The PIPER Project

An Internal Examination of Colorectal Cancer Management in New Zealand

Executive Summary & Conclusions

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Executive Summary

Background
Colorectal Cancer (CRC) is a major cause of morbidity and mortality in New Zealand (NZ), with 3030 new diagnoses and 1191 deaths reported in 2011. The report “Unequal Impact II: Māori and Non-Māori Cancer Statistics by Deprivation and Rural-Urban Status” found that rural residents were less likely to be diagnosed with CRC, but were more likely to die of the disease. Additionally, differences according to ethnicity are apparent. Māori have lower rates of CRC than non-Māori, however there are differences in treatments received and outcomes by ethnicity that are incompletely accounted for by stage at presentation. To date, little information has been available about incidence, treatment or outcome for people of Pacific ethnicities.

In response to a Ministry of Health (MoH) and Health Research Council of NZ (HRC) Request For Proposals (RFP) to support a project that would “examine bowel cancer from presentation, to diagnosis, through to management and include treatment outcomes” including reporting on “variations across NZ...to gain a greater understanding of the local context”, we undertook the PIPER Project (Presentations, Investigations, Pathways, Evaluation, Rx [treatment]) from 2011. We detail actual patient presentation, diagnosis, treatment and management data for a national cohort of CRC patients, including description of variations resulting from differences in ethnicity, location of residence and socioeconomic status.

We brought together a research team and advisory group with expertise in population health, general practice, rural health, medical and radiation oncology, general and specialist surgery, Māori and Pacific health, health management, as well as academic biostatisticians, health research staff and patient representatives.

Methods
We undertook a national retrospective cohort study of all NZ residents diagnosed with colorectal adenocarcinoma in NZ from 1 Jan 2007 – 31 Dec 2008. We included an extended cohort of all Māori and Pacific diagnosed 1 Jan 2006 - 31 Dec 2006 and 1 Jan 2009 – 31 Dec 2009, and a randomly sampled equal number of non-Māori non-Pacific (nMnP) cases over those same time frames, to enable adequate explanatory power.

A list of key performance indicators (KPIs) based on national and international guidelines were identified by the project Investigators and Advisory Group members as being the most likely indicators to capture quality of care across the various components of management of CRC. Several iterations were reviewed and a final version agreed upon. Data extraction from this initial list was undertaken for a pilot period of 4 months and timeliness of data collection and quality of data extracted (by means of proportion missing data for each field) was reviewed on the first 226 cases collected. On the basis of this review a final fields list was created and approved. Data for the study was collected from public and private medical records from across the country.

The main outcome measures were proportions of patients meeting KPIs relating to patient presentation, management, treatment and follow-up according to rurality, ethnicity or socioeconomic deprivation. In this report we present crude proportions that are not adjusted for age or gender. Thus comparisons between groups should be interpreted carefully, bearing in mind
the associations between patient and clinical characteristics outlined below. Comprehensive modelling to account for age, gender, disease stage, co-morbidity and other modifiers of outcome will be undertaken using the data generated from this study and published in academic peer reviewed journals. Once updated survival data is available, papers examining the relationship between KPIs and survival will be published.

Results

We hand-searched the medical records of 6387 patients, resulting in 5667 eligible patients. The process of data collection took over 9,000 hours. Over 960,000 individual data points were entered onto a sophisticated, purpose built database housed at Cancer Trials New Zealand (CTNZ). The pilot phase identified the following data fields that had missing data for greater than 25% of cases: age of family member with malignancy, ECOG performance status, planned duration of chemotherapy and response to chemotherapy.

Patient characteristics

Overall, 4193 (74%) were diagnosed with colon cancer, 1401 (25%) with rectal cancer. Site of tumour was collected preferentially from operation note (where available), and tumours denoted as rectosigmoid were grouped in colon cancer. Distance of tumour from anal verge was not documented clearly enough in the cohort to denote rectal location as upper, middle or lower. The site of the primary CRC was unknown for 73 (1%).

Of the patients with CRC, 8% were recorded as Māori (either within the medical record or on the NZ Cancer Registry (NZCR)), 3% as Pacific, and 2% as Asian. The proportions of Māori and Pacific CRC patients with rectal cancer (versus colon cancer) were 30 and 41% respectively, and the proportions of European and Asian CRC patients with rectal cancer were 24 and 26% respectively. The proportion of male CRC patients who had rectal cancer (versus colon) was almost twice as high as the proportion in females.

