Methods of a national colorectal cancer cohort study: the PIPER Project

Melissa J Firth, Katrina J Sharples, Victoria A Hinder, Jerome Macapagal, Diana Sarfati, Sarah L Derrett, Andrew G Hill, Charis Brown, Papaarangi MJ Reid, Ross A Lawrenson, Carol Atmore, John P Keating, Mark Jeffery, Adrian H Secker, Charles De Groot, Christopher GCA Jackson, Michael PN Findlay

ABSTRACT

AIM: Colorectal cancer is one of the most common cancers, and second-leading cause of cancer-related death, in New Zealand. The PIPER (Presentations, Investigations, Pathways, Evaluation, Rx [treatment]) project was undertaken to compare presentation, investigations, management and outcomes by rurality, ethnicity and deprivation. This paper reports the methods of the project, a comparison of PIPER patient diagnoses to the New Zealand Cancer Registry (NZCR) data, and the characteristics of the PIPER cohort.

METHOD: National, retrospective cohort review of secondary care medical records (public and private) of all cases of ICD-10-AM C18-C20 on the NZCR in the calendar years 2007 and 2008 (main cohort) and an extended sample of Māori and Pacific cases, and non-Māori non-Pacific controls in 2006 and 2009 (extended cohort).

RESULTS: Of the 6,387 patients identified from the NZCR 5,610 (88%) were eligible for PIPER. Reasons for exclusion were non-adenocarcinoma histology (3%) and non-colorectal primary (2%). Data were collected on 3,695 patients with colon cancer, 1,385 with rectal cancer and 466 with cancer of the recto sigmoid junction.

CONCLUSIONS: The PIPER Project has generated comprehensive population level data detailing the diagnosis and management of colorectal adenocarcinoma in New Zealand. This will be used to assess the care provided to patients, and the impact of variations in care occurring between patient groups.

Colorectal cancer (CRC) is the second most common cancer in New Zealand (with 3,016 new cases in 2012) and the second-leading cause of cancer-related death.[1] Australia and New Zealand have similar incidence rates; the highest recorded worldwide.[2] Multiple studies, however, suggest survival post-CRC diagnosis is lower in New Zealand.[3–7] Differences in survival are likely due to both diagnostic and treatment factors.[3,7] Identification of these factors requires detailed investigation of the access to, and quality of, care for patients with CRC in New Zealand.

Professional guidelines relating to the optimal management of CRC exist, but there are no mandated minimum quality standards for delivery of CRC care in New Zealand. Previous attempts at comparing outcomes, for example via the Colorectal Surgical Society of Australia and New Zealand audit are limited by incomplete population coverage. A National Cancer Tumour Standards work programme is underway, but—at the time of writing—standards remain provisional.[8] Audits undertaken to date against these provisional standards are not uniform nationally, are not mandated, are not reported centrally, and results have not been published.

Disparities in survival post-CRC diagnosis are known to exist between groups of patients based on rurality, ethnicity and socioeconomic status.[9–14] Although CRC incidence is lower in rural areas and among Māori, once diagnosed, these groups are more likely to die of the disease compared to urban and non-Māori groups.[9–11] These disparities are not fully explained by

differences in stage at diagnosis. Some residual confounding is likely because stage at diagnosis is an imperfect measure of disease status. It is also possible, however, that variation in care post diagnosis is affecting survival outcomes. Reasons for poorer survival for Māori with colon cancer have been explored; several differences in quality of care indicators were found that were not explained by measured disease variables (such as stage at diagnosis) or patient characteristics.[11]

Pacific peoples also have substantially lower incidence rates of CRC, however estimates of survival are quite unstable due to small numbers; further research into the care received by Pacific patients, and their outcomes is needed.[12] Deprivation status and household income have also been suggested to adversely affect cancer outcomes in CRC patients in New Zealand,[13,14] over and above the influence of disease stage at diagnosis and ethnicity.[14]

