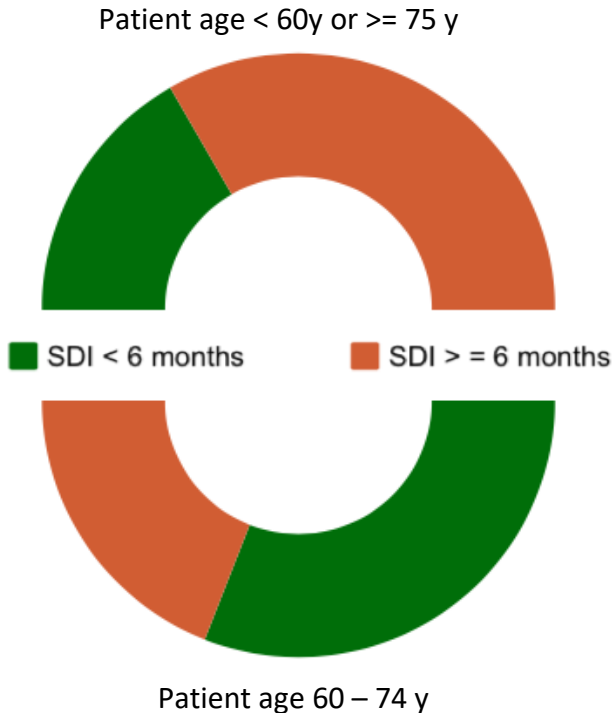
Poor or neutral experience at first HCP appointment	5 (12)	24 (42)	3.70 (1.25 – 10.96)	
<3 HCP visits before diagnosis	25 (61)	21 (37)	1.00	**0.02**
3 or more HCP visits before diagnosis	12 (29)	28 (49)	2.78 (1.14 – 6.77)	
No healthcare insurance	19 (46)	30 (53)	1.00	0.47
Healthcare insurance	19 (46)	22 (39)	0.73 (0.30 – 1.70)	
Diagnosed in the private system	18 (44)	12 (21)	1.00	**0.01**
Diagnosed in the public system	19 (46)	40 (70)	3.16 (1.27 – 7.86)	

**Do not always sum to 100% because of missing values.*

***Excludes missing responses. P-values refer to the association between the outcome and whole variable and were obtained using univariate logistic regression with SDI of 6 months or more as the outcome.*

➢ Demographics and Delay

Figure 6: Graph showing SDI distribution within **age categories**



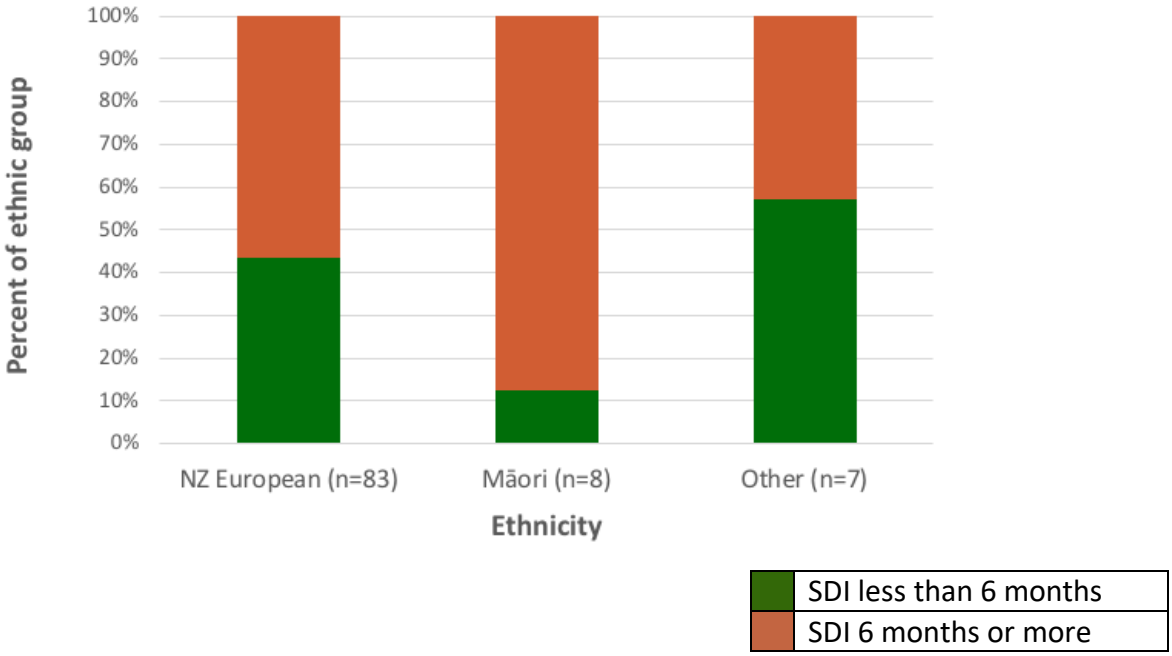
Those between the ages of 60 and 74 were significantly more likely to be diagnosed within the first 6 months of experiencing symptoms than those outside this bracket. Those inside the bracket will be eligible for the new screening programme.

There was no significant difference between the age groups in time taken to approach an HCP, when tested at the 1 month (*P*=0.23) or 3 month (*P*=0.15) boundaries from symptom onset.

There was no apparent difference between age categories in the type of HCP first approached (*P*=0.36). However, those first approaching alternative HCPs (examples include midwives and naturopaths) appear more likely to be younger. All of the patients in our sample (n=7) who first approached an alternative HCP were under 60 years of age.

Those outside the screening bracket also appear less likely to report a good experience at their first HCP contact (borderline significant, *P*=0.066).

Figure 7: Bar graph showing SDI distribution by Level 1 **prioritised ethnicity**[36]



Ethnicity did not have a statistically significant impact on SDI category, nor on the time taken to approach an HCP (*P* = 0.56 when boundary set at 3 months). Any link was similarly insignificant when grouped as New Zealand European and not New Zealand European (*P* = 0.47).