The proportion of colon cancers that were right sided (located proximal to the splenic flexure) was 51% and the proportion that were left sided (located at or distal to the splenic flexure) was 48%; sidedness was unknown for 1%. Females were more likely to have a right sided colonic tumour (57%); males were more likely to have a left sided tumour (54%). Our findings confirm the previously reported right to left shift in colon cancer4 and the previously observed male: female imbalance in sidedness. Site of primary tumour is relevant to epidemiologists and policy makers when considering different screening methods for colorectal cancer, and may also be relevant to tumour prognosis and chemotherapy response.5 There were no clear differences in cancer site by deprivation score, rurality of place of residence at diagnosis or distance from the health facility where their CRC was diagnosed.

The distribution of age at diagnosis differed by ethnicity, with Māori patients tending to be younger than nMnP patients. Pacific had a larger proportion under 60 at diagnosis than either Māori or nMnP. These population groups have different age structures from the nMnP population which needs to be considered, and this will be investigated in on-going analyses.

Comparison of ethnicity to deprivation, rurality, and distance of residence from health facility of diagnosis demonstrated strong relationships; these will need to be taken into account in order to understand patterns of care. A higher proportion of Māori and Pacific patients were living in deprived areas compared to nMnP patients. The proportions in quintile 9-10 (the most
The proportions deprived) were: Māori 41%; Pacific 45% and nMnP 14%. There was also a strong association between rurality and NZ Deprivation Index of residence at diagnosis. This is not a linear relationship from most urban to most rural, but a peak in deprivation was noted for independent urban areas: the areas with the greatest deprivation were the independent urban areas. These areas include “towns and settlements without significant dependence on main urban centres. Independent urban communities are urban areas (other than main urban areas) where less than 20 percent of the usually resident employed population's workplace address is in a main urban area e.g. Westport”. The proportions in the highest quintile of deprivation (9-10) were: independent urban 26%; urban 18% and rural 8%.

**Presentation to hospital care, and staging**

**Colon cancer**

The mode of first presentation was to the emergency department (ED) for 34% of patients with colon cancer as, compared with 44% for Māori and 51% for Pacific patients. In the UK, 21% of CRC patients have this mode of admission. In PIPER, 22% of patients with colon cancer presented with obstruction; the proportion was highest for independent-urban patients (28%).

The department of First Specialist Assessment (FSA) was surgical for 60% of patients with colon cancer and gastroenterology for 25% of patients. There was a statistically significant association between the department of FSA and distance to health facility of diagnosis, with those living 10-20km from health facility of diagnosis being most likely to present to gastroenterology. This may be linked to the size of the hospital where the FSA was undertaken, and the influence of facility of diagnosis on this finding will be investigated in further planned analyses.

Less than half the patients were completely staged, as defined by the presence of key diagnostic procedures. Completion colonoscopy was achieved either pre-operatively or within a year of diagnosis 61% of the time. The initial source of pathological confirmation of cancer was colonoscopy for 57% of patients.

**Rectal cancer**

The mode of first presentation was to the ED for 14% of patients with rectal cancer, compared with 21% for Māori and 24% for Pacific patients. 8% of patients presented with obstruction.

The department of First Specialist Assessment (FSA) was surgical for 67% of patients with rectal cancer and gastroenterology for 26% of patients. There was a statistically significant association between department of FSA and rurality, with those living in independent urban areas being most likely to present to a surgical department. Again as for colon cancer this may be linked to size of the hospital where the FSA was undertaken and will be further investigated.

Pre-treatment stage was not clearly documented for the majority of patients with rectal cancer, and so was categorised as "localised/regionally advanced" (non-metastatic) and "metastatic". Only a third of patients were completely staged as defined by the presence of key diagnostic procedures. Completion colonoscopy was achieved either pre-operatively or within a year of diagnosis in 62% of patients. The initial source of pathological confirmation of cancer was colonoscopy for 63% of patients.
Stage at diagnosis