Given the high incidence and within-population disparities in outcome, we hypothesised that health service factors relating to CRC treatment, as well as patient and disease characteristics, were likely to negatively impact on outcome. The objectives of the PIPER Project (Presentations, Investigations, Pathways, Evaluation, Rx [treatment]) were:

(i) to describe the patterns of presentation to secondary care, diagnosis, staging, treatment, follow-up and survival

(ii) to compare these patterns according to rurality, ethnicity and deprivation

(iii) to investigate the relationship between these factors and outcome (cause specific and overall survival).[15]

The PIPER Project is a national, retrospective cohort study including all patients diagnosed in New Zealand with colorectal adenocarcinoma in 2007 and 2008, along with an extended cohort (2006 and 2009) for analysing patterns of care for Māori and Pacific patients. The project is the largest of its kind conducted in New Zealand to date and utilises data collected directly from medical records, including from the private sector.

In this paper we report the methods of the PIPER Project, compare the CRC diagnoses recorded by PIPER to those on the New Zealand Cancer Registry (NZCR), and describe the characteristics of the patients included in the PIPER cohort.

Methods

Study population: All registrations for CRC (ICD-10-AM codes C18-C20) in 2006–2009 were provided by the NZCR[16] in a data set extracted on 17 May 2012. The NZCR is the central repository for all new cancer diagnoses (excluding non-melanoma skin cancers) that occur in New Zealand, as mandated by the Cancer Registry Act 1993.[16] In New Zealand, all patients are allocated a unique health system identifier, known as the National Health Index (NHI); this was used to link people across different health-related data sets such as the registry, the mortality collection and medical records.[17]

Two cohorts of patients were selected: (i) Main cohort: patients diagnosed between 1 January 2007 and 31 December 2008. This period was chosen to be recent enough to be relevant to current resource planning (given the relatively minor changes in management since that time) and provide sufficient follow-up time (6–7 years); (ii) Extended cohort: this comprised all participants in the main cohort as well as all Māori and Pacific patients diagnosed between 1 January 2006 and 31 Dec 2006, and 1 Jan 2009 and 31 Dec 2009, to provide greater numbers of Māori and Pacific patients for subsequent analyses. To obtain comparative data over the extended time frame we added a stratified random sample of non-Māori non-Pacific (nMnP) patients also diagnosed in 2006 and 2009. The stratification factors were year of diagnosis (2006, 2009) and cancer centre region (cancer services are delivered via six regions: Auckland, Waikato, MidCentral, Capital and Coast, Canterbury, and Southern District Health Boards); the number of nMnP patients selected matched the total numbers of eligible Māori and Pacific patients in each stratum.

We included all patients whose diagnosis of adenocarcinoma of the colon or rectum was confirmed by either histology, radiology or visualisation of tumour (during colonoscopy, sigmoidoscopy or surgery). Exclusion criteria were: date of diagnosis outside 2007–2008 for patients in the main

cohort, and outside 2006 and 2009 for the extended cohort; patients with recurrent disease (this included recurrent tumour at the site of a previous tumour, at the anastomosis following previous surgical resection of a CRC, or new metastatic disease on the background of a previous CRC tumour); patients who presented, were diagnosed, or received treatment for their primary CRC outside New Zealand; and patients who were not residents of New Zealand at the time of diagnosis. Cases were checked for eligibility by review of public and private secondary care clinical records. We defined date of diagnosis as the date of the first pathological report confirming CRC (where pathology was available). This date is often later than the date recorded on the NZCR, creating some shift in cohorts between NZCR diagnosis date and PIPER diagnosis date. The scope of the project did not include going back through NZCR late 2006 diagnoses to check if these would have fallen in the 2007 cohort as per the PIPER definition.