Figure 8: Diagram showing SDI distribution by **highest qualification**

Primary: 100% 6 months or more

Secondary: 75% 6 months or more

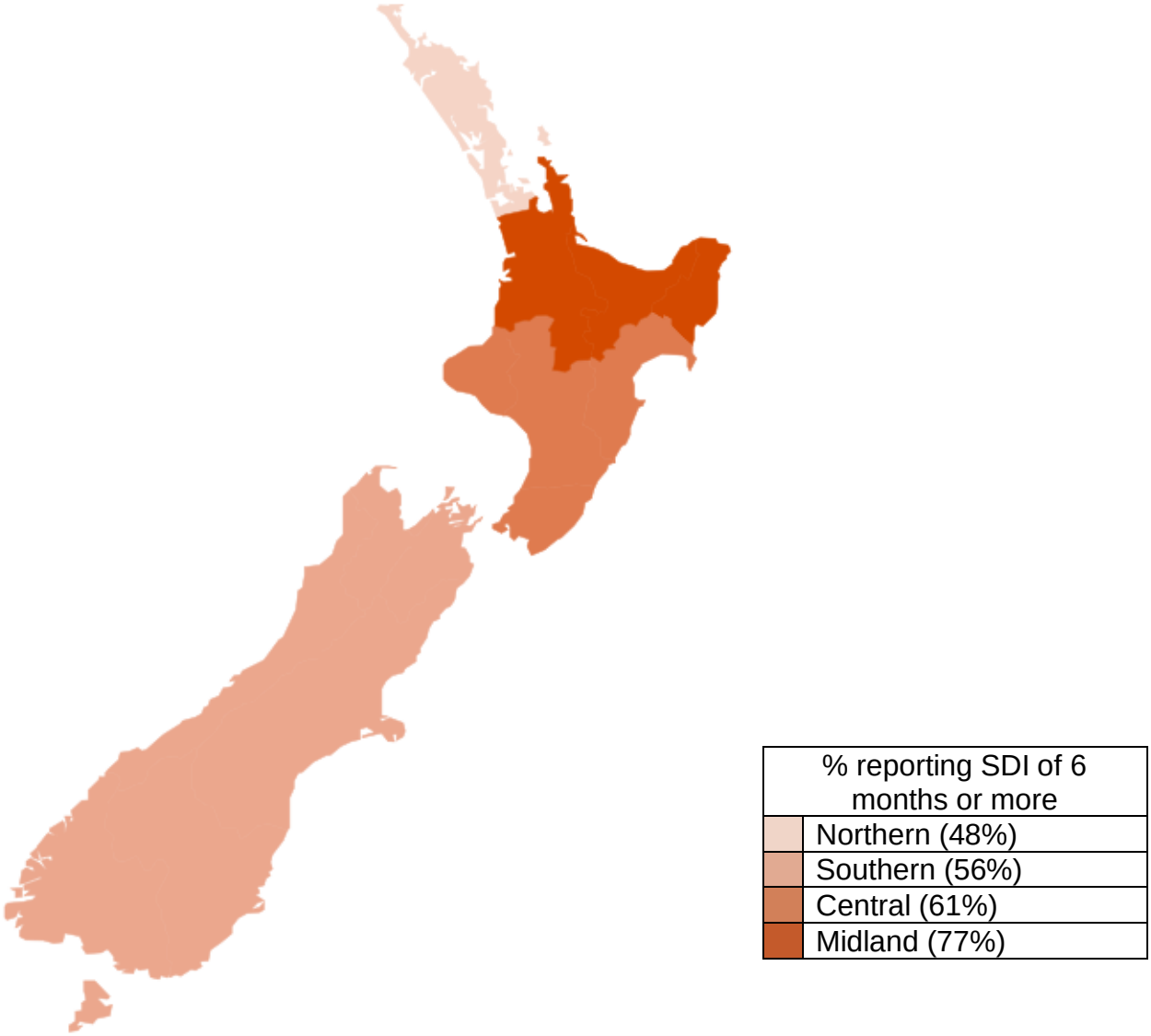
Non-university tertiary: 54% 6 months or more

University: 51% 6 months or more

Tertiary education raises income prospects, however, on isolating those employed, there was no association found between income and SDI (*P* = 0.95).

Figure 9: Map showing patient-reported SDI by **cancer network**

Those in darker regions appear to be experiencing more delay

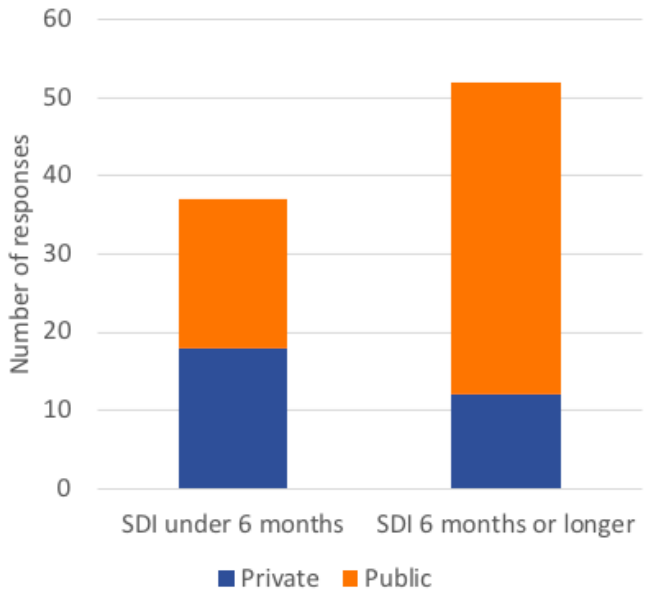


➢ Presentation, Care and Delay

No significant differences were found across SDI categories when considering individual symptoms. No significant differences across symptoms were found with respect to the length of the appraisal interval, when using the 1 month and 3 month boundaries.

Nearly all patients reporting an SDI of less than 6 months also reported a good experience the first time they approached an HCP for this problem and this was statistically significant ($P = 0.01$). However, patients reporting a good experience at this point did not appear to approach their HCP earlier ($P = 0.19$ when set to 3 months after symptom onset). Patients reporting a good experience were more likely to fit into the 60-74 year age group, this was borderline significant ($P = 0.066$) and may be more significant in a larger sample.

Figure 10: Bar graph showing patient-reported SDI distribution by **diagnosing healthcare system**



The difference in SDI across healthcare systems (public and private) was significant ($P = 0.01$). All 9 patients diagnosed more than 2 years after symptom onset were diagnosed in the public sector. This weakened when isolating patients based on age (using the screening categories). In the group eligible for screening (aged 60-74), P increased to 0.15. In the group ineligible, P increased to 0.04.