**Colon Cancer**

- Stage I: 12%
- Stage II: 27%
- Stage III: 25%
- Stage IV: 24%

**Rectal Cancer**

- Non-metastatic (stage I-III): 76%
- Stage IV: 19%
- Unknown: 5%

Non-metastatic, unable to be further defined: 5%

Unknown: 7%

The stage of CRC at diagnosis is the single most powerful prognostic variable, and is the principal determinant of treatment. NZ has a relatively higher proportion of patients diagnosed with stage IV (metastatic) disease than other countries, Australia has 19% and 17% stage IV for colon and rectal cancer respectively, and the UK 17% for both stage IV colon and rectal. Higher proportions of metastatic disease were seen in Māori and Pacific patients: the proportions diagnosed with stage IV colon cancer being 32% and 35% for Māori and Pacific respectively, and for rectal cancer being 29% and 22% respectively. The stage distribution seen in NZ is that of an unscreened population, with the lowest proportion of cancers being stage I. Results from population screening trials demonstrate that the proportion of stage I CRC increases by 4-6% when screening is introduced, some areas having up to 18% stage I cancers. Although there was no clear pattern in stage at diagnosis by deprivation, it is noted that those in the group with most deprivation (Dep9-10) were least likely to be diagnosed with stage I disease.

Treatment

**Non-metastatic colon cancer**

Resection of primary disease was undertaken in 95% of patients with non-metastatic colon cancer. From this operation 90 day post-operative mortality was 5%, anastomotic leak rate was 4% and unplanned return to theatre rate was 6%. Definition and consistent reporting of anastomotic leak is challenging, and the proportion identified in this study is double what has recently been reported in the Colorectal Surgical Society of Australia and New Zealand (CSSANZ) Bi-National Colorectal Cancer Audit (BCCA) across Australia and NZ. However, this audit involved voluntary submission of data limited to participating centres and combined Australian and NZ data, thus it is likely that the proportion we report is a more accurate reflection of the overall NZ cohort during the timeframe of the study.

Examination of 12 or more lymph nodes was not recorded in pathology reports for a third of patients. Again this contrasts with the BCCA which found a median lymph node harvest of 15 nodes retrieved for colon cancer cases reported voluntarily to BCCA database between 2007 and 2014. Only 56% of pathology reports in our cohort were in synoptic (structured) form, written to include key prognostic information.
Of the patients with resected stage III colon cancer, 59% received adjuvant chemotherapy. Less than half of the treated patients completed 24 weeks of the initially prescribed adjuvant therapy.

**Non-metastatic rectal cancer**

Radiotherapy (RT) was received by 52% of patients with non-metastatic rectal cancer. Of the pre-operative strategies, 18% received short course and 82% received long-course. 10% of patients who received radiotherapy were treated post-operatively rather than pre-operatively.

Resection of primary disease was undertaken in 92% patients with non-metastatic rectal cancer. From this operation 90 day mortality was 3%. Anastomotic leak rate was difficult to identify with accuracy. Unplanned return to theatre rate was 8%.

Examination of 12 or more lymph nodes was recorded in pathology report for 49% of patients. 51% of pathology reports were in synoptic (structured) form, written to include key prognostic information. Mesorectal grading information was missing in 65% of reports. Distance to circumferential resection margin (CRM) was unknown for 37% of cases.

Adjuvant chemotherapy was received by 36% of patients with non-metastatic rectal cancer. Again completion of 24 weeks of initially prescribed chemotherapy was low – 47% of patients who had received pre-operative chemotherapy received at least 18 weeks of adjuvant chemotherapy and 41% of patients who did not receive pre-operative chemotherapy completed 24 weeks of initially prescribed adjuvant therapy.

**Metastatic colorectal cancer**

Resection of primary disease was undertaken in 52% of patients with stage IV disease; the proportions who had a resection of their primary disease were slightly higher in rural vs. urban (55% vs. 45%) patients. Most patients who had not had their primary removed did not have stoma (83%).

Overall 7% of patients had liver resection and 1% of patients had lung resection with no clear differences by ethnicity, distance or rurality but patients residing in NZDep Index 1-2 (least deprived) vs. 9-10 (most deprived) regions had a greater rate of liver resection.

Overall only 49% of patients with stage IV CRC received chemotherapy. There were no clear trends in proportion of patients receiving chemotherapy by ethnicity however these proportions were not adjusted by age or comorbidity therefore potential important findings may be discovered with later planned analyses. Un-adjusted proportions suggested that rural patients with metastatic CRC were more likely to receive chemotherapy than urban patients.