Data sources: Data were obtained from three main sources: i) retrospective review of patients' clinical records (from both public and private sectors) from the first presentation to hospital care resulting in the diagnosis of CRC until the time of case-review; ii) the national databases of hospital discharge diagnoses (National Minimum Dataset, NMDS) and mortality (Mortality Collection); iii) national data used to derive New Zealand Deprivation Index (a measure of deprivation based on regularly collected National census data)[18] and rurality for meshblocks of residence, and the GPS coordinates of meshblock centroids. A meshblock is a New Zealand-wide system of identifying geographical units, and is the smallest geographical unit for which Statistics New Zealand collects and provides statistical data.[19] National database data were merged with the clinical data using NHI numbers.

Demographic characteristics: Date of birth, gender and ethnicity were determined from NZCR data. Ethnicity fields on the NZCR are continually updated based on hospital and mortality data to improve accuracy[16] with a prioritisation process allowing for multiple ethnic affiliations to be recorded, with priority ordering to Māori followed by Pacific groups, Asian groups, other groups and New Zealand European.[20] Ethnicity data from hospitalisation events are self-determined from patients or their families using a standard question allowing multiple categories of ethnicity.[20] Data on all hospital discharge diagnoses were obtained from the NMDS from five years pre-diagnosis to estimate baseline comorbidity levels. Previously validated ICD-10 codes were used to identify these conditions.[21]

Rurality was assessed for each patient according to their residential address at the time of diagnosis. A Statistics New Zealand 2011 meshblock was assigned to each of the addresses using QAS Batch software by Experian™. This was then mapped to 2006 meshblocks, the closest to our main cohort. We used the Statistics New Zealand urban/rural profile classification system to obtain a rurality classification. This assigns meshblocks to one of three urban and four rural categories based on the dependence of the meshblock on a main urban area (assessed by comparing residential and employment addresses).[22] In our main analyses we grouped the seven categories into two categories, urban and rural, as recommended by the National Health Committee: rural = rural areas with moderate urban influence, rural areas with low urban influence, highly remote/rural areas and independent urban communities; non-rural = main urban areas, satellite urban communities and rural areas with high urban influence.[23] Centroid coordinates were also assigned to each meshblock to calculate a measure of travel distance to the diagnostic or treatment centre.

A deprivation score was assigned to each patient using the NZDep 2006 Index of Deprivation, which provides an area-based measure of deprivation for each meshblock (derived from New Zealand Census data) in deciles based on census variables such as financial benefit receipt, earning under an income threshold, housing tenure, and access to car or phone (1=lowest level of deprivation and 9=highest level of deprivation).[18] The NZDep score was assigned to each of the patients' addresses. Data presented in this paper uses the rurality category and the NZDep score of the address recorded for the patient at the time of diagnosis.

Key Performance indicators (KPIs) for measuring quality of care: PIPER's inves-

tigators and advisory group members consisted of individuals with expertise in colorectal surgery, medical oncology, radiation oncology, Māori health, Pacific health, general practice, rural health, patients' perspectives, biostatistics, health management, and clinical data collection. We identified a list of KPIs based on national and international guidelines.[24–28] A list of the data fields required to assess these KPIs was developed and piloted, with amendments based on availability and completeness of data in hospital notes. Data collected included patient demographics and co-morbidity, method of referral to secondary care, First Specialist Assessment (FSA), diagnosis, disease characteristics, cancer treatment, timelines, follow-up and outcome. A full list of data fields collected is provided in (Table 1).

The following fields were deemed unable to be collected during the pilot phase, due to a high proportion of missing data: baseline aspirin/ NSAID use; age of family member diagnosed with cancer (medical history); pre-chemotherapy height and weight; Eastern Cooperative Oncology Group (ECOG) performance status; planned duration of chemotherapy; response to chemotherapy; stage of disease as recorded by medical or radiation oncologist.

Outcomes: Data on disease outcomes were collected in the clinical record review (Table 1). Data on all hospital discharge diagnoses (adverse events) from 1 Jan 2001 (pre-CRC diagnosis) to post-CRC diagnosis until 10 April 2014 (date of extraction) were obtained from the National Minimum Dataset. Mortality data were obtained from the Mortality Collection, which provided mortality data to 28 Feb 2015 and coded cause of death until 31 Dec 2013.