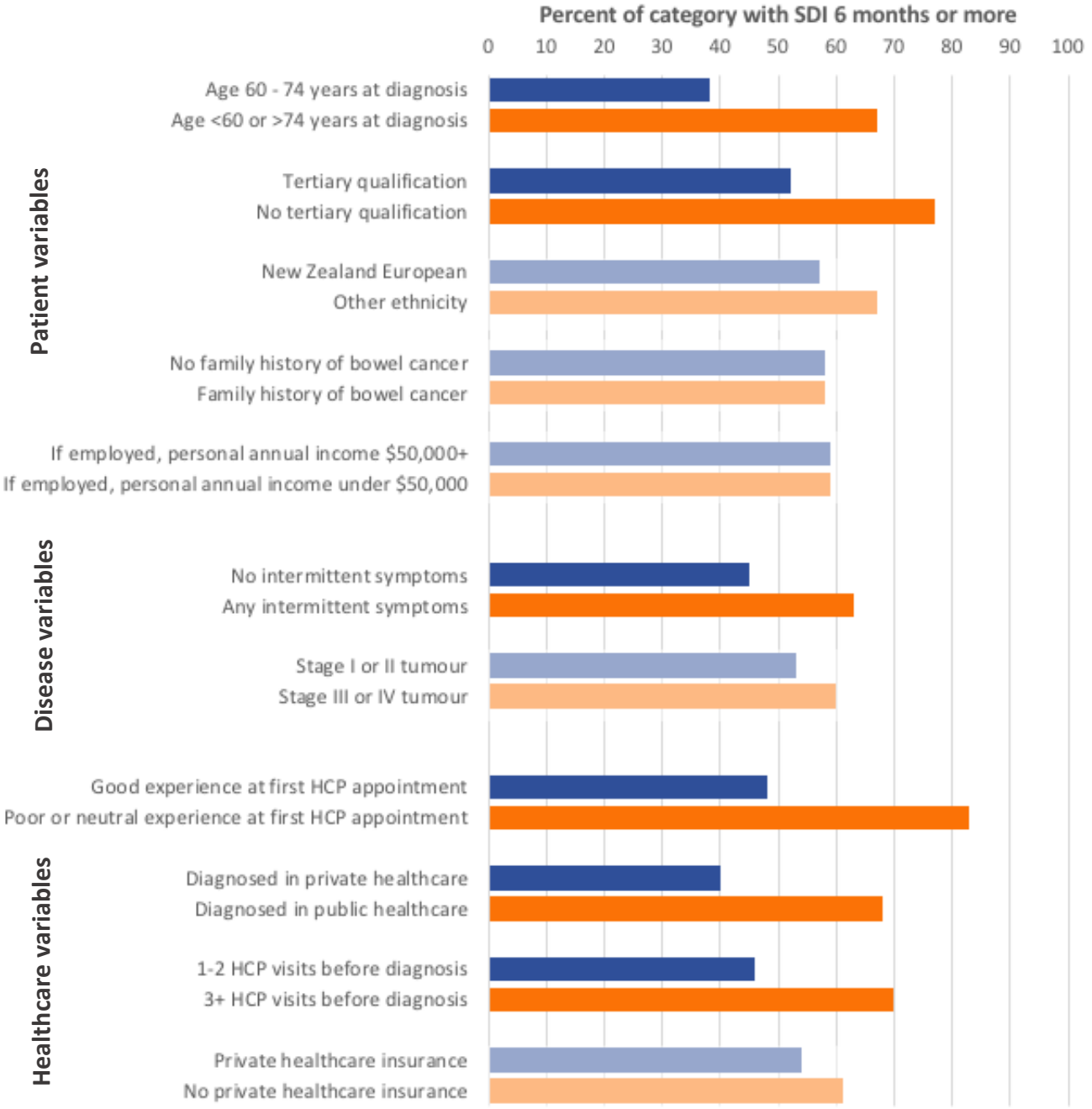
Of those diagnosed through private healthcare, most had healthcare insurance (80%, $P < 0.001$). However, there was no significant difference in insurance status with respect to SDI ($P = 0.47$). When patients with insurance were isolated, patients diagnosed in the private sector remained more likely to report an SDI under 6 months ($P = 0.03$). This was insignificant in patients without insurance ($P = 0.66$). We did not find a relationship between tertiary education and insurance status ($P = 0.26$), or being of screening age and insurance status ($P = 0.62$).

Patients diagnosed through private and public healthcare were similarly likely to seek care within the first month of symptoms (46% and 48% respectively, P=1.0) and in the first 3 months of symptoms (62% and 69% respectively, $P = 0.61$).

➢ Delay Summary

Figure 11: Summary bar graph showing proportion reporting Symptom-to-Diagnosis Interval of 6 months of longer, by variable status

Variables showing statistically significant (P<0.05) or borderline significant differences in SDI have been shaded darker



➢ Diagnostic Facilitators and Barriers

Figure 12: Patient-reported HCP Approach Facilitators

Area of circle proportional to response

Suspecting bowel cancer	Suspecting another disorder	Acute symptoms	General symptom worry	Family, medical history	Family, friend encouragement
					
Patient n = 17 (17%)	Patient n = 27 (28%)	Patient n = 12 (12%)	Patient n = 59 (60%)	Patient n = 13 (13%)	Patient n = 9 (9%)

Figure 13: Patient-reported HCP Approach Barriers

Area of circle proportional to response

Constructed symptom explanations	Waiting and monitoring	Private symptom nature, embarrassment	Limited access to a trusted HCP	Reluctance to worry someone, or take up time
				
Patient n = 41 (42%)	Patient n = 27 (28%)	Patient n = 12 (12%)	Patient n = 2 (2%)	Patient n = 7 (7%)

Of those reporting reluctance to worry someone about their health, or take up someone's time, most did not have a tertiary qualification (*P*=0.01).