**Multidisciplinary Meeting (MDM) Discussion**

Overall two-thirds of CRC patients had no evidence of discussion at an MDM at any stage in their treatment. In the UK, during a similar time frame 82% of CRC cases were discussed at an MDM. In our study non-metastatic rectal cancer had the highest proportion discussed at an MDM (42%), followed by metastatic CRC (24%) followed by non-metastatic colon cancer (15%). Data from the BBCA audit suggests 51% of submitted rectal cancer cases were discussed at an MDM (from 2007-2014).
Conclusions

1. **High rates of emergency presentation**

   Over a third of patients with colon cancer presented to the ED, considerably in excess of the UK (21%). Further work is needed to better understand the pathway leading to diagnosis. This was not within the scope of the project.

2. **A high proportion of NZ patients are diagnosed with metastatic disease**

   The proportion of patients diagnosed with metastatic colon (24%) and rectal (19%) cancer in NZ is higher than in the UK (17% for both) and Australia (19% and 17% respectively) and is particularly high for Māori and Pacific patients (32% and 35% respectively for colon cancer). The implementation of a screening programme has the potential to shift stage at diagnosis. Again further work investigating the pathway leading to diagnosis is warranted.

3. **Improvements in pathology reporting are necessary**

   Just over half of the pathology reports reviewed for this study were in synoptic (structured) format. The Royal College of Pathologists of Australasia have undertaken significant work on developing structured and synoptic reporting since 2009. Universal structured/synoptic reporting would greatly assist quality national data collection.

4. **Chemotherapy intervention rates appear lower than expected**

   Less than 50% of patients with stage IV disease received chemotherapy, which is known to prolong survival. Barriers to receiving chemotherapy for stage IV disease require attention. Proportions receiving chemotherapy in non-metastatic CRC are also lower than expected.

5. **MDM discussion was low for this cohort**

   Our rates of documentation of MDM discussion were very low compared to international standards. Patients with non-metastatic rectal cancer were most likely to be discussed (42%) whilst across the same time frame 82% of all CRC cases were discussed in the UK.

The PIPER project is the most comprehensive colorectal dataset ever assembled in NZ, covering public and private sectors. It sets a foundation for future quality improvement initiatives and identifies several areas of research priority.
Areas for future consideration

- **The interaction between comorbidity, treatment and outcome requires careful consideration**

  Comorbidity appears to influence the proportion of patients receiving intervention. Future analyses of the PIPER dataset are planned to understand the relationship between comorbidity, ethnicity, deprivation, rurality, treatment received and outcomes. This will help inform the design of relevant future interventional and observational studies.

- **A high proportion of patients are elderly, and the optimal treatment paradigm for this group is unclear**

  Intervventional studies are needed in this area which will be well informed by further examination of the PIPER dataset for this age group.

- **Prospectively collected national data with quality assurance and coverage of private providers is needed to assist ongoing monitoring of quality service delivery**

  Standardised definitions are required and a minimum data set requires delineation. Such a data collection process would improve the capture of key fields that were abandoned during the pilot phase due to poor documentation. We anticipate that some data elements will need to be entered and captured manually, possibly expanding on the work of the Colorectal Surgical Society of ANZ dataset. Greater detail regarding non-surgical cancer care treatment and toxicity is also required.

- **Genomic correlation with clinical outcome data may yield valuable additional information**

  The integration of genomics and prognostic signatures with this dataset could provide an internationally valuable resource.
Concluding Statements and Future Recommendations

Outcomes from the PIPER Project – what have we learned?

The PIPER project provides the most comprehensive description of the presentation, diagnosis, and management of CRC that has ever been undertaken in NZ. One of the major strengths of the project has been the inclusion of data from the private sector, as well as the public sector, to ensure a genuine national overview.

The PIPER cohort was taken from 2007-2008, to enable a period of follow up and so that mature survival data are available for examining the influence of the key indicators described on disease outcomes.

During the intervening time, the major change in systemic therapy was the introduction of adjuvant oxaliplatin. Other changes in treatment included the broader utilization of PET, wider uptake of Enhanced Recovery After Surgery (ERAS) protocols, and the beginning of the Waitemata Bowel Screening pilot. While considerable policy changes have occurred since, the medical and surgical management of colon and rectal cancer has evolved slightly rather than radically.