Data collection: Clinical data were extracted from local hospital databases, patient electronic records and hard copy medical files. Data for patients treated in the private sector were collected from private clinicians' medical records following the clinician's written agreement. Data collection for each patient was carried out by regional data managers, trained in the use of PIPER's standardised data collection manual. Data managers reviewed potential cases for eligibility based on the DHB of domicile of the patient as recorded on the initial NZCR data set. If no information or no relevant (eg, cancer-related) information was found at the centre closest to the patient's domicile, a check against the national database of hospital admissions was undertaken to identify patients who may have been diagnosed or treated in regions other than their DHB of domicile as recorded by the NZCR. Data were extracted and either written onto a case report form and then entered into the project database, or entered directly into the project database. In each field the "Unknown" category refers to fields that were still unknown after all available information for the patient had been reviewed.

The PIPER Project database: A central Microsoft Access database was designed, developed and maintained by Cancer Trials New Zealand. This is housed on the University of Auckland secure server and is accessible only by secure log-on and password. Data managers at external sites accessed the database via remote sessions to the host server, which required individual user log on and password. Data sourced from national databases were also stored in a Microsoft Access database housed on the secure server. Data were anonymised for analysis.

Quality control: The database was developed using the fundamentals of good database design, including branch logic, limited field entry and dropdown lists to attain quality data entry. Reports were produced to ascertain completeness of data collection for individual patients. The following steps were taken to maintain consistent data extraction across the various centres: data managers underwent induction by the project manager; a data collection manual was developed which contained a definition for each data field and suggested documents to obtain the data from, listed in order of priority or relevance if more than one source was identified; the project manager made two visits to each site to conduct duplicate data extraction with review and feedback of any issues; queries on clinical data were reviewed by the project manager or clinical investigators and discussed at monthly data manager teleconferences. Checks were carried out across all sources of data to identify incongruities, including date order checks and

Table 1: Summary of the PIPER Project Data Fields.

Demographics	**Treatment**
Patient ID Date of Birth Gender Ethnicity	Not for active treatment Date of decision not for active treatment First treatment received Surgical referral Surgical FSA Surgical FSA date Primary resected Other cancer-related surgical procedure Surgical procedure Indication of surgery Date of surgery Date of discharge Length of stay Main surgical procedure Return to theatre Anastomotic leak 30 day mortality 90 day mortality Myocardial Infarction (MI) Pulmonary Embolism (PE) Completeness of excision Endoscopic excision only Multidisciplinary review Medical Oncology (MO) referral MO FSA MO FSA date Offered chemotherapy Chemotherapy regimen Chemotherapy start and stop dates Duration of chemotherapy Stopped chemotherapy early Reason for stopping chemotherapy Radiation Oncology (RO) referral RO FSA RO FSA date Offered radiotherapy Radiotherapy treatment regimen Radiotherapy start and stop dates Completeness of radiotherapy treatment Incomplete radiotherapy due to toxicity
Presentation	
Method of referral Date of referral Evidence of obstruction Date of First Specialist Assessment (FSA) FSA Department Emergency presentation to secondary care	
Staging	
Initial diagnosis method Date of initial diagnosis Site of primary tumour Tumour sidedness Synoptic pathology report Post-op T stage Post-op N stage Post-op M stage No. lymph nodes examined No. positive lymph nodes Lymphovascular invasion Tumour differentiation Distance of tumour to circumferential margin Mesorectal quality Computed Tomography (CT) of abdomen/pelvis CT chest Colonoscopy Completeness of pre-op colonoscopy Sigmoidoscopy Pre-operative stage Post-operative stage Stage at start of adjuvant therapy Completeness of staging	
Follow up	
Date of follow-up visit Department of follow-up visit	
Progressive Disease	**Outcome**
Site of first progressive disease Date of diagnosis of first progressive disease Method of diagnosis Treatment of progressive disease yes/no Surgical treatment detail Chemotherapy treatment detail Radiotherapy treatment Interventional radiology treatment detail	Reversal of stoma Diagnosis of metachronous tumour Diagnosis of new primary disease Date last seen For those who died: - cause of death - date of death

cross checks of related variables. Queries generated by these checks were forwarded to the regional data managers or to the project manager for resolution. Free text fields on the database were coded by an investigator or advisor with the appropriate expertise. Final cohort membership was determined based on the PIPER date of diagnosis post final data cleaning.