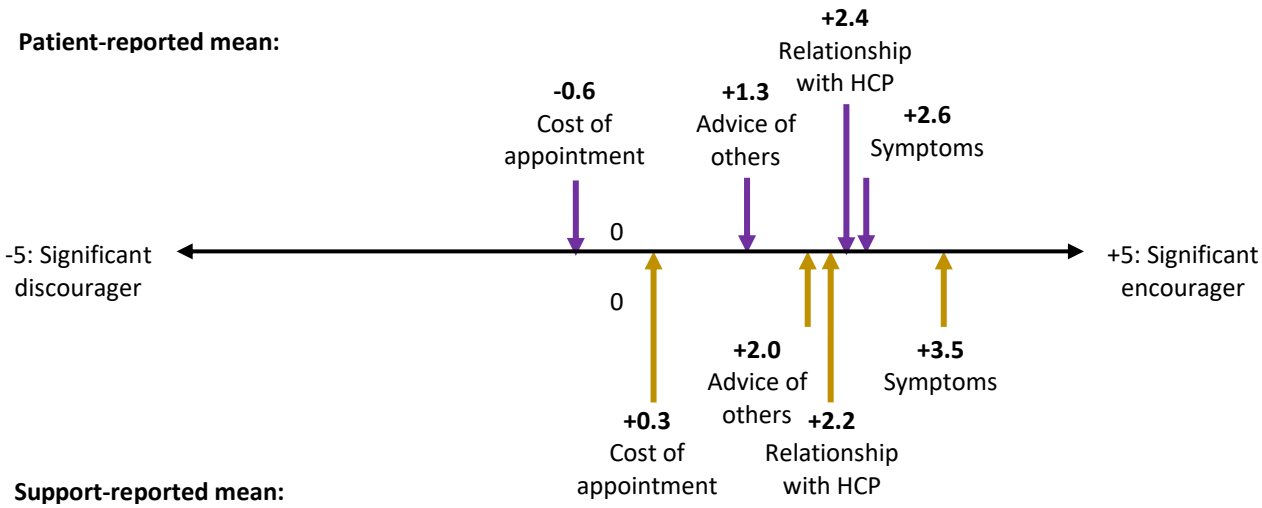
Table 5: Table of Selected Patient-Reported HCP Approach Facilitators and Barriers, by Symptoms Reported

Statistically significant differences between those with/without symptom bolded

Symptom	Facilitator		Barriers	
	Suspected bowel cancer n=17 n (% row)		Symptoms better explained by something else n=41 n (% row)	Embarrassed by private symptoms n=12 n (% row)
Change in bowel habit: Y / N	**16 (31) / 1 (2)**		20 (53) / 21 (60)	**10 (26) / 2 (6)**
Rectal bleeding: Y / N	**16 (29) / 1 (2)**		20 (49) / 21 (66)	**11 (27) / 1 (3)**
Abdominal pain: Y / N	9 (23) / 8 (14)		13 (46) / 28 (62)	5 (18) / 7 (16)
Unexplained weight loss: Y / N	2 (20) / 15 (17)		4 (57) / 37 (56)	0 (0) / 12 (18)
Low energy: Y / N	7 (18) / 10 (17)		16 (57) / 25 (56)	7 (25) / 5 (11)
Anaemia or iron deficiency: Y / N	3 (13) / 14 (19)		8 (50) / 33 (58)	2 (13) / 10 (18)

None of the above facilitators and barriers appear to influence SDI (*P* = 0.55, 0.54 and 0.75 respectively).

Figure 14: Diagram showing patient and support-reported significance of facilitators and barriers in HCP approach:



➢ Symptom Concern

Table 6: Table showing concern about symptoms

Symptom	Change in bowel habit	Rectal bleeding	Abdominal pain	Unexplained weight loss	Low energy	Anaemia or iron deficiency	Palpable mass
Mean concern /5, all patients	3.3	4.4	3.8	3.7	3.1	3.1	4.5
Mean concern /5, patients with that symptom	3.5	4.2	3.8	3.8	3.0	3.4	4.5
Mean concern /5, patients without that symptom	3.0	4.6	3.8	3.7	3.2	3.0	4.5
Difference: mean (with) – mean (without)	+0.5	-0.4	0.0	+0.1	-0.2	+0.4	0.0
Mean concern /5, tertiary-educated patients	3.2	4.4	3.8	3.7	3.0	3.2	4.6
Mean concern /5, non-tertiary educated patients	3.5	4.5	3.6	3.8	3.2	3.1	4.5
Difference: mean (tertiary) – mean (non-tertiary)	-0.3	-0.1	+0.2	-0.1	-0.2	+0.1	+0.1
Mean concern /5, all support people	3.8	4.4	3.3	3.8	3.3	3.4	4.5

Patients with a change in bowel habit or anaemia/iron deficiency reported being slightly more concerned about these symptoms than patients not experiencing them. Patients with rectal bleeding reported being slightly less concerned about the symptom than patients not experiencing it.

There was little difference in symptom concern reported by tertiary-educated and non-tertiary educated patients.

Figure 15: Flow chart showing patient-reported pathways

Patients move from left to right; each bubble represents a help-seeking approach and is sized to represent the number of patients following this particular pathway. Only pathways followed by at least 2 respondents are shown in full (solid lines). Where steps have been omitted, this is shown with a dotted line.