Several key facts about CRC in NZ have been established and are covered in detail within the body of the report. These key facts include:

Tumour staging and patient characteristics:
- 12% of colon cancer was stage I, 27% stage II, 25% stage III, 23% stage IV, 5% non-metastatic not further classified, and 7% unknown;
- 76% of rectal cancer was non-metastatic, 19% metastatic and 5% unknown.
- 24% of patients are 80 or older;
- Māori and Pacific have higher proportions who present with metastatic disease;
- Despite hand-searching original clinical records we were unable to identify staging for some patients. This has important implications for understanding stage-specific survival, and comparing stage-specific outcomes against international data sets.

Presentation and clinical staging procedures:
- Emergency presentation with colon cancer was common, more so for Māori (44%) and Pacific (51%), but overall was much higher than comparable results from the UK, where the corresponding proportion is 21%;
- The proportion of patients with colon cancer presenting with obstruction was 22%;
- Minimum staging with CT abdomen/pelvis and complete colonoscopy with a year was incomplete in almost half of the patients.

Multidisciplinary team discussion:
- MDM discussion was not documented for 70% of patients with colon cancer, and was not documented prior to first treatment in rectal cancer for 65% of patients. In the UK, MDM discussion is mandatory, and the "not discussed" target is 0%.
Surgical outcomes
- 90 day post-operative mortality for rectal cancer was 3% and for colon cancer was 5%;
- Major post-operative complications such as PE and MI are recorded in fewer cases than in published literature. This suggests we may be under-capturing peri-operative morbidity;
- Anastomotic leak rates are challenging to capture using existing methods. To allow routine monitoring of this, changes to current methods of reporting will need to be made.

Pathology reporting:
- Synoptic (structured) reporting was evident for 56% of colon cancer patients and for 51% of rectal cancer patients;
- Mesorectal quality was unknown in 65% of rectal cancer specimens, and distance to mesorectal fascia (circumferential resection margin) was unknown in 37%;
- 34% of patients have fewer than 12 nodes examined, according to their pathology report.

Chemotherapy for stage 3 colon cancer:
- 59% of patients with stage 3 colon cancer receive adjuvant chemotherapy (26% of those with colon cancer are 80 or older);
- Less than half of the treated patients complete 24 weeks of full therapy.

Therapy for metastatic CRC:
- 49% of patients receive chemotherapy;
- 51% of those who present with metastatic disease and synchronous primary tumours (true stage IV disease) have primary tumour resection;
- 7% of those with metastatic disease (synchronous presentation) undergo liver or lung resection.

As expected with an ambitious project with a large dataset, many additional analyses are possible, and indeed many are planned. The impact of demographic, clinical and disease characteristics need to be taken into account, and the complex interplay between rurality, ethnicity, and deprivation needs to be explored, in order to identify inequities of treatment or outcome in more detail.

There are some areas that already stand out for comment:

1. High rates of emergency presentation

Why do so many people present to the emergency department with colon cancer? Why is it worse for Māori and Pacific? Are there barriers to patients accessing general practice (such as financial or structural), and is this worse for certain groups within our community? Do general practitioners have sufficient access to the necessary tools to investigate patients with symptoms? Do we need better tests to discern benign abdominal symptoms from ones which are more sinister? Is there sufficient awareness of the importance of bowel symptoms within the community?
2. The interaction between comorbidity, treatment and outcome requires careful consideration

Comorbidity appears to influence the proportion of patients receiving intervention. A wealth of domestic and international literature shows that comorbidity mediates treatment received, and that this negatively impacts on cancer-specific and patient-related outcome. How can we restructure our services in order to better address this major area of need? A rigorous health care implementation study, preferably randomized, could examine novel methods of service delivery in order to ensure that service intervention is evidence based and cost effective, and delivers meaningful health gains.

3. Genomic correlation with clinical outcome data may yield valuable additional information

We have a preponderance of right sided tumours, particularly in females. This is higher than in many other countries. Recent evidence suggests that right sided tumours may be biologically different to left sided tumours. We will analyse our data set according to right or left side, particularly for chemotherapy use, response and outcome. The integration of genomics and prognostic signatures (including immune scores) is likely to gain traction in clinical practice in the foreseeable future, and our dataset, if combined with archival tumour samples, could provide a very rich data source.