Statistical methods: Analyses are stratified by cancer site (colon vs rectal). The demographic and clinical characteristics of the cohort are described using appropriate numerical summary measures and graphs. Comparisons between groups (rurality, ethnicity and deprivation) in terms of presentation, staging, treatment and management (Table 1) are adjusted for: age, stage, co-morbidity and other prior factors (as appropriate), using generalised linear models.[29] Specific analyses are carried out for comparisons by ethnicity, using data for patients diagnosed in 2006–2009, using sampling weights to allow for the sampling of nMnP patients in the years 2006 and 2009. For each site and stage, where numbers permit, statistical models (including Cox regression and competing risk models) are used to explore the factors that may determine differences in patient outcome (cause-specific survival and overall survival) by rurality, ethnicity and social deprivation.

Sample size justification: Sample size calculations were done for the main PIPER cohort, years 2007 and 2008 (n=4,950), as some analyses are limited to this group. Of the 3,630 colon cancer patients and the 1,165 rectal cancer patients with known rurality in the main cohort, 26% lived in rural areas at diagnosis. To detect a difference in proportions meeting KPIs between urban and rural patients of 0.11 at the 0.05 level (2-sided) with a power of 80%, we would need 840 patients. Thus we have at least 80% power to detect differences in KPIs as small as 0.11 for the colon cancer group, the rectal cancer group, for stage II and III colon cancer patients (n=1,016 and 916 respectively), the group with non-metastatic rectal cancer (n=912) and the group with metastatic colorectal cancer (n=1,098). For evaluation of care for Māori and Pacific patients we use the extended PIPER cohort. The total number of Māori patients, with a known diagnosis, over the four years was 445. Of these, 308 had a diagnosis of colon cancer (including recto-sigmoid) and 137 rectal cancer. With these numbers we have 80% power to detect differences in proportions greater than 0.17 between Māori and nMnP at the 0.05 level in the overall comparisons and stage-specific comparisons. There were a total of 133 Pacific patients with a known diagnosis; 78 with colon cancer and 55 with rectal cancer. The smaller number of Pacific patients (even using total ethnicity rather than prioritsed ethnicity), means we have 80% power to detect differences greater than 0.3.

Project approval and conduct: Ethical approval for this project was granted by the Multi-Region Ethics Committee (reference number MEC/12/EXP/022). Approval was granted for data to be collected without individual patient consent. The project was overseen by the PIPER Study Management Group.

Results

There were 5,612 diagnoses of CRC registered on the NZCR during the years 2007 and 2008. In the extended cohort, there were an additional 244 Māori patients, 99 Pacific and 432 nMnP patients. This gave 6,387 potentially eligible cases for review. Of these 6,387 patients, 5,610 (88%) were determined to be eligible for the PIPER study. Exclusions included: non-adenocarcinoma morphology (n=172; 2.7%); no evidence of CRC found in the available clinical records (151; 2.4%); diagnosed outside study years (147; 2.3%); non-colorectal primary (120; 1.9%); no clinical records available on the patient (67; 1%); diagnosed or treated outside New Zealand (58; 0.9%); recurrent disease (47; 0.7%); not a New Zealand resident (10; 0.2%) and clinical diagnosis only (ie no pathology or radiology to confirm diagnosis (5; 0.1%)). Review of eligibility by patient variables demonstrated little variation by rurality and deprivation status, however Māori and Pacific patients had a greater proportion ineligible due to non-adenocarcinoma (6% for Māori and 7% for Pacific compared to 2% in nMnP).