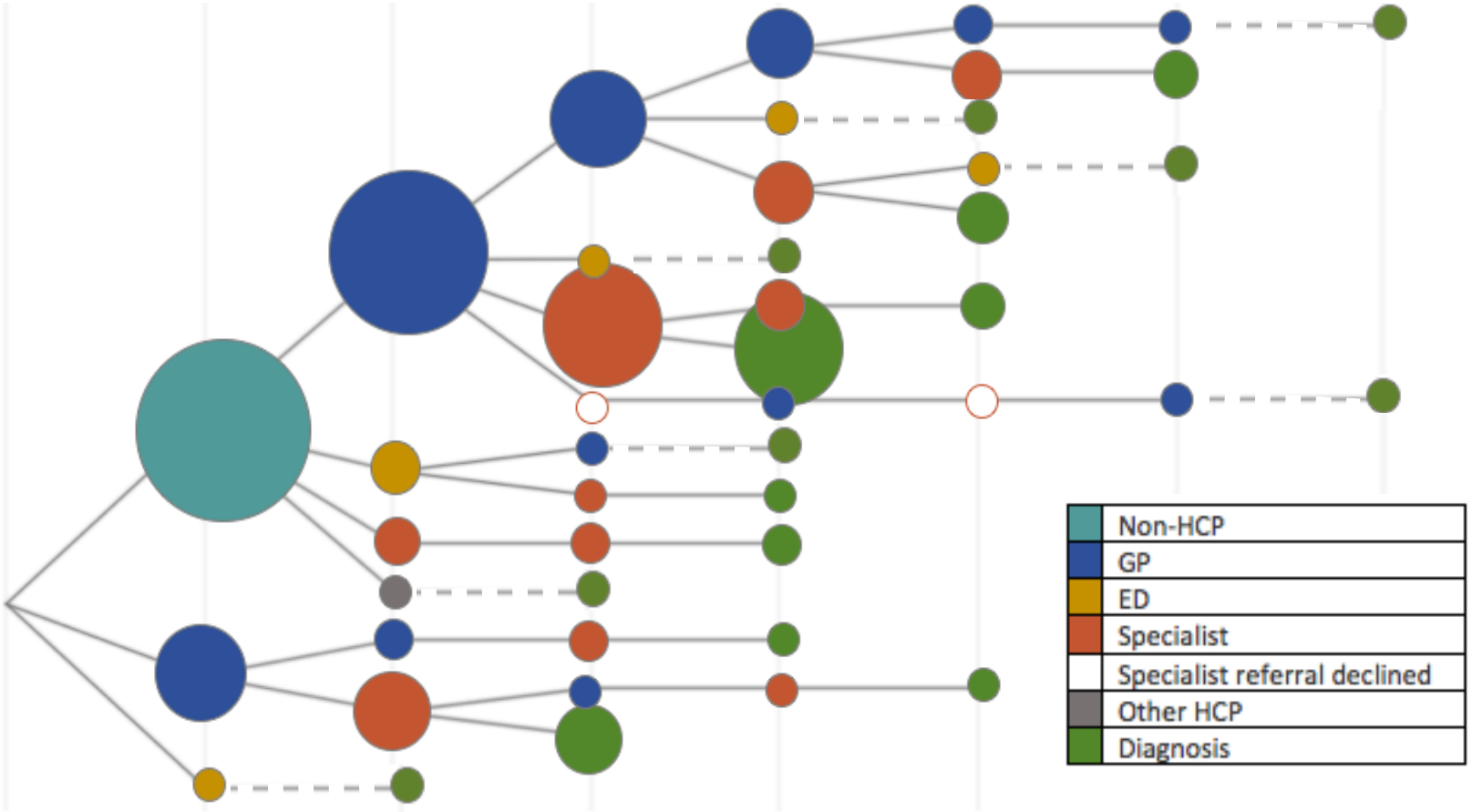


Figure 16: Series of graphs showing patient-reported contacts at each step in their pathway to diagnosis

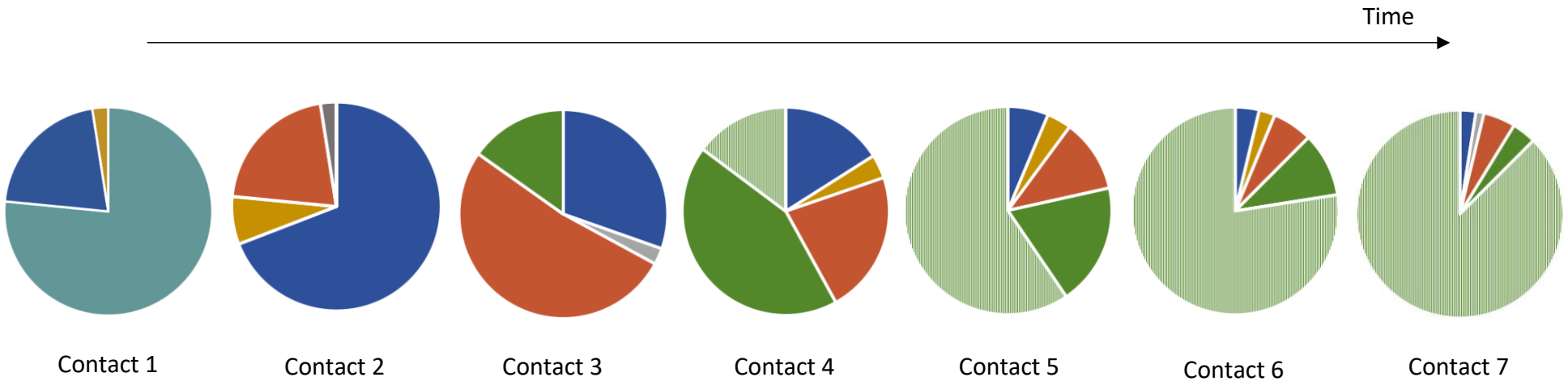
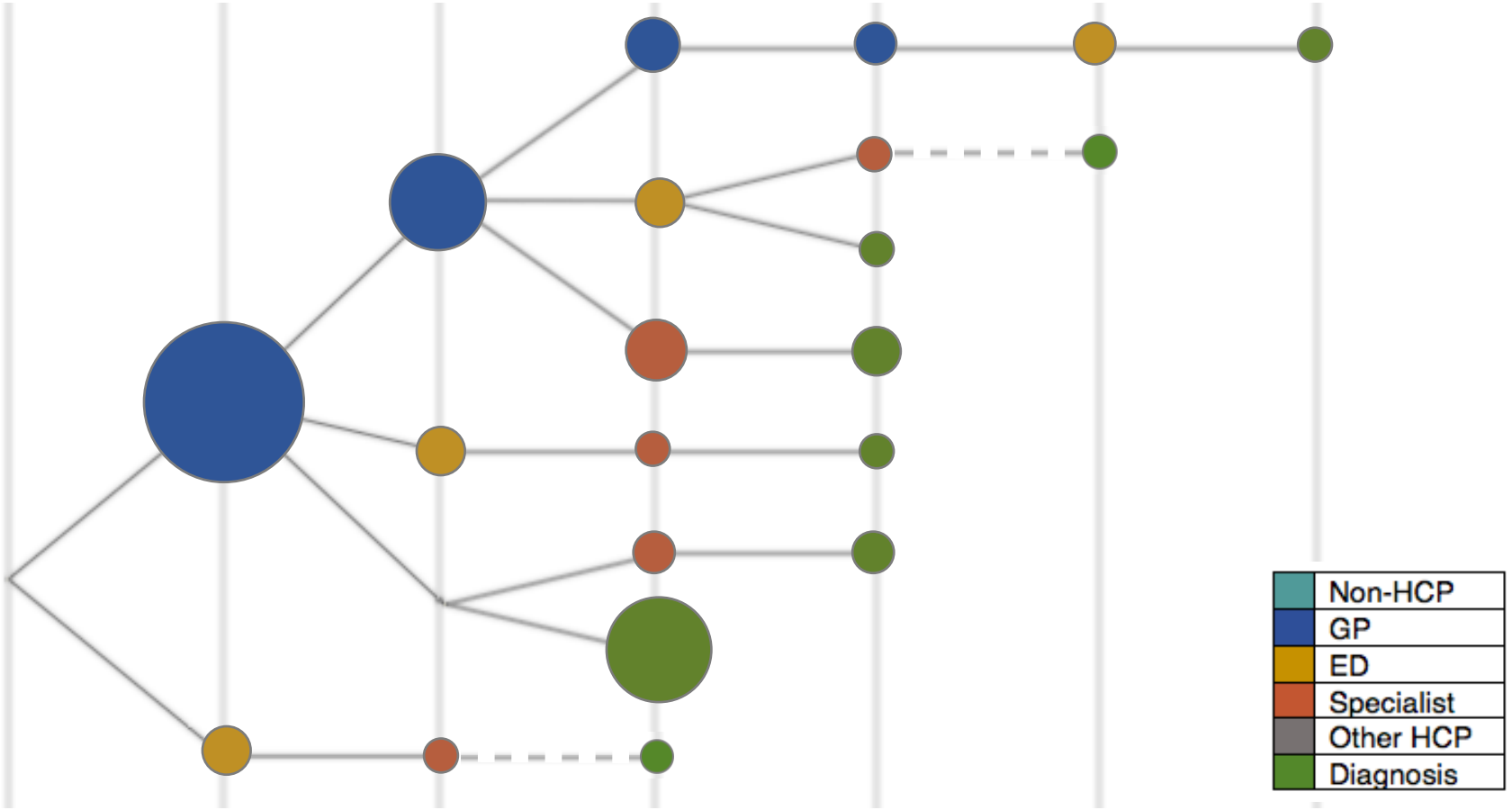