4. Improvements in pathology reporting are necessary

Our pathology reporting may need further attention, although it should be noted the Royal College of Pathologists of Australasia has undertaken significant work on developing structured and synoptic reporting since 2009. Until these structured reports are mandated and standardised the potential for lower quality information will persist. The pathology report remains a significant opportunity for routine data capture which is rich and meaningful. Standard 8 in the Standards of Service Provision for CRC stated that pathology reports be reported in synoptic format. There was not additional granularity about the content (such as number of lymph nodes retrieved, R status, distance to circumferential margin in rectal cancer) of synoptic reports.

Until we have more comprehensive coverage of synoptic reporting, many of our attempts to improve quality outcomes particularly in rectal cancer will be stymied.
5. **MDM discussion was low for this cohort**

Our rates of documentation of MDM discussion were very low. Multidisciplinary collaboration is increasingly important with greater sub-specialisation, and the broader range of therapeutic options that may improve survival for the modern patient. Concern persists within the Cancer Sector regarding regional variation in MDM functionality and capacity. The MDM has also been mooted by some as a potential mechanism of data collection – until we can be assured of greater coverage than we have seen in this report, then the MDM may not be an appropriate vehicle to capture data from the broader population.

6. **Chemotherapy intervention rates for stage IV disease appear lower than expected**

We treat less than half of our patients who have metastatic disease with chemotherapy, yet we operate on more than half. Resection of the primary tumour has not been clearly shown to improve survival, whereas chemotherapy can improve survival three-fold or more. Surgery is frequently undertaken for palliative reasons including obstruction, and few would question this approach. However given that deferred primary tumour resection is viable for many non-obstructed patients, we should not resile from discussing whether we have the emphasis and balance in managing stage IV CRC completely right.

7. **Surgical intervention with curative intent for stage IV disease**

7% of patients undergo secondary resection of metastatic disease. We do not yet know whether there is regional variation in this, or whether increasing multi-disciplinary collaboration improves access to secondary resection. Giving this area further attention would enable greater understanding of how best to serve those patients with potentially curable stage IV disease, and how to increase the proportion of patients considered for curative therapy.

8. **A high proportion of patients are elderly, and the optimal treatment paradigm for this group is unclear**

It remains unclear how we should treat our elderly patients (aged over 80) with CRC, who make up approximately ¼ of those newly diagnosed. Our intervention rates with chemotherapy in this cohort are lower than for other age groups, yet for many in this group colorectal cancer remains the life-limiting comorbidity. This raises challenging questions about patient selection, understanding patient choice, the interplay between age, comorbidity and treatment, and understanding any potential health-services factors that may contribute to patterns of care.
Some of these facts are confronting. Many are comforting. It may be tempting to dismiss the ones we don't like as "old" data that we have moved beyond by improvements in systems or services.

However we now have measured the baseline, and any attempts to dismiss or refute these findings as irrelevant should be accompanied by robust data, and importantly include careful consideration of appropriate denominators for key performance measures.

**What changes have there been since the PIPER cohort?**

The changes in clinical management of CRC since 2007 have been incremental and minor, and whilst we would expect there to have been improvements in care, these have been minor shifts rather than tectonic ones.

The policy environment around bowel cancer has however changed meaningfully.

Since 2007, some of the policy and structural changes include:

- Faster cancer treatment initiative – this government initiative requires that patients diagnosed with cancer receive first treatment within 31 days of decision to treat (not date of diagnosis), and those with a high suspicion of cancer receive treatment within 62 days of first referral.
- Standards of Service Provision for CRC have been produced.
- There has been an increase in the number and effectiveness of MDMs around the country, with progress on electronic recording of data in several regions.
- The National Bowel Cancer Work Group has been formed and is active on a national work plan
- The Waitemata Bowel Cancer Screening Pilot has progressed – this is particularly important with fewer than 12% of tumours being diagnosed at stage 1 in NZ
- Direct access colonoscopy criteria have been formed and implemented, with criteria for 2 and 6 week access, with proportions meeting these criteria now reported to the Ministry of Health
- Patient and Consumer groups such as the Gastrointestinal Cancer Institute of NZ (GICI) and Bowel Cancer NZ (formerly known as Beat Bowel Cancer Aotearoa) have become increasingly active, and demand a high level of transparency in the national debate about cancer service provision and direction
- Enhanced recovery after surgery (ERAS) services have grown with shorter length of stay and lower post-op morbidity
- There has been outsourcing of many pathology laboratories to private providers, which has attracted considerable media attention and professional debate. We did not examine whether there was a relationship between public or private service providers and the level of detail contained within pathology reports. A minimum pathology dataset can be required of any publically funded laboratory, and therefore outsourcing is not a barrier to comprehensive synoptic reporting.
The data contained in this report demonstrate that doing things faster is only one part of the outcome puzzle, and that there remains room for emphasis on “Better” in the health policy framework of “Better, Sooner, More Convenient Cancer Care”.