Comparison of site of primary cancer collected for the PIPER project compared to that recorded on the NZCR showed reasonable consistency for colon cancer; of the 3,695 patients with colon cancer according to the PIPER notes review, 3,565

Table 2: Site of primary tumour as found in the PIPER Project compared to that recorded on the NZCR.

PIPER site of cancer										
NZCR site of cancer	Colon		Rectum		Recto-sigmoid		Unknown			
	N	%	N	%	N	%	N	%	Total	%
Colon	3,565	96.5	72	5.2	118	25.3	56	87.5	3,811	67.9
Rectum	54	1.5	1,226	88.5	140	30.0	6	9.4	1,426	25.4
Recto-sigmoid	76	2.1	87	6.3	208	44.6	2	3.1	373	6.6
Total	3,695	100.0	1,385	100.0	466	100.0	64	100.0	5,610	100.0

(97%) were classified as colon cancer on the NZCR (Table 2). Greater variability was seen with rectal cancer; of the 1,385 classified as rectal cancers in PIPER, only 1,226 (89%) were classified as rectal cancer on the NZCR. The remaining 11% of cases classified as rectal in PIPER were recorded on the registry as being located in the rectosigmoid (6%) or in the colon (5%). The discrepancy is due in part to differences in the source of information (PIPER used the operation note where this was available, as opposed to the pathology report which is used by the NZCR) and in part to the difficulty in classifying cancers near the rectosigmoid junction. Tumours classified as being located in the recto-sigmoid in PIPER showed the greatest variability with 208/466 (45%) also being classified as recto-sigmoid by the NZCR.

Characteristics of the PIPER patient cohort

The number of cases included for each year, based on date of diagnosis, by site of primary tumour and prioritised ethnicity is given in Table 3, illustrating the sampling for the extended cohort (years 2006 and 2009). Across the four years, the estimated percentages of patients whose tumour site was the colon, rectum and recto-sigmoid junction were 66%, 25% and 7% respectively. For 2%, the tumour site was unknown. These percentages are weighted back to the population according to the sampling weights. Table 4 presents the numbers and percentages of patients by demographic characteristics for colon, rectal and recto-sigmoid cancers (also weighted back to the population). Overall 5% of the CRC population were Māori and 1% Pacific, reflecting the lower CRC incidence among Māori and Pacific.

Discussion

The PIPER project has generated a data set of over 960,000 data points for 5,613 patients diagnosed with CRC in New Zealand. Cases were identified from the mandatory population-based NZCR. We observed a reasonable level of accuracy with respect to CRC diagnosis on the NZCR; 2% of those coded as ICD-10-AM codes C18-20 were found to have a non-colorectal primary on hand search of the medical record. For a further 2.4% we found no evidence of cancer in their medical records; however these cases included people diagnosed and managed conservatively outside the secondary care setting, or patients who were managed solely within the private sector but for whom no private sector records could be accessed. Secure storage, filing and access to retired practitioners' records in the private sector were found to vary greatly between individuals, and complicated data retrieval. We confirmed that the majority of cases of C18-C20 recorded on the NZCR are adenocarcinoma morphology (97%).

Further work is planned to compare the data held by the NZCR and the PIPER data. The classification of primary site as colon or rectum varied between the registry and the PIPER data set, particularly for rectal and recto-sigmoid cancers. This is likely to be due to differing definitions; in PIPER we classified site of primary disease by prioritisation from operation note, followed by pathological report for surgical specimen, followed by other pathological report (eg, biopsy post-colonoscopy), followed by colonoscopy report, and followed by other as written in medical record. The NZCR appears to use the first pathological diagnosis that would, for many cases, arise

Table 3: Numbers of patients with colorectal cancer included in the PIPER cohort by year of pathological diagnosis.