Figure 17: Flow chart showing support person-reported patient pathways

Patients move from left to right; each bubble represents a help-seeking approach and is sized to represent the number of patients following this particular pathway. Only pathways followed by at least 2 respondents are shown in full (solid lines). Where steps have been omitted, this is shown with a dotted line.



Discussion

This study appears to be the first to present patient perspectives of the pathway to a diagnosis of CRC in New Zealand. The majority of patients sought care for general symptom worry. While few suspected bowel cancer, those who did were most likely to be experiencing a change in bowel habit, rectal bleeding, or both. Paradoxically, patients with these symptoms were also most likely to feel embarrassed about their symptoms. This, and the low concern attributed by patients to more vague symptoms, suggests a poor public awareness about important health markers. While this did not appear to influence delay (overall or in healthcare-seeking), these are important perspectives to focus on in public and HCP awareness programmes.

The most common healthcare-seeking barrier in our sample was the patient normalisation of symptoms or construction of alternate explanations. Examples of these explanations include haemorrhoids, pregnancy and infection. For most in the population, these alternate explanations will be accurate - those with CRC are the minority.[45] Healthcare-seeking behaviours likely follow sudden symptom changes, incompatible with prior explanations. In this way, delay may be attributable to a form of patient-centred confirmation bias. This has been well-documented in healthcare professionals.[46] We suggest this is not restricted to the HCP.

Most patients first sought the opinion of a non-HCP (usually a partner or friend), before turning to their GP. Non-specific symptom concern appears to be the most important facilitator of this step. Most visits in each patient's pathway were with this GP. This puts a resourcing and accessibility target on primary care. Very few patients in our study were unable to access an FSA after consulting a GP. However, many reported considerable delay between referral and this scheduled FSA. In this time between referral and the scheduled FSA, many decided to seek other care (e.g. through a GP or ED) because of their symptoms.

Delay was significant in our sample. We found those ineligible for the new screening programme to be more likely to report delay; but in our sample, these people were nearly all younger than the age of entry to the bowel screening programme. Debate exists about the resources available in New Zealand and the implications of this for any screening programme.[39] Stretching resources potentially limits access to diagnostic procedures for those ineligible for screening, which could exacerbate their tendency to delay.

When assessing symptom-to-diagnosis interval (SDI), Māori appeared in particular to be more likely to report a longer SDI. While our sample size is underpowered to determine the strength of this association, existing research suggests poor outcomes for Māori, so careful attention must be paid to this group in future research.[4, 40]

Patients educated to a tertiary level were more likely in our sample to report a shorter SDI, supported internationally.[41] Tertiary education is linked to higher income later in life, but income (when analysing only those employed, to remove the effect of retirement) did not appear to impact SDI.[42] This may, however, be influenced by other factors. Lower-income individuals in New Zealand may be eligible for discounted healthcare, minimising a potential barrier.[43] Tertiary-educated patients did not appear to be more concerned about symptoms, nor did they appear to explain symptoms differently to non-tertiary educated patients, or report encouragers more frequently. However, our sample size is very small at this level, and more research into the internalisation of and response to these symptoms is needed.

The primary care interval (the time spent under care of a primary healthcare professional) is often the largest component of post-appraisal diagnostic delay and this is supported by our findings.[47] However, those first seeking hospital-based care appeared equally likely to report an SDI of 6 months or more, when compared to those seeking primary care. This suggests that the interval spent in hospital-level care may be shorter when first approaching a primary care HCP. Longer-term relationships with a primary HCP, which seem important in the decision to seek care in the first place, may support this acceleration.

Our study found those reporting a good experience at their first appointment were less likely to report delay than those reporting a poor or neutral first experience. However, the cause-and-effect nature of this relationship is unclear. It is possible that experiencing delay makes a patient more likely to report poor or neutral experiences and more research is needed to clarify this.

Those diagnosed in the publicly-funded healthcare system were more likely to report delay, supporting localised research in the United States which indicates that those diagnosed in the private sector were more likely to be diagnosed at an early stage.[49] Delay does not appear to be associated with insurance status. Those in public care do not seem to seek care later, indicating the difference may lie in the care received or resources available in the public system. Regardless of insurance status, it is likely that socio-economic status is related to this finding – whereby wealthier New Zealanders are able to afford to pay for private healthcare services out-of-pocket to hasten diagnosis and poorer New Zealanders do not have such access, leading to inequities.