National tumour standards will provide this focus, but ongoing monitoring and reporting of outcomes in this framework is essential, and is currently missing.

At present we have concentrated many of our policy outcome measures on who we are treating. The results from PIPER also challenge us to consider whom we are missing.

*Where has PIPER taken us, and where to from here?*

The PIPER project is the culmination of 4 years of work beginning with a tender process from the Ministry of Health and HRC aiming to understand the breadth and depth of the pathway of presentation, diagnosis and management of CRC in NZ.

The research team we constructed aimed to bring together individuals with diverse expertise across a range of areas with an interest in CRC. These experts came from population health, general practice, rural health, medical and radiation oncology, general and specialist surgery, patient representative groups, Māori and Pacific health experts, health management, as well as academic biostatisticians and health research staff.

Following consultation with investigators and advisors, with careful review of relevant domestic and international guidelines, as well as cross referencing the Colorectal Surgical Society of Australia and NZ (CSSANZ) database and other international colorectal databases, we piloted an ambitious list of quality indicators and time points on a patient journey that could be related to quality of experience, quality of care, and overall outcome. We tested our list of key indicators on many members of the NZ colorectal community and listened to feedback, improved and refined.

We piloted this list with 226 cases and found that there were too many data-points to collect within the constraints of time and funding that we had available. Additionally, there were several data items that were very poorly recorded in patient notes or other source documents, which were contradictory within the notes, or were too open to subjective interpretation to be useful.

Some of these variables included: distance of rectal tumour from the anal verge; pre-operative tumour stage in rectal cancer; distance to circumferential resection margin in rectal cancer (pre-operative); family history; smoking status; duration of chemotherapy; chemotherapy dose reductions or treatment delays; whether patients were offered a clinical trial; and ECOG performance status. Frequently, treatment intent (palliative or curative) was vague or unstated. Our clinical detection rates of post-operative pulmonary embolus are considerably lower than published comparators, potentially highlighting poor capture of meaningful complications.

We hand searched the records of 6387 patients in both public and private settings, investing in over 9,000 hours of clinical notes review. Over 960,000 individual data points were entered onto an original database housed at CTNZ. Thousands of comparisons and analyses were and are possible with this cleaned and high-grade clinical data set.
The PIPER project is a landmark in CRC research in NZ.

However, we do not want to have to do it again.

The process of manual data collection is time consuming, but is useful to provide a national stock take and identify areas for immediate policy focus, and validates or repudiates the routine data sources and informs our ability to rely on them for monitoring purposes.

PIPER has given us considerable insight into data quality of routine datasets, and planned publications include a comparison of our hand-searched data with that held by the cancer registry, and data from other centrally held routine datasets. We have formed relationships with other international CRC registry projects which will enable future collaboration and comparison of outcome measures.

Our project has highlighted some major constraints to ongoing monitoring of cancer outcomes. Even the most (apparently) simple but fundamental data point – cancer stage – is dynamic over the pre-operative, operative and early post-operative stage, and requires that strong, clear and reliable business rules be written around data required for defining stage and how that is recorded and reported.

Our data recording on a day-to-day basis in clinical practice needs to improve if we are to examine quality in a more real-time and meaningful way. If we can achieve this, we can detect systems issues and drive quality improvements for the people of NZ, whom we are employed to serve. Manual data entry is unappealing for the overloaded clinician, but perhaps nationally standardized collection methods, for example through a mandated surgical database, or through cancer multi-disciplinary meetings (with joined up IT infrastructure) could be feasible.

CRC is a leading source of morbidity and mortality in NZ. It is our most common cancer and our rates are amongst the highest in the world. Our outcomes are worse than Australia, with death rates 35 percent higher than in Australia for women and 24 percent higher for men.

Our collective challenge is to design and implement changes in our health system that transforms us from being a country with a high mortality rate from CRC to one that leads the world in colorectal cancer survival.
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