Year of diagnosis						
Site	**Prioritised Ethnicity**	**2006*** *N*	**2007** *N*	**2008** *N*	**2009*** *N*	**Total** *N*
Colon	Māori	64	60	60	72	256
	Pacific	21	9	18	18	66
	nonMāori - nonPacific	101	1,531	1,576	109	3,317
	Unknown	0	29	24	3	56
Rectum	Māori	34	39	22	42	137
	Pacific	12	10	13	20	55
	nonMāori - nonPacific	41	566	518	39	1,164
	Unknown	1	11	16	1	29
Recto-sigmoid	Māori	14	14	10	14	52
	Pacific	3	0	7	2	12
	nonMāori - nonPacific	12	178	189	14	393
	Unknown	0	6	2	1	9
Unknown	Māori	4	2	2	3	11
	Pacific	1	1	0	0	2
	nonMāori - nonPacific	0	18	16	12	46
	Unknown	0	3	0	2	5
All	Māori	116	115	94	131	456
	Pacific	37	20	38	40	135
	nonMāori - nonPacific	154	2,293	2,299	164	4,920
	Unknown	1	49	42	7	99
Total		308	2,477	2,473	352	5,610

*The cohort was extended to include patients diagnosed in 2006 and 2009 to provide more information on Māori and Pacific patients. All Māori and all Pacific patients were included, and a random sample of nonMāori-nonPacific patients.

from the colonoscopy pathology report. During data collection we noted regular variation between the site of disease as documented across multiple documents, eg, operation note versus discharge summary versus colonoscopy report; and between pathology report of endoscopic biopsy specimen and surgical specimen. For 1% of the study population, the site of primary disease was not able to be defined below the level of colorectal. This included patients for whom data were unable to be accessed, for example portions of the medical record (eg, volumes) were missing or access to private sector data were not approved by a private physician.

Data were collected from source documentation in both public and private medical records. While retrospective review presents challenges and limitations with respect to consistency and accuracy of data collection, we minimised the impact of this through: clear documentation of field definitions and source data; training, monitoring and regular meetings of project-specific data managers; and review of all available records and data sets for individual cases. Selection of the study cohort was considered to provide a balance between the age of the data and the ability to include a minimum of five-year follow-up for outcome assessment. There

Table 4: Demographic characteristics of the patients included in the PIPER cohort (so include patients in both the main and extension cohorts).

		Colon		Rectum		Recto-sig-moid		Un-known		Total	
		N	%†	N	%†	N	%†	N		N	%†
Gender	Female	1,944	52.28	521	33.92	194	34.64	31		2,690	46.63
	Male	1,751	47.72	864	66.08	272	65.36	33		2,920	53.37
Age at diagnosis	<40	66	1.24	29	1.98	11	1.50	0		106	1.42
	40–49	145	3.75	90	8.06	23	5.44	0		258	4.87
	50–59	368	10.84	226	16.21	66	10.60	13		673	12.45
	60–69	870	21.17	399	26.82	137	28.42	16		1,422	23.19
	70–79	1,261	36.39	399	31.49	145	35.48	15		1,820	34.89
	>=80	985	26.62	242	15.43	84	18.56	20		1,331	23.18
	Unknown Age	3		0		0		0		3	
Prioritised Ethnicity	Māori	256	3.87	137	5.62	52	7.28	11		456	4.60
	Pacific	66	1.00	55	2.26	12	1.68	2		135	1.36
	non Māori - nonPa-cific	3,317	95.13	1,164	92.13	393	91.04	46		4,920	94.04
	Unknown Ethnicity	56		29		9		5		99	
Rurality of residence at time of diagnosis	Urban	2,650	72.64	992	71.04	338	74.10	19		3,999	72.33
	Rural	954	27.36	357	28.96	120	25.90	9		1,440	27.67
	Unknown Rural	91		36		8		36		171	
New Zealand Deprivation Index of residence at time of diagnosis	1–2	714	22.25	262	15.58	83	19.92	3		1,062	20.36
	3–4	713	19.55	268	19.54	87	17.88	8		1,076	19.45
	5–6	801	19.69	278	22.92	105	19.86	6		1,190	20.52
	7–8	744	24.65	278	23.88	92	21.56	4		1,118	24.20
	9–10	612	13.87	256	18.08	88	20.77	7		963	15.47
	Unknown Dep	111		43		11		36		201	
Total	Total	3,695	100.0	1,385	100.0	466	100.0	64		5,610	100.0