Another possibility is that any patients delayed in private healthcare eventually end up in the public system, as their condition progresses. We did not collect specific data on this

point but note several reports of healthcare-seeking in the private system, followed up in the public system, usually via an Emergency Department. In these cases, delays were recorded under the public system as the system of diagnosis. However, we did not find those diagnosed in the public system to report significantly more total HCP visits, prior to diagnosis. Regardless, it is concerning that it appears public care exaggerates delays. Public funding is a limited resource, and its allocation is oft-debated.[50] This allocation stands to make an enormous difference to outcomes.

The majority of our sample first approached a non-professional, then their GP. This was also where the most visits to an HCP in each individual's pathway were spent. This reliance on primary care keeps strain off hospitals but suggests many are being turned away. We note many repeat visits, more so in primary care than in hospital-level care. Free-format responses in our questionnaire suggested that much effort was needed, on the part of the patient and the primary HCP, to reach further care. Once a referral was put through, wait times also appeared long. Many reported needing to be accelerated after re-visiting their GP or presenting to ED.

For those unsure about the significance of their symptoms, or who are unable to communicate their concerns to their GP, the consequences of this are potentially serious. Programmes like that for direct access to colonoscopy aim to prioritise care but our results suggest that, in some cases, this is insufficient. Careful planning must be undertaken to optimise this system. It is encouraging, however, to see that very few patients in our sample reported a declined referral to hospital-level care. Several patients reported mis-diagnosis and confusion about their diagnosis in free-format sections. Examples of these included kidney stones, appendicitis and diverticulitis. Many were confused at the time of diagnosis - several were reassured by their HCP that they did not have cancer. This suggests poor communication in many cases, though communication is integral to the functional doctor-patient relationship.[51]

The primary limitation in this descriptive study is our sampling.

Our sample was young - two-thirds of patients responding were diagnosed under the age of 60. This is a minority group when looking at CRC diagnoses in New Zealand, with those under 64 accounting for 29% of new registrations in 2015, and 78% of our sample.[1] However, their experience is particularly important as the nationwide screening programme, targeting those aged 60 - 74, is implemented.

In New Zealand, females with bowel cancer are also the minority.[1] In our patient-reported sample, they were the vast majority. The effect of this on our results is debatable. Females in the US, at least, may be more risk-averse, suggesting they may seek care earlier.[52, 53] However, a Spanish study into CRC SDIs found women to report significantly longer SDIs.[25]

The patient-reported distribution of tumour sites loosely resembles that expected. Staging aligns with expected values when split into earlier (I and II) and later (III and IV) brackets, but not when considered individually.[2] Symptom prevalences can be validated against those previously determined in the US, against which we did not find any overwhelming variation.[54]

Our sample was therefore younger, with more females and fewer metastatic cases than the population diagnosed with CRC in New Zealand.[1] This sampling introduces potential confounders, the effects of which are unknown. Given that our participants are not representative of the New Zealand population diagnosed with CRC, it is important for further studies with larger, more representative samples, to be undertaken. We also relied on self-reported data, which we could not verify against routinely collected data sources. Several relationships, such as those between SDI and ethnicity or symptom intermittency, did not reach statistical significance in our sample but appear worthy of investigation in future studies.

Despite these limitations, we have contributed first insights into the patient perspective of the pathway to diagnosis for a major cancer in Aotearoa/New Zealand. Our findings are potentially relevant for three main groups: the general population, HCPs, and policymakers.

- Firstly, for individuals in the general population, although symptoms were the primary driver of healthcare-seeking, attribution of non-specific symptoms to a serious cause was uncommon in our sample. This suggests that greater awareness of common symptoms may be required, which can direct future education initiatives. It is also possible that awareness about the importance of reporting intermittent symptoms to HCPs is also a useful focus for public awareness campaigns.

- Secondly, for HCPs, we have confirmed general practice as an important source of care in the diagnostic pathway. Delays in diagnosis appear prevalent, and several groups appear to be at particular risk. Careful attention must be paid to Māori, those aged < 60 years, and those with less formal education.

- Finally, for policymakers, we have provided first insights into the patient pathway and have suggested areas worthy of investigation in future studies. Potential associations between delayed diagnosis and publicly funded care, in particular, ought to be investigated further.

While our results are not directly applicable to the population diagnosed with CRC in New Zealand, we have provided some of the first data points, established areas for further consideration and indicated early areas for improvement in the diagnostic process. With careful consideration and future research, New Zealand has the opportunity to transform this process, and the lives of thousands of people.

Adapted from a patient report:

Vile-smelling sludge gushed from my mouth into the hand basin, over the bathroom floor. I knelt by the toilet, clutching the bowl for support, rattled by what was happening. Constipation wasn't new, but faecal vomiting was. It was as unpleasant as it sounds.

For the first time, I suspected bowel cancer, and wondered at my chances.

As medics wheeled me to the ambulance, my elderly neighbour stood by in her nightgown, in tears. She didn't believe my reassurances I'd be okay. Neither did I. Nor did my wife, stunned by another health crash, when I told her to leave the mess - I'd be back later in the day to clean up.

My estimate of when I'd be home was wrong by three weeks.

At the hospital, scans revealed a tumour blocking my bowel. It needed urgent removal.

"You may require a stoma," the surgeon said. "How do you feel about that?"

Chilled, stunned. A stoma meant colostomy bags. Others had those, not me. Could I cope? Defecating through a hole in my stomach? I didn't know. I'd never thought about it. And there was no time to dwell on it, either. An orderly had arrived to wheel me to the theatre.

"Anything that will save my life, do it."

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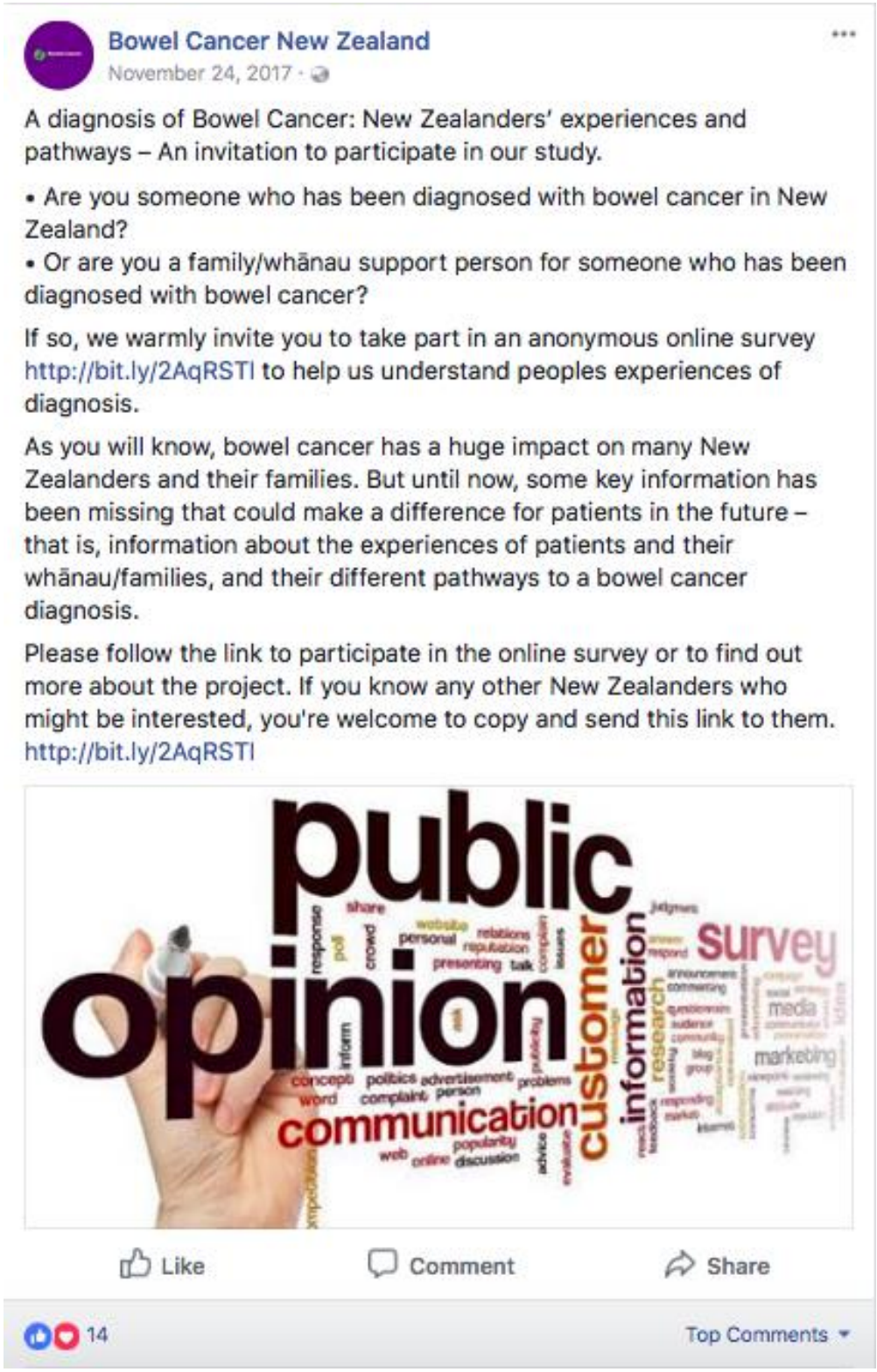
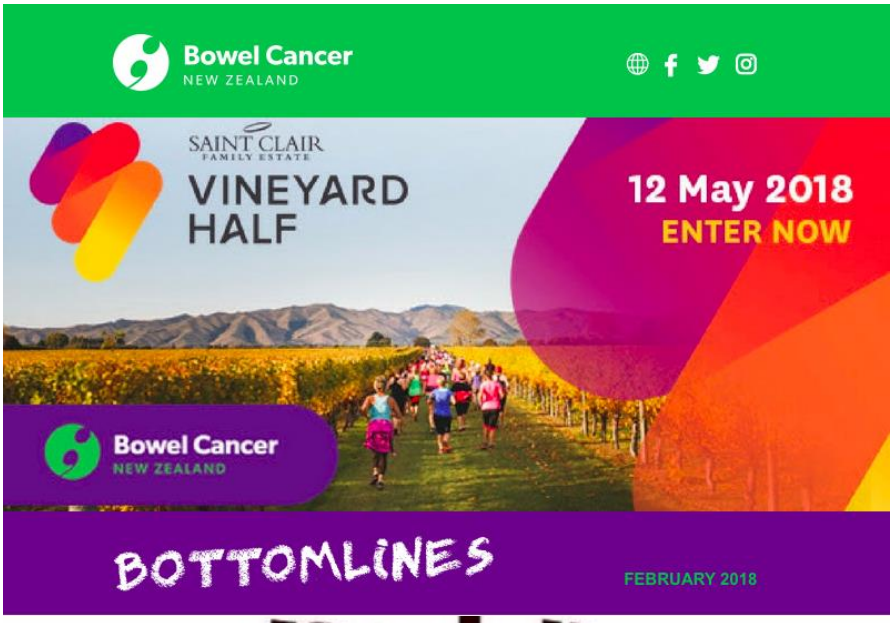
Appendices

Appendix 1: Example of Facebook advertisement





Patient Pathway Survey

A diagnosis of bowel cancer: New Zealanders' experiences and pathways.

- Are you someone who has been diagnosed with bowel cancer in New Zealand?
- Or are you a family/whānau support person for someone who has been diagnosed with bowel cancer?

If so, we warmly invite you to take part in an anonymous online survey.

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Thursday, 11 January 2018

Bowel symptoms often ignored

By Eileen Goodwin (/author/Eileen%20Goodwin)

"Powerful" stories are emerging in a study of bowel cancer sufferers that will highlight symptoms people often ignore.

University of Otago medical student Zoe Windner (19) said people in their 20s and 30s were among about 100 bowel cancer cases in her summer grant study.

"You see the numbers, you see 3000 people are diagnosed per year, but the work I am doing, I am seeing their stories and what is happening to them and their families, and that's really powerful."

The study looks at how long it took for people to be diagnosed, and what prompted them to seek medical attention.

In some cases family members are taking part on behalf of patients who had died.

Embarrassment about symptoms like blood in stools could delay diagnosis.

"We're trying to look at the different things that might encourage or discourage someone from seeking that help in the first place."

Zoe Windner.

Miss Windner had noticed anaemia and iron deficiency were often ignored.

"For some people, that might be the only symptom.

"Some of the ones you might not associate with bowel cancer ... those are really common, but people just don't recognise them."

A change in bowel habits was often ignored too - "people don't think it could be as serious as bowel cancer".

What triggered patients to seek help was usually "blood, pain, and weird out of the ordinary things", such as feeling a lump.

Miss Windner said there were fewer cases than she had expected of patients being denied care due to waiting lists.