†Percentages have been calculated weighted back to the population values using the sampling weights, to account for incomplete sampling of nMnP in 2006 and 2009. Percentages do not include unknowns.

have been limited changes to treatment practice of CRC in New Zealand in the interval between the cohort timeframe and the present day.

The data collected in PIPER will also allow us to investigate issues such as the group of data fields that were unable to be captured retrospectively from the medical records. We believe that this and on-going findings from the data set will highlight the need for a method of routine/prospective data collection across both the public and private sectors if we wish to continue to monitor quality of care provided to patients with CRC in New Zealand.

Conclusions

The PIPER Project has provided a population level, comprehensive data set detailing the diagnosis and management of CRC in New Zealand, a disease with significant disparities in outcome for patients in New Zealand. It provides a rich resource for studying the factors which may explain these disparities and further analyses of the collected data are currently underway.

Competing interests:

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Author information:

Melissa J Firth, Project Manager, Discipline of Oncology, University of Auckland, Auckland; Katrina J Sharples, Associate Professor of Biostatistics, Department of Mathematics and Statistics and Department of Medicine, University of Otago, Dunedin; Victoria A Hinder, Research Fellow/Biostatistician, Discipline of Oncology, University of Auckland, Auckland; Jerome Macapagal, Database Development Officer, Discipline of Oncology, University of Auckland, Auckland; Diana Sarfati, Professor and Co-Head of Department, Department of Public Health, University of Otago, Wellington; Sarah L Derrett, Associate Professor, Public Health (Health Systems and Public Policy) and Director – Injury Prevention Research Unit, Department of Preventative and Social Medicine, University of Otago, Dunedin; Andrew G Hill, Consultant Colorectal Surgeon, Counties Manukau DHB and Professor, South Auckland Clinical School, University of Auckland, Auckland; Charis Brown, Senior Research Fellow, National Institute of Demographic and Economic Analysis, the University of Waikato, Waikato; Papaarangi M J Reid, Associate Professor and Tumuaki, Te Kupenga Hauora Māori, University of Auckland, Auckland; Ross A Lawrenson, Professor of Population Health, National Institute of Demographic and Economic Analysis, the University of Waikato, Waikato; Carol Atmore, Foxley Fellow, General Practice and Rural Health, University of Otago, Dunedin; John P Keating, Consultant Colorectal Surgeon, Capital and Coast District Health Board and Clinical Senior Lecturer, Wellington School of Medicine, University of Otago, Wellington; Mark Jeffery, Consultant Medical Oncologist, Canterbury District Health Board, Christchurch; Adrian H Secker, Consultant Colorectal Surgeon, Nelson-Marlborough District Health Board, Nelson; Charles De Groot, Consultant Radiation Oncologist and Clinical Director, Radiation Oncology, Waikato District Health Board, Waikato; Christopher G C A Jackson, Consultant Medical Oncologist, Southern District Health Board and Senior Lecturer, Dunedin School of Medicine, University of Otago, Dunedin; Michael P N Findlay, Consultant Medical Oncologist, Auckland DHB; Professor of Oncology, University of Auckland; Director Cancer Trials New Zealand, Auckland.

Corresponding author:

Melissa Firth, Cancer Trials New Zealand, Discipline of Oncology, Faculty Medical and Health Sciences, The University of Auckland, Private Bag 92019, Auckland.
m.firth@auckland.ac.nz

URL:

https://www.nzma.org.nz/journal/read-the-journal/all-issues/2010-2019/2016/vol-129-no-1440/6970

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